The Preliminary Essential Dataset for Clinical Care and Management of Diabetes

by

Russell William Padgham

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We accept this thesis as conforming

to the required standard

[redacted]

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

[redacted]

Dr. J. Moehr, Departmental Member (School of Health Information Science)

[redacted]

Dr. A. Molzahn, Outside Member (School of Nursing)

[redacted]

Dr. R. Skelton, External Examiner (Department of Psychology)

Supervisor: Dr. Paul D. Fisher

## ABSTRACT

This study developed a preliminary essential dataset that could be used in an electronic patient record for the care and management of diabetes by family physicians. Family and specialist physicians, nurse educators, and others (n=29) were interviewed in Victoria, British Columbia. The study focused on the care family physicians provided in the community rather than care provided in institutions. The dataset was defined using the Essential Data Set Approach of Moidu et al. Systems analysis techniques were used to construct data and a conceptual models to show how this dataset could be stored in an electronic database. Rather than being tested this preliminary essential dataset was compared to existing diabetes datasets to see if the data elements described in this study are collected by those datasets. The study dataset and data structure could support provision of diabetic care according to the Canadian guidelines, if the necessary supportive data is collected.

Examiners:

[redacted]

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

[redacted]

Dr. J. Moehr, Departmental Member (School of Health Information Science)

[redacted]

Dr. A. Molzahn, Outside Member (School of Nursing)

[redacted]

Dr. R. Skelton, External Examiner (Department of Psychology)

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# 1 Introduction

## 1.1 Computer-Based Patient Records

### 1.1.1 Computer-Based Patient Records and Clinical Care

A patient record is the repository of health care information about a single patient generated by health care professionals as a direct result of interactions with a patient and/or individuals who have personal knowledge of the patient. This record is used by caregivers to keep track of the care they are providing, communicate with other health care professionals, and coordinate patient care.[1]

Traditionally, patient records have been kept on paper.[1] Major disadvantages of paper records are that the original up-to-date record is only available in one place to one person at any given time, and data are often missing, illegible, or inaccurate.[1,2] Inaccuracy and illegibility are often due to poor handwriting. With paper records, it is usually impossible to know if pages or data are missing, as there is no recording of the specific contents other than references such as tests or examinations being ordered or performed without subsequent results. As well, the manner of presentation of paper records cannot be changed unless pages are rewritten.

A computer-based patient record (CPR) is an electronic patient record that resides in a system specifically designed to support users by providing accessibility to complete and accurate data, and to aids such as alerts, reminders, clinical decision support systems, and links to medical knowledge.[1] The definition of a CPR does not include the records produced by those systems that are designed to serve the needs of a single department or specialty as these records only contain a subset of the patient record. Departmental systems are not designed to access the complete patient record or information not specifically recorded by the departmental system. Financial or

administrative systems with functions such as order entry, admitting or billing can be defined as departmental systems. The definition of a CPR system is restricted to systems that are designed to manage the entire patient care record.[3]

CPRs have been proposed as a way of addressing some of the shortcomings of paper records. For example, CPRs allow health care providers to retrieve data simultaneously in separate locations or institutions. As well, computers can be used to index or display data in ways that a paper record would not be able to support.[4] A computer can rearrange data or allow different ways of accessing or presenting data, such as graphing a series of test results. Within a CPR, information gathered over time, such as a patient history, can be displayed together. By using a longitudinal[i] computer-based record health care, professionals could reduce their reliance on patients' memory and reduce the time spent taking histories.[ii]

Despite the touted benefits and development of CPRs over the last 40 years, they are still rarely used by health care providers for patient care.[5] Most of the early systems failed to provide professionals with the information required for patient care. The main difficulty in developing CPRs is the difference between the existing paper record and the structure needed for a CPR to be effective in health care.[6] The traditional paper patient record is unstructured, mostly free-form text, with subject headings or dividers between separate sections. There are few standards for the paper record unless forms are used, apart from general guidelines on which sections to

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i A longitudinal record is one that covers a wide span of time and multiple care encounters rather than single episodes of care.

ii In fact, patient recall of episodes of acute illness has been found to be less than 50% after one year. (Rogler, L. H., R. G. Malgady and W. W. Tryon. "Issues of Memory in the Diagnostic Interview Schedule," *The Journal of Nervous and Mental Disease,* Vol. 180, No. 2., 1992, pp. 215-222.)

include.[7] Moving such a record to a computer merely transfers the burden of recording data to a different medium. If CPRs are to be successful, their content must be determined and structured according to users' needs, rather than simply being free text.

### 1.1.2 Cost Savings with Computer-Based Records

For patients with chronic conditions, records accessible by computer have been found to improve long term management and follow-up, and reduce the use of hospital resources.[8] For example, CPRs reduced the cost of caring for elderly veterans by 40% by giving all members of the health care team access to an up-to-date record. This record was used to directly record all assessments, diagnoses and therapies for patients who often had multi-faceted problems that required the attention of various specialist physicians and health care professionals.[9]

As another example of cost savings, CPRs were used in conjunction with rule-based reminders, resulting in significant improvement in compliance with diabetic care standards.[10] Compliance with care standards or guidelines has been shown to reduce the complications and costs associated with diabetes.[7,11,12,13,14] Any system that prompts clinicians for specific data items, whether directly by a reminder message or via an encounter form, will improve completeness. For example, structured data collection improved recording of recommended checks for diabetic complications.[15] In a diabetes clinic, after the introduction of a computer system, the rate of missing data for four significant findings was reduced seventeen-fold.[16] Even if a system does not have rule-based reminders, guidelines that lead to cost savings could be made available in a hypertext format for quick access.

The above examples of cost savings all require a certain structure and definition of the patient record. The CPR must contain certain data for health care professionals to efficiently determine a patient's condition and to determine which services the patient has received. Only then can the professional decide what new action to take

By complying with care standards, some cost savings could be achieved through the exchange of data and information on paper among professionals providing care and supporting people with a chronic condition. Even if data is to be exchanged on paper, this data should be defined and should only be that which is most essential to decisions on patient care.

### 1.2 Datasets and Databases

A dataset is a list of the data elements or metadata that dictates the data that should be collected about a patient on a form or within a system for a specific application or reason.[iii] Metadata in this case is synonymous with the term data field in a database record. The data entered for each data element, together with the dataset, form a database. The data entered for a data element could be logical, numerical or even a word, phrase or sentence.[17] The entire health care record can be viewed as the superset, everything from everywhere for all time. An individual dataset can be developed as a subset of the health record to serve specific decision-making purposes.

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[iii] Data are the individual values collected; metadata are descriptions of the type of data. For example Russell is to data as name is to metadata.

### 1.2.1 Need for Defined Datasets

The benefits of CPRs are contingent upon the amount, type and reliability of the information they hold as well as the structure of the information. Medicine does not have any standards for the content of patient records or for organizing that data and information except when pre-formatted forms are used.[18] Before a CPR can be designed or implemented, the content and structure of the record must be defined, otherwise the record could be created using a word processor and free text.[2] Words and phrases in sentences and paragraphs, like a letter, are free text while data stored in discrete chunks on forms or in databases are structured. Free text will not allow the application of decision support tools, such as advice according to clinical guidelines, and structured views of data; it would merely make the record more legible and available.[19]

Research and decision support require more than electronically stored free text - they require structured data entry.[20,21] A dataset is fundamental to structuring the delivery of care to follow care guidelines.[22] As well, it has been suggested that due to the lack of structure in the medical record, there is either excessive detail or a paucity of clinically relevant data.[23] For these reasons, what is needed is a way to define the data required in CPRs. To define the data required for health care overall is a daunting and overwhelming task. Defining a dataset for specific domains within health care has been recommended as a staring point for defining the structure required in the CPR.[20,23]

A way to define data essential to patient care for specific conditions is needed. Development of standards of care is often done for a specific problem or patient population.[24] To date, structured data entry for CPRs has been most successful in

more narrow areas of care such as summaries of nursing care.[5] The present project will focus on the development of a dataset for diabetes care as the single health care condition. Such development has been done for outcomes-based research for a single condition, but the level of detail in the dataset required too much time for data entry in a busy clinical setting as the focus was on research rather than patient care.[23]

One study used simulated cases to find out what data elements are collected in family medicine and what actions are taken.[25] Its author suggested that an interface should support the individual clinician's data collection habits and rules. The general goal of a good computer interface for capturing clinical data is to get an accurate clinical image of a patient into the computer in as efficient a manner as possible. A defined dataset is required *before* an interface can be developed that accommodates variability in clinical care processes. Although the design described in that study is one where the clinicians automatically generated their own sets of commonly used data elements, the design still required a pool of data elements specific to a particular class of problems.[25]

### 1.2.2 Analytic versus Operational Databases

Analytic databases typically carry all variables of interest in a single record that describes one patient, patient encounter or patient procedure. They are usually designed for direct statistical analysis. Analytic databases are used for administrative or management purposes such as studying a disease or the care provided within a defined population. A variable in an analytic database is identified by the name of the field where its value is stored. This means that the definitions of the data in an analytic database are lost if the data is moved outside of this set structure. In addition,

all data fields must be repeated in the record if this database is used to record an additional data value for a patient with an existing record.[26]

An operational database devotes an entire record to each item type and observation. In contrast to an analytic database, variables in an operational database are often defined by a code or name stored in one field, with their values stored in another field. New observations or data values for a patient may be added to an operational database without repeating all other values in the patient record.[26]

By these criteria every dataset or system reviewed for this study, where the structure is described in the reviewed article or a description of the structure been obtained from the authors, is an analytic database. Yet the article that defines the criteria for analytic database says that data for analytic databases are best obtained from operational databases.[29] This is because analytic databases are not suited to providing clinical care with its need to store every instance of test results or observations. In clinical care multiple values are needed to allow comparisons to baseline values and to see trends. The data for analytic databases should be obtained from the records being used to provide care.

### 1.2.3 Methods for Developing Defined Datasets for Databases

The data elements necessary in a patient record are predictable and are those which are relevant to the clinical decision-maker. In general, these data elements are those that provide a description of the patient in sufficient detail to support the application of clinical logic.[24] This indicates that the set of data elements necessary in the health record can be defined by considering the needs of the clinical decision-maker.

Descriptions of the process for deciding upon and determining a level of agreement on the data elements for a dataset are lacking in publications. One article contains extensive discussion of efficiencies to be achieved through structuring the diabetic patient record and the electronic interface, but this article and many others have not described the actual development of the dataset or how the data elements were selected.[27,28] For example, no standard methodology was used to decide on the data collected in the forms used for a computerized diabetes record.[12] Even the author who describes the Essential Data Set Approach used in this study does not discuss the development of the dataset in an article with a title that implies discussion of this subject.[23] This shows that studies are required which use a standard methodology for determining the elements of a dataset.

Many articles describe datasets that were developed for administrative purposes. For example, one article mentioned above describes a dataset for use in resource allocation and evaluation.[28] This is also a common feature of dataset development in the U. K., where the business processes examined in developing datasets are administrative. But it has been stated that the only way to reliably get data of sufficient quality for administration is to make its collection an integral part of the patient record system that is used for patient management.[29] This means that the processes of patient care must be examined in defining a dataset for patient management rather than focusing on administrative needs or processes.

### 1.2.4 Physician Involvement

The availability of relevant data and information, through the use of CPRs, at the place and time that care decisions are made, can positively affect the quality and cost of care.[30] However, in some institutions physicians have boycotted or vigorously

resisted the introduction of computer systems used to view results and to issue orders.[31,32] Resistance to the use of computers is often wrongly attributed to the age of physicians or lack of experience with computers.[19] Studies have shown that physicians will use computers if they believe them to be valuable for diagnosis and care.[33]

Methods that involve physicians in the development of computer systems and datasets are needed to ensure that the resulting design are of value to physicians. Any new systems that are developed must support the contemporary model of care including the way family physicians practise medicine. Physicians are becoming more familiar with computer technology, as shown by the increasing use of electronic mail, bibliographic retrieval services and practice management software.[34,35] In the last five years there has been great interest in involving physicians in computer system testing, including physicians outside of academic medical centres. However, the focus seems to have been on testing whether systems can improve the quality or efficiency of care overall, often with no regard for whether it is efficient for physicians to use these computer systems. In fact, according to a British Workshop Report, lack of involvement of physicians and other potential users of systems accounts for four of the six main reasons for failures of computer-based diabetic record systems.[36]

In the U. K., a significant proportion of family physicians' offices have computers - 50% in 1992 with this forecasted to rise to 75% by the end of 1993. However, this has been done with much support from the National Health Service. In an area of London with about the same population as British Columbia, £2 million (approximately $5 million Canadian) was allocated for computerization of all primary care practices by 1994. Even at this level of support, it was expected that the government would have to make computerization mandatory, provide substantially more funding and make

computers more effective for individual physicians' offices or else significant numbers of practices would remain without computers.[29]

In the Netherlands, by 1992 50% of family physicians had purchased computer record systems and 25% of these were systems with physicians performing the data entry.[4] By 1995, about 26% of the family physicians had adopted a paperless office.[20] As in the U. K., this was done with government assistance. In the Netherlands, national standards were set for vendors and purchase of approved computer hardware and software was subsidized.

In British Columbia's fee-for-service environment, there is no reimbursement for the time family physicians spend coordinating care and sharing information with other physicians and agencies. This makes this information-sharing a much lower priority than attending to the patients present in physicians' offices and patients contacting the offices by telephone.[37] A defined dataset could lead to less time and effort being used in sharing data by eliminating the exchange of extraneous data. Only data that is essential to decision-making or to assessing a patient as part of the decision-making process should be exchanged and that data should be identified.

## 1.3 Coordinating Care for Chronic Conditions

### 1.3.1 Care for Chronic Conditions

Although chronic conditions and illnesses are now the greatest burden on the health care system, the system and medical education are still focused on diagnosing and treating acute illnesses.[11] Acute and emergency care focus on immediate assessment and action whereas indications of trends and changes are more important in managing chronic conditions.[38] The availability of long term or longitudinal

patient information is much more important in treating chronic conditions than acute medical problems.

A health record that coordinates patient treatment by recording scheduled visits and visits that occur between scheduled visits can improve the continuity and coordination of care. This record is only effective if it records both visits to the usual care facility and elsewhere.[39] In treating diabetes, for example, it is very important to have a continuous record of the observations made, and actions taken as a consequence of each visit.

### 1.3.2 Diabetes as a Model for Chronic Conditions

Chronic conditions have some characteristic features. They typically involve a number of other diseases resulting in the patient being treated by several health care providers. The medical record is distributed at various locations, examinations often are performed more than once, and any physician involved in the care of a person with a chronic condition cannot provide optimal care if any vital information is missing.[40] Diabetes is a good model for chronic conditions as it involves education, support and checking for and/or treating complications that involve many health care providers and agencies.

Guidelines for the care of diabetic patients specify tests and examinations at certain intervals to reduce complications. If these are done too frequently, the cost and effort for the health care system increases. But if these actions are not performed and referrals to specialists are not made when required, complications might result that could have been delayed or avoided.[41] For example, enrolling a diabetic person into ophthalmologic care, recommended by the American Diabetic Association, can save more than $1,000 per person as well as reduce needless vision loss.[42] Unless

prompted by reminder mechanisms such as office staff or computers, some procedures, especially those for preventive care, are often forgotten in light of the urgent problems presented by patients.[43] Also, coordinating the exchange of information with other physicians and care providers is a low priority if a physician is very busy providing care for patients who are present in the office or examining room.[37]

### 1.3.3 Coordinating Care for Diabetes

More than 1.5 million Canadians have been diagnosed as diabetic and one in twenty Canadians can expect to develop diabetes at some point in life.[44] It is believed that for each case that is diagnosed there may be another undiagnosed case, resulting in diabetes possibly affecting approximately 3 million Canadians.[45] The Canadian Diabetes Association predicts that by the year 2000, 1 in 4 Canadians over the age of 45 will have diabetes. The risk of developing diabetes is even higher in certain populations, such as older adults and native peoples.[45,46] Diabetes costs the Canadian health care system $2.5 billion annually.[46]

The major clinical toll of diabetes, in morbidity, mortality and economic burden, is the consequence of the devastating complications of the disease, many of which are also chronic in nature.[47] In Canada, diabetes is the third leading cause of death by disease, a leading cause of adult blindness and renal failure, and the leading cause of non-trauma amputations. Seventy per cent of deaths of persons with diabetes are due to cardiovascular complications.[46]

In Europe, diabetes has been recognized as one of the diseases that is both common and expensive, and a disease for which there is general agreement on what care needs to be provided.[29,48] The patient delivers more than 95% of diabetic care.[11] The

role of the health care system is very much that of diagnosing diabetes, supporting self-care and monitoring for evidence of complications. The Diabetes Control and Complications Trial and other studies in the 1990s have shown that there is a significant decrease in complications for diabetics who maintain good control over their blood glucose levels.[49] Recent and ongoing trials show the long-term value to the patient and to the health care system of constant vigilance in diabetic care.[47]

The Diabetes Control and Complications Trial used intensive diabetes management, provided through frequent visits to a multi-disiplinary team and around the clock support. This intensive therapy was shown to significantly reduce complications due to diabetes. For example, after three years the mean risk of retinopathy was lowered by 76%. However, such intensive therapy required an expert team of diabetologists, nurses, dieticians and behavioural specialists. The time, effort and cost of this were considerable and the resources needed are not widely available. New strategies are needed in the general community to provide such benefits for less cost and effort.[49]

The Canadian Diabetes Advisory Board recommends an integrated approach for diabetes care at all levels of the health care system.[45] Its recommendations include having centres that provide multi-disciplinary care for persons with diabetes. In a community without such centres, as is the case in Victoria, data must be shared among health care professionals who care for persons with diabetes as each professional maintains their own records for each patient or client.

### 1.3.4 Computers in Diabetes Care

Studies in the U. K. are often referred to in this paper because of the dataset and database work for diabetes care that has been conducted in that country. Most of the diabetes care in the U. K. is delivered in diabetic clinics and this has led to the

development of computer systems to help with administration and, occasionally, clinical record keeping.[36,50] Only a decade ago the stated hope for computerized diabetic record systems was that they would enable improvements in organization and efficiency of services that would ultimately benefit patients.[36] As of April 1987, every hospital in the U. K. was legally required to collect a minimal set of data on every clinical encounter and the demographics of the patient. This was an incentive to develop systems that could deliver this data electronically to the National Health Service.[36]

In the U. S., there have been several factors that have led to the use of datasets and computers in patient care. The U. S. federal government Health Care Financing Administration purchases about 25% of all long-term care. Its development of a Minimum Dataset for Long Term Care has led to the introduction of computers in long term care facilities.[51] In the U. S., information systems of the past few decades have not been designed with a clinical focus. This is rapidly changing as further integration of health insurance organizations, hospitals and physician practices increases the demands upon information systems.[52] The use of clinical pathways derived from clinical guidelines for treating conditions is creating a demand for systems that handle data in a highly structured way.[53] On August 8, 1997, U. S. President Bill Clinton announced a major new public-private initiative called the Diabetes Quality Improvement Project. Its objective is to greatly improve diabetes care through the development of a set of diabetes-specific performance and outcome measures.[54]

A 1990 U. K study tested an expert system that gives advice on diabetic care and found that there were only two major problems. The computers for the system were too slow for use in direct patient care and the clinic had only enough staff to see

patients about half as often as the experts had advised.[55] Changes in technology may have solved the first problem and the second could be solved by a change in staffing or guidelines. In fact, in the U. K., increased payments are now given to physicians treating patients with diabetes in recognition of the extra effort required to provide diabetic care.

Some structured records for diabetes care have been defined within agencies or institutions. Structured data collection with paper or computer forms has been used within institutions or single site multi-disciplinary clinics for diabetes care.[12,28,36,56,57] However, these structured records are not always intended to contribute to a physician's assessment of a patient's status. For example, discussions with the principal investigator and a co-author of one of these studies revealed that the forms used in their study were developed to remind physicians of care guidelines rather than to assess the condition of the patient.[12]

## 1.4 Defining a Diabetes Dataset

### 1.4.1 Focus on Patient Care Services

This study focuses on the data in the health record used by health care professionals while providing patient care services, to review a patient's status or to document their own observations, actions or instructions. The primary purpose of this health record is to support individual patient care by coordinating and documenting this care.[1] Patient care information, from the health or patient record, is essential for quality assessment and improvement in patient care, and for evaluating outcomes of patient care.[58,59] However, secondary uses of the data in the health record, such as administration or research, cannot determine the model for the information in the

health record as models for these secondary uses typically omit much of the information used in clinical care.[18]

Designing a CPR requires a model of the information used in patient care. This information model should be derived from modelling the data that supports the processes or business model of providing care and support for patients. The Essential Data Set Approach says that the data necessary to study the impact of care and to evaluate clinical performance and justify resource utilization should normally exist in the record of a clinical encounter.[23] Another design approach focuses on the information necessary for judging the quality and success of care. This was justified by the authors by the assumption that almost all the fields necessary for such evaluation are in a record of adequate quality.[60] Therefore, a CPR design that models patient care information should be expected to support evaluation of care.

Even the development of a dataset that sounds as if it were designed for patient care, the Nursing Care Minimum Dataset, seems to be aimed at administration. This dataset was designed for analysis in large databases and is not rich enough or fine grained enough for many clinical problems. The dataset includes sixteen items, only four of which are for recording nursing care and five of which are concerned with demographics. In fact, it is intended that the elements be contained in clinical records and abstracted from them for studies of the effectiveness and costs of nursing care. This would not fulfill the criteria of an essential dataset as it would not support decision-making in clinical care. To be more useful, this Nursing Care Minimum Dataset should include problems, patient care actions and expected outcomes.[24] This shows that datasets must still be developed for clinical use.

### 1.4.2 Development of Defined Datasets for Diabetes Care

Datasets have been defined for diabetes by different projects. The World Health Organization established a dataset for investigating insulin dependent diabetes.[61] Nilasena et al defined paper forms that are used for data entry to a computerized reminder system for diabetes care.[12,62]

Too little time has traditionally been spent on defining the data items that are necessary to cover the 'diabetic life' of a patient.[55] Many of the studies on diabetes record systems have focused on developing datasets based on the data required by care evaluation guidelines rather than the data to support the work processes of the persons who deliver care. In spite of this, these authors expect the elements of these datasets to be collected during patient care.

A dataset in the U. K. was developed for a system that would fulfil the functions of a Diabetes Register using specific parts of the U. K. guidelines on diabetes care. The stated purpose for developing this dataset was the evaluation of care.[50] Although this system can produce clinical data sheets on paper to be filled in at the time of care, it is expected that the data will be supplied to this system by other systems used by family physicians. However, use of computer systems by family physicians has not led to the availability of high quality data that could be used for research into health and disease; there is still confusion over the amount of data that should be collected in clinical care to allow evaluation of the care.[63]

Other authors in the U. K. say that the only way to reliably get data of sufficient quality for the evaluation of care is if its collection is an integral part of the patient record system that is used for patient management.[29] But they also say that record systems designed for the breadth of diseases seen in a family physician's practice are,

by definition, diametrically opposed to those needed for the structured longitudinal care needed in chronic diseases such as diabetes; the chronic conditions require a greater level of detail than that provided in systems designed to cover a wide range of conditions. In spite of these opposing views on the aims of systems, the development of the U. K. Diabetes Dataset was driven by a desire for auditing diabetes care and comparing different districts and services rather than the aim of supporting care for diabetic patients.[64]

It is only recently in the U. K. that the focus in information technology has shifted from administration and management to clinical care. The National Health Service in the U. K. has a new information management and technology strategy that is "person centred" and should benefit patients.[65] The strategy states that management information should be derived from operational clinical systems. Although this sounds as if diabetes datasets and computer systems for diabetes care would now be designed by modelling the processes of patient care, no evidence was found of such a shift away from development for administrative purposes.

### 1.4.3 Existing Diabetes Datasets

In Europe, the Eurodiabeta Dataset was developed by consensus through group consultation with experts. Although the names of the groups involved in the development and their aims were published the actual dataset was not.[66,67] The DiabCare Initiative developed a dataset following consultations with more than 130 diabetologists from 21 countries using the Eurodiabeta Dataset as a starting point.[68] For this study, repeated attempts to obtain the Eurodiabeta Dataset were made, by letter and electronic mail, to the contact listed in the article reporting on the development of the Eurodiabeta Dataset and contacts listed on the DiabCare Initiative

website. Despite this effort, only the DiabCare Dataset, which has its roots in the Eurodiabeta project, was obtained close to the end of this study. The dataset generated in the present study is compared to this previously established dataset.

The DiabCare Initiative developed three ways to collect data, implying that the purpose of the initiative was to support patient care. The three data collection methods are a Basic Information Sheet, the DiabCare Computer Program and the DiabCare Dataset. These were intended to cover a range of data collection methods in diabetes care including use of paper-based records and access to computers or existing databases. This sounds as if the dataset, underlying these three tools, was designed for clinical care, however the stated aim of the DiabCare Dataset was to monitor patient outcomes for the purposes of quality improvement. This dataset was designed to allow the performance comparisons between centres, regions and countries. The naming of centres and the stated protocol for data recording also show that this is a dataset designed to be used in a clinic or diabetes centre rather than one designed to be used by family physicians in community practice.[68]

In the U. K., a dataset was jointly developed by the Royal College of Physicians and the British Diabetes Association to collect almost all of the elements of the DiabCare Dataset.[60] The U. K. Diabetes Dataset extended a previously developed dataset to cover specialist care. The older dataset was developed as a basis for judging the quality and success of diabetes care.[69] Further work on this older dataset was done to allow existing databases to format data for this dataset and to enhance compatibility with the DiabCare Dataset used in the rest of Europe.[64] Although the U. K. Diabetes Dataset was developed for Quality Assurance auditing, the authors say almost all data should exist in a patient record of adequate quality so this British dataset will be compared to the data elements defined in this study.

A project at the LDS Hospital in Salt Lake City, Utah used forms to collect information for a computerized system.[12] The forms used for data collection for the computerized system were obtained from the principal investigator and these are used in the analysis of the dataset described in this study.

### 1.4.4 Scope of the Study

For the purpose of this study, diabetes includes gestational diabetes, Type I diabetes (also known as juvenile diabetes or insulin-dependent diabetes) and Type II diabetes (also known as adult-onset diabetes or non-insulin dependent diabetes).[44] The range of diabetic care analysed as part of this study is limited to the diagnosis and management of diabetes only and does not include the diagnosis and care of the comorbid conditions frequently associated with diabetes. The dataset described in this study is intended to support a range of providers, consisting of family physicians, specialist physicians, nurses and diabetes nurse educators.

### 1.4.5 Research Objectives

The essential diabetes dataset can be defined as one which describes the data that is required by a range of health care professionals involved in the diagnosis and clinical care of diabetic patients or clients. The dataset must be structured to support clinical decision making by, and communication of clinical data among, the health care professionals and organizations involved in diabetes care. Finally, the preliminary essential dataset must provide a conceptual base for a computer-based diabetic record that can function as part of a larger electronic health care record.

The present study uses systems analysis techniques[iv] for defining a preliminary essential dataset for use by family physicians providing care and support in the community to persons with diabetes.[70] Developing a dataset to serve family physicians' need to exchange data with specialist physicians and organizations in the

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[iv] Systems analysis models are, for the most part, abstract representations of what will eventually become a combination of computer hardware and software.

community will show whether a systems analysis approach can be applied in the development of heath care datasets. As well, developing this preliminary dataset should show if this approach is appropriate for diabetes and if this approach can be applied to other chronic conditions. The questions addressed in this work are:

1. What are the essential elements of a preliminary dataset for a chronic condition, such as diabetes mellitus, if the dataset was defined, structured and developed using the "Essential Dataset Approach" and techniques of systems analysis?
2. How does this preliminary essential dataset compare to diabetes datasets developed by others?

General or family physicians are the usual first point of contact in the health care system for persons with diabetes in the community.[71] The family physician coordinates care, acting as the "gate keeper" to most other health professionals or services. Consequently, this project focused on family physicians, the specialists and agencies to which they refer patients, and the community services they recommend for their diabetic clients.

The purpose of this project was to define, structure and develop a preliminary essential dataset by applying traditional systems analysis techniques to a limited range of health care processes. The resulting preliminary essential dataset is intended to be further developed and then tested before use by family physicians in clinical decision making and for communication with other professionals and organizations concerned with the diagnosis and management of diabetes.

# 2 Methods

## 2.1 The Essential Dataset Approach

The preliminary essential dataset was developed using systems analysis data modelling techniques after study participants were interviewed. The objective of the data modelling was to identify information requirements for diabetes care providers, the potential users of applications based on this dataset.[17] The focus of the data modelling was on the data collected by family physicians to assess and manage diabetic patients in the community.

The dataset was developed following the steps defined by Moidu et al:[17]

1. Collect data sheets and forms used in the system being studied, and review the literature.
2. Identify:
   - the information objects;
   - the goals of the providers, organizations, and programs; and
   - the types of encounters and the care-level activities.
3. Define what is required to identify care providers and beneficiaries.
4. Create a logical data model and articulate / define the data elements through information analysis and normalization.
5. Aggregate the derived elements into data groups, such as socio-demographic data, history, findings at the encounter, and therapeutic intervention record.
6. Relate the aggregate data groups to the functions of the professionals.

The process is cyclical as feedback during the process produces new information, knowledge and techniques to be included in the development of an Essential Data Set (EDS).

An important step in this methodology is modelling data, a technique that allows the dataset designer to see the information content as metadata rather than as individual

values. The objective of this modelling is to represent the structure of the data as it is perceived by the clinicians, in this case family physicians.[17] The resulting data structure models are what computer system developers use for designing and implementing computer systems.

## 2.2 Interview Participants

Development of the dataset was mainly based on interviews with the following agencies and professional groups in Victoria, British Columbia. These were identified in preliminary interviews with providers directly involved in care and support of persons with diabetes. The participants are shown below with number of persons in each professional group or number of representatives of each agency, who were interviewed, shown in brackets:

- Family Physicians (5)
- Specialist Physicians: (9)
  - endocrinologist (4)
  - nephrologist (1)
  - paediatrician (1)
  - ophthalmologist (1)
  - hospital emergency room (1)
  - foot care (1)
- Diabetes Education Centre, Greater Victoria Hospital Society (5)
- Diabetes Nurse/Educators, Home Care Nursing (1)
- Diabetes Nurse/Educators, Juvenile Diabetes Program (2)
- Diabetes Nurse/Educators, Gestational Diabetes Program (2)
- Clinical Laboratories (2)
- Pharmacist (1)
- Canadian Diabetes Association (2)

Figure 1 provides a view of diabetic care developed from preliminary interviews with family physicians, representatives of the Diabetes Education Centre (DEC) and an endocrinologist. Family physicians are very important as they provide the regular care

for persons with diabetes and provide referrals to specialists and other services when these are needed.[v] The Canadian Diabetes Association (CDA) and Capital Regional District Health Department were also contacted.[vi] Access to and use of the services, shown in Figure1, in Victoria is by referral from the family physician except for emergency hospital services and the Canadian Diabetes Association.

The flows of patient data, shown in Figure 1, almost all involve written reports to the family physician rather than the patient. The exception is the Canadian Diabetes Association, which provides support and education directly to persons with diabetes. The Diabetes Education Centre and Home Care Nursing provide education and support directly to persons with diabetes after a referral for these services has been received from a physician. These two agencies send reports on the services that a person receives to the person's family physician.

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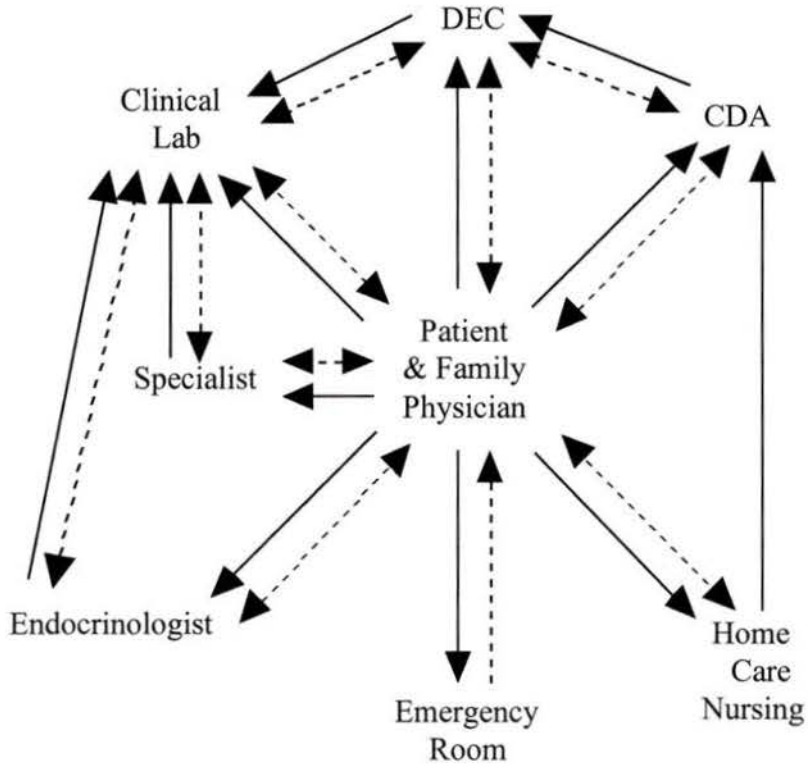
[v] Dr. Macgregor, Chief, Department of Family Practice and Director of Continuing Medical Education for the Greater Victoria Hospital Society (GVHS) provided support to this project by providing a list of family physicians who took a recent seminar on diabetes. He allowed the use of his name in contacting these physicians.

[vi] The Capital Regional Health Board now administers services formerly delivered by the Capital Regional District (CRD) and the Greater Victoria Hospital Society (GVHS).

**Figure 1**: The flow of patients and patient data between care providers and agencies in the process of diabetic care in greater Victoria. The flow of written data is almost exclusively to the family physician.




The data that supports the assessment and management of diabetes were identified by interviewing members of each of the professions and agencies shown in Figure 1 and others listed above. Interview subjects were recruited by letter and telephone. Each person was given a description of the study and asked if they would participate by

being interviewed. At the time of the interview, participants were given a written summary of the project and asked to sign a consent form[vii] (see Appendix 1).

The interviews were semi-structured according to the questionnaire included as Appendix 2. As well, any forms used by a care provider or agency were collected for analysis. While the questionnaire includes many questions aimed at identifying metadata for the dataset, others are more qualitative, which allowed the providers to identify the subjective factors or discrete data that contribute to their decision-making. The questionnaire was initially developed for family physicians and was then adapted for specialist physicians, other professionals and agencies. A standard set of questions was used as the starting point for every interview (see Appendix 1). Each subject was interviewed using qualitative techniques so that the subject was free to cover subjects as they wished and the interviewer could expand questions or add questions to fully cover any issues.

In interviews of family physicians, the focus was on the data they collect and need to describe and care for patients with diabetes, as well as the data that they communicate to other care providers to support care referrals. With specialist physicians and other care providers, the foci were upon the data that they receive with referrals and the data collected in diabetic patient consultations, and what data, recommendations and actions are reported to the family physicians. After most of the participants had been interviewed, three family physicians were interviewed again to cover new issues and techniques that had been discussed by participants interviewed after these three family physicians.

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[vii] The consent form shown in this appendix fulfills all the criteria of University of Victoria, Human Research Ethics Committee

Systems analysis techniques were selected for identifying and modelling business processes and the data used in these processes as identified in the interviews. The qualitative approach allowed the interviewer to elicit the value of data for diabetes care from each participant. Interview questions for all participants focused on how data collected by each participant or received from other care providers contributes to assessing patients and making decisions about their care. This interview approach was used to be consistent with systems analysis which requires identification of business processes, data flows and data stores.[70]

The Canadian guidelines on diabetes care could be used to determine the data is required to support the provision of diabetes care.[71] This approach for identifying essential dataset elements is possible, but was not selected. Working back from these guidelines would not identify the data exchanged among professional groups and agencies. As well, this approach of using the Canadian guidelines would require training in medicine to determine the data that is required for patient assessment and diabetes management. Instead, this study relied on the medical training and experience of the participants to identify the data that is important in diabetes care. Preliminary interviews also indicated that physicians were very sensitive about being questioned about data that should be collected according to other persons or guidelines.

The intended benefit to the participants in this study includes the identification of the data currently being exchanged, and comments on participants' value of this data. This has been done to a certain extent but there were obstacles to doing this for all the data being exchanged. These difficulties are discussed in the Results section.

### 2.2.1 Rigour in the Development of the Dataset

Prior to the preliminary interviews and development of the questionnaire used in this study, the subject of diabetes care in Canada and other countries was examined in the literature. This provided background on diabetes and the complications that typically accompany diabetes. As well, this provided an understanding of the care processes involved in diabetes care necessary to use qualitative interviews in the research. This knowledge of the processes helped to establish a relationship between the interviewer and the participants as the participants could talk about their work in their own terms. This learning continued through all the interviews so that the distance between the interviewer and the participants could be reduced. One physician was comfortable enough to admit attending a diabetes seminar for the education credits more than out of professional interest.

After the preliminary interviews, the different players and processes involved in diabetes care in Victoria were modelled. Through interviews with the study participants this preliminary model was confirmed and then revised as necessary. The processes and dataflows in diabetes care were checked throughout the interview process and exceptions to the revised model were noted.

The preliminary essential dataset described in this study was developed, using systems analysis techniques, to support direct patient care by family physicians. Rather than testing the dataset generated by this study, the preliminary essential dataset was compared to diabetes datasets that were developed for other purposes. These comparisons were used to indicate if the preliminary essential dataset could be generalized to apply to diabetes care outside of that provided by the participants in

this study. The use of standard analysis techniques, such as data models, should allow others to audit the findings of this study and to build on these findings.

### 2.2.2 Exclusion of Patients from the Development of the Dataset

Persons with diabetes were not interviewed and used in this study for a number of reasons. Adding patients to developing an essential data would focus on self-monitoring of blood glucose and timing of medication.[viii] Although some blood glucose monitors are capable of storing and sending all of their collected data to computer software, very few diabetics are now using this hardware and software. With some diabetics performing three or more tests per day, the volume of data is too great for manual entry and analysis at a physician's office.[ix] To test a dataset with the involvement of patients would require records that are available to patients through some type of a computer network. Use of such a network for records would require extensive resources such as Internet servers and computers available to patients in their homes or a convenient place. This makes the utility of including patients very doubtful without an infrastructure in place to support patient access to such records.

The last reason is an issue of care provider-patient ethics, which affects the manner in which patients of the participating physicians can be recruited. Patients must be contacted through health care providers to preserve provider-patient confidentiality; a

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[viii] The computer system designer who was interviewed regarding this issue is a Type I diabetic. This designer has consulted other persons with diabetes and physicians to determine the information important to persons with diabetes. Also, most of the physicians interviewed for this present study and the diabetes logbook supplied by the Canadian Diabetes Association identified these elements.

[ix] The family physicians and endocrinologist interviewed for this study will ask a patient about the blood glucose monitor readings or review a patient's logbook of the readings to get an idea of the patient's glucose control.

patient may only be identified to a researcher after the patient gives consent to participate in a study. This would be difficult due to the low numbers of patients with diabetes per physician. As the scope of this study is limited to clinical service providers, it was decided to exclude the patient as a provider type for the purpose of this study.

### 2.3 Modelling Diabetic Care Processes

The data and processes in this present study were modelled using business process, function hierarchy and data diagrams. These diagram types were chosen as a way to model the system of diabetes care so the preliminary essential dataset could be checked for internal validity. By using different diagrams the dataset could be examined to ensure that the dataset supports the professionals providing care, and the processes and functions used in diabetes care.

The actions of persons or agencies providing services to persons with diabetes were modelled in several ways using the data and processes identified in the interviews. First, the care processes were modelled to show how data are generated by processes and to show the flow of data between those processes. The business functions were modelled to ensure that all functions were included in the process and data object models. Hierarchies of functions related to each of the processes were developed. These high level functions were each progressively decomposed to a level of granularity that permitted identification of the data elements required for each function.

The data elements identified in interviews and the business process and the function hierarchy diagrams were incorporated into an object oriented data model. This data model represented both the content and the structure of the dataset. Object orientation

was chosen as a modelling paradigm because data elements can be represented as attributes or methods of inter-related objects; in this case, patient, providers and care processes. An object is an abstraction of a real-world entity that exhibits states and behaviours.[72]

## 2.4 Defining the Dataset

The purpose of this research is to develop a comprehensive, preliminary essential dataset for the diagnosis, treatment and management of diabetes. This dataset could be used in the health care record, often known as the patient "chart", as well as for communication among the different professionals and agencies providing care for persons with diabetes within and outside of the acute care environment. Because one of the objectives was to define the dataset for an electronic database, the dataset had to be defined in terms of discrete elements rather than free-form text typical of the paper based record.[2,18]

Five family or primary care physicians, nine specialist physicians, one or more from each speciality listed earlier, and four nurses or diabetes nurse/educators were interviewed. Field notes were taken and forms collected, wherever possible, during each interview. The notes were transcribed almost immediately after every interview and compared to previous interviews. These comparisons were used to identify differences and similarities in the processes and data used by each care provider. When the participant did not identify specific data collected for or used in a process, the data required for the process was inferred from the process or the conclusions reached. Such inferences were only used when the data required was very obvious or the inference was used to formulate questions for a follow-up interview. For example, one of the family physicians did not specify that he assesses a patient's self-care

ability. Yet this physician stated that he refers patients to Home Care Nursing if they are not able to care for themselves or if they are unsuited to receiving diabetes education in a classroom setting, so it was inferred that he makes a judgement of a patient's self-care ability.

Each interview identified care processes and the data elements used in each process. Modelling the business processes and data objects revealed data elements that would be necessary to identify care providers and sources of data. As well, some data elements, such as types of laboratory test and dates, are necessary to establish a context for other data elements such as test results.

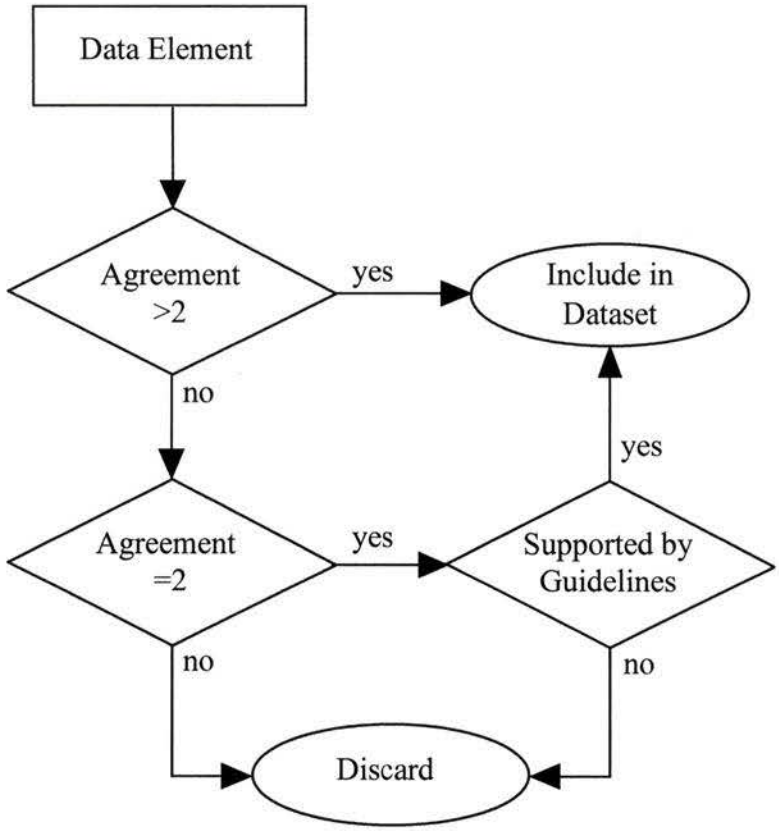
Reviewing the interview results and data models was an iterative process that required comparing different interviews and helped determine the need for follow-up interviews. During the summarizing and modelling of data, the interview notes and transcriptions were reviewed to check the models and in regard to the interviewer's increased knowledge of the processes. The data elements identified in the interviews revealed similarities and individual differences in the data used in clinical practice.

Reasonable agreement on the importance of a data element had to be achieved for it to be included in the preliminary essential dataset. Although interviews were a qualitative process, which identified the value of data elements to the care providers, quantitative criteria were used to select data elements for the preliminary essential dataset. Any data element that a majority of family physicians agreed needed to collected or shared among the different providers was included. Any element used exclusively by a single family physician was not included. As shown in Figure 2, any element that is required by at least half of the family physicians was included in the preliminary essential dataset. Any element that is required by more than one provider

but not a majority of them was investigated and such an element was included if the existing Canadian clinical guidelines support its inclusion in the preliminary essential dataset.

Some of the family and specialist physicians collect certain data to aid in processes not performed by other physicians. For example, two physicians collect extensive information on a patient's other family members' experiences with diabetes. One specialist uses this information to explain why a patient should not blame herself or himself for having diabetes. The other, a family physician, uses this to explore a patient's fears with regard to diabetes and complications. This family physician also uses this process as a way to help motivate the patient to avoid complications through diabetes management. Although these processes and data are important to these two physicians, this data is not used by other physicians and is not recommended in the guidelines. The algorithm shown in Figure 2 led to such data being excluded from the preliminary essential dataset.

**Figure 2**: Decision process for inclusion of data elements in the preliminary essential dataset, according to the use of data elements by family physicians. The Canadian "Clinical Practice Guidelines for Treatment of Diabetes Mellitus" were used as the guidelines.[71]




According to Moidu et al. a data element in an Essential Dataset must fulfil some of the following criteria:

- provide information related to the health status;
- assist in risk and clinical assessment during encounters;
- reflect the actions or interventions taken;
- should assist in the assessment of outcomes or have a predictive value for outcomes;
- be easy to collect, preferably at low cost; and

- have the least ambiguity possible, or else be explicitly described.[17]

These criteria were applied to the process of collecting and using data in diabetes care processes, using the interview results and the data models, as part of defining the preliminary essential dataset. Cost was not considered as almost all the data elements are currently being collected by the physicians. Definition of a structure to store data elements was used to address the question of explicit descriptions. As well, data elements were defined to ensure identification of patients or clients and care providers. The rest of the criteria were applied to data elements as appropriate to ensure that an element has value to the care process. Without a prospective assessment, the dataset developed is known as a Preliminary Essential Data Set (PEDS).[23]

The dataset was developed only to support provision of care to persons with diabetes. While clinical care for diabetes must be provided in consideration of any comorbidities, such as renal failure, these conditions must be dealt with separately for the development of datasets. Including other conditions would make the purpose of this study too broad. However, the existence of any comorbidities must, as a minimum, be recorded within the diabetes dataset, thereby providing a point of reference to datasets for the other conditions and allowing the delivery of integrated care to the patient. The dataset was limited to what is essential to the routine care of a diabetic patient and, although it includes examinations for and detection of complications, it does not extend to the details of comorbidities.

## 2.5 Analysis

After the preliminary essential dataset was drafted, it was examined to see if these data elements would support diabetic care according to the Canadian guidelines on diabetes care.[72] There are suggestions that new guidelines are being developed that include a lowering of the criteria used for the diagnosis of diabetes. However, the 1992 guidelines are the latest recommendations of an expert committee jointly sponsored by the Department of National Health and Welfare, the Canadian Diabetes Association, the Juvenile Diabetes Foundation Canada and Association du Diabète du Quebec, and are the guidelines that were distributed and promoted by the Greater Victoria Hospital Society.[37]

In Europe, guidelines have been developed for enhanced diabetes care through the use of information technology. The guidelines are extensive but are mainly concerned with how the information technology works. The only reference to datasets, aside from references to the DiabCare dataset, is that they should be minimal. When these guidelines were used to evaluate two existing systems, the elements used in the systems' datasets were compared to the DiabCare Dataset as suggested.[73] This shows that the DiabCare Dataset is the dataset of reference in Europe. The preliminary essential dataset developed in this study was compared to the DiabCare Dataset and the U. K. Diabetes Dataset that has been adapted to the DiabCare requirements.

In addition, the findings in this study were compared to the forms or datasets used in other studies to find differences in the purposes of datasets.[12,28,37,57] The study described in this paper attempted to explain the differences by examining the business model that this study defines. Data elements that were not initially included in the

preliminary essential dataset through this study but appear to be necessary to support the Canadian guidelines on diabetes care or the application of clinical logic are discussed.[71] The dataset was revised to include these data elements as recommendations with an accompanying justification.

# 3 Results

## 3.1 Canadian Diabetes Association

The Canadian Diabetes Association was included in this project, as a diabetes care provider, because of its role as an advocacy group and its provision of services to persons with diabetes. Almost every physician and agency representative interviewed recommends this association to their patients or clients for supplies, services and peer support. The exceptions are one family physician, who was not sure of the benefits, and the Gestational Diabetes Program, because representatives said that gestational diabetes is usually a short-term condition. The Canadian Diabetes Association does not collect patient specific data from persons with diabetes; the association provides support but does not provide advice based on individual cases. For example, the association offers seminars for different types of diabetics but it is up to diabetic persons to classify themselves and decide which seminars to attend. In the past, the association did do some glucose monitoring or testing for individuals, but this has been discontinued due to the potential for liability in performing a test and giving any advice or interpretation regarding test results.

## 3.2 Forms

A review of the forms used in a system is usually an important part of the systems analysis approach. However, in the clinical practice of family physicians interviewed for this study forms are rarely used unless they are needed to make a referral to an agency such as the Diabetes Education Centre. Only one family physician used a form for clinical purposes, but this form was only a means of organizing free text into columns. The portion of the dataset derived from physicians had to be constructed entirely from interviews with physicians.

The agencies involved in providing education to persons with diabetes use some forms for patient-specific data collection and these were examined along with some of the manuals used by staff. The data collected using these forms is presented with the interview results shown below. Agencies providing education are the Diabetes Education Centre (DEC), the Gestational Diabetes Program and the Juvenile Diabetes Program of the Greater Victoria Hospital Society.[x] Home Care Nursing of the Capital Region Health Board was also included as they provide education and in-home care for people who require home nursing and are unsuited or unable to attend sessions at the DEC.

Some agencies use forms or questionnaires such as a Health Survey to assess the limitations and quality of life of a patient or client.[74] Nurses and physicians in this study do not use a specific form for this, but some do question patients about what activities have been curtailed due to diabetes and what aspects of diabetes care they need assistance with to make life as normal as possible.

### 3.3 Interview Participants

None of the recruited participants refused to give consent at the time of the interview. Some family physicians contacted did not have time for the study interview and one physician refused for the reason of having very few diabetic patients. Specialist physicians were very difficult to recruit as many specialists involved in diabetic care said they were too busy and could not accommodate the study. The following physicians, and representatives of the following agencies who provide health care

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[x] The Greater Victoria Hospital Society is now amalgamated into the Capital Region Health Board.

services or support to diabetics, consented to interviews. The participants are shown below with the number of persons in each professional group or number of representatives of each agency shown in brackets:

- Family Physicians (5)
- Specialist Physicians: (9)
    - endocrinologists (4)
    - nephrologist (1)
    - paediatrician (1)
    - ophthalmologist (1)
    - emergency room (1)
    - preventative and rehabilitation specialist, foot care (1)
- Diabetes Education Centre (DEC), Greater Victoria Hospital Society (5)
- Diabetes Nurse/Educators, Home Care Nursing (1)
- Diabetes Nurse/Educators, Juvenile Diabetes Program (2)
- Diabetes Nurse/Educators, Gestational Diabetes Program (2)
- Clinical Chemists or Physicians, Clinical Laboratories, Greater Victoria Hospital Society and MDS Metro Laboratory Services (2)
- Pharmacist, who has taken an interest in supporting persons with diabetes (1)
- Canadian Diabetes Association (CDA) (2)

### 3.4 Interview Responses

In the interviews, all primary care or family physicians stated that they use a process of an initial consultation or a series of consultations after diagnosis of diabetes. Consults are longer than routine appointments and can last up to an hour. During these visits, patients are counselled and initial or base values, such as blood sugar levels, incidents of hyperglycaemia and risk factors, are recorded. These base values are used to assess the patient and for comparisons with subsequent values or observations to track trends.[71] As well, tests or examinations are carried out for the

presence of complications or comorbidities that may have developed while diabetes was present but undetected.

Shorter routine visits to family physicians follow the initial consultations and there may be a longer annual check-up. Some primary care physicians incorporate annual checks into the routine appointments. In addition, patients will usually see their family physician if they are having problems with complications or with controlling their blood glucose. The initial consultations or subsequent patient visits to family physicians may result in a patient with diabetes being referred to specialist physicians.

Table 1 is a summary of the groups of data collected by family and specialist physicians for treatment of patients with diabetes. In addition, Table 1 shows the groups of data that specialist physicians would like to receive, from another specialist physician or a family physician, before seeing a patient with diabetes. The capital letters in the table are used to designate individual physicians while ensuring the confidentiality of each physician as required by the University of Victoria Human Research Ethics Committee.

**Table 1**: Summary of physician interviews indicating the groups of data, collected by family or primary care physicians and specialist physicians for diabetes management, that were used to develop the preliminary essential dataset. For specialists, the table also summarizes which groups of data the specialists want to receive with diabetic patient referrals.

| | **Primary Care** Collected (x) | | | | | **Specialists**[1] Collected (x) or Desired (d) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Data** | A | B | C | D | E | F | G | H | I | J | K | L | M | N |
| Medical History[2] | x | x | x | x | x | d | d | d | d | d | d | d | d | d |
| Physical Exam[3] | x | x | x | x | x | | | | | x | x | | | |
| Family History | x | x | x | x | x | x | | | | | | x | | d |
| CHD Risk Factors | x | x | x | x | | x | x | | | | | | | d |
| General Risk Factors[4] | x | x | x | x | x | | x | | x | | | x | | d |
| Lifestyle | x | x | x | | | | x | | x | | | x | | |
| Exercise | x | x | x | x | | | x | | x | | | | | |
| Diet[5] | x | x | x | x | | | | | x | | | | d | d |
| Level of Glucose Control | x | x | x | x | x | d | d | | d | | | d | d | d |
| Self-Care Ability | | x | x | | x | | d | | d | | | d | | d |
| Referrals | x | x | x | x | x | d | d | | d | d | d | d | d | d |
| Counselling/Education[7] | x | x | x | x | x | d | d | | d | | | d | | d |
| Lab Tests, general | | x | x | x | x | d | d | d | d | d | d | d | | |

**Table 1 Notes:**

1. The nine specialist physicians are endocrinologists, a nephrologist, a paediatrician, an ophthalmologist, an emergency room physician, and a preventative and rehabilitation (foot care) specialist.

2. Medical history is both collected by and recorded by a physician. Details of events that were treated by others are collected in reports and from a patient, and recorded when problems are diagnosed and treated by the primary care physician. Physicians indicated it is important in diabetes care to list any complications resulting from diabetes and any other conditions. Some physicians use this part of the patient record to record risk factors for the development of complications of diabetes.

3. The presence of vascular problems or disease and neuropathies are checked by all interview subjects to some extent and would be noted under physical exam.

4. Risk factors generally include those used to screen for diabetes testing such as age, obesity, and family history. Drs. A, B and C mentioned regularly screening for diabetes if risk factors or signs and symptoms, such as recent weight loss, blurry vision, and certain types of frequent infection, warrant such testing. Used retrospectively by physicians, these may be an indication of the presence of undiagnosed diabetes.

5. Diet is only checked by Dr. C if this is indicated as necessary due to problems such as poor glucose control.

6. Dr. G, a specialist, desires information about any other referrals if such a referral has lead to a treatment and/or medication.

7. Dr. I, another specialist, says that studies show education changes patients' knowledge but not necessarily behaviour so it is more important to ask about behaviours and actions taken by the patient rather than ask about the education a patient has received.

Table 2 is a summary of specific data collected by physicians. The information shown below referral information in the table, for family physicians, must be interpreted with caution. Family physicians said they always send this data in a referral letter but only one family physician allowed any examples of referral letters to be examined for this study. A similar situation existed with specialist physicians; only two of these physicians would allow any consultation reports to be examined. All physicians refused to let any examples of referral letters or consultation reports be used in this study even if any data that could identify a patient was removed. Emergency room physicians are the only specialists to act without referrals although they will attempt to obtain information, like that included in a referral, from the patient or others. The blank entries for referral data for the emergency room physician have been randomly assigned in Table 2 so that this physician cannot be identified in this summary table.

**Table 2**: Summary of physician interviews indicating the specific data, collected by all physicians for diagnosis, care and management of diabetes, that were used to develop the preliminary essential dataset. Also shown is what data specialists want to receive with diabetic patient referrals.

| | **Family Physicians** Data Collected (x) | | | | | **Specialist Physicians** Data Collected (x) or Desired (d) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Data** | A | B | C | D | E | F | G | H | I | J | K | L | M | N |
| Date of Diagnosis | x | x | x | x | x | d | d | d | d | d | d | d | d | d |
| Diabetes Type | x | x | x | x | x | d | d | d | x | d | x | d | d | d |
| Weight | x | x | x | x | x | | | | | | | d | | |
| Height[1] | | | | | x | | | | | | | d | | |
| Blood Pressure | x | x | x | x | x | x | | | | | | | | |
| Smoking | x | x | x | x | x | x | x | | x | | | | | |
| Alcohol[2] | | | | | x | x | x | | x | | | | | |
| Blood Glucose[3] | x | x | | x | x | d | | d | d | | d | d | | d |
| Haemoglobin (HbA1c)[4] | x | x | x | x | x | d | d | | d | d | d | d | d | d |
| Microalbumin tests | x | x | x | x | x | d | d | | d | | d | | d | d |
| Lipids Tests | x | | x | x | x | d | d | | d | d | d | | | d |
| Gestational Diabetes | | | x | | x | | | | | | | | | d |
| Home Glucose Monitor | x | x | x | x | x | d | | d | d | d | | d | d | d |
| Referral Information | | | | | | | | | | | | | | |
| Recommends Canadian Diabetes Association | x | x | | x | x | | | | | | | d | | |
| Ophthalmologist exams | x | x | x | x | x | | d | | d | d | d | d | d | d |
| Current Medications[5] | x | x | x | x | x | d | d | d | d | d | d | d | d | d |
| Past Medications[6] | | | x | x | x | d | d | d | d | d | d | d | d | d |
| Referral Reason | x | x | x | x | x | d | d | d | d | d | d | d | d | |
| Date of Problem Onset | x | x | x | x | x | d | d | d | d | d | d | d | d | |
| Treatments | x | x | x | x | x | d | d | d | d | d | d | d | d | |
| Tests Ordered | x | x | x | x | x | d | d | d | d | d | d | d | d | |
| Test Results | x | x | x | x | x | d | d | d | d | d | d | d | d | |

**Table 2 Notes:**

1 Height is probably visually checked against the patient's weight and appearance or may not have been mentioned as this measurement is made by office staff rather than the physician.

2 Alcohol consumption is probably noted under general history for all patients and was not mentioned specifically for diabetics.

3. Blood glucose tests are only used by Dr. C if this is necessary due to problems such as poor glucose control. Dr. K wants to see the two fasting blood glucose or random glucose blood serum tests that were used for diagnosis if diabetes was diagnosed within the last three months.

4. For this blood test and other laboratory tests, all physicians emphasized the importance of comparing the latest test result to previous results to assess a patient by seeing trends and understanding any changes over time.

5. According to most of the physicians interviewed and the Canadian guidelines, it is important that the medications recorded in the patient chart include medications of all types such as vitamins, herbal remedies or supplements, and dietary supplements. There are a variety of substances that can interact with each other or produce adverse effects. These effects include errors in blood glucose tests or other tests. Dr. G records only those medications related to the current problem or treatment. Other physicians record a more compete medication history.

6. Drs. J and K want to know the reasons for changes in diabetes medication.

In addition to the data collection summarized in Tables 1 and 2, most specialists want to know about other investigations and referrals, and the results. These can indicate the types of problems a patient is having or help the physician gauge the overall stage of diabetes and complications. Although specialists appeared willing to rely on family physicians to detail the family physicians' investigations and actions, about three-quarters of the specialists said they do a complete history as this will be more accurate than one received from a family physician. This may in part be because, according to the specialists, referral letters are sometimes late, not received or are incomplete. It is possible that the dialogue with the patient during the collection of this history helps to build a relationship between the specialist and the patient or that the dialogue is part of an inductive process of assessing a patient.

Even though Table 1 shows that every family physician collects a family history from each diabetic patient, the specialist physicians do not think of any history received as a good starting point for their own history taking. All family physicians, on the other hand, are interested in receiving a patient's chart or a chart summary from the previous family physician for a new patient who was previously diagnosed and treated for diabetes.

After a consult or follow-up visit, specialist physicians send a report to the referring physician. All specialists say this report includes the following about a patient:

- basic demographic information to identify the patient such as name, age and gender;
- reason for referral;
- what the specialist found on examination;
- details of progress on diagnosing;
- any tests ordered and results if available;
- what education or instructions the patient was given;
- any medications or changes in existing medications ordered or recommended;
- recommendations for observation and/or follow-up by the family physician;
- any referrals or recommendation of referrals for the family physician;
- date of the next appointment often with the reason or when they would like to see the patient again, as a referral in British Columbia is only in effect for six months.

In addition, three specialists stated they include reasons for not prescribing medication. This includes recommendations for the patient to change behaviours, diet, or existing medications, and how this should be monitored by the family physician. Specialists usually dictate a letter to the family physician which covers the entire process, including history taking. This letter, along with any notes made during the

appointment, is the only medical-legal record of the encounter that the specialist will have on file.

The statements by specialists, as detailed above and their summary in Table 2, regarding the content of the consultation letters must be interpreted with caution as only two of the specialists allowed examples of the letters to be examined for this study. There is a danger that the specialists stated what they were taught to report on or what they think they are doing rather than what they are actually reporting in the letters. However, family physicians report that the consultation letters are useful and do supply this information. This may be because the consultation letter is usually the only medical-legal record of a patient encounter with a specialist physician.

The results in Tables 1 and 2 mostly relate to adult patients as children with Type I diabetes usually see their paediatrician or paediatric specialists in Vancouver for management of diabetes. This is because such paediatric patients are rare and family physicians are not experienced with these cases; family physicians usually hand over care to a specialist. However, these patients will usually be seen by their family physician for almost all other care and diabetes must be taken into consideration. The main differences cited for children with diabetes are more frequent laboratory testing when a child is undergoing major changes, such as puberty or growth spurts, and the need for reassessing a child's capabilities more often that those of an adult.

Almost all of the physicians and agencies interviewed are advocating tighter control over blood glucose for most patients in the manner recommended by the Diabetes Control and Complications Trial (DCCT).[49] This study states that intensive therapy is likely to lead to more hypoglycaemic reactions than traditional diabetes treatment. Hypoglycaemic reactions often require the assistance of ambulance staff or a visit to a

hospital emergency room. This underscores the importance of the hospital emergency room reports to the family physician. However, if a patient is seen by ambulance staff and does not go to the hospital, the patient is the only source of information about such an encounter, as ambulance staff do not send reports to physicians.

As well as advocating tight glucose control, family physicians in this study indicate they refer Type I (or insulin-dependent) diabetics to endocrinologists. However, the endocrinologists say some Type I diabetics are seeing only their family physicians and many do not see an endocrinologist regularly.

There are Canadian guidelines on the frequency of ordering routine lab tests, such as blood glucose and glycated haemoglobin, for diabetic patients.[71] The ratios and number of tests in the Victoria area, as reported by the clinical chemist and laboratory physician interviewed, suggest that not all physicians providing care to diabetics are following the guidelines on the frequency of routine blood tests for patients with diabetes.

One of the endocrinologists interviewed for this study said he wanted to see Type I diabetics regularly and teach the tight blood glucose control advocated by the DCCT trials. Another endocrinologist said he wanted to give this type of instruction to all diabetics, but said this teaching must be supported and recommended by the family physician. The concerns expressed by these endocrinologists suggest that not all family physicians are following the Canadian guidelines on diabetes care, which advocate patient education, and recent treatment recommendations stemming from studies such as the DCCT trials.

Table 3 summarizes the data that agencies collect, on diabetic clients, that is also collected by a majority of family physicians. Currently, the family physicians send a generic referral form to the agencies for patients, which may contain the date of diabetes diagnosis, the type of diabetes, and results from the latest laboratory tests. In many cases, the agencies report that this information is not included and that the referral only indicates the type of services that the family physician is requesting for the patient with diabetes. The table shows that groups of data that the agencies are seeking is available in the records of family physicians. This means that much of the data collection performed by the agencies is duplicating data collection done by family physicians.

Tables 3 and 4 do not show some of the agency specific information collected by agencies. Examples include detailed information on a client's pregnancy collected by the Gestational Diabetes Program, information on a client's living conditions and specific self-care abilities collected by the Diabetes Education Centre and Home Care Nursing. This information is not collected, from every patient with diabetes, by family physicians so it is not included in the summary table. One of the agencies provides a care plan for the hospital emergency room if the person has problems, in addition to diabetes, that will likely lead to visits to the emergency room. This is not summarized in the tables as this is only done by one agency and this study must assume that the factors that led to such a plan are known by the family physician.

**Table 3**: Summary of interviews with agency representatives. The table indicates the groups of data collected by agencies for diabetes care and the groups that agencies would like to receive in referrals. The last column shows that a majority of the family physicians interviewed are collecting this data for their own records.

| | Agencies | | | | Family |
|---|---|---|---|---|---|
| **Data** | **A** | **B** | **C** | **D** | **Physicians** |
| Medical History[1] | x | x | x | x | x |
| Physical Exam[2] | x | | x | x | x |
| Family History[1,3] | x | x | x | x | x |
| CHD Risk Factors | | | x | x | x |
| General Risk Factors[3] | x | x | x | x | x |
| Lifestyle | x | x | x | x | x |
| Exercise | x | | x | x | x |
| Diet | x | x | x | x | x |
| Level of Glucose Control | x | x | x | x | x |
| Self-Care Ability | x | | x | x | x |
| Other Referrals | x | x | x | x | x |
| Counselling/Education | x | x | x | x | x |
| Lab Tests, general | | | x | | x |

**Table 3 Notes:**

1. Agency A collects specific parts of family history and major illnesses to explain the reasons for and/or causes of the person's diabetes and the risk of diabetes for other family members. This is to allay client's fears and feelings of guilt about being diabetic. The majority of family physicians are not collecting such data and using it for this purpose.

2. Agency A checks insulin injection sites rather than performing a full physical exam. Agency C checks the feet and skin of the feet in lieu of a full physical exam.

3. Agency B uses a client's risk factors and family history to indicate the possibility of complications and to recommend the use of home glucose monitoring.

**Table 4**: Summary of interviews with agency representatives indicating what specific data is collected by agencies. The last column indicates if a majority of family physicians interviewed are collecting this data for their own records.

| | Agencies[1] | | | | Family Physicians |
|---|---|---|---|---|---|
| **Data** | **A** | **B** | **C** | **D** | |
| Date of diagnosis | x | x | x | x | x |
| Diabetes type | x | x | x | x | x |
| Weight | x | x | x | x | x |
| Height | x | x | x | | |
| Blood pressure | x | x | x | x | x |
| Smoking | | | x | x | x |
| Alcohol | | | x | x | |
| Blood sugar | | x | x | x | x |
| Haemoglobin (HbA1c) | x | x | x | x | x |
| Microalbumin | x | | x | x | x |
| Lipids | | | x | x | x |
| Gestational Diabetes | | x | | x | |
| Home glucose monitor | x | x | x | x | x |
| New Client Information | | | | | |
| Recommends Canadian Diabetes Association | x | | x | x | x |
| Ophthalmologist exams | x | | x | x | x |
| Current Medications | x | x | x | x | x |
| Past Medications | | x | x | x | x |
| Referral/Attendance Reason | x | x | x | x | x |
| Date of Problem Onset[2] | x | x | x | x | x |
| Treatments | x | x | x | x | x |
| Tests Ordered | x | x | x | x | x |
| Test Results | x | x | x | x | x |

**Table 4 Notes:**

1. One agency does not require a referral for admittance but it does send reports to the family physician and contacts the family physician as required.

2. This may not be strictly a medical problem and in the case of some education, diabetes may be the only defined problem. Although the physicians usually

have the date of diagnosis, agencies report it is frequently missing from referrals.

## 3.5 Data and Process Modelling

### 3.5.1 Business Process Diagrams

Interview responses and the relationships among the different service providers were used to construct business process diagrams, function hierarchy diagrams and data models (see Section 3.6 for function hierarchy diagrams). The business process diagrams show the types of actions or processes that are performed by persons with diabetes. As well, the business process diagrams indicate the processes and actions that involve the health care providers who diagnose and manage diabetes and its complications. The high level or summary information that is collected or communicated during care processes is also represented.

The business process diagrams, Figures 3 and 4, show the high level processes for persons with diabetes and care providers. The major difference between the two figures is that in routine care (Figure 4) physicians want to have a recent set of laboratory test results before a routine appointment with a diabetic patient. The business process diagrams are used to check that all the processes can be accommodated within the data model of the system.

**Figure 3**: The business processes in diagnosis and treatment of diabetes or problems related to diabetes. The boxes indicate processes and the arrows show data flows among the processes. The left column shows the person or agency acting in the processes.

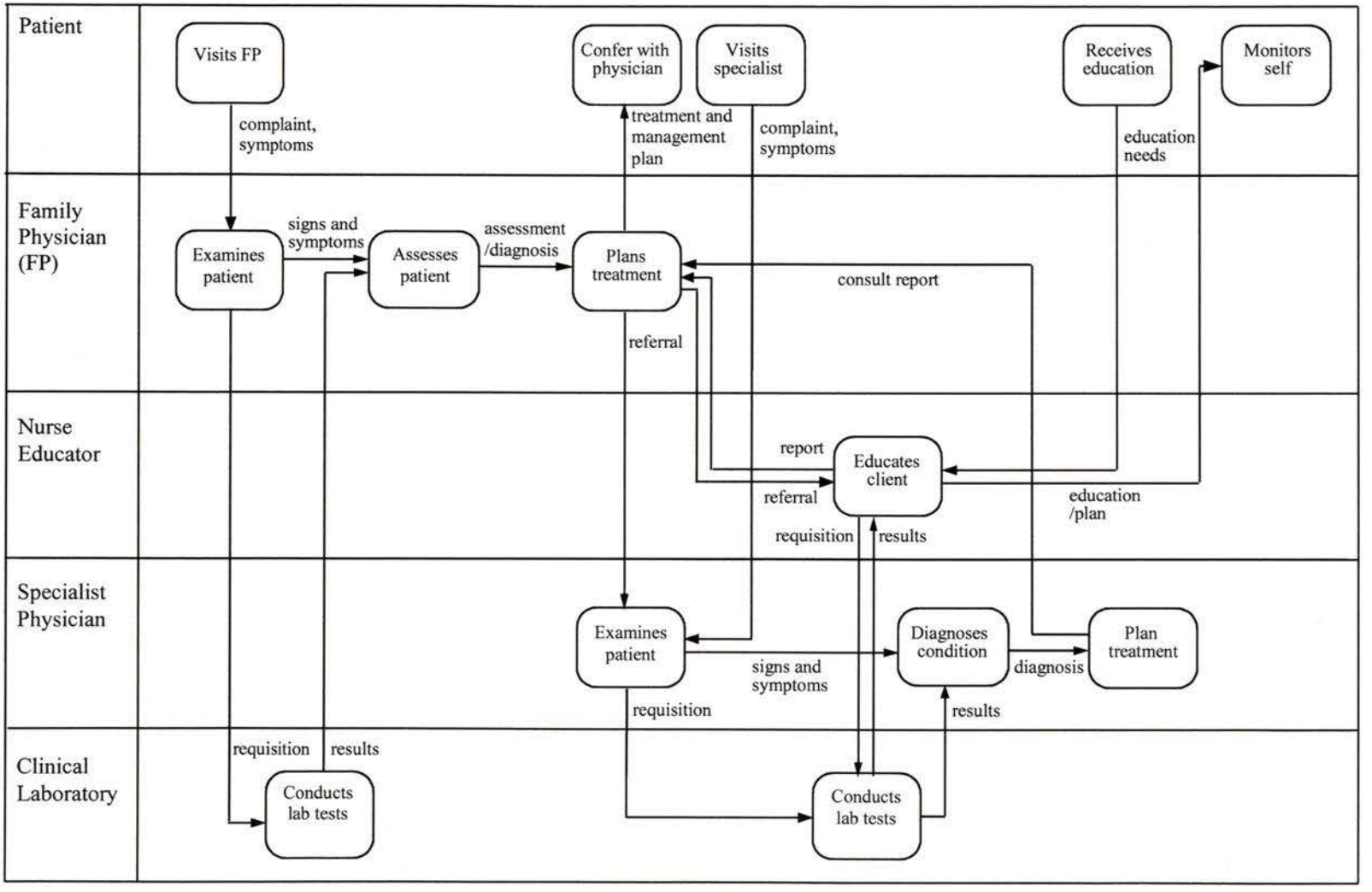
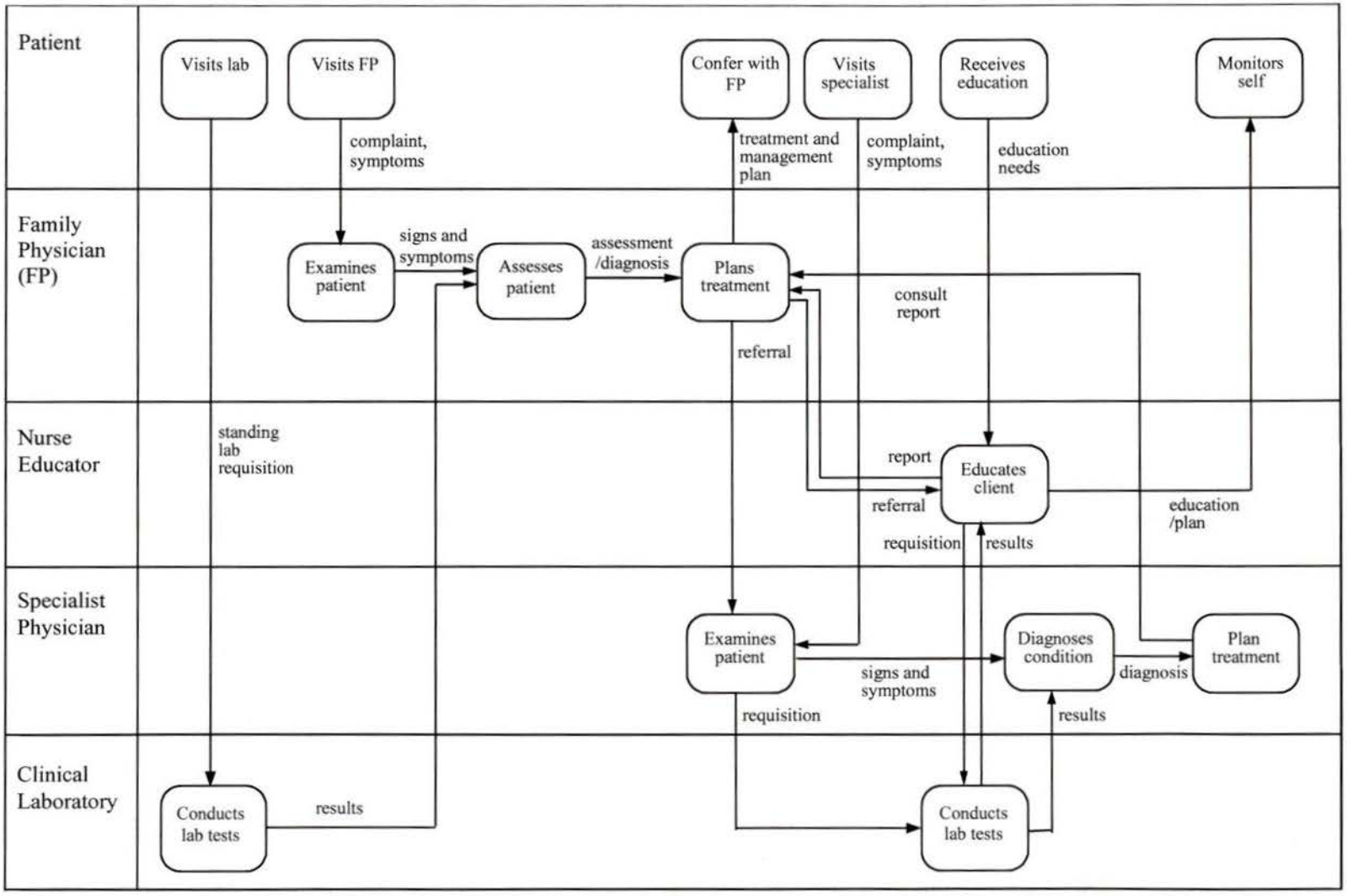


**Figure 4**: The business processes in routine diabetes care. The boxes indicate processes and the arrows show data flows among the processes. The left column shows the person or agency acting in the processes.



In both Figures 3 and 4, there may be multiple patient visits to a family physician and specialist. A family physician's treatment plan may, for example, require a consultation report from a specialist; a patient will have another visit with the family physician after the family physician receives the consultation report. In Figures 3 and 4, the chronology of the processes is roughly indicated by their order from left to right. For example, a patient can be examined almost immediately after a family physician has made a referral to a specialist physician. This is the most urgent case, such as when the aid of an endocrinologist is needed to immediately start or change insulin medication. In the case of emergencies or multiple visits, the order of the processes could change or a person may cycle through a subset of the processes.

### 3.5.2 Function Hierarchy Model

The function hierarchy model begins with the highest level functions in diabetes care: diagnosing diabetes; routine or regular follow-up care; and diagnosing complications or problems as described in this study (see Figures 5 through 9). The second level of this model breaks down each of the highest levels to show the functions within each higher level. The third level breaks down each function from the second level, if necessary, and groups the functions to show which profession, specialty or agency is responsible for each functional area. This lowest level of decomposition, along with the business process diagrams, is used in the design of the data model. The function hierarchy was used to check the data model, to ensure that the functions and data to support the functions are accounted for in the data model.

**Figure 5**: Level one of the diabetes care function hierarchy, showing that diabetes diagnosis and management breaks down into three functional areas.

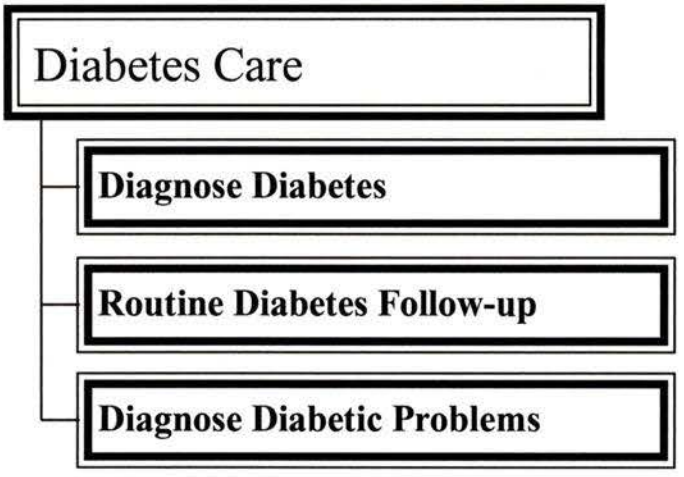



**Figure 6**: Level two of the diabetes care function hierarchy, including family physicians diagnosing diabetes and diabetes related problems.

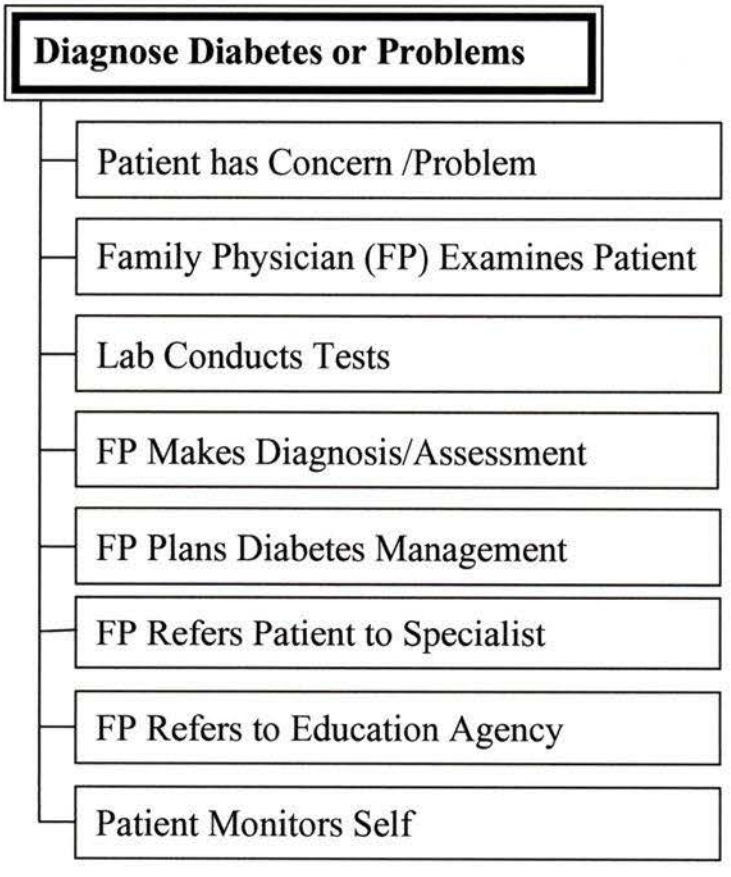


**Figure 7:** Level two of the diabetes care function hierarchy (continued). This figure shows lower level functions that make up routine patient follow-up visits to a family physician for diabetes care.

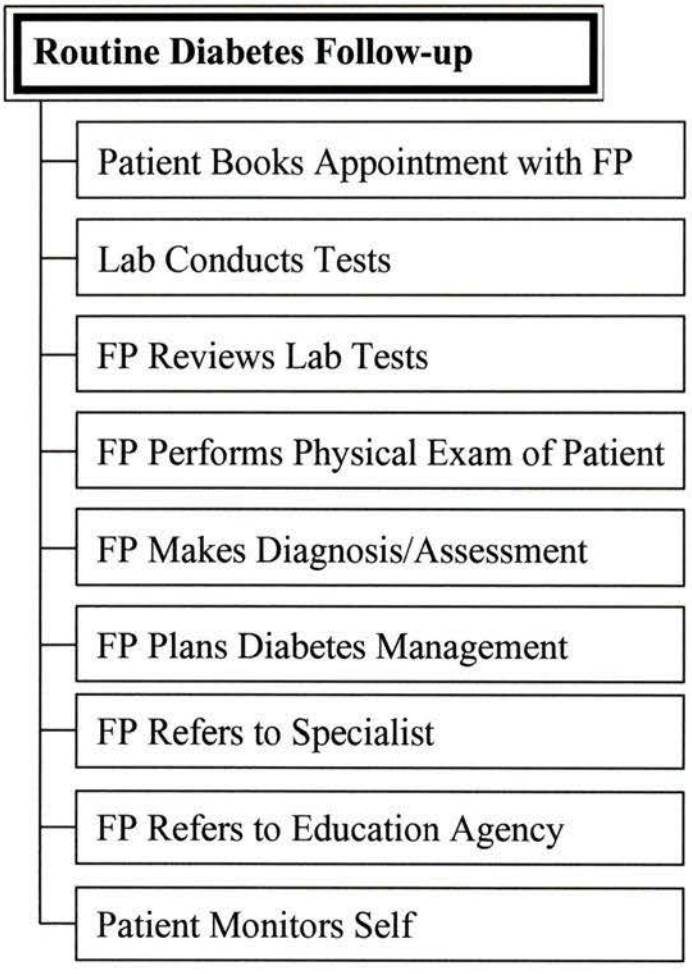


**Figure 8**: Level three of diabetes care function hierarchy showing the lowest level of functions required for data modelling within the higher functions of a family physician examining a patient, laboratory testing and a family physician diagnosing or assessing a patient with diabetes.

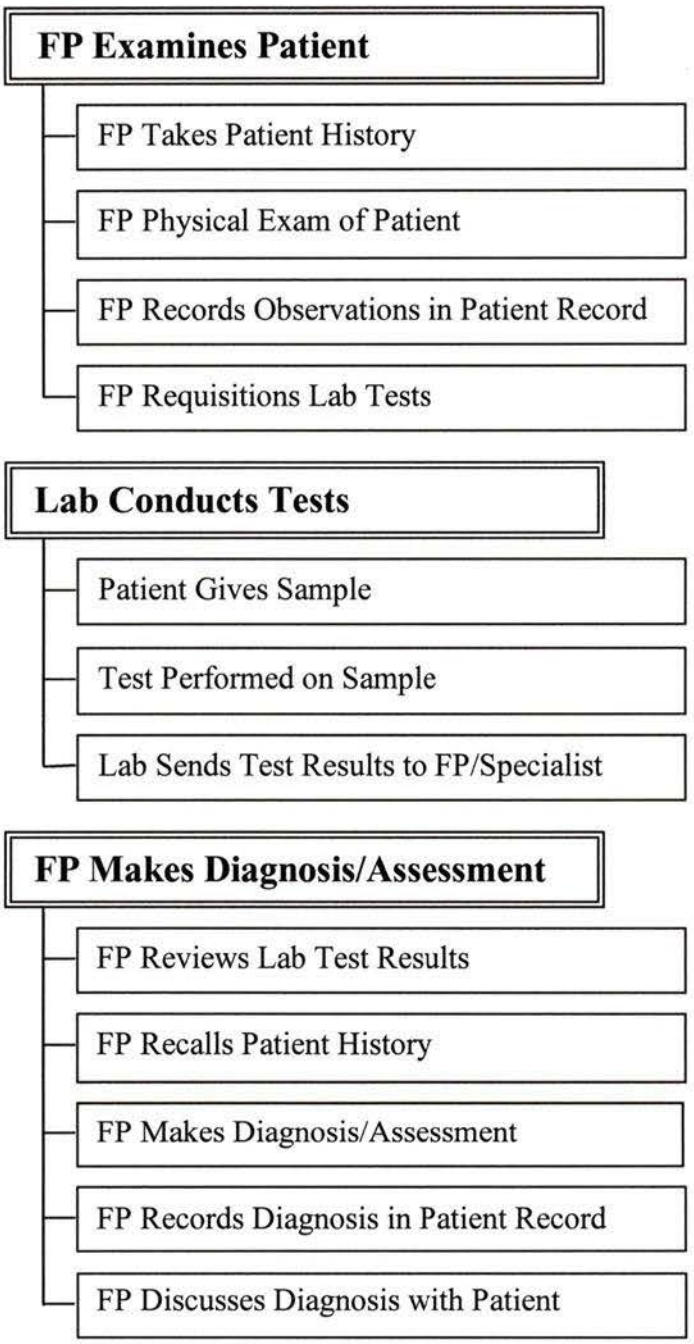
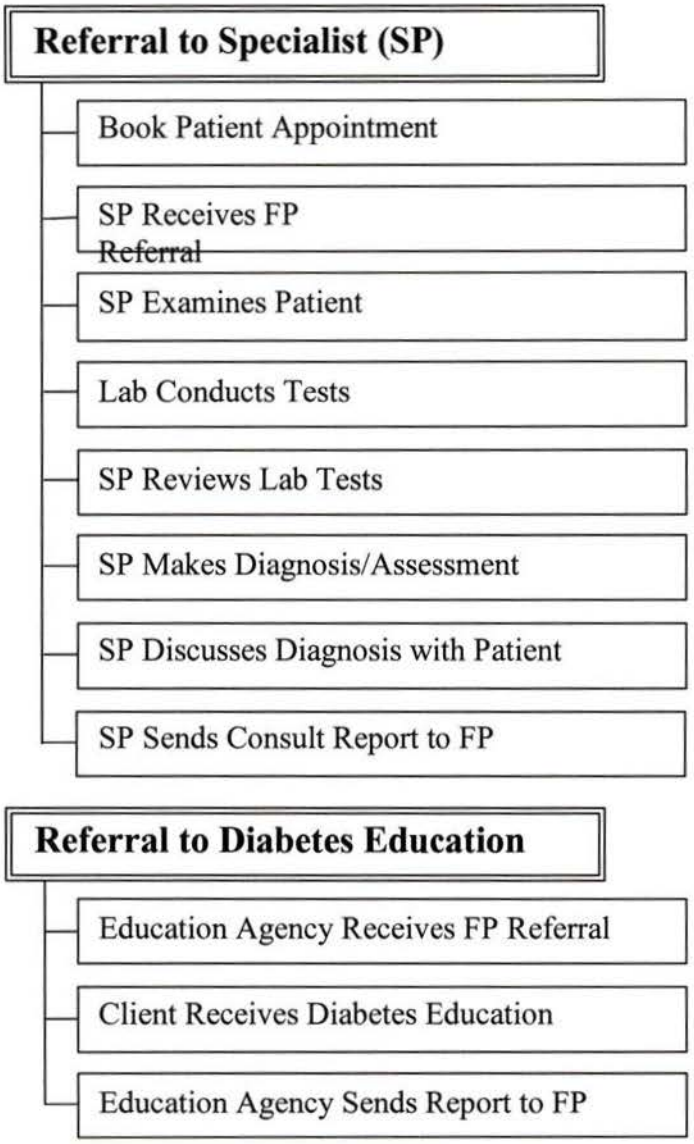


**Figure 9:** Level three of diabetes care function hierarchy (continued) showing the lowest level of functions, required for data modelling, within the higher functions of a patient referral to a specialist physician and a patient referral to a diabetes education agency or program.



### 3.5.3 Data Model

The data model shows data objects: persons, agencies or functions that represent reality in diabetes care. Data objects and the relationships among these objects are shown in Figures 10 and 11. Each data object includes examples of its attributes (data about the object or process) including those necessary to identify separate instances of the object (keys). Table 4 describes the data objects and Table 5 shows all the attributes of each data object. Each of the attributes is described in a data dictionary (see Appendix 3).

Within the data model, each object is related to one or more other objects. In reality, considering the care system being modelled, it is possible that each object is related to only one, or one to many, or to none of the objects it is connected to in the data model. Whether this relationship must exist and the possible number of the other object involved are shown in the model by symbols for cardinality. A relationship may be:

- optional, zero to one or zero to many; or,
- mandatory, one to one or one to many.[72]

The methods that would be used in a computer system to retrieve or calculate values are usually shown within an object in an object-oriented data model. However, methods are not shown here for two reasons: because there is not enough space to show methods in every object; and because the methods used to display data or perform calculations would be determined by further study and testing that would be done to design an implementation model.

**Figure 10**: Level one of the diabetes care data model. Data objects represent persons, agencies or processes involved in diabetes care; connecting lines show a relationship between objects.

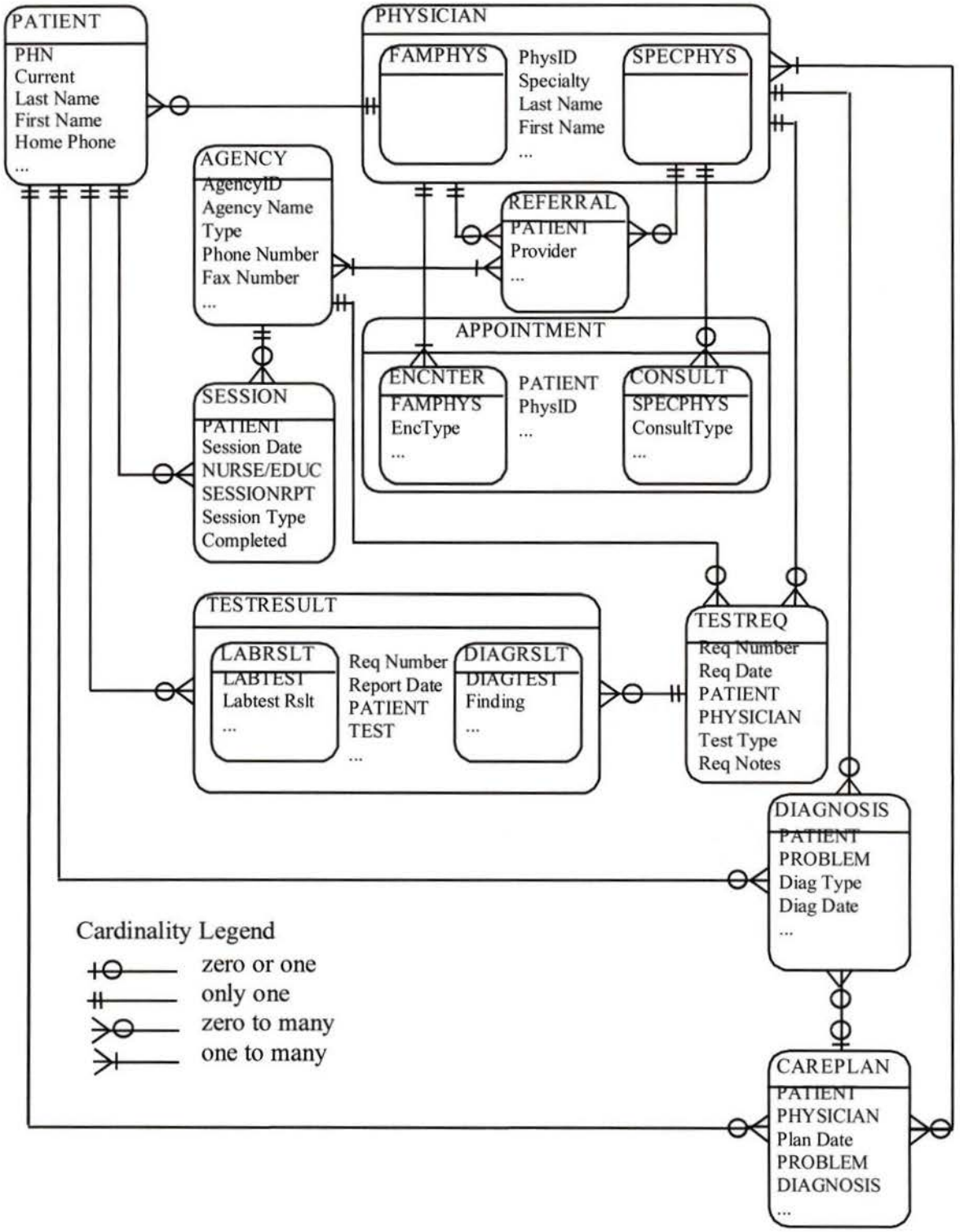
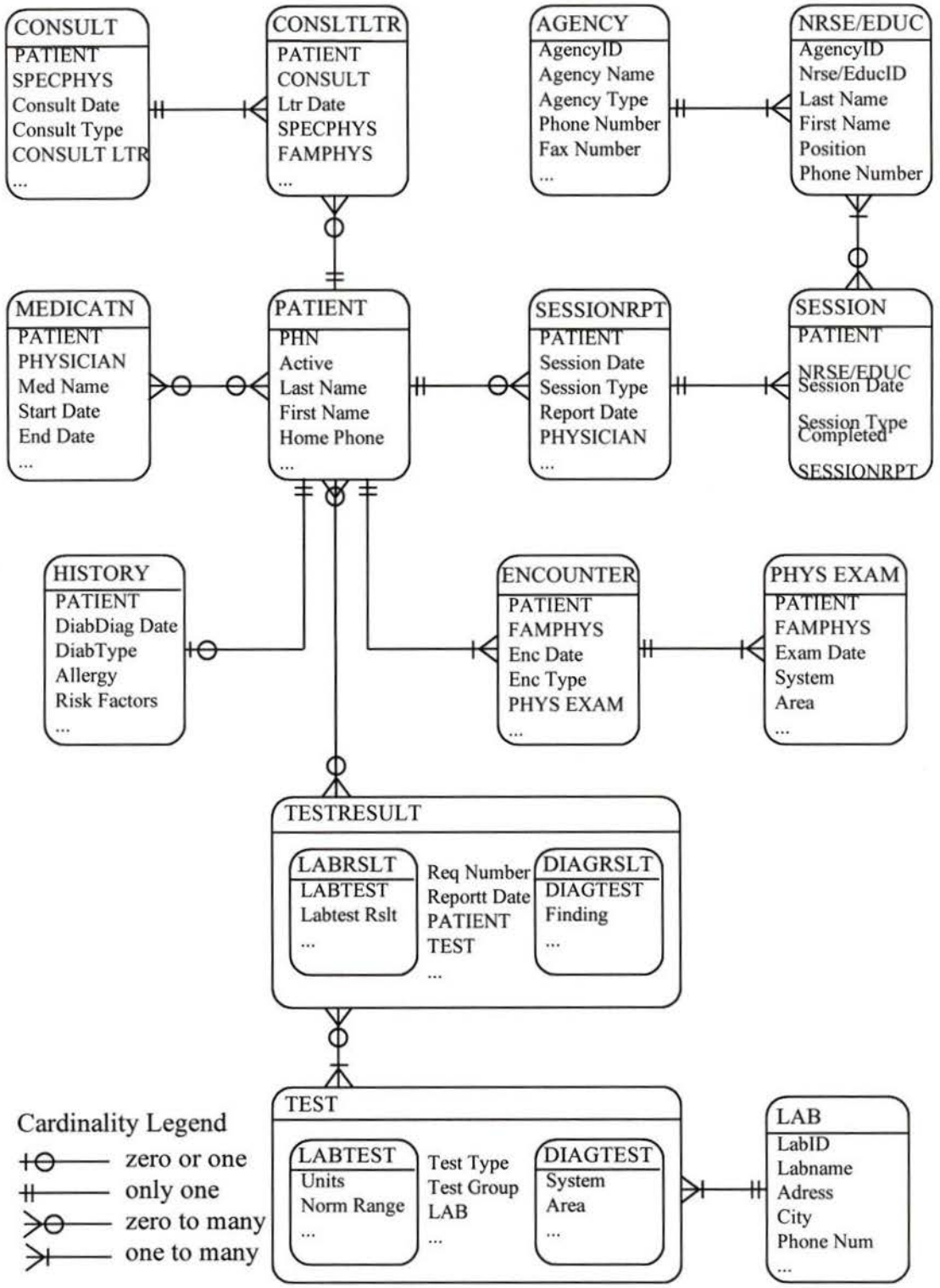


**Figure 11**: Level two of the diabetes care data model showing greater detail in data objects. Data objects represent persons, agencies or processes involved in diabetes care; connecting lines show a relationship between objects.



Relationships among the data objects in the data model may be optional or mandatory for a specific pair of data objects. In Figure 11, for example, a patient must have at least one encounter (one to many encounters) because a record or chart is not created for a new patient until they attend the family physician's office for an appointment. In contrast, the relationships of a test requisition to a test result and of a specialist physician to a consultation are shown as optional. These optional relationships indicate that a patient might miss or might choose to not attend a consultation although the specialist must exist in the system for a referral letter, and that a patient does not necessarily have tests performed. For both medical and legal reasons, family physicians stated in interviews that it is important for them to record actions such as referrals or test orders, even if patients do not receive tests or attend consultations. Family physicians said they always record a reason for an encounter, even if the reason is a patient's worry rather than a diagnosed condition. So, the relationship, in Figure 8, of an encounter to a diagnosis is mandatory.

The data modelling is an important step in deciding how the preliminary essential dataset would be implemented electronically. For example, Figure 10 shows that a patient may have more than one test result, but a single test result must have only one requisition number. This means that a test result must be identified by more than a patient's health number for it to be useful in patient care. For the test result to be in context it must be associated with the order date, type of test and the person ordering the test. This additional data can be obtained from the test requisition. This indicates that a requisition number must be connected to each test result in an electronic database. This is an example of how the data model dictates the electronic data structure for data objects and attributes (see Appendix 3).

**Table 5**: Full names and definitions of the data model objects defined in the data model described in this study. The data model is shown in Figures 10 and 11.

| | |
|---|---|
| Patient | Demographic and identifying attributes of a person receiving care for diabetes, a patient or client. |
| Physician | This is an object class with general or family physicians described as such in the Specialty attribute. Only specialist physicians rather than family or general physicians may receive referrals. |
| History | Describes the medical history of a diabetic patient. This includes the date and method of diagnosis, type of diabetes, risk factors for diabetes and complications, and allergies. |
| Encounter | Patient appointment with a family physician. This may lead to referrals, prescriptions, education, care planning, etc. |
| Physical Exam | Patient examination by a family physician. |
| Diagnosis | Determination of the cause or nature of a problem for each patient encounter, reason a patient is seen by a physician even if the patient's concern does not lead to any action other than reassurance. |
| Care Plan | Details of recommended care and actions for management of diabetes and complications. |
| Medication | Details of medications being taken or used by a patient/client including non-prescription medications such as vitamins.* |
| Referral | Form or letter from a physician. A referral from a specialist or family physician gives access to specialist physician or education services. |
| Consultation | Patient examination by a specialist physician, initiated by a referral. Specialist is allowed to see a patient more than once in a six-month period per referral. May lead to other referrals, medication changes, education, etc. |
| Consultation Letter | Report by a specialist physician to the referring physician and family physician if these are not the same person or a report to the referring family physician. This report includes details of history, problems, diagnosis, findings, assessment and plan, and is kept in the specialist's patient chart as a legal record. |
| Agency | Agency, hospital department or outpatient clinic, regional health board agency, etc. that delivers education or services to diabetic patients/clients. |
| Nurse/ Educator | Nurse, nurse educator, nutritionist, dietician who deliver education or services to a diabetic patient/client. |
| Session | A patient/ client visit with nurse/ educator for services or education. |
| Session Report | Report to the referring physician and family physician if these are not the same person. Includes details of type of education and services provided, and any lab results of tests ordered. |

| | |
|---|---|
| Test Requisition | Requisition for lab or diagnostic test(s). Must be made by a physician or agency for a patient with a B. C. Care Card for Medical Services to pay for the test(s). |
| Test Result | Object class, which is broken into 1) result of a lab test or a calculated result, derived from another lab test(s), or 2) result, finding or interpretation of a diagnostic test. |
| Test | Object class for reference information such as type or the way a test is performed, which is broken into 1) clinical lab test, or 2) diagnostic test. |
| Lab | Identifies a clinical laboratory providing diagnostic testing such as blood testing, x-rays, ultrasounds, etc. |

**Table 6**: Attributes of each data model object described in Table 5. Attributes describe a person, item or process named as a data model object.

| Object | Attributes |
|---|---|
| Patient | Personal Health Number (PHN) |
| | Current |
| | Last Name |
| | First Name |
| | Middle Name |
| | Address Group* |
| | Home Phone |
| | Alternate Phone |
| | Date of Birth |
| | Gender |
| Physician | Physician ID |
| | Specialty |
| | Last Name |
| | First Name |
| | Middle Name |
| | Address Group* |
| | Phone Number |
| | Fax Number |
| | Alternate Phone |
| Encounter | PHN |
| | Physician ID |
| | Encounter Date |
| | Encounter Type |
| | Reason |
| | Attended |
| | Test Result Review |
| | Test Type |

| | |
|---|---|
| History | PHN |
| | Diabetes Diagnosis |
| | Diabetes Type |
| | Allergy |
| | Risk Factor |
| | Diet |
| | Lifestyle |
| | Exercise |
| | Glucose Control |
| | Updated |
| | Medical Event |
| | Start Date |
| | End Date |
| | Reported By |
| Physical Exam | PHN |
| | Physician ID |
| | Encounter Date |
| | System |
| | Area |
| | Finding |
| Problem | PHN |
| | Encounter Date |
| | Problem Type |
| | System |
| | Area |
| Diagnosis | PHN |
| | Physician ID |
| | Problem Type |
| | Diagnosis Type |
| | Diagnosis Date |
| | System |
| | Area |
| | First Seen Date |
| | Confirmation Date |

| | |
|---|---|
| Care Plan | PHN |
| | Physician ID |
| | Plan Date |
| | Exercise Rec |
| | Diet Rec |
| | Next Appt |
| | Next Appt Type |
| | Referral Type |
| | Referral Frequency |
| | Diagnosis Type |
| | Diagnosis Date |
| | Problem Type |
| | Action |
| | Action Date |
| | Provider |
| Medication | PHN |
| | Medication Name |
| | Start Date |
| | End Date |
| | Dose |
| | Frequency/ Time |
| | Physician ID |
| | Reason |
| Referral | PHN |
| | Physician ID |
| | Reason |
| | Provider |
| | Referral Date |
| Consult | PHN |
| | Physician ID |
| | Consult Date |
| | Attended |
| | Consult Type |
| | Letter Issued |

| | |
|---|---|
| Consult Letter | PHN |
| | Report to Physician ID |
| | Specialist Physician ID |
| | Consult Date |
| | Letter Date |
| | Reason |
| | System |
| | Area |
| | Finding |
| | Recommendation |
| | Action |
| | Prescribing |
| Agency | Agency ID |
| | Agency Type |
| | Agency Name |
| | Address Group* |
| | Phone Number |
| | Fax Number |
| Nurse/Educator | Agency ID |
| | Nurse/Educator ID |
| | Last Name |
| | First Name |
| | Position |
| | Phone Number |
| Session | PHN |
| | Nurse/Educator ID |
| | Session Date |
| | Session Type |
| | Completed |
| Session Report | PHN |
| | Nurse/Educator ID |
| | Session Date |
| | Session Type |
| | Report Date |
| | Physician ID |
| | Test Result Date |

| | |
|---|---|
| Test Requisition | Requisition Number |
| | Requisition Date |
| | PHN |
| | Physician ID |
| | Test Type |
| | Requisition Notes |
| Test Result | Requisition Number |
| | Report Date |
| | PHN |
| | Physician ID |
| | Test Type |
| | Lab ID |
| Lab Result | Lab Test Result |
| | Sample Date |
| | In Range |
| Diagnostic Result | Finding |
| | System |
| | Area |
| Test | Lab ID |
| | Test Type |
| | Test Group |
| | Test Method |
| | Test Notes |
| Lab Test | Units |
| | Normal Range |
| | Sample Method |
| Diagnostic Test | System |
| | Area |
| Lab | Lab ID |
| | Lab Name |
| | Address Group* |
| | Phone Number |
| | Fax Number |

* Address Group is made up of three elements, as shown in Appendix 4 Data Dictionary for the Essential Dataset.

### 3.6 The Dataset Elements

**Table 7**: The preliminary essential dataset showing the types of data that should be collected in diabetes care with the number of each type of interview subject in agreement and a comparison to four other datasets.

| | **Participant** (n) | | | **Dataset** (n) | | | |
|---|---|---|---|---|---|---|---|
| **Type of Data** | Primary Care (5) | Specialist Care (9) | Agency Care (4) | CMAJ[xi] (1) | Diab Care[xii] (1) | RCP-BDA[xiii] (1) | LDS[xiv] (1) |
| Medical History[1] | 5 | 9 | 4 | 1 | 1 | 1 | 1 |
| Physical Exam[2] | 5 | 2 | 3 | 1 | 0 | 0 | 1 |
| Family History | 5 | 3 | 4 | 1 | 0 | 0 | 0 |
| CHD Risk Factors | 5 | 3 | 2 | 1 | 0 | 1 | 1 |
| General Risk Factors[3] | 4 | 4 | 4 | 1 | 0 | 0 | 1 |
| Lifestyle | 3 | 3 | 4 | 1 | 0 | 0 | 1 |
| Exercise | 4 | 2 | 3 | 1 | 0 | 0 | 1 |
| Diet[4] | 4 | 3 | 4 | 1 | 0 | 0 | 1 |
| Glucose Control | 5 | 6 | 4 | 1 | 0 | 0 | 0 |
| Self-Care Ability[5] | 3 | 4 | 4 | 1 | 0 | 0 | 0 |
| Referrals, general | 5 | 8 | 4 | 1 | 0 | 0 | 0 |
| Counselling/Education | 5 | 5 | 4 | 1 | 1 | 0 | 1 |
| Lab Tests, general | 4 | 6 | 1 | 1 | 0 | 0 | 0 |

See the next page for notes.

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xi The Canadian Diabetes Advisory Board, an expert committee jointly sponsored by the Department of National Health and Welfare, the Canadian Diabetes Association, the Juvenile Diabetes Foundation Canada, and the Association du Diabète du Québec Board, developed clinical practice guidelines for treatment of diabetes mellitus. The guidelines were published in the Canadian Medical Association Journal (CMAJ).[71]

xii DiabCare Diabetes Dataset Version 2. Received from: Dieter Westphal, Project Manager, DiabCare Quality Network in Europe, DiabCare Office, Kobellstr. 3, D-80336 Munich, Germany. e-mail:dwe@diabcare.de, Website: http:www.diabcare.de, May 05, 1998.

xiii The Royal College of Physicians (RCP) and the British Diabetic Association (BDA) co-sponsored the Diabetes Audit Working Group, which developed the U. K. Diabetes Dataset.[65]

xiv LDS Hospital, Salt Lake City, Utah. Dataset determined from the data collection forms, David Nilasena, personal communication, February 5, 1996.[12]

**Table 7 Notes**:

1. The Medical History should include surgeries and major illnesses, including endocrine disorders and hyperglycaemic or hypoglycaemic incidents, to give background for patient encounters and referrals. This information is collected by a majority of the family physicians and all the specialist physicians interviewed in this study. The RCP-BDA and LDS Datasets collect data on hyperglycaemic and hyperglycaemic episodes, symptoms of these episodes and other diabetes complications such as current or past neurologic complications in specific fields.

2. The Physical Exam should include findings from examining the skin, feet and heart as this information is collected by all the family physicians and a majority of the specialist physicians. Some physicians examine lungs, teeth and gums but this was not common enough for inclusion, although the CMAJ guidelines recommend examining the oral cavity.

3. Risk factors should include those used to diagnose diabetes by clinical laboratory testing when there is a suspicion of diabetes due to factors such as age, obesity and family history.

4. The LDS forms only collect a yes or no for whether the patient is following the American Diabetic Association Diet.

5. The CMAJ guidelines do not use this term but self-care ability is inferred from the guideline's instructions to assess: a patient's coping skills; ability to adjust diabetes medication dosages; and current understanding of diabetes and its management.

**Table 8**: The preliminary essential dataset showing specific data that should be collected in diabetes care with the number of each type of interview subject in agreement. The preliminary essential dataset is compared to four other datasets.

| | **Participant** (n) | | | **Dataset** (n) | | | |
|---|---|---|---|---|---|---|---|
| **Essential Data** | Primary Care (5) | Specialist Care (9) | Agency Care (4) | CMAJ (1) | Diab Care (1) | RCP BDA (1) | LDS (1) |
| Date of Diagnosis | 5 | 9 | 4 | 1 | 1 | 1 | 0 |
| Diabetes Type | 5 | 9 | 4 | 1 | 1 | 0 | 0 |
| Weight | 5 | 1 | 4 | 1 | 1 | 1 | 1 |
| Height[1] | 1 | 1 | 3 | 1 | 1 | 1 | 1 |
| Blood Pressure | 5 | 1 | 4 | 1 | 1 | 1 | 1 |
| Smoking | 5 | 3 | 2 | 1 | 1 | 1 | 1 |
| Alcohol[2] | 1 | 3 | 2 | 1 | 1 | 1 | 1 |
| Blood Sugar | 5 | 7 | 3 | 1 | 1 | 1 | 1 |
| Haemoglobin (HbA1c) | 5 | 8 | 4 | 1 | 1 | 1 | 1 |
| Microalbumin tests | 5 | 6 | 3 | 1 | 1 | 1 | 1 |
| Lipids Tests | 4 | 6 | 2 | 1 | 1 | 1 | 1 |
| *Serum Creatinine Test*[2] | 1 | 4 | 0 | 1 | 1 | 1 | 1 |
| Gestational Diabetes [3] | 2 | 1 | 2 | 1 | 1 | 0 | 1 |
| Patient uses Home Glucose Monitor | 5 | 7 | 4 | 1 | 1 | 1 | 1 |
| Referral Information | | | | | | | |
| Recommends Canadian Diabetes Association[4] | 4 | 1 | 3 | 0 | 1 | 0 | 0 |
| Ophthalmologist exams[5] | 5 | 7 | 3 | 1 | 1 | 1 | 1 |
| Current Medications[6] | 5 | 9 | 4 | 1 | 1 | 0 | 0 |
| Past Medications[7] | 3 | 9 | 3 | 1 | 1 | 0 | 0 |
| Referral Reason | 5 | 8 | 2 | 1 | 0 | 0 | 0 |
| Date of Problem Onset[8] | 5 | 9 | 2 | 0 | 0 | 0 | 0 |
| Treatments[8] | 5 | 9 | 4 | 0 | 1 | 0 | 0 |
| Tests Ordered[8] | 4 | 9 | 4 | 0 | 0 | 0 | 0 |
| Test Results | 5 | 9 | 4 | 1 | 1 | 0 | 0 |

See the next page for notes.

**Table 8 Notes:**

1. Height should be measured to allow automatic calculation of body mass index as specified by the Canadian guidelines.[71]

2. The serum creatinine test is included in the preliminary essential dataset because it is recommended by all the datasets examined and the Canadian guidelines, as well as some physicians.

3. The amount of alcohol use should be noted, according to the Canadian guidelines, as this is a risk factor for other conditions as well as having effects on glucose level.[71] Higher alcohol consumption is used by some physicians and agencies as an indication of psychosocial problems.

4. Pregnancy must be noted under finding of physical exam or as a lab test result so that an automated system could find this for the physician and other health care providers.

5. The DiabCare dataset has a field for membership in a diabetic patient organization.

6. The DiabCare and RCP-BDA datasets have fields for the results of eye exams and treatments.

7. The RCP-BDA and LDS Datasets only collect a yes or no for whether the patient is currently treated with insulin or an oral hypoglycaemic agent.

8. Past medications and changes are important to specialists in this study. The length of time between diagnosis of diabetes and the type and level of medication needed to control blood glucose are used as indicators of the long-term control of glucose, a patient's response to treatment and a measure of the likelihood of complications.

9. These data are all recommended as part of histories by the Canadian guidelines if the problem is related to diabetes. For most of those interviewed, these are collected as part of history and care planning rather than specifically as referral information. The DiabCare Dataset collects a yes or no for a list of complications such as ulcers of the feet, hypertension, cardiac failure and stroke rather than every problem related to diabetes.

### 3.7 Feedback to Participants

At the beginning of this project, it was thought that the benefits to the participants would include a description of the data currently being shared or exchanged among different health care providers. This was not possible as almost every physician was reluctant or even refused to show any examples of referrals or consult letters. This research relies on what physicians say is contained in these and what they feel should be included. Some of the issues raised by this and the value placed on information currently received from other care providers will be covered in the Discussion.

A summary of this study will be prepared for the participants. A copy of the study was presented to Dr. Macgregor, Chief of Family Practice Medicine, Capital Regional Health Board as the board is conducting a study of implementing clinical guidelines on diabetes care.

# 4 Discussion

## 4.1 Defining the Preliminary Essential Dataset for Diabetes Care

### 4.1.1 The Preliminary Essential Dataset

This study describes an operational database structure to store a diabetic patient record that could be used by family or primary care physicians. This data structure is not designed to fill the needs of a particular institution; it is designed for family physicians practising in the community (see Figures 10 and 11, and Appendix 3). The diabetic patient record is defined by the preliminary essential dataset described in Tables 8 and 9, and by the data dictionary that defines the dataset elements (see Appendix 4). The dataset is referred to as preliminary because it has not been prospectively tested.[17] The operational database structure is necessary to contain the many entries a single patient record may have for some parts of the dataset. Examples of this need for multiple entries for a single patient, as shown in Figure 10, are many encounters with a family physician, frequent laboratory testing and a patient being referred to several specialist physicians.

The preliminary essential dataset is described in this study in conjunction with a patient-centred data structure that could be used to store data from a series of encounters between family physicians and a patient. This data structure could also be used to store data on referrals to specialist physicians and diabetes related services, and data from reports received from specialists and agencies. The dataset structure includes the ability to store data from referrals and reports because family physicians said these services and the reports received from specialists and agencies are important. The present study describes a preliminary essential dataset for use by

family physicians, but, because of its structure, this dataset could easily be modified for use by other care providers.

### 4.1.2 Further Development Required for the Preliminary Essential Dataset

The methods of systems analysis applied in the study interviews do not fit within a quantitative model. Also, in the preliminary interviews physicians seemed more inclined to participate fully in interviews if they were not questioned on every aspect of the history and the physical examination of a diabetic patient that is recommended in the Canadian guidelines on diabetes care.[71] However, this means that the present study does not specify every element of a history and physical examination that should be recorded by family physicians. Specifying these elements would require further work, including questioning family physicians on the areas recommended in the Canadian guidelines and the data elements specified in the other datasets used for comparison in Tables 7 and 8. . The Canadian guidelines on diabetes care are not specific enough in these two area to infer what data elements should be collected.[71] Expert advice would be required to decide what data elements would be included in further questioning of physicians.

Interviews and follow-up interviews with family physicians and interviews with endocrinologists showed that there is a high degree of variability in medical history-taking and in the physical examinations of patients with diabetes. In fact, this variability was surprising as preliminary interviews had indicated that the methods used and data collected by physicians during diabetes care were fairly similar. This only held true for a few areas such as medication and laboratory testing as shown in Table 8. Systems analysis techniques are better suited to selecting data elements in systems where there is agreement on which data elements are being used. Even if

further research determined specific data elements for history-taking and the physical examination, there is no guarantee that most physicians would agree with the selection of data elements.

To produce a successful electronic system it is likely that a small number of data elements would have to be specified for categories, such as the physical examination, with a list of optional elements to allow physicians the flexibility to investigate individual cases as each physician sees fit. This could produce an essential dataset, but such a dataset would not necessarily support evaluation of diabetic care according to the Canadian guidelines.

Possible differences between the family physicians interviewed for the present study and the general population of family physicians in Victoria, British Columbia are discussed later. If the family physicians interviewed for this study are more informed about diabetes care, introducing any system with specific data recording requirements could be difficult. This present study indicated that a minority of family physicians are performing care according to the Canadian guidelines. For example, the notes to Table 7 indicate that most physicians interviewed are not examining the lungs and the oral cavity and Table 8 indicates that most family physicians are not ordering serum creatinine testing as specified in the guidelines.

The Canadian guidelines were developed by an expert committee using critical reviews of the current literature and consultation with leaders in diabetes care.[71] One is forced to assume that the guidelines are a kind of "gold standard" of best practices in diabetes care and that not all the recommendations are being followed, even by the physicians who are aware of the guidelines. In our contemporary health care system, physicians are not required to collect specific data. Physicians are

accustomed to working independently with their own methods of investigation and record taking. Further development of the preliminary essential dataset would require choosing between essential as determined by guidelines or by a majority of a sample of physicians. Introducing a system for which physicians were expected to collect specific data would only be possible if physicians saw great benefit in using such a system or if the physicians using such a system agreed on which data elements should be mandatory for every patient with diabetes.

### 4.1.3 Potential Benefits of Using an Essential Dataset in Diabetes Care

Data collected using the preliminary essential dataset and data structure described in this study could be used to prepare letters to patients, medical reports and referral letters. The preparation of medical reports and referral letters occupies a significant portion of a clinician's time.[75] As well, specialists interviewed for the present study complain that referral letters are frequently not received before patients' appointments. A system developed in the U. K. can produce recall letters to remind patients to book an annual review with their physicians as recommended by guidelines.[50] These recall letters improve both care for patients and office efficiency. A system that could automatically produce most text for reports, referral letters, and recall letters to patients could save physicians and physicians' office staff some time. Such a system could improve care and provide justification for a system that uses an essential dataset by ensuring that such reports and letters are produced.[36]

A defined dataset and structured way of storing this dataset could provide a consistent basis for the decision-making required of family physicians providing care for patients with diabetes. Many of the physicians interviewed for this present study said

that one of the ways they learn about managing a chronic condition is to compare the care provided to different patients and compare the patient outcomes. A consistent dataset and structure would provide a framework for this experiential learning for family physicians. As well, if there is to be any comparison of the type of care and outcomes, a standard method of data collection is necessary.[76]

Tables 3 and 4 show that the family physicians who participated in this study are collecting data that agencies would like to receive before seeing diabetic client. Currently most of this data is not sent to the agencies because a generic referral form must be used for all referrals within the Greater Victoria Hospital Society. Often this means that inquiries are made by telephone and /or letter to a family physician to get more information before the agency sees a patient and sometimes this lack of information delays the scheduling of patient appointments. If family physicians provided this data, data which is almost all available in patient records, the physicians and their staff would have fewer interruptions and patients would be better served.

### 4.1.4 Benefits of an Operational Database Structure

The operational database structure outlined in this study for the preliminary essential diabetes care dataset would be able to exchange data with other electronic systems. For example, the data structure defined to hold test results, shown in Figure 11, could contain the results of any test rather than there being a structure defined for each specific test. By storing a name or code for a laboratory test, the value of the test result, the units of measurement and the normal range, this structure could be used in conjunction with standards such as the Logical Observation Identifier Names and Codes (LOINC) Database to send data to or receive data from other systems. The LOINC database has been adopted as a standard for identifying clinical laboratory

tests and results in Ontario, by laboratories in the U. S. A. that account for more than 30% of commercial testing in that country, and by many computer system vendors and health care providers in the U. S. A.[75] The data structure defined for the preliminary essential dataset in this study would be able to electronically receive laboratory test results from other systems.

An operational database, with a defined dataset, can be used to provide decision support in clinical care. Technology and software are available that allow rules to be included in a computer program or database interface. These rules can be used to prompt the computer user to collect or update data elements which are then used to give advice on diabetes care.[55] When data are stored in an organized way in a computer, standardized algorithms or computer programs can be applied to the data. For example, rules defined by guidelines or clinical experts could be used to give advice on diabetes care.[55] Repetitive activities of diabetes management could be performed by computer to determine the type of diabetes and recommend the initial treatment regimen.[77]

If the data structure outlined in this study was implemented in an electronic database, rules or algorithms in a program or even the manner of displaying data items could prompt a user to collect data or take certain actions. For example, previous glycated haemoglobin test results could be displayed in a series beginning with the most recent. Although these results would be stored in a generic structure for laboratory tests, they could be selected from a database as long as a standard name or code identified each result. Then system users could be prompted to order a new test by a rule in the system or their own judgement using the advice and data displayed according to a rule. This new order would be based on data in the preliminary

essential dataset such as the patient's age, level of glucose control, presence of other conditions or complications and the date of the last test.

Table 7 and its accompanying notes in the Results show the categories of data that should be collected in the preliminary essential dataset. In addition to the items listed for the physical examination in the Notes to Table 7, a minority of physicians in this study reported checking the peripheral circulation and bruits, as recommended by the Canadian guidelines. These tests and others in Table 8, such as blood pressure, can be stored in the defined test results structure. Therefore, the operational structure for storing the preliminary essential dataset does not rule out additional tests and observations as the usefulness of a system would be reduced by such limits. This is important as the Canadian guidelines specify that certain tests and examinations should be made according to a physician's judgement rather than being performed on all patients with diabetes.[71]

Testing serum creatinine is recommended by all the datasets used for comparison in Table 8 and the Canadian guidelines for diabetes care. This test is included in the preliminary essential dataset although a majority of family physicians reported that they do not order this test for patients with diabetes. Rules in an electronic interface or program could be used to suggest this test for new patients and patients newly diagnosed with diabetes as recommended by the Canadian guidelines.[71]

### 4.1.5 Exclusion of Patients

Patients were not interviewed and used in this study for a number of reasons already discussed in the Methods. Adding patients to the study of developing a preliminary essential dataset for family physicians for use in diabetic care would focus on self-monitoring of blood glucose (SMBG) and timing of medication. The data elements of

SMBG and medication are fairly simple and have been defined in the development of computer programs to accept downloads of data from blood glucose monitoring units.[78] When monitors that can download this data are in common use, these data elements could be added to the dataset.

The Canadian Diabetes Association distributes a diabetes logbook which focuses on SMBG data, medication, laboratory test results, lifestyle and diet as well as any recommendations from physicians to change diabetes medications and treatments for complications received. In interviews, family physicians said that this is the data that they discuss with patients with diabetes. This shows, except for the SMBG data, that the preliminary essential dataset supports these patients' needs by collecting this data for the family physician. In our current health care system, except for discussions between a patient and specialist physicians, the family physician is always the original source of this data for a patient with diabetes.

### 4.1.6 Bias in the Selection of Participants

All family physicians interviewed for this study indicated that they refer diabetic patients to an ophthalmologist. However, almost every agency representative and specialist physician who was interviewed said that many diabetics are not being referred to ophthalmologists. Referrals to an ophthalmologist are recommended in the Canadian guidelines on diabetes care.[71] This indicates that the family physicians who were interviewed are probably using at least part of the current guidelines on diabetes care.

The frequency of comments and worry shown by agency representatives and specialist physicians regarding family physicians not referring patients to specialists could indicate that many diabetics in Victoria are not being referred to specialists as

specified by the guidelines. This is supported by statements from a majority of family physicians interviewed for this study that they send newly diagnosed Type I (insulin-dependent) diabetics to an endocrinologist and recommend intensive therapy for most of their patients with diabetes. The endocrinologists, however, report that they are not seeing Type I diabetics often enough and that they would like more diabetics to be encouraged to use intensive therapy. This indicates that the family physicians who were interviewed may differ from the general population of family physicians in Victoria.

Perhaps differences should be expected among all family physicians in Victoria and those who participated in this study. All the family physicians who were interviewed attended a seminar on diabetes in the fall of 1996, although one family physician admitted having attended to obtain needed continuing education credits. As well, all participants were aware of the nature of this project when they consented to participating in the study. Although all the family physicians interviewed were selected at random from the list of approximately fifty who attended the seminar, all persons interviewed in this study should be considered as "self-selecting" rather than having been randomly chosen.

There were two reasons for selecting family physicians from a group that had received some recent education on diabetes care. The first is the difficulty in recruiting physicians for a study in which the physicians give their time but receive little benefit. Dr. Macgregor, who presented the previously mentioned diabetes seminar to family physicians, gave his support to this study and it was felt that the physicians who attended the seminar would be more likely to participate in the

study.[xv] The second reason is that these family physicians were judged as most likely to be physicians who see diabetic patients and provide a reasonable standard of care for such patients. As the preliminary essential dataset would be developed through interviewing physicians, a group of family physicians that had some education on diabetes seemed to be the best choice as an informed group. This issue will be returned to later in the discussion of limitations of this study.

### 4.1.7 Choosing Dataset Elements

It is important to consider two interlinked problems in deciding which data items to collect for an electronic record:[55]

- What functions will a computer be used for?
- Why should this item of data be collected?

This study answers the second question from the viewpoint of persons who would use such a system, and points the way to answering the first.

Methods of history taking, physical examination and acts of clinical designation and inference are generally untested and undeveloped.[79] Because there is no standard way or format for acquiring clinical data, the present study defines a structure for storing such data without mandating how this collection is to be done. There is agreement on the inclusion of certain elements and types of information. Therefore, the types of data and the data elements within categories, which should be collected to describe a patient and their care, are specified in Tables 7 and 8 of the Results.

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[xv] Dr. Macgregor, Chief, Department of Family Practice and Director of Continuing Medical Education, Capital Region Health Board, allowed the use of his name in contacting physicians.

## 4.2 Comparisons to Existing Diabetes Datasets

Diabetes datasets have been developed for evaluating care in hospitals and outpatient clinics. However, for important medical decisions, the emphasis has been shifting from hospitals to physicians' offices.[80] Implementing or even testing a computer-based record system for diabetes in a community practice setting would be difficult due to the cost of computer systems and training, and the complexity of having physicians use existing paper-based records for all patients who do not have diabetes. An appropriate first step would be a test of the preliminary essential dataset using paper forms rather than a more expensive and complex computer solution. Before any test can be done, it is necessary to have agreement among family physicians on the use of guidelines for clinical care.[81] Agreement on guidelines would allow specific forms to be developed for different types of encounters or office visits. Partly for these reasons, the dataset developed in this study has been compared to existing datasets for diabetes care, although these datasets were not developed to support direct patient care.

The DiabCare Dataset, the British Dataset and the LDS forms were developed for the purposes of evaluating the care of patients with diabetes. The DiabCare Dataset and the British Dataset were developed through consultation with experts on diabetes care for the purpose of evaluating whether overall diabetes care in a clinic or region was meeting standards established in Europe.[60,68] The LDS forms were developed to evaluate the diabetes education and preventative care of individual patients in a teaching hospital outpatient setting. The principals of the LDS study chose their dataset elements to judge if patient education and preventative care were being delivered according to the American Diabetic Association guidelines for diabetes care.[12]

The development of the preliminary essential dataset in the present study was focused on supporting family physicians providing care to patients with diabetes. The preliminary essential dataset elements are the elements that family physicians indicated are essential in their current practices for the assessment and description of care of patients with diabetes. Using the approach of examining actual practice led to a preliminary essential dataset that requires more development to fully support the provision of care according to the Canadian guidelines on diabetes care. As discussed earlier, the physicians who were interviewed did not agree on specific data elements in certain categories, such as the patient history and the physical examination. However, implementing a dataset in an electronic system requires that all data elements be defined.

The DiabCare Dataset, the British Dataset and the LDS forms seek specific data items as shown in Tables 7, 8 and the notes to these tables. These datasets seek specific data about certain conditions and treatments from medical history-taking and physical exams rather than having categories of recommended data related to diabetes like the Canadian guidelines. The DiabCare dataset is a single record collection of the state of a diabetic patient and some of his or her illnesses and care received within a twelve-month period. It is not designed to support care provided by a family physician as it does not show the details of the illnesses and care; it shows merely their presence or absence. As well, only a single test result can be recorded for any test specified in the DiabCare Data set. In the DiabCare Dataset the presence (or absence) of conditions and treatments means that a computer program can be used to evaluate the progression of diabetic complications within a population of patients for comparison to other groups of patients.[82] The preliminary essential dataset described in the present study was designed to collect more details of care, including multiple test

results for a single patient, to allow a physician to assess changes in a patient's condition.

The DiabCare Dataset was designed to support the evaluation of patient care in a multi-disciplinary diabetes clinic. Also, the DiabCare computer program can use the DiabCare Dataset to evaluate diabetic patient care according to guidelines established by the DiabCare Quality Network in Europe.[82] The British Dataset was designed to judge the quality and success of diabetes care, and is designed to be compatible with the DiabCare Dataset.[60,64] Due to the project descriptions of the development of these two datasets, fields for a data entry person in the DiabCare Dataset, and a data entry date in both datasets, it can be assumed that completing a single patient record would be done annually from paper records. In contrast, the preliminary essential dataset described in the present study is designed to support direct patient care by family physicians and to provide data for patient referrals, made by family physicians, to specialist physicians and agencies that provide diabetes care.

The LDS forms are designed to improve physician compliance with guidelines on diabetic preventative care when used in a hospital outpatient setting.[12,62] Almost half of the questions in the LDS forms are used to check whether education has been performed in the past, whether it was done during the current visit and whether the patient understood counselling and education. However, one of the objectives for the preliminary essential dataset in the present study is to describe a diabetic patient and their care. The preliminary essential dataset could be used by a family physician to assess the appropriateness of the education a patient has received. This is because the preliminary essential dataset includes education and factors, such as type of diabetes, type of medication and level of glucose control, that can be used to judge what education a patient with diabetes should receive.

The differences between the preliminary essential dataset and the datasets used for comparison are due to the stated purposes for developing the datasets and methodological differences. The dataset in the present study was developed by modelling the processes of diabetes care delivery used by a small group of health care providers in one community. The other datasets were developed as ways to evaluate diabetes care and guidelines and models of the best practices in diabetes care were used to develop these datasets.[12,60,68] The dataset described in the present study contains data elements that physicians said are necessary to support their assessment of patients. These other datasets are not suited to patient care because they contain limited detail as they usually only include the presence or absence of conditions or treatments. As well, in any evaluations using these other datasets it must be assumed that conditions do not exist and treatments have not occurred if any of these are not recorded using the datasets. However, in direct patient care physicians could usually investigate missing details by simply questioning the patient.

The datasets compared to the preliminary essential dataset described in this study are not designed to support direct patient care. However, Tables 7 and 8 show that many of the preliminary essential dataset elements are included in these other datasets. If standard phrases or codes were used to describe patient education, illnesses and treatments, the preliminary essential dataset could provide the data sought by the LDS, the British Diabetes Association and the DiabCare datasets.[12,64,82] This indicates that the preliminary essential dataset described in this study could support evaluation of the care received by persons with diabetes if physicians agreed to collect the required data using standardized methods of description.

## 4.3 Limitations of the Preliminary Essential Dataset

### 4.3.1 Applicability of the Preliminary Essential Dataset

As discussed in the previous section, there are similarities between the preliminary essential dataset and the datasets used for comparison. This occurred in spite of the different purposes that these other datasets were developed for and the different approaches used to develop them. The similarities mean that the preliminary essential dataset may have wider application than the limited number of physicians interviewed in Victoria, British Columbia. However, further testing is required to define every data element required in the essential dataset before further comparison with other diabetes datasets.

As already discussed in section 4.1.4 and the Methods patients were not included in this study. Although this means that the dataset described in this study was not designed to be used by patients, it should support family physicians in providing information to patients with diabetes. Also, how the data structure defined in this study for the dataset would allow expansion of the dataset to directly support patients was discussed earlier

Bias in the selection of the family physicians who participated in this study was discussed earlier in section 4.1.5. The family physicians who were interviewed are probably better informed regarding diabetic patient care than the general population of family physicians. If family physicians who were less informed about diabetes care were interviewed, a preliminary essential dataset could be developed that is less suited to supporting family physicians who provide diabetes care. Such a dataset, one less likely to provide a sound basis for decision-making, would be of lower value to

family physicians and to the Capital Region Health Board's study on implementing diabetes care guidelines.

The preliminary essential dataset described in the present study is not completely appropriate for children with diabetes. Very few of the family physicians interviewed for this study have treated paediatric patients with diabetes and only one of the physicians reported having such a patient currently. Agencies and physicians dealing with paediatric patients or clients indicated that self-care ability and the developmental stages of a child must be monitored regularly to ensure that teaching and support are appropriate. The preliminary essential dataset described in this study would have to be expanded to cover children with diabetes.

### 4.3.2 Efficiency and Effectiveness in Recording Data

There must be a balance in a computer-based record system between efficiency and effectiveness, and between creating an unwieldy system through collection of too much data and a useless one by collecting too little data.[4,55] For recording of diabetic complications, it has been suggested that a simple statement of the type of complication present and date examined is much more acceptable to physicians than a long list of positive and negative findings.[36] In a printed or computer screen summary, recording a finding or date of an examination shows that this part of follow-up care has been done. A workshop in the U. K. found that the most useful summaries are those setting out the details of the first visit and routine follow-ups.[36] The dataset and structure proposed in the present study would allow for such summaries but would not create an unwieldy system by expecting physicians to explain how each conclusion was reached.

Data in computer-based patient records, like data in a paper record, are subject to different interpretations by different physicians. Because of the tension between benefit and effort in entering data, physicians are usually content with such statements as "no abnormalities".[4] However, there must be sufficient detail to show that the recommended checks for complications have taken place even if the findings are negative or normal.[15] This could be achieved in the data structure described in this study by stating "normal" or "no abnormalities" found for the body system and area, and giving the date.

This means that a statement such as "no abnormalities" must be accepted as evidence of an investigation knowing what was done to arrive at this conclusion. Such a statement may be appropriate for summary purposes but is not suitable for other purposes that require unambiguous data.[4] As the development in this study was focused on patient care, a summary statement is probably acceptable as it would tell a physician that on a certain date the investigation was performed and no abnormality was found. If data expressed in this way are to be used for evaluation or research, the data would have to be interpreted with caution unless the methods used to arrive at the conclusions are also recorded.

### 4.3.3 Structuring Records

When paper records are structured, physicians can easily find the observations, findings or test results. As well, the absence of any of these can often allow the physician to conclude that no previous observations or findings were abnormal or that tests were not required. One study assumed that an expectation of what to find under a certain heading makes for a faster interpretation of the text and recognition of deviations from the normal. [83] For a physician, abnormal laboratory test results are

informative, but so are normal ones. The fact that a certain test was performed and was normal at a certain point in time can be highly informative.[83]

How the display or presentation of a record in diabetes care should be structured is not examined in this study. For example, should the presentation of this record include examinations that have been made without abnormal results, or should these "normal" findings only be displayed when a family physician requests all examinations. The absence of test results or observations could be shown as a message from a database to the database user or as blanks in a display. Deciding how the display of an electronic diabetic patient record should be structured would require further study.

## 4.4 Barriers to the Use of Computers in Clinical Care

### 4.4.1 Cooperation and Coordination in Diabetes Care

In this study, it was difficult to get most specialist physicians to specify the information that they want to receive in a referral letter. Aside from the medical reason or question that led to the referral, specialists frequently indicated that they do not trust or are not comfortable with details of a patient's history unless they collect the information themselves. The majority of the specialists interviewed do not even regard a patient history received from a family physician as a good starting point for history taking. The specialists prefer to question the patient, even though studies have proven that patients' memories are not that reliable.[84] In contrast to this, every family physician, except for one, wanted to receive a chart summary or chart for a patient transferring from another family physician. This indicates that some specialists do not value exchanging information with physicians in the community who are providing diabetic care.

In addition, some of the specialist physicians who were interviewed questioned the value or type of work that is being performed by agencies involved in diabetic care. For example, they feel that non-physicians may be practising medicine by testing blood glucose levels and then recommending changes to medication regimens. Two of the specialists were concerned that diabetic education serves to increase patient knowledge but has never been proven to affect behaviour. This seems similar to a study that showed physicians were unwilling to delegate responsibility for patient visits to a nurse practitioner or physicians' assistant even when the physicians thought that the visit could be delegated.[85] Family physicians were interested in knowing what other services patients are receiving and said that services such as home care and education are important. This shows a lack of consensus among physicians on the value of services provided by non-physicians.

### 4.4.2 The Interpretation of Terms in Datasets

The interpretation of medical terms is a problem that has affected the use of datasets. In nursing care, for example, data elements have been identified for nursing care databases. However, standard definitions, terminology and codes have not been established and incorporated into automated clinical records for nursing. The development of standard codes and definitions will have to go along with establishing standards for nursing care to ensure that data is interpreted the same way by all users of datasets.[24] Even with the previously mentioned high rate of computerization in the Netherlands, there have been problems with the interpretation of medical terms.[4]

Use of an essential dataset in diabetes care could lead to problems similar to those discussed above. For example, most of the specialists indicated that other physicians

often incorrectly defined patients as insulin-dependent if the patients are using insulin medications. The specialists stated that other medical criteria, such as manner of onset of diabetes and the patient's age at onset, should be used to determine the type of diabetes. This shows that before computerized patient records are introduced, health care professionals need to be in agreement about the roles they play in diabetes care and about the terms that are used in diabetes care.

### 4.4.3 Introducing Computers

In other countries, the use of computers by family physicians has been supported and subsidized by governments. In the U. K., a significant portion of family physicians have purchased computers using subsidies from the National Health Service (NHS).[29] As well, the NHS has developed a networking infrastructure and a new health identification number to support the use of computer systems.[65] In the Netherlands, 50% of family physicians purchased computer record systems, with about one quarter of them adopting a paperless office.[4,20] As in the U. K., this was done with government assistance; national standards were set for vendors and purchases of approved systems were subsidized. In Canada, there has been no such support for the use of computers by family physicians.

In Canada, greater demand for computerization of physicians' offices could be created by changes to the funding and organization of health care. An integrated delivery system that incorporates a network of health care organizations and physicians funded on a per capita basis has been suggested as a new model for Canadian health care. This type of health care could produce dramatic changes such as the increase in use of computers by physicians in organized health care delivery systems.[86]

A difficulty in introducing CPRs is the change in health care provider behaviour that is required for the success of these CPRs. For example, if specialists placed a higher value on the data received with patient referrals, providing this data would be more important. Even if all of the conditions necessary for introduction of computer systems were met, the introduction of standardized work methods for family physicians would be difficult. Practice patterns would have to be surveyed so that new methods required in using CPRs would fit with the existing patterns.[81]

### 4.5 Future Work

The results of this study could be used by others who require a pool of data elements specific to a particular condition or class of problems. An example of this is an author who designed a computer interface that can support variable clinical practice patterns.[87] That interface allows data elements to be arranged according to individual preference, but still requires a standard dataset as the source of these data elements. The preliminary essential dataset described in this study could be used in designing a computer-based diabetes record and computer interface for this record.

If a payment scheme is used that removes the barriers that exist in the current fee-for-service care, a patient record could be designed using this dataset as a starting point. In the U. K., under the roster or per capita form of compensation, there are additional payments to physicians caring for diabetics in recognition of the extra effort required. This makes money available for use of computers and nurses where these are warranted in diabetes care.[29] This also led to efforts to develop systems that allow evaluation of the quality of care, as physicians were unable to show that they meet the population's needs and provided value for the money spent.

Some changes would have to take place in the health care system before an essential diabetes dataset could be used. Even then, this dataset would require further work if the diabetes care guidelines change. As well, another study is required to define specific data requirements in some data categories.

## 5 Conclusions

This study developed a preliminary essential dataset and a model of how this dataset should be stored electronically for use by family physicians providing care to patients with diabetes. Using this dataset in the described data structure should benefit family physicians by providing a consistent basis for decision–making. If data was stored in a defined structure in a computer system, decision support, such as advice, clinical care guidelines, and alerts, could be provided to the family physicians. Health care professionals could reduce the time spent taking histories by using a computerized record that includes some details of patients' encounters with other providers. Such a record would be more reliable than patients' memories and more available than a paper record. This could be especially important in monitoring the care of persons at risk for complications due to diabetes. These benefits could justify the use of this preliminary essential dataset in an electronic patient record.

It has been stated that health care data in an electronic format is like money; once you have it there are many uses for it. The difficulty lies in getting data into an electronic form.[1] Many authors have stated that data collected by those directly involved in patient care is more accurate and will not include transcription errors. The solution, according to developers of diabetes datasets intended to support evaluation and administration, is to have the data entered into a computer when patient care is provided. Patient data must be structured if it is to be used for purposes other than direct patient care. The present study describes a preliminary essential dataset and data structure to organize the data collected by family physicians for diabetes care and management. Once data is collected, it can be used for a myriad of other prescribed purposes, including resource allocation, policy decisions, research, statistics and administration. However, for such data collection to take place, systems must be

developed that benefit the users of the systems rather than secondary users of the data. The present study describes a preliminary essential dataset and data structure intended to benefit family physicians when the dataset is used for diabetes care in an electronic patient record.

In treating diabetes, a complete record of a patient's visits to care providers and actions taken is very important.[39] The Canadian guidelines for the care of diabetic patients specify tests and examinations at certain intervals to reduce complications.[71] If these are done too frequently, the cost and effort for the health care system increases. But if these actions are not performed often enough and referrals to specialists are not made when required, serious complications could result – complications that could have been delayed or avoided.[41] The data structure described in this study allows recording of medical history, details from specialist consultations and encounter reports to track patient visits to other care providers.

Before any steps can be taken to improve diabetes care through the use of information technology, the dataset to be used in a patient record must be defined. Very few articles on computer-based or electronic patient records discuss the development of a dataset for such applications. It is important for the development of such records to understand how to define a dataset. By using the established techniques of systems analysis and data modelling, the dataset and structure can be put in a form that can be understood by computer system developers.

This study used established techniques of systems analysis and data modelling to develop a preliminary essential dataset and data structure using interviews to examine the processes of care for persons with diabetes. There are similarities between the preliminary essential dataset and other datasets used for comparison in the present

study. As discussed earlier, this indicates that the preliminary essential dataset could support the provision of care according to the Canadian Clinical Practice Guidelines for Treatment of Diabetes Mellitus and provide data for the evaluation of diabetes care.

For diabetes care, it is useful to see that such a dataset could be developed within a community rather than an institutional or academic setting. However, there must be greater agreement among family physicians on what actions should be taken and what information should be collected in caring for diabetic patients before the preliminary essential dataset can be further developed. Development of this dataset for diabetes care using the techniques of systems analysis and data modelling implies that similar techniques can be used to develop datasets for other conditions. But the present study also indicates that such techniques would be much easier to apply in a well defined system; a system where there is agreement on the ideal or best practices in care and this ideal model is being followed by a majority of physicians.

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## Appendix 1:

### Project Summary

**Aim: To define a comprehensive set of essential data that can be used collectively by different health care providers to assess, treat and manage diabetic patients.**

Identifying what information contributes to health care decisions for diabetes will contribute to the development of a comprehensive dataset that can be structured to better support decision making by health care professionals. This could help in developing communication procedures between the multi-disciplinary members of the health care team that provides care for diabetics.

Diabetes was selected as a good example of a widespread and manageable chronic condition for which treatment is received from different health care professionals practicing both within and outside of the acute care system. Further, diabetes is a condition for which the diabetic him/herself is one of the main sources of health care. The Canadian Diabetes Association predicts that by the year 2000, 1 in 4 Canadians over the age of 45 will have diabetes. Complications due to diabetes result in increased morbidity and mortality, and decreased quality of life

Health care professionals will determine what data and information is of value or utility in decision making. Data is collected and produced during client assessment and treatment and that data is analyzed to become information. That information supports outcomes based treatment and management decisions made by the provider and the patient. Professionals who provide support and care to diabetics will be identified. A number of persons from each profession will be interviewed. The questions fall into the following broad categories:

- What data and information is currently collected and what is its source? Why is it collected and what are its destinations?
- What data and information, in what format, is received from other health care professionals and other sources and why?
- What data information do you as a health care professional produce about your client? What do you produce for your own decision-making and what do you produce for other caregivers?
- What data and information is considered essential and why? What other data and information would help in assessing and making care decisions and why?

This is a study of process; how data becomes information and how it is used to support decision making. The final report from the project will be given to all interested participants to help to better understand the process of care and help support decision making. If any changes are to be made it will be up to the parties consulted in this study to determine what the changes should be and how to implement them.

Russell Padgham, M. Sc. Student, University of Victoria, 595-8028

## Consent Form for Participation in the Study Entitled:

**An Essential Data Set to Support Clinical Decision Making by Health Professionals Providing Diabetes Care and Management**

This research project is studying the type of data collected by health care professionals providing care to persons with diabetes as described in the attached project summary. You will be asked questions about the types of visits patients have with you and the data collected from or about the patients in these visits. Your participation should require about 30 minutes. The results will be used to produce a data model of diabetes care and develop a set of the data essential to the provision of this care. This information will be presented in my Master's Thesis, but none of the participants will be identified. The results from the interviews will be pooled to produce the data model and dataset.

Your participation is completely voluntary and you can withdraw from the study at any time without explanation. You have the right to refuse to answer any questions you do not wish to answer.

Any data collected in this study will remain confidential; interview results will be kept in a locked filing cabinet in a locked office. Only the researcher will have access to the data. Your name will not be attached to any published results and as interview data will be pooled with that of other professionals to produce the dataset there will be no way to identify the responses of individuals.

Name of Participant:_____

Signature of Participant: _____

Date: _____

Researcher: Russell W. Padgham, M. Sc. Candidate
Phone: 595-8028
Supervisor: Dr. Paul D. Fisher, Director, School of Health Information Science, University of Victoria
Phone: 721-8576

## Appendix 2:

### Physician Interview Questions

For the questions, please consider how the information you collect or receive from others aids you in decision making. Decisions in this case include assessing a patient's status and risk factors, care planning, diabetes management goals, etc.

Please add anything you like as we go along. You only have to answer those questions that you want to answer.

Before we begin do you have any questions?

Q1 Can you give estimates of the number of diabetic patients in your practice and what per cent of your practice this represents?

Do diabetic patients visit your office more often than other patients?

**During Appointment between Dr. and Client**

Q2 What are there different types of appointments you have with diabetic patients? How many of each type per patient per year?

consult/follow-up/check-up

Q3 What is the purpose and what is gained during each type of appointment?

Consult?

Follow-up?

Check-up?

Q4 How much of the disease management process is guided by the type of diabetes? What is the protocol for each type? What are the differences in process due to?

Q5 For suspected or confirmed diabetes, is there data/information collection on diabetes risk factors (not on complications), such as risk behaviour, environment, family history, ethnicity, other conditions? If so, to what extent?

Q6 Do you use any forms for history, data collection, etc.? (samples)

Q7 What data is collected from the patient through history and discussion during office visits of diagnosed diabetes?

- For example DoB, age at diagnosis, medications, weight changes?

risk factors i.e. Smoking, obesity, high BP

- What tests are done on the spot, such as BP/ Ht/ Wt?
- If patient is using HGM do you look at the log book or ask about values?

  What weight is placed on these versus other tests? (i.e. vs. Hb1Ac)

Q8 What data is vital in assessing a patient's condition?

- For example, fasting blood sugar, HbA1c?
  If these or other tests are used:
  Where do the results come from? (lab, previous physician, patient, DEC)
- For these or other results:
  Are results compared to previous results?
  If there are no previous values available, is an assumption used and how does this influence decision making?
  If a patient is newly diagnosed, are results considered versus a "normal"?
  Do you direct patients to the Canadian Diabetes Association?
  If so, for what kind of support?
  On examining systems (Skin, Feet, Eyes, Heart, Lungs) what is evidence (signs and symtoms) of complications in each area? How do you decide it is a complication of the diabetes?

Q9 Do you make a measure of functions/ quality of life for diabetics? How do you measure it? Do you use an instrument such as SF36?

Q10 What is changed or done differently if a patient is a diagnosed diabetic but new to your practice?

Q11 If a new patient, is info sought from previous FP? What?

1) Entire chart 2) Portions of the chart (if so what portions?)

3) Entire chart after a particular date 4)Summary of chart

What information is especially important or looked for?

How about: What are the 5 most important things you are lookung for in the history of a diabetic? Suspected diabetic?

**After Appointment between Dr and Client:**

Q12 Is there any form of summary of the appointment? for the chart?

If so, is it structured or does it vary according to need?

If structured, how is it structured? And why is it structured?

Q13 Are there follow-up tests and/ or appointments?

If so, what type and what data is usually sought?

What determines the need for subsequent investigation?

Q13 If a referral is made - what is sent to others?

GVHS form Referral letter Referral note Chart

Q14 Do you have a set process or procedures such as using forms?

(Forms – Request blank copies or with personal information blacked out)

Q15 What referrals to specialists or exams are you especially interested in?

Q16 How do you keep track of any visits to the Diabetes Education Centre?

Q17 Is there anything you would like to add?

## Appendix 3:

### Data Tables for Family Physician View

Underlined element (or group of elements) make up the primary keys for a table.

**Patient**

| PHN | Current | Last Name | First Name | Middle Name | Street | City |
|---|---|---|---|---|---|---|
| Postal Code | Home Phone | Alternate Phone | Date of Birth | Gender | | |

**Physician**

| Physician ID | Specialty | Last Name | First Name | Middle Name | Street | City |
|---|---|---|---|---|---|---|
| Postal Code | Phone Number | Fax Number | Alternate Phone | | | |

**Encounter**

| PHN | Physician ID | Encounter Date | Encounter Type | Reason | Attended |
|---|---|---|---|---|---|
| Test Result Review | Test Group | | | | |

**History**

| PHN | Updated | Diabetes Diagnosis | Diabetes Type | Reported By | Diet |
|---|---|---|---|---|---|
| Lifestyle | Exercise | | | | |

| PHN | Updated | Allergy |
|---|---|---|

| PHN | Updated | Risk Factor |
|---|---|---|

| PHN | Updated | Diet | Lifestyle | Exercise | Glucose Control |
|---|---|---|---|---|---|

| PHN | Updated | Medical Event | Start Date | End Date | Provider |
|---|---|---|---|---|---|

**Physical Exam**

| PHN | Physician ID | Encounter Date | System | Area | Finding |
|---|---|---|---|---|---|

**Diagnosis**

| PHN | Physician ID | Problem Type | Diagnosis Type | Diagnosis Date | System |
|---|---|---|---|---|---|
| Area | First Seen Date | Confirmation Date | | | |

**Care Plan1**

| PHN | Physician ID | Plan Date | Next Appt | Next Appt Type |
|---|---|---|---|---|

| PHN | Physician ID | Plan Date | Referral Type | Referral Freq |
|---|---|---|---|---|

| PHN | Physician ID | Plan Date | Problem Type | Action | Action Date | Provider |
|---|---|---|---|---|---|---|

| PHN | Physician ID | Plan Date | Exercise Rec | Diet Rec |
|---|---|---|---|---|

**Medication2**

| PHN | Med Name | Start Date | End Date | Dose | Frequency | Physician ID | Reason |
|---|---|---|---|---|---|---|---|

**Referral3**

| PHN | Physician ID | Referral Date | Reason | Provider | Attended |
|---|---|---|---|---|---|

**Consult Letter4**

| PHN | Physician ID | Consult Date | Report to Physician ID | Letter Date |
|---|---|---|---|---|
| Reason | System | Area | Finding | Recomendation | Action | Prescribing |
|---|---|---|---|---|---|---|

**Agency**

| Agency ID | Agency Type | Agency Name | Street | City | Postal Code |
|---|---|---|---|---|---|
| Phone Number | Fax Number |
|---|---|

**Nurse/Educator**

| Nurse/Educator ID | Agency ID | Last Name | First Name | Position | Phone Number |
|---|---|---|---|---|---|

**Session Report5**

| PHN | Nurse/Educator ID | Session Date | Session Type | Completed | Report Date |
|---|---|---|---|---|---|
| Physician ID | Test Result Date |
|---|---|

**Test Requisition**

| Requisition Number | Req Date | PHN | Physician ID | Test Type | Req Notes |
|---|---|---|---|---|---|

**Test Result Tables**

Lab Result

| Requisition Number | Report Date | Lab ID | Lab Test Result | Sample Date |
|---|---|---|---|---|

Diagnostic Result

| Requisition Number | Report Date | Lab ID | Finding | System | Area |
|---|---|---|---|---|---|

**Test Tables**

Lab Test

| Lab ID | Test Type | Test Group | Test Method | Test Notes | Units |
|---|---|---|---|---|---|

| Normal Range | Sample Method |
|---|---|

Diagnostic Test

| Lab ID | Test Type | Test Group | Test Method | Test Notes | System | Area |
|---|---|---|---|---|---|---|

**Lab Table**

| Lab ID | Lab Name | Street | City | Postal Code | Phone Number | Fax Number |
|---|---|---|---|---|---|---|

**Notes:**

1 Care Plan could be linked to Diagnosis Table using the Problem Type and Plan Date.

2 Physician is necessary as prescriptions may be made by physicians other than the Family Physician. Reason allows the medication to be linked to a problem using the reason and start date.

3 The element Attended is in the Referral Table for tracking referrals that a patient does not attend. Attended is an attribute of the consult but the object Consult is only required for the specialist view.

4 The object Consult is not needed for a primary care physician view as a Consult Letter indicates a consult has taken place and Consult Type should be included in the letter. The element Attended is in the Referral Table.

5 The object Session has been incorporated into the Session Report as the only element unique to the Session is the Completed attribute. If a session was not completed this should be included in the Session Report and for physicians of diabetic patients only a report table is needed as it can be assumed there was a Session if a report is received.

## Appendix 4:

### Data Dictionary for the Preliminary Essential Dataset

| Data Element | Description |
|---|---|
| Action | Action(s) taken, provided by another provider or specified in Care Plan in response to a problem or diagnosis. |
| Action Date | The date an Action is done or a service is provided. |
| Address Group: | Three Data Elements as below.[1] |
| Street | Usual residence (patient) or office (caregiver or agency) street address. |
| City | City, town, etc. to complete the address. |
| Postal Code | Canadian Postal Code. |
| Agency ID | Unique ID number to identify an agency providing education, nursing, counselling, home care, etc. to a client with diabetes. |
| Agency Name | Name of an agency that provides health care services. |
| Agency Type | Type(s) of activities or services an Agency provides. |
| Allergy | Allergies of any kind can or may affect a patient. |
| Allergy Date | Date that a specific allergy was known and recorded. |
| Alternate Phone | Alternate phone number such as workplace or cellphone for patient; cellphone, pager for or residence for caregiver. |
| Area | Specific area of body system that is examined, tested or diagnosed. |
| Attended | Yes or No to track patients attending appointments.[2] |
| Completed | Yes or No, for completion of session with or service by Nurse/Educator. |
| Confirmation Date | Date a diagnosis is confirmed by physician, specialist, diagnostic testing, etc. |
| Consult Date | Date that a specialist physician examines a patient. |
| Consult Type | The type of visit, i. e. initial consult, routine check, follow-up. |
| Current | Yes or No, necessary in electronic records to sort out those no longer receiving active care due to death, terminal illness, moved, using another physician, etc.[1] |
| Date of Birth | Patient/ client birthdate to aid in identification, assessment and treatment. |
| Diabetes Diagnosis Date | Date that lab test results confirmed that a person is diabetic. |
| Diabetes Type | Type of diabetes, i. e. Type I or II. |
| Diagnosis Date | Date that physician makes a diagnosis or strongly suspects a certain diagnosis. |
| Diagnosis Type | Clinical term or code for a diagnosis. |

| | |
|---|---|
| Diet | Measure of the type of diet a diabetic is consuming. |
| Diet Rec | Type of diet recommended to a patient for control of diabetes and complications. |
| Dose | Amount of a medication to be taken at one time. |
| Encounter Date | Date that a primary care physician examines a patient. |
| Encounter Type | Allows a physician track the type of a visit, i. e. initial consult, routine checkup, diagnosis follow-up. |
| End Date | Date a medical event or medication prescription ended, or blank to indicate that it is ongoing. |
| Exercise | Measure of the frequency and intensity of exercise or activity that a diabetic is participating in. |
| Exercise Rec | Level and frequency of exercise recommended to a patient for control of diabetes and complications. |
| Fax Number | Facsimile machine phone number for caregiver office. |
| Finding | Interpretation of testing or examination of a body area. |
| First | Usual given name for identification. |
| First Seen Date | Date that the problem leading to diagnosis was first reported or date that it was first noted by physician. |
| Frequency | Number of times per day a medication is taken or the time of time for a single daily dose such as insulin. |
| Gender | Patient/ client gender or sex to aid in identification, assessment and treatment. |
| Glucose Control | Measure of the level of blood sugar control that a diabetic has as shown by self monitoring of blood glucose and/or HbA1c test and/or lab blood sugar testing. |
| In Range | Yes or no, to report if a lab result is out of the normal range as defined by the lab for a particular test. |
| Lab ID | Unique ID number for a laboratory that performs diagnostic test or procedures. |
| Lab ID | Unique identification number such as MSP billing number or a number created to uniquely identify labs. |
| Lab Name | Name for a laboratory. |
| Lab Test Result | Result expressed as a number or indication of positive or negative as appropriate. |
| Last Name | Usual surname or family name for identification of a person, patient, client or caregiver. |
| Letter Date | Date Consult Letter is written or dictated. |
| Letter Issued | Yes or No, as letter may be not sent before test results are received or follow-up visit is made. |
| Lifestyle | Measure of the type of lifestyle a diabetic has. |
| Medical Event | Any major illness, medical treatment such as surgery or medication that should be recorded for referrals, may affect diabetic complications or diabetes management. |

| | |
|---|---|
| Medication Name | Standard name of a medication prescribed or being taken. |
| Middle Name | To help in identification of patients, clients and providers. |
| Next Appt | Suggested date of next appointment or length of time until next appointment. |
| Next Appt Type | Type of next scheduled or suggested appointment using the same terms as Encounter Type element. |
| Normal Range | Expected or usual normal range |
| Nurse/Educator ID | Unique ID number to identify a specific Nurse/Educator. |
| Personal Health Number (PHN) | Unique 9 digit number that is assigned to a person for life in B. C., can be used as a unique identifier.[3] |
| Phone Number | Usual residence phone number for patient/ client; office phone number for caregiver. |
| Physician ID | Unique identification number such as MSP billing number or a number created to uniquely identify physician or records generated by a physician. |
| Plan Date | Date that the Care Plan is made or updated. |
| Position | Type or position of nurse, educator, counsellor, etc. |
| Prescribing | Yes or No, as an alert that referral has lead to new medication(s). |
| Problem Type | Reported problem with a body area or general complaint that is investigated even if no diagnosis is made. |
| Provider | ID number to identify physician or agency receiving a referral and /or providing a service. |
| Reason | Problem or reason the patient makes an appointment or family physician makes a referral. |
| Recommendation | Any change in diet, exercise, lifestyle, medication, treatment, etc. made due to Consult. |
| Referral Date | Date a referral was made. |
| Referral Freq | Suggested frequency for patient visits to specific specialists such as every year or 2 years for ophthalmologist. |
| Referral Type | Specialist type that patient will be seeing regularly such as ophthalmologist. |
| Report to Physician ID | Family Physician and other physicians who will be receiving a Consult Letter. |
| Requisition Date | Date the test(s) or procedure(s) are ordered. |
| Requisition Notes | Note by ordering physician giving reason or justification for a test or procedure.[4] |
| Requisition Number | Unique ID number on a laboratory test or diagnostic procedure order form.[5] |
| Result Date | Date that test or procedure results are issued. |
| Risk Factor | Anything that increases the risk of poor glucose control or diabetes complications. |

| | |
|---|---|
| Risk Factor Date | Date that a specific risk factor was known and recorded or a change in a risk factor was recorded. |
| Sample Date | Date a sample is obtained for a test. |
| Sample Method | Notes on how a sample must be gathered to give correct test results, could include what a patient must do or not do before a test. |
| Session Date | Date a session with or service by Nurse/Educator occurs. |
| Session Type | Type of session with or service by Nurse/Educator. |
| Specialist Physician ID | Specialist Physician issuing the Consult Letter. |
| Specialty | Specialty(s) practiced by a physician. This is the only element that will distinguish between family or general and specialist physicians. |
| Start Date | Date a medical event began or a medication or medication change was prescribed. |
| System | Body system that is examined, tested or diagnosed. |
| Test Group | Group a test belongs to such as X-ray, blood tests, etc. When used in conjunction with Test Result Review the most important or group of greatest interest would be named. |
| Test Method | Method of testing a sample or performing a diagnostic procedure. Necessary to differentiate between different methods or different labs. |
| Test Notes | Notes on effectiveness of test, interpretation of result outside of normal range, how result is calculated, accepted uses of test, etc. as determined by the lab. Notes could be added to a result on the basis of rules according the level or range of the result.[6] |
| Test Result Date | To allow Family Physician to check if the results have been received.[7] |
| Test Result Review | Yes or No to allow linking to latest lab results.[8] |
| Test Type | Names a specific test or diagnostic procedure. |
| Units | Scientific units that a test result will be expressed in. |
| Updated | Date that Diet, Lifestyle, Exercise, and Glucose Control measures are recorded or updated. |

87 elements

Notes:

1. For storage in electronic databases it is best to split addresses into more data elements as these can always be combined. If the street, city and postal code portions of addresses are stored as one element it is more difficult to perform searches or queries upon them. As well, with each portion stored separately, each element can be formatted for letters, reports and mailing labels.

2. May be used to track patients who choose not to attend checkups and /or appointments and thereby receive less than optimal care. Could show a patient has mobility or access problems in attending the office.

3. Often not used in paper communication, the PHN is necessary as a unique identifier in electronic records. Client Registry, Vital Statistics, Ministry of Health maintains a database that other systems can electronically search which contains PHNs with name, address and date of birth for all numbers issued. When a PHN is entered in an electronic record the PHN can be checked with an algorithm to ensure that it is a possible valid number. Although this does not guarantee the correct patient number has been entered, it eliminates most data entry errors.

4. Under Medical Services guidelines, certain tests or procedures may only be ordered for certain conditions or if considered "medically required".

5. In the current system, Requisition Numbers are not used. Instead, a combination of report date, collection date, and PHN uniquely identify a result.

6. For example, glycosolated hemoglobin test(HbA1c) result may be used to calculate an expected average blood glucose expressed in the same units used by a Home Glucose Monitor.

7. If a physician is using an electronic system but is receiving paper-based reports this element could be used to alert the physician that tests were ordered by an Agency even if the physician has not received a copy of results. In Victoria the Diabetes Education Centre has a waiting list of up to eight weeks for non-emergency education or counselling. This agency often orders lab tests just before an initial session as test results after weeks of management are usually quite different from those at the time of the diagnosis of diabetes which has lead to the referral.

8. In an electronic system a Yes could be used to initiate an automatic look-up of recent lab results for routine check-ups or follow-up on complications, etc. If results are paper-based records this could show that results were reviewed. Test Type could be used to show specific tests have been reviewed.

**Reference:**

1. Alexander, W., C. Bradshaw, R. Gadsby, P. D. Home, P. Kopelman, M. McKinnon, S. Redmond and N. Vaughan for the British Diabetic Association. "An Approach to Manageable Datasets in Diabetes Care," *Diabetic Medicine,* Vol. 11, No. 8, 1994, pp. 806-810.

# VITA

Surname: Padgham Given Names: Russell William

Place of Birth: Madison, Wisconsin, U. S. A.

Educational Institutions Attended:

University of Alberta 1979 to 1980

University of Victoria 1983 to 1986

University of Victoria 1993 to 1998

Degrees Awarded:

B. Sc. (Second Class) University of Victoria 1987

Honours and Awards:

Government of British Columbia Scholarship 1985

Publications:

"A Methodology for Defining a Data Set for a Computer-Based Patient Record," *Proceedings of the Sixth National and Fourth International Conference on Information Technology and Community Health,* University of Victoria, Victoria, 1996, pp. 28-33.

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The Essential Dataset for Clinical Care and Management of Diabetes

Author 

Russell William Padgham

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