

Canadian Institute for Health Information Pilot Project Report

Rehabilitation Data Standards for Canada

February 1999



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

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The CIHI project, *Development of Rehabilitation Data Standards for Canada*, has reached a successful conclusion after three and half years of dedicated and thorough work by numerous individuals and organizations.

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In closing, as the project manager, I wish to extend the Institute's sincere thanks to the National Rehabilitation Advisory Group, to all pilot sites and contributors to this project and to the CIHI staff. Their contributions have brought the Institute one step closer to developing a national reporting system for rehabilitation services in Canada.

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Table of Contents

Section 1—Executive Summary	1
Section 2—Introduction	3
Section 3—Goal/Objectives	5
Section 4—Project Management Structure	6
4.1 Project Team	6
4.2 National Rehabilitation Advisory Group	6
4.3 Clinical Focus Group	7
4.4 Expert Working Group	7
4.5 External Field Review Groups	7
4.6 National and Provincial Organizations	7
4.7 CIHI Rehabilitation Network	8
Section 5—Development of Rehabilitation Information Standards for Canada—Project Phases	8
Section 6—Phase 1: Development & Evaluation of National Minimum Data Set.....	9
6.1 Environmental Scan and Review of Existing Standards	9
6.2 Conceptual Model for Rehabilitation Information Standards	11
6.3 Rehabilitation Information Needs Analysis	13
6.4 Working Definition, Core Rehabilitation Services and Project Scope.....	14
6.5 Development of Minimum Data Set for Pilot Testing	19
6.6 Pre-test and Evaluation	21
Section 7—Phase 2: National Pilot Test	28
7.1 Purpose	28
7.2 Objectives	28
7.3 Methodology	28
7.4 Education and Site Preparation	30
7.5 Data Collection and Submission	31
7.6 Site Support and Communication	32
Section 8—Phase 3: Results of Statistical Analysis	33
8.1 Objectives	33
8.2 Types of Analyses	33
8.3 Results of Reliability Testing	34
8.4 Results of Validity Testing	37
8.5 Predictive Validity.....	41
8.6 Content/Face Validity Pilot Site Evaluations—Interim and Final	43
8.7 External Field Review	45
8.8 Evaluation of Intervention Reporting.....	47

Table of Contents (cont'd)

Section 9—Phase 4: Conclusions and Recommendations	50
9.1 Conclusions	50
9.2 Recommendations for National Rehabilitation Data Set and Grouping Methodology	52
Section 10—Summary	53
Appendix A—External Reviewers	A-1
Appendix B—Pre-test Site Participants.....	B-1
Appendix C—Pilot Sites & Participants	C-1
Appendix D—Recommended Data Elements	D-1
Appendix E—Sample Reports	E-1
References.....	F-1
Bibliography	G-1

Section 1 – Executive Summary

The Canadian Institute for Health Information (CIHI) has completed a landmark study in the field of rehabilitation services. In 1995, CIHI initiated a major project to develop and evaluate a minimum data set and grouping methodology for rehabilitation services across service settings in Canada. By September 1998, CIHI had collected and analyzed a large sample of rehabilitation clinical data from multiple sites across Canada and had consulted with over 350 experts and key stakeholders in the rehabilitation field. This report provides an overview of the project, results of statistical analysis and recommendations for a national reporting system for rehabilitation services in Canada.

The purpose of this study was to develop a minimum data set that was client-centred and applicable across service settings (inpatient to home care). A second purpose was to develop/adopt a grouping methodology or 'case mix tool' that would:

- identify clinically homogenous client groups in rehabilitation;
- predict resource utilization;
- predict client outcome; and
- serve as a basis for rehabilitation indicators and a national reporting system.

CIHI established a national forum for consultation and direction for this project. The National Rehabilitation Advisory Group (NRAG) was established to lead this process with CIHI. A number of other expert groups, rehabilitation networks and organizations were included at different stages of the project. The NRAG was a representative group of rehabilitation stakeholders, provided regional representation from across Canada and included individuals who were participating in related provincial initiatives.

A successful pre-test was completed in the Toronto region in 1997 and was followed by an extensive pilot test in 31 inpatient facility and home care sites in 6 provinces. The pilot data set included the Functional Independence Measure (FIM) and a number of CIHI data elements developed to enhance the cognitive domain of FIM. Admission and discharge data, workload and intervention data were collected and submitted for over 2000 rehabilitation clients. In addition, a comprehensive External Field Review was conducted to solicit feedback from a variety of groups including clinicians, researchers, consumers, funders and administrators.

The pilot data was analyzed using the most robust statistical analyses available. The primary objectives of the analyses were:

- to test the reliability, validity and utility of the data set; and
- to evaluate an existing grouping methodology, the FIM-FRG (Function Related Group) using Canadian data.

Specifically, the analysis was designed to answer the following questions:

- Should FIM be part of a national data set for rehabilitation?
- Do CIHI data elements enhance this data set?
- What enhancements/revisions to the data set are recommended?
- Based on rehabilitation pilot results, should the FIM/FRG be recommended as a grouping methodology for facility inpatient rehabilitation clients?

The results of the statistical analysis, the pilot site evaluations and external field review provided solid evidence that the data set had very strong reliability and validity. The data set was shown to be internally consistent, with high structural integrity. The high reliability estimates showed that differences in client scores were due solely to differences in client function. The composite measure of FIM + CIHI data elements demonstrated that the measurement of the cognitive domain was significantly enhanced. The data set was sensitive to change in client functional status in the majority of rehabilitation client groups.

Analysis of the grouping methodology, FIM-FRG using Canadian data provided evidence that Canadian client groups are predictive of resource utilization and compare favourably with US results and with the predictive ability of CMG™ used for acute care in Canada.

Based on these results, the National Rehabilitation Advisory Group recommended that this data set be used to develop a national reporting system for inpatient rehabilitation services. The results of the home care data analysis were positive and could contribute to future initiatives in national database development for home care services. In addition, the NRAG recommended that the associated grouping methodology, the FIM-FRG, be adopted for use in Canada as a starting point for an inpatient rehabilitation classification system.

This project has achieved a milestone in the development of rehabilitation data standards for Canada. It is the first time that a Canadian organization has coordinated the collection and tracking of this type of data across Canada. The data set will provide comparative indicators and client outcome information that can be used by clinicians, program planners, accreditation surveyors, regulatory and licensing bodies, funders and health policy makers.

Section 2—Introduction

Canadian health reform in the 1990's has been characterized by universal and dramatic change. Fundamental changes to the funding, governance and delivery of health services are a response to escalating provincial and national debt. Restructuring and reform of the health system has aimed at cutting costs while achieving more effective high quality health services.

Common themes of reform in Canada have been identified although provinces and territories have employed a variety of strategies to achieve their goals:

- a move toward *client-centred* services-putting the client first;
- a commitment to *healthy public policy*, and a desire to improve the health status of individuals and communities;
- increased emphasis on *evidence-based decision making* and development of a more *cost-effective* and *accountable* health system;
- a shift from institutional care and focus on illness, to *community-based* services and focus on wellness;
- the development of *integrated* provider organizations and greater *collaboration* between health providers to achieve a seamless continuum of services, and reduce duplication and overlap;
- greater *community participation* in priority setting and decision-making; and
- an emphasis on health promotion and promoting *individual responsibility* for health.

A critical underpinning of these themes is good information. Timely, accurate and relevant information across the continuum of health services has been targeted as a priority by a number of health forums in recent years (National Health Forum 1996, Health Information Needs in Canada, CIHI 1998).

To meet the growing demand for better information products, the Canadian Institute for Health Information (CIHI) launched the project, *Development of Management Information Standards Across Health Services* in June 1995. Included in this initiative was the development of national information standards for rehabilitation services in both facility-based and community-based settings.

Rehabilitation services in Canada are noted for their complexity, variety of payers (public, private, WCB, auto insurers), diversity of service provider groups, recent expansion of private practice, the emergence of managed care models and a significant increase in the delivery and need for facility-based outpatient programs and home care services. A number of driving factors have resulted in an exploding need for standardized information products:

- Ageing population and growing number of Canadians living with activity limitations and restrictions in participating in their social, cultural and economic lives;
- demands for indicators of quality services through legislation/regulation of standards;
- linkages between rehabilitation effectiveness/outcomes and reimbursement models;
- national accreditation standards requirements;
- shifting rehabilitation services from acute based services to community requiring integrated standards; and
- focus on evidence based practice, clinical outcomes, benchmarking and accountability requires comparable and timely information.

The rehabilitation sector has probably been one of the leaders in recent years for developing outcomes-based indicators in the non-acute care area. Notably, the Canadian Physiotherapy Association published a compendium on physical rehabilitation outcome measures in 1994 and has developed a unique accreditation process which is based on a new national data set standard. Another significant initiative was led by a consortium of national service provider associations, the 'G4', made up of the Canadian Association of Occupational Therapists, Canadian Nurses Association, Canadian Association of Dietitians and Canadian Physiotherapy Association. This group produced a report on generic and unique information needs that paralleled the CIHI development.

Another significant initiative was supported by the Greater Vancouver Regional Health District Rehabilitation Planning Subcommittee. The Outcomes/Data Elements Working Group completed a comprehensive review of outcome measures suitable for physical, cognitive and social domains. A critical component of their work focussed on the preferences and recommendations of consumer groups for outcome information.

Finally, a number of provinces were, and continue to be, very active in the development of provincial rehabilitation information standards. These initiatives in British Columbia, Alberta, Saskatchewan, Ontario and Quebec have been important contributors to the CIHI project plan, goals and objectives.

In summary, standardized information will support rehabilitation service providers, managers, program planners and health policy experts to plan, deliver and evaluate services more effectively. Standards will allow for the comparison of information both within an organization over time, and across a number of organizations. More importantly, standards are essential for linking data and data sets. The ability to link data and databases is critical to our ability to effectively analyze data. Management information standards across health services will facilitate provincial/territorial efforts to integrate planning, management and evaluation of health services within defined regions, and across the continuum of care.

The purpose of this report is to outline the objectives, planning, implementation and results of a national pilot project to develop and test a minimum data set and grouping methodology for adult rehabilitation services in inpatient facility settings and home-based service settings.

Section 3— Goal/Objectives

The goal of this project was to develop client-centred management information standards for adult rehabilitation services across service settings.

Specific objectives of the project were to:

- conduct an environmental scan (national and international) to identify existing standards and related initiatives for rehabilitation information standards;
- conduct an information needs analysis for adult rehabilitation services across service settings;
- develop a conceptual model and information standards that will meet management information needs across health services and those specific to adult rehabilitation services;
- develop, define and draft a minimum data set for national pilot testing;
- pre-test and pilot test the data set across service settings using client-specific data collection and external field review protocols;
- analyze data set for validity, reliability and utility;
- develop, evaluate and recommend a national grouping methodology for adult inpatient rehabilitation services;
- recommend appropriate rehabilitation indicators and presentation formats for users; and
- disseminate project results and recommend a national minimum data set for adult rehabilitation services across health services.

Section 4—Project Management Structure

The CIHI development of rehabilitation information standards was supported by CIHI working groups and external field consultation. This project was managed by a CIHI Consultant. Due to the wide range of rehabilitation services, provider types and client groups it was important to incorporate the multi-disciplinary nature and consumer perspectives in the development process. For technical and research input, an Expert Working Group was established and for data set development, a number of external field reviewers were recruited at different times during the project.

The project was carried out by a CIHI project team with guidance from the National Rehabilitation Advisory Group (NARG).

4.1 Project Team

The project team was comprised of a project manager, project consultants and other CIHI staff with experience or expertise in rehabilitation, management, costing/grouping methodologies, information systems and development of standards. In addition, external methodologists were consulted for project design, data analysis and report generation.

4.2 National Rehabilitation Advisory Group

The National Rehabilitation Advisory Group was established to assist CIHI in achieving the project objectives. The composition of the group brought regional representation across Canada, a cross-section of rehabilitation stakeholders across health services (administrators, managers, clinicians, consumers and researchers) and representatives of related provincial initiatives in BC, AB, ON and PQ.

The NARG was responsible to propose and make recommendations for the following project deliverables:

- rehabilitation information needs across health services;
- scope and working definition of rehabilitation for pilot project;
- conceptual approach to define rehabilitation information standards;
- draft data set for pre-test and pilot test;
- review of project results and recommendations for national data set and grouping methodology; and
- facilitate communication, promotion for pilot project participation, dissemination of results in respective regions.

4.3 Clinical Focus Group

A clinical focus group was established specifically to solicit input on content validity and feasibility from representative service providers and site types prior to finalizing the pre-test data set. A group of selected experts from facility-based and home care programs in the Ottawa region were invited to review the data set and to provide recommendations for refinements and enhancements to the data set.

4.4 Expert Working Group

An Expert Working Group was established to provide CIHI with expert advice and assistance in the development, scaling and scoring of national clinical data sets for rehabilitation services and continuing care. This group was recruited to:

- work with the CIHI project team to standardize the content and scaling of the national clinical data sets;
- plan the process for a clinical field review for validation and testing of these data sets; and
- provide input on the feasibility, comprehensiveness, utility and applicability of the national clinical data sets across the continuum of care.

4.5 External Field Review Groups

Clinicians—Rehabilitation Interventions Draft Document, 1996

Administrators & Health Policy—Pilot Data Set, 1998

Clinicians—Pilot Data Set, 1998

Researchers—Pilot Data Set, 1998

Consumer Networks—Pilot Data Set, 1998

4.6 National and Provincial Organizations

CIHI established regular liaison with a number of organizations across Canada that represented rehabilitation stakeholders including but not limited to national professional associations, provincial working groups and ministries of health. These organizations were instrumental in recommending advisory and working group members, disseminating project information and coordinating external field reviews.

Appendix 1 includes a listing of individuals and organizations who participated in the Clinical Focus Group, Expert Working Group and External Field Reviews.

4.7 CIHI Rehabilitation Network

CIHI has developed and benefited from an increasingly active and interested rehabilitation community since the early 1990s. A number of linkages and associations have been developed with national professional organizations, NGOs and disability networks. In addition, a number of provincial initiatives have included CIHI representation and consultation on related topics. As a result of these activities and the growing interest, related initiatives and core competence in rehabilitation at CIHI, a diverse and active network developed and provided invaluable support and input to this pilot project.

Section 5—Development of Rehabilitation Information Standards for Canada—Project Phases

The goals and objectives of this project were met through a step-by-step approach over a period of three years, 1995–1998. The following figure outlines the major objectives and timelines for each project component:

	Goal	Objectives	Timeline
Phase 1	Development & evaluation of national minimum data set	<ul style="list-style-type: none"> ▪ Environmental scan & review of existing standards ▪ Conceptual models ▪ Purpose, vision & guiding principles ▪ Information needs analysis ▪ Scope & working definition ▪ Draft data set ▪ Pre-test 	1995–1997
Phase 2	National Pilot Test	<ul style="list-style-type: none"> ▪ Pilot test & data collection 	1997–1998
Phase 3	Analysis & Evaluation	<ul style="list-style-type: none"> ▪ Data set analysis ▪ Analysis of grouping methodology 	1998
Phase 4	Conclusions & Recommendations	<ul style="list-style-type: none"> ▪ Revision of data set ▪ Recommend national data set & grouping methodology ▪ Indicators & reports ▪ Promotion & dissemination of results 	1998

Section 6—Phase 1: Development & Evaluation of National Minimum Data Set

6.1 Environmental Scan and Review of Existing Standards

This CIHI project was initiated in September 1995 with the publication of *Rehabilitation: Existing Standards and Related Initiatives for Management Information*. This background document was prepared for the NARG to provide an initial orientation to the status of management information standards for rehabilitation services and the unique issues affecting rehabilitation services in the context of the evolving Canadian health system. Included in this environmental scan is a review of national and international research and development initiatives.

One of the major findings of this review was that the rehabilitation field in Canada has few systems available and in use. The most widely used clinical data set for inpatient rehabilitation in the United States and Canada is the Functional Independence Measure (FIM), a 'burden of care' measure. It was developed at the State University of New York by Uniform Data System (UDS^{MR}) for Medical Rehabilitation. FIM is a functional status measure that has been used widely in the United States and in a number of other countries. At the time of this project review, between 15–20 sites in Canada collected and submitted FIM data to UDS^{MR}. In addition to inpatient rehabilitation services, UDS^{MR} has developed systems for ambulatory and home care service settings.

Finally, a rehabilitation grouping methodology, Function Related Groups (FRG) was developed by the University of Pennsylvania and is exclusively distributed by UDS^{MR}. This system (FIM–FRG) is based on the client's FIM score, rehabilitation impairment group and age. This prototype version has been studied extensively by the RAND corporation to evaluate FIM–FRG as a prospective payment system in the US for inpatient medical rehabilitation (Carter GM et al, RAND 1997).

6.1.1 Emerging Issues for Rehabilitation Services

This review of the current standards and development initiatives for management information for rehabilitation services has highlighted a number of key issues for consideration in developing Canadian standards. They are:

1. Rehabilitation core services are identified in many jurisdictions as being provided in a wide variety of acute care and specialized facilities, ambulatory care settings, the home, schools and long term care facilities.
2. Payors for rehabilitation services include public funding, Workers' Compensation Boards, Automobile Insurance Industry, other third party payors and fee for service by clients/patients. Some regional health districts will contract with private service providers to provide services that were traditionally delivered by funded institutions/agencies. All of these stakeholders are seeking adequate information systems to track activity, utilization, efficiency and cost-effectiveness indicators.

3. Provider groups vary greatly between jurisdictions and many include a growing component of human resources including professional support personnel (e.g. PT/OT/RN assistants) and informal caregivers (e.g. volunteers, family/friends network).
4. The rehabilitation industry and stakeholders have consistently expressed the need for a grouping methodology that reflects functional status and the impact of impairments.
5. With the exception of those facilities that submit FIM data to Uniform Data System in the US, data collection for rehabilitation services has been limited to the individual facility and to facilities reporting designated rehabilitation service cases to CIHI. Data collection methods that are compatible between inpatient and all outpatient services will need to address the issue of linking data through visits or episodes of care.
6. Rehabilitation services are also provided to clients who may be captured by a continuing care classification. The services and providers may be identical or very similar in both instances. It will be necessary to ensure that there are comparable principles and methods of identifying minimum data sets, indicators and outcomes in these client service groups.
7. A number of Canadian initiatives including CIHI are developing intervention classifications or categories for rehabilitation. *The CIHI National Ambulatory Care Reporting System (NACRS)* and *the Canadian Classification of Health Interventions (CCI)* are two initiatives that include rehabilitation interventions. Development of rehabilitation interventions for the national data set project would be timely and converge with work in these other areas. Alberta and British Columbia have also begun work in the area of identifying common rehabilitation interventions.
8. A significant number of initiatives in paediatric and adult rehabilitation programs are underway in Canada at this time that address information systems incorporating outcomes evaluation. These initiatives are a major step towards meeting the important objectives of a health information framework i.e. outcomes and cost/effectiveness.

6.1.2 Conclusions

This overview of the status of existing and emerging information in rehabilitation served as a starting point and foundation for the CIHI project. In general, the status of current standards for rehabilitation management information in 1995 was weak and lacking in the area of minimum data sets, indicators and grouping methodologies. However, there was significant progress being made by a number of jurisdictions in defining some of these components for various rehabilitation settings and populations. These include:

- several initiatives building on the experience and strengths of the UDS^{MR} by expanding the database to suit Canadian needs;
- performance indicators for service delivery, outcome/effectiveness and access have been addressed by several groups;
- recognition that the inpatient setting is limiting and that any development must be flexible and should incorporate the growing ambulatory, community and home care components of these services; and
- some initiatives address varied client groups and needs including paediatrics, injured workers and long term care.

These initiatives have similar and complementary objectives as compared to this CIHI project. This presented opportunities to build upon and to co-ordinate efforts of this project with those of other key stakeholders.

6.2 Conceptual Model for Rehabilitation Information Standards

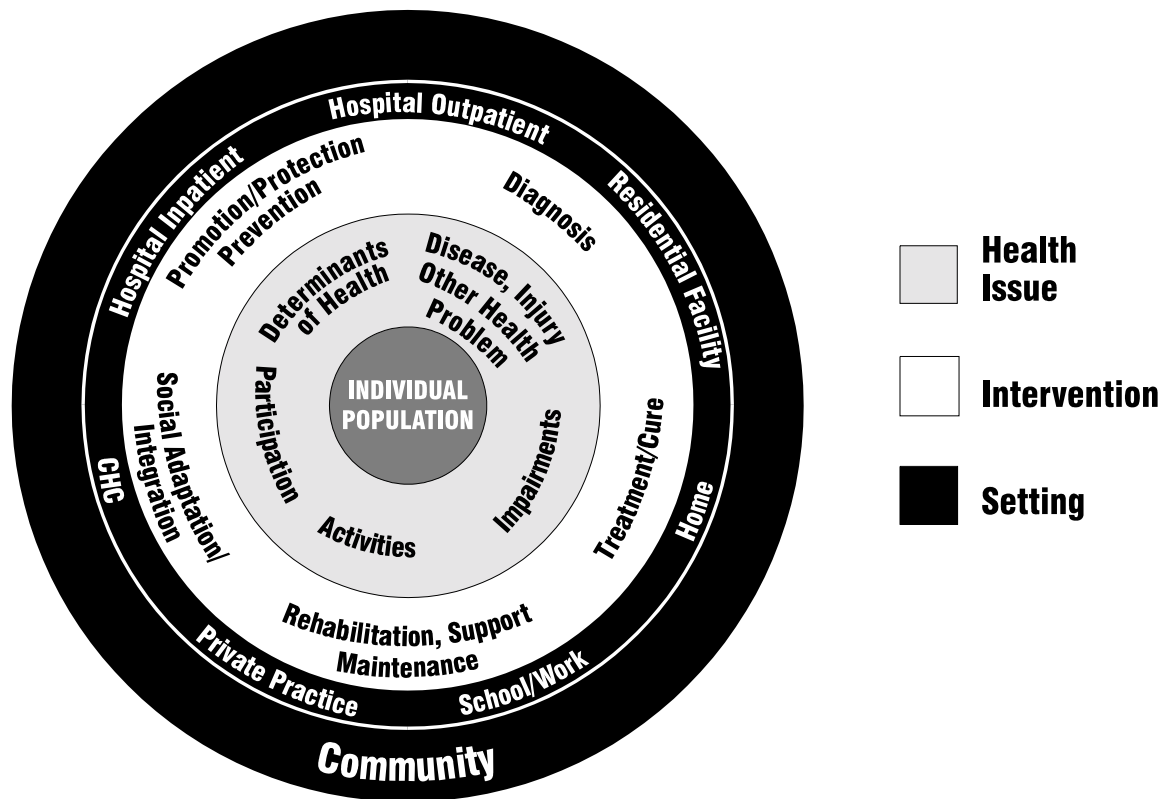
In keeping with the vision of client-focused information across a seamless continuum of services, a conceptual model should include the concepts of data linkage that spans the 'episode of care' and crosses service settings. This is particularly well suited to the current rehabilitation model which includes prevention, health promotion, preadmission activities, acute care, sub-acute care, rehabilitation and community re-integration. For example, an elderly client requiring elective surgery for a hip replacement would have an episode of care that may begin with a pre-hospitalized screening process for rehabilitation needs and goals, an inpatient acute care stay, a finite period of rehabilitation in a sub-acute setting and a home visit schedule to ensure adaptation to the home environment.

This example also fits well with the conceptual model proposed by the National Rehabilitation Advisory Group. The NRAG recommended that the rehabilitation data set be developed based on the conceptual framework of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), developed by the World Health Organization (WHO) in 1980. The advantage of incorporating this conceptual framework for rehabilitation is that it has a focus on the *consequences of disease or injury* which has been proven to be more predictive of resource utilization and client outcome than the disease entity or pathology.

The WHO ICIDH was developed to contribute to the evaluation of the effectiveness of health services particularly for long term and chronic disorders. As a member of the WHO 'family' of health related classifications, the ICIDH describes the consequences of health conditions. Since its publication in 1980, it has been utilized around the world in a variety of areas including rehabilitation assessment, disability policy planning and survey research. CIHI is the Canadian Field Trial Centre for testing ICIDH-2, the second version. This new version, *ICIDH-2*, will provide an improved framework for the description and evaluation of a person's impairments, activity limitations and resulting participation in life situations. In addition to new terminology ('activities' replaces 'disabilities' and 'participation' replaces 'handicap'), an important difference is the inclusion of categories of environmental factors which is considered an important influence affecting a person's community integration and social participation. Additional information on the WHO revision process and current drafts of ICIDH-2 are found on the WHO website: www.who.ch/icidh.

CIHI has developed a conceptual representation of information needs for health and health service, (specifically health issues, service settings and interventions) with ICIDH as a basis of the model. The conceptual model is depicted as follows:

Figure 1. Health and Health Services



6.3 Rehabilitation Information Needs Analysis

The information needs analysis was completed with input from the following groups and perspectives:

- National Rehabilitation Advisory Group (administrative, program planning, clinical, consumer, health policy, research);
- conceptual models (ICIDH, Health & Health Services);
- input on common/core data elements from the CIHI Expert Working Group (research, clinical) and CIHI Continuing Care Advisory Group (chronic and long term care);
- CIHI Standards, including existing standards, and preferred data based on future initiatives; and
- requirements of research design, e.g. actual time workload.

Information needs are identified under general and client-specific categories:

6.3.1 *General*

Demographic data
Administrative data
Client-specific data
Health provider data
Informal support data
Workload (formal & informal) data
Interventions
Length of stay/duration of service data (admission & discharge dates)

6.3.2 *Client-specific Data*

Identifier
Diagnostic (ICD)
Complications/comorbidities (ICD)
Impairment Group (ICIDH)
Health issues/goals (provider perspective/client perspective)
Activities (Disabilities—ICIDH)

- self-care/activities of daily living
- mobility
- ambulation
- communication
- cognitive
- behavioural
- sensory

Participation (Handicap—ICIDH 1980)

- advanced ADL (IADL)
- problem-solving
- social interaction
- community integration
- vocational/leisure/spirituality
- community mobility
- sexuality

Nutrition

Pain

6.3.3 Indicators

Prognostic indicators

Severity of disability

Functional status & gains

Quality of Life

Community Re-integration

6.4 Working Definition, Core Rehabilitation Services and Project Scope

The environmental scan and review of existing standards provided a starting point for development of a working definition of rehabilitation. Key sources for this included:

- WHO definition and services; and
- ICIDH definitions and terms.

6.4.1 WHO Definition & Terms

The definitions used by various jurisdictions for rehabilitation are commonly based on the World Health Organization (WHO) definition (1983):

" Rehabilitation means a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment. "

The WHO lists services commonly included in rehabilitation:

- early detection, diagnosis and intervention;
- medical care and treatment;
- social, psychological and other types of counselling and assistance;

- training in self-care activities, including mobility, communication and daily living skills, with special provisions as needed, e.g. for the hearing impaired, the visually impaired and the mentally retarded;
- provision of technical and mobility aids and other devices;
- specialized education services;
- vocational rehabilitation services (including vocational guidance), vocational training, placement in open or sheltered employment; and
- follow-up.

(United Nations 1983)

6.4.2 ICDH Definitions and Terms

Rehabilitation terminology frequently includes reference to impairments, disabilities and handicaps, dimensions of the WHO *International Classification of Impairment, Disabilities and Handicaps (ICIDH)*, 1980. The second version, *ICIDH-2 1997* revises some of the terms and includes a new category, *Environmental Factors*. These are defined as follows:

ICIDH 1980	ICIDH-2 1997
<p>Impairments</p> <ul style="list-style-type: none"> ▪ is any loss or abnormality of psychological, physiological or anatomical structure or function. 	<p>Impairments</p> <ul style="list-style-type: none"> ▪ is a loss or abnormality of body structure or of a physiological or psychological function.
<p>Disability</p> <ul style="list-style-type: none"> ▪ is any restriction or lack of ability to perform an activity in a manner, or within the range, which is considered normal. Disability represents a departure from the norm in terms of performance of the individual, as opposed to that of an organ or mechanism. 	<p>Activity/Activity Limitation</p> <ul style="list-style-type: none"> ▪ is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
<p>Handicap</p> <ul style="list-style-type: none"> ▪ a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal for that individual (depending on age, sex, social and cultural factors). 	<p>Participation/Participation Restriction</p> <ul style="list-style-type: none"> ▪ is the nature and extent of a person's involvement in life situations in relationship to impairments, activities, health conditions and contextual factors. Participation may be restricted in nature, duration and quality.
	<p>Environmental Factors</p> <ul style="list-style-type: none"> ▪ include the features, aspects and attributes of objects, structures, human-made organizations, service provision and agencies in, the physical, social and attitudinal environment in which people live and conduct their lives.

6.4.3 Rehabilitation and Provincial Core Health Services

A number of Canadian jurisdictions have identified core health services, as part of their health reform process. A number of similarities with respect to rehabilitation services are noted across jurisdictions. These include:

- provision of services in acute care settings (primary, secondary, tertiary);
- provision of services in community and/or home-based settings;
- inclusion of services for Workers' Compensation Centres;
- provision of services for a range of ages including the seniors/geriatric programs and child/paediatric programs;
- identification of services for mental health and addiction clients;
- inclusion of services for long term care clients, home-based and facility-based; and
- provision of services in privately funded clinics (funded by auto-insurance, private health insurance plans, and privately by clients).

6.4.4 Working Definition for CIHI Project

The National Rehabilitation Advisory Group reviewed all definitions and provided input from their respective jurisdictions. They recommended the following working definition for this project:

Rehabilitation is a goal oriented and often time-limited process which enables an individual with impairments and disabilities to identify and reach his/her optimal mental, physical and/or social functional level. Rehabilitation provides opportunities to the individual through a client-focused partnership with family, providers and the community, to accommodate a limitation or lack of function. Rehabilitation focuses on abilities and aims to facilitate social integration and independence.

Rehabilitation services include, but are not limited to services that:

- prevent, identify/diagnose and manage complications of disability;
- are provided in an inter-disciplinary or single-discipline model;
- enable the individual to identify and adapt to altered life circumstances;
- span the continuum of health promotion, prevention of disease or dysfunction and correction or minimization of impairments and disabilities; and
- include habilitation.

(National Rehabilitation Advisory Group, December 1995)

6.4.5 Project Scope

The rehabilitation data set development is targeted for adult clients (18 years and over) in the following service settings:

- specialty facilities—inpatient services in free-standing rehabilitation hospitals or specialized facilities designated for rehabilitation;
- general facilities—inpatient services in general hospitals with rehabilitation units, programs or designated rehabilitation beds; and
- home care—variety of agency types providing rehabilitation services in the home including contracted services, provincial or regional agencies.

Rehabilitation clients receive multi-dimensional (physical, cognitive, psychosocial) diagnostic, assessment, treatment and service planning interventions. These services are commonly inter- or multi-disciplinary in facility-based inpatient settings and may be single or inter- or multi-disciplinary in home care settings.

Inclusion Criteria

The pilot project included adult rehabilitation clients that have a time-limited episode of service, individualized and documented rehabilitation plans, predicted discharge date and expected improvements in functional status.

Rehabilitation client groups include those with impairments, activity limitations and/or participation restrictions associated with the following types of conditions:

- Musculoskeletal e.g.:
 - Arthritis & connective tissue disorders
 - Joint replacement
 - Pain syndromes
 - Amputation
 - Joint & soft tissue disorders
- Neurological e.g.:
 - Stroke
 - Non-traumatic spinal cord dysfunction
 - Post neuro-surgery
 - Other neurological conditions such as MS, ALS etc
- Cardio-respiratory e.g.:
 - Myocardial infarction
 - Post cardiac or thoracic surgery
 - Chronic obstructive pulmonary disease
 - Cardiac or pulmonary transplantation
 - Debilitating conditions

- Injury/trauma e.g.:
 - Fractures
 - Joint and soft tissue injury
 - Multiple trauma
 - Burns
 - Brain injury
 - Spinal cord injury

In addition, clients receiving geriatric rehabilitation services that meet the project criteria are included.

Exclusions

- Clients receiving screening and/or assessments for rehabilitation services that do not include follow-up services are excluded.
- Episodic rehabilitation services provided to clients receiving continuing care/long term care services are not included.
- Clients with a primary health condition and/or requirements for active mental health rehabilitation services are not included in the scope of this data set.
- Paediatric rehabilitation is not included due to the unique needs of this population. However, ongoing monitoring and communication with experts in the field will be maintained to insure information links for clients in transition from paediatric to adult services.
- Client groups with primary diagnoses and/or requirements for mental health active treatment and rehabilitation services will not be included at this time in the scope of rehabilitation services.

6.5 Development of Minimum Data Set for Pilot Testing

The overall process used to select and define the individual data elements was a standard business approach for defining information requirements. This includes defining the important functions in rehabilitation at a broad level, such as program planning and evaluation, and the related indicators, such as length of stay, number of visits, improvement in functional status.

The data elements are those building blocks needed to derive the indicators and answer the key questions of the rehabilitation planner or service provider. The elements fit into various categories considered important to the data set, such as:

- Identifier
- Administrative
- Socio-demographic
- Health characteristics
- Activities and participation
- Interventions

A number of the required data elements are found in existing acute care data bases used in Canada, e.g. *date of birth*. Of particular interest to service providers and researchers are the clinical data elements describing the client's level of function (Activities category) in the motor and cognitive domains. These elements are referred to as 'attributes'. For example, a cognitive attribute would be 'Memory' and a scale is used to describe the client's level of function. Other elements are important to describe a level of symptomatology such as pain, which may be characteristic of a health condition that requires specific rehabilitation intervention.

The approach CIHI used to develop and evaluate the rehabilitation minimum data set, is outlined in the following seven (7) steps:

	Activity	Content	Source(s)
Step 1	Compare relevant national & international clinical data sets & measures	<ul style="list-style-type: none"> ▪ FIM ▪ FAM ▪ COVS ▪ RIC-FAS ▪ RNLI ▪ COPM ▪ SF36 ▪ Berg Balance ▪ Timed 'Up & Go' ▪ Barthel ▪ Katz ADL ▪ Kenny Self Care ▪ VAS ▪ LORS ▪ PECS ▪ AAPI ▪ MDS ▪ MDS-HC ▪ MMS ▪ SCMI ▪ SIRUS ▪ Sperry-Lear ▪ NPHS 	<ul style="list-style-type: none"> ▪ CIHI databases ▪ CIHI Environmental Scan (rehab & cont care) ▪ National Rehabilitation Advisory Group & Cont Care Advisory Group ▪ Expert Working Group ▪ CIHI Rehabilitation Network
Step 2	Identify core clinical data elements across target services	<ul style="list-style-type: none"> ▪ Self care/activities of daily living (ADL) ▪ Mobility ▪ Locomotion ▪ Advanced ADL ▪ Cognition ▪ Behaviour ▪ Communication ▪ Pain/Sensory ▪ Participation/Community Integration 	<ul style="list-style-type: none"> ▪ Rehab & cont care information needs analysis ▪ NRAG & CCAG ▪ Expert Working Group
Step 3	Summarize key issues in review of data sets	<ul style="list-style-type: none"> ▪ Definitions ▪ Variables ▪ Scales ▪ Scoring 	<ul style="list-style-type: none"> ▪ Expert Working Group ▪ External methodologist
Step 4	Standardize the content and scaling of data elements	<ul style="list-style-type: none"> ▪ Type of scale ▪ Size of scale ▪ Measurement variables ▪ Scoring ▪ Definitions 	<ul style="list-style-type: none"> ▪ Expert Working Group ▪ External methodologist

	Activity	Content	Source(s)
Step 5	Identify & develop unique data elements for rehabilitation	<ul style="list-style-type: none"> ▪ Vocational status (admission & discharge) ▪ Service interruptions ▪ Main health condition/ rehab groups ▪ Date of onset ▪ ASIA Impairment Scale ▪ Impairments (ICIDH) ▪ Rehab Interventions ▪ Rehab service provider groups 	<ul style="list-style-type: none"> ▪ NRAG ▪ CIHI Rehab Network ▪ Expert Working Group ▪ Clinical Focus Group ▪ Rehab Environmental Scan
Step 6	Identify alternative directions for rehabilitation data set	<ul style="list-style-type: none"> ▪ CIHI data set ▪ CIHI data set & test FIM ▪ Hybrid data set- CIHI & FIM 	<ul style="list-style-type: none"> ▪ NRAG
Step 7	Draft data set and pre-test	<ul style="list-style-type: none"> ▪ Hybrid data set- CIHI & FIM ▪ Pre-test in 4 service settings 	<ul style="list-style-type: none"> ▪ NRAG ▪ Clinical Focus Group ▪ Pre-test sites

Steps 1, 2, 3 and 4 in this process were conducted in collaboration with the CIHI Project Team for *Development of a Continuing Care Data Set*. The guiding principles for development were the same for these two projects and the CIHI project teams were directed by both National Advisory Groups (NRAG & CCAG) and the Expert Working Group to identify data elements that were similar and core across the target groups of rehabilitation and continuing care.

6.6 Pre-test and Evaluation

The final activity of *Phase 1—Development & Evaluation of National Minimum Data Set*, was a pre-test and evaluation of the proposed data set.

Purpose

The purpose of this activity was to finalize a minimum data set, a user guide, educational materials and processes for data collection in the pilot test phase of the project.

Objectives

The objectives of the pre-test and evaluation were to:

1. Test the feasibility of the data collection process.
2. Estimate the data reliability (inter-rater).

3. Test the content/face validity of the data set.
4. Test the feasibility of workload data collection.
5. Evaluate the orientation and education materials and process.

Methodology

This section reviews the various components of the pre-test and evaluation activities which include:

- research design and sample;
- clinical focus group;
- pre-test orientation, education and site support;
- pre-test debriefing; and
- data analysis.

6.6.1 Research Design & Sample

The pre-test sample was determined by selecting the same strata that would be included in the national pilot test. Therefore, the following two service settings were included:

- facility-based inpatient rehabilitation
 - specialty facilities, free-standing rehabilitation centres; and
 - general hospitals with designated rehabilitation units or beds.
- home care rehabilitation services
 - urban focus; and
 - rural focus.

The selected sites constituted a convenient sample in the Toronto metropolitan and south-central region in the Toronto area. Sites were selected if they had a variety of clients with musculo-skeletal, trauma/injury, neurological, cardio-respiratory health conditions. The additional criteria for inclusion were:

- primary goal/expectation of service is improvement in client function;
- there is an individualized and documented rehabilitation plan for each client; and
- rehabilitation episode is time-limited, with a predicted/estimated discharge date.

The sample was calculated to provide accurate estimates of inter-rater reliability within 10% confidence limits, 19 times out of 20 (95% confidence interval). A total of 120 clients across 4 sites types (30 clients per type) were required. This provided for a 10% attrition rate. The following table illustrates the distribution of the sample across sites:

Facility—Inpatient Rehabilitation	Home Care Rehabilitation	Sample Size
SITE 1 Specialty Facility St. John’s Rehabilitation Hospital 30 Clients	SITE 2 Home Care-Urban Metropolitan Home Care 30 Clients	60
SITE 3 General Facility Scarborough General Hospital 30 Clients	SITE 4 Home Care-Rural The Arthritis Society 15 Clients Waterloo Region–CCAC 15 Clients	60
60 Clients	60 Clients	120

6.6.2 Clinical Focus Group

The purpose of this focus group was to solicit input on content validity and feasibility from representative service providers and site types prior to finalizing the pre-test data set. A group of selected experts from facility-based and home care services in the Ottawa region were invited to review the data set and to attend a 3 hour session with CIHI project consultants at the Ottawa office.

A number of refinements and enhancements were made to the data element definitions and proposed data collection processes.

6.6.3 Pre-test Data Collection

Each site had at least one pair of rehabilitation clinicians that assessed and recorded data for each client in the sample. One clinician conducted the assessment/interview and the other clinician observed. Each clinician recorded data on separate assessment forms and were requested to keep their ratings independent. The purpose of this dual observation method was to measure inter-rater reliability for a subset of the data elements, including the FIM and CIHI elements. This ensured that client status did not change and the burden of assessment on the client was minimized. Data collection was paper based.

The feasibility of workload data collection was also tested. The data collected included the service provider type and self-reported actual time in minutes spent by the service provider in delivering client interventions. Both direct and indirect client related interventions were included for one 24 hour period. Service provider travel time for home care was also documented.

For home care sites only, sites collected informal service workload in minutes. Family members/others were asked to estimate the amount of time they assisted the client over a 24 hour period.

Appendix 2 provides a list of the Pre-test site participants.

6.6.4 Pre-test Debriefing

Following the data collection period (March 30—April 29, 1997), site representatives attended a Pre-test Debriefing session on April 30, 1997. The objectives of the session were to provide an update on the pilot project, to gather input from sites regarding content validity, feasibility of data collection and CIHI support. Issues arising from the Pre-test were also reviewed. Finally, all site participants completed two standardized case studies in order to determine test rater reliability.

6.6.5 Pre-test Data Analysis

A profile of the data collected across 5 sites and submitted to CIHI is as follows:

- 113 clients;
- 53 facility inpatients;
- 60 home care clients (30 urban, 30 rural); and
- variety of health conditions
 - 50% musculo-skeletal, e.g. arthritis, joint replacement, amputation, pain, post surgery
 - 30% trauma/injury, e.g. fractures/dislocations, brain injury, joint sprains & strains
 - 10% neurological, e.g. stroke
 - 5% cardiorespiratory, e.g. cardiac surgery
 - 5% other, e.g. debilitating conditions.

The analysis of the pre-test included the following aspects:

- content validity and feasibility of data collection-evaluation of site input, issues and recommendations for revision;
- rater reliability on case studies; and
- inter-rater reliability.

Content Validity and Feasibility

Pre-test sites provided input on content, data elements and definitions at the education session and at the de-briefing session. Recommendations for revision of definitions, guidelines and recording forms were incorporated in the pilot test version of the data set.

Feasibility of data collection was reviewed at the de-briefing session. The following points are highlighted as they provided key input to the next phase of the pilot project:

- on average, it took one to one and a half hours to collect and record the full data set;
- time to collect depended primarily on the complexity of the health condition and the current data collection practices at the site (in some cases FIM was already collected and therefore available for pre-test documentation);
- home care sites utilized interview methods for a number of data elements, particularly for those that were not observed in the home care setting and were considered to impinge on the client’s privacy, e.g. toilet transfer, dressing;
- workload data collection was already collected by most of the sites in the form required, i.e. actual time minutes, client-specific; and
- informal workload was available by interviewing the respective caregiver; and
- travel time for service providers was available although some sites normally recorded distance (miles or kilometres) instead of time.

Sites provided input on CIHI site preparation, education session and materials and site support. Overall sites considered the education, training materials and CIHI support to the pre-test sites to be excellent. Sites recommended that more time be provided between the education session and start of data collection. Site participants also emphasized the need for site administrators and CIHI to communicate details of time commitments and site preparation time.

Rater Reliability

All pre-test raters completed 2 case studies at the de-briefing session. Rating case studies is a common approach for maintaining a high standard of interpretation of data element guidelines. This is a quality assurance method used by the Uniform Data System to credential sites and their clinicians who submit FIM data for UDS^{MR} reporting. CIHI adapted this approach and developed case studies that included both FIM and CIHI data elements. These standardized case studies were scored at the de-briefing session and feedback was provided to each participant. The benchmark of 80% correct responses was used to determine if participants were adequately prepared to use and train others in the data set.

The results for case studies are averaged across site types as follows:

Site Type	Average Scores For Case 1		Average Scores For Case 2
	FIM	FIM + CIHI	FIM + CIHI
Facility Inpatient (4 raters)	80%	89%	90%
Home Care (8 raters)	86%	88%	92%

These results are considered excellent and demonstrate that the education and guidelines provided for interpretation and scoring both FIM and CIHI data elements were appropriate and could be duplicated for pilot test purposes. Minor revisions and enhancements were made to the case studies based on input from pre-test participants.

Inter-rater Reliability Estimates

The data for inter-rater reliability included 226 data response forms (2 forms for each 113 clients in the sample). Quantitative analysis included the statistical test of Cohen’s Kappa for inter-rater reliability. The results of inter-rater reliability testing were considered excellent and demonstrated consistency of interpretation of the data elements and the overall robustness of definitions and scales of the data elements.

The following table outlines the estimates of data reliability for groups of data elements.

Data Elements	Average Correlation Coefficient
FIM	0.90
Advanced ADL (e.g. meal preparation)	0.93
Cognitive (e.g. written communication)	0.95
Mood/behaviour	0.84
Social Participation	0.96
Health Conditions	0.99
Provider types	0.97

Estimates of data reliability were also determined across site types for FIM and CIHI data elements as follows:

Site Type	Average Correlation Coefficient	
	FIM	CIHI
Facility Inpatient sites	.884	.921
Home Care sites	.918	.941

6.6.6 Conclusions

The results of the Pre-test of the CIHI Rehabilitation Minimum Data Set were used to prepare, enhance and facilitate the next phase of the pilot project, the National Pilot Test. Specifically, the pre-test results of qualitative and quantitative data analysis supported the:

- proposed research design and sampling approach;
- inter-rater reliability testing approach;
- minor revisions/enhancements to the pre-test data set;
- workload and intervention data collection; and
- education, materials and site support methods.

The next section of this report will focus exclusively on the preparation, process and implementation of the National Pilot Test.

Section 7—Phase 2: National Pilot Test

7.1 Purpose

The purpose of the National Pilot Test of the CIHI Rehabilitation Minimum Data Set was to evaluate a data set across health service settings and to develop/adopt a grouping methodology appropriate for rehabilitation case mix purposes for facility-based inpatient services.

7.2 Objectives

The objective of the national pilot test were to:

1. Test the feasibility of the data collection process.
2. Identify the data elements that are predictive of resource use.
3. Test the sensitivity of the data set to change in client status.
4. Estimate the data validity, e.g. content validity.
5. Evaluate the orientation/education materials and process.

7.3 Methodology

This section of the report includes the following steps in designing and implementing the National Pilot Test:

- Research design and sample;
- Site selection and approval;
- Education and site preparation;
- Data collection and submission; and
- Site support and communication.

7.3.1 Research Design and Sample

The sample size was based on the assumption of 60 cells in the rehabilitation grouping methodology (FIM–FRG, Version 1). It was preferable to have 30 clients in each cell for a minimum number of 1800 clients per service setting. An additional 180 cases (or 10%) were incorporated into the sample to account for client attrition and invalid data. Based on the sampling approach, the total sample of 3960 would be evenly distributed across 2 service settings, i.e. 1980 cases for facility inpatient services and 1980 cases for home care services. This sample size would allow for the detection of change in client status within 10% confidence limits, 19 times out of 20 (95% confidence interval). Within each service setting a variety of sites would be recruited to ensure that the site types in the Pre-test were represented. The sample was projected as follows:

Facility—Inpatient Rehabilitation Services	Home Care Rehabilitation Services	Sample Total
1980 Site Type 1—Specialty Facilities Site Type 2—General Facilities	1980 Site Type 3—Home Care Agencies providing mix of urban and rural services	3960

Provincial sample sizes were determined based on population base and ability to participate in the pilot project.

7.3.2 Site Selection

From January 1997–July 1997 CIHI actively recruited potential pilot sites through a variety of communication channels including telephone, email, communiques, CIHI newsletters and existing field networks. Information was provided to a number of provincial ministries and the recruitment was facilitated in some cases by ministry or other provincial organization representatives. In addition, the members of the National Rehabilitation Advisory Group were directly or indirectly involved in recruiting at least 6 of the 31 pilot sites.

Site Selection Criteria

The following criteria were used in selecting rehabilitation pilot sites within a province/jurisdiction:

- site provides rehabilitation service to one or more of the 4 rehabilitation client groups;
- site provides resources required for training, site coordination and data collection over the pilot test period;
- variety of facility/agency size and type; and
- geographical representation within the province.

Sites also required the ability to collect service provider workload for the full rehabilitation episode (admission to discharge) that met these criteria:

- actual time, retrospective workload in minutes;
- client-specific;
- by designated service provider group, e.g. RN separate from RPN/RNA, PT & PTA; and
- Validation of prospective system being equivalent to retrospective method.

Site Approval

A total of 35 sites were approved for participation in the pilot project as follows:

Specialty Facilities— 15
 General Facilities— 15
 Home Care Agencies— 5

A dedicated process to recruit home care agencies was undertaken by circulating project information to all Community Care Access Centres in Ontario, to ministry and regional representatives in all provinces and through direct calls to CIHI contacts. Although there was significant interest in participating in this project, most home care agency representatives were unable to fund the dedicated time of a project coordinator and the extra time needed for service providers to participate. Four of the facility sites withdrew from the pilot project prior to the data collection phase due to organizational changes and resource availability.

The following table illustrates the profile of 31 sites across 6 provinces.

Site Type	# Sites	Province(s)	Features of Sites
Specialty Facilities	14	BC, AB, SK, ON, PQ	Free standing facilities Geriatric facilities Regional/provincial rehabilitation facilities Tertiary rehabilitation Teaching hospitals Specialty, e.g. Spinal Cord
General Facilities	12	BC, MB, ON	Municipal hospitals Health science centres Specialty, e.g. Brain Injury, stroke
Home Care Agencies	5	SK, ON	Integrated home care services Community Care Access Centres Contracted health services

Appendix 3 provides a list of pilot sites and participants.

7.4 Education and Site Preparation

7.4.1 Education Sessions

All participating pilot sites received a 2 day education session from a CIHI consultant. This session was developed and based on experience in the Pre-test. The primary objectives of the education sessions were:

- to provide site coordinators and data collectors with a good understanding and interpretation of the guidelines for scoring and scaling clinical data elements;
- to provide guidelines on hard-copy and electronic data recording;
- to provide site participants with recommendations for managing the project on site, problem solving and coordination activities;

- to evaluate site participants performance on interpretation of the guidelines through use of case studies;
- to provide guidelines for workload, intervention and inter-rater reliability data collection; and
- to outline responsibilities of sites and CIHI for data collection, submission, site support and other related activities.

The education was provided at the site or in the general proximity of the site. In some cases, 3 or 4 local sites participated in the same session. A maximum of 12 participants attended the sessions. A total of 14 2-day sessions were held beginning in July 1997 and finishing in September 1997.

7.5 Data Collection and Submission

Pilot sites were provided with two alternatives for data collection. The first and most commonly used approach was paper based data recording. CIHI provided sites with copies of Admission Recording Forms and Discharge Recording Forms. The second approach was electronic data recording. CIHI developed an electronic version of the data recording forms on Access. Ten of 31 pilot sites elected to use electronic data recording and submission.

7.5.1 Workload Data Collection

Workload data collection was a major component and time consuming aspect for pilot sites. Sites were required to collect service provider workload for the duration of the episode of rehabilitation, i.e. from admission to discharge. The purpose of collecting workload was to have an indicator of resource utilization by client group. This was important in the evaluation component of the grouping methodology and specifically the evaluation of workload data in the Function Related Group (FIM-FRG), Version 2.

The requirements for workload data collection varied across site types. Facility inpatient sites (specialty and general) required:

- actual time, retrospective, client specific time in minutes (or the equivalent of);
- workload by designated service provider groups, e.g. occupational therapist and occupational therapy assistant, registered nurse and nurse assistant; and
- physician reported workload if possible.

For home care the requirements were similar but also included travel time and informal support time:

- actual time, retrospective, client specific time in minutes (or the equivalent of);
- workload by designated service provider groups, e.g. home support worker, registered nurse, nurse assistant;
- informal workload in minutes for a two week period of time; and
- travel time for service provider.

7.5.2 Inter-rater Reliability

This type of reliability is an important component of analysis to demonstrate the overall robustness of the definitions and scales of the data elements, and the consistency of interpretation of the data elements by raters.

Each site was responsible to conduct an inter-rater assessment (admission or discharge) using a subset of data elements for a minimum of 10 clients in the sample. A recording form was submitted for each of the 10 assessments for sites using manual submission, and an electronic record was identified as 'Inter-rater' and submitted on disc for sites using electronic data submission. Required data elements focussed on those elements that required client assessment, interpretation, scoring and use of scales such as the FIM and selected CIHI data elements. This minimum number of matched pairs was considered sufficient to detect any differences between raters or matched sets of raters.

7.6 Site Support and Communication

Pilot sites were supported by two CIHI consultants. This insured that there was a CIHI consultant at all times to facilitate and help sites with project requirements. Support was provided by telephone, email and in some cases on-site.

A regular newsletter was developed, *The Rehab Reporter*, to provide sites with relevant project information and support. The newsletter served to answer common questions, provide project updates and specific information on requirements such as workload data collection and inter-rater reliability testing. In addition, sites were invited to submit 'feature articles' that provided a unique perspective and site experience. The four issues of the newsletter were also posted on the CIHI website.

Section 8—Phase 3: Results of Statistical Analysis

8.1 Objectives

The statistical analysis was designed to answer a number of key questions about the CIHI Rehabilitation data set. Specifically:

- Is the CIHI data set reliable and valid?
- Should FIM be part of a national data set for rehabilitation?
- Do CIHI clinical data elements enhance this data set?
- What enhancements/revisions to the data set are recommended?
- Based on rehabilitation pilot results, should the FIM/FRG be recommended as a grouping methodology for facility inpatient rehabilitation clients?

8.1.1 Principles of Analysis

The principles that were adhered to in the statistical analysis approach were as follows:

- utilization of psychometric testing approaches that are consistent with current rehabilitation research and measurement analysis approaches;
- selection of the most robust and sophisticated analyses available;
- application of a step-wise approach to testing, starting with elementary statistical tests followed by more advanced procedures;
- comparative analysis of the performance of FIM items and the performance of FIM + CIHI items; and
- evaluation of an existing grouping methodology (FIM–FRG) using CIHI pilot data.

8.2 Types of Analyses

The following statistical analyses were used for testing reliability and validity:

8.2.1 Reliability

- match rate
- confirmatory and exploratory factor analysis
- measures of association
- Rasch analysis
- generalizability study

8.2.2 Validity

- dimensionality
- Rasch analysis
- sensitivity to change
- predictive validity—FIM/FRG analysis
- pilot site evaluations
- external field review
- evaluation of rehabilitation interventions

8.3 Results of Reliability Testing

8.3.1 Inter-rater Reliability

Inter-rater reliability examines whether two raters assessed and coded the same client in the same way. Each of the 31 pilot sites were asked to collect inter-rater data for 10 clients in their sample. The second rater had to conduct the assessment within 24 to 48 hours (3 days for Home Care) of the first raters' assessment. For purposes of reliability testing, sites that collected 9 or more inter-rater records were used. In total, 185 inter-rater records were used for this analysis: 87 from general facilities, 88 from specialty facilities and 10 records from home care. Inter-rater reliability was tested using match rate, measures of association and Rasch analysis.

8.3.2 Match Rate

Purpose: To test inter-rater reliability.

Description: The percent agreement in scores for each data element between two raters or 2 sets of raters. All FIM items and selected CIHI items were included in the test.

Result: Summary results are as follows:
All sites—FIM motor = 83%, FIM cognitive = 87%, CIHI = 85%
Site Type 1 and 2—FIM items = 84%
Site Type 1 and 2 CIHI items = 84%
Site Type 3 FIM = 84%
Site Type 3 CIHI = 92%

Interpretation: Overall, there was an extremely high match rate between data collectors. The high match rates were consistent for both motor and cognitive domains and both FIM and CIHI data elements.

8.3.3 Measures of Association

- Purpose:* To test inter-rater reliability.
- Description:* Determines that correlation between raters is acceptable in the FIM and CIHI clinical data elements.
- Result:* The gamma statistic is used. Gamma was $>.85$ for all items except foot care (.83), and self-report items–Impact of Pain (.69), and Intensity of Pain (.73).
- Interpretation:* These results are extremely high and demonstrate excellent agreement between raters.

8.3.4 Rasch Analysis

- Purpose:* To test inter-rater reliability and data element structure.
- Description:* Rasch is a model using Item Response Theory (IRT). Item and scale properties of responses to the FIM and CIHI items are described using this model. The analysis looked at the usefulness of items and response options (sensitivity of each item to range of functioning of rehabilitation clients). Rasch item analysis provides several methods of determining scale reliability and potential gains in reliability due to added items. The IRT reliability estimate is calculated as an intra-class correlation coefficient (ICC). The relative efficiency is calculated to reflect any gains in measurement precision by using the composite measure with FIM + CIHI.
- Result:* The following table presents the ICC reliability estimate and relative efficiency

Rasch modified reliability estimates

Scale—Data Elements	IRT reliability estimate 'ICC'	Relative efficiency adding CIHI
FIM motor	.913	–
FIM + CIHI motor	.915	1.03
FIM cognitive	.869	–
FIM + CIHI cognitive	.892	1.25

- Interpretation:* The ICC estimates are considered very high and further demonstrate the strong reliability of both FIM and FIM + CIHI. The reliability and information estimates are fairly high partly due to the large sample size and the larger number of items in the composite scores. The value of 1.25 for relative efficiency can be interpreted to mean that the precision of measurement of the cognitive domain has been increased by 25%. In other words, the FIM cognitive items would have to be increased by 25% to achieve the precision of the composite (CIHI + FIM) cognitive sub-scale. Smaller gains are reflected by the lower relative efficiency of only 1.03 (3 % increase) for the motor sub-scale.

8.3.5 Confirmatory and Explanatory Factor Analysis (EFA)

- Purpose:* To test internal consistency, reliability, construct validity and domains of data element structure.
- Description:* Performed on the clinical data elements to determine the existence of motor and cognitive domains. In addition, 6 client groups were targeted to repeat EFA—traumatic brain injury, right-sided stroke, amputations, arthritic/pain, joint replacement and cardio/vasc/pulmonary. Each group had in excess of 100 cases and included client groups with expected motor and cognitive limitations in function.
- Result:* All items contributed or `loaded` on either the cognitive or motor domain exclusively except Mood/Behaviour. Financial Management was loaded to some extent in both domains.
- The FIM data elements had 13 motor data elements and 5 cognitive data elements.
- The CIHI motor elements are: Meal preparation, light housework, and heavy housework. CIHI cognitive elements are: communicating messages-verbal, communicating messages-written, understanding verbal, understanding written, and orientation. Results were similar when tested on the 6 client groups.
- Interpretation:* The structure of the data set contributes to both motor and cognitive domains as expected with only two exceptions. The CIHI communication data elements contribute to the cognitive domain as expected and the CIHI advanced ADLs contribute to the motor domain. Additional testing on client groups with expected cognitive and motor impairments demonstrates similar results.

8.3.6 Generalizability Analysis

- Purpose:* To test the reliability and data element structure.
- Description:* The industry standard of using Cronbach Alpha to measure internal consistency has little or no meaning in instruments with very few items measuring construct and therefore was not used in this analysis.
- Generalizability (G Study) is the most rigorous analysis presently available to assess the reliability of any measure. The G Study in particular, is “state-of-the-art”. G Study identifies the true client score and the sources of variation from the true score. This variation can come from real differences in clients, data collectors, or how the data elements work across clients. FIM scores and scores from a composite scale (FIM + 6 CIHI cognitive items) were examined.

- Result:* General and specialty facilities had high reliability estimates for motor and cognitive domains. Reliability estimates were higher for scale scores representing motor activities when compared to estimates based on cognitive items. Lack of variation in client scores in the home care setting resulted in the lowest estimates for score stability.
- Interpretation:* The results indicate that the measurement differences are due only to differences in clients and not data collectors or data elements. Items are precise and focus only on the real differences in clients in motor and cognitive domains, and are not influenced by differences in raters or unrelated data elements.

8.4 Results of Validity Testing

8.4.1 Dimensionality of Data Elements

- Purpose:* To test validity of response options.
- Description:* Dimensionality examines the distribution of available response options for each data element. This is important to determine if the data element is sensitive enough to discriminate between clients with different levels of function. An example of response items are the codes 1 through 7 for Eating. These response items which describe levels of dependence through to independence respectively.
- Result:* Items were flagged based on a decision rule that less than 2% in a particular response category may represent an inappropriate distribution, based on N = 1949. All items except Mood, Light & Heavy Housework meet this criteria. The same analysis was completed for each of the 17 client groups. A vast majority of data element response categories (90%) were found to work appropriately. Some of the results are not interpretable due to low volumes.
- Interpretation:* The high rate of distribution of responses is likely a function of the comprehensive field input from external reviewers and the National Rehabilitation Advisory Group who provided ongoing input into the design of the data set; and to any enhancements made to the data set following the pre-test. Only those data elements that were found to work appropriately were included in subsequent analyses.

8.4.2 Sensitivity to Change Analysis

- Purpose:** To determine if the FIM and CIHI data elements are able to detect change between admission and discharge across client groups.
- Description:** Two tailed Bonferroni t-tests were conducted on the following groups of data elements:
- FIM motor, FIM cognitive,
 - CIHI foot care, medication management, communication data elements (4), orientation, mood/behaviour, general health status
- Result:** Across all client groups – all elements were sensitive to change at a significance level of $p < .01$, except for mood/behaviour. This was tested by 17 client groups (excluding 2 groups with $n < 30$ – Cardiac & Other Disabling Impairments) for the following:
- FIM/CIHI composite motor
 - FIM/CIHI composite cognitive
 - FIM motor
 - FIM cognitive
 - CIHI Pain
 - CIHI Communication
 - CIHI ADL (Meal Preparation, Light & Heavy Housework)
 - CIHI General Health Status
- All groups were sensitive to change except for :
- CIHI Communication in 'Other Neuro'
 - CIHI ADLs in 'Neuro, Other Neuro, Other Ortho, Vascular, Other Debility', due to low volume (< 30) with scored data
- Interpretation:** The majority of data elements were sensitive to change across client groups except for those with small sample sizes. This provides some indication that the FIM + CIHI composite measures and that the client response items for pain and general health status will contribute to functional status outcomes where a change/improvement is expected with rehabilitation.

8.4.3 Construct Validity

Construct validity is an evaluation of the accuracy of a construct, as measured, relates to others in ways that are predicted from relevant theory. IRT methods were developed to describe the relationship between responses to items and the underlying construct that is the object of measurement. In this analysis, the construct of interest is the functional impairment of rehabilitation patients. There are a wide variety of IRT models to allow for different item properties. One commonly applied version of this method is Rasch analysis (one-parameter logistic model), where items are described by a single parameter, namely difficulty. The advantage of using IRT analysis lies in the estimation of the latent construct for patients, and the estimation of item characteristics on a common scale. A well fitting Rasch model will allow valid comparisons between the relative difficulty of items. In this case, item difficulties are analogous to the severity of the health condition related to the selection of response options for different items. Also, valid comparisons of scale and item properties derived from different forms of the scale can be made.

8.4.4 Rasch Analysis

Purpose: To test construct validity of domains.

Description: Rasch analysis using the IRT model was used to determine data element or item severity estimates. These estimates identify the items that most accurately measure greater functional impairment or less severe impairment. In addition, it identified the domains that the CIHI data elements contributed to.

Result: The analysis showed that 9 CIHI items (3 motor, 6 cognitive) contributed to the motor and cognitive domains:

- Motor—meal preparation, light & heavy housework; and
- Cognitive—financial management, communicating and understanding messages verbal/written, orientation.

Items that did not measure consistently were Mood/Behaviour, Foot Care and Medication Management.

The following table summarizes the results of Rasch analysis for the various data elements based on their measurement effectiveness for clients with different levels of dependence and functional impairment.

Levels of Dependence/Severity of Impairment		
Dependence/More Functional Impairment	Moderate	Independence/Less Functional Impairment
FIM Bladder & Bowel Mgt	FIM Grooming	FIM Locomotion, Stairs
FIM Eating	FIM Dressing upper body	FIM Tub transfer
	FIM Problem Solving	FIM Bathing
	FIM Memory	FIM Dressing lower body
	CIHI Communicating–verbal & Written	FIM Social interaction
	CIHI Understanding–Verbal & Written	FIM Comprehension
		FIM Expression
		CIHI Meal preparation
		CIHI Light & heavy housework
		CIHI Orientation

Interpretation: The data elements for Mood/Behaviour, Foot care and Medication management do not measure consistently and should be considered as possible deletions for the data set. The FIM and CIHI items appear to provide measurement accuracy for a range of functioning of rehabilitation clients.

8.4.5 Workload Data Collection

Workload data was a key component of the research design for this project. The purpose was to use workload as a ‘surrogate’ of resources in rehabilitation for the validation of the grouping methodology. Features of the workload that was collected were:

- client-specific;
- minutes by designated service provider group, e.g. therapist and therapy assistant;
- retrospective actual time or the equivalent; and
- inclusion of physician workload if possible.

The analysis of workload data was conducted to characterize 'typical workload' levels for each episode of rehabilitation. There is no 'gold standard' by which to compare the workload data analysis, thus the objective of the analysis was to distinguish 'good' from 'bad' data using internal references.

The analysis involved aggregating the workload data at the client level and creating total times for each client. Client times were averaged at the site level to provide an overall picture of the workload for each site. Standard deviations were calculated for each facility to aid in understanding the variation in workload at each site. The coefficient of variation (cv) was also calculated for each site.

The calculation of the coefficient of variation allowed relative comparisons to be made between sites. The results indicate that all sites have a similar degree of variation in their workload times, indicating homogeneity of workload times within sites. The exception to this was observed in home care sites. These sites demonstrated a significantly higher degree of variation than the facilities. This variation was attributed to the presence of a small number of highly time intensive 'outliers'. The home care sample (113) was also significantly smaller than the samples for facilities.

Notwithstanding the outliers in the home care sites, the results of this analysis indicate that the workload data is internally consistent within sites and that no major anomalies are apparent in the data. It should also be noted that physician workload was not consistently reported across sites.

8.5 Predictive Validity

Development of a grouping methodology was a major objective of this project. The purpose of the grouping methodology is to predict resource requirements for various client groups. Predictive validity in this analysis was used to estimate how much variance in a dependent variable (length of stay and workload) is explained by the various client groups.

The only existing methodology developed for a comparable client population is the Function Related Groups (FIM-FRG) developed by the University of Pennsylvania (M. Stineman) and the Uniform Data System, State University of New York. FIM-FRG is designed to classify medical rehabilitation clients into homogeneous groups based on length of stay (Stineman et al, 1994). There are now three different types of FIM-FRGs-LOS FIM-FRGs (dependent variable is LOS); the DMF-FRG (Discharge Motor FIM is the dependent variable); and the Gain-FRG (FIM gain between admission and discharge is the dependent variable).

Recently FIM-FRGs have undergone an extensive evaluation by the RAND Corporation to determine the potential of FIM-FRG as a prospective payment system for rehabilitation services in the United States (Carter G.1997). This study determined that the FIM-FRGs were robust, effective predictors of resource use. Recommendations for enhancements were made to more adequately capture main

effects. These include service interruptions, complications and co-morbidities. The study concluded that the FIM–FRG is feasible and meets the expected goals for a rehabilitation prospective payment system.

For purposes of this study UDS^{MR} provided CIHI with the necessary software to test Canadian pilot data.

8.5.1 FIM–FRG Analysis—Validation of FIM–FRG using Canadian Pilot Data

Purpose: To examine the performance of the FIM–Function Related Group (FRG), Uniform Data System (Version2); and the distribution of rehabilitation client groups across FRG groups.

Description: Analysis of Canadian pilot data using the FIM–Function Related Group (FRG), Uniform Data System (Version 2), was conducted using two different dependent variables:

1. Length of Stay (LOS)
2. Standardized Workload

Regression analysis was used (R^2) to determine how much variance was explained in the dependent variable by the independent variables.

Result: The rehabilitation data fell into 62 of the possible 67 FIM–FRGs across all site types).

The R^2 for LOS by site type:

Specialty facilities–	.263
General facilities–	.224
Home Care–	.273

(Stineman reported an R^2 of .317, 1997)

The R^2 for resource use by site type;

Specialty facilities–	.455
General facilities–	.383
Home Care–	.492

The predictive ability of the FIM–FRG improves when using standardized workload vs LOS.

(The Rand study, 1997, reported R^2 of 0.35 for LOS, R^2 of 0.32 for resource use. These results were obtained using a modified version of FIM–FRG)

The cells with 20 or more cases showed that within cell homogeneity as measured by the coefficient of variation (c.v.) is very good. Only one cell with 20 or more cases has a coefficient of variation greater than 1.0.

Interpretation: The predictive ability for LOS was somewhat less than the results reported by Stineman (1997). The differences may be due to different service delivery patterns and length of stay in Canada, and due to the mapping of client groups.

The predictive ability using workload for resource utilization compare favourably with the RAND study results. In addition, the results compared favourably with the predictive ability of CMG used for acute care in Canada.

8.6 Content/Face Validity Pilot Site Evaluations—Interim and Final

Purpose: All pilot sites were required to participate in site evaluations at an interim stage and on completion of the pilot project. This was a key component of content or face validity testing. The purpose of this evaluation was to solicit a wide range of input from pilot site participants, clinicians and other data collectors who had some ‘hands-on’ experience with the data set process, content and logistics. Sites were requested to involve as many of the site participants as possible.

Description: **Interim Evaluation**

The objectives of this evaluation included obtaining:

- Input on project process issues such as CIHI preparation and education, time commitment of the site and recommendations for future projects.
- Input on the range of site participants, their expertise and clinical background, the site’s clinical programs/client groups.
- Input from site participants on the ease of data collection.
- Input on whether the data collected could detect change/improvement in client functional status.

Results: The interim evaluation was completed by a wide range of pilot project participants who were involved in some aspect of data collection. A profile of respondents is provided below:

Total Respondents	Specialty Facilities	General Facilities	Home Care
N = 218	N = 134	N = 70	N = 14

Profile of Participants		Average—All Sites
Nursing		25%
Physiotherapy		22%
Occupational Therapy		17%
Social Work		7%
Speech/Language		5%
Physician		5%
Other:		19%
Psychologist	Pharmacy	
Rec Therapist	Care Coordinator	
Administrator	Support personnel	
Health Records	Psychometrist	
Clerks	Dietitian	
Pastoral Care	Medical Secretary	

Data from these evaluations was summarized in the following categories:

1. Feasibility of data collection

Responses varied across site types. In general, specialty sites collected the majority of data elements as part of regular assessment and follow-up. General facility sites required special effort to collect the cognitive data and the advanced activities of daily living. Home care sites required special effort for FIM items that involved personal care such as bowel/bladder management and for some of the cognitive items.

2. Ability of data elements to detect change in client status

80% of respondents thought that:

- FIM could detect change in 16 out of 17 client groups;
- CIHI advanced activities of daily living could detect change in 15 of 17 groups; and
- CIHI communication items could detect change in 9 groups of 17 groups.

Description: *Final Evaluation*

The purpose of this evaluation was to solicit the site’s recommendation on whether to retain certain aspects of the data in a national data set. In particular, site’s were asked whether the FIM should be retained for all client groups, some groups or not at all. Sites were also asked to comment on which data elements should be mandatory or optional for reporting, and which elements required revision.

Results:

The final evaluation was completed by the site coordinator of the pilot site. Sites were requested to submit one questionnaire per site with input from pilot project participants at the site.

8.6.1 Final Site Evaluation—Key Questions

Total Respondents	Specialty Facilities	General Facilities	Home Care
N = 30	N = 14	N = 11	N = 5

The following questions were answered by respondents:

Should FIM be a part of a national data set for Rehabilitation?

The majority of all sites responded that FIM should be part of the data set.

Should Impairments be retained?

The majority of all sites responded that impairments at the 1st level be retained. Approximately 50% respondents stated that they should be retained at the 2nd level.

Should Participation be retained?

The majority of respondents said that participation should be included if it is revised.

Should CIHI Communication be retained?

The majority of respondents said that this should be retained with revisions.

Should CIHI Advanced ADLs be retained?

The majority of respondents said that this should be retained with revisions.

Is this data set appropriate for other service settings?

Approximately 50% respondents said it was appropriate for inpatient acute.

The majority said it would be appropriate for outpatients.

Approximately 50% respondents said it was appropriate for home care.

8.7 External Field Review

Purpose: The external field review was another major test of Content Validity. CIHI conducted a comprehensive field review with Canadian rehabilitation stakeholders concurrently during the second half of the pilot project (February–April 1998). A review questionnaire was developed specifically for four types of stakeholder groups:

- Clinicians/service providers;
- Administrators/health policy experts;
- Researchers; and
- Consumer networks.

Description: Reviewers were recruited from the CIHI rehabilitation network, recommendations from the National Rehabilitation Advisory Group, national professional organizations, consumer advocate and disability networks, provincial ministries of health and other related organizations.

Input was requested in the areas of data set content, feasibility and utility of the data set, preferred tests and measures, rehabilitation indicators and outcomes, adequacy of the participation and environmental factors component of the data set.

Results:

Respondent Types	N
Clinicians	26
Administrators/Ministries of Health	26
Researchers	10
Consumer Network/Advocate	2
Total	64

The results of the External Field Review are summarized under the following headings:

8.7.1 Utility of Data Set

Respondents involved in service planning and evaluation, development of health policy and resource allocation were asked to comment on the utility of the data set using a number of criteria. The majority of respondents reported that the data set would meet their needs. The highest scores were given to socio-demographic, administrative, health characteristics, FIM and intervention data.

8.7.2 Indicators

Respondents were asked to identify the indicators that would be important in a rehabilitation reporting system. Seventy-three percent (73%) of respondents said that the CIHI Rehabilitation Data Set contributes to important indicators for rehabilitation. .

8.7.3 General Questions

Based on the objectives of the CIHI rehabilitation pilot project, respondents were asked specific questions on the utility of FIM, the client focus of the data set, relevance of the data set across service settings and the applicability of the data set for different client groups. The majority of respondents provided positive responses to these questions for the range of rehabilitation client groups.

8.8 Evaluation of Intervention Reporting

Purpose: The purpose of this evaluation was to determine whether the proposed intervention categories were valid and relevant across rehabilitation service providers, sites and services. The objectives of the study were:

- to validate the intervention categories and identify any gaps;
- to identify common profiles of rehabilitation interventions across client groups and across site types (specialty facility, general facility and home care); and
- to conduct a preliminary mapping of the interventions to the *Canadian Classification of Health Interventions (CCI)* which was intended to include a comprehensive list of rehabilitation interventions.

Description: A simple frequency tabulation of the number of interventions that were recorded by client group and by site type was determined. This provided a ranking of the most common interventions provided to clients with specific health conditions. There were a total number of 52 intervention types including the differentiation between interventions delivered by 'Single Provider' or by 'Team', and interventions delivered for an 'Individual' or a 'Group'.

Results:

- The first type of analysis focussed on the frequency distribution of interventions across sites. This analysis showed that all three site types share the top 7 intervention categories:
 - Initial Assessment (Individual)
 - Therapeutic-Physical (Individual)
 - Education (Individual)
 - Reassessment (Individual)
 - Equipment & Assistive Technology
 - Screening Assessment (Individual)
 - Service Planning & Coordination

In addition the following observations were made:

- specialty and general facilities have the same top 12 categories with the exception of 1;
- specialty facilities had the most interventions provided by 'Team'; Home Care recorded 'Team' for only one client out of the home care sample of 113;
- home care is the only site that includes 'Consultation' in the top 12; and
- the most uncommon types of interventions in home care were 'Team' interventions and 'Group' interventions.

- The second type of analysis focussed on the frequency distribution of interventions within client groups. All client groups with a sample of > 100 were included in the review. This analysis showed that:
 - spinal cord clients receive more ‘Team’ based interventions than other client groups;
 - all client groups have ‘Team’ based interventions for ‘Service Planning & Coordination’ in the top 12;
 - arthritis clients are the only group that have ‘Education-Group’ in the top 12; and
 - all groups with > 100 in the sample share the following interventions in the top 12:
 - Initial Assessment
 - Service Planning & Coordination (Team based)
 - Therapeutic-Physical (Individual)
 - Therapeutic-Psycho-social (Individual)
 - Education (Individual)
 - Equipment & Assistive Technology
 - Social Participation.

- The third objective of the intervention evaluation was to compare the pilot project list of intervention categories to the newly developed *Canadian Classification of Health Interventions (CCI)* developed concurrently with the pilot project.

A preliminary mapping exercise was conducted to determine if each of the 52 rehabilitation interventions used in the pilot project. Three questions were addressed:

1. Are all 17 of the major categories of interventions in CCI?
Yes, all categories are present including ‘Therapeutic-Nutrition’ which was identified as a gap in the pilot project.

2. Are there qualifiers for ‘Individual’ and ‘Group’ in each category used in the pilot project?
No, only ‘Screening Assessment’ in CCI has qualifiers for this.

3. Are there qualifiers for ‘Single Provider’ and ‘Team’ for each category used in the pilot project?
No, there are no qualifiers for this purpose in the CCI.

- The final objective of this study was to determine the usefulness/feasibility of this type of data collection. Results showed that although tracking interventions is considered very important to health administrators/health policy experts, clinicians consider the categories too broad and would prefer data that is linked to or integrated with workload measurement systems. From a content perspective, the area of Nutrition was noted as a gap and recommended for inclusion.

Section 9—Phase 4: Conclusions and Recommendations

9.1 Conclusions

The results of the statistical and qualitative analysis conducted on the CIHI National Pilot Project data have provided CIHI and the National Rehabilitation Advisory Group with conclusive evidence that the objectives of the project have been met. Specifically, the results provide answers to the key questions as follows:

9.1.1 *Is the CIHI data set reliable and valid?—Yes*

The reliability analyses that were conducted on the CIHI Rehabilitation Data Set proved that the instrument is reliable across settings. Results indicate that the rater teams are not an important source of measurement error, and that most variability in scores is associated with differences in client function at each site. These results also demonstrate that the site education and materials for training in the use of the measures was appropriate and effective. Home care sample numbers were too low to complete a full reliability analysis. Based on this study and the other reliability tests, accurate and consistent interpretations may be made from ratings on the composite measure of client function incorporating both FIM and CIHI items. These analyses are among the most rigorous tests carried out to date on this type of data set.

The results of validity testing showed that the data set was valid across a wide and representative range of rehabilitation clients, and across service settings. The enhancement of the cognitive domain was achieved by adding CIHI cognitive and communication items to the FIM items. These results demonstrated that there is an improved precision of measurement of the cognitive domain by adding CIHI items (25%) and that there is a gain in the overall reliability when FIM and CIHI items are combined to measure function across rehabilitation client groups. In addition, it is concluded that the data set is capable of detecting change in client status between admission and discharge for the majority of data elements and client groups. Finally, content or face validity was confirmed through input from over 350 rehabilitation experts in Canada.

9.1.2 *Should FIM be part of a national data set for rehabilitation?—Yes*

Based on the strong reliability and validity results it is concluded that the FIM is an appropriate measure for use in facility based settings for a wide range of rehabilitation clients. In addition, the FIM is well recognized and utilized at rehabilitation centres across Canada. There is good support from the rehabilitation community, administrators and ministries of health to endorse the FIM as a standard for inpatient services. Although home care pilot sites also endorsed the use of FIM for a national data set, there were relatively few sites participating to draw conclusions.

9.1.3 Do CIHI data elements enhance this data set?–Yes

Activities (FIM & CIHI)

The testing demonstrated that the CIHI data elements were reliable and their respective scales sensitive to the range of client function in rehabilitation. Specifically the analysis showed that 9 CIHI items (3 motor and 6 cognitive) contributed to the measure. It is concluded that the 6 CIHI cognitive items have the most significant value-added contribution to measurement precision of the cognitive domain which was a very desirable project outcome. CIHI data elements that should be removed from the data set are Foot Care, Medication Management and Mood/Behaviour. These elements did not measure consistently. CIHI data elements were supported by a majority of sites and external field reviewers as mandatory or optional items. Some of the data element definitions require minor revisions. These conclusions are specific to facility-based settings. Although home care numbers were small there is an indication that CIHI data elements are appropriate and applicable to client groups in the home. Results of this study should be considered as a starting point for further development of home care standards for rehabilitation.

Participation

Although there is unanimous support to include this component of the data set, the ICIDH–2 (1997) format was too complex to administer reliably. The general categories were considered appropriate for all client groups but more applicable to the community/home care setting. One aspect that is considered lacking is the client's response to their satisfaction with the level of participation. Based on these results it is concluded that the ICIDH–2 version which is still under revision is not yet ready to include in the data set. An existing measure for participation that meets the CIHI criteria for inclusion in the data set is the *Reintegration to Normal Living Index* (refer to Appendix 4, 4–2).

Health Characteristics

The majority of sites endorsed the inclusion of ICIDH–2 impairments at the broad level. There are concerns regarding the adequacy and comprehensiveness of the list for physical impairments commonly seen in rehabilitation. It is concluded that additional review and revision is required before incorporating this component into the reporting system. This may be appropriate when the ICIDH–2 is finalized.

Interventions

The broad categories of interventions that were tested are comprehensive with the exception of Nutrition. It is possible to map it to the *Canadian Classification of Health Interventions*. The results of the evaluation will provide CIHI with additional enhancements for rehabilitation interventions. The categories are consistent across service settings and vary only slightly in their profiles by client group. Interventions should be integrated with other data collection efforts.

9.1.4 What enhancements/revisions to the data set are recommended?

Based on the statistical analysis, the qualitative review and the recommendations of the National Rehabilitation Advisory Group, a list of mandatory and optional items were recommended for inpatient rehabilitation services (refer to Appendix 4).

9.1.5 Based on rehabilitation pilot results, should the FIM/FRG be recommended as a grouping methodology for facility inpatient rehabilitation clients? – Yes

The results achieved with testing of Canadian pilot test data in the FIM–FRG provide similar results to those reported by Stineman *et al.* The predictive ability of the FIM–FRG improves when using Canadian standardized workload. These results compare favorably with the predictive capability of the acute care grouping methodology, Case Mix Groups (CMG™). Based on these results and the positive results of the RAND study, it is concluded that the FIM–FRG is an appropriate starting point for a Canadian case mix tool and that future development and ‘Canadianization’ of FIM–FRG should take place.

9.2 Recommendations for National Rehabilitation Data Set and Grouping Methodology

The results and conclusions of this study were compiled and presented to the National Rehabilitation Advisory Group at a two day meeting in August 1998. Based on the strength of these results, the NRAG recommended that this data set be used to develop a national reporting system for inpatient rehabilitation services. The results of the home care data analysis were positive and could contribute to future initiatives in national database development for home care services.

In addition, the NRAG recommended that the associated grouping methodology, the Functional Independence Measure-Function Related Groups (FIM–FRG), be adopted for use in Canada as a starting point for an inpatient rehabilitation classification system.

The NRAG also made a number of recommendations for dissemination of project results and conclusions, and for key opportunities to present and promote the significant findings of this study.

Finally, recommendations for presentation of site-specific pilot data and general reports were made. These were consistent with recommendations from pilot site evaluations. Reports are a critical product of the pilot project and will serve as a template or prototype for future development (refer to Appendix 5 for Sample Reports).

Section 10 – Summary

The completion of this national pilot study by CIHI to collect and analyze rehabilitation data, in three different service settings, means Canada is one step closer to having a consistent tool to measure the effectiveness of rehabilitation services.

This is a landmark study. It is the first project of its kind undertaken by a Canadian organization to collect and track data for persons receiving rehabilitation services. In addition to the robust evaluation of a significant sample of representative rehabilitation client groups, this study has completed the most comprehensive consensus and field review exercise involving key partners and stakeholders. Over 350 participants including researchers, consumers, funders, clinicians, national organizations and others contributed.

Finally, this study has shown that client-centred information for rehabilitation is consistent across service settings and that the vision of integrated information systems for rehabilitation is realistic and achievable.

Appendix A
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Canadian Physiotherapy Association
Canadian Association of Occupational Therapists
Canadian Association of Physical Medicine & Rehabilitation
RehabNet
Canadian Nurses Association
Canadian Association of Speech Language Pathologists & Audiologists
Canadian Psychological Association
Ontario Hospital Association
Ontario Ministry of Health
Ontario Association of Speech Language Pathologists & Audiologists
Metropolitan Toronto Acquired Brain Injury Network
Institute for Work & Health
Community Occupational Therapy Associates
Greater Vancouver Regional Health District
Department of Health & Social Services, Prince Edward Island
Saskatchewan Health
David Thompson Health Region, Alberta
Department of Health & Social Services, North West Territories
Yukon Government, Yukon

Appendix B
Pre-test Site Participants

Pre-test Site Participants

Betty Cheung
Wendy Doyle
Debbie Greenham

Scarborough General Hospital

Ilene Cohen
Diane Kizik-MacDonald
Hazel Wood

The Arthritis Society

Vicki Faulkner
Alexis Dishaw
Mimi Lowi

St. John's Rehabilitation Hospital

Nancy Dane
Betty Rivington-Law
Kirsten Bennick
Bill Forsyth
Heather Brien

Home Care Program of Metropolitan Toronto

Anita Cauldwell
Patricia Turner
Kim Voelker

Waterloo Regional Home Care Program

Appendix C
Pilot Sites & Participants

Pilot Sites & Participants

Type 1 – Specialty Facilities

Richardson Hospital
Montreal, QC

Libby Emond, Site Coordinator
Dr. Ronald Ludman

St. Joseph's Care Group (St. Joseph's site)
Thunder Bay, ON

Verna Ortgiese, Site Coordinator
Janet Sillman

St. Joseph's Care Group (Hogarth-
Westmount site)
Thunder Bay, ON

Verna Ortgiese, Site Coordinator
Janet Sillman

Parkwood Hospital
London, ON

Sharon Jankowski, Site Coordinator

St. Vincents Pavilion, SCOHS
Ottawa, ON

Sylvie Corbeil, Site Coordinator

The Rehabilitation Centre
Ottawa, ON

Louise Seaby, Site Coordinator
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Irene Giustini

Lyndhurst Centre,
Rehabilitation Institute of Toronto
Toronto, ON

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St. John's Rehabilitation Hospital
Toronto, ON

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Mimi Lowi

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Toronto, ON

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Clare Adie

West Park Hospital
Toronto, ON

Mark Tonack, Site Coordinator
Miranda Kutnjak

Glenrose Rehabilitation Hospital
Edmonton, AB

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Linda Szabo

Wascana Rehabilitation Centre
Regina, SK

Diana Adams, Site Coordinator
Sylvia Jones

Holy Family Hospital
Vancouver, BC

Gabriele Yoneda, Site Coordinator
Patti Erlandson

GF Strong Rehabilitation Centre
Vancouver, BC

Machid Namazi, Site Coordinator
Dr. Hugh Anton

Type 2—General Facilities

Laurentian Hospital
Sudbury, ON

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McMaster Site, Hamilton ON

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Liz Whetham

Hamilton Health Sciences, Henderson Site,
Hamilton ON

Enoch Ho, Site Coordinator
Barb Ansley

St. Joseph's Health Centre
London, ON

Lynn Wick, Site Coordinator
Lesley Bisbee

Belleville General Hospital
Belleville, ON

Paulette Jamieson, Site Coordinator

Cornwall General Hospital
Cornwall, ON

Nicole Comte, Site Coordinator
Kim Peterson
Bonnie Destounis

York County Hospital
Newmarket, ON

Lynn Bonk, Site Coordinator
Judy Ritchie

Credit Valley Hospital
Mississauga, ON

Cindy Van Horn, Site Coordinator
Dr. P. Defeudis

Winnipeg Health Sciences
Winnipeg, MB

Chris Snow, Site Coordinator
Mary Lessing-Turner

Royal Inland Hospital
Kamloops, BC

Dr. Jill Calder, Site Coordinator
Darlene Arsenault, Site Coordinator

Vancouver General Hospital
Vancouver, BC

Pam Aikman, Site Coordinator
Dr. Hugh Anton

Type 3—Home Care

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Toronto, Kingston, Belleville ON

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Sydney Lineker
Mea Renahan
Ilene Cohen
Trish Beckett
Kathryn Brown
Diane Kizik-MacDonald

ParaMed Health Services
London, ON

Marel Fielding, Site Coordinator

Community Care Access Centre, Peel
Region, Brampton ON

Eileen Lee, Site Coordinator
Kathy Lexow
Jeanette Gray

Community Care Access Centre, Waterloo
Region, Waterloo ON

Kim Voelker, Site Coordinator
Pat Turner

Regina Health District
Regina, SK

Jo Baumgartner, Site Coordinator
Karen Miller
Dawn McNeil

Appendix D
Recommended Data Elements

Recommended Data Elements

Category	Data Element	Revisions	Mandatory	Optional
Identifier	Chart number		✓	
	Health care number		✓	
	Health care number N/A		✓	
	Prov/terr issuing HCN		✓	
Socio-demographic	Gender		✓	
	Birth date		✓	
	Primary language		✓	
	Postal code		✓	
	Country of residence		✓	
	Prov/terr of residence		✓	
	Pre-admit living arrangement		✓	
	Post-dsch living arrangement		✓	
	Informal support received			✓
	Pre-admit vocational status	Revise	✓	
	Post-dsch vocational status	Revise	✓	
Administrative	Admission date		✓	
	Referral source		✓	
	Referral source prov/terr		✓	
	Referral source facility #		✓	
	Responsibility for payment		✓	
	Service interruptions		✓	
	Therapy start & end date	Addition		✓
	Provider type(s)		✓	
	Discharge date		✓	
	Reason for discharge		✓	
	Referred to	Revise	✓	
	Referred to prov/terr		✓	
	Referred to facility #		✓	
Health Characteristic	Main health condition		✓	
	ASIA Impairment Scale		traumatic spinal cord	
	Date of onset		✓	
	Other health conditions		✓	
	Impairments	Delete		
	Height			✓
	Weight			✓

Category	Data Element	Revisions	Mandatory	Optional
Activities & Participation	Eating – FIM		✓	
	Grooming – FIM		✓	
	Bathing – FIM		✓	
	Dressing–upper body – FIM		✓	
	Dressing–lower body – FIM		✓	
	Toileting – FIM		✓	
	Bladder management – FIM		✓	
	Bowel management – FIM		✓	
	Transfers: bed, chair, w/ch – FIM		✓	
	Transfers: toilet – FIM		✓	
	Transfers: tub or shower – FIM		✓	
	Locomotion: walk or wh/ch – FIM		✓	
	Locomotion: stairs – FIM		✓	
	Comprehension – FIM		✓	
	Expression – FIM		✓	
	Social interaction – FIM		✓	
	Problem solving FIM		✓	
	Memory – FIM		✓	
	Foot care	Delete		
	Impact of pain		✓	
	Meal preparation			✓
	Light housework			✓
	Heavy housework			✓
	Financial management		✓	
	Medication management	Delete		
	Communicating messages vocal		✓	
	Communicating messages written		✓	
	Understanding messages vocal		✓	
	Understanding messages written		✓	
	Orientation		✓	
Mood/behavioural symptoms	Delete			
Participation	Replace RNLI*		✓	
General Health Status		✓		
Rehabilitation Interventions		Revise		✓

* RNLI—Reintegration to Normal Living Index—The inclusion of this standardized measure meets the gap in the data set in the area of ‘Participation’. The RNLI meets the criteria for inclusion in the data set, i.e. ease of administration, application across service settings, validated for rehabilitation clients; comprehensive in categories of participation; time to administer < 10 minutes; includes the concept of client satisfaction and validated for rehabilitation clients (Wood-Dauphinee S. et al 1987 & 1988; Korner-Bitensky N et al 1994 & 1994). This measure is in the public domain and permission from the developers to publish it has been granted.

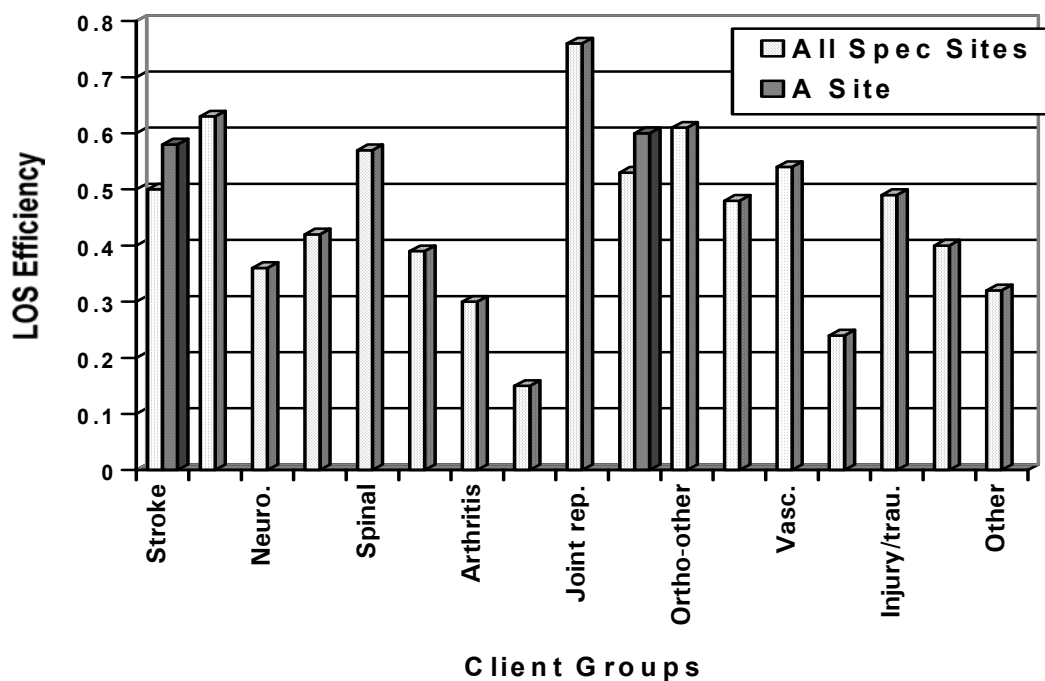
Appendix E

Sample Reports

A Specialty Site: Comparative Reports by Client Group—Stroke

Socio-demographic	A Specialty Site N = 42	All Specialty Sites N = 312
Average age in years	74.4	71.3
% Gender male	42.9	53.5
% Living at home on admission	100	96.8
% Living at home on discharge	73.8	77.9
Administrative		
Average weeks from onset to admission	2.7	9.3
Average length of stay (LOS) in days	36.3	58.0
Average workload/day in minutes	217.8	304.7
% Referral or transfer to other service at discharge	16.7	12.2
Functional Status/Outcome		
Average FIM score on admission	76.8	70.0
Average FIM score on discharge	100	92.8
% Improvement in FIM score	30.0	33.0
% Clients with improvement in level & impact of pain	88.1	71.2
% Clients with improved general health status	54.8	58.0
% Clients achieving service goals on discharge	83.3	86.2
Average LOS efficiency	0.58	0.50

Length of Stay (LOS) Efficiency by Client Group



The Length of Stay (LOS) Efficiency indicator is the average change in functional independence (FIM) per day of rehabilitation inpatient stay. This is an indicator developed by UDS^{MR}. It is considered a rough but useful measure of service efficiency; the higher the number the greater the efficiency.

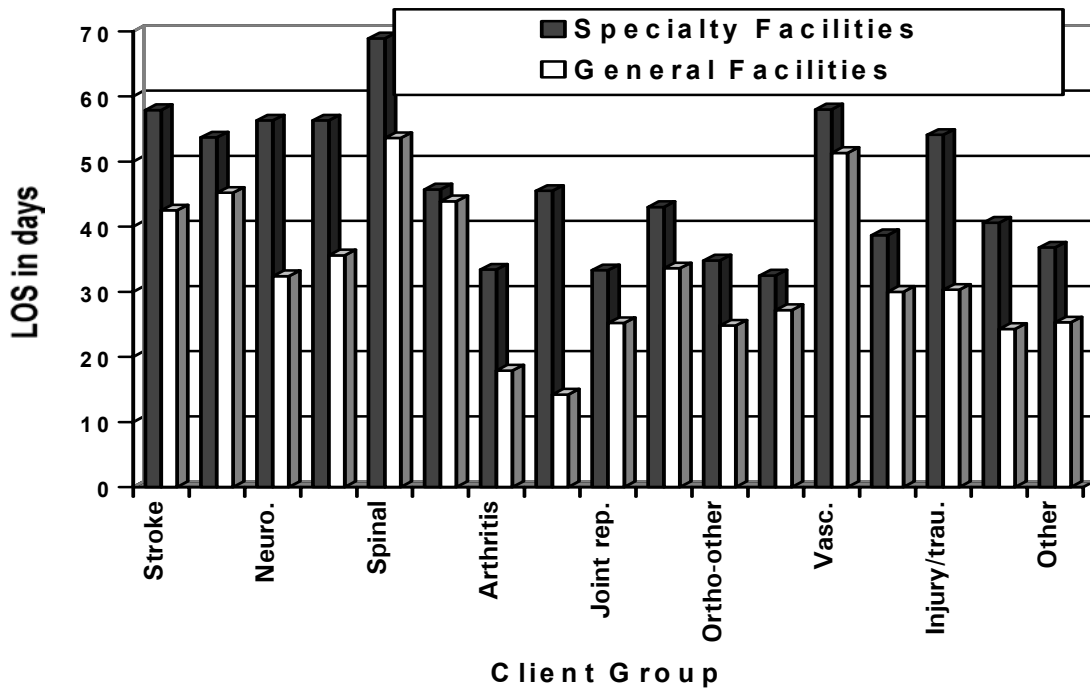
Indicators by Client Group

Reports also present comparative indicators for different client groups. The following table compares two client groups across all specialty sites.

Socio-demographic	Joint Replacement N = 108	Brain Dysfunction N = 80
Average age in years	69.9	40.8
% Gender male	32.4	67.5
% Living at home on admission	98.1	98.8
% Living at home on discharge	93.5	95.0
Administrative		
Average weeks from onset to admission	13.1	43.7
Average length of stay (LOS) in days	33.3	53.7
Average workload/day in minutes	205.6	403.2
% Referral or transfer to other service on discharge	2.8	8.8
Functional Status/Outcome		
Average FIM score on admission	95.9	74.0
Average FIM score on discharge	112.4	105.6
% Improvement in FIM score	17	43
% Clients with improvement in level & impact of pain	59.3	55.0
% Clients with improved general health status	63.9	55.0
% Clients achieving service goals on discharge	95.4	91.3
Average LOS efficiency	0.76	0.63

Average LOS in Facilities by Client Group: Specialty and General Facilities

The following graph presents a comparison of average length of stay across client groups in two site types-inpatient specialty and general sites:



Home Care: Comparative Report for All Client Groups

Socio-demographic	A Home Care Site N = 29	All Home Care N = 113
Average age in years	75.8	68.3
% Gender male	20.7	31.0
% Living alone on admission	55.2	34.8
% Clients receiving full informal support	27.6	48.7
% Clients receiving restricted support	10.3	8.0
% Clients receiving no informal support	3.4	1.0
Administrative		
Average weeks from onset to admission	6.2	144.1
Average duration of service in weeks	13.0	11.2
Average service provider workload (min/week)	70.8	76.5
Average informal workload (min/week)	153.3	177.9
% Referral or transfer to other service at discharge	31.0	16.0
Functional Status/Outcome		
Average FIM score on admission	107.1	109.1
Average FIM score on discharge	117.9	117.6
% Improvement in FIM score	13.7	13.0
% Clients with improvement in level & impact of pain	76.0	83.5
% Clients with improved general health status	45.5	66.7
% Clients achieving service goals on discharge	69.0	82.3

Level of Participation at Discharge

Personal Maintenance	A Home Care Site N = 29	All Home Care N = 113
% Clients with full participation	37.0	51.8
% Clients with at risk full participation	59.3	28.2
% Clients with restricted participation	0	19.1
% Clients with no participation	0	0
Mobility		
% Clients with full participation	14.8	26.4
% Clients with at risk full participation	74.1	46.4
% Clients with restricted participation	7.4	26.4
% Clients with no participation	0	0
Education, Work, Leisure and Spirituality		
% Clients with full participation	25.9	36.4
% Clients with at risk full participation	7.4	13.6
% Clients with restricted participation	0	28.2
% Clients with no participation	0	0

All Home Care Sites: Reports by Client Group

Socio-demographic	Arthritis N = 41	Joint Replacement N = 28
Average age in years	63.6	70.7
% Gender male	73.2	25.0
% Living alone on admission	27.5	39.3
% Clients receiving full informal support	51.2	32.1
% Clients receiving restricted support	7.3	0
% Clients receiving no informal support	0	0
Administrative		
Average weeks from onset to admission	257.4	32.4
Average duration of service in weeks	13.4	10.5
Average service provider workload (minutes/week)	47.8	90.9
Average informal workload (minutes/week)	83.6	150.7
% Referral or transfer to other service at discharge	12.2	17.9
Functional Status/Outcome		
Average FIM score on admission	112.3	109.0
Average FIM score on discharge	116.7	121.9
% Improvement in FIM score	11.0	13.0
% Clients with improvement in level&impact of pain	79.3	92.3
% Clients with improved general health status	50.0	96.4
% Clients achieving service goals on discharge	85.4	82.1

Level of Participation at Discharge

Personal Maintenance	Arthritis N = 41	Joint Replacement N = 28
% Clients with full participation	52.5	57.1
% Clients with at risk full participation	7.5	42.9
% Clients with restricted participation	37.5	0
% Clients with no participation	0	0
Mobility		
% Clients with full participation	22.5	28.6
% Clients with at risk full participation	32.5	64.3
% Clients with restricted participation	42.5	7.1
% Clients with no participation	0	0
Education, Work, Leisure, Spirituality		
% Clients with full participation	20.0	39.3
% Clients with at risk full participation	17.5	14.3
% Clients with restricted participation	50.0	3.6
% Clients with no participation	2.5	0

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