Continuity of Care Dataset

by

Patricia Disa Flanagan

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to the required standard

[redacted]

Dr. Paul Fisher, Supervisor (School of Health Information Science)

[redacted]

Gerhard Brauer, Departmental Member (School of Health Information Science)

[redacted]

Ged McLean, Outside Member (Associate Professor, Mechanical Engineering)

[redacted]

Pat Coward, External Examiner (Vice President of Primary, Secondary & Tertiary Care, Capital Health Region)

University of Victoria

Supervisor: Dr. Paul Fisher

ABSTRACT

The smooth transfer of a patient's care from the hospital to the community is achieved through a process that is referred to as continuity of care. Continuity of care assists in the monitoring of a patient's needs and the management of a patient's health care over time. Its success depends upon the communication which occurs among the health care providers involved in the patient's care. Communication facilitates the sharing of patient information. This information is necessary to support the clinical decisions of health care workers. In addition this information needs to be timely, relevant and accurate if it is going to be of value.

Currently, most health care decision-making is based on information derived from the paper-based medical record. This record, however, is a poor tool for clinical decision making because it is not easily accessible to all health care providers. In addition, the information in the paper-based record is not organized around the patient. Instead, it is organized around the interests of the various health care professionals who provide care to the patient. As a result, there is no summary of patient information that allows health care providers to view the patient's physical, social and psychological history at a glance. Without this information, health care providers cannot make decisions that guarantee that health care is delivered in respect of the whole patient.

The use of a computer-based patient record has been strongly advocated as the most likely means of resolving the problems surrounding the paper-based record. A computerized patient record would provide the right patient information to the right provider, in the right format and at the right place. The first step, however, does not simply involve transferring of the information from the paper-based record to a computer-based record, but rather in identifying the information that health care providers need in order to make better clinical decisions.

One means of identifying this information is to examine the data collection tools currently being used to collect health care information. The primary purpose of these tools, referred to as datasets, is to gather information that would support decision making. Although many health care datasets have been developed, most are used to collect information about a specific aspect of health care. At present, no dataset provides a holistic profile of patient information that integrates data from a multidisciplinary group of health care providers.

A more systematic process of identifying the information needed by health care workers is to use a methodology called data modeling. Data modeling is a method that identifies the information requirements of the users of a system. This research identifies the information requirements of community physicians, nurses and social workers who provide care to an AIDS patient who is discharged from the hospital and requires community follow-up services. It also identifies the information hospital emergency department staff need when an AIDS patient arrives in the emergency department and has been receiving health care services in the community. The data identified from this methodology is referred to as the continuity of care dataset.

The continuity of care dataset contains 125 data elements which makes it considerably smaller than the paper medical record. It is not meant to be a complete patient record, but rather a summary or profile of relevant patient information that is needed by physicians, nurses and social workers to facilitate continuity of care across the hospital community interface.

From this dataset, a high-level conceptual data model was designed. This model represents the "real world" of clinical health care delivered to AIDS patients. It is also the foundation upon which an information system can be built. This information system could be the first step to enable the development of a computerized patient record that would be accessible to health care providers, researchers and policy makers alike.

Examiners:

Dr. Paul Fisher, Supervisor (School of Health Information Science)

[redacted]

Gerhard Brauer, Departmental Member (School of Health Information Science)

[redacted]

Ged McLean, Outside Member (Associate Professor, Mechanical Engineering)

[redacted]

Pat Coward, External Examiner (Vice President of Primary, Secondary & Tertiary Care, Capital Health Region)

[redacted]

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Introduction

When the delivery of a patient's health care spans the hospital and the community, it becomes more difficult to integrate the various episodes of the patient's care into a meaningful whole. These difficulties are caused by communication and information sharing problems that occur among the various health care providers involved in a patient's care. However, these two health care environments can be integrated with the availability of timely, relevant patient information at the point of care. The purpose of this paper is to use a data modeling methodology to identify this information. The information identified is referred to as the continuity of care dataset. The continuity of care dataset provides a summary or profile of a patient's health care history that is needed to assist health care workers with their clinical decision-making.

Chapter one examines a process called continuity of care. Continuity of care ensures the smooth transfer of a patient's care between one health care setting and another. In today's health care system, continuity of care is at its greatest risk of failure when a patient is discharged from the hospital and requires community follow-up services and when a patient requires services from a hospital emergency department during exacerbations of an illness or injury. It is here that a patient often enters the "no care zone." Most of the problems experienced between the hospital and community stem from the current format of the paper-based medical record. Because this record is only available to one health care provider at a time, there is no complete record of a patient's health care history. As a result, health care professionals are forced to make decisions without timely, relevant data. Clearly, if a patient is to be viewed holistically, his or her clinical information, and thus, his or her medical record, must be made more accessible.

The computerized patient record is seen as the ultimate solution to this problem. A computerized medical record is an on-line longitudinal record of a patient's care and treatment modalities. It provides the technology to facilitate access to patient information that has been distributed among diverse health care sites. However, there has been little success in the development of a computerized patient record since information sharing does not depend solely on information technology but rather on the quality of the data that is collected.

Chapter two discusses the information systems that have been developed in health care. Most hospital systems have been developed to capture administrative and financial data. In the community, which includes ambulatory care clinics, physicians' offices, community health centers, home care and long-term care, the majority of community information systems have been designed to support billing practices. Although a few of these systems have been developed to support the delivery of patient care, most produce a summary sheet that complements rather than replaces the paper-based medical record. A few attempts have also been made to integrate hospital and community information systems.

Chapter three examines the tools (datasets) that have been developed to collect health care information. The primary purpose of a dataset is to identify the data elements that are needed by health care professionals to support their decision making. Although many datasets have been developed, most only support administrative and financial health care decisions. What is lacking is a dataset that focuses on the patient and supports the decisions needed to facilitate continuity of care for the patient.

Chapter four describes the methodology used to identify the continuity of care dataset. The methodology chosen was data modeling. This research begins with a review of the health care needs of AIDS patients. Next, it examines the health care settings and the providers who care for these patients. Interviews were then conducted with the health care providers located at two specific health care settings - a hospital emergency department and a community health center. The interface between these two health care environments is where many communication and information sharing problems exist. The information derived from the data modeling method is called the continuity of care dataset. The continuity of care dataset was identified using Acquired Immunodeficiency Syndrome (AIDS) as a model. AIDS was chosen because it is an information intensive disease, it affects all areas of a patient's life and it requires care from multiple providers located at multiple health care sites. From this dataset, a model was built to reflect the "real world" of clinical care delivered to people with AIDS.

In an ideal health care system, health care professionals would have access to patient data generated by providers in the hospital and the community. The development of a shared patient record would improve the communication needed to integrate a patient's treatment episodes and facilitate continuity of care. The continuity of care dataset provides the first step in defining this record.

Chapter One: Continuity of Care

In today's health care environment most individuals receive a combination of hospital and community-based health care services. Lack of communication among those health care providers providing the services frequently contributes to problems in health care such as duplication of tests and procedures, inappropriate hospital admissions and increased length of stay (Heywood, Knock & Bingham, 1990; Holle, Rick, Sliefert & Stephens, 1995; Lee & Dean, 1995; Baker & Vischi, 1989). Resolving some of these problems requires sharing of vital patient information. This information is needed to support the decisions health care providers make about the care they provide. However, the quality of these clinical decisions is dependent on the availability of relevant patient information at the point of care (Working Group on HIV Infection and Mental Health, 1992; Morrison, 1993; Lee & Dean, 1995; Zilm, Carroll & Baldwin, 1994).

Communicating patient information is necessary to facilitate continuity of care. Continuity of care is the means by which separate parts of a patient's illness, either the follow-up of an acute illness or the ongoing care of a chronic illness, are joined together. It assures the patient of a consistent pattern of health care since it encompasses as many services, service providers and facilities as the patient requires (Vivier, Lewander, Block, Simon, Alario & Linakis, 1995; Bachrach, 1981).

The amount of information communicated among health care providers to facilitate continuity of care varies according to the type of health care problem an individual experiences. For example, the immunization of a healthy child requires very little information sharing. On the other hand, patients with chronic health care problems have multiple health care needs. These patients generally require acute hospital services that addresses their physical needs, as well as community-based services that addresses their psychological and social needs. Most of the communication and information sharing problems occur between these two health care environments because of the enormous amount of information that needs to be shared among them. Specifically, continuity of care is at its greatest risk of failure when a patient is discharged from a hospital ward or emergency department and requires community-based services, or when a patient who has been receiving community-based services utilizes the emergency department. Patients making the transition from one health care environment to another are frequently trapped in what is referred to as "the no care zone." (Jewell, 1993; Boydell & McAllister, 1994; Bachrach, 1981; Bachrach, 1993; Silva, Cabral & Zuckerman, 1993; Lin, 1994; Vivier et al., 1995; Nackashi, Shenkman, Reiss & Sideritis, 1993;

Pemble, 1994; Moran, Messick, Guerette, Anderson, Bradham, Wofford, Velez, 1994; Lee & Dean, 1995; Zilm et al., 1994).

Transfer of Care from Hospital to Community

The most common transfer of care from the hospital to the community is when a patient is discharged from the hospital. Upon a patient's discharge, a discharge summary form is completed. This form is the principal means of communicating the important events which have occurred during a patient's hospitalization to community care workers. It includes a summary of operative procedures, medications, pertinent laboratory and radiology results, and orders for follow-up treatments and community supports which are needed after discharge (Heywood et al., 1990; Lenhard, Buchman, Achuff, Kahane & Macmanus, 1991).

Without this discharge information, community health care workers cannot organize resources and provide prompt post-hospital follow-up care. Besides the information identified above, community workers also need timely notice of the impending discharge, a list of the medical treatments the patient will need at home, an assessment of the patient's home environment, the availability of informal supports and the patient's ability to care for his or her self. This type of information is especially crucial to facilitate continuity of care in the patient's home (Lenhard et al., 1991; Fargason, Ashworth & Haddock, 1995; Branger, van der Wouden, Schudel, Verboog, Duisterhout, van der Lei & van Bemmel, 1992; Jewell, 1993; Heywood et al., 1990).

In spite of the information exchange that should occur between the hospital and the community when a patient is discharged from the hospital, there are many reasons patients still do not receive adequate follow-up care. First, despite recommendations that discharge summaries precede the discharge of the patient, many of these summaries are not received by community health workers until after the patient has been discharged. Second, although discharge planning should include community caregivers, very few are ever involved in the process. Third, after the discharge summary is dictated, transcribed, reviewed and signed by the discharging physician, it is sent to those responsible for the patient's next medical encounter, usually the family physician. This poses a problem for patients who do not have a family physician or who require follow-up care from numerous health care providers located in the community (Tuzman & Cohen, 1992; Fargason et al., 1995; McWilliam and Sangster, 1994; Lenhard et al., 1991; Jewell, 1993). Finally, the discharge summary has traditionally had a very medical-orientated focus. According to Tuzman & Cohen (1992), discharging a patient rests on factors other than the resolution of his or her medical problems. For those patients requiring follow-up services from the community, it is crucial that a support structure be in place to meet the patient's psychological and social needs, as well as their physical needs. Similarly, when an individual in the community requires treatment from the emergency department, problems in delivering health care are just as prevalent.

Transfer of Care from Community to Hospital

The emergency department is a major entry point from the community to the hospital. It is here that emergency room staff must make decisions quickly, often without prior knowledge of a patient's medical history. The information emergency room staff need when a patient arrives in the emergency department includes the patient's current medications, allergies, lifestyle risks, past medical history, current medical problems and next of kin. Even when a patient is well informed about his or her illness, continuity of care in the emergency department is difficult to sustain because this department is designed to provide acute medical services and is rarely staffed or equipped to ensure comprehensive, ongoing, follow-up care (Vivier et al., 1995; Jewell, 1993).

For the patient who does not require acute medical hospital care, but does require community follow-up care, additional information is needed. Deciding whether or not to discharge a patient into the community requires information on the patient's informal and community supports, their functional, behavioral and mental status and the name of their primary health care provider (Jewell, 1993; Anderson, 1993; Myers, Pfeiffle & Hinsdale, 1994).

Overall, the lack of communication and information sharing among health care providers located at different health care facilities results in poor continuity of care. This has implications for the patient, the health care provider and the overall health care system. For patients, poor continuity of care results in his or her accessing emergency departments and walk-in clinics more frequently. In addition, these patients experience delays in necessary treatments and tests and repeatedly relay the same health care information to multiple health care providers. As a result, patients often endure more pain and suffering, demonstrate less compliance with treatments prescribed and, overall, experience poorer satisfaction with the health care system (Lee & Dean, 1995; Sweeney & Gray, 1995).

Poor continuity of care forces health care providers to expend inordinate amounts of time and energy trying to communicate with other professionals involved in the patient's care (Zilm et al., 1994). Some data elements are duplicated, triplicated or quadruplicated throughout the system while other data elements are completely omitted. This leads to the frustration of most health care providers through decreased job satisfaction and time management. Because of the difficulty in obtaining and using information, managing patient data is often considered the worst part of a health care provider's professional experience (Korpman, 1994; Lee & Dean, 1995).

The inability of health care professionals to access relevant patient data creates inefficiencies in the health care system. Strict boundaries between areas of health care make it difficult to track patients. These boundaries also slow the discharge planning process and result in increased hospital stay, increased or inappropriate admissions, increased re-admissions after discharge and increased emergency room visits. Finally, these boundaries result in inadequate utilization of services or the use of such costly, inappropriate services as duplication of tests and procedures (Nackashi et al., 1993; Heywood et al., 1990; Holle et al., 1995; Lee & Dean, 1995).

AIDS and Continuity of Care

AIDS is an example of a disease that benefits from continuity of care. AIDS is an information intensive disease which affects all areas of a patient's life. Managing the treatment and course of the disease requires a multidisciplinary group of health care providers who provide health care services in a variety of different health care settings (Baigis-Smith, Gordon, McGuire & Nanda, 1995; Metrikin, Zwarenstein, Steinberg, Van Der Vyver, Maartens & Wood, 1995; Safran, Rind, Davis, Currier, Ives, Sands, Slack, Makadon & Cotton, 1994; Piette, Fleishman, Mor & Thompson, 1992).

With the advent of new drugs and therapies, AIDS has moved from an acute, fatal condition to a chronic disease with a longer life expectancy. Although frequent hospitalization of AIDS patients is still necessary, most patients now respond to medical treatment and survive these acute episodes. However, the AIDS patient who leaves the hospital frequently requires a transfer of his or her care to the community. Additionally, the initial point of contact in the health care system when an AIDS patient is experiencing an acute illness is usually the emergency department (Smith & Rapkin, 1995; Safran, et al., 1994; Koch, 1992; Berk, Poe and Baigis-Smith, 1992; Morrison, 1993; Baigis-Smith et al., 1995).

As indicated, AIDS is a chronic condition with progression taking place over one to two decades. Although there is a lack of research on the exact financial benefits of moving health care from the hospital to the community, the following studies do indicate that much of the care for AIDS patients can be provided by primary care professionals in less expensive local clinics or office settings.

Mansfield & Singh (1993), found that there were three key components to caring for AIDS patients. These components included the hospital, the patient and the community. During the past decade, the Riverside health authority was able to involve all three of these components in the treatment of AIDS patients. As a result, the health authority reduced the number of AIDS patients hospitalized from 15% to 6.9% and the mean length of hospital stay from 15 days to 12 days. This was achieved by educating hospital workers about the resources available to AIDS patients in the community and assisting community health care workers with organizing these community resources.

The Denver Department of Health and Hospitals (DHH) has set up a consortium that has been instrumental in the 56% reduction in the cost of medical care for AIDS patients. The DHH established an integrated care system which addressed the complex needs of people with AIDS from diagnosis to death. Before this consortium, the average length of stay for people with AIDS was 11.3 days in 1986 compared to 5.5 days for the average hospital patient. The consortium found that a strong network of community resources could shorten hospital stays for AIDS patients by up to 60%. In 1990, costs per patient were $17,765 which was 56% less than the costs of $31,180 in 1986. The average length of stay in the hospital was reduced from 11.3 days in 1986 to 8.2 days in 1990 (Myers, Pfeiffle & Hinsdale, 1994).

Finally, a study done between September and November 1992 in a teaching hospital outpatient clinic in South Africa found that 59.2% of the AIDS patients treated at the hospital facility could have been cared for by their family physician just as appropriately as in the hospital's specialized clinics (Metrikin et al., 1995).

Some of the financial benefits of delivering the right care in the right setting can be demonstrated when hospital and community resources for AIDS patients are correctly utilized. However, achieving these benefits depends primarily upon the continuity of an individual's care.

Framework for Continuity of Care

In the past, continuity of care was defined on the basis of one dimension -- that of the relationship between the primary care physician and the patient. Today, most definitions recognize that continuity of care is a process which consists of seven dimensions (Morrison, 1993; Bachrach, 1981; Baker & Vischi, 1989; Bachrach, 1993).

The dimensions of continuity of care can be categorized according to the attributes of the services delivered to the patient or the attributes of the health care delivery system. These dimensions are shown in Figure 1.

Figure 1 Framework for Continuity of Care

Attributes of	**Dimensions of Continuity of Care**
Services delivered to the patient	**- Longitudinal** **- Individual** **- Comprehensive**
Health care delivery system	**- Flexible** **- Accessible** **- Relationship**
Communication	

The attributes of the services delivered to the patient include longitudinal, individual and comprehensive dimensions (Morrison, 1993; Bachrach, 1981; Baker & Vischi, 1989).

- **Longitudinal** - ensures the health care services delivered to a patient over time are consecutive and related. These services can begin at whatever point the patient enters the health care system.
- **Individual** - ensures that the patient is the reference point of care. Services provided to the patient focus on the patient's needs rather than the needs of the provider or agency that delivers a service. These services are delivered with respect to the patient's physical, psychological and social needs.

- **Comprehensive** - describes the spectrum of services needed by a patient. Some of these services include hospital, community, laboratory, rehabilitation and housing.

The attributes of the health care delivery system include flexibility, accessibility and relationship dimensions (Morrison, 1993; Bachrach, 1981; Baker & Vischi, 1989).

- **Flexibility** - ensures that services provided to the patient change as the patient's needs change. This promotes easy movement back and forth across the continuum of care.
- **Accessibility** - ensures that the delivery of health care services to a patient is free of barriers. Barriers can be physical, psychological or financial.
- **Relationship** - the original definition of "relationship" pertained to the doctor-patient association. Today, this relationship can still be between the patient and one health care provider but it is usually maintained by a multidisciplinary team of providers who make up the service delivery system.

Communication

Communication permits the six other dimensions of continuity of care to be realized and is therefore, the most important dimension of continuity of care. Communication is the essential integrating mechanism needed to link the different episodes of a patient's care together. In the past, it was the family physician who was responsible for communicating relevant patient information to other health care providers involved in a patient's care. In today's health care system, patients receive health care from numerous health care agencies and providers. Consequently, the only tool available to facilitate communication and information sharing between different health care providers is the medical record (Morrison, 1993; Fargason et al., 1995; Bachrach, 1981; Baker & Vischi, 1989; Morrissey, 1993). However, the medical record in its current form does not support effective decision making. Effective decision making is dependent on the availability of timely, relevant and accurate information at the point of care. A well-designed information system would provide this information to the right provider, in the right place, at the right time and in the right format. However, the quality of an information system depends on the quality of the data collected. The better the data collected, the better the decisions health care providers will make. Identifying the data health care professionals need to make these decisions is the issue central to this thesis.

Communication in Health Care

In order for information to be shared, a communications event must occur. This event comprises a sender, a receiver, a medium and a message. The sender (a provider) must have a message and be able to send it and the receiver (another provider) must be able to receive and understand it. There must be a medium to carry the message; this could be a courier, the telephone or a computer network. The medium or mechanism is the easiest problem to solve because technology is readily available and is actively utilized by other industries (Tan, 1995).

The biggest problem with communication in health care lies in the messages that are exchanged between senders and receivers. Addressing this problem is difficult because there is not enough formal communication taking place in health care to adequately examine the messages being exchanged. In addition, even though these messages are exchanged frequently, albeit informally, there is little information on what a health care message should contain or how it should be structured. In order for messages to be of value, they must be well defined, concise and clear to both senders and receivers. The primary communication tool in health care, the paper-based medical record, contains messages which are not well defined and, consequently, are not useful for clinical decision making.

The Paper-Based Medical Record

There are many problems associated with using the paper-based medical record to share patient information. First, health care providers spend large amounts of time sifting through paper charts trying to isolate the data which is relevant to their clinical decision making. Within this global body of patient information there are two types of data: those related (significant) and unrelated (insignificant) to the condition under consideration. The significant data from the patient record, together with the current data, tells the health care provider if any changes have occurred in the patient's condition since the last encounter. The significant data is often in the wrong section of the chart or altogether absent. Additionally, health care professionals then spend between 35% and 50% of their time communicating the information to other health care providers (Johnson, 1994). The effort required to retrieve and communicate patient data from the paper-medical record is usually greater than the effort required to make decisions about the data.

A second problem with the paper-based record is that it is not permitted to leave the facility in which it originated. Currently, both hospitals and community-based agencies keep their own comprehensive patient record which prevents the integration of patient information from one facility with another facility. In addition, these health care records are designed to meet the internal objectives of the organization instead of the broader goal of coordinated, comprehensive care (Heywood et al., 1990; Moore & Busing, 1993; Lee & Dean, 1995; Rodnick, 1990; Murphy, 1994; Hodgkins, 1995; Johnson, 1994). Finally, the paper-based medical record does not focus on the patient but rather is organized in a way that serves each individual health care provider or discipline. Since the medical record does not consolidate relevant information from all health care providers, each health care provider has to settle for a limited view of the patient's total medical history (Korpman, 1994).

Computerized Patient Records

The ultimate solution to solving the current communication and information sharing problems in health care is the Computerized Patient Record (CPR). The CPR, which has been the subject of research for over 25 years, is in its simplest form the patient chart in electronic format (Braunstein, 1994). The Institute of Medicine (IOM) describes the CPR as an electronic patient record that permits users access to complete and reliable medical data, provides links to current medical knowledge and assists in clinical decision making (Bergman, 1993; Andrew & Dick, 1995). The idea is for all sources of clinical information, from hospitals, physicians' offices and various community health centers, to contribute their patient assessments and results to a centralized computerized medical record. Ideally, this record would be organized around the patient instead of around the patient's encounters with the health care system (Morrissey, 1993). This organization would enhance information value, contributing to an improvement in the delivery and management of patient care.

The CPR, which is longitudinal by nature, would be updated by physicians, nurses, social workers and other care providers who monitor and observe changes in the condition of a patient. Additionally, health care personnel who use the CPR would be able to determine whether each aspect of the patient's health status is stable, improving or worsening (Ornstein, Oates & Fox, 1992; Johnson, 1994; Andrew & Dick, 1995; Hodgkins, 1995; Deutsch, Fisk, Olson & Bronzino, 1994; Kahn, 1995).

With the adoption of the IOM's vision of a CPR, it becomes apparent that most computerized systems fall short of this goal. Furthermore, not all CPR advocates support the IOM's vision (Bergman, 1993). Some argue that it is too extreme and will take many years to implement because of the numerous barriers that prohibit its widespread use. Some of these barriers include the lack of communication and data standards, regulations that protect patient privacy, the allegiance to the paper-based record, inadequate data input mechanisms, lack of health care system designers and the simple lack of acceptance of computers in the health care field (Curtis, 1994; Coley, 1992; Kuperman, Maack, Bauer & Gardner, 1991).

Additionally, even if there was a CPR the value of having so much information available to health care providers at the point of care is questionable. Currently, much of the information now recorded in the paper-based record loses its value quickly, becomes irrelevant and often masks that which is relevant. Furthermore, most health care providers only want 10% of the information that is being collected. They want a summary or profile about the patient's relevant physical, psychological, social and medication history. Lastly, most health care disciplines have no interest in the assessments of other health care disciplines. However, it is the outcomes drawn from those assessments such as diagnoses or treatment plans that provide the important information needed for clinical decision making (Korpman, 1994; Morrissey, 1993; Rodnick, 1990; Murphy, 1994; Hodgkins, 1995; Johnson, 1994).

Nonetheless, because computer technology is now available and affordable, a growing number of computer systems have been developed to assist health care professionals with the process of delivering patient care. Chapter two discusses these information systems.

Chapter Two: Information Systems in Health Care

Chapter two discusses some of the information systems that have been developed in various areas of health care. It begins by examining hospital and community information systems. It then examines integrated delivery information systems. Integrated delivery information systems attempt to integrate hospital and community-based organizations.

Hospital Information Systems

The information requirements of a hospital fall into three categories; planning, operational and documentation. These categories support the administrative, financial and clinical decisions needed to manage and deliver inpatient hospital care. Most of the information needed to make these decisions is collected in the hospital medical record. This record is a legal document used to maintain continuity of care for patients within a hospital and to determine if a patient is receiving adequate care (Wiederhold & Perreault, 1990).

Hospital Information Systems (HIS) were introduced into hospitals in the 1960s to facilitate the capture, storage and retrieval of the extensive amounts of information produced from delivering and supporting patient care. Their primary purpose was to integrate data from such hospital ancillary departments as admission, transfer and discharge (ADT), laboratory, radiology and pharmacy. Very few of these systems integrate data from such direct patient care areas as the intensive care units or nursing wards (Wiederhold & Perreault, 1990).

Some of the more well known HISs are the Technion System (TMIS), the Patient Care System (PCS), SMS, HELP and PHEONIX. Besides the ability to integrate data from diverse hospital departments, TMIS and PHEONIX are also used to transmit patient orders (Wiederhold & Perreault, 1990; Hughes, 1995; Kuperman et al., 1991; Yoshihara, 1994). Two newer HISs are the Kaiser Permanent Northwest Region System and the Advanced Clinical Information System (ACIS). Both of these systems are used to collect such clinical patient data as admission histories, discharge summaries and allergies, as well as a certain amount of information about a patient's medical problems and treatments (Krall, Mysinger, Pearson, Chin, McClure & Collins, 1995; Warner, Guo, Mason & Livingston & 1995).

Despite the current automation in hospitals, few HISs are central to the process of delivering patient care. Their primary purpose is to transmit orders and results from one area of a hospital to another. The strength of most of these systems lies in their automating hospital clerical tasks, tracking finances and controlling inventory. Few systems are used to support clinical decision making because they have not been designed to incorporate the assessments and care plans of most health care disciplines. Some of the newer patient care information systems being developed are used to assist health care professionals with their clinical decision-making. These systems include patient-monitoring and nursing information systems.

Patient Care Information Systems

Patient-Monitoring Systems

Patient-monitoring systems were introduced into hospitals in 1987 to record and display such data as blood pressure, heart rate, respiratory rate and blood oxygen content. These systems are used to alert health care professionals to potentially life threatening situations and to provide support so that therapeutic decisions can be made quickly. Most patient-monitoring systems were designed to collect large amounts of physiological data and display it in a flowsheet format. These systems are used in the emergency room, in the operating room and in the intensive care unit (ICU) (Gardner, 1990; Hughes, 1995; Gardner & Stanley, 1992). The most well known patient monitoring systems are the Mennen Medical, Roche, Kontron, Siemens, Little Datamedix, General Electric, Spacelabs, EMTEK System 200 and CareVue 9000. Currently, few of these systems are able to integrate data from other hospital departments (Gardner, 1990; Hughes, 1995).

Nursing Information Systems

Most of the nursing information systems (NIS) developed took a limited view of nursing by primarily supporting only the record-keeping and nursing administrative functions. Very few supported the nursing process. This process includes assessing and diagnosing a patient's problem and planning, implementing and evaluating the care delivered. The result is a nursing care plan. This care plan is a legal document and communication tool that assists nurses with their decision making. It also facilitates continuity of care between nursing shifts (Ozbolt, Abraham & Schultz, 1990; Hughes, 1995).

One system, TMIS, is used to collect some nursing related data but lacks any connection between the data and the generation of nursing care plans (Wiederhold & Perreault, 1990). The COSTAR, PROMIS and MSS systems also fail to offer any understanding of the nursing process. None of these systems incorporate a great deal of nursing knowledge and function primarily to make the nurse's work load easier by producing an automated kardex (Williams, 1991; Ozbolt et al., 1990; Hughes, 1995).

The first systems to incorporate some of the components of the nursing process were point of care systems. These systems, commonly referred to as bedside terminals, workstations or clinical information systems were used to capture patient data at the bedside. Instead of competing for the patient's chart, health care providers now have simultaneous, immediate access to data located at multiple locations. Examples of these systems include CliniCom's Cliniccare, the Medtake System and the Information Network for ON-Line Retrieval & Medical Management Nursing Information System (INFORMM). As yet, these systems provide little decision making support for nurses. Nurses did, however, report less time spent on charting and more time in contact with their patients (Hughes, 1995; Williams & Brown, 1994; Prophet, 1995; Wiederhold & Perreault, 1990).

Two newer systems, the Creighton On-Line Multiple Medical Expert System (COMMES) and ULTICARE, do assist nurses with decision making. Both of these systems guide nurses in developing nursing care plans from patient specific data by interacting with a nursing knowledge base (Ozbolt et al., 1990).

Although health care information technology within the hospital setting has progressed significantly over the past 20 years, the focus has been on independent application. Today, stand-alone systems are still very common but are not cost-effective. In order to ensure better quality and cost efficiency, a system which integrates clinical and administration data must be established. Also, stand alone systems were never meant to connect and share information with health care providers located in the community.

Community Information Systems

Community Information Systems assist health care providers in delivering care to outpatients. These systems are found in ambulatory care clinics, physicians' offices, community health centers and community-based organizations. Although all of these settings can meet a patient's physical, psychological and social needs, ambulatory care and physicians' offices tend to focus more on a patient's physical problems. Community health centers address more of the psychological and social consequences of a patient's physical problem whereas community-based organizations address a patient's social and lifestyle needs (Moran, Wofford, Hamrick, Myers, Cooper, Doby, FitzGerald, Spence & Velez, 1994; Makadon & Aseltyne, 1995). Finally, home care and long-term care provide supportive and restorative care for a patient. They are considered part of the community because they do not require the more sophisticated, acute care treatments delivered by hospitals (Wiseman, 1990; Warner-Handelsman, 1991; Braunstein, 1994; Morrison, 1993).

The first systems developed in the community were designed to support ambulatory care clinics and physicians' offices. Many of these systems have been in existence for over 25 years. The original systems were designed as administrative packages to support the billing functions of a clinic and the scheduling of patient visits. Some computerized systems allow physicians to document a patient's history, physical examination and treatments rendered. More sophisticated systems generate automatic health care reminders such as follow-ups and immunizations and allow for searching and retrieving of bibliographic references. In general, these systems have computerized more of the patient medical record than the HIS and therefore do provide more information for clinical decision making (Hughes, 1995; Higgins & Newman, 1990).

Ambulatory Care Information Systems

Four popular systems have been used in ambulatory care clinics for quite some time. These systems all support basic billing and patient management functions such as scheduling and registering patients, generating medical letters, maintaining inventory and managing accounting practices. In addition, they all are used to collect a patient's medical history, diagnoses, allergies, procedures, test results, medications and encounter information. The Computer-Stored Ambulatory Record (COSTAR) that was developed in the late 1960's is the most widely used of all ambulatory care systems. One of COSTAR's strengths is its ability to provide physicians with health maintenance reminders that encourage more preventative, less expensive care (Spann, 1990; Rodnick, 1990; Chessare & Torok 1993). The Regenstrief system was developed in 1974 and produces cumulative problem lists, patient-specific reminders and allows for interactive querying of a database for research purposes (Martin, 1992; McDonald, Tierney, Overhage, Martin & Wilson, 1992; Rodnick, 1990). The Medical Record (TMR) was developed in 1975. One of its strengths is to calculate drug dosages and issue cautions about drug interactions (Johnson & Michener, 1994). The Summary Time Oriented Record (STOR), developed in 1979, is used to integrate inpatient and outpatient records by gathering information from various ancillary hospital departments. An evaluation of STOR indicates that it provides more information to health care providers than the paper-based record in about 75% of outpatient visits. In addition, when a computerized summary sheet is made available, physicians seldom request the whole chart (Rodnick, 1990; Whiting-O'Keefe, Simborg, Epstein & Warger, 1985; Cheong, Goh, Ong, & Wong, 1992).

Two less known ambulatory care systems are the Primary Care Clinic Encounter Record System (PCCERS) and the Computer Based Ambulatory Care Record. Both of these systems permit the capturing and summarizing of health care problems, medications, screening procedures and interventions (Smith, Johnson & Jackson, 1992; Safran, Rury, Rind & Taylor, 1991).

Physician Office Information Systems

Some of the more well known information systems developed for physician offices are the Primary Care Health Information System (PCHIS), Medsum, the Mini Medical, CLINIC, MEDMOS, the Practice Partner Patient Record and the EpiCare Electronic Medical Records System. These systems are used to collect a patient's demographics, medical, family and social history, immunization status and allergies. The main strength of these systems are that they produce a master problem list or profile of relevant information which includes the patient's surgeries, diagnosis, medications and allergies. This profile is especially useful when caring for patients with chronic health problems. Most physicians found that, when completed, these profiles provide enough relevant information to maintain continuity of care between patient visits (Manchester, Raia, Scott, Emery & Russo, 1992; Bridges-Webb, 1986; Carey, Thomas, Woosley, Proctor, Philbeck, Bowen, Blish & Fletcher, 1992; Warshawsky, Pliskin, Urkin, Cohen, Sharon, Binztok & Margolis, 1994; Ornstein et al., 1992; Hughes, 1995).

The computerized medical systems used in ambulatory care clinics and physicians' offices perform similar functions as the standard paper medical record as far as collecting, organizing, storing and presenting the medical information required to manage a patient's health care needs. Most of the systems identified in the literature were designed by physicians either at a medical university, hospital or both. Additionally, most were modeled after the paper chart. Some used the subjective, objective, assessment, plan (SOAP) format when gathering encounter data while others are organized according to the problem oriented medical record (POMR) format which structures medical data according to categories of problems having common signs and symptoms. Most produce a summary sheet or patient profile that assists physicians with clinical decision making (Bergman, 1993; Rodnick, 1990; Whiting-O'Keefe et al., 1985; Cheong et al., 1992; Ornstein et al., 1992; Warshawsky et al., 1994; Wiederhold & Perreault, 1990).

History of the Patient Profile

It is important to mention the history of the patient profiles or summary sheets that are produced by most of the information systems developed for ambulatory care clinics and physician's offices. According to Bridges-Webb (1986), there was a belief among the medical community that the most valuable part of the medical record, besides billing information, was the creation of a summary patient problem list. The goal of this single page summary list was to facilitate communication between patient visits. It supplied the most relevant clinical information in a standardized format, thus eliminating the large amount of low-priority information which has little importance to current decision making. It included four essential components:

- Medical and Surgical History
- Family History
- Medications
- Allergies

In addition, the name of the patient's primary care provider was included. The belief in the importance of a summary patient problem list was supported when, in 1987, the Joint Commission on Accreditation of Healthcare Organizations in the United States mandated medical chart summaries for all clients treated in ambulatory care clinics. The most current summary sheet (commonly referred to as a patient profile) was to be kept in the front of the patient's chart at all times (Manchester, 1992). Most physicians use a more comprehensive profile then the one mandated by the Joint Commission. This profile includes the patient's past medical, family, social, immunization and screening history, as well as a list of active and inactive medical problems, surgeries performed, significant medications prescribed and allergies (Whiting-O'Keefe et al., 1985).

As yet, there are very few information systems developed for use in community health centers, home care or long-term care. Apparently many vendors are starting to develop systems in these areas. Some of the more well known systems are discussed below.

Community Health Center Information Systems

Most ambulatory care and physicians' office computerized systems would support the functions of a Community Health Center. Some systems, such as Med/Track and the Patient Care Information Systems (PCIS), are used to collect health care data that is of more use to nurses and social workers. This includes medical, socio-economic and environmental data which is used for preventative care and chronic disease tracking. These systems also produce summaries or profiles of patient information which augments the paper-based record (Moran et al., 1994; Ozbolt et al., 1990).

Community care case management systems such as the Information Management of AIDS Cases and Services (IMACS system), the Intelligent System Access to Automated Clinical Charting (ISAAC) and the Professional Care System (PCS), are also used by nurses and social workers to document patient care. These systems also produce a summary patient problem list (Swoben, 1993; Bliss-Holtz, 1995).

Home and Long-Term Care Information Systems

The first computers in home care were used to ease the tasks of data collection for the billing and payroll functions of a home health care agency. Patient Care Technologies (PCT), the Visiting Nurses Association (VNA) and the Wiseman Project all developed point-of-care systems (a palm-top computer weighing approximately 1.5 pounds) that is used to input data that records nursing activities, evaluates a patient's progress and updates care plans (Hughes, 1995; Hassett & Farver, 1995). A memory card is kept in the patient's home. During home visits, the nurse inserts the card into his or her computer, receives current patient information and enters new information. After the card is updated, the computer is taken back to the home care office where the information is down loaded into a central computer. A permanent paper report is usually produced for the patient's medical record (Noone, Cavanaugh & McKillip, 1995; Wiseman, 1990). Overall, all the home care systems provide nurses with up-to-date clinical information. The availability of this information improves patient care and saves nurses time when delivering this care (Hassett & Farver, 1995).

In the area of long-term care, the Learnmore Project focused on the information problems related to the capturing of patient data as well as educational and expert knowledge related to geriatric patients. Its major focus was on the information needed by health care professionals who did not have access to experts in the area of long-term care (Meyer, Dimond, Shaver, Canfield, Mookerjee, Mannin, Mookerjee & Abbott, 1995).

Integrated Delivery Information Systems

An integrated delivery system (IDS) attempts to create a health care system in which patients can move from one health care agency to another in a coordinated fashion. The functions of an IDS include coordinating inpatient and outpatient care, reducing duplication of effort between inpatient and outpatient staff, reducing unnecessary hospital admissions and length of stay, facilitating more effective discharge planning and improving communication between hospital and community health care workers (Korpman, 1994; Morrissey, 1993; Holle et al., 1995; McQueen, 1989).

Although numerous attempts have been made to restructure health care and to break down some of the communication and information sharing barriers that exist between the hospital and the community, there is presently no complete, integrated, health care network in place (Holle et al., 1995; McQueen, 1989; Morrissey, 1993; Abrahams, Macko & Grais, 1992).

The following discussion describes some of the systems which have been developed in Canada that attempt to integrate hospital and community-based organizations. In Kelowna, British Columbia, the Continuing Care division of a health unit in Kelowna was given access to the Kelowna General Hospital's information system. Information such as demographics, services patients were receiving, wait list status, discharge planning information, clinical/historical background and doctors' orders were sent between the hospital and the health unit (Zilm et al., 1994). A similar collaborative project was developed in Victoria in 1990 between the Greater Victoria Hospital Society (GVHS) (which includes two acute care and two long term care facilities), the Capital Regional District (which includes home support agencies and home nursing care services), the Quick Response Team and the Ministry of Health (MOH). The goal was to determine whether the benefits derived from a shared information system would warrant further attempts at integration. Access to the MOH database permitted hospital staff access to the patient's case manager, as well as information on the community services the patient was receiving and on the services they were eligible to receive (Heywood et al., 1990). A mental health project was also undertaken in Victoria in 1992. This project included three mental health offices, the GVHS emergency response team, the psychiatric early response team and the GVHS inpatient psychiatric unit. The MOH again granted caregivers access to relevant information in the continuing care database (Thompson, 1994). In 1995, the Calgary Mental Health Service implemented a similar project. A central database furnished both hospital and community health care workers with timely access to information about mentally ill patients who had used inpatient, outpatient and emergency services. This system provided these workers with current patient data which allowed them to better assess the patients they were treating (McDougall, Adair-Bischoff & Grant, 1995).

Several systems in the United States have been developed to support the functions of an IDS. In Boston, a distributed database was developed for remote use to target the health care needs of the homeless population. This project increased the availability of health care data beyond the traditional walls of the hospital and promoted patient-oriented care (Chueh & Barnett, 1994). In Hartford, Connecticut, a city-wide computer-based paediatric health care network was established between three community health centres, three hospital outpatient departments and a school-based health service. Information collected over this network included student demographics, medical histories, medical treatments and recommended follow-ups. The goal was to maintain student records, improve decision making and provide better patient follow-up (Deutsch et al., 1994).

In other areas of the world, such as the United Kingdom, the Plymouth Integrated Record Project has designed a shared electronic patient care record to assist in the delivery of mental health services and to monitor the use of health care resources. This information system serves some 35,000 patients with 90 terminals providing real time access to over 400 mental health care professionals. It allows providers to immediately determine whether or not a patient who presents him or herself to a mental health service is previously known and, if so, to obtain all relevant past and current medical information. The system has been implemented in other mental health units in various communities throughout the United Kingdom and Ireland (Robins & Rigby, 1995).

Summary of Information Systems in Health Care

Overall, none of the computerized systems used in the various areas in health care will meet the IOMs requirements for a computerized patient record. Additionally, very few of these systems have allowed health care professionals to move to a completely paper-less office. Most efforts to fully automate the paper-based record have failed because developers attempted to replace the paper chart by simply duplicating it electronically. The systems that appear to have been accepted and have added the most value to the work of health care professionals are those that were designed to produce summary data, a problem list or patient profile that complements rather than replaces the paper-based record. Most health care providers who use these systems found such a profile to be of the most value because it meant less data entry, was easily accessible, was a good supplement to the paper chart and provided relevant information between patient visits (Morrissey, 1993; Whiting-O'Keefe et al., 1985; Hodgkins, 1995). However, as valuable as this patient profile is, it is not multidisciplinary or readily accessible to health care providers located at different health care sites. It is however, the basis of the continuity of care dataset.

Research Question

What information is needed by physicians, nurses and social workers to facilitate continuity of care for AIDS patients across the hospital community interface?

Chapter Three: Datasets

One way of identifying the information requirements of health care professionals is to examine the current data collection tools in health care. These tools, referred to as datasets, are used to collect a core set of data elements in a specific area of health care. The information collected in a dataset is used to support the decisions made by health care providers and administrators. In addition, a dataset supports the development of standard definitions, codes and classifications of health care data. Finally, it provides a framework of specifications for the design and development of an information system (Anderson & Hannah, 1993; Hassett & Farver, 1995; Barthell, 1997; Moidu, 1992; Williams, 1991; Werley, Devine, Zorn, Ryan & Westra, 1991; Moidu, Falsone & Nair, 1994).

The concept of a dataset was first identified by Florence Nightingale. She designed a comparative reporting system for London hospitals based on minimum uniform data elements. This concept was also applied to the collection of vital statistics in the United States. Both of these datasets were used primarily to collect statistical data. It was not until the late 1960s that the need for better information to plan, measure and improve the process of delivering health care was realized. However, it quickly became apparent that the information needed was neither in a standardized format nor universally available (Anderson & Hannah, 1993; U.S. Department of Health and Human Services, 1980).

Most of the information that is available to health care providers is contained in the paper-based medical record. This record is the most common, comprehensive and clinically-focused dataset in health care. However, the sheer volume of information in the record makes it a poor tool for clinical decision-making. Consequently, many datasets which are smaller and have a narrower focus have been developed (Anderson & Hannah, 1993; Hassett & Farver, 1995; Williams, 1991; Moidu, 1992; Werley et al., 1991).

According to the U.S. Department of Health and Human Services 1980, most datasets have, as a minimum, a collection of information that describes the following:

- medical data elements - describes the characteristics of a patient's medical problem
- provider data elements - describes the professional who delivers care to a patient
- encounter data elements - describes the services provided to a patient

Additionally, most datasets can be classified as either site-specific, provider-specific, program-specific or patient-specific. Table 1 below summarizes the different types of datasets.

Table 1 Summary of Types of Datasets

Focus	Type of Dataset	Functions Supported	Identified by
Site-Specific	Hospital Discharge Ambulatory Care Long-Term Care Home Care & Hospice	Administrative, Financial & Statistical Activities	Technical Panel & Consultations
Provider-Specific	Nursing	Nursing Care Activities	Literature Review & Consultations
Program-Specific	Maternal Health Emergency Care	Physician Care Activities	Data Modeling with limitations
Patient-Specific	Continuity of Care	Physicians, Nurses & Social workers Activities	Data Modeling

Types of Datasets

Site-Specific Datasets

Site-specific datasets primarily support administrative and financial decisions in health care. They include hospital discharge, ambulatory care, home and hospice care and long-term health care datasets. They are commonly referred to as minimum datasets (MDS).

Hospital Discharge MDSs

The Uniform Hospital Discharge MDS (UHDDS) was developed to monitor, improve and coordinate issues surrounding costs and quality of inpatient hospital services. It consists of 14 data elements which are collected from the discharge summary sheet and insurance claim forms when a patient is discharged from the hospital (U.S. Department of Health and Human Services, 1980; Anderson & Hannah, 1993; Huber, Delaney, Crossley, Mehmert & Ellerbe, 1992).

In Canada, the Health Medical Records Institute (now Canadian Institute for Health Information) has developed an abstracting manual for standardizing data collection. This manual identifies the hospital data to be collected at discharge. The data collected is similar to that collected in the UHDDS in the United States. In the United Kingdom, the Korner dataset is also used to collect data and information from medical records when a patient is discharged from the hospital (Anderson & Hannah, 1993).

Uniform Ambulatory Care MDS

The Uniform Ambulatory Medical Care MDS (UAMCMDS) was developed for ambulatory care clinics and physicians' offices. Its primary purpose is to identify the services provided to a patient during the course of an outpatient encounter. Its supporters claim that it is more patient centered as opposed to provider centered because it is also used to collect data on services provided by non-physicians. It contains 18 data elements, some of which come from the medical record and some from the registration or billing record (U.S. Department of Health and Human Services, 1981).

Long-Term Health Care MDS

The Long-Term Health Care MDS (LTHCMDS) is used to collect data that monitors long term health care services. These services are received on a recurring or continuing basis by individuals with a chronic illness or permanent physical or mental impairment. Besides the patient's medical problems, the LTHCMDS emphasizes the psychological and social aspects of illness and disability. It is used in a variety of settings such as nursing homes, rehabilitation homes, day care centers and the patient's home but it is geared toward the long-stay, institutionalized patient. This dataset includes 24 data elements. The LTHCMDS is primarily used as a patient assessment tool and is completed by health care providers when a patient is admitted to a long-term care facility and at regular intervals afterwards (Schlentz, 1993; U.S. Department of Health and Human Services, 1980).

The discharge, ambulatory care and long term health care MDSs were all developed in the mid 1970s by a Technical Consultant Panel in the United States. They are encounter focused and developed primarily for hospital administrators. They provide data that allows health care administrators to code patient problems and interventions for hospital billing and reimbursement, protecting against malpractice suits and making financial forecasts. The Canadian and United Kingdom discharge datasets have a similar focus as their American counterparts. Although some clinical data can be derived from these datasets, because of the administrative and financial focus most of the data collected is not useful for clinical decision making (U.S. Department of Health and Human Services, 1980; Anderson & Hannah, 1993).

Home Care and Hospice Dataset

In the United States, the National Association for Home Care's Information Resources and Quality Assurance Committee have begun work on a standardized comparable home care and hospice dataset. It has been designed through a literature review on the needs of home care patients and by soliciting input from health care workers in the area of home and hospice care. This dataset incorporates data elements from the nursing minimum dataset (NMDS) and includes organizational, discharge and ambulatory care data elements (Anonymous, 1994; Hassett & Farver, 1995). Although there are some clinical data elements in the home care and hospice dataset its main purpose is to support administrative and financial decisions.

Provider-Specific Datasets

Provider-specific datasets are used to collect data that supports the decisions made by a health care discipline. The discipline doing the most work in this area is nursing. Although not fully implemented, the nursing minimum dataset (NMDS) was developed in the United States to standardize and evaluate what nurses do for patients by describing patient problems, outcomes and nursing interventions. It is intended for use in nursing practice, research, education and administration, and is to be used by all nurses across all health care settings. It contains 16 data elements. Canada has a slightly expanded version of the original NMDS called the Health Information: Nursing Components (HI:NC) dataset. It contains 18 data elements. It is used to collect more patient demographic elements but has far fewer service elements than its American counterpart. Lastly, the emergency NMDS (ENMDS) includes the basic nursing data elements plus admission date, discharge date, discharge time and triage classification code (Hannah & Anderson, 1995; Williams, 1991; Werley et al., 1991; Hassett & Farver, 1995; Bradley, 1995).

The provider-specific NMDS was identified through literature reviews and consultations with various experts in the field of nursing. An important goal for the nursing profession is to define their dataset in terms that reflect the decisions nurses make and the decisions others make about the nursing profession.

Program-Specific Datasets

Program-specific datasets are used to collect data that supports the clinical activities of health care providers. These datasets focus on a specific program or domain in health care. Program-specific datasets have been developed in the areas of mental health, alcohol and substance abuse, chronic neuromuscular disease and community rehabilitation. These datasets were identified through a consultative approach that utilizes working and focus groups to identify the data elements of importance (Brooks, 1990; Ministry of Health, 1996; Strong, 1996).

Most of the work completed on program-specific datasets has been in the area of maternal health services (MHS). There are 86 data elements in the MHS dataset. These data elements were identified by analyzing the information requirements of numerous maternal health care centers located in different countries. The ultimate goal of the researchers was to identify an optimal dataset for each medical domain in health care. They believed that the shared data elements between domain datasets could provide the foundation for horizontal integration in the health care system. For example, demographic data should be the same irrespective of the domain. As well, information would be available to all those who share an interest in the patient's clinical history (Moidu, Singh, Bostrom, Chowdhury, Trell, Wigertz & Kjessler, 1992; Moidu, 1992).

Another well developed program-specific dataset is in the area of emergency care. Referred to as the EMDS, its goal is to facilitate the exchange of a patient's medical history. The idea is to have a central repository of past patient medical history data that would be accessible to hospital staff working in emergency departments across the United States. The EMDS was identified by analyzing over 1000 emergency medical records. It works in conjunction with the data elements for the emergency department (DEEDS) dataset which is a dataset that describes a patient's single encounter in the emergency department (Barthell, 1997).

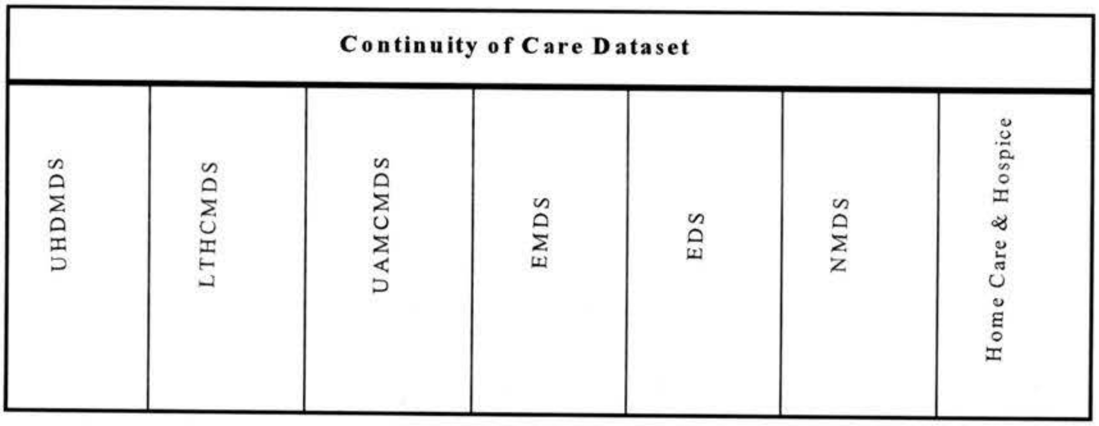
The MHS and EMDS program-specific datasets were identified using a method called data modeling. Data modeling is systematic process used to identify the information requirements of a group of users. Despite the more systematic process used to identify the information requirements of the users, and although these datasets do cover more levels of clinical care than previously defined datasets, the researchers did not identify the information needs of all groups of health care providers. The identification of the EMDS only included the analysis of medical forms and records used in the emergency department. There were no interviews with health care providers (Barthell, 1997). The identification of the MHS dataset analyzed obstetrical forms and included interviews with health care providers. Although the developers of this dataset claim it covers all groups of care providers, the only providers interviewed were physicians (general practitioners and obstetrical consultants). As a result, even though the focus was on the collection of clinical data, most of the information identified in these datasets would primarily support the decisions made by physicians (Moidu et al., 1992; Moidu, 1992).

Many datasets have been defined to support the different areas in health care. However, none of the datasets discussed so far will provide hospital and community health care workers with a summary of a patient's physical, psychological and social history. The continuity of care dataset (CCDS) is this summary.

Patient-Specific Continuity of Care Dataset (CCDS)

The CCDS focuses on the patient and his or her health care needs. It identifies the information required by health care professionals who care for patients at various types of health care organizations and stresses a more clinical, as opposed to administrative, collection of patient data. The CCDS does not define data which is unique to a particular site, provider or program but only defines those data elements that have universal application. Therefore, the CCDS would be useful to all health care providers involved in a patient's care. Lastly, the CCDS is the foundation on which these other datasets can be built. See Figure 2 below.

Figure 2 Continuity of Care Infrastructure



The CCDS was identified using a method called data modeling. The disease Acquired Immunodeficiency Syndrome (AIDS) was chosen to identify this model. AIDS was chosen because it is an information intensive disease, it affects all areas of a patient's life and it requires care from multiple providers located at multiple health care sites.

Chapter Four: Methodology

This study was designed to identify the information that needs to be shared between a hospital emergency department and a community health center both located in the Downtown South area in Vancouver, British Columbia. The objective was to identify the data elements recorded and used by physicians, nurses and social workers who care for AIDS patients at the hospital community interface. The goal was then to identify the shared data elements needed to facilitate continuity of care. These shared data elements represent a profile or summary of a patient's physical, psychological and social health history.

The methodology chosen for this study was data modeling. Data modeling is a recognized form of planning used in systems development (Moidu, 1992; Moidu et al., 1994; Hansen & Hansen, 1992). Its purpose is to increase the understanding of a business problem or environment and to represent the structure of the data within that environment as it exists in the real world. Data modeling begins with an analysis of the problem under investigation followed by an audit of the end-users requirements. From the analysis, a set of data models are designed. These models can be grouped into two categories; conceptual models and implementation models. Conceptual models focuses on the logical relationships of the data representation. They are concerned with "what" data is represented rather than "how" it is represented. Implementation models are concerned with how the data is represented (Moidu, 1992; Moidu et al., 1992; Hansen & Hansen, 1992).

Data modeling was the methodology chosen for this study because it provides a systematic process of identifying the clinical data generated and processed during patient care (business) activities. In addition, it provides the investigator with an accurate understanding of the business problem at hand. A further advantage of using this methodology is that it produces a well designed data model. This data model is the first step in the design of an electronic patient record system and serves as a common framework and medium of communication between those who will use the system and those who will implement the system. At the same time, data modeling is an iterative process in which the investigator must frequently go back to the users to verify that the information being identified is correct. This can be a very time-consuming task. In all it requires an individual who can analyze and determine end-user requirements, study existing systems of data, review processes and documentation and design a model that accurately reflects the environment being studied (Moidu, 1992; Moidu et al., 1992; Hansen & Hansen, 1992).

Table 2 below lists the data modeling steps that were used to identify and verify the CCDS as well as building a high level conceptual data model.

Table 2 Steps in Methodology

Activity	Purpose
1. Review literature on AIDS management and treatment	• identify the agencies that deliver care to AIDS patients and the health care needs of these patients
2. Develop function models - identify and interview the major health care disciplines who care for AIDS patients	• identify the functions of the health care providers who care for AIDS patients
3. Analyze the forms that are used to collect and disseminate information about AIDS patients	• determine datasets used to complete each of the identified functions
4. Verify the continuity of care dataset	• identify the overlap in data elements
5. Develop a high-level conceptual data model	• produce a foundation for the design and development of a continuity of care information system for AIDS

Scope of the Methodology

The scope of this study is as follows:

1. The literature reviewed included all areas in health care that provide health care services to AIDS patients.
2. The interviews were limited to the physicians, nurses and social workers who deliver care in the emergency department of a hospital and a community health center.
3. The forms analysis was broader in scope. Forms were collected from all the health care organizations that are part of the "cycle of care" for AIDS patients.
4. An implementation model was beyond the scope of this study.

Development of Function Models

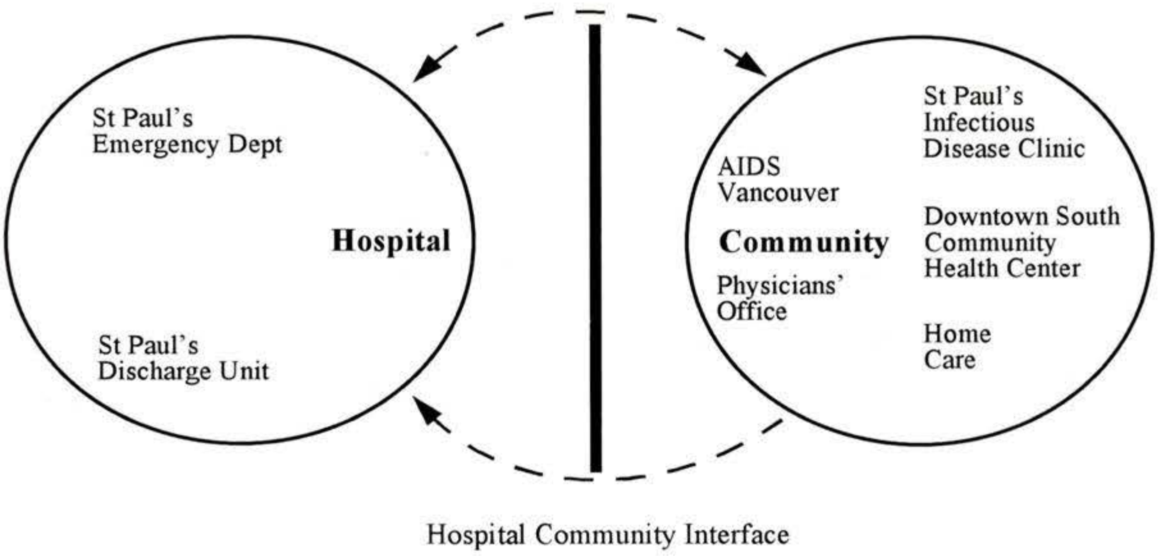
Function modeling is used to identify the information requirements of the users of a system. This is a "top-down" approach where an analyst identifies, through interviews, the functions of the users (Hansen & Hansen, 1992). In this case the users who were interviewed were health care providers. The interviews determine what these providers do when they carry out patient care activities. From this interviewing process, a model of the functions performed is developed and the information requirements (data) needed to accomplish these functions are identified. These models contribute to an increased understanding of the purpose of the system (Hansen & Hansen, 1992). In this case, the overall purpose of the system was to facilitate continuity of care for AIDS patients at the hospital community interface. The functions were progressively decomposed to as many levels as was necessary to identify the data health care providers need to fulfill their functions.

The first health care providers interviewed in this study represented the acute hospital environment. These providers included physicians, nurses and social workers from the emergency department and discharge planning unit at St. Paul's Hospital (SPH). The community health care providers interviewed were from the Downtown South Community Health Center (DSCHC). The DSCHC is a clinic which provides community based health care to a large population of AIDS patients. Its staff are representative of a multidisciplinary group of health care professionals and it is considered a miniature model of the community health care environment. All health care providers were interviewed for approximately one hour. Respondents were asked what they did when an AIDS patient was referred to them.

Forms Analysis

The objective of the forms analysis is to examine the individual datasets currently being used by health care providers and agencies who are part of the AIDS "cycle of care." See Figure 3 below. This is considered a "bottom-up" approach (Hansen & Hansen, 1992). The forms used in this study were collected from the health care agencies identified in the Vancouver Strategic Plan for HIV/AIDS Care (1995-1998 prepared by the HIV/AIDS Care Coordinating Committee). All encounter and referral forms which were used to record and communicate information about AIDS patients were examined.

Figure 3 "Cycle of Care" for AIDS Patients



Verification of the Continuity of Care Dataset

Each of the approaches above contributes to an understanding of the information requirements of the system being examined. The literature, function models and forms analysis identified a comprehensive set of data elements. The group of health care professionals who were initially interviewed were asked to complete a questionnaire which listed all these data elements. The objective of this step was to take all the data elements identified from the literature review and the data modeling process and identify the "shared elements." These shared elements would make up the continuity of care dataset.

The health care providers were asked the following questions:

1. Please identify which of the following data is helpful to you in providing care for a AIDS patient by putting a check mark in the **Yes** column. Please complete this questionnaire under the assumption that all information identified will be subject to strict rules of privacy and confidentiality.

2. What is your Discipline?

Modeling the Data

Identifying the conceptual data model began by grouping the final set of data elements into logical categories of data. In data-modeling terminology, data elements are referred to as "attributes." Attributes are specific facts that describe an object. Objects are uniquely identifiable persons, places, concepts, events or things which are of interest to an organization. Objects are given a name which conveys the meaning of the object (Hansen & Hansen, 1992). Patient, encounter, provider and medical history are examples of health care objects.

After the objects are identified, a model can be built to portray the relationships between these objects. Relationships are shown as lines between two objects. The exact nature of the relationship between objects is depicted through its degree or cardinality. The cardinality, depicted at one point where the relationship line meets the object, describes how many objects participate in the relationship. A "1" next to an object means that only one instance of the object can be related to the object on the other end. A "M" next to an object means that multiple instances of the object can be related to the object on the other end. An example of this is the relationship between a patient and a health care encounter. A patient can have multiple health care encounters, but a health care encounter can only have one patient at a time. The relationship is read in both directions to fully understand its meaning (Hansen & Hansen, 1992). The final diagram is a logical representation of the data requirements of health care providers and is meant to be a model of the "real world" of clinical AIDS care (See Figure 4 pg 39).

Chapter Five: Results

Currently, there is no patient profile that summarizes the physical, social and psychological needs of an AIDS patient who receives care from the hospital and the community. The methodology discussed in this paper was used to define this profile.

Health Care Needs of AIDS Patients

AIDS patients receive the majority of their care from hospitals, emergency rooms, specialized AIDS ambulatory care clinics, physician's offices, community health centers, community based organizations, home care, hospice and long-term care agencies. Within these settings, physicians, nurses and social workers provide the majority of care for AIDS patients. Within these disciplines, there are areas of speciality such as mental-health workers, drug and alcohol workers, counsellors and educators. In addition, volunteers play a large role in the care and support of AIDS patients (Baigis-Smith et al., 1995; Koch, 1992; Safran et al., 1994; Metrikin et al., 1995).

Despite the numerous health care agencies, providers, medications and treatments available for treating the disease, AIDS still causes much disability and affects a person's physical, psychological and social needs. Appendix 1 outlines in detail the health care needs of AIDS patients (Anderson, 1993; Berk et al., 1992; Bally, 1993; Coodley, 1993; Eisenstein & Coleman, 1990; Hurley & Ungvarski, 1994; Ungvarski, Schmidt & Neville, 1994; Makadon & Aseltyne, 1995; O'Brien & Pheifer, 1993; Knox, Davis & Friedrich, 1995; Koch, 1992; Lyketsos, Fishman & Treisman, 1995; Marco, 1995; Varghese & Crane, 1994; Lempp, deBoard & Brown, 1994; Giuse, Huber, Giuse, Brown, Bankowitz & Hunt, 1994).

Function Models

The first level of the function model identifies the purpose of a system. In this case, the purpose is to provide health care to AIDS patients across the hospital community interface. Since health care for these patients is provided by hospitals and community-based agencies, the second level of the model is to provide "hospital based services" and "community-based services." The third level identifies the types of hospital and community services that are delivered to AIDS patients. These services were identified according to the type of health care provider who provided the service.

The fourth level of the model identifies the functions performed by the health care providers during their encounter with an AIDS patient. These models reveal that in the delivery of health care, the clinical functions performed by physicians, nurses and social workers are highly similar across diverse health care settings. These functions include assessing, diagnosing and treating a patient's problems as well as counseling and teaching to provide support for or prevent further health care problems. Although there is much overlap in the data collected by health care professionals, the focus of the data varies according to the needs of the health care provider collecting the information. For example, physicians focus on the physical aspects of a patient's medical history and the presenting disease or illness. Nurses also need to know a patient's medical history, but focus more on describing and treating a patient's reaction to a disease rather than the disease itself. Thus, they require more detailed information on the patient's ability to cope with a disease or illness. Social workers focus on the factors which may affect a patient's ability to maintain his or her health. Despite these different focuses, health care information from all three disciplines must be readily available and integrated if health care providers are going to treat the patient holistically. For a list of the function models created from the interviewing process, see Appendix 2.

Forms Analysis

The forms analysis identifies the information health care providers collect as well as the format in which the information is collected. Even though the clinical data collected by the three disciplines interviewed is similar in most institutions, the ways it is collected, documented and viewed does differ. Appendix 3 lists the names of the forms collected from various health care sites that are part of the AIDS "cycle of care."

Overall, there are few standard communication tools or forms used to collect and disseminate health care information, either within specific health care agencies or across the health care spectrum. Three predominant types of forms did emerge from the forms analysis:

- the progress record
- the checklist form (collection of metadata elements)
- the specific categories form

1. **Progress Record** The progress record is basically a "blank form" and is the most common type of form used by health care providers located within an institution or agency (See Appendix 4). In the past, each health care discipline had its own progress note (usually color coded) to chart their patient

assessments, treatments and observations. A more recent trend is for all health care disciplines to chart this data on one form so that information from all disciplines is integrated. This newer form is commonly referred to as a "multidisciplinary" form. Some defined data elements, such as patient demographics, appear at the top of the form but the remaining information is documented as free-form text. The health care providers at the DSCHC use a multidisciplinary form to document and communicate patient information amongst its team members. St. Paul's Hospital staff also use this type of form to document patient information.

2. **Checklist Form** The second type of form is a simplified "checklist" of metadata elements (See Appendix 4). This type of form is not commonly used in health care, but is extremely valuable for collecting specific types of information such as HIV screening, AIDS diagnoses and clinical trial information. Most medication administration forms are also of this type. Although the format of the medication form varies in every institution or health care agency, the data collected is essentially the same. Standardized checklist forms are used at the DSCHC, AIDS Vancouver and the infectious disease clinic at SPH.

3. **Specific Categories Forms** The third type of form, "specific categories," is the most common-used form in health care for sharing information between health care providers. This form identifies the specific categories of health care information that are to be collected and documented. Common categories include medical, family and medication history but these can vary depending on the health care discipline involved. For example, physicians use a form called the patient summary or profile to summarize and communicate relevant information between patient visits (See Appendix 4).

The specific categories form is most commonly used when a patient's medical information needs to be transferred from one health care institution to another. The following are four examples of situations when this type of form is used. First, when a patient is discharged from the hospital, a "medical summary form" is dictated by the discharging physician. This form is used to summarize the medical treatment the patient was given during his or her hospital stay. It is most relevant to the patient's family physician and does little to address the needs of other health care disciplines such as nursing or social work. Nurses and social workers use an "interdisciplinary discharge plan" form to document and communicate relevant discharge information. Many of the CCDS discharge data elements are derived from this form. Second, home care nurses complete a lengthy "referral" form when a patient is discharged from the hospital and referred for home care. Some of the information needed by home care nurses may be provided in the physician's medical summary form, but this form may not be available to them before the patient is discharged. Other information, such as data on the patient's current level of functioning and nursing needs, is sometimes received but is often illegible or lacking in sufficient description to meet the needs of home care nurses. Third, a "custom" form has been designed by a local physician to be completed when AIDS patients with drug addictions are discharged from SPH. The form is primarily used to collect medical data. No nursing-related data is collected but it does provide space for information about the community agencies which are going to be involved in the patient's care after discharge. Despite its potential value, the form is rarely completed by hospital staff. Finally, an "interfacility" form is used to assist health care providers by communicating information between mental health community agencies and SPH's emergency department. Although this form was developed for patients diagnosed with mental health problems, much of the information that is collected, such as past medical history, current medications and the names of the community agencies involved in the patient's care, are just as relevant to the health care providers who care for AIDS patients.

Verification of the Data Elements - the CCDS

The CCDS contains 125 data elements and thus, is considerably smaller and less complex than the paper-based medical record. It is used to collect information on the relevant clinical data needed to support clinical decision-making across the hospital community interface. The CCDS focuses on the patient rather than the patient's encounter with the health care system. It is a holistic health care profile, not a complete patient record. It gets its basis from the patient profile, which as mentioned previously, is commonly used by physicians. It meets the needs of physicians, nurses and social workers but does not define data which is unique to a particular site, program or provider. It only identifies those clinical data elements which need to be "shared."

Two exceptions to the strictly clinical data being collected in the CCDS are the name of the facility where care is delivered and the unique lifetime patient identifier. The facility name identifies the point where the patient's encounter with the health care system took place. The patient identifier links all of a patient's encounters together. There is currently much debate around the use of one unique identifier. First, because of privacy and confidentiality reasons and second, because not every individual has one.

CCDS Data Model

The CCDS data model was built based on the data elements identified in the CCDS. A diagram of the these objects, their object names and the relationships between the objects is illustrated in Figure 4 below. In order to clearly illustrate this model, only the data groups of each object are listed. A data group summarizes the specific attributes that describe each object. For example, the address group contains the street, city, province and postal code attributes. For a more complete description of the data categories, objects, data groups, attributes and definitions of the attributes of the CCDS see Appendix 5.

The objects identified in the CCDS data model are those that are essential to facilitating continuity of care across the hospital community interface. The relationships between each object are shown by their cardinality. Identifying a specific member of each object (such as a patient) is achieved by the use of specific attributes called keys. Primary keys are the minimal set of attributes that uniquely identify each object member. The primary key or set of keys of each object in the CCDS data model are underlined. An example of a primary key in the patient object is Patient #. A foreign key is an attribute in one object which is a key in another (or possibly the same) object and provides a link between the two objects. The foreign keys are shown in italics.

A concept called specialization also allows objects to be "linked" together. The linked objects not only inherit attributes and relationships from their parent object, but can also have their own attributes and relationships. An example of specialization objects are the diagnostic tests and medication objects. They inherit properties from the intervention object. The "U" symbol illustrates objects that inherit attributes and relationships from other objects (Hansen & Hansen, 1992). Table 3 provides the name and description of each of the objects illustrated in the CCDS data model.

Figure 4 CCDS Data Model

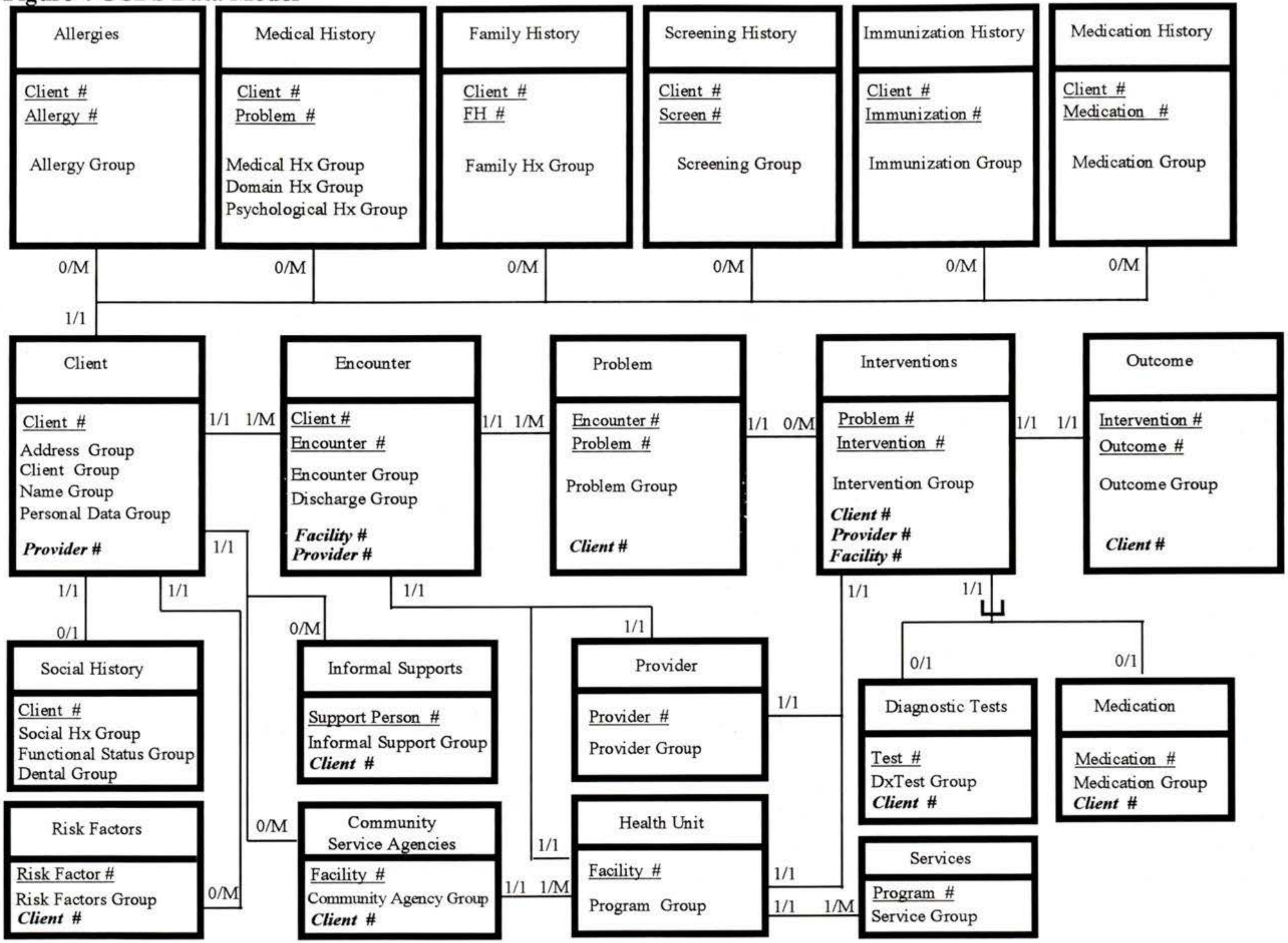


Table 3 Object Names and Descriptions

Object Name	**Description**
Patient	Demographic characteristics of a patient/patient who is the recipient of a health care service
Medical History	List of past medical diseases, conditions, procedures, surgeries and hospitalizations
Family History	History of family medical conditions which may have impact on a patient's health
Medication History	List of significant medications a patient is currently taking
Allergies	List of known allergies and reactions that a patient has to drugs, foods, etc
Screening History	List of significant past health screening services a patient has received
Immunization History	List of significant past immunizations a patient has received
Provider	Demographic characteristics of health care professional who provides services to a patient
Health Unit	Physical agency that provides a program of services
Services	Specific service provided by a program
Encounter	Interview or examination during which the provider collects and records data about a patient following which an intervention can be delivered
Problem (diagnosis)	Description of patient's reason for visit or diagnosis
Intervention	Delivery of a health related activity to a patient by a provider following an encounter (treatment/procedure/referral/test)
Diagnostic Tests	List of diagnostic tests performed or ordered during an encounter
Medication	List of medications prescribed during an encounter
Outcome	Measurement of the effectiveness and/or result of an intervention
Social History	List of social and lifestyle factors and functional status which impacts on a patient's health
Risk Factors	List of risk factors or behaviors which impact on the patient's health (smoking, alcohol)
Community Service Agencies	Name of community services a patient uses on a routine basis (ex meals on wheels)
Informal Supports	List of patient's next of kin, companions and non-professionals who provide support to a patient

Chapter Six: Discussion

This chapter discusses some of the issues that arose during the process of identifying the CCDS. It begins by discussing the information gaps that occur between the hospital and the community and the forms used in health care that contribute to these gaps. It then discusses how the CCDS supports the dimensions of continuity of care. Finally, some of the systematic benefits of using the CCDS are also discussed as well as some of the issues or problems that may arise if a CCDS is implemented.

Information Gaps Between the Hospital Community Interface

Communication problems in the current delivery of health care continue to exist. These problems will continue as the shift in health care from the hospital to the community continues. Solving these problems requires that hospital and community health workers have access to relevant patient information at the point of care.

Hospital emergency room staff need access to the following community information:

- patient's past medical history (including AIDS related data)
- primary provider (physician, case manager, social worker)
- primary caregiver and his or her phone number
- current level of functioning in the community
- community supports the patient is currently receiving

The availability of the information above would assist health care professionals in the emergency department in deciding whether or not a patient could be discharged back into the community.

Community health care workers need access to the following hospital information:

- patient's primary care provider and phone number (case manager or physician)
- copy of lab tests (if ordered in emergency department)
- follow-up supports needed
- medications prescribed (on discharge from the emergency department or a ward)
- name of the pharmacy that would fill the patient's prescriptions
- discharge status information

Although community workers do receive some standard information when a patient is admitted and then discharged from a hospital, the area where information is rarely exchanged is when the patient is treated and then discharged from the emergency department. Often the patient's family physician is not even aware that his or her patient was treated in the emergency department.

The effect of missing patient information is very significant for AIDS patients who are seen at the DSCHC. Most of the AIDS patients seen at the DSCHC are poor, have few supports in place and are taking many different medications. These patients also tend have a lengthy medical history which can include mental illness and/or drug and alcohol abuse. Furthermore, these patients are often not well informed about their illness or the medications they are taking. As a result, the AIDS patients seen in the DSCHC generally require a great deal of community support and have many health care providers involved in their care. Gathering the relevant information from other health care providers is very time consuming for community health care workers.

Evaluation of Health Care Communication Tools

1. **Progress Record -** If information is to be relevant to the intended recipient it must be organized and made legible. Although the "progress record" or blank form does provide continuity in the flow of information within an organization, it presents many problems. First, it does nothing to standardize, make legible or ensure that the information collected has the same relevance to all health care providers. Second, because of its free-text format, the amount and type of information recorded by health care providers varies. Lastly, when information needs to be communicated to health care providers located at different health care sites, it becomes difficult and time-consuming to locate specific pieces of information in free-form text.

2. **Checklist Form -** The advantage of the "checklist" form is that it enhances both the amount and type of information collected. It is legible and does not allow for misinterpretation of data. Additionally, health care providers are more apt to complete this type of form because of its convenient and standardized format. On the other hand, the checklist form is time consuming to develop and demands that a consensus be reached on all the items collected. Also, due to the complexity of health care problems, this type of form may not identify all the information health care providers need in order to make informed decisions. Finally, although many of these types of forms have been developed, most are specific to one health care agency. As a result, few have identified standardized data elements that can be shared with other health care agencies.

3. **Specific Categories Forms** - The problem with the current design and usage of the "specific categories" form is that, although it does offer the health care professional some guidance in his or her data collection, it still results in wide variations in reporting. Currently, due to the absence of policies and standardized formats pertaining to the collection and the transfer of health care information, the amount of data being documented varies among and within health care agencies. Furthermore, very few forms integrate the data collected by physicians, nurses and social workers. Most of the information collected comes from physicians. This type of data, though not always of the highest priority, is often the most accessible. Very little nursing or psychosocial data appears on the specific categories forms. Nursing-related data is often considered to be of lower priority and psychosocial information is often difficult to convey in concise form.

Overall, the data collection problems in health care increase the barriers to facilitating continuity of care. Forms that do not integrate patient information will not present a holistic view of the patient. Furthermore, relevant patient information that needs to be shared between health care providers must be extracted and re-transcribed onto other forms before it can be shared. This is a time consuming process. Most importantly, the structure of information in free-form categories or text cannot be collected or analyzed in an information system. Greater standardization of forms will help diminish these problems.

CCDS and Continuity of Care

The CCDS supports the following dimensions of continuity of care.

- **Longitudinal** - the CCDS is not a repository of all conceivable health care information. It contains the data which is necessary to link the episodes of a patient's care together and facilitate continuity of care.
- **Individual** - the CCDS is patient focused. Care is delivered with regard to the patient rather than centered around a program, service, site, or provider. It provides a holistic picture of the patient's past and present health care status.
- **Comprehensive** - the CCDS was identified by examining the health care needs of AIDS patients across many health care sites rather than at one site.
- **Flexible** - the CCDS is used to collect data that reflects changes in the patient's health care needs. For example, the availability of a recent lab value (CD4 count) or the patient's normal

functional or mental status helps health care providers quickly assess changes in the patient's condition. This may result in a change in the treatments ordered.

- **Accessible** - the CCDS assists with information sharing and communication across the hospital community interface. This reduces the barriers to health care.
- **Relationship** - the CCDS reflects the needs of a multi-disciplinary team of health care providers. This team includes physicians, nurses and social workers.

Communication

Continuity of care is a patient centered process, but the current health care system is not. Supporting continuity of care requires a dataset that can be used to collect information from a broader health paradigm than the traditional medical model which focuses on illness and disease. The CCDS accomplishes this by providing health care providers with the information they need to view a patient holistically. It is independent of any one organization and therefore can be used in any health care setting. It is closest to the program-specific datasets because it was identified through the process of data modeling. Finally, the CCDS can provide the infrastructure necessary to improve communication among hospital and community health care workers by improving the management of critical health care information when a patient is transferred between the hospital and the community. Appendix 6 provides a more detailed explanation of the CCDS as compared to other datasets.

Verifying the CCDS

Collectively, the continuity of care dataset will meet the needs of the three disciplines interviewed. However, the continuity of care dataset is still considered a preliminary dataset because it has not been tested across the continuum of care. An attempt was made to verify the CCDS through the use of a questionnaire. The responses to the questionnaire revealed several important issues.

First, although all health care professionals claim they view a patient holistically, many appear to work in isolation. This was evidenced by some health care professionals who did not see the value of collecting certain types of information that they considered irrelevant to their area of practice. For example, physicians seemed to be less interested in nursing assessments and a patient's ability to function on a daily basis. Generally, physicians were primarily interested in an ongoing problem list or patient profile. Although the physicians did indicate that all the information in the CCDS would be useful, they felt there was too much data being collected. This perception may be attributed to their lack of understanding and knowledge on information systems and on how a system would present the information to them.

Various nurses working in the community health center were also interested in different types of information. For example, the alcohol & drug abuse nurse was primarily interested in the patient's social history and discharge information. The mental health nurse was more interested in the patient's psychological history, medications and the community supports the patient was receiving. The community clinical nurse was the least interested in discharge summary information. Since discharge information has traditionally not been shared with community nurses, excluding home care nurses, some nurses may not recognize the value of having this information easily accessible to them. Home care nurses found all patient information relevant. These nurses usually work in isolation and have the least access to current patient information. Furthermore, because of the setting in which home care is delivered, communication among other health care professionals is limited.

Finally, some concerns were expressed by the hospital social workers. One concern was noted in a comment made by a social worker concerning psychological history and discharge information. She indicated that this information would be assessed at the time a patient was seen by the social worker and she would not rely on the assessments of other health care providers, including other social workers. The CCDS is not intended to replace the assessments of other health care providers; rather, its purpose is to provide important information to facilitate continuity of care. A second area of concern to hospital social workers was the implications of sharing information due to the Freedom of Information and Protection of Privacy Act. Social workers could not accept the possibility of certain types of information being made available to other organizations even though this information is routinely shared over the telephone or in writing.

Generally, community workers were less concerned with the confidentiality of information. These individuals have traditionally lacked access to hospital information and do not seem to have the feeling of strict ownership of information that hospital health care providers tend to have. This is not surprising considering hospitals have tended to be the dominant player in the health care system and have been reluctant to share information with family physicians or other health care agencies in the community. In today's health care environment, hospital and community information must be viewed as a shared resource without the strings of ownership. As the need for accurate, reliable information increases, this issue will become even more important.

Limitations of the Verification Process

One limitation to using a questionnaire to verify the CCDS was that most of the health care providers identified the information which was most relevant to their area of practice. It must be stressed that even this information is not always easily accessible to these providers on a timely basis; however, identifying this information was not the purpose of the verification process. The purpose of verifying the CCDS was to identify the data elements that need to be "shared" between disciplines.

The limitation in using the previously described verification process led to the identification of an alternative method of verifying the CCDS. Instead of using a questionnaire, the different health care disciplines would be asked to identify the information they needed from other health care disciplines to facilitate continuity of care. For example, physicians would be asked what information they needed from nurses and social workers. The same question would then be asked of nurses and social workers. These responses would then be compared to the original CCDS and the shared elements would be extracted. The advantage of using this type of verification process is it will encourage health care professionals to focus less on their own information needs and more on the information they need from other health care professionals.

Another method of verifying the CCDS, to ensure that it supports the functions of the health care professionals and the concept of continuity of care, may be to first implement an information system built on the CCDS. A feedback mechanism could be developed to monitor the information being collected by the users to identify missing or redundant data elements. However, the strengths and weaknesses of the system could be made only after the system was in widespread use.

Systematic Benefits of the CCDS

The primary purpose of identifying the data elements in the CCDS was to provide the information necessary to support the clinical decisions needed to facilitate continuity of care. The benefits of providing timely, accurate and relevant information do, however, extend beyond supporting clinical care. These benefits include the following.

First, because the information collected in the CCDS reflects a patient whose health care episodes spans many health care sites, it would provide the information needed to support the decisions made by health care planners. This information could help settle such concerns as the factors that influence the different aspects of health, such as poverty and unemployment, the resources that are required to support improvements in health, the social and economic demographics of certain patient populations, the current utilization level of services and lastly, who patients are being referred to. Such information would assist in the development of more effective health care policies as well as the monitoring, managing and evaluating of the quality of health care that is delivered.

Second, the emphasis in health care has shifted from one that monitors the process of delivering health care to one that monitors the outcomes of delivering health care. To measure these outcomes, it is necessary to track the progress of patients over a period of time in order to determine the effects of health care interventions. Determining these effects requires not only valid, reliable outcome measures, but also information about certain health care behaviors that may influence these outcomes. The prevalence of such behaviors as smoking and alcohol and drug abuse will have an adverse effect on most interventions and thus, have to be taken into account when evaluating the success of that intervention.

Lastly, the practice of evidence-based medicine includes integrating individual practitioners' clinical expertise with external clinical evidence from systematic research. The data collected in the CCDS can assist health care researchers and professionals by supplying information that provides insight into the accuracy and precision of diagnostic tests as well as the efficacy of therapeutic, rehabilitative, and preventive interventions.

Future Issues

The vision of replacing the entire paper chart with an electronic record is a distant reality. Ultimately, the information identified in the CCDS would be accessible via a computer network anytime or anywhere health care is delivered. Successful implementation of this network will create significant benefits for patients, health care providers and the health care system as a whole.

However, successful implementation is dependent on more than the definition and design of an information system. Other issues will need to be addressed before an information system can become fully functional.

One issue encountered in this study was the apparent need to change health care providers' attitudes and behavior with regards to information management. Information systems are tools that assist health care providers with managing patient information. However, they are only as good as the data they hold. Therefore, does a system need to be built to accommodate the way health care professionals currently work or will these professionals need to change their attitudes and behaviors surrounding the use of technology?

A second issue involves identifying significant encounters over insignificant ones and deciding which ones will be recorded. The CCDS was not designed to be a complete patient record. The relevance of recording every patient's encounter with the health care system is questionable. For instance, a laceration, cold or sore limb are not usually considered significant encounters and would not necessarily be recorded in this dataset. Also, significance does not imply severity, especially with patients inflicted with a chronic health care problem. The significance of an AIDS patient developing flu or cold like symptoms is far more significant than a cold or flu in a normally healthy individual. The issue of significant versus insignificant encounters will have to be examined further. Furthermore, for every encounter there is an intervention and an outcome or evaluation of that intervention. Determining the exact outcome immediately after an intervention is not always possible. It may be the next health care provider who sees the patient who is in a better position to evaluate the original intervention prescribed. Identifying the health care provider who will be responsible for collecting these outcomes is an issue that needs further discussion.

A third issue arose in regards to the length of time required by health care providers to collect all the data elements identified in the CCDS. Health care professionals are very busy people. Often they do not complete their charting until the end of the day. It is easy to foresee that the data collection process could quickly fall behind. Without timely data collection, health care providers will not have up-to-date information at the point of care. A strong commitment from health care providers is needed for this dataset to be of any value.

A fourth issue centered around the person who would enter the data into an information system. Ideally, data entry should be completed by the same health care provider who examines the patient at the time of the encounter. Typically, physicians want better access to a patient's medical history but correspondingly do not want to enter that information on a regular basis. They do agree, however, that the information identified in the CCDS is important and should be entered by someone. Data entry appeared to be less of an issue for nurses and social workers.

Lastly, patient confidentiality is a basic requirement for the ethical and legal use of information technology in health care. Currently, several measures in other computerized systems are in place to ensure patient confidentiality. Some of these measures include unique user access codes (passwords), audit trails and archive capabilities to store corrections, updates and alterations made to the patient's medical record. Additionally, safeguards in software against unauthorized access by computer hackers or disgruntled employees are in place (Infante, 1992). These measures tend to work well within an organization. The problems and controversies are more evident when patient information crosses organizational boundaries. More effective safeguard measures, such as software that records and monitors attempts to gain access to remote systems and encryption (coding of patient information) need to be in place (Goblis, 1994).

The concern with confidentiality and privacy surrounding the communication of health data is an important issue that arose as a consequence of this work. It is acknowledged that this issue is of major concern to health care providers and patients alike. However, addressing this issue further is beyond the scope of this thesis. It is considered an issue that could be addressed by a physical data model during the implementation of a database. It is important to note that although patient confidentiality is best protected by restricting access to patient data, patient care is best delivered by ensuring that health care providers have access to relevant, timely, accurate data at the point of care. Finding a balance between these two issues is the challenge.

Conclusion

Facilitating continuity of care becomes increasingly difficult as the shift from hospital-based care to community-based care continues. Consequently, there is a growing need for better communication and information sharing to accommodate this shift. The continuity of care dataset is the first step to supplying this information. The information contained in the continuity of care dataset focuses on a patient's psychological, social and physical problems. Due to this focus, the continuity of care dataset is useful to physicians, nurses and social workers located at the hospital community interface. This dataset is not meant to be a complete patient medical record, but rather a summary of relevant patient information that could address the problem of poor information exchange between the hospital and community.

The successful implementation of the continuity of care dataset can only be adequately assessed through a more rigorous verification process. Even if an information system based on this dataset is built, several issues will need to be addressed. For instance, who will enter the data, how will confidentiality be protected and will health care professionals rely on the information available to them? Lastly, the continuity of care dataset is not meant to replace the assessments of health care providers. Rather it will make available important information that, traditionally, has not been accessible to providers.

However, the availability of timely and valuable information may not improve the clinical decisions health care providers make. Information technology alone cannot solve the information management problems that exist in health care. Hardware and software technology are only tools that can be of assistance in solving these problems. Instead, it is the human components of the process who must learn to rely on and utilize the data that is collected.

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Appendices

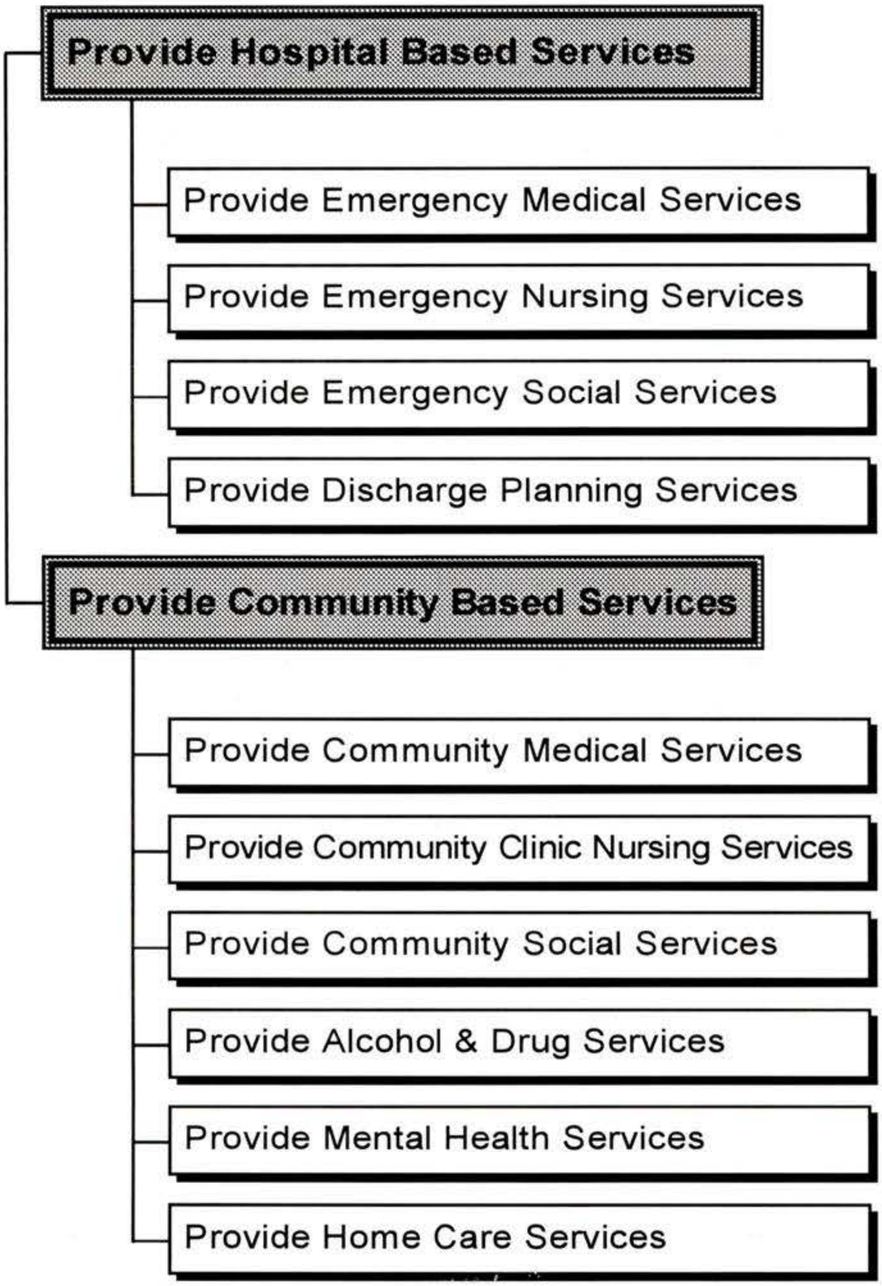
Appendix 1 Health Care Needs of AIDS Patients

Data Area	Data Element
Demographics	personal health number, patient service enrollment, SIN, eligibility for entitlements, full name, full address, home & work phone number, DOB, gender, race, ethnic background, wait list status, date of death
Legal Data	durable power of attorney, healthcare proxy, living will, guardianship, patient special requests (DNR orders)
Physiological Data	pain, discomfort, fever, chills and sweats, dyspnea, weakness, fatigue, lethargy, cough, skin lesions, nocturia, visual impairment, paraparesis, oral lesions, weight loss and diarrhea, infections, bowel/bladder function, renal function, appetite, nutrition (diet), weight, oral intake, disfigurement, insomnia
Medical History Data	medical problems, date identified, how long ago, code, date resolved, previous hospitalizations, surgeries
HIV/AIDS Data	Date of HIV Positive test, test type (western blot), date of first AIDS dx, CDC classification or HIV Stage, risk group, opportunistic infections
Psychological Data	mental disorders, psychiatric disorders, mood swings, mania characteristics, drug & alcohol abuse, personality disorders, antisocial behavior, major depressions, cognitive, behavioral and emotional problems, memory deficit, depression, anxiety, impaired judgment, dementia, intoxication, suicide attempts
Psychosocial Data	mental status, fear, poor self concept, loneliness (due to losses), anxiety, unresolved grief, perceived lack of control, poor coping mechanisms, sexual dysfunction, social isolation, multiple looses and death, anticipatory grieving, decisional conflicts, hopelessness, powerlessness, panic attacks, stress
Social Data	primary language spoken, life partner, availability of transportation, welfare assistance, religious beliefs (spiritual needs), employment, legal & financial assistance, child care services, income, living arrangements, type of housing, security of housing, family interactions, marital status, motivation, self concept, sleep, activity, smoking, sexual practices, personal hygiene, risk factors (stressors, smoking, alcohol or drug abuse), primary health care provider's name, patient's knowledge of health status, compliance with treatment, prognosis (as per GP)
Family Data	problem, relation, HIV status of patients sexual partner, family members, children, family history
Cognitive Impairment Data	affect (violent, suspicious, aggressive), consciousness, orientation, normal mental status, altered mental status (alert/oriented, confused), speech impaired, ataxia, memory deficit, communication problems, emotional status
Laboratory Values & Diagnostic Testing Data	T4 cell count, current CD4 count, hematology, biochemical, immune testing, chemistry profile, CBC, blood cultures, (aerobic, anaerobic and fungal), U&A C&S, liver function tests, serologic testing for syphilis serum testing for cryptococcal antigens, toxoplasma and coccidioides serologies and CXR, name, date & result of test
Allergy Data	type, reaction

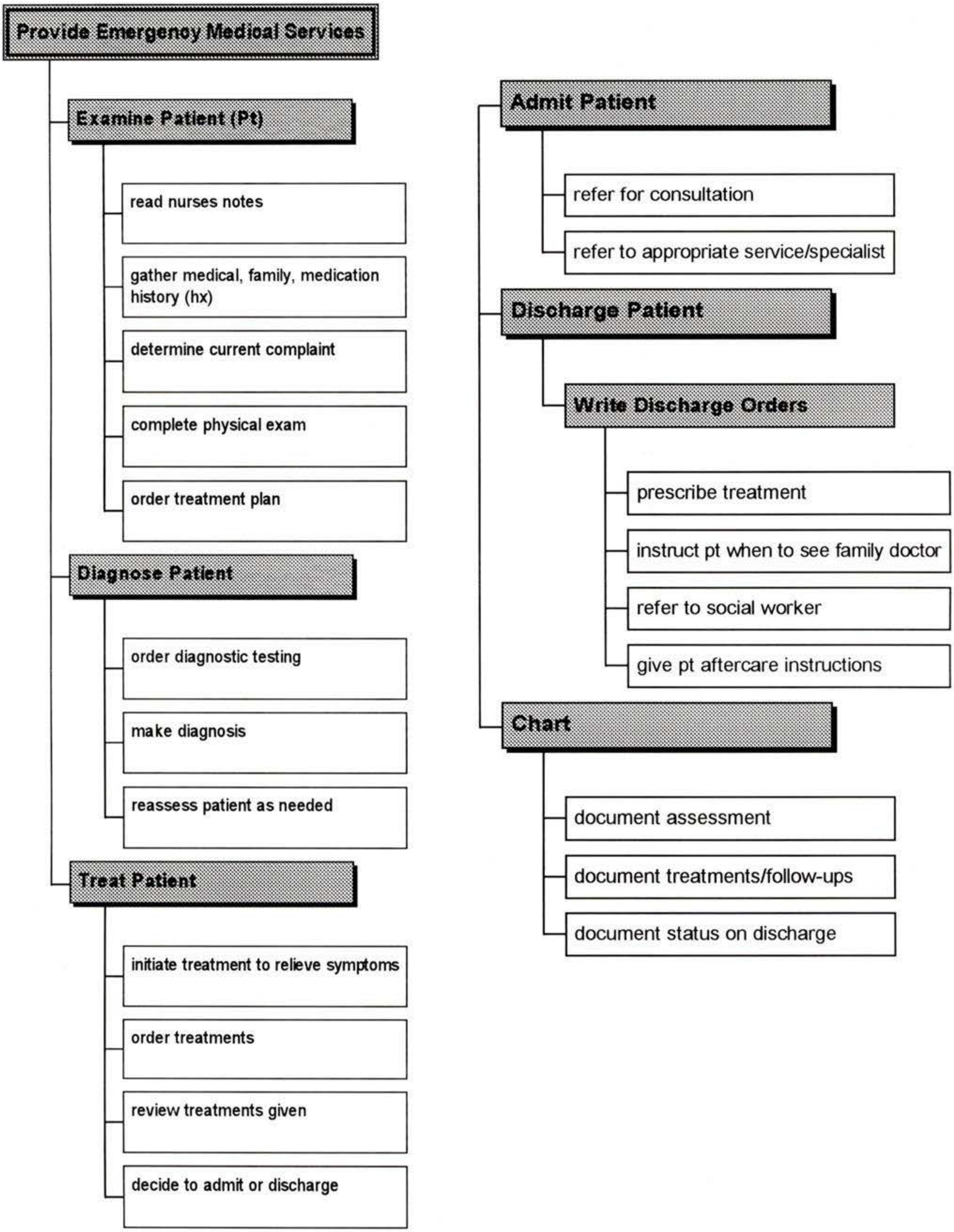
Data Area	Data Element
Medication Data	antivirals, clinical trials medications, ability to take medications, prophylaxis drugs, drug interactions, ability to self medicate, medication supervision and administration, name, type, duration, dose, frequency, start & stop date, reason for discontinuation, discontinuation date
Functional Status Data	assistance with cleaning, laundry, shopping, meal preparation, bathing, dressing, treatments, stairs, walking, mobility, transferring, dressing, toileting, eating, equipment or physical aids needed, sensory impairments--speech, sight, learning or areas of anesthesia and or paresthesia bladder/bowel incontinence, physical disabilities
Screening Data	date done, type - TB screening
Immunization Data	date, type, series no. - tetanus, diphtheria, toxoid, poliovirus, pneumococcal, hepatitis B
Dental Data	dentist's name, last seen
Encounter Data	date, time of visit, patient's reason for visit, admission or primary diagnosis, referrals, referral location, referral date, interventions (treatments, tests, procedures and result of interventions)
Discharge Data	location, transportation, medication administration, supports needed, supports available, help at home, who's notified of discharge, follow-up appointments needed, discharge date, discharge diagnosis
Health Care Providers Data	name, type, affiliation, phone and/or fax number
Health Care Organization Data	name, number of facility, type of facility, service or department in facility, contact person
Community Networking Data	informal social network - personal support, family, caregivers personal relationships names and phone numbers, notified of admission or discharge, services and contact names from other agencies involved in patient's care (referrals to AIDS clinics, public health departments, home health care, social services, volunteer agencies vocational medical care services nutritional needs) follow-up appointments, community supports accessing (PWA, AIDS Van)
Agency Data	name, type, service provided, contact names, phone & fax numbers, date services started
Health Management Data	education, preventing transmission--safer sex, safer drug use, donation of sperm or organs, reproduction, risk category, noncompliance, supportive counseling, exercise and stress reduction, need for rehabilitation therapy, specific nursing and medical treatments required

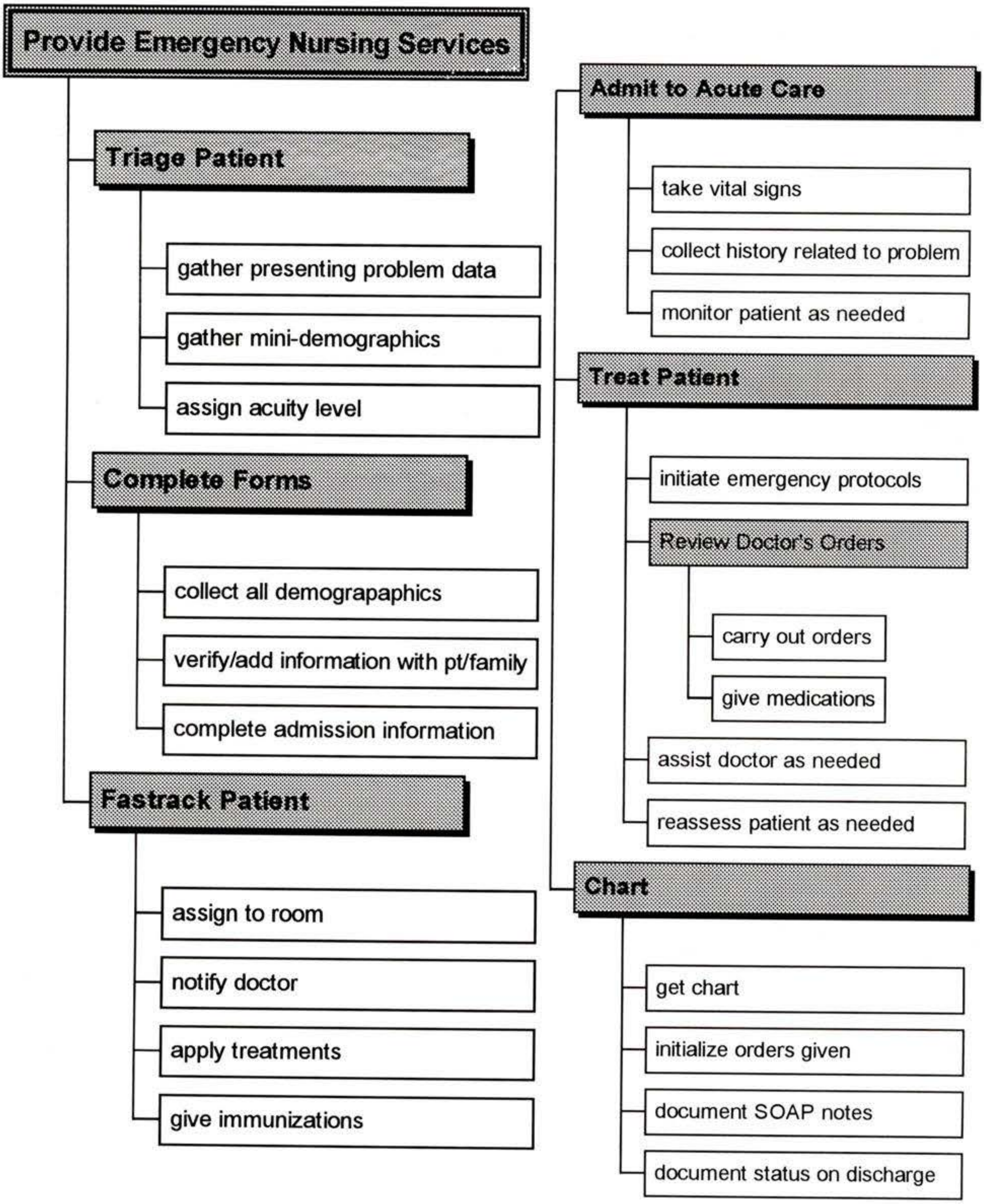
Appendix 2 Function Model Diagrams

Provide Care to AIDS Patients at Hospital Community Interface

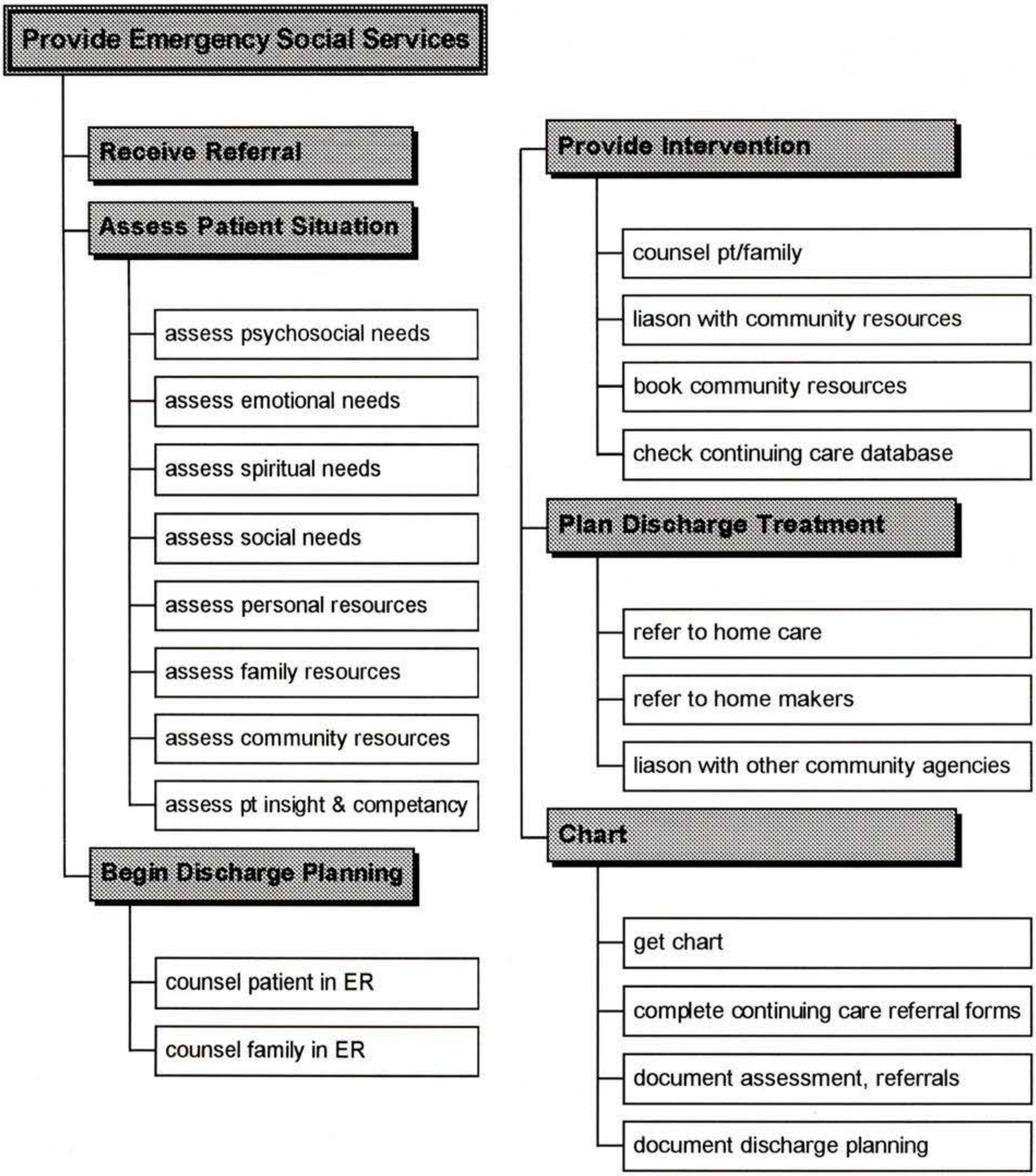


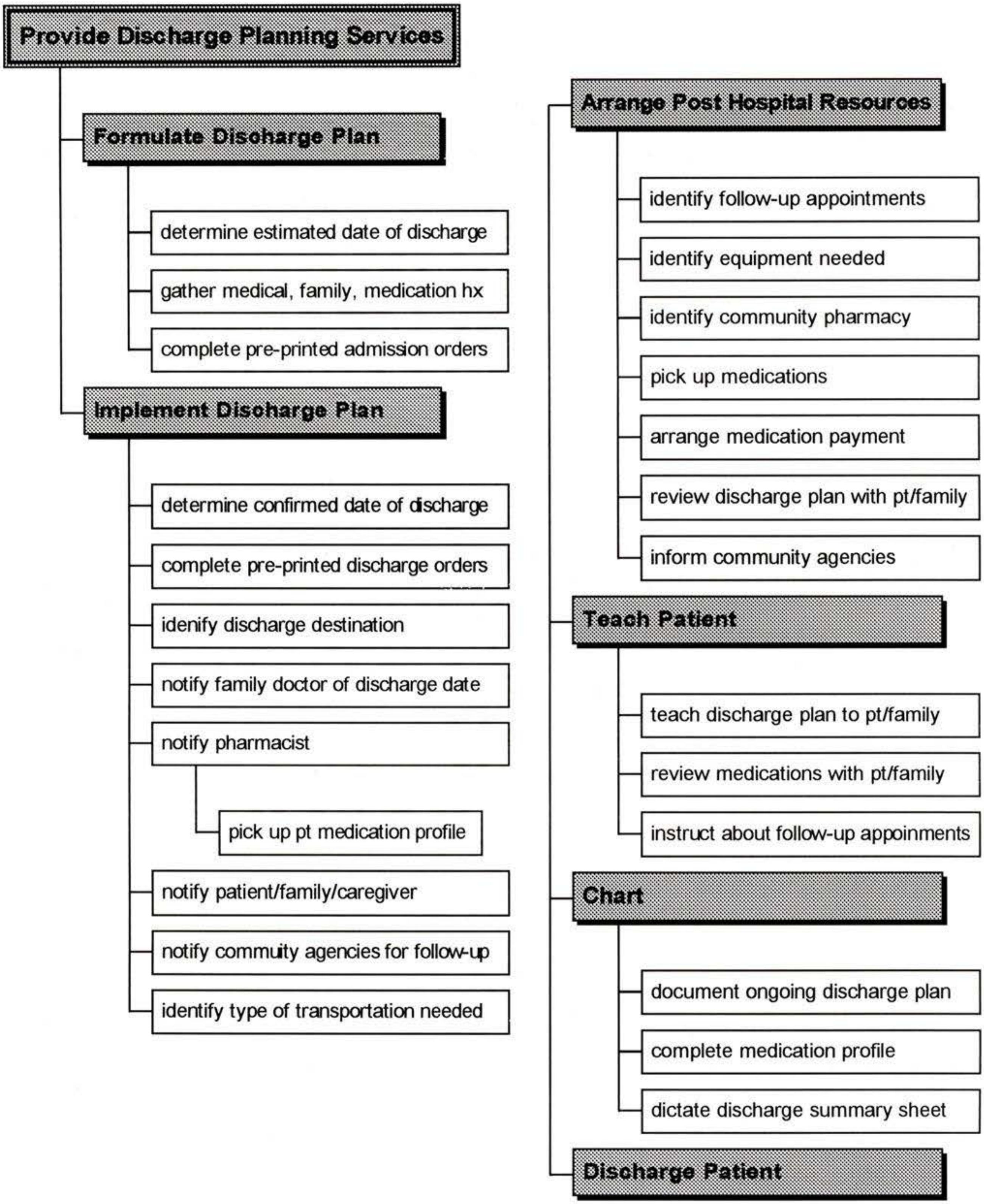
Emergency Department - Emergency Physician




Provide Emergency Nursing Services
Triage Patient
gather presenting problem data
gather mini-demographics
assign acuity level
Complete Forms
collect all demograpaphics
verify/add information with pt/family
complete admission information
Fastrack Patient
assign to room
notify doctor
apply treatments
give immunizations
Admit to Acute Care
take vital signs
collect history related to problem
monitor patient as needed
Treat Patient
initiate emergency protocols
Review Doctor's Orders
carry out orders
give medications
assist doctor as needed
reassess patient as needed
Chart
get chart
initialize orders given
document SOAP notes
document status on discharge

Emergency Department - Social Worker




Provide Discharge Planning Services
Formulate Discharge Plan
determine estimated date of discharge
gather medical, family, medication hx
complete pre-printed admission orders
Implement Discharge Plan
determine confirmed date of discharge
complete pre-printed discharge orders
idenify discharge destination
notify family doctor of discharge date
notify pharmacist
pick up pt medication profile
notify patient/family/caregiver
notify commuity agencies for follow-up
identify type of transportation needed
Arrange Post Hospital Resources
identify follow-up appointments
identify equipment needed
identify community pharmacy
pick up medications
arrange medication payment
review discharge plan with pt/family
inform community agencies
Teach Patient
teach discharge plan to pt/family
review medications with pt/family
instruct about follow-up appoinments
Chart
document ongoing discharge plan
complete medication profile
dictate discharge summary sheet
Discharge Patient

Community Doctor - Family Physican

- **Provide Community Medical Services**
  - **Assess Client**
    - determine reason for encounter
    - take medical/family/social/medication hx
    - take hx of present problem
    - review systems
    - complete physical exam
    - continue history taking
  - **Make Diagnosis**
    - order lab tests
    - order x-ray
  - **Provide Treatment**
    - determine protocol for diagnoses
    - give reassurance
    - order drugs
    - order treatments
    - give treatment
  - **Refer Client**
    - refer to internal health care provider
    - refer to external health care provider
    - refer to other health care agency
  - **Evaluate Treatment**
    - reassess client
  - **Chart**
    - document initial assessment
    - document treatments given
    - document outcome
    - code ICPC diagnoses
  - **Discharge Client**
    - write follow-up instructions
    - write medication perscriptions

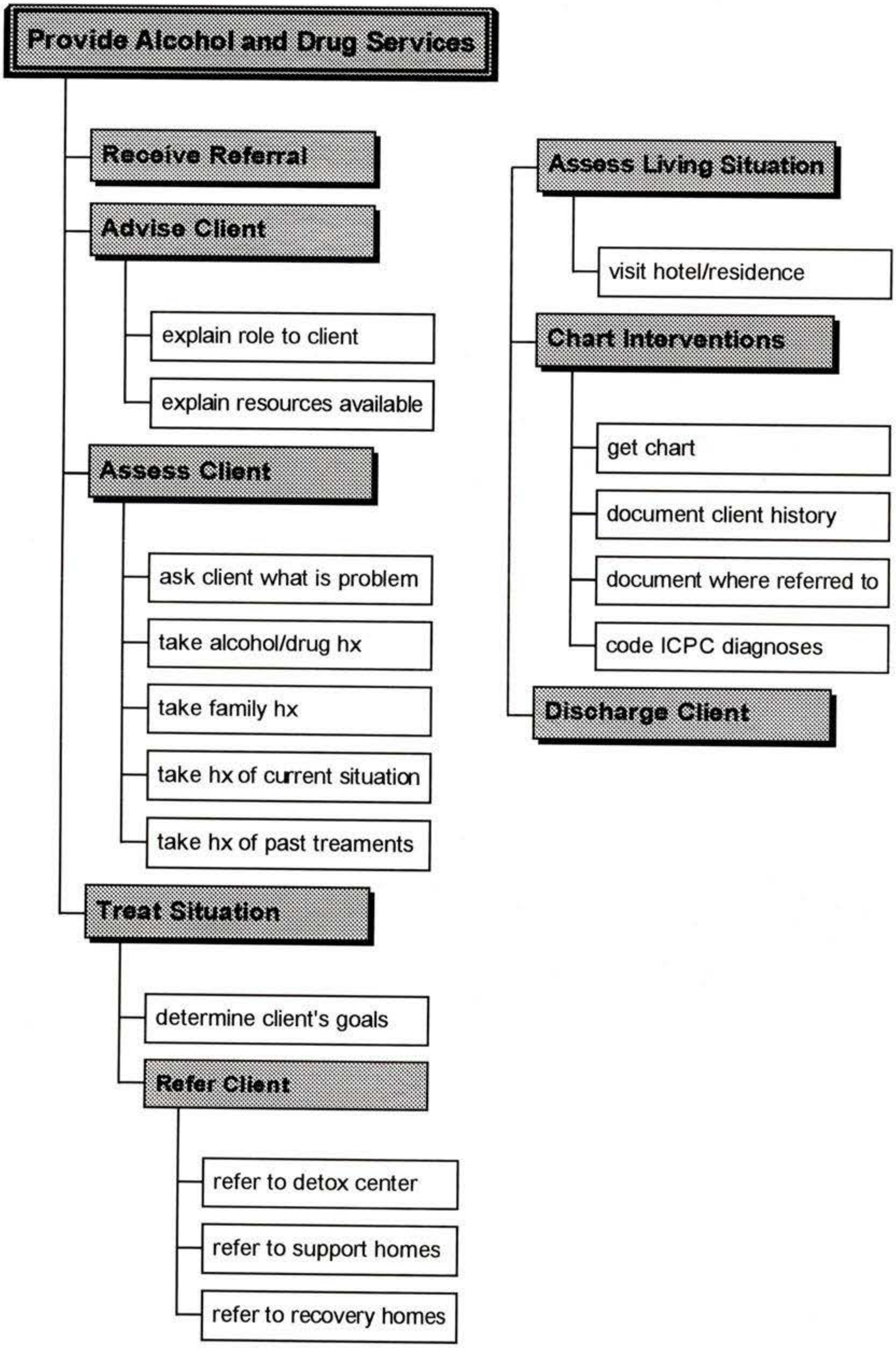
Provide Community Clinic Nursing Services

- **Receive Referral**
- **Assess Client**
  - collect screening, family, medication hx
  - determine current complaint
  - perform pre-counselling
  - perform risk assessment
- **Order Diagnostic Tests**
  - collect blood and urine samples
  - test for HIV/STD
  - screen for TB
- **Treat Client**
  - vaccinate and immunize
  - treat wounds/change dressings
  - check for parasites
  - teach client
  - coordinate case conferences
- **Refer Client**
  - refer to hospital specialists/clinics
  - refer to other health care providers
  - refer to other community agencies
- **Chart**
  - get chart
  - document care provided
  - document treatments/follow-ups
  - complete AIDS and STD forms
  - complete TB forms
  - code ICPC diagnoses
- **Liason with Community Agencies**
  - call other community agencies
  - complete forms for TB clinic
  - teach patient care groups at PARC
  - trace TB contacts
- **Dicharge Client**

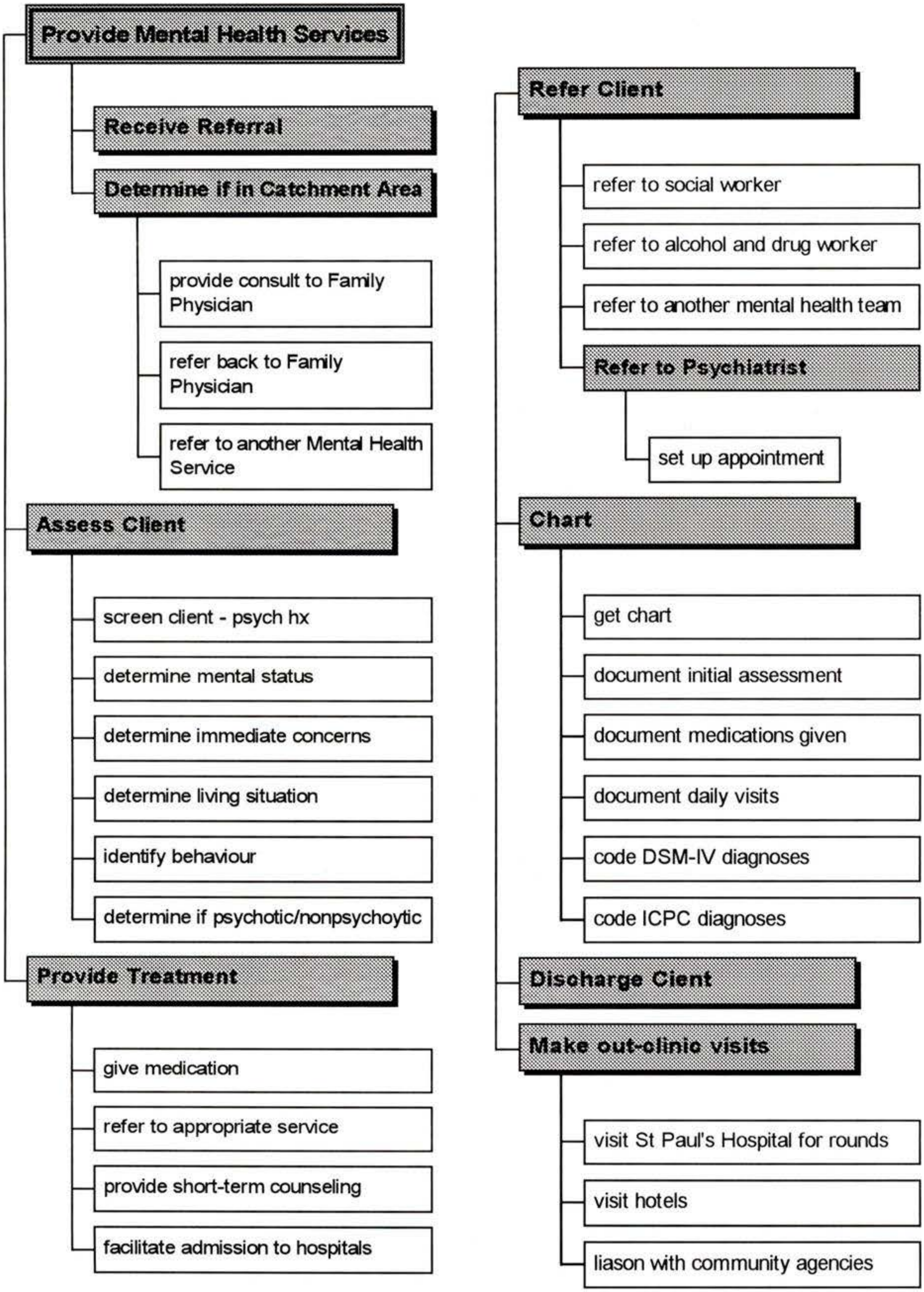
Community - Social Worker

- **Provide Community Social Services**
  - **Receive Referral**
  - **Assess Client Situation**
    - identify current issues
    - gather social history
    - make bond with patient
    - provide support
  - **Treat Situation**
    - encourage into care
    - provide options
    - provide support
    - provide short-term counseling
  - **Refer Client**
    - refer for longer counseling
    - refer to family services
    - discharge without referral
    - re-book for follow-up
  - **Chart**
    - get chart
    - document current situation
    - document where referred to
    - document whether coming back
    - code ICPC diagnoses
  - **Develop Community Support**
    - attend AIDS dementia meetings
    - liason with Neighborhood Advisory Council
    - identify community health/social issues
    - review continuing care policies

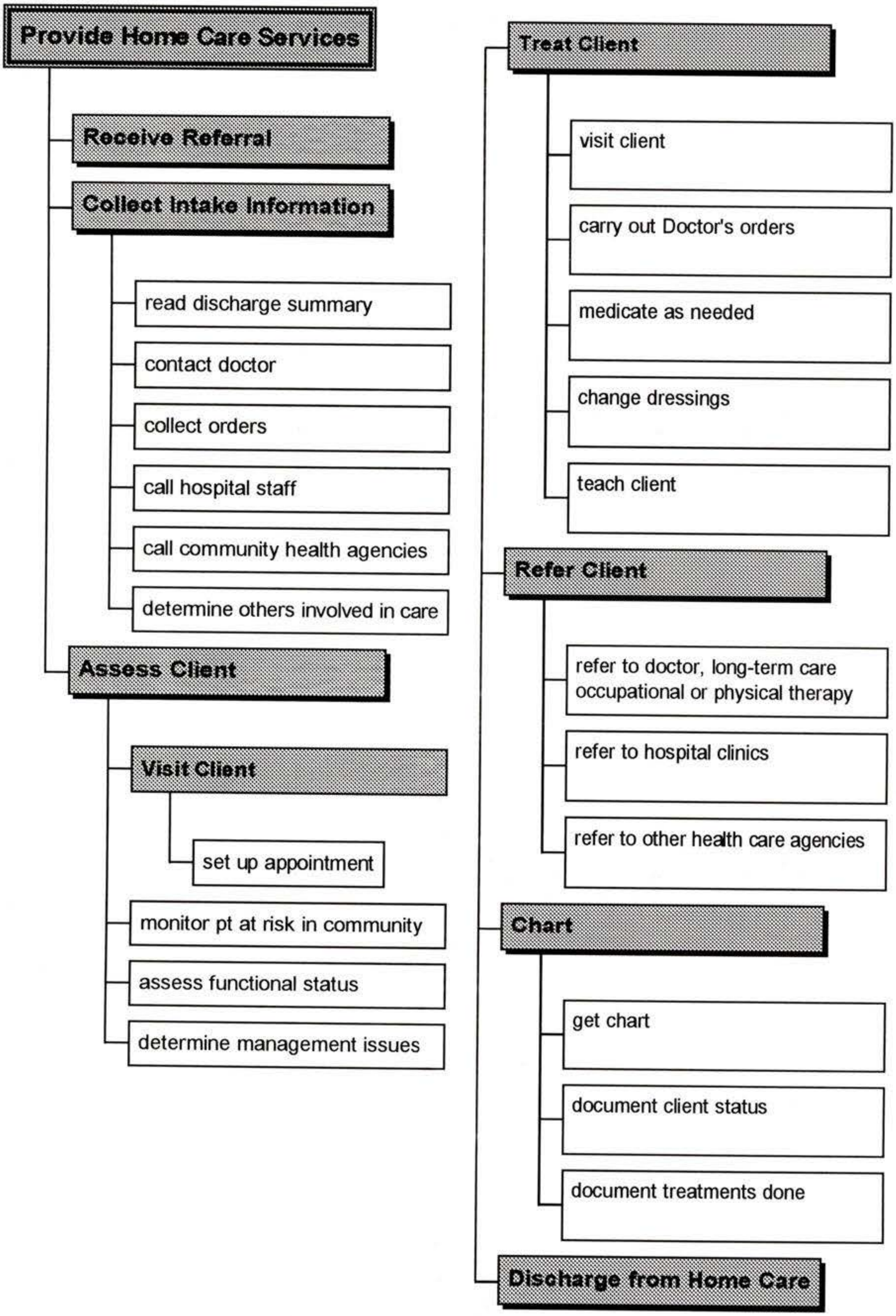
Community Nurse - Alcohol & Drug Worker



Community Nurse - Mental Health Worker



Community Nurse - Home Care



Appendix 3 List of Forms Analyzed

Location		**Form Name**
St. Paul's Hospital	**Emergency Department**	Continuing Care Clinical Services Referral
		Physician Admission Orders for CTU/Family Practice
		Emergency Physician Assessment
		Community Agency Communication Form
		Emergency Department Communication Form
		Emergency Nursing Triage/Fast Track Treatment Record
		Emergency Nursing Assessment
		Emergency Dept. Report After Care Patient Instructions
	Discharge Planning Unit	Summary Sheet (Medical)
		Patient Medication Profile
		Social Work Department Report Form
		Interdisciplinary Discharge Plan
		Physician Orders - Discharge Orders
		SPH HIV/IDU Flow Sheet
	Infectious Disease Clinic	Progress Record
		Referral Form
		Continuing Care Clinical Services Referral
		Physician's Orders
		Consultation Record
		Social Work HIV Psychosocial Assessment
Downtown South	**Community Health Center**	Patient Record Summary, Patient Profile, Patient Summary
		Virology and Reference Lab Form
		DTC (Chemistry, Hematology, etc) Lab Form
		Syphilis & HIV (Tests) Lab Form
		Encounter Sheet
		HIV/AIDS Related Illness/Medications
		HIV/AIDS Flow Sheet
		Release of Information
		STD/HIV Pre-Test, Post-Test, Follow-Up Counseling Visit
		Health Needs Assessment
		Medication Order Sheet
		Doctor's Medication Order
		Progress Notes (Medical, Allied Health, Mental Health)
Physician's Office		Progress Note
		Patient Profile
		Heroin Sheet
Continuing Care	**Home Care**	Community Health Referral
		Physician's Referral/Orders
		Drug Profile
Community Based Organization	**AIDS Vancouver**	Project Sustain: Patient Assessment Form

Appendix 4 Examples of Forms

St. Paul's Hospital
1081 Burrard Street, Vancouver, British Columbia V6Z 1Y6
(604) 682-2344

PROGRESS RECORD

DATE	

STD/HIV PRETEST COUNSELLING VISIT

Client ID: ____________________ **DOB:** ______________ **Sex:** __________

City: ____________________ **Postal Code:** __________

Previous HIV Test: __________ **Date:** __________ **Where:** ____________________

Previous STD: __________ **Date:** __________ **Previous STD Screen:** ______________

Sexual Preference: __________ **No. Partners (6 months):** __________

Present Health: ______________ **Symptoms:** ______________________________

Risk Factors:

Blood/Blood Products: ______________________________

IVDU: __________ Last Used: __________ Shared Needles: ______________

High Risk Partners: ________________ Occupational: ______________

Unprotected Sex: __________ Last Encounter: ______________

Sexual Activities:

	Protected	Unprotected	N/A	Date
Genital	______	______	_____	________
Oral	______	______	_____	________
Anal	______	______	_____	________
Rimming	______	______	_____	________
Sex Toys	______	______	_____	________

Counselling Completed:

_____ Transmission (Body Fluids)

_____ Risk Activities (Past/Present)

_____ Window Period

_____ Interpretation of Results

_____ Safer Sex Guidelines

_____ Needle Exchange

_____ Follow-up Counselling

_____ Repeat Testing __________ Months

Client's Concerns/Reaction: ____

____

____

Tests Done: ____

Comments: ____

Clinician: ____________________ **Date:** ______________

5/2/96

4-93/01

PATIENT SUMMARY

AME: ____________________

OB: ____________ GENDER: M F

HN: ____________________

IN: ____________________

ALLERGIES / ADVERSE DRUG REACTIONS

ONGOING MEDICAL CONDITIONS

PAST MEDICAL HISTORY

SCREENING / IMMUNIZATIONS / MISC.

LONG TERM MEDICATIONS

FAMILY & PERSONAL HISTORY

Appendix 5 Continuity of Care Dataset (CCDS)

Data Category	Object	Data Group	Attribute	Definition of Attribute
Patient Elements	**Patient**	**Patient ID Group**	Personal Health No	Medical insurance number - links encounters across health care system
			SIN	Personal identification number
			DOB	Date of Patient's birth
			Gender	Classification of sex based on reproductive function for a Patient
		Address Group	Street Address	Street location or other designation of a Patients usual residence
			City	City of address
			Province	Province of address
			Postal Code	Postal code of address
			Home Phone Number	Home phone number
			Work Phone Number	Work phone number
		Name Group	First Name	Current legal first name of Patient
			Middle Name	Current legal middle name of Patient
			Last Name	Current legal last name of Patient
		Personal Data Group	Marital Status	Single, Married, Divorced, Separated, Partner
			Height	Patient's height
			Primary Language	Language Patient most commonly uses to converse in
			Race	Patient's nationality
			Ethnicity	Patient's cultural group
			Religion	Patient's practicing religion
			Continuing Care No.	Continuing care database number
			Date of Death	Date of Patient's death
			Primary Provider	Primary provider who manages a Patient's care (family physician, case manager)
Encounter Elements	**Encounter**	**Encounter Group**	Encounter Date	Date Patient is seen by health care professional

Data Category	Object	Data Group	Attribute	Definition of Attribute
			Encounter Type	Type of interaction with a health care provider (ex home care, clinic, hospital)
			Encounter Location	Name of location where encounter took place
			Reason for Encounter	Patient's reason why they are seeking health care
			Wt	Patient's weight at this encounter
			Comments	Additional comments on encounter
		Discharge Group	Discharge Date	Date encounter ended (either discharge or departure date)
			Most Responsible Diagnosis	Final diagnosis submitted by health care provider which has been responsible for the greatest portion of the encounter
			Discharge Disposition	Disposition provides statement of next step in care of Patient
			Managing Medication	Can patient take, pay for and obtain medications prescribed
			Notified of Admission/Discharge	Persons aware of Patients discharge
	Problem	**Problem Group**	Diagnosis	Disease associated with the condition for which the Patient seeks care
			Diagnosis Code	Numeric coding scheme for diagnosis (ICD, ICPC)
	Intervention	**Intervention Group**	Intervention Type	Type of intervention prescribed during an encounter or upon discharge (procedure, treatment, referral, consultation test, medication)
			Intervention Name	Name of specific intervention
			Date Completed	Date intervention was performed
			Referral Name	Name of provider Patient referred to for follow-up
			Referral Location	Name of facility (agency) Patient referred to for follow-up
			Comments	Comments on intervention prescribed

Data Category	Object	Data Group	Attribute	Definition of Attribute
	Medication	**Medication Group**	Name	Name of medication prescribed
			Dose	Quantity of medication prescribed in a single dose
			Frequency	Frequency of which medication is to be taken
			Route	Identification of the medication route
			Indication	Reason medication prescribed
			Start Date	Date medication to be commenced
			Discontinue Date	Date medication discontinued
			Reason for Discontinuation	Indication of why medication was discontinued
	Diagnostic Tests	**Diagnostic Group**	Date of Test	Date test done (laboratory, procedure)
			Name of Test	Name of test performed
			Result	Result of test
	Outcome	**Outcome Group**	Evaluation Date	Date outcome recorded (follow-up date)
			Outcome	Evaluation or result of the intervention prescribed during the encounter
Clinical Care Elements	**Allergies**	**Allergy Group**	Diagnosis Date	Date allergy diagnosed
			Name	Name of allergen causing an allergic or adverse reaction in a Patient
			Reaction	Clinical description of the reaction to a particular allergen or agent
	Medical History	**Medical Hx Group**	Medical Diagnosis	Previous significant medical diagnosis
			Date Done/Diagnosed	Date medical problem was first encountered by the Patient
			Hospitalizations	Previous significant hospitalizations
			Surgeries	Previous significant surgeries
			Procedures	Previous significant procedures
			Date Resolved	Date medical problem resolved
		Domain Hx Group	CDC Classification	Stage of HIV/AIDS disease

Data Category	Object	Data Group	Attribute	Definition of Attribute
			Risk Group	Heterosexual/Homosexual/IVDU/Bisexual
			Date of HIV+ test	Date Patient diagnosed as HIV positive
			Date of First AIDS Dx	Date of first AIDS disease
		Psychological Hx Group	Diagnosis Date	Date of psychological diagnosis
			Psychological Diagnosis	Psychological diagnosis
	Family History	**Family Hx Group**	Diagnosis Date	Date medical problem diagnosed
			Disease	Medical problem/disease of family member
			Relation	Relationship of family member to Patient
	Screening Hx	**Screening Hx Group**	Date	Date of screening
			Test Type	Previous screening test performed
	Immunization Hx	**Immunization Group**	Date	Date of immunization
			Type	Previous immunizations performed
			Series No.	Series no. of immunization
	Medication Hx	**Medication Group**	(See Medication Hx Group)	(See Medication Hx Group)
Health Status Elements	**Social History**	**Social Hx Group**	Date of History	Date social history taken
			Living Arrangements	Patient's current living arrangements (hotel, apartment, street)
			Living With	Primary person Patient currently resides with
			Education Level	Highest level of education Patient has achieved
			Employed	Patients employment status
			Occupation	Patients occupation
			Income	Identifies employment income, long-term disability
			Social Assistance	Supplement income received from social assistance

Data Category	Object	Data Group	Attribute	Definition of Attribute
			Advance Directive	Special instructions regarding organ donation, resuscitation, power of attorney
			Pharmacy (R)	Pharmacy which fills Patients prescriptions (restricted pharmacy)
			Knowledge of health status	Patient's understanding of his or her health problems/medications etc.
			General Compliance	Patient's compliance with treatment regimen, follow-ups
			Prognosis	Prognosis of disease condition
			Normal Mental Status	Patient's normal affect/mental status (depression/aggressive/suicidal)
		Functional Status Group	Ambulation	Patient's ability to ambulate with or without mechanical aids
			Disabilities	Physical or mental limitations
			Vision	Patient's ability to see with glasses if normally worn and in good light
			Hearing	Patient's ability to hear with hearing aid if usually worn
			Communication level	Patient's usual method of conveying information, ideas and needs to others
			Physical Aids	Mechanical aids needed to assist with activities of daily living
			Dressing/Bathing	Patient's ability to dress/bathe self
			Shopping/Cooking	Patient's ability to shop/cook for themselves
			Bowel Control	Amount of control over bowels
			Bladder Control	Amount of control over bladder
			Activity Tolerance Limitations	Level of activity Patient can tolerate without fatiguing
			Nutrition/Diet	Assessment of Patient's nutritional status
	Community Service Agencies	**Community Agencies Group**	Facility Name	Name of health care agency delivering services

Data Category	Object	Data Group	Attribute	Definition of Attribute
			Service Type	Type of service, program or care being provided
			Date Care Initiated	Date patient started receiving agency services
		Dental Group	Dentist's Name	Name of Patient's dentist
			Date Last Seen	Date dentist last seen
	Risk Factors	**Risk Factors Group**	Risk Factor	History of alcohol/drug/ abuse or smoking
			Frequency	Frequency of risk behaviors
Patient Support Elements	**Health Care Provider**	**Provider Group**	Provider Name	Name of health care provider
			Provider Type	Classification of health care provider (doctor, nurse, social worker)
			Phone Number	Provider's phone number
			Fax Number	Provider's fax number
	Informal Supports	**Informal Support Group**	Contact Name	Name of Patient's informal support contact
			Relationship	Relationship between the Patient and the contact person for that Patient
			Full Address	Address of contact
			Phone Number	Phone number of contact
	Health Unit	**Program Group**	Facility Name	Name of Facility that provides medical attention & health care for Patients (Continuing Care)
			Contact Name	Name of health care provider in this Facility who manages the Patient's care
			Facility Address	Location of facility
			Facility Phone Number	Phone number of facility
			Facility Fax Number	Fax number of health care facility
	Services	**Service Group**	Service Name	Name of service being provided (home support)
			Service Description	Description of service being provided

Appendix 6 CCDS Compared to Other Datasets

Data Categories

1. **Patient Elements** - Standard patient elements found in all datasets include patient identification number, date of birth, sex, race, ethnicity and residence. The number of patient elements collected in the CCDS is comparable to the emergency care dataset. The range was between 12 and 17 elements. The maternal health services (MHS) dataset was used to collect the most patient demographic elements but lacked a unique patient identifier.

2. **Encounter Elements** - In every sector of the health care environment there is a need for the development of a standard service encounter record. This record should include, as a minimum, the following standard elements: facility number or site of service, patient record number, provider name or number, episode/admission date and reason for encounter. Ideally, a summary of the problems, interventions and outcomes of the encounter should also be recorded. The datasets examined in this study all include the minimum encounter elements. The discharge and ambulatory care minimum datasets (MDSs) include data elements that describe a patient's medical diagnosis as well as the major procedures performed on the patient. The CCDS includes physical, psychological and social data elements as well as interventions and outcomes of an encounter.

   An important set of service elements are those which describe information about a patient who is discharged from a health care facility. The purpose of the discharge MDSs was to collect discharge information to monitor the costs of providing health care services. This information is only collected when a patient is discharges from a hospital ward. Discharge information is just as important when a patient is discharged from the emergency department or from a community health agency, and to be of relevance to health care providers, it must focus on the needs of the patient. The CCDS identifies a comprehensive list of discharge elements not identified in the other datasets.

3. **Clinical Care Elements** - Clinical care elements refer to past health information needed to adequately assess a patient, make a diagnosis and suggest appropriate treatments. The information needed to do this includes allergies and past medical, psychological, social, family,

screening, immunization and medication history. The data collected in the emergency care dataset is strictly a patient's physical and psychological history. The CCDS is used to collect data about a patient's complete, holistic health care history.

To adequately address the needs of a patient with a specific health care problem or disease requires some information about that problem or disease. The domain elements identified in the CCDS provide information specific to AIDS patients. Determining the domain elements that need to be shared to facilitate continuity of care is an area that needs to be examined further. Since the CCDS is only a summary of significant patient information, only the most important elements, those having universal value, should be part of this dataset. The MHS dataset is an example of a domain dataset. However, it is obvious that not all of these elements need to be shared. Examples of elements that should be shared are expected date of delivery, pregnancy risk factors, baseline blood pressure and the patient's last weight. This type of information would provide health care providers, such as emergency department staff, with information that is not easily accessible to them.

4. **Health Status Elements -** Health status elements are collected in the nursing and long-term health care MDSs. Most of the elements come from nursing derived data and focus on the functional status of an institutionalized patient. Nursing care provided to patients in the community are geared more to assisting a patient with his or her activities of daily living rather than doing these activities for the patient. The CCDS does not assume the patient is or should be institutionalized; it only addresses whether the patient is deficient in any of these areas. For example, a change in the functional status of a patient would alert a health care provider and prompt an appropriate referral to another health care provider.

5. **Patient Support Elements -** Not surprisingly, the major difference between the CCDS and other datasets is the lack of information being collected from community-based settings and providers. Patient support elements include a patient's support network. This network consists of formal, informal and community service agencies that provide assistance to a patient. The formal support network refers to health care professionals. These elements do appear in other datasets but the focus is on hospital or ambulatory clinic personnel. Informal supports are those caregivers who are not "officially" part of the health care system, yet often provide the most

assistance to a non-institutionalized patient. Examples of informal supports include family, friends and volunteers. People with AIDS have one of the most intricate informal support structures in place. Finally, the CCDS includes data elements that identify the types of community services being used, such as Meals on Wheels, as well as his or her contact names, addresses and phone numbers. Informal support and community health care services used by a patient do not appear in other datasets. Since community care is considered an integral part of the health care system, these missing support elements are significant. Without this information, a patient centered dataset cannot be considered complete.

VITA

Surname: Flanagan Given Names: Patricia Disa

Place of Birth: Saskatoon, Saskatchewan, Canada

Educational Institutions Attended:

University of Alberta, 1981 to 1983

University of British Columbia, 1989 to 1991

Degrees Awarded:

Registered Nurse Diploma 1983

Bachelor of Science in Nursing 1991

Honors and Awards:

University of Alberta	Eva Schimizu Memorial Prize	1981 - 1983
	Queen Elizabeth Scholarship	1981 - 1983
	Louise McKinney Scholarship	1981 - 1983

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Title of Thesis/Dissertation:

Continuity of Care Dataset

Author Patti Flanagan (signature) [redacted]

Patricia Disa Flanagan

February 25, 1997