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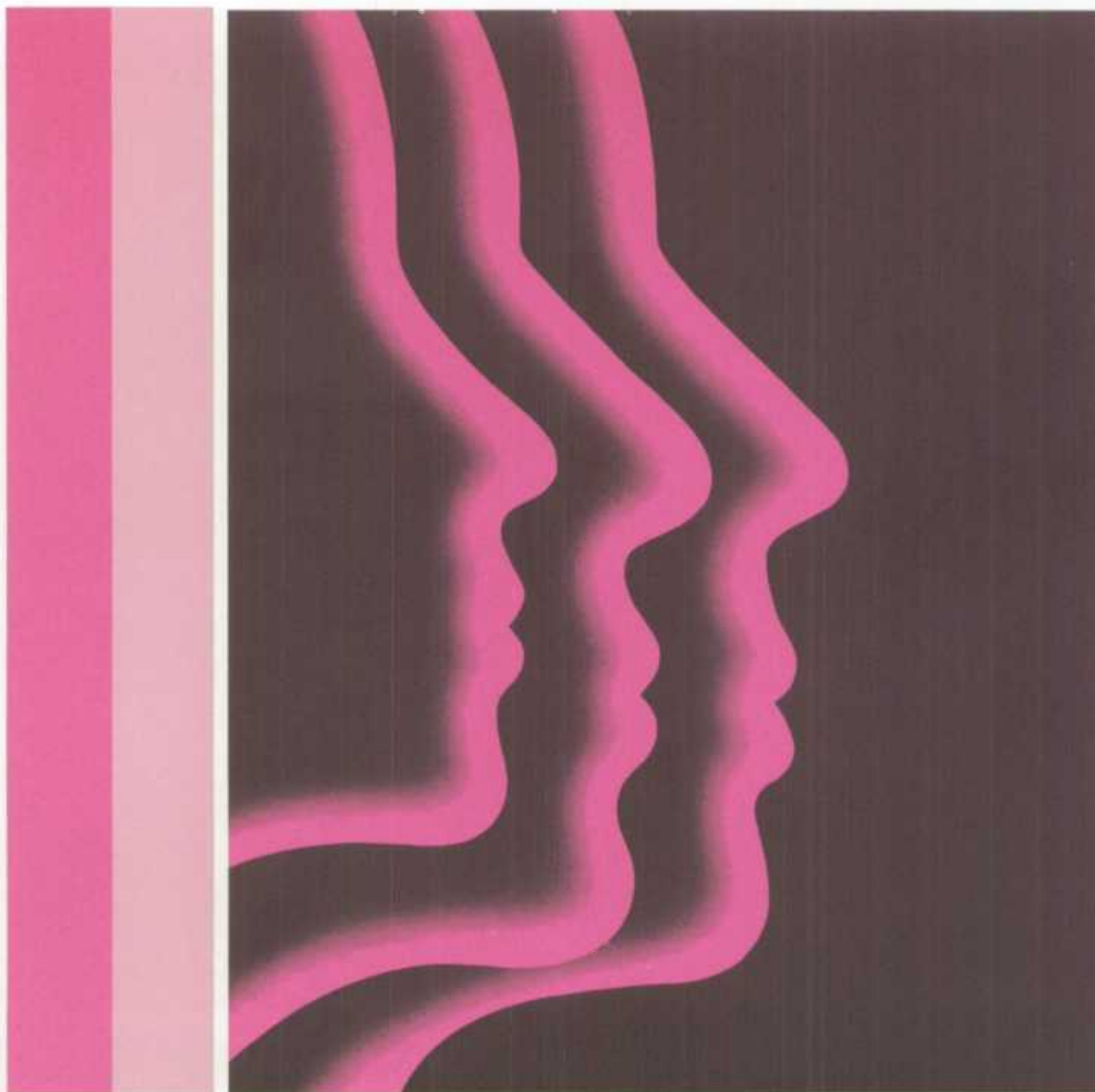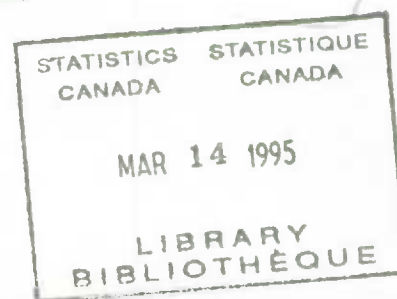
DATA BASE ON CONTINUING CARE

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REPORT OF THE PROJECT TO REVIEW THE
NEED FOR, AND FEASIBILITY OF, A NATIONAL
DATA BASE ON CONTINUING CARE

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INTRODUCTION

Aside from the survey of Residential Care Facilities for the Aged, conducted by Statistics Canada, little national data is collected on Continuing Care services. There is currently no system of collecting national data on Home Care and Home Support services. The objectives of this study were to review the nature and scope of the data currently collected across Canada and to determine the interest in, and feasibility of, developing a national data base on Continuing Care.

AN INTRODUCTION TO CONTINUING CARE

It is estimated that Continuing Care represents the third largest component of government expenditures on health care, after hospitals and medial services, in Canada. It accounted for an estimated $7-$8 Billion of government expenditures in the 1993/94 fiscal year. The components of the Continuing Care service delivery system are defined as including: Assessment and Case Management; Meals-on-Wheels; Adult Day Care; Group Homes; Homemakers; Home Nursing Care; Community Physiotherapy and Occupational Therapy; Long Term Care Facilities; Chronic Care Units; and, Assessment and Treatment Centres and Day Hospitals. Other services such as respite care, adult foster care, assistive devices programs, and quick-response teams may also be included.

METHODOLOGY

The major methodological activity for this study was the conduct of a number of face to face and telephone interviews with key provincial and territorial officials and with senior representatives of national and provincial service provider Associations.

A comprehensive literature review was also conducted.

FINDINGS

The literature review revealed that a Minimum Data Set has been developed for Long Term Care facilities in the United States. Perhaps the most significant work on instrument development to take place in Canada has been the work conducted in Alberta to establish the Alberta Assessment and Placement Instrument and the Alberta Resident and Home Care Classification Systems.

It was found that there was general support for the development of a national data base, particularly if timely feedback, in the form of summary statistics, could be made available from such a data base.

There was essentially unanimous agreement that the initial scope of the data base should be relatively small and should be limited to a modest number of key variables. It was also agreed that there should be an even balance of clinical, financial and staffing data and that the system should initially monitor, rather than evaluate, activities. Service providers, some Association representatives, and Provincial and Territorial officials, wanted to ensure that a modest, but adequate, degree of clinical data were collected so that they could better compare their clients to clients in other agencies and jurisdictions.

A significant issue which needs to be addressed in the development of a national data base on Continuing Care is how to handle the Chronic Care Hospital sector. In some provinces this sector is essentially funded, and integrated into, the Division responsible for Long Term Care facilities and data are reported as part of Statistics Canada's survey of Residential Care Facilities. In other provinces Chronic Care is part of the Hospital system and data are reported to Statistics Canada as part of its HS1 and HS2 hospital returns. In many jurisdictions, Chronic Care beds are often housed in wings of acute hospitals and are treated as part of the acute hospital for reporting purposes. Therefore, it is, at best, difficult to integrate data from Chronic Care Units in hospitals with data from the Residential Care Facilities survey in order to have a national picture of Continuing Care residential services.

Ideally, data should be collected for all components of Continuing Care. However, if priorities for data collection need to be set, emphasis should be placed on home and community based services.

There are differences in the methods of classifying clients into levels of care across jurisdictions. Changing provincial and territorial care level designations is not an easy matter because funding for residential services is, in many jurisdictions, related to the care level mix in facilities. Therefore, it may be necessary to consider care level systems which can be used for statistical comparisons, across jurisdictions, but which allow existing provincial practices to remain in place.

It should also be recognized that there are benefits to be derived from having similar classification systems for Continuing Care clients whether they are treated in a residential setting or in the community as more appropriate comparisons can be made across the residential/community continuum. For the acute care substitution component of Home Care, data should be collected which allow for comparisons with acute hospital data.

While the people interviewed agreed that the confidentiality of client data was an important issue, there was a range of opinion regarding the extent to which it would be possible to collect client specific data using some form of a unique identifier. Finally, in discussions, it was found that interviewees were also interested in larger analytical issues such as the impact of Continuing Care on health status.

THE RECOMMENDED APPROACH TO DEVELOPING A
NATIONAL DATA BASE ON CONTINUING CARE

It is recommended that a national data base be developed which is sensitive to the unique aspects of Continuing Care and which recognizes existing information systems realities. Therefore, a hierarchical listing of six possible models which build on the strengths of existing approaches can be considered. Minimum Data Sets should be established for each of these six models in a hierarchial manner so that they can be rolled up from the least aggregated (i.e., most detailed) to the most

aggregated. Each jurisdiction would determine the level at which it would participate in the national data base in accordance with its own unique circumstances. These six models are:

- **The Aggregate Statistics Model**: This model provides for the collection of aggregate Provincial/Territorial statistics which would be combined into a national picture.

- **The Basic Agency Based Information Systems Model**: This model provides for the collection of basic client, financial and staffing data at an agency level. It presents "bottom line" financial and staffing data such as total expenditures, total revenues and total number of staff, and a count, by age and sex groups, and by level of care, of the number of clients served.

- **The Advanced Agency Based Information Systems Model**: This model is similar to the basic model but provides for the collection of more detailed financial and staffing data such as the number of paid hours by type of worker and expenditures by type of worker. It also provides for a count of clients by all combinations of age groups, sex, and levels of care.

- **The Basic Client/Agency Model**: In this model, the financial and staffing data collected would be similar to the Advanced Agency Model with some upgrades to collect data on capital expenditures. Basic data would also be collected, at a client specific level, on variables such as date of admission, date of discharge, type(s) of service(s) provided, age, sex, and level of care. In addition, some type of unique identifier would be collected for each client. This identifier would, ideally, be unique to the jurisdiction in which care is provided.

- **The Intermediate Client/Agency Model**: This model provides for enhancements in the collection of financial and staffing data so that the information collected is comparable to the current Departmental level of reporting for acute care hospitals under the MIS Guidelines. The number of variables collected on individual clients is also increased to include variables which have been shown to be correlated with service utilization such as living arrangements and socio-economic status. This model also provides for the collection of key variables which are used in more advanced care level classification systems so that care levels can be defined more precisely across jursidictions.

- **The Advanced Client/Agency Model**: This model provides for the collection of financial and staffing data, possibly at the Departmental level but, preferrably, at the Global level of reporting (i.e., a level of reporting in which costs can be assigned to individual clients). A much more comprehensive range of information is collected on clients than in the Intermediate Model.

RECOMMENDATIONS

1. As a great deal of information is already collected in each jurisdiction, research funders, such as the National Health Research and Development Program, should give consideration to promoting the conduct of a range of analytical studies on Provincial and Territorial Continuing Care services using existing data bases. A priority should be placed on the publication of the findings of these studies so that the results are readily available to researchers, planners, administrators, and policy makers, both in Canada and in other countries.

2. In order to make information from existing data bases more readily available to senior decision makers, and to the Continuing Care industry, Statistics Canada and Health Canada should consider facilitating the preparation of a national report, or a series of articles for publication in major health journals, on the findings of the survey of Residential Care Facilities.

3. If a national data base is established, a system of providing concise and relevant feedback, on a complementary basis, to service provider agencies, provincial and territorial Associations, and provincial and territorial officials, should be developed and implemented and should form an integral part of such a data base. The complementary data would consist of one to two pages of key indicators and statistics and would not be inconsistent with current policies on the sale of data products.

4. The information provided as feedback from the national data base should be made available on a timely basis such that it could be provided to its recipients in less than nine months after the end of the fiscal year, i.e., before Christmas, and preferably in October or November, given a fiscal year end of March 31. If there are delays in obtaining data from a few jurisdictions, feedback should still be provided to those who submitted their data in a timely manner.

5. The initial scope of the national data base should be relatively modest, should have a balance of clinical, financial and personnel data and should have enough clinical data to be of interest to service providers and to facilitate an analysis of the comparability of clients across agencies and jurisdictions. Ideally, data should be collected at both the client and agency levels.

6. Steps should be taken by the appropriate authorities to facilitate changes in data collection procedures so that data from Chronic Care Units can be easily compared to, and integrated with, data from both acute hospitals and Long Term Care residential services.

7. To the extent priorities need to be established for the development of data bases for the various components of the Continuing Care system:

- The first priority for data base development should be given to the largest and most costly sectors, for which no data are currently collected, particularly professional Home Care services and Homemaker services. An initial start in this direction should be to develop a listing of all Home Care and Home Support organizations across Canada.

- The second priority should be to make Chronic Care data easily retrievable and comparable to both acute care data and Long Term Residential Care data.

- The third priority should be to upgrade the existing Statistics Canada survey of Residential Care Facilities.

8. Any method of classification adopted for Continuing Care clients as part of a national data base should be used for both residential and community/home based services.

9. It is vital to ensure that common client classification systems are used in a national data base to ensure comparability over space and time. To ensure comparability, data should be collected, to the extent possible, for residential and community/home based services for:

- The Types of Care classification system currently used for Statistics Canada's survey of Residential Care Facilities (i.e., the 1973 model);

- The care level system used to classify a client in his or her own jurisdiction;

- The series of questions used to assign the client to the Alberta Resident Care and Home Care Classification Systems, or the assigned care levels based on these systems; and,

- Questions which could be used to assign clients to classification systems used in other countries, e.g., Katz's Index of Independence in Activities of Daily Living.

10. The Canadian Institute for Health Information should develop and maintain a detailed and up-to-date description of how Continuing Care services are delivered in each Province and Territory of Canada. This information should be published on a regular basis to ensure that the Continuing Care Industry, and Governments, have timely and accurate information on the organization and policies of the service delivery systems in each jurisdiction.

11. The approach selected, to developing a national data base, should build on the strengths of current approaches and models while recognizing the diversity of service delivery systems and practical constraints. Therefore, a negotiated, consensual, hierarchical approach is recommended. This is an approach in which jurisdictions can choose to participate at different levels of complexity i.e., they can choose which model is most congruent with their existing information systems realities.

12. The process of implementing a national data base should include discussions with provincial and territorial officials and service provider Association representatives to ensure that the unique circumstances of each jurisdiction are appropriately addressed.

13. Meetings should be held with key national Associations and groups to obtain their input and endorsement of the national data base and to keep them informed of the progress being made.

14. The Canadian Institute for Health Information should consider drawing on the experience of those in the Continuing Care industry and of its four founding members, i.e., the MIS Group, the Health Medical Records Institute, Statistics Canada, and Health Canada, to facilitate the integration and standardization of Continuing Care information into a comprehensive national health data base, while maintaining the unique characteristics of the Continuing Care sector.

LONG TERM GOALS FOR THE NATIONAL DATA BASE

While it will take some time to develop, implement, operate and refine a national data base on Continuing Care, the following goals should be used to guide the process along its way:

- Data should be collected at the client level across the spectrum of Continuing Care services with Province or Territory wide unique identifiers.

- Comprehensive client level data should be collected across the following domains: socio-demographic, health status, cognitive status, functional status, environmental context, care requirements, service use, and family and community supports, annually and at intake and discharge.

- For community and home based services, data should be collected for each visit or care encounter.

- A registration system should be employed for each service component so that it is clear when the client started and stopped any given Continuing Care service. This will allow for tracking the movement of clients within the care delivery system and for determining the proportion of clients receiving more than one service at a given time.

- There should be a standard Minimum Data Set for client data across jurisdictions to ensure the comparability of data, and the questions and scales in this data set should be tested for validity and reliability.

- There should be one standard method for designating care levels for both residential and community and home based clients and this method should be tested for validity and reliability.

- There should be a standard approach, such as ICD-9, ICD-9CM and/or Case Mix Groups, for classifying diseases and disabilities between hospitals and the acute care substitution component of Home Care programs.

- The data collected for Continuing Care purposes, and the unique identifier used, should be as compatible as possible with data collection systems for other sectors of the overall health care system. This will allow for the integration of Continuing Care data with data on the larger health system and will allow for the tracking of clients across all health services.

- Financial and personnel data should be collected using a reasonably detailed chart of accounts, or comparable sets of charts of accounts, for all components of the Continuing Care system. Ideally, the system should have the ability to determine the costs of service for each client within each component of the system.

- If it is not possible to obtain financial data at the client level, estimates, or standard protocols, should be developed for each jurisdiction as to the personnel and financial resources expended at each level of care., i.e., a method of determining per diem costs by level of care.

1. INTRODUCTION AND NEED FOR A NATIONAL DATA BASE

This study was undertaken to review the nature and scope of the data currently collected on Continuing Care services across Canada and to determine the interest in, and feasibility of, developing a national data base in this sector. As the details of the project were developed, it was decided that this project should be integrated into the existing stream of national health information activities by coming under the umbrella of the National Health Information Council and its Community Health Information Systems Project. Aside from these groups, and Statistics Canada, the report of this project may be of interest to Health Canada, the newly formed Canadian Institute for Health Information, and to the Continuing Care industry.

A one page overview was developed to guide the work of the study and to describe it to others. This document is presented in Appendix A and states that the purposes of the study were:

> To review the need for, and interest in, a national data base on both residential and community/home based Continuing Care services. To determine the feasibility of establishing such a system and to outline its possible nature and scope. To review the content and methodologies of existing systems and to prepare options, as appropriate, for a national data base.

It is estimated that Continuing Care represents the third largest component of government expenditures within the Canadian health care system, after hospitals and medical services, and may have accounted for some $7-$8 Billion of government expenditures in the 1993/94 fiscal year[1]. However, compared to the two largest sectors relatively little national data is currently collected on Continuing Care. A survey of Residential Care Facilities, which includes institutions for the "Aged", has been conducted by Statistics Canada since the mid-1970s. However, the scope of this survey is somewhat limited. There is currently no program of national data collection for home and community based Continuing Care services, i.e., Home Care and Home Support Services.

Given the current fiscal climate, one may ask why one should establish a national data base on Continuing Care services. There are several reasons for establishing such a data base. At the national level, a data base on all Continuing Care services would improve the data for Statistics

Canada's system of national accounts in regard to community based Continuing Care services. It is estimated that this sector of the industry currently accounts for over one billion dollars of the $7-$8 Billion expended on Continuing Care services by governments alone.

Given current trends toward decentralization (in order to obtain a better integration of services at the local level) and toward the downsizing of hospitals (so that services can be provided "closer to home" by community-based agencies), data are required to analyse the nature of linkages in the health care industry, at a broader systems level. While this data can be collected provincially, it is only by having national data that comparisons can be made across jurisdictions so that the experience of any given province or territory can be put into perspective in relation to other jurisdictions, i.e., so that one can compare and contrast a number of "natural experiments" in the organization and delivery of health services. These kinds of comparisons are of relevance to provincial, territorial and national decision makers.

While there is currently a system of collecting data on Long Term Care Residential Services, the development of a national data base for community and home based services would allow decision makers to understand how their services compare with similar services in other jurisdictions.

From the perspective of the Continuing Care industry, and particularly for the Home Care and Home Support sectors, a national data base would allow the industry, for the first time, to describe itself to others. Currently, we do not know, nationally, how many people receive Home Care and Home Support services, what their characteristics are, or how much is expended on their care.

At the national level, a data base would increase the accountability of the Home Care and Home Support sectors.

At a more detailed level, national data allows those responsible for the management of Continuing Care services to make comparisons of key indicators, across jurisdictions, in regard to similar types of services. For example, it is possible, with some massaging of the data, to make at least

rough comparisons of Long Term Care facilities, across jurisdictions, in regard to matters such as staff per client ratios, per diem costs, costs of supplies, and other such matters. This can be done by using Statistics Canada's survey of Residential Care Facilities. Similar comparisons could be made for community and home based services with a national data base. Once there is comparable data across components of the Continuing Care service delivery system, it will be possible to conduct analyses of the cost-effectiveness of different approaches to service delivery.

A sequence of positive actions may be put into motion once a national data base is established. A national data base would, initially, allow for at least rough comparisons across jurisdictions. These comparisons would lead, given existing differences in service delivery arrangements across jurisdictions, to questions about the extent to which such comparisons are valid. These questions, in turn, may stimulate action to bring about greater comparability across jurisdictions in regard to service delivery models, nomenclatures, client classification systems, and methods of financial reporting. A national data base could, therefore, be a stimulus for the growth and development of the Continuing Care industry.

An important caveat to the above points is that the data which are collected should be analysed in sufficient depth and breadth to be meaningful to service providers and decision makes. Analyses should be shared across jurisdictions in order to promote discussion and thinking about how services can be provided in a more efficient and effective manner. Good analysis maximizes the benefits to be derived from the investment in a national data base.

This paper presents the findings and recommendations of the study on the interest in, and feasibility of, a national data base on Continuing Care services. It is organized into the following sections: an introduction to Continuing Care, methodology, findings, discussion, the recommended approach to developing a national data base on Continuing Care, possible next steps, long term goals for the national data base, costs, and conclusions.

2. AN INTRODUCTION TO CONTINUING CARE

2.1   An Overview of Continuing Care

The term "Continuing Care" is an umbrella term for a comprehensive and coordinated system of service delivery for the elderly and disabled. In some provinces such as Newfoundland and Manitoba the term is, or has been, used to refer only to community and home based services, not to residential services. However, its more common usage includes residential Long Term Care services, Home Care services, and Home Support services. The components of the Continuing Care service delivery system are defined as including: Assessment and Case Management; Meals-on-Wheels; Adult Day Care; Group Homes; Homemakers; Home Nursing Care; Community Physiotherapy and Occupational Therapy; Long Term Care Facilities; Chronic Care Units; and, Assessment and Treatment Centres and Day Hospitals. Other services such as respite care, adult foster care, assistive devices programs, and quick-response teams may also be included. For a comprehensive overview of the Continuing Care system, the interested reader is referred to the report entitled Future Directions in Continuing Care[2] which provides definitions for each of the components of the system, the major challenges facing the system, the principles which guide the system, and the key future directions for the system. The reader is also referred to a companion report entitled Report on Home Care[3] for an overview of Home Care. For a comparative province by province description of the services delivered and the costs involved, for Continuing Care, the reader is referred to the report Description of Long-Term Care Services in Provinces and Territories of Canada[4].

While the types of clients who need care, and the types of services delivered, are similar across provinces the ways that provincial Continuing Care service delivery systems are organized are quite different. This presents a unique challenge to the development of a national data base in this sector. For example, some provinces have established single entry systems for all Continuing Care services while others have not. While most provinces have a method of designating care levels for residential clients, they generally do not have methods for designating care levels for their community and home based clients. A few jurisdictions do, however, have a similar method for designating care levels for both residential and community/home based services. Some provinces purchase community and home

based services from third-party providers while others provide such services directly by government staff, or indirectly, through designated, regional, Home Care agencies funded by government.

2.2   The Current Status of Continuing Care in Canada

The Continuing Care sector is currently in a significant state of change. Some provinces have made, are making, or are planning to make, significant changes to their Continuing Care systems. A number of provinces are also in the process of decentralizing the delivery of health services in general. This is having a significant impact on Continuing Care. It was not the purpose of this study to provide an overview of how Continuing Care services are delivered. However, given the current significant state of flux, a few illustrative comments are in order to highlight some of the constraints which exist in the development of any national data base in this sector. It should be noted that the following comments are believed to be accurate as of the time the interviews were conducted, but given the rapidity of change, they may be, or may shortly become, outdated.

As part of its reorganization, Saskatchewan has combined Continuing Care services with acute care and emergency health services. British Columbia, Manitoba, Prince Edward Island, and Newfoundland are engaged in significant regionalization initiatives which will affect the way Continuing Care services are delivered, and Quebec is looking to re-enforce its existing regional system.

Given these changes to a more regionalized system, Regional Boards may become key actors in any attempt to develop a national data base on Continuing Care, particularly if data are to be collected from such regional organizations rather than directly from service provider agencies, or from provincial or territorial governments. Currently, for the survey of Residential Care Facilities, data are generally collected directly from the facilities themselves. However, Alberta and Quebec provide computer tapes, with data for each facility, to Statistics Canada.

For most of the provinces not mentioned above, major changes are also being undertaken. New Brunswick plans to integrate mental health and other community health services with Continuing Care. Ontario has a major initiative under way to change its current system of Home Care agencies and third-party providers to a system of regional Multi-Service Agencies which will provide Home Care and Home Support services. Nova Scotia recently conducted inter-Ministry transfers for components of its Continuing Care system.

In addition to the above structural changes, there are also significant information systems initiatives under way. For example, the provinces of Alberta and New Brunswick are in the process of developing large scale, multi-year systems plans for the full range of health services in their respective Ministries. Manitoba has prepared a Request for Proposal to fully computerize its Continuing Care services. Most other provinces are also reviewing, to at least some degree, their information systems, and their information requirements for Continuing Care.

The above factors complicate the development of a national data base. Does one set up a system to collect data from organizations which may not exist in one or two years? How does one integrate a minimum data set for national purposes with major multi-year systems developments at the provincial and territorial levels where the primary concern is intra-provincial/territorial comparability? These are significant challenges to which answers must be found if one is to establish a national data base. It is hoped that the suggestions made in this report can provide the beginnings of a response to these challenges.

2.3 Terminology and Nomenclature

Given that there are significant differences in nomenclature across jurisdictions, this paper will use the generic term Long Term Care residential services to refer to Long Term Care institutions (for-profit, not-for-profit and governmental) which provide services for persons with some measure of functional disability. The term "Chronic Care Unit" will be used to refer to separate wings, or units, of acute care hospitals which are specifically designated to care for Chronic Care clients i.e., those with high levels of functional disabilities. It will also be used to refer to stand alone institutions caring

for Chronic Care clients. With regard to home and community based services, separate services will be called by their respective names e.g., Home Nursing Care. The term "Home Care" will be used to refer to a range of services which may be primarily professional in nature, particularly when such an aggregation of services in defined as constituting a "Home Care Program". The term Home Support will be used to refer to an aggregation of supportive services such as Homemakers.

3. METHODOLOGY

The major methodological activity for this study was the conduct of a number of interviews, by the author, with the key Provincial and Territorial officials responsible for the delivery of Continuing Care Services, and with senior representatives (usually Executive Directors) of provincial service provider Associations. Some actual service providers were interviewed as well. These interviews were conducted during the summer and early fall of 1993. The questions used in the semi-structured interviews are presented in Appendix B.

Discussions were held in regard to this project with the Executive Directors of the Canadian Home Care Association, the Canadian Long Term Care Association, and HomeSupport Canada. This study was endorsed by each of these organizations. Discussions about the project were also held with representatives of a number of other national groups and organizations including: The National Health Information Council (NHIC); The Community Health Information Systems (CHIS) Project; The Health Medical Records Institute (HMRI); The Management Information Systems (MIS) Group; The Canadian Hospital Association (CHA); The Canadian Council on Health Facilities Accreditation (CCHFA); The Seniors' Secretariat; The National Advisory Council on Aging (NACA); Health and Welfare Canada; The Seniors Independence Research Program (SIRP); Welfare Grants; The National Health Research and Development Program (NHRDP); and, Statistics Canada's Canadian Centre for Health Information (CCHI), now referred to as the Health Statistics Division.

A comprehensive literature review was also conducted as part of this study and discussions were held with key international contacts.

4. FINDINGS

4.1 Literature Review and Key Respondent Survey on National Data Bases

An international literature review was conducted to see if there was material in the published literature on national data bases for residential and/or community and home based Continuing Care services. With a few exceptions, this review did not find any significant documentation on comprehensive, client-based national data collection systems for Continuing Care. What was found was primarily American material on a range of assessment and classification instruments which have been used for research studies. Among this material, the pioneering work of Katz and his colleagues[5], and the Older Americans Resources and Services (OARS) system developed at Duke University[6] stood out as classic works. Many of these instruments were developed prior to the 1980s and have had an influence on the development of data collection instruments in Canada. For an overview of key issues in measurement, and of the major assessment and classification tools noted in the literature, the reader is referred to the book by Rosalie and Robert Kane entitled Assessing the Elderly: A Practical Guide to Measurement[7].

For Canada, one article was found on the Canadian government report, prepared in 1973,[8] which developed the basis for the care level system which is used in some provinces and in the existing Statistics Canada Survey of Residential Care Facilities for the Aged. There have also been some papers published on the survey of Residential Care Facilities[9] and on provincial assessment and classification systems.[10]

In addition to the literature review, a small key respondent survey was carried out among national and international colleagues. This resulted in the author being asked to attend an invitational Conference in Washington, D.C., in November 1992, to learn about the work being done in the United States, and internationally, on the Federally mandated Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS) and the Resident Assessment Instrument (RAI)[11]. This was a key Conference as it brought together leading international academics, representatives of the American government, and representatives of the World Health Organization, to discuss early

findings from countries such as Italy, Denmark, Sweden, Switzerland, the Netherlands, Australia and Japan where the MDS has been translated, tested, and implemented on a research basis. The MDS is currently mandated for use in all Nursing Homes in America and forms the basis of the Resource Utilization Groups (RUGs) system of funding currently in place in some States.

Two groups have worked on the development of a comprehensive assessment tool for community and home based services. Dr. Brant Fries, one of the originators of the MDS, and his colleagues in other countries, are working on a MDS for community/home based services to be used internationally. The Health Care Financing Administration has developed a Uniform Needs Assessment Instrument (UNAI) to be used for community based services.[12]

Perhaps the most significant work on instrument development found in Canada was the work conducted in Alberta to establish the Alberta Assessment and Placement Instrument (AAPI) and the Alberta Resident Classification System (RCS). This Resident Classification System has been adapted for use in Ontario while the AAPI has been adapted for use in New Brunswick.

4.2   The Nature and Scope of Provincial/Territorial Data Collection on Continuing Care

A positive finding of this study was the extensive nature and scope of the data currently collected on Continuing Care services across Canada. However, not all jurisdictions had standardized forms for client assessment. Some jurisdictions did not have detailed financial reporting for the full range of service provider agencies. In some jurisdictions, financial reporting did exist but was not closely integrated with data on clients. In most jurisdictions only a small proportion of the data collected were computerized. In some jurisdictions only aggregate data were provided to the respective Ministries of Health.

Another finding was that in spite of all the data which are collected, there appears to be relatively little analysis, aside from that required for operational matters. Therefore, it is recommended that:

1.   As a great deal of information is already collected in each jurisdiction, research funders, such as the National Health Research and Development Program, should give consideration to promoting the conduct of a range of analytical studies on Provincial and Territorial Continuing Care services using existing data bases. A priority should be placed on the publication of the findings of these studies so that the results are readily available to researchers, planners, administrators, and policy makers, both in Canada and in other countries.

In terms of developing a national data base, the amount of effort required to collect a comprehensive range of data is, essentially, already being expended. In addition, very similar data are being collected across jurisdictions. Therefore, with some exceptions, a data collection infrastructure already exists at the Provincial/Territorial levels, and a rough consensus exists on the domains which should be covered in a Continuing Care data base. Given the above, one may hypothesize that the impediments to developing and implementing a national data base may lie not so much in the determination of the variables to be collected, or in the information systems technology to be used, as in the degree of administrative will to modify existing practices to facilitate cross jurisdictional comparisons.

4.3   Knowledge of Statistics Canada's Survey of Residential Care Facilities

There was some degree of knowledge of the Statistics Canada survey of Residential Care Facilities for the Aged among those working in the residential sector. However, this survey was generally not well known to those working in the Home Care and Home Support sectors.

While the survey of Residential Care Facilities was generally known to those in the residential sector, relatively few interviewees were aware of the two major reports produced by Statistics Canada which relate to the survey on the Aged i.e., Residential Care Facilities - Aged and List of Residential Care Facilities.[13] In addition, given the relatively few articles which have been published on this survey, little was known about the results of the survey. Given these findings it is recommended that:

2.   In order to make information from existing data bases more readily available to senior decision makers, and to the Continuing Care industry, Statistics Canada and Health Canada should consider facilitating the preparation of a national report, or a series of articles for publication in major health journals, on the findings of the survey of Residential Care Facilities.

4.4   Interest in a National Data Base

There was essentially unanimous agreement among provincial and territorial officials, and service providers, that it would be desirable to have a national data base. There was an interest in being able to compare key indicators and statistics across provinces and regions.

It was noted that more active participation could be fostered if there was feedback of data to agencies, service provider Associations, and provincial officials. It was also noted that this feedback should be timely. Currently, when provincial officials need comparable data to brief their superiors and Ministers they telephone each other not only to obtain the most up-to-date information, but also, to ensure that they are making valid, i.e., "apples to apples", comparisons across jurisdictions. It was also noted, however, that as this method of collecting data has come to be used more often, it is taking up an increasing amount of time for those providing the information.

Service providers and their respective Association representatives indicated that providing survey information does take time and resources and that improved response rates, and quality, could be obtained if local agencies and provincial Associations were provided with timely, and complementary, feedback. This could be as simple as one or two pages showing key statistics for the agency, the province, and Canada as a whole. The Association representatives also noted that in addition to general interest, and as a means of informing their membership, the information could be used for education and training purposes. Some interviewees also noted that summary feedback could be used to advertise the sale of more detailed data products. Providing summary feedback is not inconsistent with current policies on the sale of data products and could, perhaps, even serve to stimulate the sale of such products.

In summary, there was generally good support for the development of a national data base and it was found that there was a genuine interest in the information. Provincial officials, Association representatives, and administrators of service provider agencies, were generally prepared to participate and to assist, as much as possible within existing constraints, in establishing and operating a national data base. Naturally, the more such a data base could assist them directly, the more actively they would be prepared to participate.

3. If a national data base is established, a system of providing concise and relevant feedback, on a complementary basis, to service provider agencies, provincial and territorial Associations, and provincial and territorial officials, should be developed and implemented and should form an integral part of such a data base. The complementary data would consist of one to two pages of key indicators and statistics and would not be inconsistent with current policies on the sale of data products.

4. The information provided as feedback from the national data base should be made available on a timely basis such that it could be provided to its recipients in less than nine months after the end of the fiscal year, i.e., before Christmas, and preferably in October or November, given a fiscal year end of March 31. If there are delays in obtaining data from a few jurisdictions, feedback should still be provided to those who submitted their data in a timely manner.

4.5 The Size and Scope of the Data Base

There was again essentially unanimous agreement that the initial scope of the data base should be relatively small and should be limited to a modest number of key variables. It was also agreed that there should be an even balance of clinical, financial and staffing data and that the system should initially monitor, rather than evaluate, activities. Services providers, some Association representatives, and provincial and territorial officials, wanted to ensure that a modest, but adequate, degree of clinical data would be collected so that they would be able to compare their clients to clients in other agencies and jurisdictions. Given this consensus, it is recommended that:

5. The initial scope of the national data base should be relatively modest, should have a balance of clinical, financial and personnel data and should have enough clinical data to be of interest to service providers and to facilitate an analysis of the comparability of clients across agencies and jurisdictions. Ideally, data should be collected at both the client and agency levels.

4.6   Services to be Covered by the Data Base

A significant issue which needs to be addressed in the development of a national data base on Continuing Care is how to handle the Chronic Care sector. In some provinces, such as Alberta, this sector is funded, and integrated into, the Division responsible for Long Term Care Residential Services while in other provinces it is funded by the Division responsible for Hospitals.

This state of affairs causes a number of problems. It is currently difficult to obtain national data for Chronic Care clients because in some provinces they are primarily housed, as high level care clients, in Long Term Care facilities. In other jurisdictions, the majority of Chronic Care clients are housed in Chronic Care Units in hospitals. For the first situation, reporting on these clients is done through the survey of Residential Care Facilities while for the second situation it is done through Statistics Canada's HS1 and HS2 hospital surveys. Given these different reporting streams, it is not currently possible to get an accurate, national, statistical picture of the Chronic Care component of the Continuing Care system.

Current reporting arrangements are also detrimental to statistical data collection for acute care hospitals as most key indicators such as lengths of stay, average costs, age and sex distributions, classifications of clients by types of diseases, and other statistics, are skewed based on the presence or absence of Chronic Care Units in hospitals. This impacts on one's ability to have valid comparisons for the acute care sector across provinces and across countries. Sorting out the issue of reporting for Chronic Care beds would improve Canada's statistics for both the Continuing Care and Acute Care sectors. Given existing realities, the most prudent course of action seems to be to consider changes in current information systems practices so that data from Chronic Care Units can be disaggregated

and can be compared to, and integrated with, both acute hospital data and data for Long Term Care residential services.

In discussions with the former MIS Group (this Group was merged into the Canadian Institute for Health Information (CIHI) in the Spring of 1994), it was noted that if every hospital was on the Global reporting system (a system in which the costs of care can be attributed to individual clients), disaggregating data for Chronic Care Units would not be a problem. However, it may take some time to achieve this level of reporting for all hospitals. Staff also noted that the MIS Guidelines are sufficiently flexible to establish Chronic Care Units in acute hospitals as separate, comprehensive, cost centres. However, this has not been done in practice and the necessary roll-up mechanisms have typically not been established in the internal information systems of acute hospitals. Therefore, it is recommended that:

6.   Steps should be taken by the appropriate authorities to facilitate changes in data collection procedures so that data from Chronic Care Units can be easily compared to, and integrated with, data from both acute hospitals and Long Term Care residential services.

Continuing Care is a complex system of service delivery with very different component parts. Ideally, and in the long run, data should be collected for all components of Continuing Care. However, as a practical matter, it may not be possible to collect data on all components of the system at once. If some priorities need to be set, emphasis should be placed on providing data on the largest and most costly components of the system for which no data are currently collected. Therefore, it is recommended that:

7.   To the extent priorities need to be established for the development of data bases for the various components of the Continuing Care system:

- The first priority for data base development should be given to the largest and most costly sectors, for which no data are currently collected, particularly professional Home Care services and Homemaker services. An initial start in this direction should be to develop a listing of all Home Care and Home Support organizations across Canada.

- The second priority should be to make Chronic Care data easily retrievable and comparable to both acute care data and Nursing Home data.

- The third priority should be to upgrade the existing Statistics Canada survey of Residential Care Facilities.

4.7   The Issue of Comparability Across Jurisdictions

The issue of the comparability of data across jurisdictions was raised many times and is one of the most difficult problems to resolve in the development of a national data base on Continuing Care. There are no easy, or "magic", solutions to this problem. It is a problem which will require ongoing work and cooperation among jurisdictions for some time to come. However, it is better to start doing something constructive which, while it may lack a certain degree of precision, gets everyone into the neighbourhood where the ball park is located than to give up due to the enormity of the task. By starting a process of looking at, and discussing, the data, the nature and scope of differences between jurisdictions will become clearer. As this happens, solutions will start to become more self-evident. There is also some good work which has been done by the former Federal/Provincial/Territorial Subcommittee on Continuing Care which can form the basis for beginning to resolve the issue of comparability across jurisdictions. The issue of comparability has two components, care level classification and service delivery systems.

4.7.1   Care Levels

In looking at the information provided to the author on the definitions of care levels in the various provinces and territories one is struck both by the differences in nomenclature and by the underlying similarities of the care level definitions themselves. The names for care level designations vary across jurisdictions, but their descriptions are strikingly similar. However, some jurisdictions have divided their care levels into three levels, some into four, and some into five or more. Another major difference is that many jurisdictions use a more subjective assessment, based on clinical

judgment, while others have adopted the Alberta model, or a similar structure, which relies more on the answers to specific questions.

It should be noted that changing provincial and territorial care level designations is not an easy matter because, in many jurisdictions, funding is related to the care level mix in the facility. Therefore, it may be necessary to consider care level systems which can be used for statistical comparisons, across jurisdictions, but which allow existing provincial practices to remain in place.

There are a number of steps which can be taken to begin to provide comparability across provinces by levels of care. The Federal/Provincial/Territorial Subcommittee on Continuing Care studied these issues and produced two reports on this subject. The first report, entitled the National Long-Term Care Classification Reporting System[14], attempted to build on the first three levels of the 1973 five part typology (i.e., Types, I, II and III). This report tried to develop a template for translating existing provincial care level classifications for both residential and community based services (the 1973 typology was designed for residential services only) into levels of care corresponding to Type I, II and II Care. This attempt had limited success because most provinces do not have classification systems for community based services and because, for a few provinces, there was not a direct fit between their levels of care and the three part typology proposed in the report.

In order to make progress on the community side, the Subcommittee recently released another report which attempted to develop a classification system for community based clients. This report is entitled Classification of Long Term Care Clients in Home Care: Proposal for the Development of a National Framework.[15] It presents a proposal which adapts the Alberta Resident Classification System to Home Care and adds another classification scheme to categorize the extent of home and community based supports which are available to the client called the Classification of Informal Support. This system is referred to as the Alberta Home Care Client Classification System. This two pronged system of classification has been well received across Canada. Another Canadian system which could also merit further consideration is the Comprehensive Heath Status Measurement System (CHSMS) being developed at McMaster University.

Another approach to classification could be to adopt the Minimum Data Set (MDS) used in the United States as it also provides the basis for a classification system for Resource Utilization Groups (RUGs) funding. Finally, it would also be possible to adopt a classification system noted in the international literature such as the one originally developed by Katz in the 1960s. Katz found that there was a hierarchical layering of decreases in functional abilities. He developed, and tested, an eight-point scale called the Index of Independence in Activities of Daily Living. This Index is based on functional abilities in six areas, i.e., bathing, dressing, going to the toilet, the ability to transfer, continence, and the ability to feed oneself.

Given that interview respondents noted that they wanted to start modestly on any national data base, use of the MDS and other large systems such as the OARS methodology may be too complex at this stage. The Katz scale and the Alberta Resident and Home Care Classification Systems use almost all of the same variables. Given the interest in obtaining at least some clinical data, it may be useful to collect data based on a set of questions which would allow analysts to classify clients both on the Katz system and the Alberta system. Using the Katz system has the advantage of allowing for comparisons between Canadian findings and findings from other jurisdictions such as the United States. If the Katz system is used, the questions should be modified to a five point scale from the original two point scale (but in a way which allows for collapsing the five point scale back into a two point scale).

The approach proposed for dealing with the matter of client classification is a strategic one. It is a system in which several different approaches are used simultaneously. The greater the congruence in the findings based on the different approaches, the greater the confidence one can have in the results. It also recognizes the benefits to be derived from having similar classification systems for Continuing Care clients whether they are treated in a residential setting or in the community, thereby allowing for more appropriate comparisons across the residential/community continuum. Therefore, it is recommended that:

8.   Any method of classification adopted for Continuing Care clients as part of a national data base should be used for both residential and community/home based services.

9.   It is vital to ensure that common client classification systems are used in a national data base to ensure comparability over space and time. To ensure comparability, data should be collected, to the extent possible, for residential and community/home based services for:

   •   The Types of Care classification system currently used for Statistics Canada's survey of Residential Care Facilities (i.e., the 1973 model);

   •   The care level system used to classify a client in his or her own jurisdiction;

   •   The series of questions used to assign the client to the Alberta Resident Care and Home Care Classification Systems, or the assigned care levels based on these systems; and,

   •   Questions which could be used to assign clients to classification systems used in other countries, e.g., Katz's Index of Independence in Activities of Daily Living.

4.7.2   Service Delivery Systems

In speaking to people across the country it became clear that they were as interested in how service delivery systems were structured across jurisdictions as they were in having nationally comparable data. This was a variant of the "comparing apples with apples" concern. As noted earlier, Continuing Care systems are structured differently across Canada. It is important to understand these differences in order to appropriately interpret the data which are collected, and published, as part of a national data base. This is not a minor concern. It must be stressed, in the strongest possible terms, that Continuing Care is a highly complex sector which continues to change and evolve, and which differs across jurisdictions. An example will illustrate this point.

Until recently, in order for clients to get homemaker services as part of the Home Care program in Ontario, clients had to have "hands on" care by a professional such as a nurse. Currently, the Ontario Ministry of Health is progressively implementing an Integrated Homemaker Program across the province. In this program, care by a professional health care practitioner such as a nurse is no longer a prerequisite to obtaining homemaker services. However, to obtain homemakers

services, the homemakers themselves must now provide some "hands on" personal care before clients can also obtain other "household assistance" services such as cleaning, meal preparation and shopping. Such "household assistance" services are available to eligible persons, without the prerequisite of "hands on" care, from the Ministry of Community and Social Services. This is a separate program, operating in a separate Ministry, on a separate information system. Responses to requests for data on "Home Care" in Ontario would, in all likelihood, not include clients who received only household assistance services from the Ministry of Community and Social Services.

In comparison, other provinces such as British Columbia and Manitoba provide "household assistance" services to clients as part of the Home Support component of their Continuing Care service delivery systems without the prerequisite of providing "hands on" care. The data from these provinces and Ontario would not be directly comparable because of the differences in the policy on "household assistance" services.

While in theory, it may be possible to include the "household assistance only" groups for Ontario in a national data base, in practice this may be more difficult. However, knowing that such differences exist assists in the interpretation of data across jurisdictions.

Until such time as there is consistency, continuity and comparability of Continuing Care services over time, and within and across jurisdictions, it will be important to collect information on the structures, components and policies of the different Provincial and Territorial Continuing Care systems across Canada. In order to do this it is recommended that:

10.   The Canadian Institute for Health Information should develop and maintain a detailed and up-to-date description of how Continuing Care services are delivered in each Province and Territory of Canada. This information should be published on a regular basis to ensure that the Continuing Care Industry, and Governments, have timely and accurate information on the organization and policies of the service delivery systems in each jurisdiction.

4.8   Confidentiality and the Collection of Client Specific Data

While the people interviewed all agreed that the confidentiality of client data was an important issue, there was a range of opinion regarding the extent to which it would be possible to collect client specific data using some form of a unique identifier such as a medical number. Some respondents felt that the use of such an identifier would be acceptable if data were only used for statistical purposes. It was also noted that if services are provided with public money government should have access to the data for statistical purposes.

In some provinces there was some sensitivity about the use of the medical number but it was noted that it may be acceptable to provide data with a unique identifier if that identifier is scrambled before the data are sent to Statistics Canada. In some provinces, such as Ontario and Quebec, client data are collected at the agency level but, at least for some matters, only aggregate data are sent to the Ministry responsible for health services. Therefore, in some provinces, sending client data, with unique identifiers, to a central national source was a concept that people wished to consider very seriously before agreeing to submit such information.

In terms of legislation, the Statistics Act, Section 13, provides broad powers for the collection of data from individuals, groups and organizations. However, in practice, most data collection efforts are conducted on a voluntary basis and the sanctions allowed for in the Statistics Act are seldom used. Some provinces have Freedom of Information and Protection of Privacy Acts and, most who do, have clauses in these Acts which allow for the release of information, for statistical purposes, by a designated authority. This is also the case with federal legislation. Thus, the legislative basis for the release of personal information for statistical purposes does appear to exist. There is, however, a range in current practice regarding the release of client specific data and it may prove difficult to obtain such data from all jurisdictions. Therefore, careful attention must be paid in the development of a national data base to working with each jurisdiction to find an acceptable method of releasing client specific data.

Some useful background work was done on the topic of confidentiality for the National Task Force on Health Information which may point the way to handling the issue of client confidentiality.

The Draft Report of the Project Team on the Implications of Privacy and Confidentiality Concerns on the Use of Health Information for Research and Statistics,[16] noted several important points. The report stated that it is critical to make the distinction between the use of personal data for research and statistical purposes versus administrative purposes. A major concern that individual citizens have is that by someone knowing something about them action will be taken to their detriment, i.e., an administrative use of information to, for example, deny someone the benefits of some program. Another point noted in the report was that there should be broad and ongoing consultations with key groups to reassure those concerned that the data which are collected will serve a useful purpose and will not harm the persons receiving care.

There are also some practical considerations, which were noted in the interviews, which act as constraints on the development of a national data base on Continuing Care, particularly for community/home based services. As most facilities have relatively modest numbers of beds, obtaining data on a short list of variables for facility clients would entail a modest amount of additional work and, therefore, obtaining the information should not be too time consuming. This is not the case for the community side. For example, it was noted in the interviews that the Regina Home Care Program had 2,900 clients. It would certainly be time consuming to collect individual data for agencies whose clients number in the thousands. The counterpart of this is that only limited client data, or no client specific data at all, are sent to the Ministry of Health in some provinces, thereby, restricting the option of collecting such data directly from some provincial Ministries.

Another concern is that for community/home based services a number of provinces do not have a standard provincial client assessment instrument. There is also some variation across provinces in the degree of financial and staffing data which is collected for this sector. While a number of provinces are working to develop and/or improve their information systems, this in itself may pose a constraint on a national data base as the variables to be collected, and their definitions, may already have been finalized at the provincial level.

Given the above, it appears that no single and simple solution is possible. Rather, what may be required is a process of discussion and negotiation, with each jurisdiction, to determine the most appropriate method of participating in a national data base.

4.9   Mechanisms for Providing Data for a National Data Base

The persons who were interviewed for this study were asked questions about the extent of computerization at the agency level, how easy it would be to abstract data and send it to a national data collection body, and whether or not they had a preference for who should send the data to such a body, the agencies or provincial or territorial Ministries of Health. Their responses indicated that there are still a significant minority of agencies which are not computerized, or only use computers for financial purposes. Therefore, there is still some way to go before agencies could, for example, provide computer diskettes of their client, financial and staffing data to a national data collection agency. It was also found, however, that some provinces such as British Columbia have relatively advanced provincial computer systems and could, if they wished, provide provincial data on computer tapes for both residential and community/home based services.

These findings again underscore the need for discussion and negotiation at the Provincial and Territorial levels to determine the most appropriate means for participating in a national data collection effort. With some exceptions, most interviewees stated that data could be provided to a national data collection agency either by service provider agencies or by Provincial/Territorial Ministries of Health. The main concern which was expressed was that duplication of effort be minimized. In some jurisdictions it was noted that, to ensure accuracy, it may be better to have the agencies provide the data directly to Statistics Canada. In other provinces it was noted that the agency's data should be provided to the respective Ministry of Health so that it could ensure the accuracy of the data prior to forwarding it to a national data collecting agency.

4.10   The Level of Commitment to a National Data Base

As noted earlier, there was general support for a national data base for Continuing Care. However, interviewees noted that the level of participation would, in some way, be dependent on the benefits to be derived. They also noted that they were in a period of fiscal restraint and, generally, were not in a position to contribute financially.

There was, nevertheless, a willingness to do as much as possible within existing constraints. This could include adding supplementary questions to existing data collection instruments or making some adjustments to the wording, or definitions, of variables already collected. It was noted that the task of justifying such changes would be easier if relevant and timely feedback was provided.

While officials were naturally circumspect in their comments, the point was, nevertheless, made that existing fiscal constraints were, at least partly, the result of existing federal policies on fiscal transfers. Given this reality, it was suggested that funding for the development, implementation and operation of a national data base could be an appropriate contribution of the Federal Government.

5. DISCUSSION

5.1 A Review of Different Approaches to National Data Collection and Their Applicability to Continuing Care

This section outlines the advantages and disadvantages of a number of existing approaches to the collection of national data and their applicability to the Continuing Care sector.

5.1.1 The Discharge Abstracts Model

The Health Medical Records Institute (HMRI), an independent, national, non-profit organization, collected data from hospital discharge abstracts and provided aggregate data back to the Provinces and Territories, and to participating hospitals. The HMRI was merged into the Canadian Institute for Health Information in the spring of 1994 and the CIHI is now responsible for the functions previously performed by the HMRI.

This model has several advantages. It allows for a range of relevant comparisons regarding types of clients, their illnesses, their use of resources, i.e., lengths of stay, and a number of other matters. In this model, the organization which collects the data from hospitals is also the one which provides data and statistics back to them. As hospitals pay to participate in this system, the likelihood of reasonably comprehensive and timely data collection and processing is maximized.

While this model has the advantages noted above, there are also some possible disadvantages to this approach from the perspective of the Continuing Care industry. Many Provinces and Territories already have, are developing, or will develop, province-wide data collection systems for Continuing Care services. It is unlikely that these efforts would be abandoned in favour of a national data collection agency which would provide data back to the agencies, Provinces and Territories. The discharge abstracts approach only focuses on client data, but interviewees indicated a desire for a system that includes a balance of client, financial and personnel data. In addition, the use of the discharge abstracts model may be less appropriate in Continuing Care than in acute care as Continuing Care clients may remain in care for years. Therefore, for Continuing Care services, it may be more appropriate to collect data annually on clients who have been discharged, and on clients who are still in care, rather than to collect data only at discharge.

5.1.2   The Management Information Systems (MIS) Guidelines Model

The MIS Group, another independent, national, non-profit organization, developed comprehensive sets of Guidelines for data collection on financial and non-financial data for acute care hospitals. The MIS Group was merged into the CIHI in the spring of 1994, and the CIHI is now responsible for the functions previously performed by the MIS Group. The MIS Guidelines have two levels. The first level provides Guidelines for reporting information by hospital Departments. This is called the Departmental level of reporting. The second level is a Global Level of reporting which allows for the determination, at an individual client level, of the services provided to the client and the costs of those services i.e., a system which directly ties costs and services to the individual client.

The strength of this model is clearly in its comprehensiveness. The adoption of the MIS Guidelines in individual hospitals results in an excellent source of data on resource utilization and

costs. Full implementation of the MIS Guidelines across Canada will allow for appropriate comparisons across jurisdictions for the acute care sector.

To some extent the strength of the MIS Guidelines system is also its weakness as it takes time to move from development to full implementation. These Guidelines were developed in the early to mid-1980s, they were pilot tested in selected sites across Canada from 1986 - 1989, and provinces began to adopt the Guidelines in 1989 and 1990. If a similar approach was developed for the Continuing Care sector it would, in all likelihood, also take some time for full adoption of an MIS Guidelines approach, although, given the experience gained with the hospital sector, the time line should be much shorter. However, interviewees were essentially unanimous in stating that a national data base on Continuing Care should start out modestly and should grow as the benefits of increased data collection become clearer to the data users. This stands in contrast to the general MIS Guidelines approach which is, typically, a comprehensive approach.

5.1.3 The Accreditation/Quality Assurance Model

The Canadian Council on Health Facilities Accreditation (CCHFA) is also an independent, national, non-profit organization. It conducts accreditation reviews in hospitals and Continuing Care Facilities and is currently working to develop accreditation guidelines for Home Care and Home Support services.

Accreditations are a type of quality assurance in which a "peer review" is conducted in an agency according to pre-established structure and process guidelines. Some client data is collected prior to site visits. The strength of this system is its focus on the quality of the care, and the quality of administration, in a given hospital or Continuing Care facility. The CCHFA has also started work on the development of outcome measures and performance indicators.

From the perspective of Continuing Care, this approach represents a valuable complement to, but not a substitute for, a national data base. In addition, most of the data are destroyed after an accreditation visit so no ongoing record is kept for research purposes. This practice may be appropriate for accreditation purposes (to ensure confidentiality) but not for a system of national data

collection. Nevertheless, there is considerable room for collaboration between the CCHFA and any group developing a national data base for Continuing Care.

5.1.4   The Annual Survey Model

There are two versions of this model. Statistics Canada collects data for the hospital sector using the HS1 and HS2 survey reporting forms and for Long Term Care residential services through its survey of Residential Care Facilities. These are well established systems of data collection which are working reasonably well to provide nationally comparable data. They include some aggregate client data as well as financial and staffing data. It is anticipated that responsibility for these annual surveys will be transferred to the CIHI during 1994. The advantage of this model is that data are collected in a structured way on finances, staffing, and client characteristics.

With regard to Continuing Care, a separate analysis of the Residential Care Facilities survey was conducted. The major observation about this survey is that it appears to lack an active process of engagement with service providers and provincial officials. While those who process the data do interact with the agencies providing the data, the survey is not that well known among provincial officials and service provider Association representatives. Another shortcoming is that there is relatively little client data, and the data which are collected, are collected on an aggregate basis. Thus, while it is possible to analyze data by age and sex categories, and by levels of care, it is not possible to directly analyze data by age, sex and level of care because there is no way to determine care level distributions within age and sex categories.

With regard to the HS1 and HS2 reporting systems, it is not currently possible to extract any significant range of data for Chronic Care Units located in acute care hospitals. Data are available, however, for stand alone Chronic Care Hospitals.

5.1.5   The Integrated Health Information Systems Model

This approach is one of developing comprehensive and integrated health information systems which are focused at the client level and include all components of the health care system. This is the approach used in the Community Health Information System (CHIS) Project and initiatives such as

smart cards. It is anticipated that the CHIS Project will be merged into the CIHI in 1994. This approach allows for an integrated and comprehensive data base on clients, finances and staffing (i.e., service delivery). Data are collected at a client specific level. It is possible to analyze the patterns of utilization for the full spectrum of health care services, and to relate service utilization to client characteristics, environmental factors and a number of other relevant matters.

The negative side of this approach is not one based on technical criteria, or on scope, it is one of timing and organizational realities. Even if roadblocks are minimized, it may still take several years to develop comprehensive health information systems in each jurisdiction across Canada. In spite of their comprehensiveness, and because of a focus on provincial and territorial needs, such systems may still not be directly comparable across jurisdictions. This is particularly so for an area such as Continuing Care where some services are still delivered through Ministries other than Health (e.g., Social Services). It is not clear whether, or how quickly, such services can be integrated into a comprehensive health data base.

From the perspective of Continuing Care, Canada, as a nation, currently has no national data on community/home based Continuing Care services. Is this still acceptable in 1994? The national Associations representing this segment of the health care industry have clearly indicated a need for national data at the earliest possible date. Therefore, at least as an interim solution, steps should be taken to actively work on the development of a national data base for the Continuing Care sector. Naturally, such a data base should be capable of being integrated into more comprehensive health information systems as they are developed.

5.2   Suggested Options for a National Data Base

Each of the models discussed previously has a number of positive aspects. The suggested options for a national data base outlined in this section try to build upon the strengths of these models.

5.2.1   The Aggregate Statistics Model

This model does not envision the development of a data base *per se*. Its most appropriate use may be as a bridging step to the development of a national data base for community/home based services. This is a model in which each jurisdiction would provide aggregate provincial/territorial statistics which would be combined into a national picture. The items collected would consist of a small range of statistics and indicators such as: total annual expenditures by type of care; unit costs by type of care e.g., nursing visits; costs per resident day; types of services provided; percentage increases in expenditures by type of service; the number, age, and sex, of people served, by type of service; and, other such statistics.

The advantages of this approach are that it is relatively inexpensive and builds on statistics most provinces already collect. It is not an intrusive system in that agencies and/or provincial governments would not be required to respond to surveys or data requests from a national data collection agency. This system also has the virtue of simplicity and would provide a minimum baseline of relevant data. This approach also avoids the problems related to obtaining client specific data and would be most consistent with the data collection procedures (i.e., aggregate data) of some provinces. This approach would still allow for some limited comparisons across jurisdictions in Canada. Finally, given the fact that Provinces and Territories are currently in a state of organizational flux, this model could still be implemented inspite of the pervasive change which is currently under way in the Continuing Care sector.

On the negative side, this system would not readily allow for an analysis of national data. It would also gloss over many of the important differences in the way services are provided across jurisdictions. It would not provide data on clients and would not readily allow for a comparison of care levels across jurisdictions. Not having care levels means that it would be difficult to make accurate cross-jurisdictional comparisons because resource use tends to fluctuate significantly by care level.

5.2.2   The Basic Agency Based Information Systems Model

This is the simplest type of information system. It is one which collects basic data at an agency level. The current Residential Care Facilities Survey (RCFS) is an example of this model. The RCFS

has two versions, a short form and a long form. The short form version presents aggregate statistics (i.e., totals) on staffing and expenditures. The long form version provides breakdowns by types of staff and types of expenditures and would be closer to an "advanced" model.

For the residential side, this approach would mean adoption of the short form version of the RCFS with perhaps one alteration, the development of a matrix type question which would allow for counts of clients, simultaneously, by age, sex, and care level.

For community/home based services this would require the development of a reporting system similar to the short form of the RCFS where data would be provided about: the age and sex of clients; the number of clients served per year, by type of service; the client's levels of care; turnover rates; type of agency ownership; total staff; total expenditures; and, a breakdown of revenue sources.

On the positive side, this system would produce more detailed data than the previous model. It would allow for analyses of the variations in costs, staffing and clientele across agencies. It would allow for various forms of peer group clustering of agencies which would increase the validity of comparisons. It would allow for the beginnings of an analysis based on care levels and would allow for an analysis of the inter-relationships of care levels and age and sex categories. By being able to estimate costs, by care level, one can then apply care level unit costs to age and sex groups to obtain estimates of expenditures by age and sex (i.e., per capita cost by age and sex).

On the negative side, this approach still does not provide any significant amount of client data and it does not provide breakdowns by types of staff or types of expenditures. However, even a basic system like this may be somewhat difficult to implement for community and home based services.

5.2.3 An Advanced Agency Based Information Systems Model

This system would be more like the long form version of the Residential Care Facilities Survey. In addition to the analyses noted in the previous section, it will be possible to obtain unit costs, by type of service provider, and type of expenditure, because this approach provides more detailed data on staffing and expenditures than the previous model. In this model some key client

variables can be added and other refinements can be made such as collecting data on hours worked as well as on hours paid, or earned. These enhancements would allow for staffing case mix analysis (e.g., ratio of professional to non-professional staff in facilities) and, if facilities are clustered, would allow for a range of analyses related to client profiles, staffing, and expenditures, which would not be possible under the previous model. By having hours worked, this would allow for the direct comparisons of hours of care per resident. Many of the staffing systems in Canada, and elsewhere, are related to the hours of care per resident day. Collecting data on hours worked is important because there can be considerable differences in the ratios of paid hours to worked hours across facilities, i.e., a facility with a large proportion of part-time staff who get few benefits versus a unionized facility with a stable staff and good benefits.

For community/home based Continuing Care services, it may be somewhat more difficult to have a high level of detail on staffing and expenditures, given existing service delivery arrangements. For example, in Ontario, the larger Home Care agencies provide a brokerage and assessment function and purchase services from third-party provides such as Homemaker agencies or the Victorian Order of Nurses. However, they only collect data on the cost per visit and do not require third party agencies to provide staffing and expenditure breakdowns as part of their reporting systems.

This approach has the potential for more sophisticated analysis. It is still only moderately problematic on the facility side as many facilities already complete the long form version of the RCFS. In discussions with service providers, and Association representatives, it was learned that it would not be too difficult to collect data on hours worked. There was also interest in a modest expansion of the expenditure categories to include matters such as benefits, raw food costs, and the costs of incontinence supplies.

This approach still has the negative that it is not possible to obtain much client related data, and to analyze the data on a client specific basis (i.e., have the ability to cross-correlate client characteristics in all possible combinations). It may be more difficult to implement this type of system in the community/home based sector given existing realities. In addition, for facilities, the matter of capital costs is currently one which is not fully dealt with in the RCFS. Finally, this model still does

not readily allow for the development of care level estimates using the Alberta or Katz models discussed earlier.

5.2.4 The Basic Client/Agency Model

This model is one in which the financial and personnel data collected at the agency level are similar to the previous Advanced Agency Based Model, with a few upgrades to collect data on capital expenditures. In this model very basic data would be collected at the client level, preferably with unique identifiers. The data to be collected for residential and community/home based clients would include: age, sex, estimates of, or actual, care levels (the actual care level in the jurisdiction, and the Type I, II, and III Care level system from the survey of Residential Care Facilities), date of admission, date of discharge, type(s) of services provided, the code of the agency providing the service, and the unique client identifier. This represents the most detailed level of a "monitoring" type information system.

This system allows for the inter-relationship of age, sex and actual, or estimated, care levels and for obtaining counts on lengths of stay by these variables. It also allows for some tracking of clients over time and across intra-Provincial or intra-Territorial boundaries if it is possible to use the same system of unique identifiers across agencies (the less desirable alternative is to use agency specific identifiers).

On the negative side, it may be a quantum leap from current practice to obtain client specific data with unique Provincial/Territorial identifiers. This model would also increase programming and data processing costs in the residential sector as new programs would have to be written to handle client specific data and edit enquiries would be multiplied as questions could be raised on client specific data as well agency specific data.

5.2.5 The Intermediate Client/Agency Model

This model represents a simple "evaluative" system and is one in which more detailed client specific data are collected. Basic socio-demographic data such as age, sex, marital status, receipt of Old Age Security and Guaranteed Income Supplement (OAS/GIS), living arrangements (for community services and all initial assessments), and other data known to be correlated with service utilization, would be collected. In addition, a minimum of data on functional deficits and mental status would be collected i.e., the items needed to classify clients into care levels with the Alberta

Classification Systems and other systems such as the one proposed by Katz. Data would still also be collected on Types I, II and III Care and on actual provincial levels of care. For community and home based services, estimates would be made of these two methods of classifying clients as most jurisdictions do not assign care levels to clients in such services.

In regard to financial and personnel data, this would include a somewhat more complex chart of accounts. This more advanced version would be similar to a simplified version of the MIS Guidelines, but, one which is specifically developed for the Nursing Home sector. This would be similar, in concept, to the Departmental level of reporting which has been developed for the hospital sector.

Comparable charts of accounts appropriate to the various components of the community/home based sector would also have to be developed. This task would be more difficult as separate sets of charts of accounts, or other appropriate financial reporting systems, will need to be prepared for the various types of agencies which provide services. These financial reporting systems may need to separate out the various product lines in a given agency in order to ensure comparability across jurisdictions. For example, Home Care programs will need to have financial systems which separate out costs and personnel for Home Nursing Care and Homemakers in order to have comparability with jurisdictions where these services are treated as separate programs and where no "Home Care" agency, *per se*, exists (e.g., British Columbia).

There is a significant and positive increase in the analytical capacity for this type of client based system. It allows for collecting the data needed to assign clients to care levels using the Alberta system, or other such systems. It allows the analyst to look at socio-demographic and clinical data in all possible combinations (e.g. functional deficits in mobility by age, sex, marital status and income). This model, assuming there is a unique identifier, allows for tracking the health and functional status of individuals over time, and across the community to residential continuum. As such, it is like a longitudinal study where subjects are assessed annually. It allows for the conduct of a range of natural experiments about the efficiency and effectiveness of service delivery systems across Provinces and Territories in terms of costs, staffing and services.

On the negative side, this model would, in all likelihood, represent increases in the costs of operating the system as data related questions could be raised on each client as well as each agency. Also, more data would be collected overall. The computer programs for this model would also be more expensive because they would have to allow for client tracking and for matching incoming data to client data collected in previous surveys. It may also be difficult to obtain client specific data, with unique identifiers, from each jurisdictions.

5.2.6 The Advanced Client/Agency Model

This model would provide for more extensive data collection on an annual basis comparable to the Alberta Assessment and Placement Instrument or the American Minimum Data Set. More domains of information would be covered and all important domains would be covered in depth. Domains to be covered, for residential and community clients, would include: socio-demographic data; health status; cognitive status; functional status; environmental factors; care requirements; family and community supports; and other related information.

With regard to personnel and financial information, this could be at the "Departmental" level or, preferably, at the "Global" level of reporting i.e., a system in which costs and resources can be assigned to each individual client.

This is really the ultimate system of detailed clinical data collected annually and a "Global" level of reporting on financial and personnel matters. All of the positive aspects of the previous Intermediate model are significantly enhanced. In addition, if a system which is comparable to the American MDS is adopted it will allow for numerous international comparisons, thereby significantly increasing the number of "natural experiments" which could be studied. This system goes well beyond a typical information system and constitutes a fully developed evaluative system.

On the negative side, the system would be even more expensive and complex to administer. Significant costs may be incurred in developing this data collection system and testing it for validity and reliability. It can also be argued that this model is no longer an information system but is a

research system. As such, the information required could be obtained by collecting data on representative samples of clients and agencies, rather than on the total universe.

6. THE RECOMMENDED APPROACH TO DEVELOPING A NATIONAL DATA BASE ON CONTINUING CARE

A number of basic principles were used in deciding which model should be recommended. These principles are:

- The comparability of future data, with what is currently collected, should be maximized.

- The comparability of data across health sectors should be maximized.

- The comparability of data with other countries should be maximized.

- The unique nature of Continuing Care should be recognized and reflected in the type of system which is developed.

- To the extent possible, one should build on high quality existing work, i.e., only invent the wheel if it has not been invented before.

- Solutions should be kept simple, defensible, and understandable.

- The inclusiveness of any national data base which is developed should be maximized, i.e., get as many organizations to participate as possible for each major component of the system.

- One should be fiscally responsible but ensure that the national data base is not under funded, i.e., propose options for a national data base that are in keeping with resources expended in other sectors.

- One should focus as much on the process as the outcome, i.e., include as many of the key actors in the solution as possible.

- One should ensure an active and engaged process in which timely feedback is provided to participants in the national data base and in which there are continuous discussions about how the data base can be improved.

- One should test data collection instruments for validity and reliability.

It is recommended that:

11. The approach selected, to developing a national data base, should build on the strengths of current approaches and models while recognizing the diversity of service delivery systems and practical constraints. Therefore, a negotiated, consensual, hierarchical approach is recommended. This is an approach in which jurisdictions can choose to participate at different levels of complexity i.e., they can choose which model is most congruent with their existing information systems realities.

All of the models discussed in the previous section should be constructed so that they can be rolled up from the least aggregated (i.e., most detailed) model to the most aggregated model. Minimum Data Sets should be developed for each of the six models noted above for both residential and community/home based services. A draft of a comprehensive Minimum Data Set for collecting client level data is presented, for discussion purposes, in Appendix C. The less comprehensive Minimum Data Sets would be sub-sets, or aggregates, of the variables presented in Appendix C.

With this recommended approach, discussions would be held with key actors in each jurisdiction about which model, or combination of models, noted above should be adopted, who would provide the data, and when data collection could commence.

It should be recognized that given the existing survey of Residential Care Facilities, and the lack of a comparable survey for community/home based services, it may be necessary, in some jurisdictions, to proceed at different levels of complexity for residential and community/home based services i.e., to choose different models for the two sectors. Naturally, it would be ideal, in a given jurisdiction, to use the same model across the care continuum.

The purpose of this recommended approach is to maximize the level of participation for each jurisdiction while still providing some reasonable degree of information at the national level. This approach does, however, have inertia working against it. Once a given jurisdiction has chosen a model, it may be difficult to move to a more complex model at a future point in time. It is, however, the opinion of this writer, based on his experience, and the interviews conducted, that if an active and engaged process is used in which all key actors and participants receive relevant and timely feedback,

and obtain copies of papers and reports which are published using the national data base, that the above noted inertia can be overcome. People will be able, in a tangible way, to see the benefits of moving to a more comprehensive model by seeing what their neighbours, who have adopted such a model, receive in terms of feedback.

The recommended approach integrates the six different data collection models noted above in Section 5.2 into an overall approach which is designed to meet the complexities and special characteristics of the Continuing Care industry. The client based models noted above use a variation of the discharge abstracts method. However, instead of collecting discharge abstracts, data is collected on an annual basis on the functional status of clients in care. Data would also be collected for those who are discharged in order to complete the client specific file. Some additional socio-demographic data would also be collected.

The agency based models noted above use an approach similar to the one currently in place at Statistics Canada to collect data from the HS1 and HS2 surveys and from the survey of Residential Care Facilities.

The recommended approach is conceptually similar to the MIS Guidelines model in that a series of Minimum Data Set Guidelines would be developed and Provinces and Territories would be encouraged to adopt them in their own jurisdictions. This approach would be most consistent with the MIS Guidelines approach for financial and staffing data. There is currently some similarity, for residential services, in the charts of accounts which are used across the Provinces and Territories. This provides the potential, in the near term, for the development of comparable MIS Guidelines for the Chronic Care Units and Long Term Care residential services in regard to financial and personnel data.

It must be noted that while the recommended approach builds on existing practices in the health sector, it is one which is unique to Continuing Care. It is also one which remains sensitive to the complexity, and special nature, of the Home Care and Home Support sectors.

The recommended approach discussed above presents an opportunity to engage in a pro-active process of national data collection in Continuing Care in which there is positive and ongoing discussion across the National, Provincial/Territorial, Regional and Service Provider sectors. This will, hopefully, heighten interest in information and analysis.

7. POSSIBLE NEXT STEPS

The CIHI, Statistics Canada and/or Health Canada may wish to sponsor a follow-up Workshop on the development of a national data base on Continuing Care. All appropriate efforts should be made to ensure that key Association representatives and the Provincial and Territorial officials responsible for the delivery of Continuing Care services, or their designates, be invited to attend such a Workshop. Another possible step would be to establish a Working Group on the development of a national data base on Continuing Care through the CIHI and/or through the Federal/Provincial/Territorial Advisory Committee structure.

Whatever actions are taken, the national data base should be developed in a way that is responsive to the unique needs of each jurisdiction. Therefore, it is recommended that:

12. The process of implementing a national data base should include discussions with provincial and territorial officials and service provider Association representatives to ensure that the unique circumstances of each jurisdiction are appropriately addressed.

13. Meetings should be held with key national Associations and groups to obtain their input and endorsement of the national data base and to keep them informed of the progress being made.

In discussions, it was found that interviewees were also interested in larger analytical issues such as the impact of Continuing Care on health status. Therefore, it may be appropriate for the Canadian Institute for Health Information to work with Statistics Canada and Health Canada to develop an analytical strategy to ensure an integration of data base efforts and analytical efforts.

In the development of a national data base, it must also be recognized that Continuing Care is part of the overall health care system. Data base development should not proceed in isolation from what is being done in other sectors. Thus, to the extent possible, the Continuing Care data base should be developed in such a way that it can become a component of a larger and more general national health data base which maximizes the integration of data and which minimizes duplication and barriers to cross-sectoral analysis. Therefore it is recommended that:

14.   The Canadian Institute for Health Information should consider drawing on the experience of those in the Continuing Care industry and of its four founding members i.e., The MIS Group, the Health Medical Records Institute, Statistics Canada, and Health Canada, to facilitate the integration and standardization of Continuing Care information into a comprehensive national health data base, while maintaining the unique characteristics of the Continuing Care sector.

8. LONG TERM GOALS FOR THE NATIONAL DATA BASE

It will take some time to develop, implement, operate and refine a national data base on Continuing Care. During this period some goals should be used to guide the process along its way. An ideal system should have the following characteristics:

- Data should be collected at the client level across the spectrum of Continuing Care services with Province or Territory wide unique identifiers.

- Comprehensive client level data should be collected across the following domains: socio-demographic, health status, cognitive status, functional status, environmental context, care requirements, service use, and family and community supports, annually and at intake and discharge.

- For community and home based services, data should be collected for each visit or care encounter.

- A registration system should be employed for each service component so that it is clear when the client started and stopped any given Continuing Care service. This will allow for tracking the movement of clients within the care delivery system and for determining the proportion of clients receiving more than one service at a given time.

• There should be a standard Minimum Data Set for client data across jurisdictions to ensure the comparability of data, and the questions and scales in this data set should be tested for validity and reliability.

• There should be one standard method for designating care levels for both residential and community and home based clients and this method should be tested for validity and reliability.

• There should be a standard approach, such as ICD-9, ICD-9CM and/or Case Mix Groups, for classifying diseases and disabilities between hospitals and the acute care substitution component of Home Care programs.

• The data collected for Continuing Care purposes, and the unique identifier used, should be as compatible as possible with data collection systems for other sectors of the overall health care system. This will allow for the integration of Continuing Care data with data on the larger health system and will allow for the tracking of clients across all health services.

• Financial and personnel data should be collected using a reasonably detailed chart of accounts, or comparable sets of charts of accounts, for all components of the Continuing Care system. Ideally, the system should have the ability to determine the costs of service for each client within each component of the system.

• If it is not possible to obtain financial data at the client level, estimates, or standard protocols, should be developed for each jurisdiction as to the personnel and financial resources expended at each level of care, i.e., a method of determining per diem costs by level of care.

It is recognized that a system with these features represents a future goal. However, it should be noted that some provinces such as British Columbia have already moved a considerable way toward having a comprehensive and integrated client/agency based information system. This system has a unique identifier, uses the same care level classification system for residential and community services, has the ability to track clients through all components of the Continuing Care system and collects comparable financial and personnel data on each agency in each component of the system.

9. COSTS

Unfortunately, it is not possible to develop realistic cost estimates for a national data base on Continuing Care until there is greater clarity about which combination of models will be adopted across jurisdictions and how data will be collected (e.g., by direct surveys or by having Ministries of

Health submit data tapes for their respective jurisdictions). It should also be noted that any cost estimates which are developed should include costs at the Agency, Association, Region, Province and Territory levels, as well as costs at the national level.

10. CONCLUSIONS

The development of a national data base on Continuing care will be complex and difficult. It will require a great deal of negotiation with Provincial and Territorial officials and with service provider Associations. The obstacles are significant. Can we establish a national system of care level classification for both residential and community/home based services? Can we rationalize data collection for the Chronic Care sector and bring it, at least statistically, into the Continuing Care fold? Can we do things nationally which have still not been achieved provincially in some jurisdictions (i.e., the provision of unique client level data to the provincial authority or the use of one standard data collection tool within a province)?

These are significant challenges, however, the call to action is equally strong. Is it acceptable to continue to have no national data on the Home Care and Home Support sectors? Concerns about the care of the elderly are currently high on the priority lists of most governments. Continuing Care is currently going through some degree of change in almost every jurisdiction. This change can present an opportunity to make significant progress quickly if one can take appropriate action now before changes are finalized.

Despite all of the difficulties which may be involved, the present time period presents a window of opportunity for action. If decisions can be made, and work can commence quickly, there is an opportunity to take advantage of the current state of flux in Continuing Care. If this opportunity is not seized, it may be much harder to make progress after changes have been finalized and a new period of consolidation (and inertia) takes hold.

NOTES AND REFERENCES

1. This is considered to be a relatively conservative estimate. An analysis was conducted of the expenditures for the 1989/90 fiscal year for Continuing Care services from the report: Federal/Provincial/Territorial Subcommittee on Continuing Care. *Description of Long-Term Care Services in Provinces and Territories of Canada*. Ottawa: Health and Welfare Canada, September 1991. While reporting is not complete, an addition of the dollar amounts noted, plus an estimate for chronic care beds in British Columbia, indicates an estimated expenditure of some $5.7 Billion for the 1989/90 fiscal year (excluding kidney dialysis and mental health services). Estimated average annual expenditure increases for population growth and inflation, over four years, i.e., to the 1993/94 fiscal year, of 6% per year result in estimated expenditures, in 1993/94 of $7.1 Billion. A 10% annual growth rate provides an estimate of $8.0 Billion.

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Appendix A

Project Overview

Overview of the Project to Review the Need for, and Feasibility of, a National Data Base on Continuing Care

Project Title: Review of the Need for, and Feasibility of, a National Data Base on Continuing Care

Project Leader: Marcus J. Hollander, Visiting Research Fellow, Statistics Canada, and: former Co-Chairperson of the Federal/Provincial/Territorial sub-Committee on Continuing Care; Acting Executive Director, Director of Programs, Director of Program and Management Analysis, and Special Consultant (at various times), Continuing Care Division, British Columbia Ministry of Health and Ministry Responsible for Seniors; and, Adjunct Professor, Gerontology Program, Simon Fraser University.

Purpose: To review the need for, and interest in, a national data base on both residential and community/home based Continuing Care services. To determine the feasibility of establishing such a system and to outline its possible nature and scope. To review the content and methodologies of existing systems and to prepare options, as appropriate, for a national data base.

Process: Conduct visits with provincial officials and service providers to determine their views; meeting with key representatives of provincial and national Associations and systems related bodies; conduct a literature review; conduct an international key respondent survey to determine what data is collected at the national level in other countries; and, obtain input from key academic experts.

Product: A report on the feasibility of developing a national data base on residential and community/home based Continuing Care services including a critical analysis of the existing Statistics Canada survey on Long Term Care facilities and a description of alternative minimum data sets which could be adopted in both the residential and community sectors.

Sponsors: This project is funded by Statistics Canada. It comes under the umbrella of the Community Health Information Systems Project of the National Health Information Council (NHIC), the Federal/Provincial body responsible for systems development in health care. The study has also been endorsed by HomeSupport Canada, the Canadian Home Care Association, and The Canadian Long Term Care Association.

Time Line: The projected will be completed on or before November 1, 1993.

Appendix B

Questions Used in Interviews
With Government Officials and
Service Provider Association Representatives

**Questions/Topics to be Covered in Visits with Provincial Officials
and Service Providers for the Project to Review the
Need for, and Feasibility of, a National Data Base on Continuing Care**

- What data is currently collected on client characteristics, presenting problem(s), referral patterns, staffing, finances, and other matters, and what data collection forms are used (obtain copies)?

- To what extent do provincial officials and service providers have knowledge of, and opinions about, the existing Statistics Canada survey of Long Term Residential Care facilities?

- How is the Continuing Care service delivery system organized in each jurisdiction?

- What method of determining levels of care is used, what nomenclature is used, and what problems are there for comparability with other provinces?

- What degree of interest is there in having nationally comparable data?

- What should the initial scope of the data base be, i.e., small and limited to key variables, large and comprehensive, or something else?

- What should be the primary and subsidiary foci of the survey, i.e., a clinical, administrative, financial, or staffing focus, or should there be an even balance between these areas.

- Should the data system monitor activity or should it be capable of evaluating service outcomes, i.e., how sophisticated and detailed should the data base be?

- Which categories of service should be included in the data base, i.e., Chronic Care Hospitals, Long Term Care Facilities, Home Nursing Care, Physiotherapy services, Homemaker services, Adult Day Care services, Group Homes, Meal Programs, and if resources are limited, in what priority order should they be incorporated into the data base?

- If a decision is made to participate in a national data base on Continuing Care, who should be involved in funding such a system and what type of feedback should be provided to those who provide the data?

- What provisions should there be to ensure the confidentiality of clients and service provider agencies and what restrictions to accessing the data base should apply?

- To what extent is it possible to collect data at a client specific level?

- To what extent is it possible to have unique identifiers for clients at the provincial and/or national level (these identifiers could be numerical and would not require actual identifying information such as names or addresses)?

- To what extent is the existing data on the various components of the Continuing Care system computerized?

- How easy is it at the provincial, regional and/or agency level(s) to abstract data and/or provide copies of existing data bases to a national collection body such as Statistics Canada?

- What preference is there for agencies to complete an annual survey administered by Statistics Canada (as is now done for Long Term Care Facilities) as opposed to having data provided through provincial Ministries?

- To what extent are provincial Ministries and service provider agencies prepared to make a commitment to the work required to develop, implement, and maintain, a national data base on Continuing Care?

- Identify and discuss any additional questions or topics raised by provincial officials and service providers or by representatives of provincial Associations.

**A Suggested List of Variables to be
Included in a Comprehensive, Client Based,
Minimum Data Set**

Suggested Variables for a Client Based Minimum Data Set

Socio-Demographic Variables

Date of Arrival in Canada

Date of Birth

Living Arrangements

Living Environment

Marital Status

Mother Tongue

Place of Birth

Receipt of OAS/GIS

Other Sources of Income

Sex

Client Process

Admitted From

Assessor/Case Manager

Client Identifier

Date of Admission

Date of Discharge

Discharged To

Provincial Care Level (Actual or Estimated, Including Dates of Changes)

Service(s) Consumed (RN, HSW, Meals, etc.)

Basic Provider Information

Name of Provider

Location of Provider

Size of Provider (Beds, Homemaker Hours, Nursing, Visits, etc).

Type of Ownership

Functional Status Indicators of Activities of Daily Living

Bathing

Bowel Continence/Ostomy Care

Dexterity

Dressing

Eating

Locomotion/Ambulation (Indoors, Outdoors, and Stairs)

Potential for Injury to Self or Others

Toileting

Transferring

Urinary Continence/Catheter Care

Social Support Indicators

Capacity of Primary Caregiver

Availability of Primary Caregiver

Availability of Other Informal Supporters

Self Care

Cooking

Financial Management

Housekeeping (Light and Heavy)

Medications

Shopping

Social Interaction

Telephone

Traveling (Walk, Drive, Ride Public Transit)

Yard Work

Communication

Hearing

Reading

Speech

Understanding

Vision

Writing

Medical Variables

Accidents in past 30 days

Allergies

Case Mix Grouping (Primary and Secondary)

Circulation

Medical Variables (Cont'd)

Chronic Conditions/Disabilities

Constipation

Diarrhea

Drinking (Alcohol)

Falls in Past 30 days

General Frailty

Height

Hydration

ICD-9, ICD-9CM (Primary and Secondary)

Medications Used (Prescription and Over the Counter)

Presence of Pain

Respiration

Skin Condition

Smoking

Weight

Treatments Required (e.g., Dressings)

Nutrition

Ability to Chew and Swallow

Diet Restrictions

Psycho-Social Variables

Aggression

Agitation

Anxiety

Cognitive Impairment

Delusion

Depression

Emotional Stability

Evidence of Organic Brain Syndrome

Expression

Judgement

Memory

Orientation

Paranoia

Psychiatric Diagnosis (if any)

Reality Orientation

Sexuality

Spirituality

Suicidal

Wandering

DATE DUE