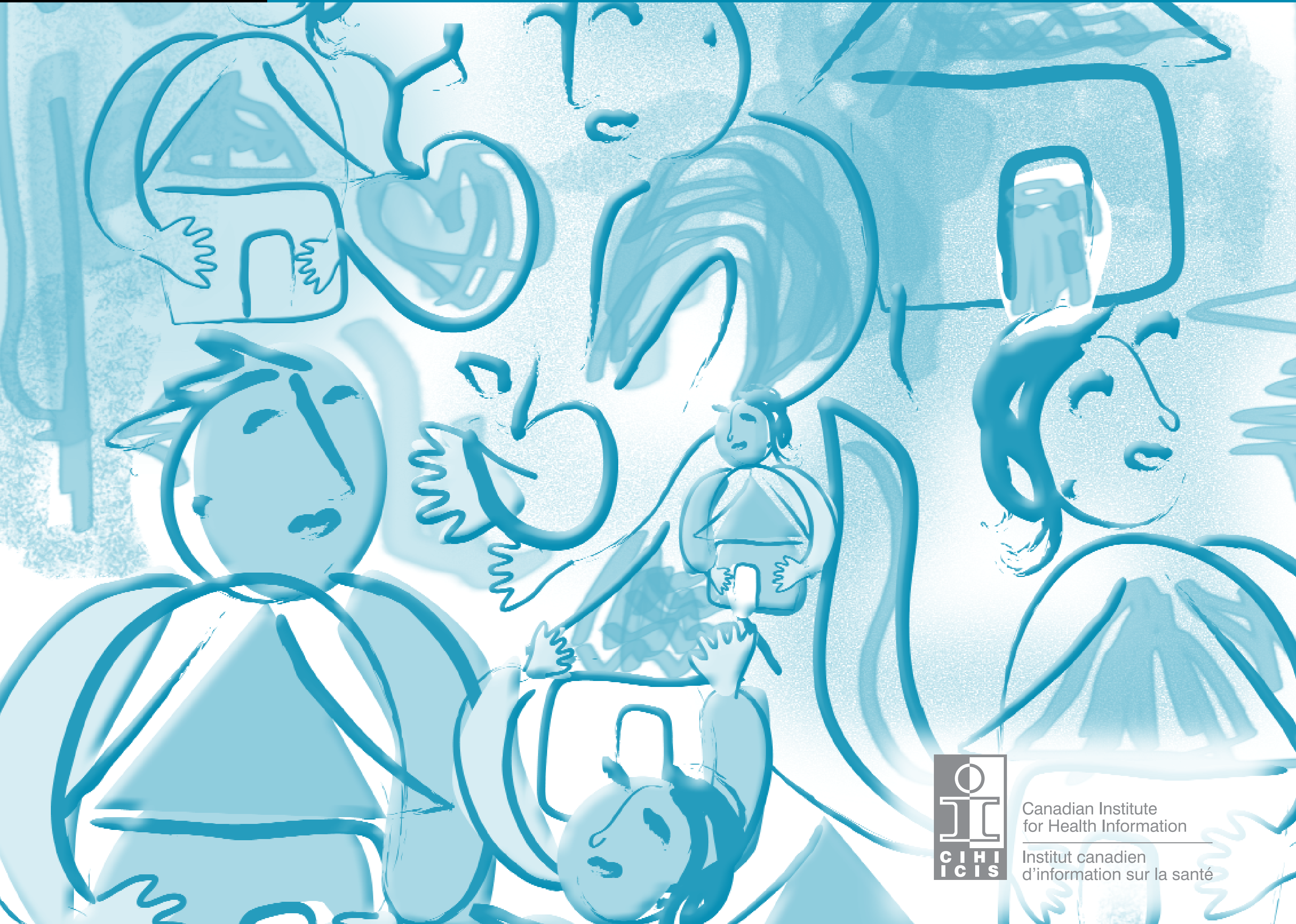
Phase 2

Final Project Report

Development of National Indicators and Reports for
Home Care



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Development of National Indicators and Reports for Home Care—Phase 2 Final Project Report

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- The Burntwood Regional Health Authority, Manitoba
- The Northwest Network Office of the Capital Health Region, Alberta
- The Regina Qu'Appelle Health District, Saskatchewan
- The Fraser Health Authority, British Columbia
- Yukon Department of Health and Social Services, Yukon

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- Dr. D.W. Molloy—*Standard Mini Mental State Examination,* Dundas, Canada: Newgrange Press, 1998, 1999.
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Executive Summary

This report is the final project report of Phase 2 of the *Development of National Indicators and Reports for Home Care Project* undertaken by the Canadian Institute for Health Information (CIHI).

The aims of this phase were to further enhance of the indicators developed in Phase 1 and to conduct a National Pilot Test (NPT) of a minimum reporting data set to populate the indicators.

Between September 2002 and May 2003, data were collected on over 2,000 new home care clients in six health regions across Canada. Information was collected on their demographic and clinical characteristics in addition to administrative and service utilization data relating to their home care service episodes. Pilot sites also provided aggregate information to populate the single financial indicator proposed.

Home care clients are not a homogenous group—they have diverse needs, receive different types of services, for different lengths of time, with different expected service goals. To facilitate meaningful comparisons, CIHI used a set of five core program components to which clients were assigned based on the type of services provided to them: Maintenance, Rehabilitation, Long-Term Supportive Care, Acute Care Substitution and End-of-Life.

The data included in the NPT represents a subset of clients from the pilot sites, as regions excluded some clients for a variety of reasons. The results presented in this report should therefore not be used as benchmarks for these regions. However, many of the findings from the NPT have face validity—in particular they show anticipated variations by core program—and represent an important step forward in understanding home care in Canada. Results from the NPT include:

- Over half of the clients received their first service within 2 days of their referral to the home care program.
- The proportion of clients aged 75 years and over ranged from 19% for Acute Care Substitution, 37% for End-of-Life, 42% for Rehabilitation, 59% for Maintenance to 71% for Long-Term Supportive Care.
- Only 6% of caregivers of Acute Care Substitution clients expressed feeling strain or burden compared with 46% of caregivers of Long-Term Supportive Care.
- As expected, functional outcomes varied by core program: clients in Acute Care Substitution and Rehabilitation programs improved their performance of Activities of Daily Living; Maintenance and Long-Term Supportive Care clients' performance remained relatively stable; and End-of-Life clients' performance deteriorated.
- The median number of service hours received by clients varied from 3 hours 30 minutes among Acute Care Substitution clients to 12 hours for End-of-Life clients and 15 hours 24 minutes for Long-Term Supportive Care clients.

During and after the NPT, CIHI and the pilot sites evaluated the various aspects of the pilot project and highlighted many of the challenges that exist in standardizing information on home care clients in Canada. These "lessons learned" related to how home care is delivered in Canada; the collection of data on home care clients; and about indicator development.

In the NPT, home care was defined as "a range of health and support services received *at home".* However, the NPT found that a number of clients, particularly Acute Care Substitution clients, received their services in other settings, for example, in community clinics run by the home care programs. CIHI has amended its working definition of home care—consistent with Health Canada's definition—to reflect that services delivered through Home Care programs, while not necessarily received at home, enable clients to remain at home.

The NPT data collection represented additional burden to pilot sites in time, cost and human resources, as many of the data elements collected during the NPT were similar to those already collected through their administrative and assessment processes. Pilot sites felt that it would be more effective and efficient if data for comparative reporting flowed from the process of care. They recognized that these processes would require standardization of the foundation data sets, for example through the use of standardized clinical assessment tools.

Although the NPT reporting data set was originally envisaged as a minimum data set, feedback from the pilot sites indicated that the burden of collecting all the data elements for certain clients—particularly the short-term clients—was not justified considering the clients' service needs. The benefits of any data must be weighed against the costs (human and financial) required to collect them.

The NPT confirmed that there is a need to distinguish, at a high level, the different types of clients who receive home care services. However, feedback indicated that such a data element should focus on the characteristics and needs of the clients, rather than the types or level of services provided (as was used in the NPT). While home care clients are likely to be similar across Canada—home care programs vary significantly. In response, CIHI has redeveloped the Core Program definitions to create a "Client Group" data element.

In order to achieve high quality data, the NPT reaffirmed the need for clear, comprehensive and feasible data standards together with ongoing, timely and effective client support and education. Most of the NPT data elements were developed by CIHI specifically for the project. Feedback from the pilot site identified several issues with the definitions of certain elements; highlighting the challenges of creating a valid and reliable measurement tools and the resources required to develop and test them.

The NPT demonstrated that a relatively small number of data elements can populate a wide range of indicators that can be used for accountability purposes. However, their level of detail would be insufficient for meaningful clinical benchmarking to support continuous quality improvement activities. Many clinical quality indicators require some degree of risk adjustment to facilitate fair comparison. Such indicators require a comprehensive clinical data set.

When the project began, there was no consensus across Canada on a standard clinical assessment instrument for home care clients: now many jurisdictions are or will be using the RAI-HC© to assess their long-term clients.

CIHI is currently developing the Home Care Reporting System (HCRS): a repository of comparable clinical, administrative and resource data. It will allow jurisdictions to participate in the reporting of the indicators developed through this project and also incorporates the RAI-HC© to provide the more detailed information required for clinical benchmarking for those jurisdictions using the instrument. CIHI has modified the specifications of the indicators to allow them to be directly populated from the RAI-HC©.

The *Development of National Indicators and Reports for Home Care Project* set the direction for the journey towards comprehensive home care reporting in Canada. Believing that an incremental approach is necessary, based on the very serious challenges of implementing new home care business processes and information systems in the field, CIHI has designed the HCRS to accommodate a phased approach to implementation.

Populating the current set of indicators represents a goal to strive for in the medium term (three to five years) and, with experience and feedback from our data suppliers, we will have opportunities to evaluate their quality and usefulness. We also recognize that ongoing health reform and other significant environmental factors may influence the evolution of the indicator set, as new priorities emerge.

In the meantime, the HCRS project continues to build the foundation for home care reporting and supporting front line providers in delivering better home care services. CIHI will continue to provide opportunities for broad consultation, and at key milestones will report on progress, solicit input and welcome feedback from all key stakeholders.

CIHI Background Information

The Canadian Institute for Health Information (CIHI) is an independent, pan-Canadian, not-for-profit organization working to improve the health of Canadians and the health care system by providing quality health information. CIHI's mandate, as established by Canada's health ministers, is to coordinate the development and maintenance of a common approach to health information for Canada. To this end, CIHI is responsible for providing accurate and timely information that is needed to establish sound health policies, manage the Canadian health system effectively and create public awareness of factors affecting good heath.

Collaboration Is the Key

The Institute’s mandate is based upon collaborative planning with key stakeholder groups, including all provincial, territorial and federal governments, national health care agencies and service providers.

Governance Structure

CIHI is governed by a Board of Directors whose members strike a balance among the health stakeholders, sectors and regions of Canada.

An Overview of CIHI’s Core Functions

The Institute’s core functions are to:

- identify health information needs and priorities;
- conduct analysis and special studies and participate in/support health care system research;
- support the development of national health indicators;
- coordinate and promote the development and maintenance of national health information standards;
- develop and manage health databases and registries;
- fund and facilitate population health research and analysis, conduct policy analysis and develop policy options;
- contribute to the development of population health information systems and infrastructure;
- provide appropriate access to health data;
- publish reports and disseminate health information; and
- coordinate and conduct education sessions and conferences (relevant to our core functions).

CIHI's mandate to provide accurate and timely health information is complemented by its pledge to respect personal privacy, to safeguard the confidentiality of information and to provide secure information systems. To ensure that health data entrusted to CIHI is protected, CIHI has established policies that address data integrity, system security, data access, data linkage, and data disclosure. Also, CIHI personnel sign a confidentiality agreement.

CIHI will publish, report or disclose data only when the requirements and restrictions in *Privacy and Confidentiality of Health Information at CIHI: Principles and policies for the protection of health information* are met. This document is available at www.cihi.ca. Click on "Privacy and Data Protection" under "About CIHI" on the Home Page. CIHI will only publish, report or disclose information that identifies individuals directly or indirectly when:

- the individuals concerned provide consent, or
- laws require the disclosure.

Chapter 1: Introduction and Background

This report is the final project report of Phase 2 of the *Development of National Indicators and Reports for Home Care Project* undertaken by the Canadian Institute for Health Information (CIHI)*.*

The CIHI Home Care Roadmap Project

To address the growing need across Canada for timely and accurate information on home care services, CIHI received funding from the Health Transition Fund (1999–2001) and the Roadmap Initiative (1999–2003) to develop national priority indicators and reports for home care. The Roadmap Initiative is a collaborative effort between CIHI, Statistics Canada, Health Canada, and a number of key stakeholder groups, including provincial and territorial health ministries, to meet priority health information requirements that serve to improve public health and the quality of the health system.

Inconsistencies in data collection for home care services across Canada have made it difficult to characterize the client populations and to understand the services provided, particularly in relation to outcomes. In April 1999, CIHI launched the Roadmap project: entitled *Development of National Indicators and Reports for Home Care* to explore this issue.

The goal of this project was to develop and establish a common set of priority indicators by which health regions, provinces and territories may compare their client and system characteristics, population access, outcomes and resource utilization for the purposes of quality improvement and accountability.

The national Home Care Expert Working Group was convened to oversee the project, which was designed to proceed in two phases:

Phase I involved the development and pilot testing of 19 indicators that could be compiled using existing data. This phase was carried out between April 1999 and May 2001. During the first phase, numerous challenges were encountered in compiling comparable statistics from existing sources. It became clear that a standardized data source was required in order to compile standard statistics on the home care population. Therefore the second phase was initiated in August 2001. Additional information on Phase 1 is available in *Development of National Indicators and Reports for Home Care; Final Project Report April 2001*.[1]

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[1] Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care; Final Project Report April 2001* (Ottawa: CIHI, 2001).

The aims of **Phase 2** were:

- the further enhancement of the Phase 1 indicators, with the addition of important new process and outcome measures; and
- pilot testing of a clinical and administrative minimum reporting data set to populate the indicators.

This report provides information on this second phase of the project.

Working Definition of Home Care

The term "home care" can mean different things to different people. For example, the purpose of care, the range of services provided, the service providers and even the setting in which the services are provided can vary depending on the jurisdiction. Most jurisdictions in Canada have developed provincial definitions of home care to reflect the range and types of services they provide. In fact, differences across Canada in the definition of home care have been one of the fundamental challenges in producing comparable statistics for this sector.

For the purposes of the Roadmap project, a working definition of home care was developed, based on the broad World Health Organization (WHO) definition of health and key concepts used by Health Canada, Statistics Canada, and the Canadian Council on Health Services Accreditation. For Phase 2 of the project the following definition was used, which had been amended slightly from the definition used in Phase 1:

> *"A range of **health and support services** received at home with costs being entirely or partially covered by a national/provincial/territorial health plan. These services enable clients incapacitated, in whole or in part, to live in their home environment. These services help individuals achieve and maintain optimal health, well being and functional ability through a process of assessment, case coordination, and/or the provision of services. Service recipients may have one or more chronic health conditions or recently experienced an acute episode of illness or hospitalization."*

This definition was augmented by a set of core program components proposed by the Federal/Provincial/Territorial (F/P/T) Working Group on Continuing Care in a presentation to the F/P/T Ministers of Health in September 2001. These program definitions provide a common set of concepts to describe the diverse needs of home care clients, families and caregivers across Canada. Core program components for home care include:

1. **Maintenance.** Health and support services, which consist primarily of supervision, psychosocial support and assistance with personal care, activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Services are designed to maintain independence and where possible to enhance client's performance of ADLs and IADLs. Services may be provided over an extended period of time, are not time-limited and may vary from low to moderate intensity. The goal of these services is to prevent/minimize premature decline in health and/or functional status.

2. **Rehabilitation.** Goal-oriented and time-limited health services, which enable individuals with impairments, activity limitations and participation restrictions to identify and reach their optimum mental, physical and/or social functional level. Service provision focuses on abilities and the goal is to improve functional status and facilitate social integration and independence. May include home support services.

3. **Long-Term Supportive Care.** Specialized health services as well as support services consisting primarily of personal care and hands-on assistance with the majority of ADLs and IADLs. Service provision is designed to substitute for services provided by a long-term care facility. Services may be provided over an extended period of time and are not time-limited. The goal of these services is to prevent or delay institutionalization. Service intensity may vary from moderate to high.

4. **Acute Care Substitution.** Specialized health and support services provided to individuals that are intended to promote recovery from an acute episode of illness or surgery and/or for individuals recently discharged from hospital. Services are time-limited and may vary from low to high intensity. The goals of these services are to prevent an acute care facility admission or re-admission and/or to reduce the length of stay in an acute care facility.

5. **End-of-Life Care.** Palliative health and support services provided to individuals, whose health condition is not responsive to curative treatment and who are dying. The intent of this service is to meet the needs of individuals who wish to receive end-of-life care at home. Services are not intended to cure or prolong life, but to alleviate distressing symptoms and to achieve the best possible quality of life for clients and their families.

The intent and intensity of home health and home support services may vary and are based on the assessed needs of each client.

Organization of This Report

Chapter 2 provides an overview of how the indicators and data standard were developed, how the National Pilot Test (NPT) was conducted and how the data were processed and indicator reports produced. It also provides a review of the quality of the data that was collected during the NPT.

Chapters 3 to **5** present the indicators using data collected during the NPT. Where necessary, methodological and/or data quality issues which affected the collection or calculation of the indicators or the interpretation of the results are provided.

Chapter 3 describes the results based on clients' demographic characteristics and personal resources including a description of the NPT sample, the population-based indicators, and indicators related to accommodation setting, living arrangements and informal caregiving.

Chapter 4 contains information on indicators based on clients' clinical characteristics, such as health status, functional status and functional outcomes.

Chapter 5 describes the indicators relating to the health system, such as waiting times, service hours and use of emergency services.

Chapter 6 describes some of the "lessons learned" during Phase 2—in particular the challenges the pilot sites faced in collecting standardized data on the home care population.

Chapter 7 provides an overview of recent developments in jurisdictions' information and reporting needs for the home care population and the development of a pan-Canadian Home Care Reporting System (HCRS) that builds on the foundation of the Roadmap project.

Chapter 2: The Phase 2 National Pilot Test

This chapter provides details on how the indicators and data standard were developed; how the Phase 2 National Pilot Test (NPT) was carried out; and how the data were processed and indicator reports produced. It also provides a review of the quality of the data that was collected during the NPT.

Indicator Development

As part of Phase 1 of the project, a review of the proposed indicators was undertaken. This consisted of an external field review, an evaluation by the participating pilot regions and an evaluation by the Home Care Expert Working Group. Further details on this review can be found in *Development of National Indicators and Reports for Home Care; Final Project Report April 2001*.[2]

In light of the comments received during the review, CIHI produced a set of draft indicators for use in Phase 2 of the project. As with the Phase 1 indicators, the Phase 2 indicators were developed within CIHI's Health Indicator Framework. This framework was developed by CIHI in collaboration with stakeholders and can be found in Appendix A.

A two-day Home Care Expert Working Group meeting was held in October 2001 to review, refine, and prioritize the draft Phase 2 indicators. Appendix B provides a summary of the indicators piloted in Phase 2, while the full descriptions and definitions that were used can be found on the CIHI Website.[3]

Data Standard Development

A minimum *reporting* data set was created containing data elements that were required to calculate the indicators. All but one of the proposed indicators required client-specific data to be collected.

The reporting data set included 43 data elements and the Standardized Mini Mental State Examination (SMMSE),[4] an optional assessment to be applied where appropriate. Wherever feasible, existing data standards were adopted and integrated with permission into the minimum reporting data set.

Detailed descriptions for each data element, including data definitions, coding guidelines, clinical decision trees and recording examples were developed by the CIHI project team. In addition, CIHI developed data collection software to support the electronic submission of data to CIHI.

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[2] Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care; Final Project Report April 2001* (Ottawa: CIHI, 2001) [on-line] at <http:www.cihi.ca>.

[3] Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care; Phase 2 Indicator Descriptions National Pilot Test* (Ottawa: CIHI, 2002) [on-line] at <http:www.cihi.ca>.

[4] D. W. Molloy, *Standard Mini Mental State Examination,* (Dundas, Canada: Newgrange Press, 1998, 1999).

Many of the proposed indicators required information to be collected at the client's admission to a home care program. Other indicators related to outcomes or events that occurred during the home care service episode, and therefore required a follow-up assessment. During the National Pilot Test it was decided to reassess the clients at their discharge or after a 90-day period, whichever was earlier.

The one indicator that did not require client-specific data—Per Capita Regional Expenses for Home Care (Home Health and Home Support)—required pilot sites to provide regional financial data (which included revenues as well as expenditure) for the fiscal year 2001–2002.

Pre-Test and Evaluation of the Data Standard

A pre-test of the reporting data set (for client-specific data) was conducted in collaboration with the Ottawa Community Care Access Centre. The purpose of the pre-test was to assess and finalize the reporting data standard, user guide, education materials and data collection/submission processes to be used during the National Pilot Test phase of the project.

The objectives of the pre-test and evaluation were:

- to test the feasibility of the data collection process;
- to estimate data (inter-rater) reliability;
- to assess the content validity of the data standard; and
- to evaluate the orientation and education materials and processes.

Twelve clients were assessed by two different assessors using the proposed data standard: three teams, consisting of two case managers, each assessed four different clients. The number of disagreements between pairs of assessors was calculated.

Following the data collection period, case managers attended a pre-test debriefing session. Case managers provided feedback on data element definitions, recording guidelines and recording forms and discussed with CIHI program staff issues encountered during data collection. Recommendations for revisions were incorporated into the Phase 2 National Pilot Test version of the data standard and data collection processes.

A list of the resulting data elements collected during the NPT can be found in Appendix C, while a full description of the data element definitions can be found on the CIHI website.[5]

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[5] Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care; Phase 2 Data Definitions National Pilot Test* (Ottawa: CIHI, 2002) [on-line].

The National Pilot Test

The objectives of the National Pilot Test (NPT) were to:

- test the feasibility of collecting required data on all new clients entering home care programs in each pilot region;
- estimate the reliability and content validity of the reporting data set, including the classification of clients by core program and health and functional status measures;
- evaluate the quality and usefulness of the indicators; and
- evaluate the orientation/education materials and processes.

Site Selection

From December 2002 to March 2003 CIHI program staff actively recruited potential pilot sites using a variety of communication strategies including direct communication with senior representatives from provincial/territorial ministries of health. In addition, members of the Home Care Expert Working Group were involved in successfully recruiting two of the six pilot sites.

The following criteria were used in selecting health regions to participate in the NPT:

- geographical representation from across the country;
- consent by the health region's governing body to participation in the NPT, to the release of required data, and to the reporting of indicator results;
- provision by the health region of a range of health and support services in which all of the proposed core programs are represented;
- provision by the health region of resources required for staff training, site coordination and data collection over the pilot test period; and
- a mix of urban and rural regions.

The following six pilot sites were selected for participation in the NPT:

Pilot Site	Short Name*
Health and Community Services—St. John's Region, Newfoundland and Labrador	St. John's
Burntwood Regional Health Authority, Manitoba	Burntwood
The Northwest Network Office of the Capital Health Region, Alberta (which covered the majority of the City of St. Albert and other surrounding areas)	Capital (NW)
The City of Regina within the Regina Qu'Appelle Health District, Saskatchewan	Regina
The City of Burnaby within the Fraser Health Authority, British Columbia	Burnaby
Whitehorse and Dawson, Yukon	Whitehorse

*This is how the pilot site is referred to within the remainder of this report.

Appendix D provides details on the home health and home support services provided by each health region, the eligibility requirements for these services, and some information on the population living in each region.

Education and Site Preparation

All participating pilot sites received a two-day orientation and education session with a CIHI consultant. The session was developed as a "train-the-trainer" session and incorporated feedback received from the pre-test. The primary objectives of the education sessions were to:

- provide site coordinators and trainers with information and tools to accurately interpret, code and submit client-specific home care indicator data to CIHI;
- evaluate the performance of participants on interpretation of the coding guidelines through the use of case studies;
- qualify participants to train other clinical staff in collection of data using the CIHI data collection tool;
- provide guidelines for inter-rater reliability data collection;
- outline roles and responsibilities of pilot sites and CIHI for data collection, data entry and submission, site support and other related activities, including time lines; and
- provide site coordinators with recommendations for managing the project on site.

Pilot site trainers did not necessarily carry out any of the data collection themselves. They trained the front-line staff who were to carry out the assessments and provided support to clinical staff and guidance on how to accurately interpret and code the data elements.

Data Collection and Submission

For five of the six pilot sites, data collection took place during a six-month period between September 2002 and March 2003. The start of data collection in the Regina pilot site was delayed due to industrial action. Therefore, their data collection period ran from November 2002 to May 2003.

Initial assessments were carried out on all new clients entering the pilot sites' home care programs during the first three months. Follow-up data were collected on each client at 90 days or at time of discharge, whichever came first.

Pilot sites were provided with two alternatives for data collection—paper-based data recording and electronic real-time data collection. This second option was not selected by any of the pilot regions.

CIHI provided sites with standardized forms to be used during data collection. There were four different forms:

- an admission form for adult clients (clients aged 18 years and over) that included the SMMSE to be completed if necessary;

- a discharge/reassessment form for adult clients;
- a pediatric assessment form; and
- an inter-rater reliability form.

The special pediatric form was designed because it was decided only a limited number of the proposed data elements were applicable or appropriate for pediatric clients. These were mainly non-clinical data elements from the initial assessment, plus two data elements from the reassessment form that were required to calculate the waiting time indicators.

One of the data quality activities carried out during the NPT was an inter-rater reliability study. Such studies require at least two raters to assess the same client in the same way and, ideally, under the same conditions. Pilot sites were therefore asked to conduct a second assessment on a sample of their clients, within 48 hours of the sampled clients' initial admission assessment. A special form was used to collect the data from the inter-rater assessments, as not all data elements from the initial assessment were included in the inter-rater study. Further details on the inter-rater reliability study are discussed in the "Data Quality section of this chapter and also in *Development of National Indicators and Reports for Home Care—Phase 2: Report on Data Quality Activities*.[6]

All the pilot sites had their own admission procedures that included some form of initial assessment. In many cases the information required by the NPT was similar to information collected in the pilot sites own initial assessments. For example, in some cases data elements had the same definition but had different coding structure and instructions. As pilot sites had to continue with their own assessment procedures in addition to collecting the data required for the NPT, pilot sites dealt with the dual data collection in one of two ways. The first method involved integrating the NPT data elements into their initial assessment process. The second method involved pilot sites continuing to do their own initial assessments and then transcribing the data onto the NPT forms back at the office.

Whichever method was employed, the collection of the NPT data elements added time onto the initial assessment process. The time to complete the NPT assessments in the clients' homes was usually between 30 minutes and an hour. The assessments took longer if the client was elderly or cognitively impaired (as the SMMSE had to be completed). Transcribing data from the pilot sites' assessments to the NPT forms added approximately 15 minutes to administration time.

The reassessment of adult clients took approximately an hour. These reassessments represented extra time and resources for the pilot sites, as they did not usually reassess their clients after 90 days or at discharge. In many cases, a special visit to carry out the reassessment was required—in particular when the last service visit was not made by a home care service provider trained to do the NPT reassessments. Full reassessments could not always be carried out. If the client died, discharged himself or herself, or moved without informing the pilot site, the reassessment of their functional performance could not

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[6] Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care—Phase 2: Report on Data Quality Activities,* (Ottawa: CIHI, 2004).

be completed. For these clients, only administrative data (such as date of discharge, service hours) was collected at reassessment. This affected the analysis of functional outcomes, the impact of which is described in Chapter 4.

Admission and discharge/reassessment data for adult clients that were recorded on paper-based forms were entered into CIHI-developed data entry software (an Access application) by data entry clerks in the pilot sites. Electronic data files were sent by diskette to CIHI at fixed time intervals. Pediatric admission assessment forms and inter-rater reliability assessments forms were sent to CIHI for data entry.

A CIHI consultant supported pilot sites during the data collection and submission period. Client support was mostly provided by telephone and e-mail. In addition, regular teleconferences were held with all pilot regions to provide project updates, answer common questions, and provide specific information on inter-rater reliability testing and data quality issues.

There was a separate data collection process to gather the regional financial information. CIHI developed an excel spreadsheet listing the types of regional revenues and expenditures on home health and home support services. The spreadsheet contained guidelines on what should be included in each type revenue/expenditure. A spreadsheet was sent to each pilot site, the necessary information was filled in and returned it to CIHI.

Data Processing

After their submission to CIHI, data were loaded into an Oracle database. After the submission deadlines, cuts of this database were taken and converted to SAS for review and analysis by the CIHI home care program team.

Several issues with the data were discovered through a preliminary review by the home care program team.

Firstly, a number of duplicate records had been created and had to be removed. These duplicates were created when the pilot sites discovered that errors had been made in the entry of the clients' identifying information (such as date of birth, chart number or health card number). These data elements were used in combination to uniquely identify records within the data entry application; if one of these elements was amended, a new record was created. Records were identified where only one personal identifier was different (for example, same date of birth and chart number but different health card numbers). Details of these records were sent back to the pilot sites for review and the incorrect records were then removed from the CIHI database.

CIHI program staff also checked the completeness of the submitted records. During the NPT data collection phase, program staff was able to monitor the progress of the pilot sites' collection. At the end of data collection, this review ensured CIHI had received all the expected data. In particular, this review identified any adult clients who had missing reassessments or where individual data elements had not been entered. Many records with missing reassessments were duplicate records and were therefore deleted. Details of all other records with missing information were sent to the pilot sites. In all but three cases, the pilot sites then submitted the missing data. There were three clients who had initial assessments carried out, but at the end the NPT data collection were still on the waiting list to receive service, meaning the reassessment information was not collected. As the NPT indicators were designed to provide information on home care clients who had received service, it was decided to delete these three records from the database.

A series of checks were run on the final data submissions that identified potential errors and inconsistencies in the assessment records (for example, date of discharge before date of first service). Again, details of the inconsistencies were sent to the pilot sites for review. Any corrections that were required were sent back to CIHI and incorporated into the final database.

The St. John's pilot site supplied data from two independently run programs—Community Based Teams and Community Living and Support Services; the data from these two programs were also sent to CIHI independently. Special analysis was undertaken on these data to identify any clients who had received services through these two programs concurrently. Two clients were identified and, for analytical purposes, the information from the two sources was combined into a single record for each client.

Prior to the compilation of the indicator reports, data summaries (in Excel) were produced for each pilot site for review and sign-off. These summaries provided frequency distributions for the data elements collected during the NPT, for adult clients and pediatric clients separately.

Production of Indicator Reports

Indicator reports were produced (in Excel) for each pilot site. Each pilot site received an indicator report based on data from their own pilot site and one for all the pilot sites combined. All results were provided by core program and for all clients combined. Some of the results in the combined report were suppressed for confidentiality reasons (see below). Pilot sites also received documentation to assist their use and interpretation of the reports.

The reports provided the results for the proposed indicators, the majority of which could be calculated from the client-specific data held at CIHI. However, in order to create the population-based indicators, additional information—estimates of the population living in each area—was required from Statistics Canada, who provides such estimates for their standard geographical classifications and health regions. Only two of the six pilot sites were complete health regions (St. John's and Burntwood). The other four sites were only selected offices or areas within their respective health regions. In these cases, the Census Subdivisions with the closest matching geographical coverage to these areas were used for the population-based indicators. Only those clients who lived in those areas were included in the numerator of the indicator. Chapter 3 provides more details on this process.

For certain indicators, alternative calculations were presented in addition to the proposed calculations. For example, the proposed indicator for wait times was the arithmetic mean number of days. However, as Chapter 5 shows, the distribution of wait times was highly skewed. For such distributions, it is usually more appropriate to use the median rather than mean to describe the central tendency of distribution. The indicator reports therefore provided both the mean (as proposed) and the median wait times.

In addition to the indicators, the reports provided supplemental information which included a demographic profile of the clients within each core program, more detailed breakdowns of indicators, frequency distributions of individual ADL and IADL elements which were combined to form the proposed indicators on function status and outcomes.

Data Quality

CIHI has incorporated five dimensions of data quality into its corporate *Data Quality Framework*, first implemented during the fiscal year 2000–2001. When used as a conceptual framework, these dimensions can facilitate the assessment of data quality in many types of system-level data holdings. These five dimensions are:

- *Accuracy*—the information collected reflects what was supposed to be collected;
- *Timeliness*—data are available to users when they need it;
- *Comparability*—data can be compared with information from other health information systems and be compared over time;
- *Usability*—information can be easily understood and is accessible; and
- *Relevance*—the information meets the needs of users.

The following sections describe some of the activities and issues relating to the *Accuracy* and *Comparability* of the data collected during the NPT.

Coverage

One major aspect of ensuring accurate data is that information is collected for all those included in the target population. For the NPT, the target population was all newly admitted home care clients to each pilot site. After the data collection, the pilot sites provided information on whether or not any new clients had been excluded from the NPT data collection, and if so the reasons why they had been excluded.

It should be noted, while certain clients were excluded from the NPT data collection, they still received the usual services carried out by the home care program at referral and admission (for example assessment of service need, eligibility and/or clinical status).

Based on estimates produced in the planning stages of the NPT, it was expected that the NPT would collect data from around 3,500 new admissions to home care. However, the actual number collected was 2,254 admissions, around two-thirds of the original estimate.

Two pilot sites, Regina and St. John's, accounted for the vast majority of the shortfall in the number of admissions. While their estimated numbers of admissions were fairly accurate, they did not collect NPT data for a number of their new clients, for a variety of reasons.

Regina estimated that they would have around 1,200 admissions, but only provided data for around a third (389) of their new admissions. Regina excluded clients who were:

- direct referrals for occupational therapy and/or physiotherapy services—most likely because none of the therapists who would usually assess clients at admission were trained to carry out the NPT assessments);
- Palliative Care clients—this program is completely separate from the other home care services and were not included in the NPT training or data collection; and
- clients who would only have one home care visit, as the pilot site felt the burden of the NPT data collection was too high.

This latter group of clients—who accounted for almost half of clients admitted to the Regina pilot site during the NPT—mainly required suture removal, which was performed at a treatment centre (and would likely to have been considered Acute Care Substitution clients).

St. John's provided data for around two-thirds of their new admissions (estimated and actual). Clients were excluded if they were:

- referred for financial services only;
- self-referred to become a caregiver;
- referred for a long-term placement assessment and received no other home care services; or
- referred for laboratory services, medical supplies or nutrition counselling; and
- were admitted between December 16 and 20—due to workload staffing issues and resulted in 200 initial assessments not being completed.

In most pilot sites, a small number of clients refused to participate in the NPT data collection. Other reasons for clients' initial NPT assessment not being carried out included: living in a remote area; staff shortages; bad weather; and language problems.

In addition, the Whitehorse and Burntwood pilot sites did not include First Nations' clients who received homemaking services through the First Nations and Inuit Health Branch of Health Canada.

It is estimated that the NPT collected information on around two-thirds of the new admissions in the pilots. However, the characteristics of those included in the NPT may not necessarily reflect the characteristics of all newly admitted clients to the pilot sites, particularly in those sites where particular programs or types of clients were excluded.

Therefore, while the results presented in this report should not be used as benchmarks for these regions, the NPT has provide useful "ballpark" information and insight into home care across Canada; and confirmed that the proposed indicators can be calculated.

Comparability

Comparing data on home care across Canada is difficult as home care clients are not a homogenous group—they have diverse needs, receive different types of services, for different lengths of time, with different expected service goals. In addition, the types and organization of home care programs provide to meet these needs, and the eligibility requirements for those programs also varies (Appendix D provides a description of the home care programs available in the pilot sites).

To facilitate meaningful comparisons of home care clients across the myriad of home care programs within Canada, CIHI developed a set core program components (see Chapter 1). Within this report, the majority of the analysis was carried out by core program.

In addition, particular care should be taken in comparing results across pilot sites, due to the coverage issues described above. For example, no clients from Regina's Palliative Care program were included in the NPT, therefore any clients included as "End-of-Life" would not be representative of all such clients in Regina, and nor would their data be comparable with other End-of-Life clients in other pilot sites.

Most of the analysis within this report is based on adult clients (aged 18 years and over). This is not only because only a limited number of data elements were collected on pediatric clients, but also because not all pilot sites provided home care services to pediatric clients. For example, in British Columbia, a different provisional ministry (Ministry of Children and Families) is responsible for delivering health and social services to children up to the age of 19.

Collection and Capture

To facilitate high quality, standardized data collection across the six pilot sites, CIHI provided a two-day orientation and education session to each pilot site to enable pilot sites to train their staff to collect the NPT data elements. CIHI also provided standardized data collection forms. During data collection, pilot site trainers and CIHI staff were available to provide client support.

As the data were collected on paper, they needed to be transferred to an electronic format. Such transfers can be a source of error in the data, therefore a quality assurance exercise was carried out that checked the information submitted to CIHI against the information on the original paper assessment forms. The exercise also assessed the impact of any errors on the analysis and reporting of indicators that would be based on these data.

A 10% random sample of client episodes was selected for verification. Details from the CIHI database were sent to the pilot sites to check against the information on the paper assessment forms. The pilot sites reported back on whether the records contained any errors, and if so, which elements had been entered incorrectly and what the correct value was.

This exercise showed that there was generally a high level of accuracy in the data entry of the NPT data. Overall, 33 of the 401 (8.2%) assessment forms checked had one or two data entry errors (no form had more than two errors). Forty-two errors were found in the 12,128 data elements entered, giving an "element" error rate of 0.35% or 3.5 elements per 1,000 elements entered.

Errors in date elements accounted for over half of all the data entry errors found. Date of Birth and Date of Assessment had the highest number of errors. However, the errors that did occur had very little impact on the estimates based on the data.

Further details on the data entry quality assurance exercise can be found in *Development of National Indicators and Reports for Home Care—Phase 2: Report on Data Quality Activities*.[7]

Inter-Rater Reliability

Most of the coding of the data elements collected during the NPT required subjective clinical decisions to be made by the clinicians carrying out the assessments. Therefore a key aspect of the quality of such data is the *consistency* or *reliability* with which these elements are coded.

As part of the NPT, an "Inter-Rater Reliability Study" was carried out to measure the extent to which different assessors coded the NPT data elements for the same client in the same way. A summary of the methods and findings from this study are presented below and further details can also be found in *Development of National Indicators and Reports for Home Care—Phase 2: Report on Data Quality Activities*.

Measurement of inter-rater reliability requires at least two raters to assess the same client in the same way and, ideally, under the same conditions. Pilot sites were therefore asked to conduct a second inter-rater assessment on a sample of their clients—to be conducted within 48 hours of the client's first assessment, in order to minimize the likelihood of the client's health status changing between the two assessments.

The sample size of the reliability study was 165. This was somewhat smaller than anticipated due to fewer clients being included in the NPT and problems pilot sites encountered in conducting the reliability assessments within the specified time limit. However, the sample was still sufficient to measure the reliability of the majority of data elements.

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[7] Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care—Phase 2: Report on Data Quality Activities,* (Ottawa: CIHI, 2004).

The following data elements from the admission assessment were assessed for inter-rater reliability:

- Birth Date
- Date of First Contact for Initial Assessment
- Core Program Component
- Support for Informal Caregivers
- Primary Functional Impairment Group (for Maintenance and Long-Term Supportive Care clients only)
- Rehabilitation Client Group (for Rehabilitation Clients only)
- Most Responsible Health Condition (for Acute Care Substitution and End-of-Life clients only)
- Presence of Cognitive Impairment
- Eight Activities of Daily Living (ADLs)
- Six Instrumental Activities of Daily Living (IADLs)

Overall, the level of inter-rater reliability for most items tested was moderate or better (kappa statistics greater than 0.4).

The study identified a few data elements where further clarification of definitions, coding practices and greater emphasis in training sessions would be of benefit.

Support for informal caregivers showed poor inter-rater reliability. Assessments did not record who the primary informal caregiver was, so it was possible raters could have identified different caregivers, and assessed their levels of support accordingly. Pilot sites reported that staff found this element was not clearly defined and therefore they had problems with coding consistently.

The *most responsible health condition* had moderate percentage agreement, which was lower than expected. This data element was coded using a picklist of ICD-10-CA codes.[8] Agreement did not increase substantially when the data were aggregated to “chapter” level. Within ICD-10-CA, there are codes that allow assessors to record states or the need for care following medical intervention. Many of the discrepancies were the result of one assessor using one of these codes and the other assessor coding a specific health condition. Other discrepancies appear to have been the result of unfamiliarity with the coding frame.

Most of the *ADL* and *IADL* elements showed at least moderate reliability. Feedback from pilot sites suggested some staff had difficulty in differentiating between the categories of the scale used.

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[8] Canadian Institute for Health Information, *The International Statistical Classification of Diseases and Related Health Problems, 10th revision, Canada (ICD-10-CA)* (Ottawa: CIHI, 2001).

Concerns were also raised about the validity of the *Outdoor Locomotion* and *Bathing* data elements as a result of the coding guideline that if the activity did not occur the client should be coded as "dependent". It was felt that this was not appropriate during a Canadian winter when a client's ability to go outside could be affected more by the weather than his or her own functioning ability. Likewise, if clients chose to bathe less than once every three days they would be assessed as being "dependent" even though it was through personal choice rather than any problems in their performance. If the frequency of bathing varied across Canada or among certain types of clients, the comparability of this ADL activity will be comprised.

The reliability of *ADL* and *IADL* elements appears to be lower in the CIHI reliability study than for similar items in other inter-rater reliability studies of clinical assessment tools for home care clients. However, care needs to be taken in comparing these studies as the items assessed were not identical, and the characteristics of the clients who participated in the studies were different. In particular, the majority of the CIHI reliability study was made up of Acute Care Substitution and Rehabilitation clients, who may be more likely to show improvements within the 48-hour period specified to carry out the two assessments.

The reliability of the Primary Functional Impairment Group[9] and the Rehabilitation Client Group[10] could not be calculated due to small sample sizes of client in the relevant core programs.

Non-Response

Many of the individual data elements allowed for "unknown" or other missing responses to be coded. This missing information is referred to as "item non-response". Information on the level of non-response provides an indication of how representative the data are. The higher the level of non-response, the greater the risk of data not being representative of the population as a whole; that is, the information may be significantly different if data were available for all clients.

In general, item non-response was low, with a few exceptions. The following table shows those data elements that had five or more unknown responses.

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[9] Coded using a picklist of functional impairments based on the International Classification of Functioning, Disability and Health. World Health Organisation, *International Classification of Functioning, Disability and Health (ICF),* (Geneva, 2001).

[10] The Rehabilitation Client Groups used in the NPT were adapted from the UDS^{MR} impairment codes. Copyright© 1997 Uniform Data System for Medical Rehabilitation, a division of U B Foundation Activities, Inc., all rights reserved. Used with permission.

Data Element	Non-Responses		Records Where Data Element Was Applicable
	#	%	
Birth Date Estimated*	9	0.4	2,254
Postal Code of Residence	85	3.8	2,254
Support for Informal Caregivers	10	0.6	1,661
SMMSE	120	46.2	260
Service Goals Met	32	1.5	2,179
Service Goals Modified	24	1.1	2,179
Temporary Transfers to Short-Term/Transitional Beds	13	0.6	2,179
Use of Emergent Care Services	11	0.5	2,179

*This data element indicated whether or not any part of the client's date of birth was estimated.

The table shows that the SMMSE test was not completed for almost half of the clients who should have had the test (that is, those showed an indication of cognitive impairment). This high level of non-response, and the potential bias that it could cause, prevented the calculation of the "Presence of Cognitive Impairment" indicator. This issue is discussed further in Chapter 4.

Postal code of residence also had a relatively high rate of non-response (3.8%). This data element was required for the population-based indicator, and was used to determine whether or not the client lived within the boundaries of the health region/pilot site. For the purposes of the NPT, those clients with an unknown postal code were assumed to live within the boundaries of pilot site/health region and were therefore included in the population-based indicators.

Non-response also occurred during the reassessment of ADL and IADL performance of adult clients. Although the intention was to assess all adult clients' ADL and IADL abilities at their initial assessment and their reassessment, the functional abilities of some clients could not be reassessed as they had either died, been admitted into an acute care facility or had moved and could not be traced. Although pilot sites attempted to get ADL and IADL information for some of those clients who had died, they met with limited success and it was decided to exclude all clients who had died from all analyses on ADL and IADL activity at reassessment and change in functional ability. Overall 5% of adult clients were excluded: 51% of End-of-Life clients were excluded, 7% of Long-Term Supportive Care clients and no more than 4% of clients in the other core programs.

"Other" Responses

During the NPT, a number of data elements allowed for "other" to be coded, if assessor could not fit the clients' circumstances or condition into the coding frame provided. High usage rates of "other" codes can indicate problems with the coding frame—for example, it is incomplete or unclear—or can be an indication that users are unfamiliar with its contents. After the data were collected, the rates of use of these “other” codes were analyzed and the pilot sites were asked to provide the reasons why the code had been used.

After the review and analysis, some data elements originally coded as “other” were recoded. In an example of using “other” when the data element was unclear, one pilot site had originally the Primary Service Delivery data element as “other” if clients received their home care at their ambulatory clinics, which should have been coded as “ community-based organizations”.

There appeared to be some evidence that assessors required more experience in using the picklists to code the most responsible health condition (based on ICD-10-CA) and primary functional impairment grouping (adapted from the International Classification of Functioning, Disability, and Health[11]) given that almost all (23 of 28) of the occurrences of “other” in these data elements were recoded.

Quality of Financial Data

Data were collected from every region to populate the single financial indicator proposed: Regional Home Care Expenditures per Capita. The challenge of this exercise related to the ability of the regions to consistently allocate all costs relating to delivery of home health and home support services as defined for the NPT.

Assistance was received from the CIHI MIS experts in ensuring clear specifications for reporting. Validation with another source was only possible for the Yukon region, which as a compete territory, has expenditures reported in the National Health Expenditures Report.[12] Significant problems were encountered with compiling the necessary data for St John’s—home health and home support expenses from various organizations needed to be included, however these organizations did not have the same geographic boundaries and no methodology existed for extracting the information that relating to the St John’s regional boundaries. Preliminary analysis of the indicator, excluding St John’s data, revealed unexpected variation that will require further investigation. Given these data quality concerns, the financial indicator will not be reported in this publication, as further work is required.

Privacy, Security and Confidentiality

The NPT collected personal health information on home care clients and therefore the data collection, submission, storage and dissemination had to conform to the privacy, security and confidentiality guidelines and policies of CIHI and of the respective pilot sites.

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[11] World Health Organisation, *International Classification of Functioning, Disability, and Health (ICF),* (Geneva, 2001).

[12] Canadian Institute for Health Information*, National Health Expenditure Trends 1975–2003,* (Ottawa: CIHI, 2003).

Personal identifiers collected during the NPT were:

- Health Card Number;
- Chart Number (the client's unique identification number as assigned by the home care program);
- Date of Birth;
- Sex; and
- Postal Code of Residence.

The names of home care clients were not sent to CIHI.

Each of the pilot sites had different privacy legislation and policies to adhere to and therefore took different steps to modify their clients' personal identifiers before submitting their data to CIHI:

- Three pilot sites encrypted clients' Health Card Numbers;
- Two pilot sites truncated clients' Date of Birth—providing only the month and year of birth; and
- One pilot site truncated the Postal Code of Residence—providing only five (rather than six) characters.

All data files that contained client personal identifiers were transferred between the pilot sites and CIHI via courier. After the data were received by CIHI, they were loaded into a restricted access database, which conformed to CIHI's security policies. For queries CIHI had regarding individual records that required investigation by the pilot sites, CIHI gave the clients' Chart Number and date of assessment to the pilot site, in order for them to locate the correct information within their own system. The clients' Chart Number was used, as it had no intrinsic meaning to anyone other than the pilot site themselves.

All the results produced from the NPT adhere to CIHI's guidelines and policies that govern the publication and release of information.

In compliance with these guidelines, any data from the pilot sites that was to be shared with others (that is, the analysis contained within this report and the pilot sites' indicator report containing data for the sites combined) were reviewed prior to release. Cell counts within data tables that were between one and four were combined with other cells, where appropriate. If such aggregation was inappropriate or unfeasible the counts and related statistics (including figures based on these statistics) were suppressed. In certain circumstances, some cells with counts greater than four were also suppressed. This was done wherever the reader would have been able to determine the suppressed value through subtraction from other cells. Therefore, within a table, each row and column containing a suppressed count of one to four, there is at least one additional suppressed cell.

Chapter 3: Demographic Characteristics, Personal Resources and Population-Based Indicators

This chapter provides an overview of the data collected during the NPT on the clients' demographic characteristics and personal resources. It includes a description of the NPT sample, the population-based indicators, and indicators related to accommodation setting, living arrangements and informal caregiving. Some indicators are supplemented with analyses of other data elements that were collected during the NPT. Where necessary, the chapter reports on methodological and/or data quality issues that affected the collection or calculation of the indicators or the interpretation of the results.

It should be noted that the original intention for NPT reporting was that the indicators be presented separately by core program for each pilot site. While the individual pilot sites received indicator reports for their own region broken down by core program, in many cases the sample sizes were too small to make the same information publicly available. Therefore the analyses in this chapter are generally based on the combined data for all six pilot sites broken down by core program.

Some of the indicators are presented by pilot site, where it was thought that there could be significant differences across sites (such as population utilization, primary service delivery setting). However, it should be noted that the results presented within this report are based only on a subset of newly admitted clients from the pilot sites (see Chapter 2 for more details), and may not necessarily reflect the characteristics of the overall home care population within those pilot sites.

The NPT Home Care Sample

Before discussing the indicators themselves, it is important to understand the home care population on which the indicators are based. This section provides information on the distribution of clients across the pilot sites and core programs, and on clients' demographic characteristics.

Sample Size

During the Home Care National Pilot Test (NPT), information was collected on 2,229 individual home care clients across the six pilot sites, who were admitted to home care programs during the NPT data collection period. Virtually all clients (99%) had only one referral and admission to the home care program during this period. After 90 days, the clients were either still receiving home care services or had been discharged without readmission. Twenty-four clients had subsequent admissions after their initial discharge from the home care program: 23 clients had two admissions to the same home care program within the data collection period and one client had three admissions. The period of care received by a home care client for each separate admission is referred in this document as a home care service episode. The St. John's pilot site had two home care programs that submitted data to CIHI independently of each other. During the data collection period, two clients had home care services concurrently from these two programs. For the purposes of the pilot, these were treated as single episodes and the information from the two programs was combined.

In total, the NPT collected information on 2,254 home care service episodes.

Number of Home Care Service Episodes by Pilot Site

The six pilot sites were chosen to cover a range of regions with different characteristics: from large urban areas with relatively large populations that would have a large volume of home clients; to remote regions, that are geographically large but have small populations and therefore fewer home care clients. See Appendix D for more details on the regional profiles of the pilot sites.

As the table below shows, the number of home care service episodes within each pilot site reflected these differences.

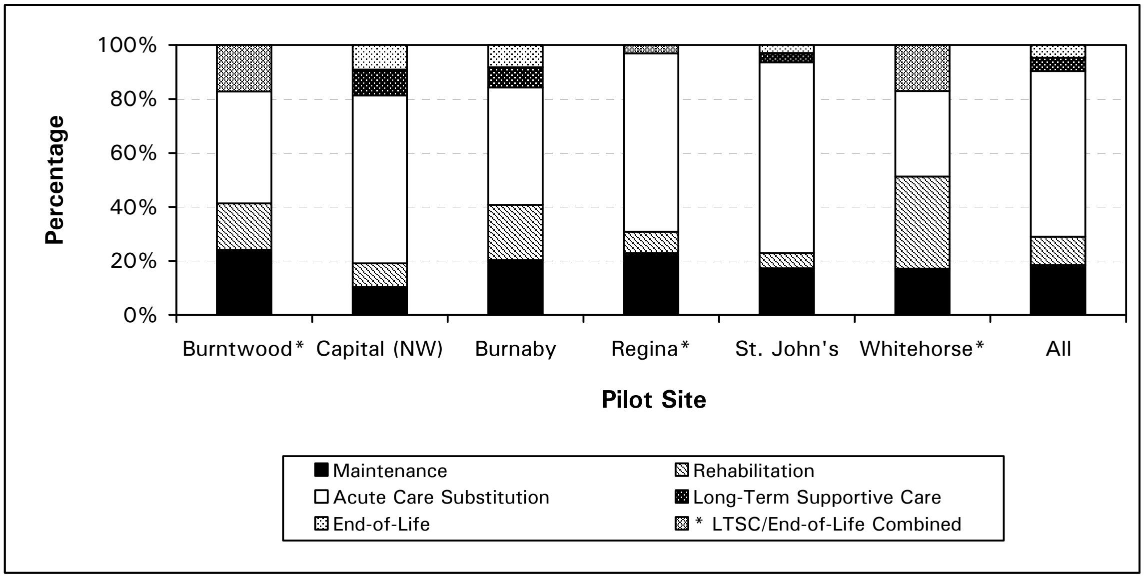
Pilot Site	Number of Episodes	Percentage of Total
St. John's	1,029	45.6
Burntwood	29	1.3
Capital (NW)	230	10.2
Regina	389	17.3
Burnaby	536	23.8
Whitehorse	41	1.8

St. John's had the largest number of home care service episodes, accounting for almost half (46%) of all service episodes in the NPT. By contrast, Whitehorse and Burntwood had small numbers of service episodes (41 and 29 respectively) and therefore care should be taken when interpreting the results for these pilot sites.

Home Care Programs by Pilot Site

Figure 3.1 shows the distribution of home care service episodes across the different core programs for the individual pilot sites and for the combined sample. It should be noted that the data for Long-Term Supportive Care and End-of-Life clients were combined in the Burntwood, Regina and Whitehorse pilot sites due to small sample sizes.

Overall, Acute Care Substitution episodes accounted for the majority (61%) of home care service episodes. The next largest programs were Maintenance and Rehabilitation, which accounted for 18% and 11% of episodes respectively. Long-Term Supportive Care and End-of-Life Care programs accounted for the smallest number of episodes, each accounting for 5%.



*Due to small numbers, data for Long-Term Supportive Care and End-of-Life clients in Burntwood, Regina and Whitehorse are combined.

Figure 3.1. Distribution of NPT Clients by Core Programs and Pilot Site

There were differences in the distribution of episodes by core program among the pilot sites. In five out of the six sites, Acute Care Substitution accounted for the largest proportion of home care service episode, however this proportion ranged from 41% in Burntwood to 71% in St. John’s. Acute Care Substitution accounted for only 32% of episodes in Whitehorse, with 34% of episodes being assigned to the Rehabilitation group. As previously mentioned these proportions should be interpreted with care as they are based on small numbers.

Some of the observed differences may reflect the different service programs available in each pilot site (see Appendix D for further information). However, care should be taken when interpreting these statistics as they are based only on a subset of all newly admitted clients; a significant number of clients were excluded from the NPT data collection in Regina and St. John’s in particular.

Demographic Characteristics

In 56% of the home care service episodes the clients were female; in the remaining 44% of episodes the clients were male.

Figure 3.2 shows the age distribution of clients at their initial assessment. Almost a third (32%) of all clients were aged 75 years and over at the beginning of their home care service episodes: 21% were aged 75 to 84 years and 11% were aged 85 years and over. A further 20% of clients were aged 65 to 74 years at the beginning of their episode. Only three per cent of home care service episodes were provided to pediatric clients (clients aged under 18 years). The average age of clients was 62 years.

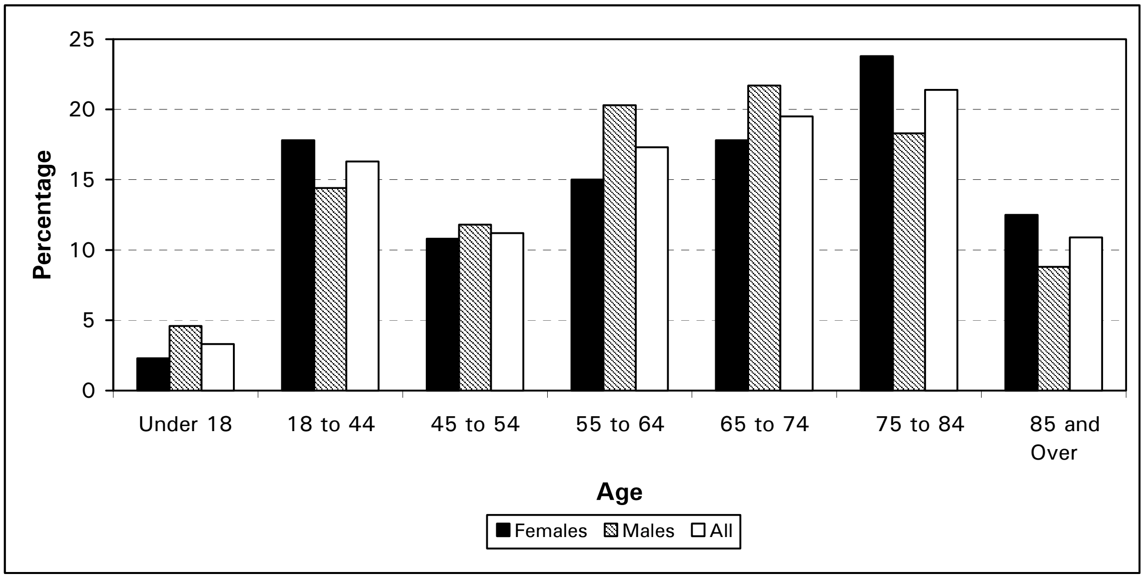


Figure 3.2. Age Distribution of NPT Clients by Sex

Figure 3.2 also shows that female clients who received home care tended to be older than male clients. For example, female clients aged 75 years and over accounted for 36% of episodes provided to female clients. The comparative figure for male clients was 27%. These differences were also reflected in the higher average age of female clients compared with male clients: 63 and 61 years respectively.

Demographic Characteristics by Core Program

There were differences in age and sex distributions of clients who received home care under the five core programs.

Figure 3.3 shows that Acute Care Substitution had the lowest proportion of episodes received by clients aged 75 years and over (19%) and had largest proportion of client episodes who were aged under 45 years (26%). This core program accounted for four-fifths of all home care episodes provided to clients aged under 45 years.

In contrast, Long-Term Supportive Care clients were the oldest; 71% of Long-Term Supportive Care episodes were provided to clients aged 75 years and over. Clients in the 75 years and over age group accounted for 59% of Maintenance episodes, 42% of Rehabilitation episodes and 37% of End-of-Life episodes.

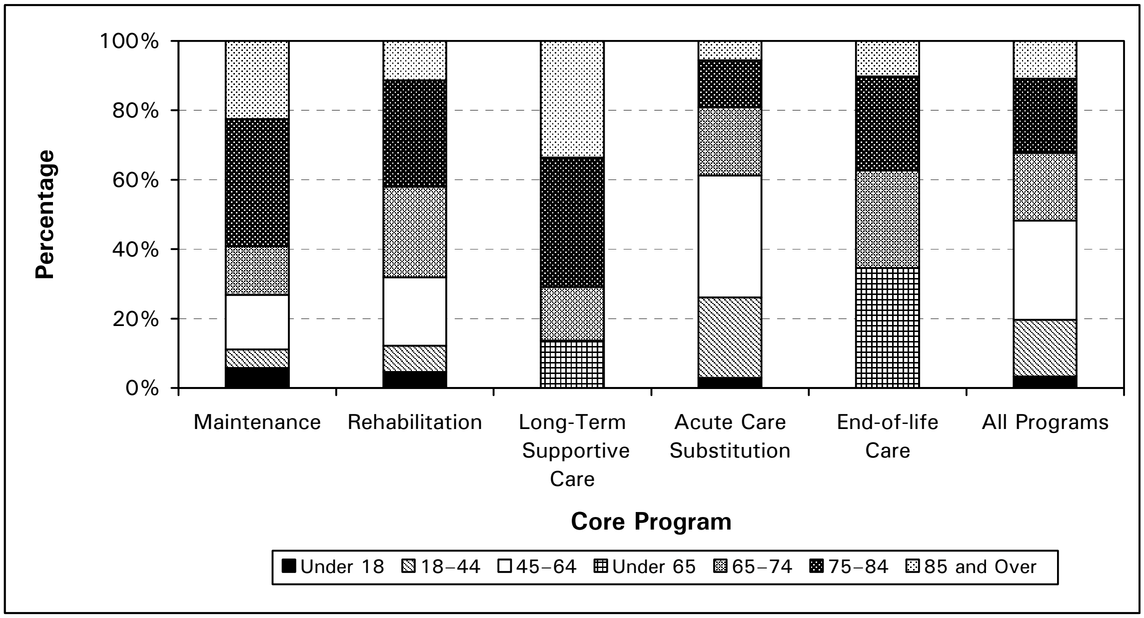


Figure 3.3. Age Distribution of NPT Clients by Core Program

As Figure 3.4 shows, the End-of-Life program was the only program that had a greater proportion of male than female clients (57% and 43% respectively). In the other core programs the proportion of female clients ranged from 54% in Acute Care Substitution and Long-Term Supportive Care to 63% in Rehabilitation.

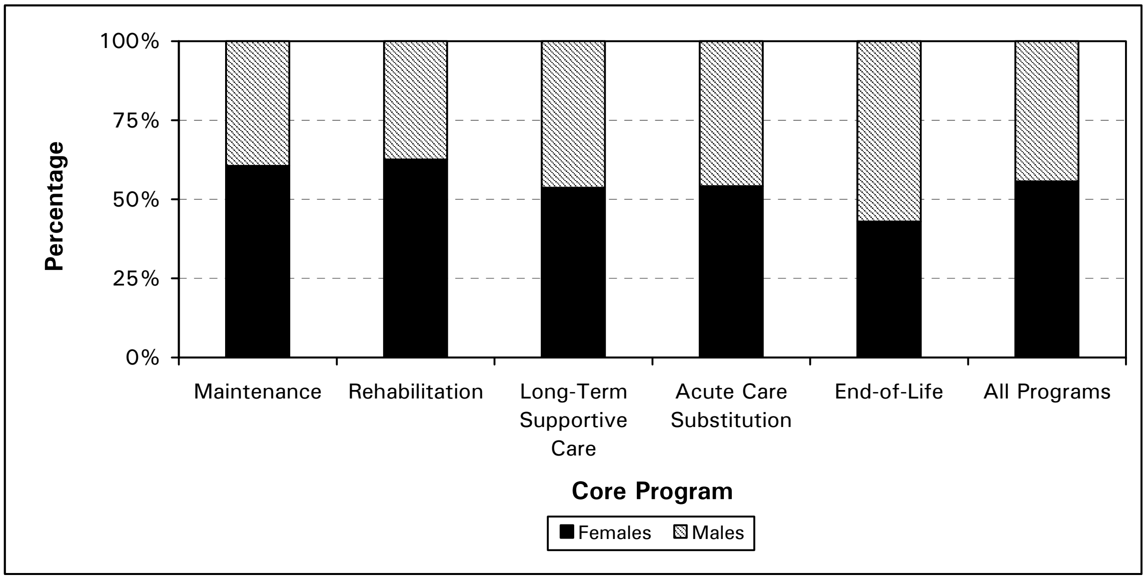


Figure 3.4. Sex Distribution of NPT Clients by Core Program

Figure 3.5 shows the average age of male and female clients at the beginning of their home care service episode for each of the core programs. On average, Acute Care Substitution clients were the youngest; both male and female clients in this core program had an average age of 57 years. The End-of-Life program was the only program where the average age of male clients was higher than the average age of female clients: 70 years and 66 years respectively.

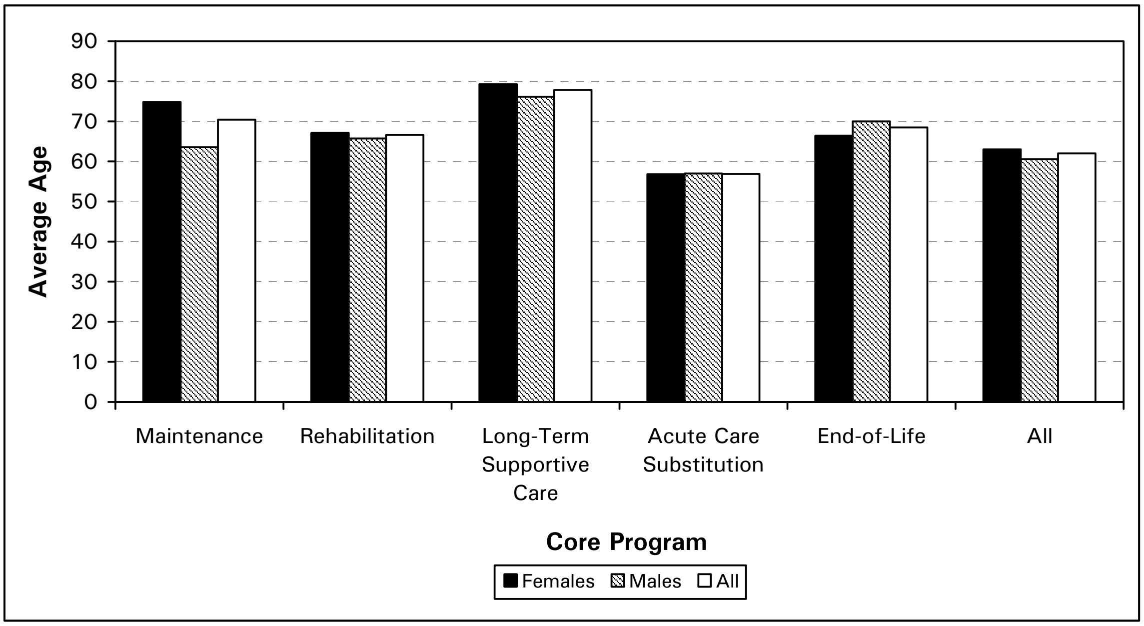


Figure 3.5. Average Age of NPT Clients by Core Program and Sex

Demographic Characteristics by Pilot Site

The age and sex distributions of the home care clients varied across the pilot sites. For example, the proportion of home care service episodes provided to female clients ranged from 52% in Burtwood and Capital (NW) to 66% in Whitehorse.

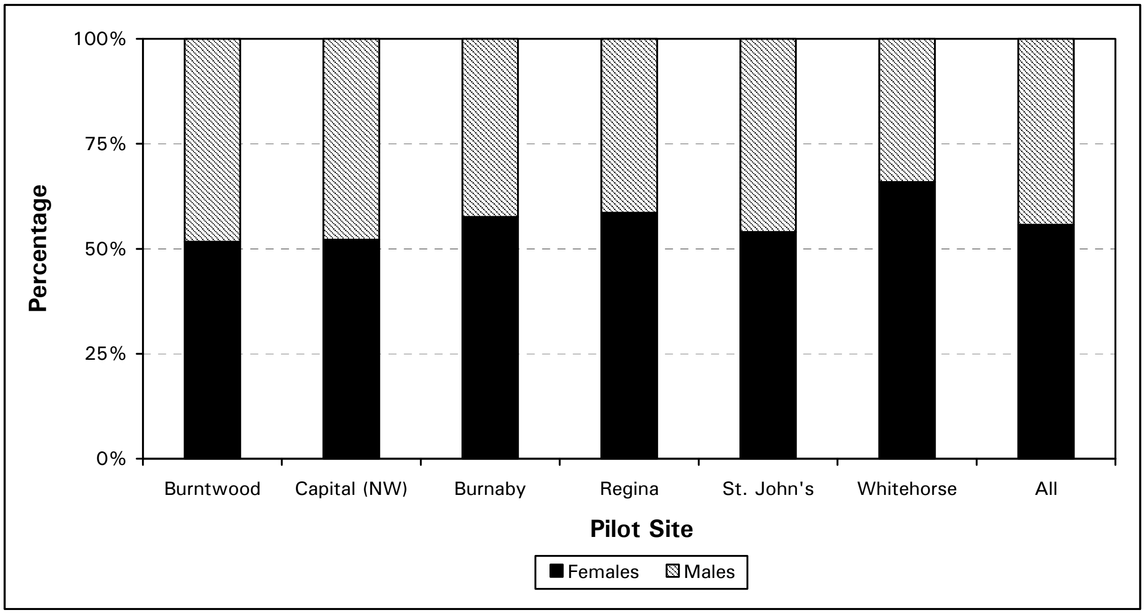


Figure 3.6. Age Distribution of NPT Clients by Pilot Site

The average age of clients varied across the pilot sites and ranged from 51 years in Burntwood to 68 years in Burnaby. Some of the differences in demographic characteristics of clients observed in the six pilot sites may be explained by the different distributions of clients across the core programs in each of the sites. In addition, there may be differences in the wider population and the health of that population which also influenced the demographic profile of the home care clients within each site (see results for the population-based indicators presented later in this chapter).

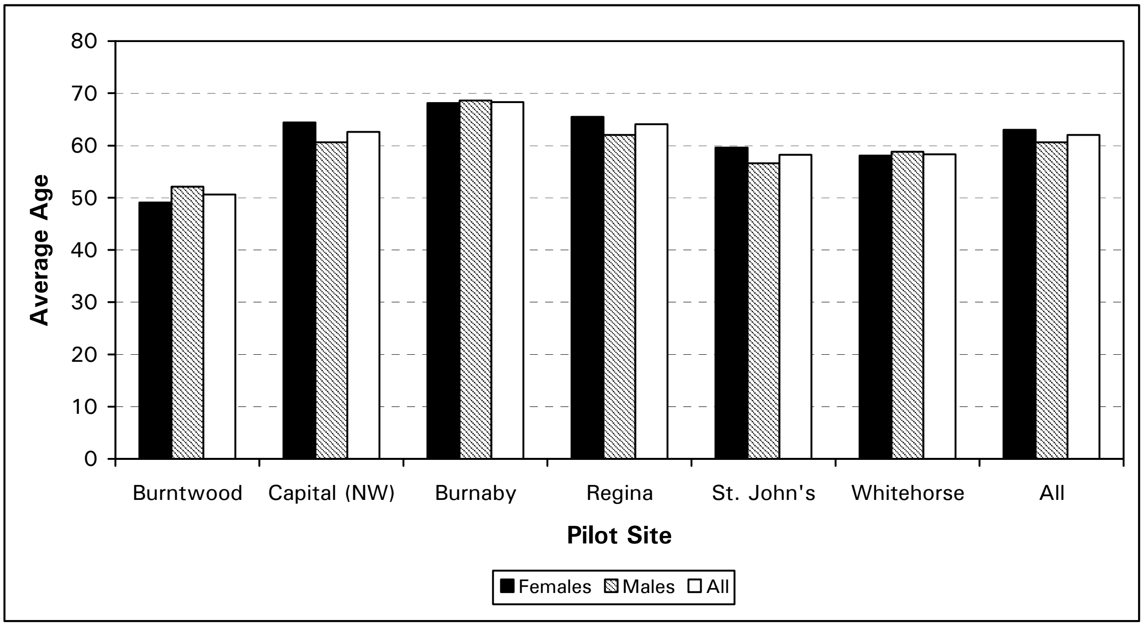


Figure 3.7. Average Age of NPT Clients by Pilot Site and Sex

Pediatric Clients

Pediatric clients (which for the NPT were defined as clients aged under 18 years) form a small, specialized group of home care clients: in many cases they have different care needs and receive different services. In some jurisdictions, pediatric clients are not served by the Ministries of Health, but other ministries dealing with issues relating to families and children.

In the NPT, only a select number of data elements were collected on pediatric clients, mainly demographic and administrative elements. It was felt that many of the more clinical elements were not appropriate for pediatric clients. Appendix C gives details of which data elements were collected for pediatric clients as well as adult clients.

In total, the NPT collected information on 75 pediatric clients. Only three pilot sites had any pediatric clients; two-thirds of which were from the St. John's site. This was not only due to St. John's being the largest pilot site but also because clients from their "Community Living and Support Services" program were included in the NPT. This program dealt with clients, including children, who had behavioural and developmental problems (more details about the types of home care services provided by the pilot sites and that were included in the NPT can be found in Appendix D).

Just over half (53%) of pediatric clients were classified as Acute Care Substitution clients, a third (32%) were classified as Maintenance clients and the remaining pediatric clients (15%) were classified as Rehabilitation clients. The majority of Maintenance and Rehabilitation clients were from the St. John's pilot site; pediatric clients in other pilot sites were usually Acute Care Substitution clients.

The indicators and other analyses described in the remainder of this report state whether they are based on all clients, including pediatric clients, or for adult clients only. In some instances, the information is presented separately for pediatric and adult clients.

Population-Based Indicators

Population-based (per capita) indicators provide information on the accessibility and utilization of home care services. These are of importance for program planning, evaluation and managing resources. These indicators are based not only on information collected in the NPT, but also on the population and geography data that are available from Statistics Canada.

Two pilot indicators were proposed:

- Home Care Access per Capita—the number of individuals receiving home care services by age group and gender per capita; and
- Population Utilization—the number of admissions by age group, gender and core program per capita.

Methodological Issues

Although the definitions of the two proposed indicators were different, the indicators from the NPT data produced very similar results. There were several reasons for this. Firstly, the Home Care Access indicator was designed to include all clients who received home care during the reporting period, including existing as well as new clients. In contrast, the Utilization indicator was to be based only on admissions for new clients. However, during the NPT, data was only collected on new clients, therefore the Home Care Access indicator did not include any information on existing clients.

Secondly, the units of analysis for the two indicators are different. The Home Care Access indicator is based on clients whereas the Utilization Rate is based on admissions. If a client had more than one admission they would contribute only once to the Home Care Access indicator, but each admission would contribute to the Utilization indicator. However, in the NPT very few clients had multiple admissions (there were 2,229 clients and 2,254 admissions).

Thirdly, although the criteria for inclusion in the numerator of the indicators were different, because the NPT was only based in six regions, they resulted in the same clients being included in the numerators for both indicators. For the Home Care Access indicator, clients are assigned to a particular region based upon their permanent residence, whereas for the Utilization indicator, clients are assigned to a region based on their permanent residence and the region from which they received home care services. With respect to the Home Care Access indicator, clients who receive home care services from a service provider in another health region would be included in the indicator for the health region they lived in and excluded from the indicator for the health region they received services from. In contrast, only clients who live in the same region that provides their home care are included in the Utilization indicators.

Due to the similarities of the results, only the Utilization indicator is discussed in this section.

The region of residence was assigned based on the postal code of client's permanent living setting at time of admission, using Statistics Canada's Postal Code Conversion File[13] and the Health regions boundaries and Census correspondence files.[14]

In order to create population-based indicators, one must have an estimate of the population living in a given area, which Statistics Canada provides for their standard geographical classifications and health regions. (For the NPT, data from the 2001 Canadian Census[15] were used.)

Only two of the six pilot sites were complete health regions (St. John's and Burntwood). The other four sites were only selected offices or areas within their respective health regions. The Census Subdivisions with the closest matching geographical coverage to these areas were used for the population-based indicators. Only those clients who lived in those areas were included in the numerator of the indicator. The table below shows the geographic areas that the population-based indicators are based upon, and the proportion of the NPT sample from each pilot site that was included.

Pilot Site	Geographic Area Used in Indicator	Proportion of NPT Sample Included in the Indicator
St. John's	Health and Community Services St. John's Region, NL*	96%
Burntwood	Burntwood Regional Health Authority, MB*	100%
Capital (NW)	City of St. Albert, AB**	57%
Regina	The City of Regina, SK**	90%
Burnaby	The City of Burnaby, BC**	96%
Whitehorse	Whitehorse and Dawson, YK***	100%
All	All above areas combined	91%

*Health Region
**Census Subdivision (CSD)
***Two Census Subdivisions combined

As the table shows, the pilot site from the Northwest Network Office of the Capital Health Region, Alberta had only 57% of its sample included in the population-based indicators—those clients living in the city of St. Albert. In addition to serving St. Albert, this office also covered surrounding areas, none of which could be corresponded to any of the Census geographic areas. The remaining pilot sites had at least 90% of their sample included in the

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[13] Statistics Canada, *Postal Code Conversion File (PCCF),* catalogue no.: 92F0153UCE, (Ottawa: Statistics Canada, July 2003).

[14] Statistics Canada, *Health regions: boundaries and correspondence with census geography,* catalogue no.: 82-402-XIE, (Ottawa: Statistics Canada, July 2003).

[15] Statistics Canada, *2001 Census Community Profiles,* extracted from Statistics Canada's website <http://www12.statcan.ca/english/profil01/PlaceSearchForm1.cfm?LANG=E> on July 2003.

calculation of the population-based indicators. The clients that were excluded either lived outside the area or their area of residence could not be determined because the postal code could not be matched.

Population Utilization by Pilot Site

Figure 3.8 shows the crude and age standardized rates for admissions to home care per 1,000 population for each of the pilot sites. Age standardization produces the rates that would be expected if all regions had the same age distribution and allows more meaningful comparisons when regions have different age distributions. Standardized rates are artificial values; while useful for comparison purposes, they have no intrinsic meaning.

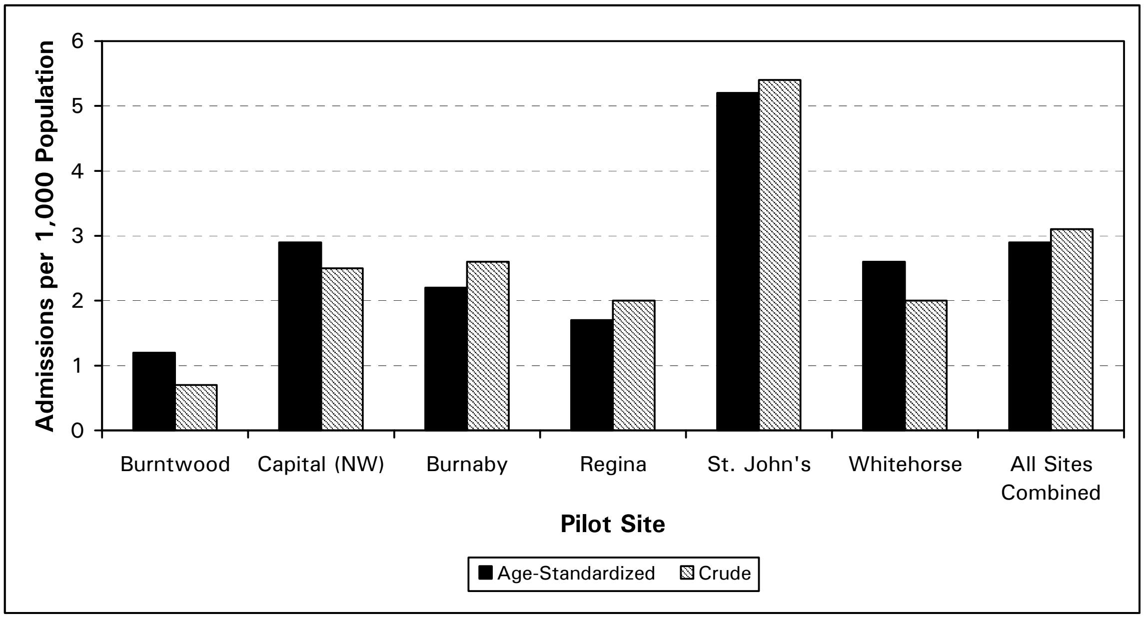


Figure 3.8. Admission Rates to Home Care per 1,000 Population by Pilot Site

St. John’s had the highest standardized rate of admissions of 5.2 admissions per 1,000 population and Burntwood had the lowest, with 1.2 admissions per 1,000 population. The rates for the other pilot sites ranged from 1.7 to 2.9 admissions per 1,000 population.

Care should be taken when interpreting these results are they are based on a subset of clients admitted to home care in the pilot sites.

Age-Specific Population Utilization

The age-standardized rates of population access provide information that can be compared across jurisdictions with different age profiles. However, they do not provide any details of the demographic profile of clients; to do this, one must look at the age-specific rates of population utilization.

Figure 3.9 shows the population utilization rates for different age groups and also by sex, for the six pilot sites combined. It shows that there were 18.9 admissions per 1,000 people aged 75 years and over. This rate was almost twice as high as the next youngest age group, 65 to 74 years, which had 9.7 admissions per 1,000 population.

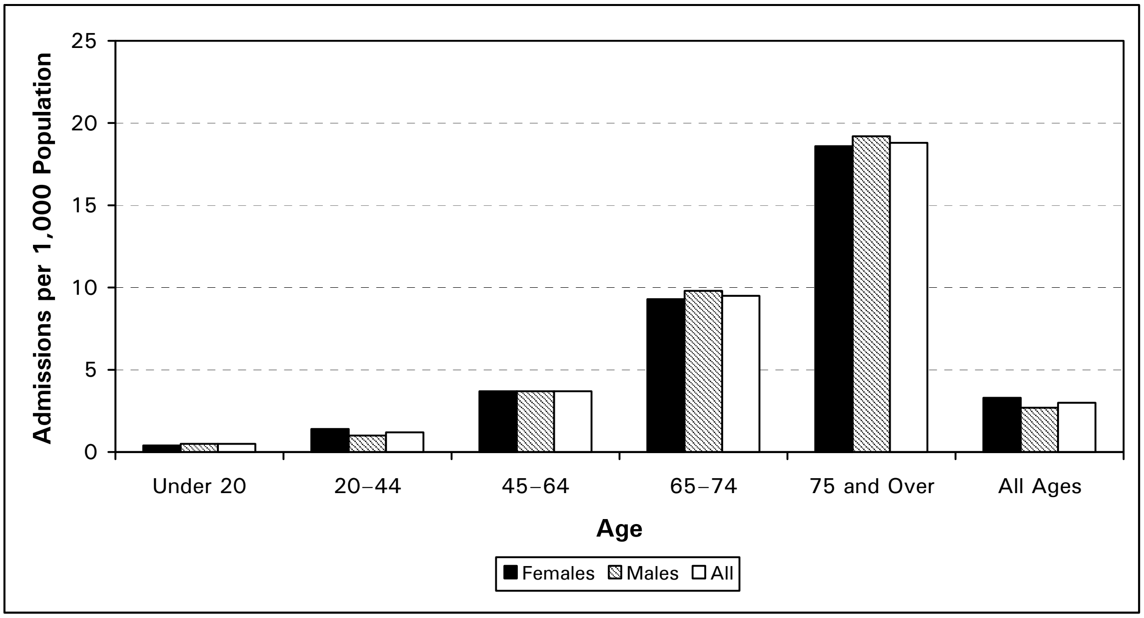


Figure 3.9. Age-Specific Admission Rates per 1,000 Population by Sex

Although women aged 75 years and over accounted for a larger proportion of home care admissions than men the same age (20% and 12% respectively), the population utilization rates for women and men aged 75 years and over were very similar (18.6 and 19.4 admissions per 1,000 population). This is due to the smaller population of men aged 75 years and over. Men and women in all age groups showed similar utilization rates.

Figure 3.10 shows the age specific rates for the four larger pilot sites (excludes Burntwood and Whitehorse). St. John's had the highest utilization rates in all age groups. Capital (NW) had a similar utilization rate to St. John's for the population aged 75 years and over. The Regina pilot site had the lowest utilization rates for the population groups aged 45 years and over; the rate for those aged 75 years and over was half that of St. John's and Capital (NW) pilot sites. As previously mentioned, some of these observed differences may be the result of the different criteria used by the sites for including clients in the NPT, in addition to any actual differences that exist in the admission rates in the different sites.

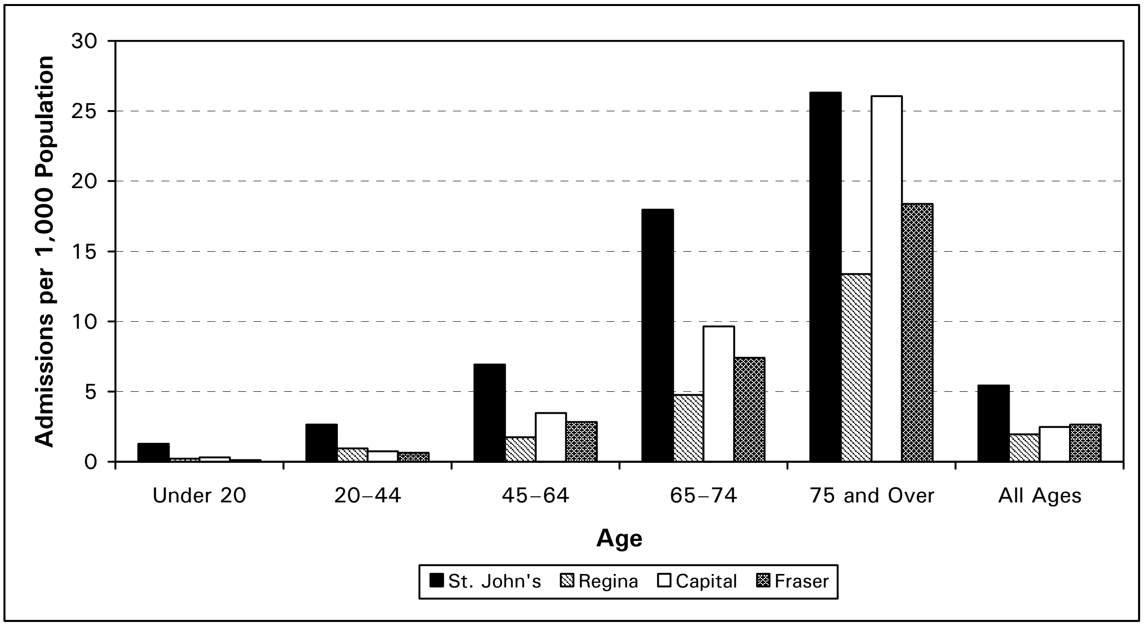


Figure 3.10. Age-Specific Admission Rates per 1,000 Population by Pilot Site

Figure 3.11 shows the age-specific admission rates for the individual core programs, for all six pilot sites combined. The highest utilization rates for all core programs were among those aged 75 years and over; the rates ranged from 1.1 End-of-Life admissions per 1,000 population to 6.6 admissions per 1,000 population to both Maintenance and Acute Care Substitution. In all other age groups, Acute Care Substitution had substantially higher utilization rates.

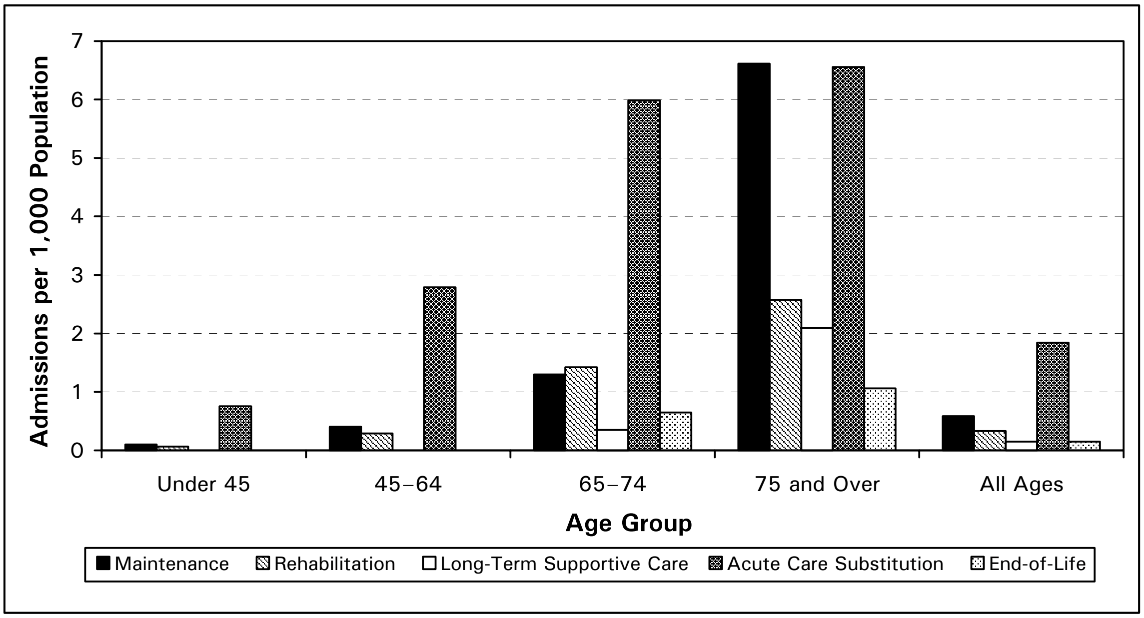


Figure 3.11. Age-Specific Admission Rates per 1,000 Population by Core Program

Indicators Relating to Personal Resources

The personal resources of an individual are essential ingredients in their ability to live within their community. Information collected on clients' personal resources in the NPT included the clients' permanent living arrangements and accommodation setting and information on informal caregivers.

Permanent Living Arrangements and Accommodation Setting

The living arrangements of home care clients can help identify those who may be at risk of physical and social isolation, which could increase the amount of formal support and assistance they may require to live at home. Appropriate living accommodation/setting that matches the client's needs is seen as fundamental to a viable community care plan, since formal home care services augment the personal resources and informal supports of the client.

The two indicators proposed were:

- the distribution of home care clients by their permanent living arrangements, age and core program; and
- the distribution of home care clients by their accommodation setting and core program.

The NPT collected information on the clients' *permanent* living arrangements and accommodation setting at the time of their initial assessment. Some clients may live somewhere else temporarily while they are receiving home care services or may have others live with them temporarily. While these temporary arrangements are not captured by the living arrangements or accommodation setting indicators, results are presented later in this chapter on the living arrangements of informal caregivers and are based on the living arrangements during the episode of care.

The information presented in this section is based on the service episodes of all clients, including pediatric clients.

Permanent Living Arrangements of Home Care Clients

Overall, 38% of home clients lived only with a spouse or partner and a further 34% lived with other family members (which may or may not have included a spouse or partner). A quarter of the home care clients lived alone. Three per cent of clients lived with non-family (2%) or a paid attendant (1%).

Permanent Living Arrangements by Age and Sex

The permanent living arrangements of home care clients generally reflected trends seen in the wider population: the likelihood of living alone increased with age and older women were more likely than older men to live alone.

Figure 3.12 shows that the proportion of clients (both sexes) who usually lived alone increased from 0% of pediatric clients (where virtually all of them lived at home with their families) to 25% of clients aged 65 to 74 and to 47% of those aged 85 years and over.

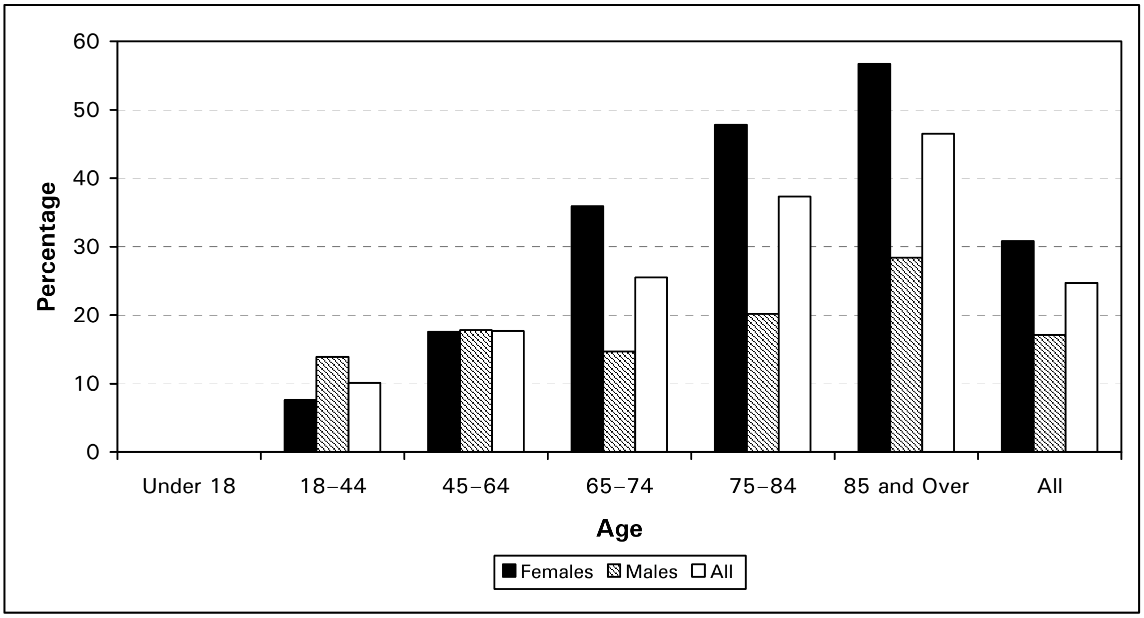


Figure 3.12. Proportion of NPT Clients Who Lived Alone

Among adult clients aged 18 to 44 a larger proportion of males than females lived alone (14% and 8% respectively). In the 45 to 64 year age group, equal proportions of males and females lived alone (18%). In the older age groups, a larger proportion of females lived alone: for example 57% of females aged 85 and over lived alone compared with 28% of males the same age.

It should also be remembered that there were more women than men in these older age groups. Therefore, older women who lived alone accounted for the vast majority of all those who live alone. For example, three-quarters of the home care clients aged 85 years and over and who lived alone were women.

Permanent Living Arrangements by Core Program

Figure 3.13 shows that compared with clients in other core programs, Acute Care Substitution and End-of-Life clients were less likely to usually live alone and more likely to live with a spouse or partner. For example, 18% of Acute Care Substitution clients lived alone and 41% lived with a spouse or partner. In contrast, 36% of Long-Term Supportive Care clients lived alone and 25% lived with a spouse or partner.

Some of these differences in permanent living arrangements of clients within the five core programs may be partly explained by their different demographic characteristics, and reflect that older people, women in particular, are more likely to live alone.

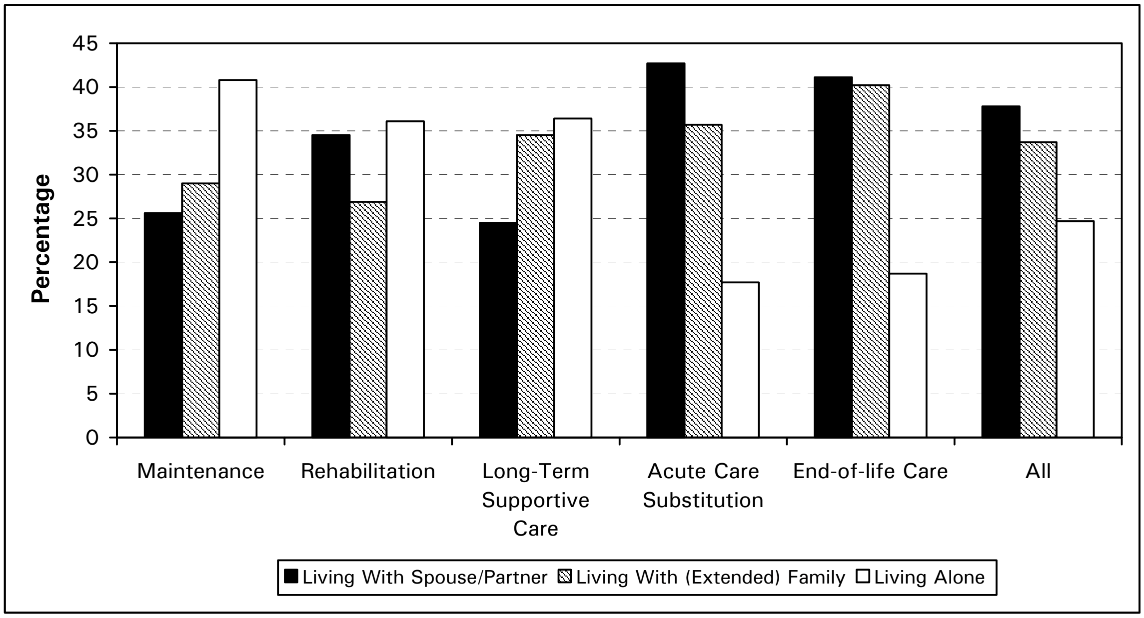


Figure 3.13. Permanent Living Arrangements of NPT Clients by Core Program

In addition, the smaller proportion of clients who live alone in the Acute Care Substitution and End-of-Life program may also influenced by way in which these services are accessed. People who are in facility-based care and require Acute Care or End-of-Life health services may be more likely to remain in facility-based care if they do not have someone who lives with them to help provide care at home and may therefore never be referred to a home care program.

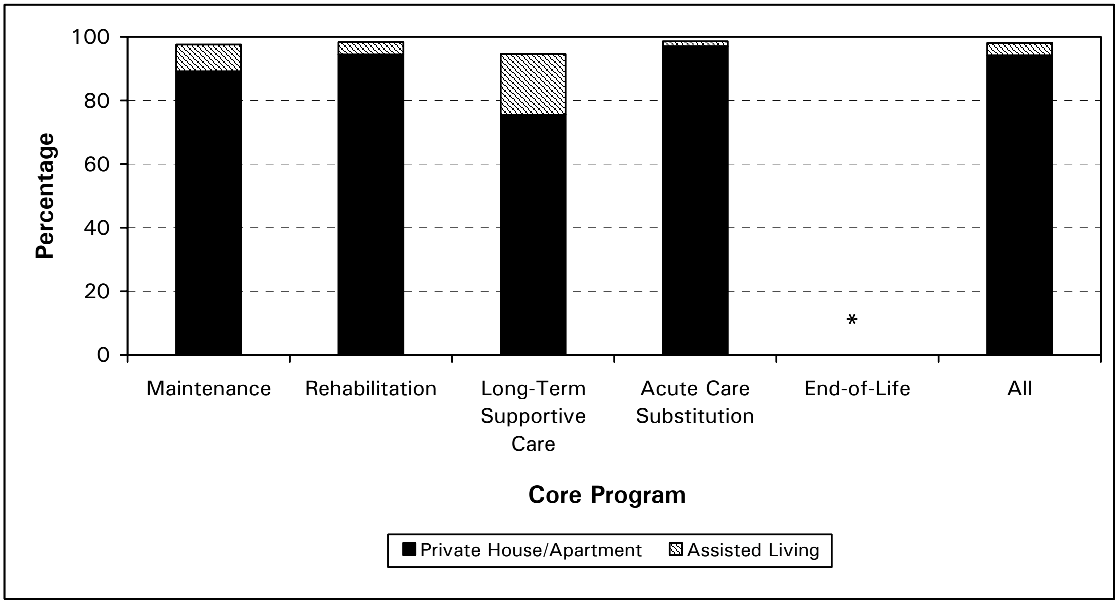
Permanent Accommodation Setting

As one might expect, the vast majority (94%) of home care clients had a private house or apartment as their permanent accommodation setting. Four per cent of clients lived in an "assisted living" setting which included such settings as group and retirement homes (but not nursing homes), supervised living settings and supportive housing.

A small proportion of clients lived in boarding houses or rented rooms (1%); in a residential care setting such as long-term care facilities or nursing homes (1%); or other places such as shelters, refuges, hostels, hospitals (less than 1%).

Permanent Accommodation Setting by Core Program

Figure 3.14 shows that the likelihood of clients living in an assisted living setting varied across the core programs and appeared to reflect the different overall levels of care required for clients in the different programs. Long-Term Supportive Care clients were the most likely to live in assisted living setting (19%) and were therefore less likely to live in a private house or apartment when compared with clients in other programs. In comparison, 9% of Maintenance clients, 4% of Rehabilitation clients and 2% of Acute Care Substitution clients lived in an assisted living setting. (There were insufficient records for End-of-Life clients to provide information on the proportion of clients living in the different accommodation settings).



*Suppressed due to small numbers.

Figure 3.14. Permanent Accommodation Setting of NPT Clients by Core Program

Permanent Accommodation Setting and Living Arrangements

There was a very strong association between the clients' accommodation setting and their living arrangements. Over 90% of those living with their spouse, partner, family or unpaid non-family lived in a private house or apartment. The 10% not living in a private house or apartment lived in mixture of other settings. A similar proportion (88%) of clients who lived alone also lived in a private house or apartment. However, if they did not, they were most likely to be living in an assisted living setting (10% of those who lived alone lived in an assisted setting).

Just over a third (35%) of home care clients who lived with a paid attendant did so in an assisted living setting. Forty-one per cent of clients with "other living arrangements" lived in residential care settings.

Informal Caregivers

There has been a growing recognition of the role and importance of informal and support networks in the provision of services to individuals in their homes. The absence of such support has been identified as a risk factor contributing to the institutionalization of the frail elderly and people with disabilities. The availability of informal support needs to be analysed in relation to other personal resources and characteristics of the clients (such as age, gender and living arrangements).

In addition to the availability of informal caregivers it is important to obtain a measure of the strain or burden the caregiver is under which can indicate the adequacy of the informal support network. Such strain or burden is often associated with problems with the caregiver's physical health and difficulties in performing necessary caregiving tasks, which in turn could impact on the client's ability to achieve service goals and/or remain at home.

Two indicators relating to informal caregiving were proposed for the NPT:

- The proportion of home care clients who had a primary informal caregiver who provided regular and sustained assistance/support; and
- Among clients with an informal caregiver—the proportion of home care clients whose primary informal caregiver expressed inability to continue in their caregiving activities, need for more support and/or feelings of distress, anger or depression.

Information is also presented on the living arrangements of the primary informal caregiver, although no indicator for this data element was proposed.

The NPT also included a data element that intended to collect information on whether the primary informal caregivers had received assistance or support from the home care program. However, the inter-rater reliability study found that this data element had very low reliability, and feedback from the pilot sites indicated that staff had found the definition of this element unclear and difficult to code. Therefore, due to these data quality concerns no analyses of this data element are presented.

Although information on informal caregiving was collected for all clients, including pediatric clients, the analyses presented relate only to adult clients. Feedback suggested that the availability of informal caregivers and the care they provided was difficult to assess for pediatric clients. As most of the pediatric clients lived at home with their parents, assessors found it difficult to determine the amount of care that was above and beyond the usual parental or familial care and that was directly related to the condition for which the child was receiving home care services.

Availability of a Primary Informal Caregiver by Core Program

Overall, just over three-quarters (76%) of adult home care clients had a primary informal caregiver during their service episode. The proportion of clients with a primary informal caregiver was highest for the End-of-Life program (90%) and Long-Term Supportive Care (88%). Around three-quarters of clients in the remaining programs had informal caregivers.

Availability of a Primary Informal Caregiver by Age and Sex

Figure 3.15 shows that the likelihood of a client having a primary informal caregiver during their service episode of care increased with age: from 70% for clients aged 18 to 44 years to 82% for those aged 75 to 84 years. Clients aged 85 years and over were slightly less likely to have a caregiver than those aged 75 to 84 years (79%).

Overall, male and female clients were equally likely to have a primary informal caregiver during their service episode (76%). Generally, similar proportions of male and female clients within the different age groups had a primary informal caregiver. There was a larger proportion of male clients aged 65 to 74 years who had a primary informal caregiver compared with female clients the same age (81% and 73% respectively).

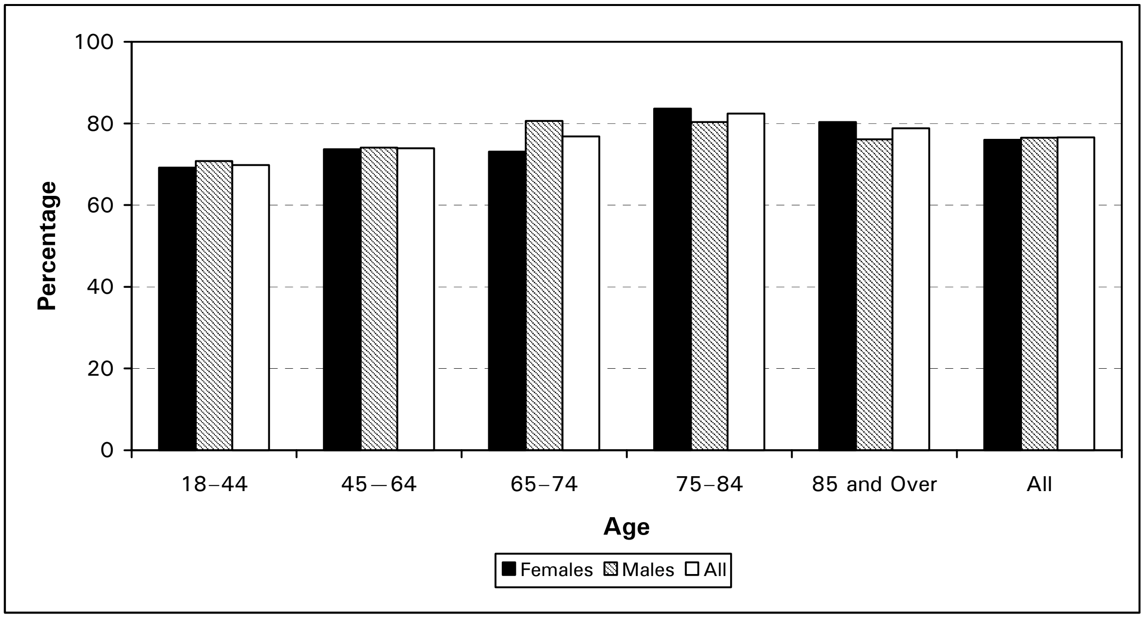


Figure 3.15. Proportion of NPT Clients with a Primary Informal Caregiver by Age and Sex

Many of the cell sizes were too small to differentiate any patterns in the availability of a primary informal caregiver among clients in the different age groups within each core program.

Availability of a Primary Informal Caregiver by the Clients' Permanent Living Arrangements

Figure 3.16 shows that there was a strong relationship between the clients' living arrangements and the availability of a primary informal caregiver. Over four-fifths of clients who lived with other family members (either a spouse or partner or other family members) had a primary informal caregiver. In contrast, only three-fifths (61%) of clients who usually lived alone had a primary informal caregiver. Among those who had other permanent living arrangements (including living with non-family or a paid attendant), just over two-fifths (44%) had a primary informal caregiver.

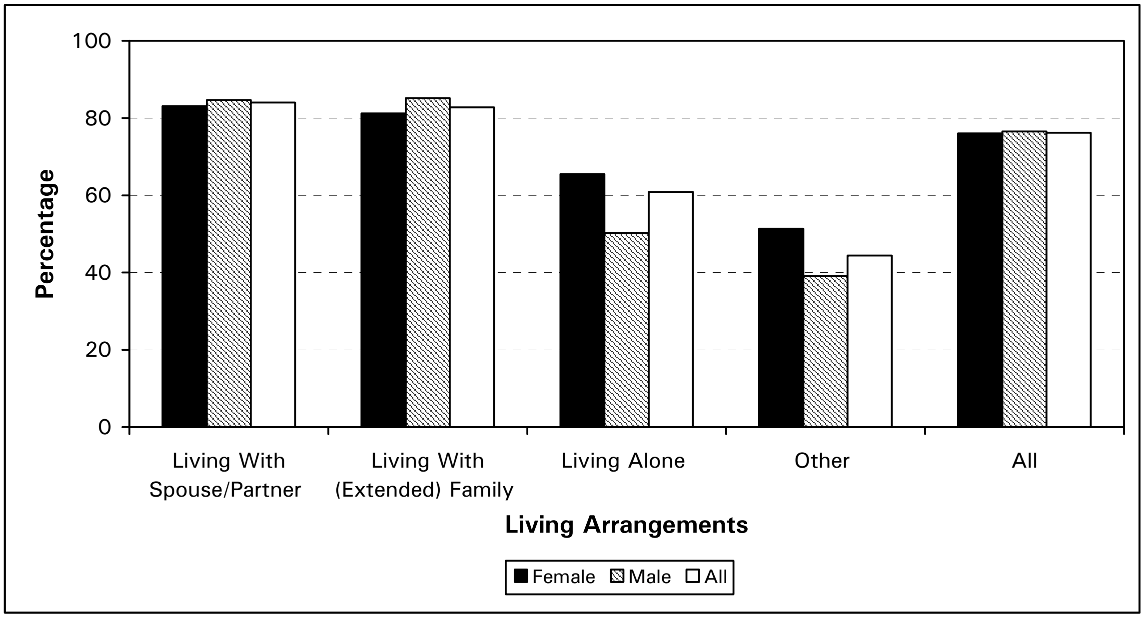


Figure 3.16. Proportion of NPT Clients With a Primary Informal Caregiver by Clients' Permanent Living Arrangements and Sex

Figure 3.16 also shows that among clients who did not live with any family members, two-thirds (66%) of female clients who lived alone had a primary informal caregiver compared with half of male clients who lived alone. However, as previously mentioned, women who lived alone accounted for the majority of all clients who lived alone. Therefore, in absolute terms, there were more female clients living alone without a primary informal caregiver.

Living Arrangements of Clients and Their Primary Informal Caregivers During the Service Episode

For clients with a primary informal caregiver, the NPT collected information on whether or not the caregiver lived with the client. Unlike the permanent living arrangements data element, this data element collected information about the arrangements during the service episode. For example, if a client normally lived alone, but his or her daughter had temporarily moved in to help take care of them while they were receiving home care, then the caregiver was considered to be living with the client. In fact, 2% of clients who usually lived alone and who had an informal caregiver were recorded as living with their caregiver during their service episode.

Figure 3.17 shows that almost three-quarters (73%) of the clients lived with their primary informal caregiver during their episode of care. Figure 3.18 also shows that the proportion of primary informal caregivers who lived with clients varied from 54% of Maintenance clients to 83% of End-of-Life clients.

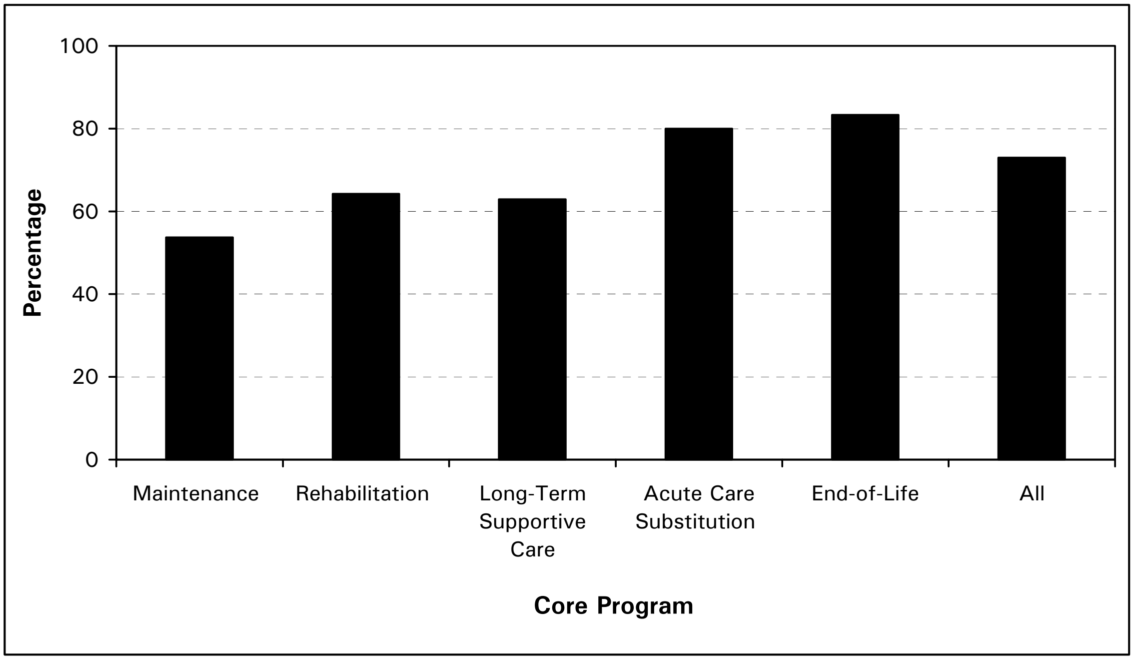


Figure 3.17. Proportion of NPT Clients Who Lived With Their Caregiver During Their Service Episode by Core Program

However as Figure 3.18 shows, the living arrangements of the client and their informal caregiver during the service episode are related to the permanent living arrangements of the clients. The variation observed in the living arrangements of the clients and primary informal caregivers across the core programs is in part a reflection of the differences observed in the permanent living arrangements of clients in those programs.

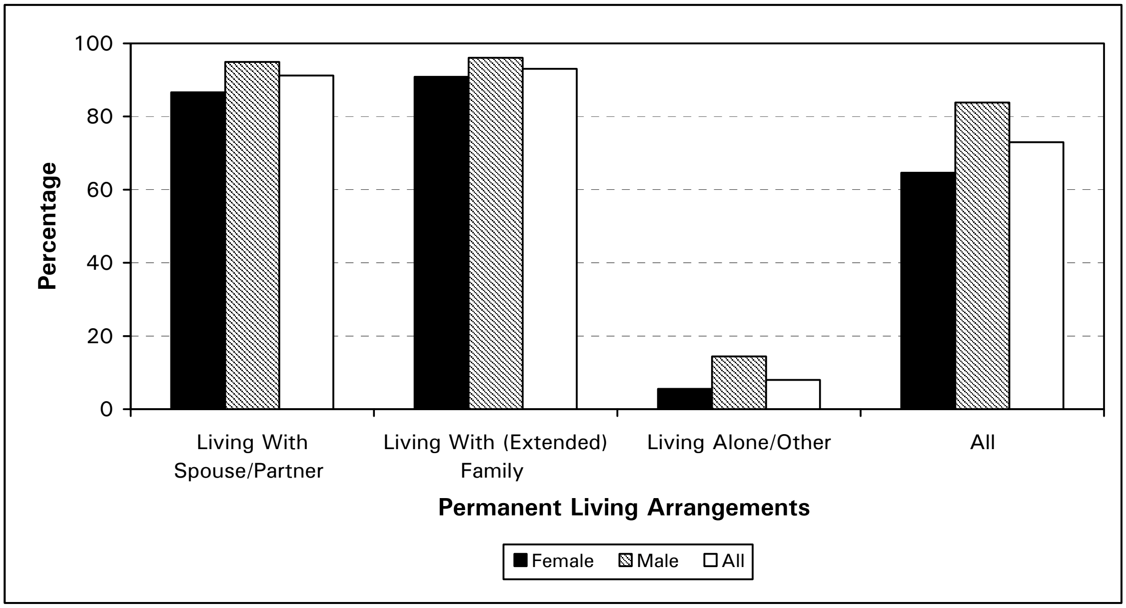


Figure 3.18. Proportion of NPT Clients Who Lived With Their Caregiver During Their Service Episode by the Client's Permanent Living Arrangements and Sex

Figure 3.18 also shows that among clients who lived with other family members, either their spouse or partner or their more extended family, female clients were less likely than male clients to live with their primary informal caregiver during their service episode. Only 87% of female clients who lived with their spouse or partner lived with their caregiver compared with 95% of male clients.

Burden of the Primary Informal Caregiver

If a client had a primary informal caregiver, the NPT assessed whether the caregiver was under any strain or burden in at least one of the following areas:

- whether the caregiver felt unable to continue in their caring activities, which included declines in the health of the caregiver which made it difficult to continue their caregiving role;
- whether the caregiver felt dissatisfied with the support and help provided to the client from other family and friends (i.e. they felt the most burden in caring for the client); and
- whether the client expressed feelings of distress, anger or depression.

Overall, 15% of caregivers were assessed as having a strain or burden as a result of their caregiving role. Figure 3.19 shows that caregiver burden varied greatly across the core programs; caregivers of Acute Care Substitution clients were least likely and caregivers of Long-Term Supportive Care clients were most likely to report feeling a burden (6% and 46% respectively).

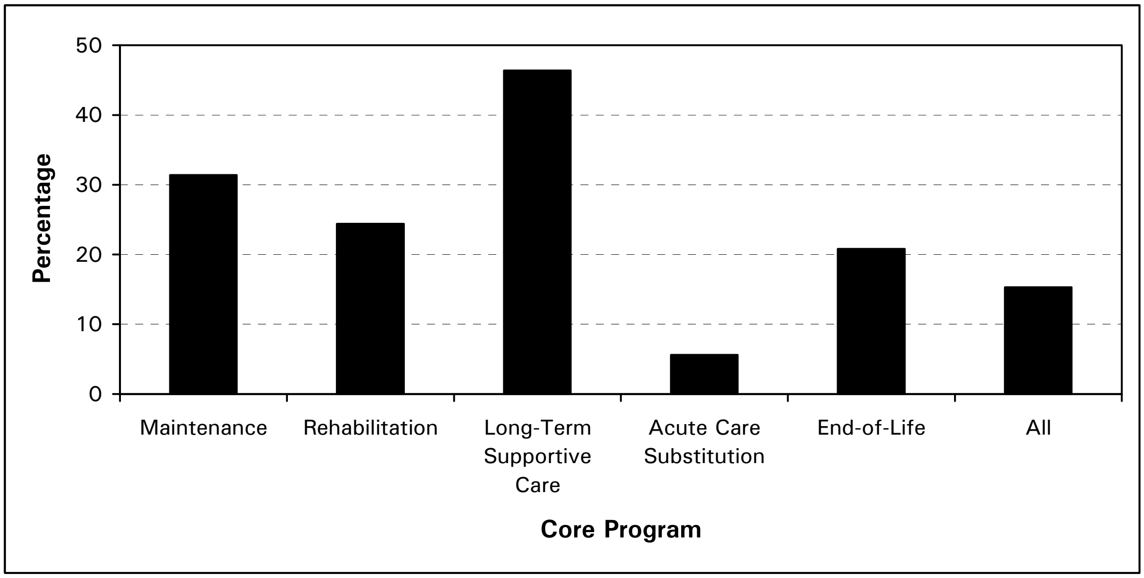


Figure 3.19. Proportion of Primary Informal Caregivers of NPT Clients Who Reported Having Strain or Burden

Whether or not the caregiver feels under strain or burden is likely to be influenced by such things as the intensity of the care required, how long the caregiver has provided care and will continue to do so, their age (as well as the age of the client) and their living arrangements.

Types of Caregiver Burden

As Figure 3.20 shows, of the three types of burden assessed, caregivers were most likely to report feeling angry, distressed or depressed (10%) or that they felt unable to continue (8%) and least likely to report that they were dissatisfied with the amount of care the client received from others (5%).

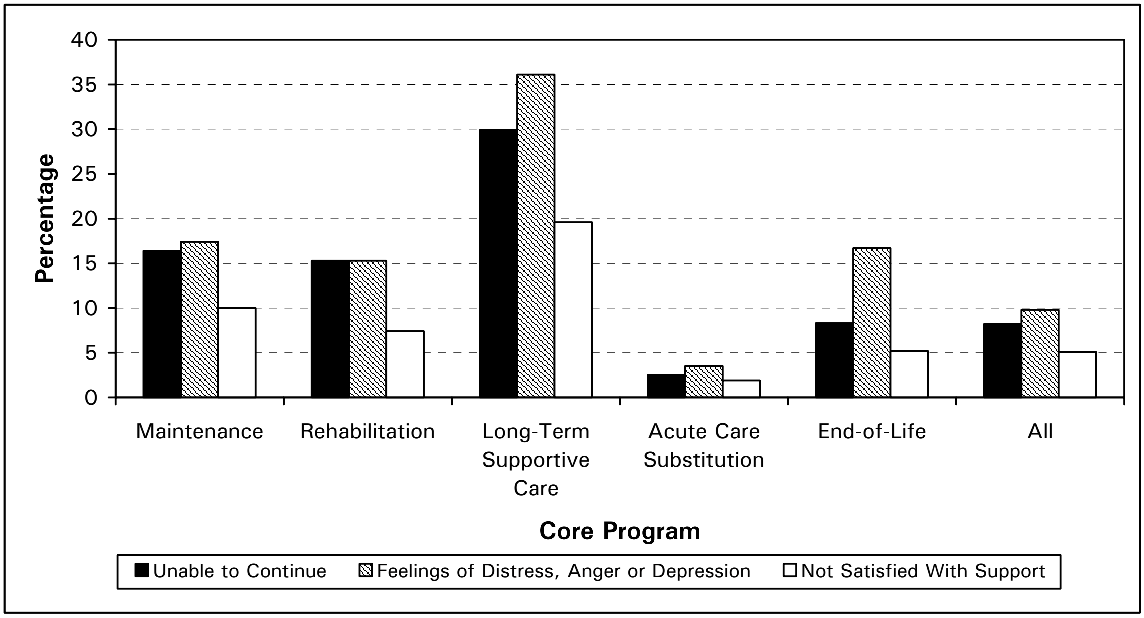


Figure 3.20. Types of Burden Reported by Primary Informal Caregivers of NPT Clients by Core Program

The proportion of caregivers to End-of-Life clients who reported feeling angry, distressed or depressed was more than double the proportion who felt they were unable to continue; 17% and 8% respectively. This may reflect that caregivers of End-of-Life clients are likely to be close relations of the clients. As the clients are dying, the period of time before the client's death would be distressing for their relations even if they were not caregivers. However, the caregivers may be less likely to feel they are unable to continue as they know their caregiving will end with the death of the client.

Chapter 4: Indicators of Health Status, Functional Status and Functional Outcomes

This chapter presents indicators based on the clinical characteristics of the NPT clients, including health status, functional status and functional outcomes.

Indicators of Health Status

The conditions that are responsible for clients receiving home care are vital to understanding the type and amount of home care used.

In the NPT, different classification systems were used to describe the health status of clients in the different core programs:

- For Maintenance and Long-Term Supportive Care clients the most significant **functional impairment** resulting in the referral to home care was recorded using a picklist based on the International Classification of Functioning, Disability and Health (ICF).[16]
- For Rehabilitation clients the Rehabilitation Client Group (RCG)[17] was used to record the **rehabilitation condition** of the client which best described the primary reason for their admission to home care.
- For Acute Care Substitution and End-of-Life Care, the **most responsible health condition**, which best described the client's health status and resource requirements at the time of admission to home care, was recorded using the Canadian version of the International Statistical Classification of Diseases and Related Problems, Tenth Revision (ICD-10-CA).[18]

These differences were supported by the Expert Working Group who recommended that functional impairments be collected for Maintenance and Long-Term Supportive Care clients instead of diagnostic descriptors because they more adequately describe levels of home care service, resource use and client outcomes; that diagnostic information was most appropriate for Acute Care Substitution and End-of-Life clients; and that RCG should be collected in order to collect consistent information across the continuum of care. (RCG is currently used in the reporting of indicators for adult inpatient rehabilitation from the National Rehabilitation Reporting System.)

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[16] World Health Organisation, *International Classification of Functioning, Disability, and Health (ICF),* (Geneva, 2001).

[17] The Rehabilitation Client Groups used in the NPT were adapted from the UDS$_{MR}$ impairment codes. Copyright© 1997 Uniform Data System for Medical Rehabilitation, a division of U B Foundation Activities, Inc., all rights reserved. Used with permission.

[18] Canadian Institute for Health Information, *The International Statistical Classification of Diseases and Related Health Problems, 10th revision, Canada (ICD-10-CA)* (Ottawa: CIHI, 2001).

Health Status of Adult Maintenance Clients

Figure 4.1 shows the distribution of the primary functional impairments of adult Maintenance clients. Three groups of functional impairments each accounted for around a quarter of clients' service episodes. These were:

- Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems (27%);
- Neuromusculoskeletal and Movement-related Functions (26%); and
- Mental Functions (24%).

The next largest group of impairments was Functions of the Digestive, Metabolic and Endocrine Systems (11%).

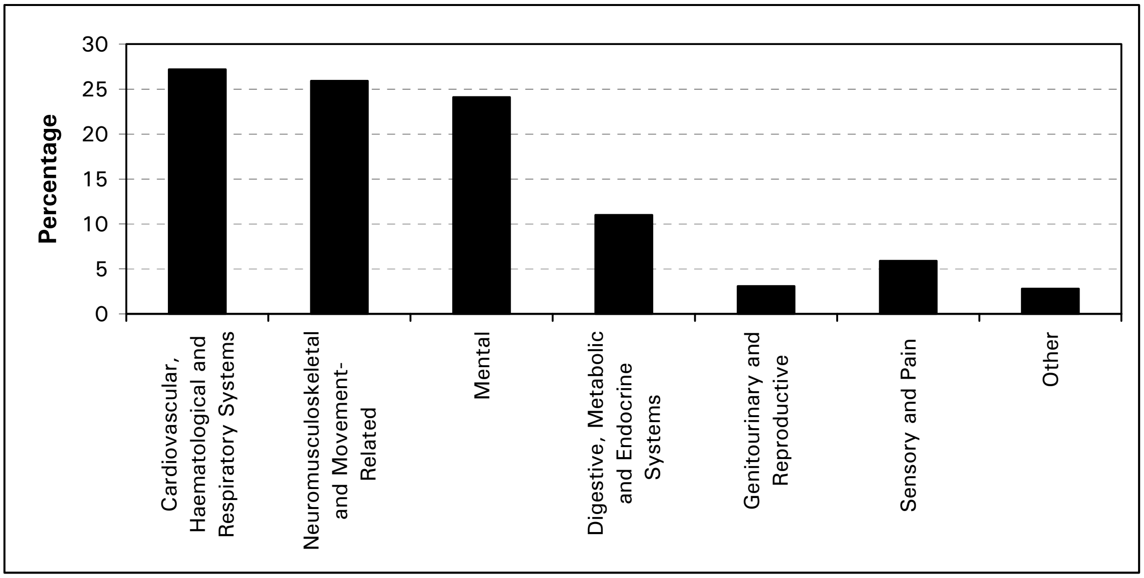

Figure 4.1. Primary Functional Impairment Group of Adult Maintenance Clients

Health Status of Adult Long-Term Supportive Care Clients

The distribution of primary functional impairments of adult clients in Long-Term Supportive Care was different to that for Maintenance clients. Figure 4.2 shows that mental functions were the most significant functional impairment for two-fifths (40%) of the service episodes of Long-Term Supportive Care clients (the comparative figure among Maintenance clients was 24%). Neuromusculoskeletal and Movement-related functions and functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems each were recorded in around a fifth of service episodes (23% and 19% respectively).

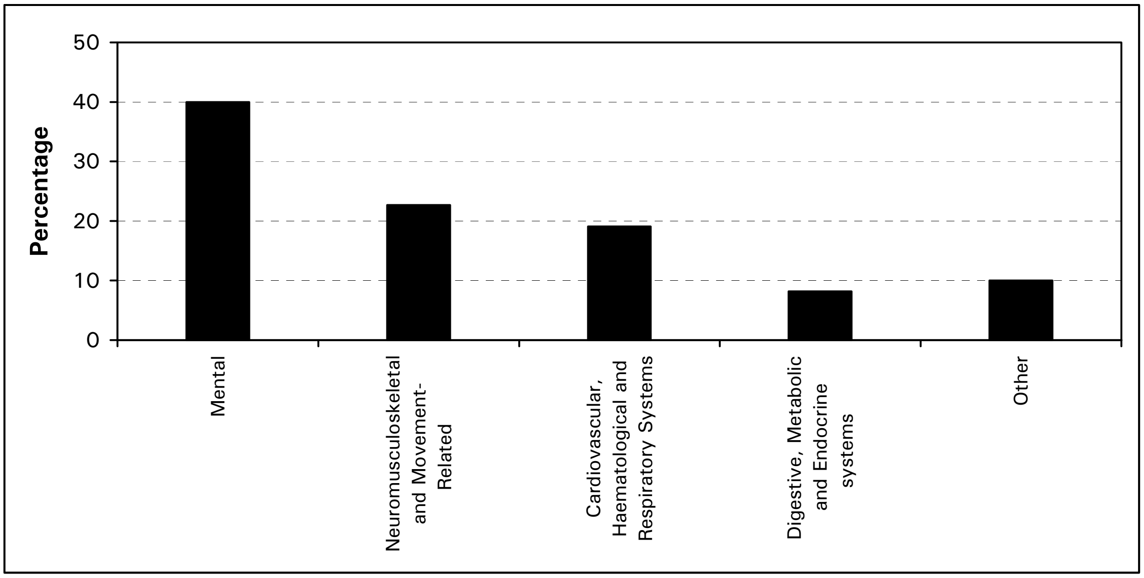

Figure 4.2. **Primary Impairment Group of Adult Long-Term Supportive Care Clients**

Health Status of Adult Rehabilitation Clients

As Figure 4.3 shows, orthopaedic conditions were reported as the primary reason for admission in 43% of the service episodes of adult Rehabilitation clients; 16% were hip and or knee replacements; 9% were fractures and 17% were other orthopaedic conditions. Stroke was the next largest rehabilitation condition reported, accounting for 14% of admissions to the Rehabilitation core program. Arthritis, Pain Syndromes, and Medically Complex Conditions were each recorded in 7% of service episodes.

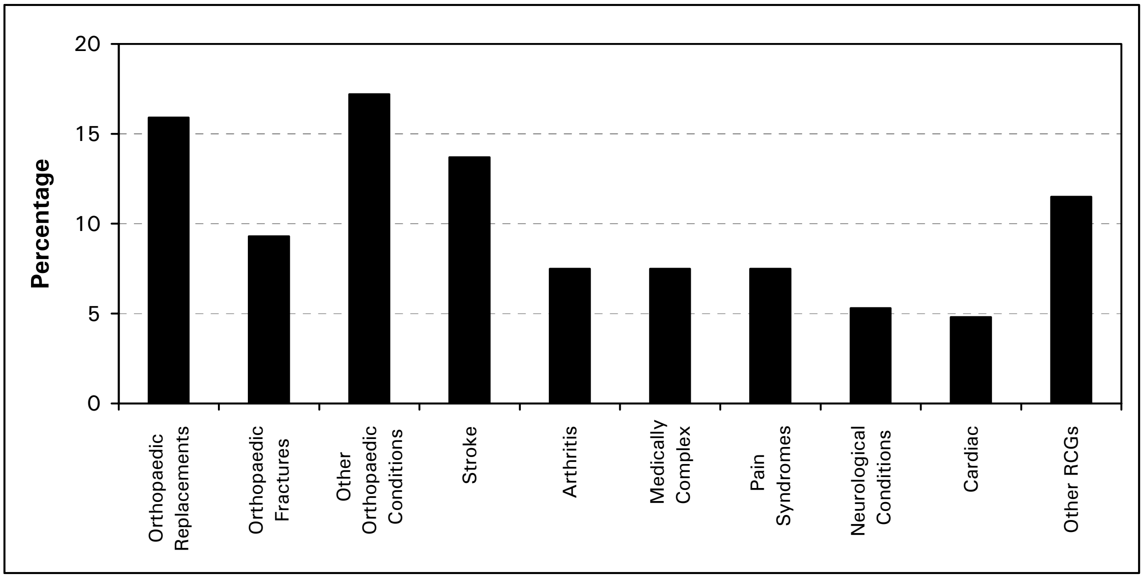

Figure 4.3. **Rehabilitation Client Group (RCG) of Adult Rehabilitation Clients**

Health Status of Adult Acute Care Substitution Clients

Many Acute Care Substitution clients received home care after having surgery or medical interventions in hospital that require follow-up care in the community. Within the picklist provided to record the Most Responsible Health Condition in the NPT, there were four codes available that allowed assessors to record the need for care following medical intervention rather than a specific health condition or disease.

One of these codes "Persons encountering health services for specific procedures and health care (including orthopaedic and surgical follow-up care and dialysis)" was the most frequently recorded code in the NPT; accounting for 15% of all Acute Care Substitution service episodes. This code, together with two of the other "intervention" codes made up the "Factors Influencing Health Status and Contact with Health Services" ICD-10-CA Chapter, which, as Figure 4.4 shows, accounted for 17% of the conditions recorded.

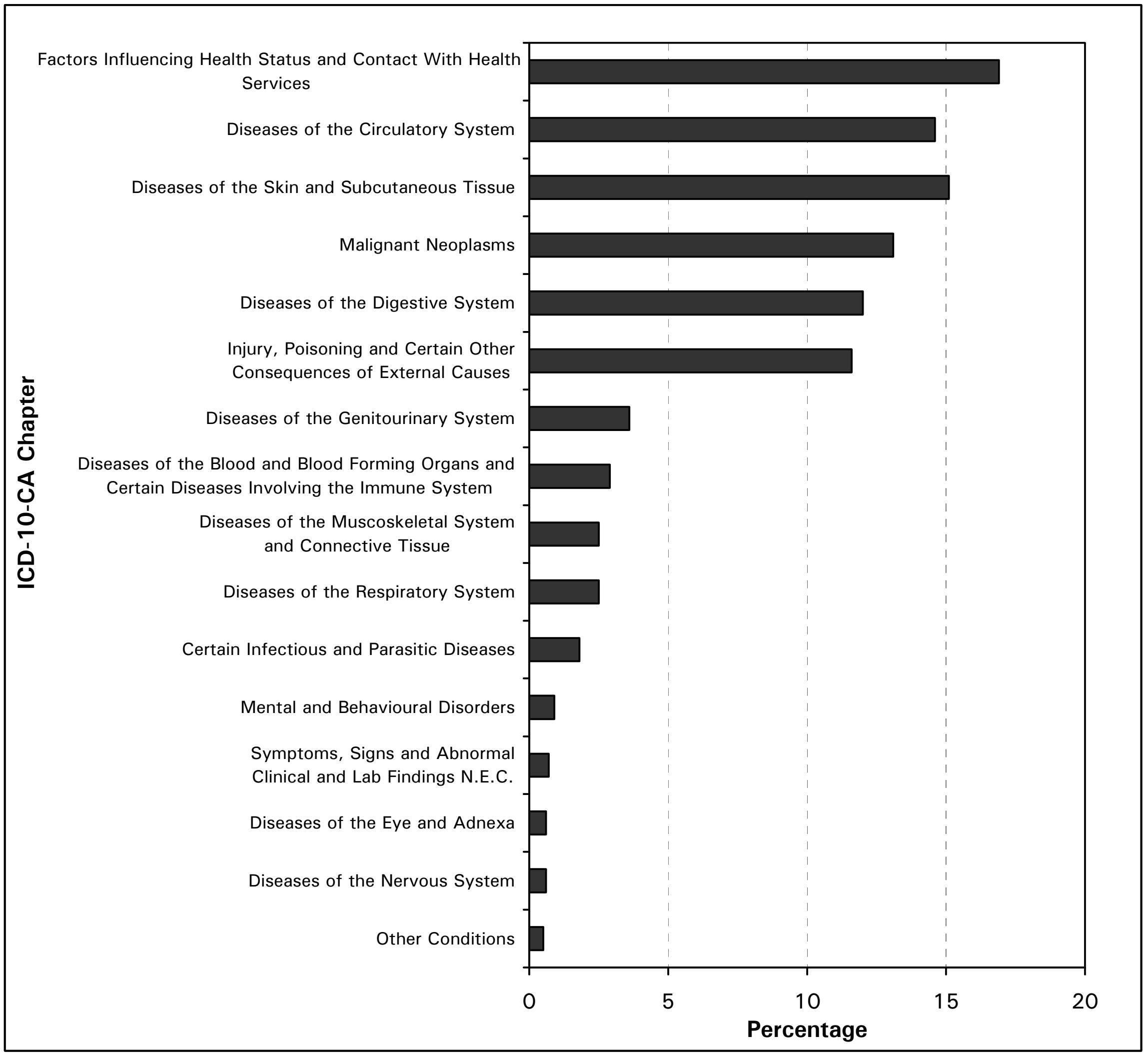

Figure 4.4. Most Responsible Health Condition (Diseases) of Adult Acute Care Substitution Clients

The other intervention code was "Complications of surgical and medical care", which contributed to the 12% of service episodes recorded in the ICD-10-CA Chapter "Injuries, poisoning and certain other consequences of external causes".

Among the other ICD-10-CA Chapters, the most frequently recorded as the most responsible health condition in adult Acute Care Substitution episodes were:

- Diseases of the Skin and Subcutaneous Tissue (such as skin infections): 15%.
- Diseases of the Circulatory System (such as pulmonary and other types of heart disease): 15%.
- Malignant neoplasms (cancer): 13%, with cancers of the breast and digestive organs being the most common (4% and 3% respectively).
- Diseases of the Digestive System: 12%.

It should be noted that during the inter-rater reliability study carried out as part of the NPT, the level of agreement in the coding of the most responsible health condition was lower than expected. Many of the discrepancies were the result of one assessor using one of the four "intervention" codes listed above while the other assessor had coded a specific disease or condition, that is, using an ICD-10-CA code from another chapter. It appears that some assessors may have coded the original cause of the hospitalization or medical intervention rather than the fact that the client required home care services as a result of that hospitalization or medical intervention. For example, one assessor recorded "Hernia" while the other recorded "Complications of surgical and medical care", which may have been the results of a hernia operation. See *Development of National Indicators and Reports for Home Care—Phase 2: Report on Data Quality Activities*[19] for further details. As a result, the NPT may have underestimated the proportion of clients that should have the "intervention" codes as their most responsible health condition and overestimated the proportion of clients that have other ICD-10-CA codes as their most responsible health condition.

Health Status of Adult End-of-Life Clients

A malignant neoplasm (cancer) was recorded as the most responsible health condition in the vast majority (93%) of service episodes for End-of-Life clients. Figure 4.5 shows that the most common neoplasms reported were of the digestive organs, such as the stomach, pancreas and colon (33%); and of the respiratory and intrathoracic organs, such as lung cancer (28%).

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[19] Canadian Institute for Health Information, *Development of National Indicators and Reports for Home Care—Phase 2: Report on Data Quality Activities,* (Ottawa: CIHI, 2004).

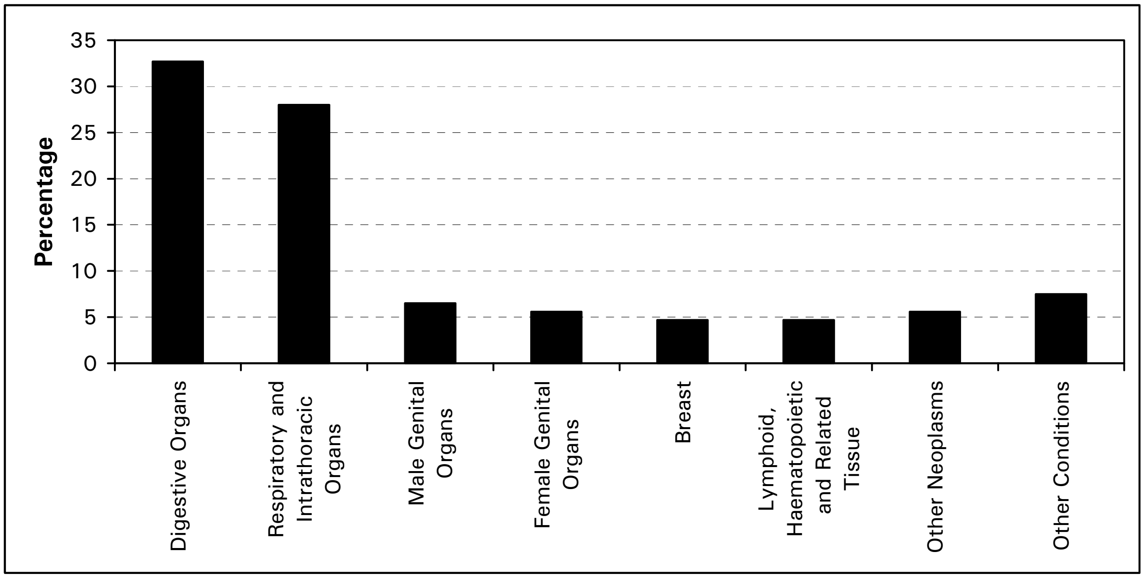


Figure 4.5. **Types of Malignant Neoplasms Reported as the Most Responsible Health Conditions for Adult End-of-Life Clients**

Health Status of Pediatric Clients

Due to the small number (75) of paediatric clients only limited information on their health status can be provided.

Of the 24 Maintenance pediatric clients, a large majority had "Mental Functions" recorded as their primary impairment. All other primary impairment groups recorded were coded for one client only.

The three most frequently recorded health conditions for pediatric Acute Care Substitution clients were coded to the following ICD-10-CA chapters:

- Injury, poisoning and certain other consequences of external causes (which includes complications following surgery);
- Factors influencing health status and contact with health services (which includes surgical follow-up, dialysis, transplants etc); and
- Diseases of the skin and subcutaneous tissue.

These findings support the feedback received from the pilot site indicated that many of the pediatric Acute Care Substitution clients had been referred to home care for the treatment of burns.

There were insufficient pediatric Rehabilitation clients to provide information by RCG. As previously mentioned, there were no pediatric Long-Term Supportive Care or End-of-life clients.

Indicators Relating to Functional Status and Functional Outcomes (ADLs and IADLs)

Information on the ability of clients to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) is considered essential in home care because a given amount of independence in functioning is necessary for clients to remain at home. ADL and IADL performance also has a strong relationship to resource use.

Information on how clients' ADL and IADL activity changes over their episode of care is important in assessing the effectiveness of the home care services provided and for resource planning. It should be noted that there would be different expectations of clients' ADL and IADL activity and how it would change over time for the different core programs. For Acute Care Substitution and Rehabilitation clients, one would expect to see an improvement in functional status over a relatively short period of time; the opposite would be true for End-of-Life clients, where one would expect a decline in the functional status during their episode of care. For Maintenance where the aim of providing home care services so that the clients can remain in their homes for as long as possible, one would like or expect to see a maintaining rather than increasing of their functional abilities, or at worst, a gradual decline. Long-Term Supportive Care clients would be expected to be more medically complex than Maintenance clients, and therefore their ADL performance would likely fluctuate as their health status changes, and again, one might expect an overall decline over time.

The proposed indicators were:

- the average functional score of home care clients for ADLs and IADLs, at time of initial assessment and reassessment, by core program; and
- the distribution of home care clients, by functional outcome and core program.

In the NPT, adult clients' abilities to carry out specific activities were evaluated during their initial assessment and, if possible, during their reassessment. In some cases it was not possible to reassess the ADL and IADL activity as the client had died, had been taken into acute care, or had moved and could not be traced. For these clients only administrative data were collected at reassessment.

Activities of Daily Living (ADLs)

The NPT collected information on clients' ability to carry out eight ADLs:

- eating and drinking;
- grooming;
- dressing;
- bathing;
- toileting;
- transferring from one position to another;
- indoor locomotion; and
- outdoor locomotion.

For each activity, the assessor determined whether the client could carry out the activity independently, with supervision, with assistance, or whether the client was dependent and relied on another person to perform and complete the tasks. This assessment was based on what the client had actually done during the previous *three* days, and not what the client might have been capable of. If the client had not performed the activity during the previous three days then they were coded as "dependent".

The individual ADL elements can be analysed separately to provide information on specific type of activity or can be combined to give an overall picture of clients' functioning abilities.

Performance of Individual ADLs at Initial Assessment

Research has shown that people do not lose their functioning abilities in these different areas at the same time; people tend to lose the ability to carry out certain tasks before others. For example, dressing and personal hygiene activities are usually classified as "early-loss" ADLs as they are among the first activities people require help with whereas eating is considered a "late loss" ADL as people tend to maintain their independence in this activity, even if they are unable to carry out other activities.

Figure 4.6 shows the distribution of clients' level of performance at their initial assessment for each of the eight ADL activities.

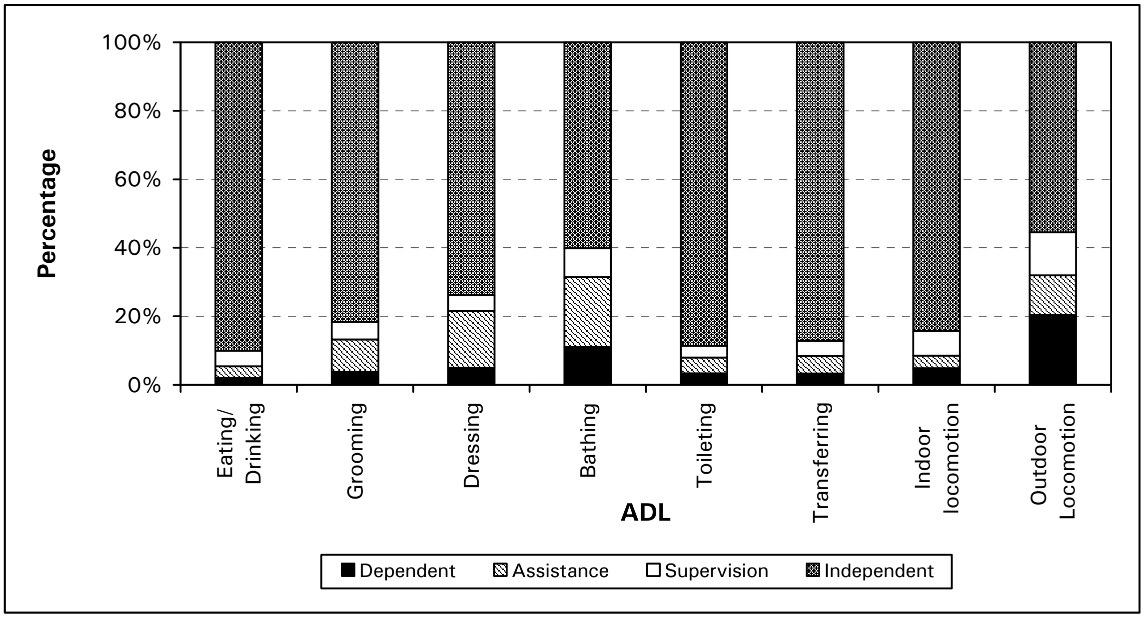


Figure 4.6. Level of ADL Performance at NPT Clients' Initial Assessment

Clients showed the most independence in eating and drinking, toileting and transferring—with around nine in ten clients being assessed as independent in each of these activities.

Clients were slightly more dependent in their indoor locomotion, with 84% able to move around indoors independently and a further 7% requiring some supervision.

Grooming and dressing also had relatively high proportions of clients able to carry out these activities independently (82% and 74% respectively). However, they also had a significant proportion of clients requiring assistance (10% and 17% respectively). The proportions requiring supervision on these tasks were lower than those requiring assistance; for example only 5% of clients required supervision in their dressing activities compared with 17% requiring assistance. This may reflect the fact that many clients had physical limitations rather than cognitive impairments.

One in five clients required some assistance to carry out their bathing activities when they were initially assessed. Around one in ten required supervision or were classified as dependent.

Outdoor locomotion showed the lowest levels of independence; just over half (55%) of clients were assessed as being independent. A fifth of clients were recorded being dependent, which were the highest proportion of any ADL activity. However, it should be noted that clients were assessed as being "dependent" if the activity did not occur in the three days prior to the assessment. Feedback from the pilot sites indicated that this guideline had the most effect on the assessment of outdoor locomotion and to a lesser degree bathing. As a result the levels of dependence for these activities, and in particular outdoor locomotion, are likely to be somewhat inflated and therefore the results should be treated with caution.

Assessing a client's outdoor locomotion as dependent if it "did not occur" may not be appropriate in Canada. During the winter some clients' ability to go outside would be more affected by the weather than their own functioning ability. As a result, a person with the same functioning capabilities would be assessed differently depending on the time of year of their assessment and where they were (as the impact of the weather will differ across the country).

Likewise, there could be differences in clients' lifestyles across Canada—in how often they bathe. Some people may usually bathe once a week. Therefore they may be assessed as "dependent" even though it was because they chose not to bathe rather than because they had any problems doing so. If the type of behaviour is more prevalent in certain areas or among certain types of clients than others, the comparability of the ADL activity will be comprised.

Despite these concerns, the overall functioning abilities of the NPT clients reflected the expected pattern: higher levels of independence in late loss ADLs (such as eating, toileting and transferring) and lower levels of independence is early loss ADLs (such as grooming, dressing and bathing).

Performance of Individual ADLs at Initial Assessment by Core Program

A score for each ADL activity was created by assigning numeric values to the level of dependence: 1 for Dependent, 2 for Assistance, 3 for Supervision and 4 for Independent. Figure 4.7 shows the average score for clients' performance of each ADL at their initial assessment by core program.

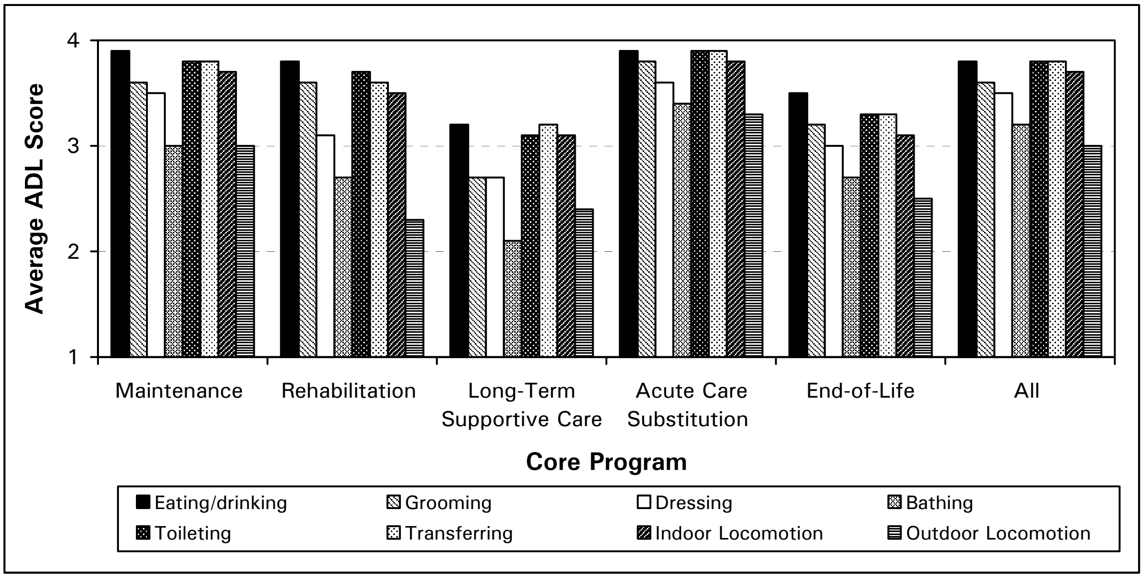


Figure 4.7. Average ADL Score at Initial Assessment by Core Program

Figure 4.7 shows that, generally, Acute Care Substitution clients had the highest average score for each ADL, while Long-Term Supportive Care clients had the lowest. It also shows that while clients in the different core programs had different levels of functional performance, their pattern of ADL functioning were similar, and consistent with the pattern described above; that is, they were most independent in eating and least independent in outdoor locomotion and bathing.

Overall ADL Performance at Initial Assessment by Core Program

The scores from the eight individual ADL elements were added together to form a single score providing a measure of the clients' overall ADL performance. The values of this summary score ranged from 8 (most dependent) to 32 (most independent).

The average overall ADL score at initial assessment for adult clients in the NPT was 28.4. Figure 4.8 shows that Acute Care Substitution clients had the highest average ADL score (29.6), while Long-Term Supportive Care clients had the lowest average score (22.6).

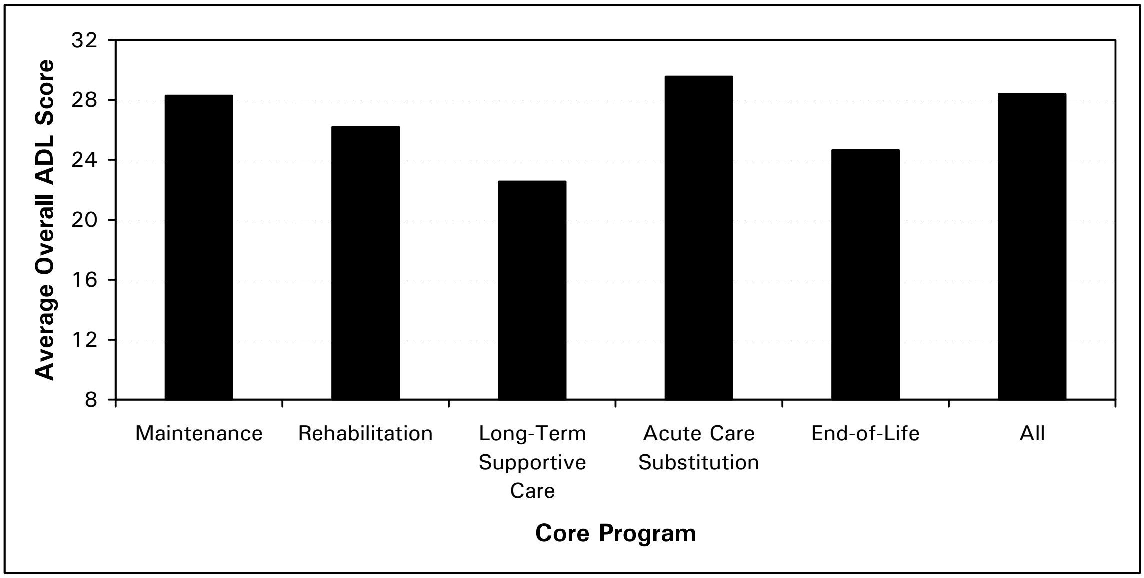


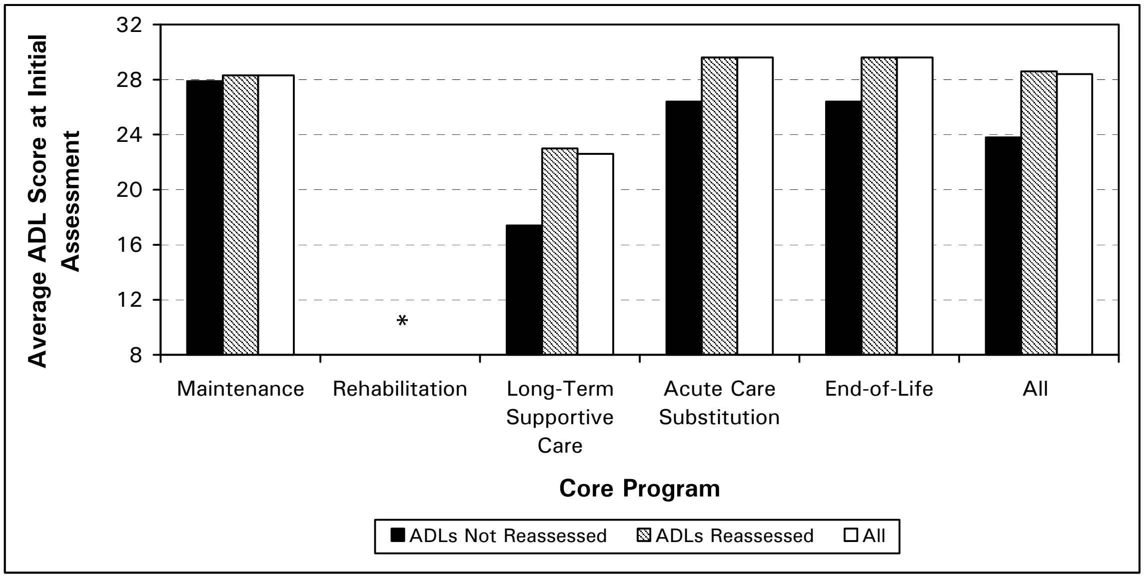
Figure 4.8. NPT Clients' Average ADL Score at Initial Assessment by Core Program

Reassessment of ADL Performance

The intention during the NPT was to assess all adult clients' ADL and IADL abilities at their initial assessment and their reassessment. However for some clients, who had died, had been admitted into an acute care facility or had moved and could not be traced, their functional abilities could not be reassessed. Although pilot sites attempted to get ADL and IADL information for some of those clients who had died, they met with limited success. It was therefore decided to exclude all clients who had died from all analyses on ADL and IADL activity at reassessment and change in functional ability.

Overall, 5% of adult clients were excluded from the analyses of the ADL reassessment and change in ADL score. The majority of clients who were excluded were from the End-of-Life core program; half (51%) of the clients from this core program died and therefore were excluded. Seven per cent of Long-Term Supportive Care clients were excluded from the analyses. Among the other core programs the proportion of clients who were excluded was no more than 4%.

Figure 4.9 shows the average initial ADL score of those clients who did not have the ADLs reassessed was lower than those whose ADL performance was reassessed. For example, End-of-Life clients whose ADLs were only assessed at their admission had an average score of 26.4 compared with 29.6 among those who also had their ADLs performance reassessed. (Information for Rehabilitation clients is not presented due to the small number of clients who did not have their ADLs reassessed.) As the proportion of clients in most core programs was small, the average initial ADL score among clients whose ADLs were reassessed was usually only marginally different from the overall average.



*Suppressed due to small numbers.

Figure 4.9. **Average ADL Score at Initial Assessment by Whether ADLs Were Reassessed**

Change in ADL Performance by Core Program

The analyses of change in ADL performance relate only to those clients for whom functional ability was assessed at both their initial assessment and their reassessment.

Figure 4.10 shows the average ADL score for these clients at their initial assessment and reassessment.

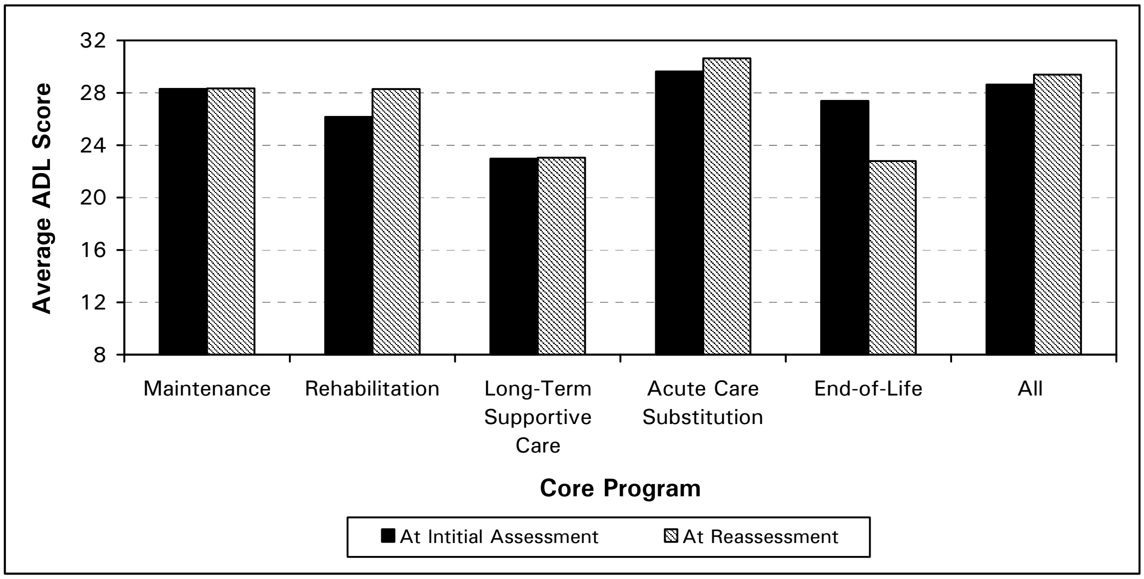


Figure 4.10. **Change in Average ADL Score by Core Program**

The average ADL score for Rehabilitation and Acute Care Substitution clients increased. Rehabilitation clients showed the largest increase in average ADL score (2.1). However, the Acute Care Substitution clients had the highest average ADL score at reassessment (30.6).

Among the End-of-Life clients whose ADLs were assessed a second time, their average score decreased by almost five points, from 27.4 to 22.8.

The average score for Maintenance and Long-Term Supportive Care clients remained virtually unchanged.

These results reflect the different expectations for ADL functioning and overall service goals that would exist for clients within these core programs.

Instrumental Activities of Daily Living (IADLs)

The NPT also collected information regarding clients' abilities to perform Instrumental Activities of Daily Living (IADLs). Six IADLs were assessed:

- meal preparation;
- medication management;
- light housework;
- heavy housework;
- shopping; and
- telephone use.

The period over which the IADLs were assessed was seven rather than the three days used for ADL assessment, reflecting the fact that some of these activities (such as housework and shopping) may only be carried out on a weekly basis.

The independence with which clients performed IADLs was measured using the same scale as the ADLs. However, assessors were also able to code "not applicable", which was to be coded if the activity was not relevant to the client's environment: that the person lived in a setting where the services were provided or if the activity was not part of the client's usual routine. Unlike the performance of ADL activity, there may be reasons other than the clients' physical or cognitive abilities (for example, social and cultural environment) that may affect clients' performance of IADL activities. For example, many men do not prepare their own meals, not because they would not be capable, but because meals were traditionally prepared by women, such as their wives or daughters. However, feedback from the field and the results from the NPT reliability study indicated that assessors also used the "not applicable" code when the activity did not occur on a more temporary basis, such as temporary physical limitations or restrictions.

Number of IADLs Performed at Initial Assessment by Core Program, Sex and Living Arrangements

Figure 4.11 demonstrates the differences in the average number of IADLs performed during the seven days prior to the initial assessment by male and female clients in each of the five core programs. It shows that Long-Term Supportive Care clients had on average performed fewer IADL activities than clients in other core programs. Figure 4.11 also shows that female clients performed similar numbers of IADLs across the core programs. In contrast, male clients performed fewer IADL activities, and also male clients in the different core programs showed more variation in the number of IADLs they performed.

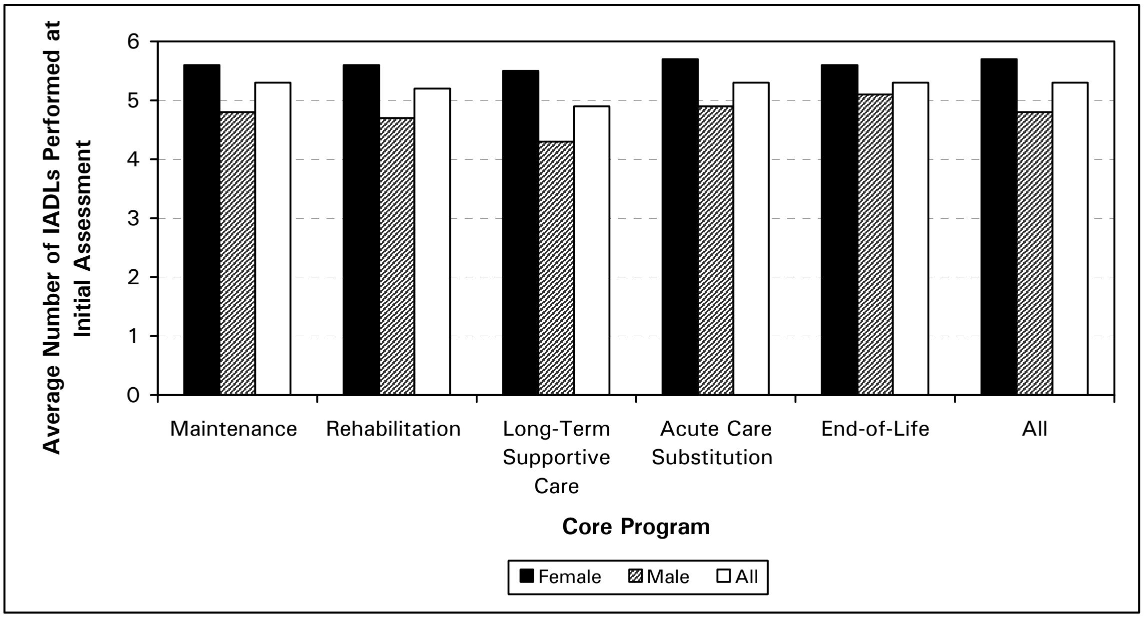


Figure 4.11. Average Number of IADLs Performed at Initial Assessment by Core Program and Sex

Figure 4.12 shows that the number of IADLs performed varied across male and female clients according to their permanent living arrangements. Clients living in “other” living arrangements performed the lowest number of IADLs on average, followed by those living with a paid attendant. As Chapter 2 described, clients in “other” living arrangements were mainly those living in residential care settings. These clients and those living with paid attendants would therefore have people available to assist with or perform their IADL activities, and were likely to be living in these settings because of the level of assistance they required.

Among the remaining clients, generally, female clients performed similar numbers of IADL activities irrespective of their living arrangements. In contrast, among clients living with a spouse, partner or other family members, male clients performed fewer IADL activities on average than female clients. However, male and female clients living alone performed similar numbers of IADL activities.

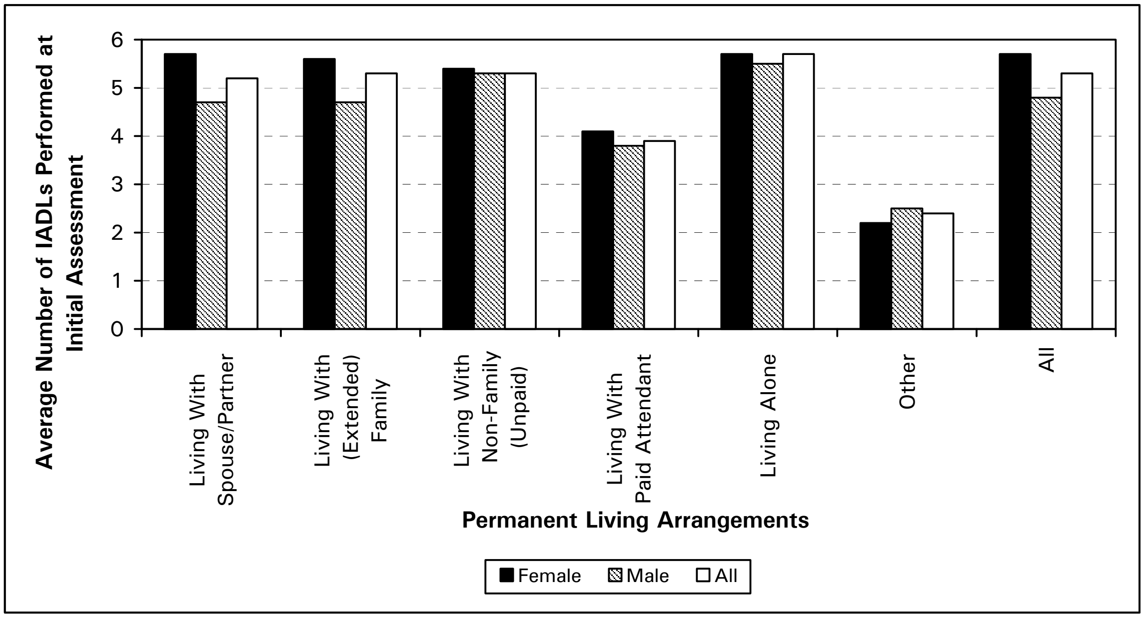


Figure 4.12. Average Number of IADLs Performed at Initial Assessment by Clients' Permanent Living Arrangements and Sex

Some of the observed differences may be the result of clients' physical or cognitive limitations. However, if these differences were due solely to these factors then one might expect similar differences in ADL activity among male and female clients in the different living arrangements. However, such an analysis of the average overall ADL score at initial assessment did not show any major differences. It therefore seems likely that at least some of the differences observed in the number of IADLs performed were related to the clients' social environment. It is also possible that the proportion of "not-applicable" coded as the result of temporary issues was higher among Rehabilitation and Acute Care Substitution clients than among the other core programs.

Methodological Issues in Analyzing IADL Information

The NPT indicators for IADL functional status and functional outcomes proposed combining the information for the six IADL elements into an summative score of overall IADL function, similar to the one used to measure ADL functional status and outcomes. However, the creation of such a summative score is complicated by how to appropriately handle the "non-applicable" code used in scoring IADL performance.

Of particular concern, the clients coded as "not-applicable" comprised of two distinct groups: clients who usually performed IADLs but did not at the time of assessment due to temporary limitations at the time of the assessment and those who did not usually perform those activities. It would be quite likely that one would want to treat these two groups differently.

One method of dealing with this issue could be to recode those who did not carry out an IADL activity as being "dependent" in that activity. While this be appropriate for those who do not perform the activity on a temporary basis, it may not be appropriate for those who do not usually perform such activities. Using this methodology would affect the comparability of IADL performance across core programs (and potentially across jurisdictions). As was shown earlier, the sex and living arrangements of clients varied across the core programs. Therefore any programs with high proportions of male clients living with family members would have overall lower IADL scores, as they would contain more clients who would not perform some IADLs (such as meal preparation and shopping).

A second method could be to exclude those elements that were coded as "non-applicable" from the calculation of an overall measure, for example, creating an "average" score based only on those IADLs that the client performed. While this would take into account differences in the number of IADLs, it creates problems when trying to make comparisons over time and measuring change in IADL functioning. For example, if a client does not perform an IADL activity at their initial assessment but is able to carry it out with some assistance at the reassessment, if their IADL performance was the same for all other IADLs during their two assessments, their average IADL score could actually decrease, even though they had an improvement in their functioning (that is doing something they could not do before). If one only based results on those IADLs that were performed, again one does not take into account any improvements or decline in the *number* of IADLs that are carried out, which in them reflect improvements or declines in IADL functioning.

As a result of these issues, no overall measure of IADL performance was calculated. Further research needs to be carried out on how to measure IADL functioning and the creation of an appropriate indicator that would be comparable across core programs and jurisdictions. However, some analyses on the individual IADL elements are provided to indicate how clients' IADL performance varied across the core programs.

Performance of Individual IADL Activities at Initial Assessment

Figure 4.13 shows the proportion of clients within each core program who performed the individual six IADL activities during the seven days prior to their initial assessment.

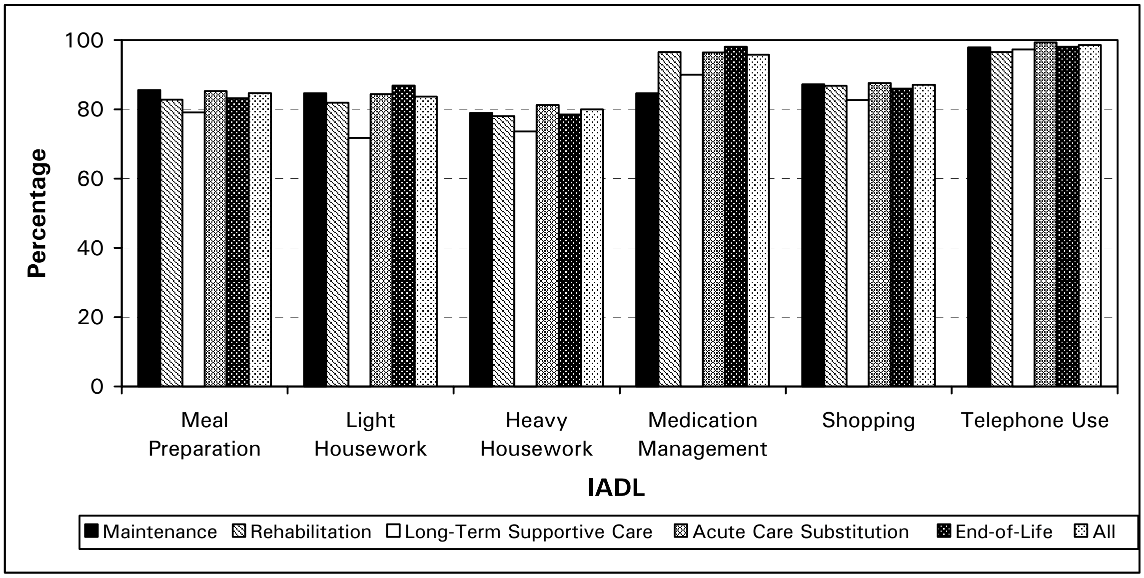


Figure 4.13. Proportion of NPT Clients who Performed IADL Activities at Initial Assessment by Core Program

Among all core programs, clients were most likely to have used the telephone; with over 96% of clients in each core program had used a telephone during the last seven days. In contrast, clients were least likely to have done any heavy housework. Overall, 80% of clients had done some heavy housework. This proportion was lowest among Long-Term Supportive Care clients and highest among Acute Care Substitution clients, 74% and 81% respectively. In fact, Long-Term Supportive Care clients were the least likely to have performed any of the IADL activities.

Figure 4.14 shows the average score for each individual activity among those clients who had performed that IADL activity. (An average score was calculated by assigning numeric values to the level of dependence for each client (1 for Dependent, 2 for Assistance, 3 for Supervision and 4 for Independent) and then the arithmetic mean was calculated).

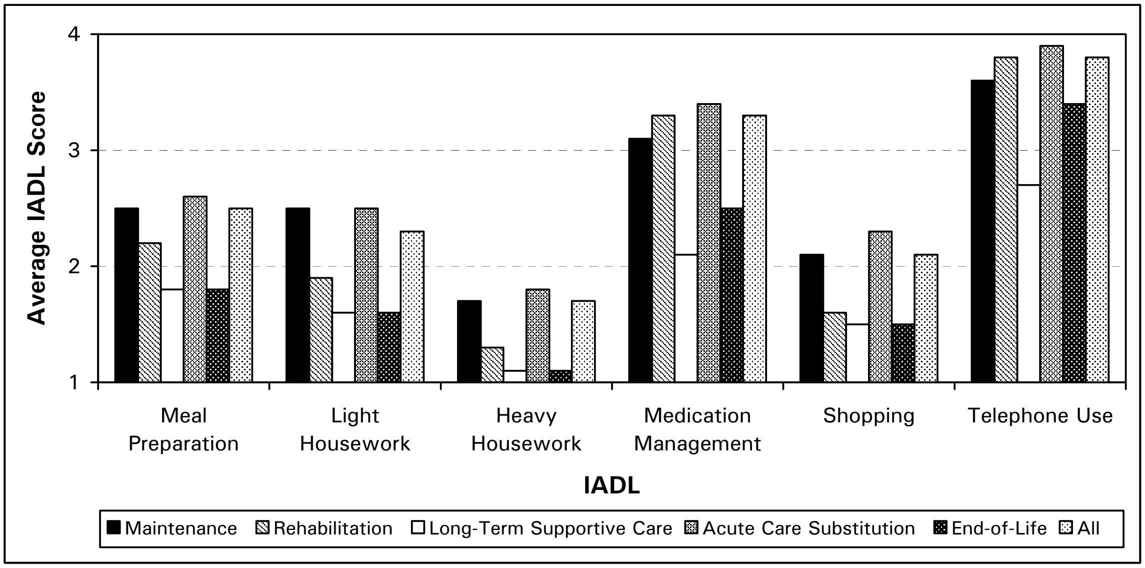


Figure 4.14. Average IADL Score at Initial Assessment by Core Program

Across the core programs, clients showed the most independence in their telephone use and were usually most dependence in performing heavy housework (the exception was Long-Term Supportive Care clients who were most dependent in light housework).

Although Figure 4.13 shows that there was a higher proportion of End-of Life clients who performed the IADL activities compared with Long-Term Supportive Care clients, Figure 4.14 shows that average level of dependency of clients who had performed the activities was similar in the two groups. For example, the average score for performing light housework for clients in both core programs was 1.6.

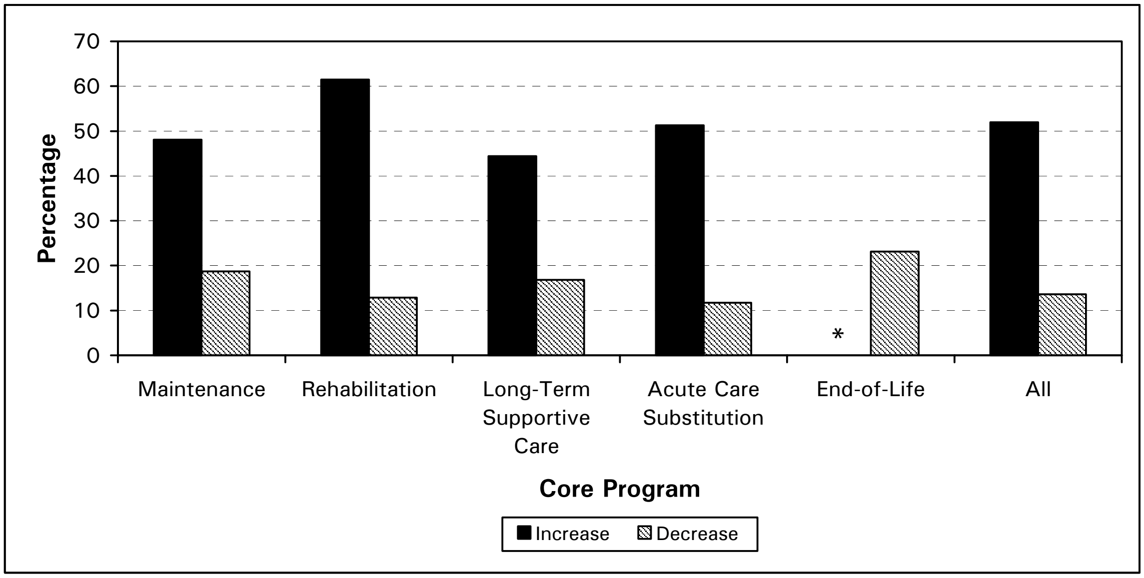
In general, Acute Care Substitution clients showed the highest levels of independence in each of the IADL activities and Long-Term Supportive Care and End-of-Life clients showed the lowest levels of independence.

Changes in IADL Performance Between Initial Assessment and Reassessment

As with the analysis of ADL performance, the analyses of IADL performance at reassessment and change in IADL performance relate only to those clients for whom functional ability was assessed at both their initial assessment and their reassessment, and excluded those who died or could not be reassessed for other reasons.

In addition, individual IADL elements may have been recorded as “non applicable” at their initial and/or their reassessment. To investigate the extent of changes in the number of IADL elements clients performed, increases and decreases in the number of IADLs performed were analyzed separately. Among clients who could potentially increase the number of IADLs they performed (that is, excluding clients who performed all six in their initial assessment) the proportion who had actually performed more IADLs at their reassessment then they had at their initial assessment was calculated. Likewise, to investigate decreases, the proportion of clients who performed fewer IADLs was calculated (excluding those who did not perform any of the six IADLs at their initial assessment and therefore could not perform fewer at their reassessment).

Figure 4.15 shows that among clients who performed less than six IADLs at their initial assessment just over half (52%) performed more IADL activities at their reassessment. This proportion was highest among Rehabilitation clients (62%) and lowest among Long-Term Supportive Care (44%).



*Suppressed due to small numbers.

Figure 4.15. Change in Number of IADLs Performed by NPT Clients at Initial Assessment and Reassessment

Figure 4.15 also shows that 14% of clients who had performed at least one IADL during their initial assessment performed fewer IADLs at their reassessment. As one might expect, End-of-Life clients were the most likely to show a decrease in the number of IADLs performed; almost a quarter (23%) of End-of-Life clients who had their IADLs reassessed, performed fewer IADLs at their reassessment.

In order to the measure changes in clients' levels of dependence, only those clients who were assessed at both the initial assessment and reassessment could be compared. Figure 4.16 shows the proportion of clients who were assessed at both initial assessment and the reassessment, and who performed the IADL activities at both intervals. A significantly lower proportion of End-of-Life clients had their IADLs reassessed as half of all clients had died within the 90-day period and were therefore did not have their functional status reassessed.

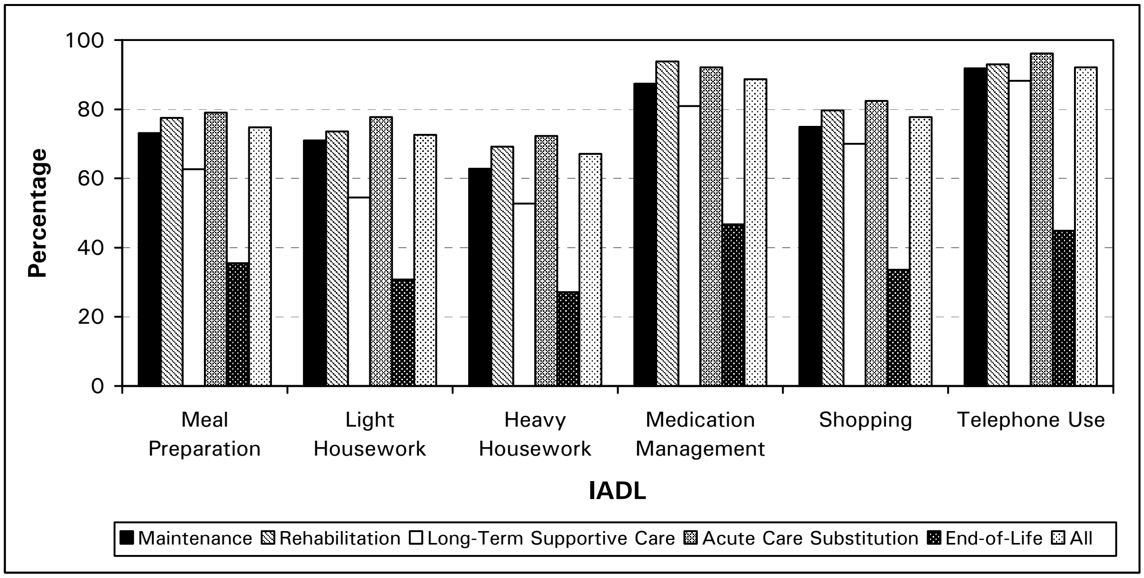


Figure 4.16. Proportion of NPT Clients Who Performed IADL Activities at Initial Assessment and Reassessment

Among the other core programs, a similar pattern emerged across most of the IADLs: Acute Care Substitution clients had the highest proportion of clients who performed each IADL at their initial and reassessment, followed by Rehabilitation clients (the exception to this was Medication Management, where the positions were reversed). Maintenance clients were more likely than Long-Term Supportive clients to have performed each IADL at both occasions.

In all core programs, clients were most likely to have used the telephone and managed their medication and least likely to have performed any housework.

Figure 4.17 shows clients average level of independence for each IADL activity at their initial assessment and reassessment. Care should be taken when interpreting these results, particularly small differences, as some of difference in average scores may be the result of coding variability rather than actual change in clients' IADL performance. Feedback from the field suggested assessors had some difficulty in distinguishing between the different levels of dependence, which could have lead to some of this variability. In particular staff found it hard to judge whether a client should be coded as "dependent" or "requiring assistance" as they found if difficult to determine the exact proportion of the assessed activity the client had completed (the cut-off point between these two codes was 25%).

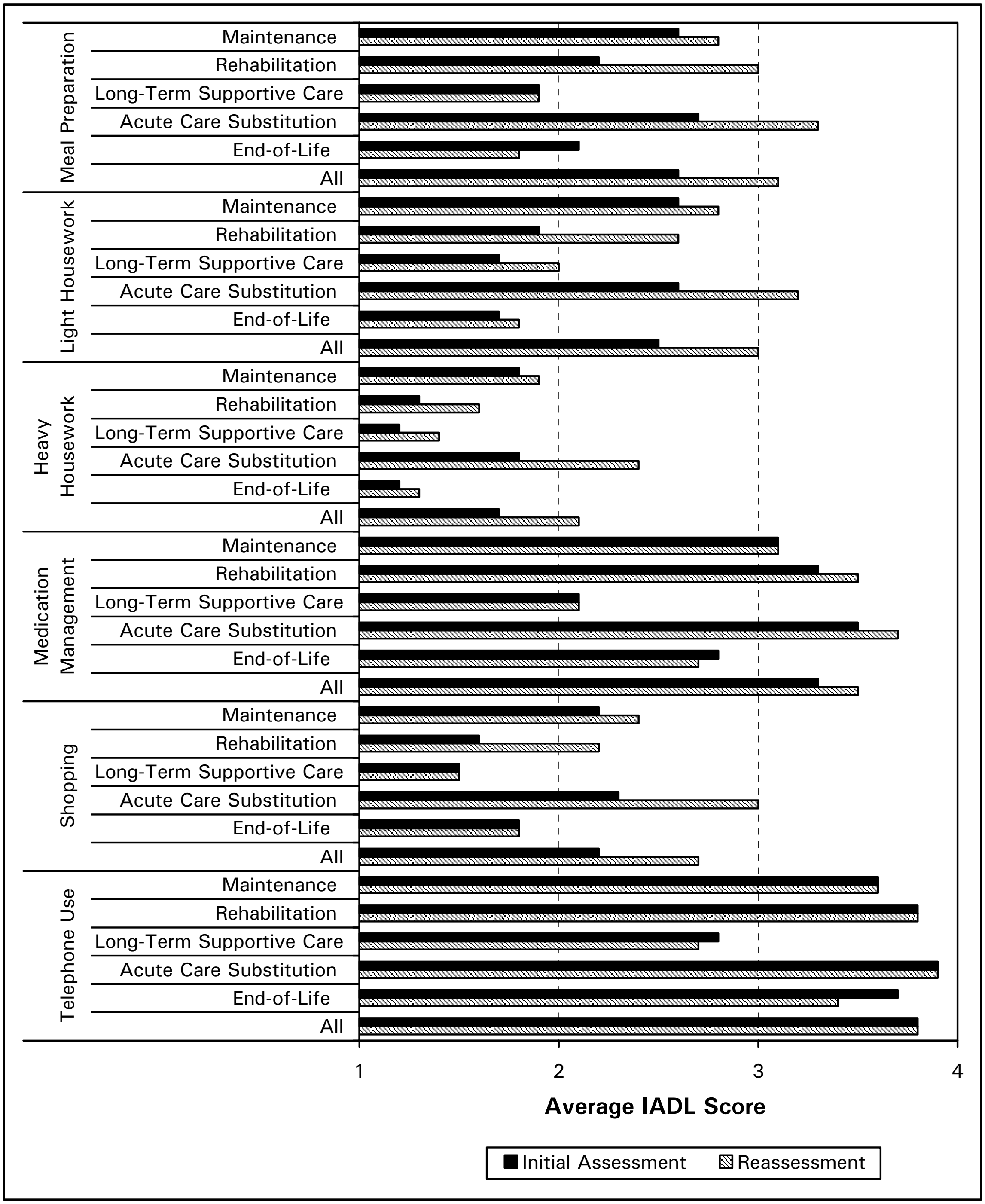


Figure 4.17. Change in IADL Performance Between Initial Assessment and Reassessment by Core Program

Rehabilitation clients and Acute Care Substitution clients showed fairly substantial increases in all IADL activities, except Telephone Use. There was no change in these clients' ability to use the telephone as the majority of clients were recorded as using the telephone independently at both of their assessments.

Maintenance clients showed small improvements in the average scores for meal preparation, light housework, heavy housework and shopping. However, as mentioned previously, these differences were small and should be interpreted with caution.

End-of-Life clients, who had not died and who had their IADLs reassessed, decreased in their independence to prepare their own meals and use the telephone. Changes in the other IADLs were small and should therefore be interpreted with caution.

Where Long-Term Supportive clients had performed an IADL activity at their initial assessment and their reassessment, there was very little or no change in their average level of independence in performing that activity.

Indicators Relating to Disruptive Behaviours and Cognitive Impairment

Indicators measuring aspects of functional status other than ADL and IADL were also proposed:

- the proportion of home care clients who exhibit disruptive behaviours, by core program; and
- the proportion of clients who have a cognitive impairment at time of assessment, by age and core program.

These indicators provide information on aspects of the functioning capabilities of adult home care clients that can impact the provision of home care services and the achievement of service goals.

Disruptive Behaviours

Some home care clients exhibit behaviours that are potentially harmful to themselves, interfere with daily activities and negatively impact on the provision of care and the achievement of service goals. Some behaviours can be altered at times but overall they have an impact on service delivery and on the client's ability to live at home either alone or with others.

Overall, 2% of adult clients were assessed as exhibiting disruptive behaviours at the beginning of their service episode. This proportion varied across the core programs. Long-term Supportive Care clients were the most likely to exhibit disruptive behaviours than clients in any other program; 11% of Long-Term Supportive Care clients exhibited disruptive behaviours compared with 4% of Maintenance clients and 2% of Rehabilitation clients. Acute Care Substitution clients were the least likely to exhibit disruptive behaviours (1%). There were insufficient clients with disruptive behaviours in the End-of-Life program to provide information on this indicator.

Cognitive Impairment

Research has shown the risk of cognitive impairment increases with age. Findings also suggest that in older adults, cognitive functioning is more likely to decline during an episode of illness or injury. Information on the cognitive status of home care clients and how it changes over time is useful for the planning and resource allocation of health and support services as the service goals and the type and amount of assistance required varies significantly between cognitively impaired and physically impaired clients.

During the NPT, the Standardized Mini Mental State Examination (SMMSE)[20] was to be used to assess clients' cognitive status. The SMMSE is a brief, objective, standardized tool that tests the following areas of cognitive function: orientation, registration, attention and calculation, recall and language. However, due to the quality issues described below the indicator relating to cognitive impairment—the proportion of clients with an impairment—was not calculated.

Quality Issues Relating to the Assessment of Clients' Cognitive Status

The assessment of client cognitive status occurred in two stages. First, the assessor used his or her clinical judgement to determine whether or not the client had a cognitive and/or communication impairment or had difficulties in performing cognitive or communication skills. Next, if the client appeared to have a cognitive impairment, the SMMSE was to be administered.

Although the first stage of this process appeared to have been completed successfully, there were indications of under recording of the presence of cognitive impairment at this stage. For Long-Term Supportive Care and Maintenance clients with Mental Functions recorded as their primary functional impairment, one would expect these clients to be assessed as having a cognitive impairment at the specific data element and then to have the SMMSE administered. However, 17% had an inconsistency between these two data elements and did not have a cognitive impairment flagged at the specific data element. Unfortunately, as primary functional impairments were not collected for clients in the other core programs, similar consistency checks could not be carried out on these clients.

More problematic was the fact that the SMMSE was only administered to just over half (54%) of those clients who had being flagged as having indications of a cognitive impairment. Due to this low response to the SMMSE test, the "presence of cognitive impairment" indicator could not be calculated, as it was felt that the indicator would significantly underestimate the proportion of clients with a cognitive impairment.

Feedback from the pilot sites suggested there were a number of reasons why the SMMSE was not completed during the initial assessment. Some clients had language difficulties as English was not their first language, which made the SMMSE difficult to administer. Other clients refused to take part in the SMMSE test. In some jurisdictions the SMMSE had already been administered as part of a previous assessment to determine the most appropriate service (such as home care or facility-based community care). In these circumstances, the

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[20] D. W. Molloy, *Standard Mini Mental State Examination,* (Dundas, Canada: Newgrange Press, 1998, 1999).

home care staff did not feel it was appropriate to administer the test again as part of the NPT. In other cases, the assessors were reluctant to administer the test: for example, if the client had an intellectual disability or because the assessor felt the elements that made up the SMMSE test were out of context with the rest of the assessment.

Chapter 5: Indicators of Health System Performance and Other Characteristics

This chapter provides indicators relating to the health system, such as waiting times, service hours, and use of emergent care services.

It should be noted that the results presented here, like those in other chapters, are based only on a subset of newly admitted clients from the pilot sites (see Chapter 2 for more details), and may not necessarily reflect the characteristics of the overall home care population or the overall performance of the health system within the respective health regions. The information is for illustrative purposes only.

Indicators Relating to Waiting Times

The length of time between a client's referral and when they receive their initial assessment, and between their initial assessment and initial service provision, provides information on the availability and accessibility of services and aids the assessment of the responsiveness of the home care system to client needs.

The two proposed indicators on waiting times were:

- the average time between the clients' referral and their initial assessment; and
- the average time between this assessment and the provision of their first service.

In addition, information is also provided on the total time between the clients' referral and provision of service.

Although the time between referral and receipt of service are commonly referred to as "waiting times" it should be noted that in many cases, clients may be referred for home care services before they are ready to receive the actual services and the time between referral and service provision is used proactively in preparing the services for when the client is ready to receive them. For example, clients who are currently receiving in-patient rehabilitation services may be referred to home care services for further rehabilitation before they are ready to be discharged from the hospital. They may receive their assessment while still in the hospital so that they are able to receive their home care services immediately upon discharge.

It should be noted that due to the restricted time period for data collection for the NPT, only those clients who had been referred and received services during the data collection period were included in the final NPT database. Those few clients who had been referred but were still waiting for services after the end of the data collection period were excluded from these analyses.

Distribution of Waiting Times

Figure 5.1 provides the distribution of total waiting time (from referral to service provision) for all client episodes in the NPT. Eleven per cent of clients received their first service the same day they were referred and 36% received their service the day after they were referred.

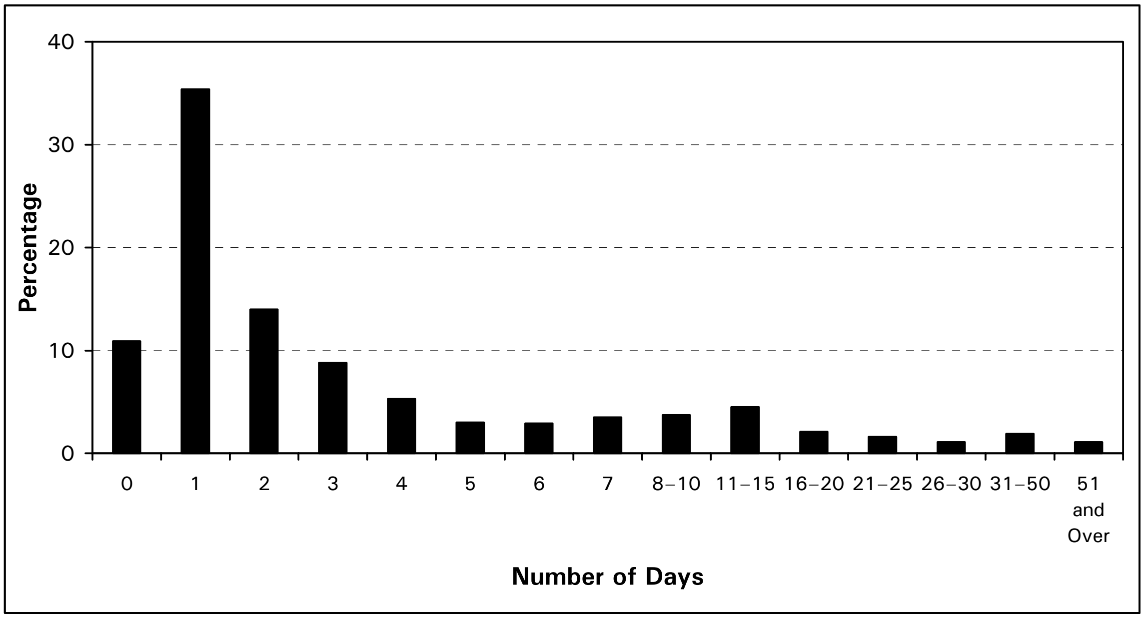


Figure 5.1. Distribution of Days NPT Clients Waited Between Referral and First Service

It was proposed to use the average (the arithmetic mean) as the indicator for wait times. However, for highly skewed distributions, such as that shown in Figure 5.1, it is usually recommended that the median rather than mean be used to measure the central tendency of a distribution. Therefore, the median, rather than mean, wait times are presented below.

The median wait for services was two days; 50% of the sample waited two days or less. Three-quarters of clients waited less than five days for their first service. There were only a few clients who waited a relatively long time for services (2% had to wait over a 30 days and the maximum wait was 132 days).

Figures 5.2 and 5.3 show, separately, the distribution of the two parts of total waiting time: the time between referral and initial assessment; and between assessment and first service. The similarity between Figures 5.1 and 5.2 suggest that the principal wait for home care services appears to be between the referral and initial assessment. Figure 5.3 supports this as it shows that 85% of clients receive their first service on the same day they are assessed. It also shows that 3% of clients received their first service *before* their initial assessment. The maximum number of days clients had to wait between their referral and initial assessment was 83 days and the maximum number of days between assessment and first service provision was 112 days.

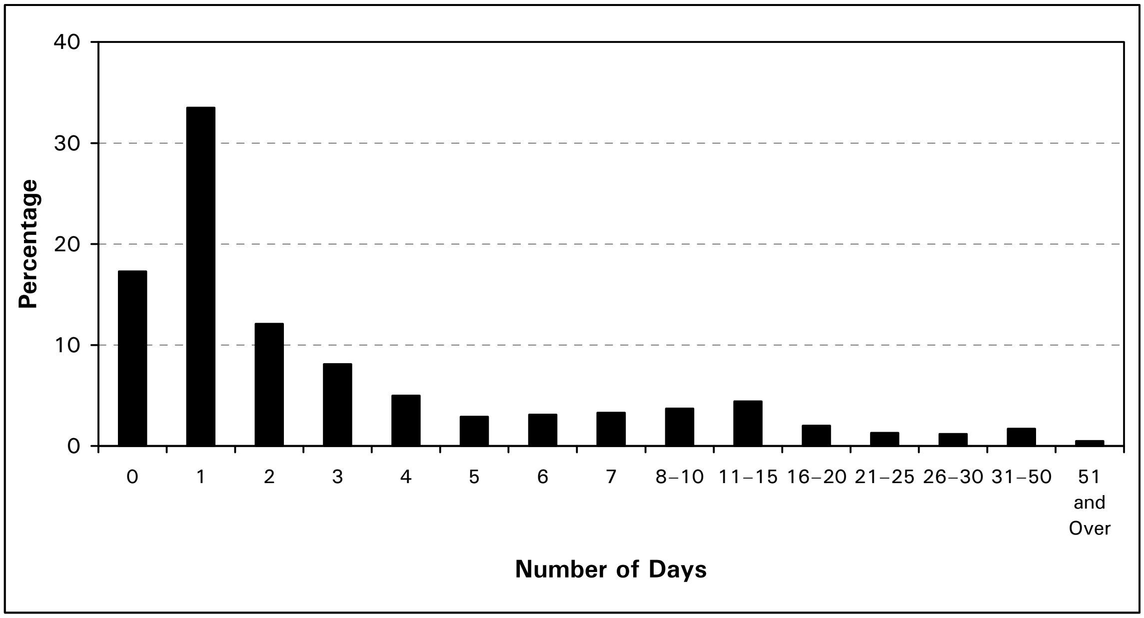


Figure 5.2. **Distribution of Days NPT Clients Waited Between Referral and Assessment**

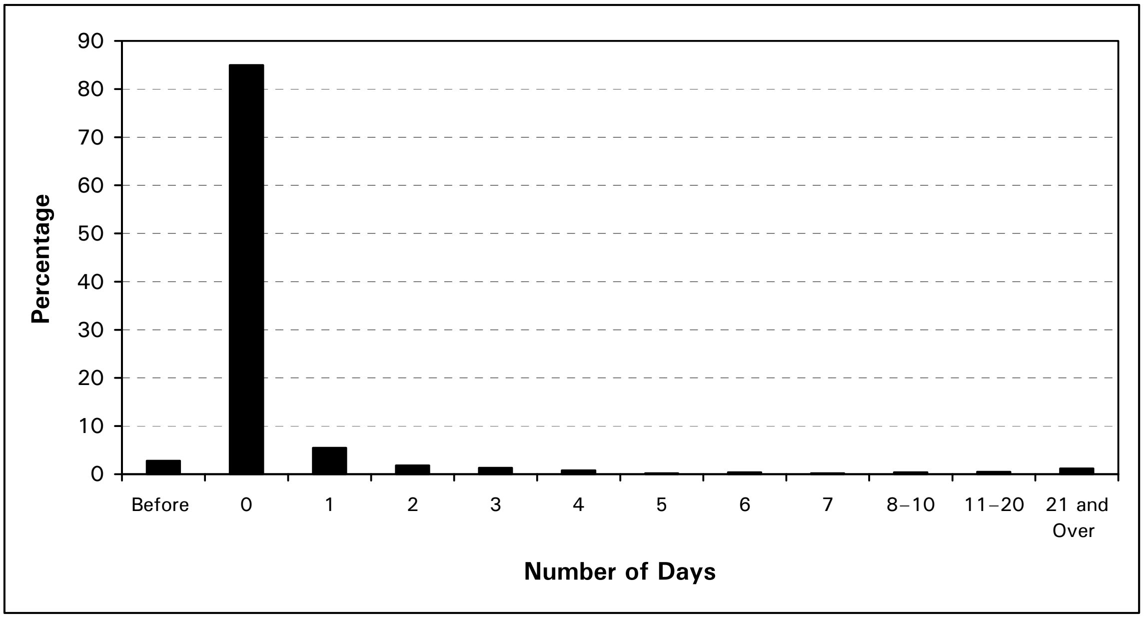


Figure 5.3. **Distribution of Days NPT Clients Waited Between Assessment and First Service**

Overall Waiting Times for Pediatric Clients

As mentioned earlier, the 75 pediatric episodes form a specialized group within the NPT sample; they are small group; with the majority of episodes coming from the St. John's pilot site, and were only part of the Acute Care Substitution, Rehabilitation and Maintenance client groups. Some pediatric clients, particularly the Maintenance clients, required very different services from different service provider than adult home care services. Therefore the wait times for adult and pediatric clients were analysed separately.

Overall, the median wait time between referral and first services for pediatric clients was three days. There appeared to be marked differences in the wait times of pediatric clients in different core programs: 1 day for Acute Care Substitution clients; 42 days for Rehabilitation clients and 69.5 days for Maintenance clients. However, care should be taken when interpreting these statistics as they are based on small numbers of clients.

Overall Waiting Times for Adult Clients by Core Program

Figure 5.4 shows the distributions of wait times for adult clients in the different core programs. Acute Care Substitution clients generally had the shortest wait for services; the median wait for these clients was 1 day and only 5% had to wait more than 7 days. End-of-Life clients had the next shortest, with a median wait of 2 days and 7% waited more than 7 days. The median wait for Rehabilitation clients was 3 days and 25% of clients had to wait more than 7 days. Maintenance and Long-Term Supportive Care clients tended to have to wait for much longer time between their referral and their first service. The median wait time for Maintenance clients was 6 days and 39% had to wait more than 7 days and Long-Term Supportive Care clients had a median wait time of 7 days and 44% had to wait more than 7 days.

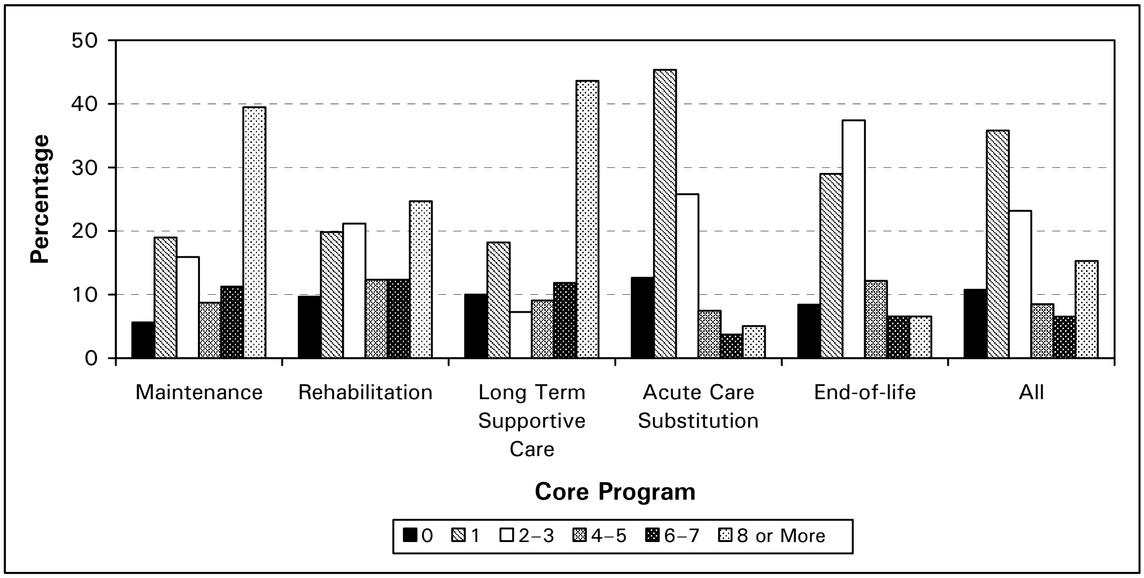
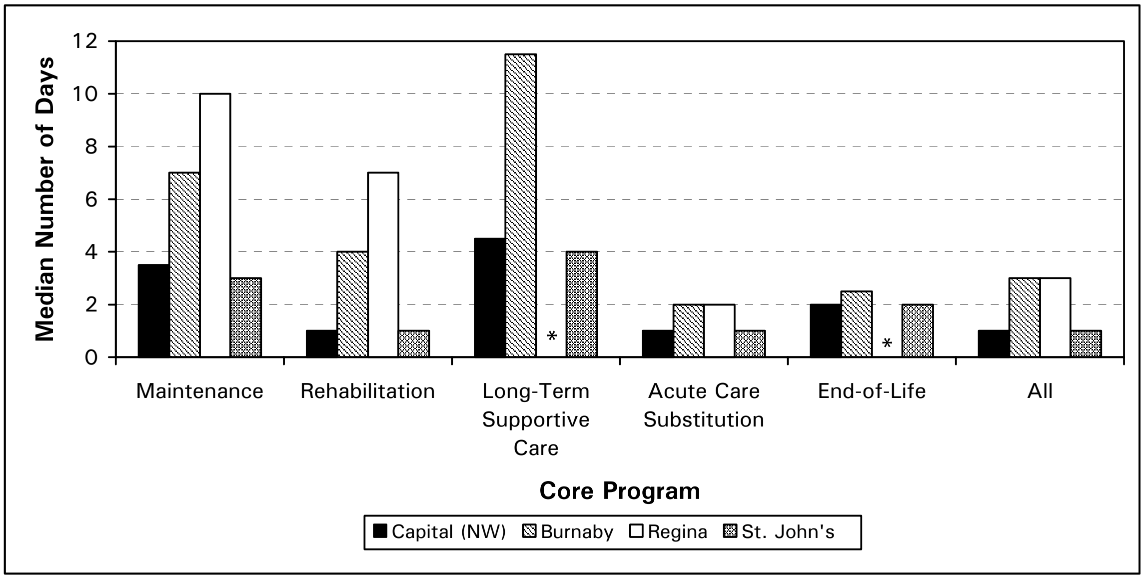


Figure 5.4. Distribution of Days NPT Clients Waited Between Referral and First Service by Core Program

Overall Waiting Times for Adult Clients by Pilot Site

The median waiting time from referral to service provision for adult clients varied across the pilot sites: in Capital (NW) and St. John's it was one day; in Burntwood, Fraser and Regina it was three days; and in Whitehorse the median wait time was four days.

Figure 5.5 shows the median wait times among the four larger pilot sites (excluding Burntwood and Whitehorse) for clients in the different core programs. Clients in the Acute Care Substitution and End-of-Life waited similar amounts of time across all the pilot sites. However, there was more variability across the pilot sites in the time clients had to wait for Maintenance, Rehabilitation and Long-Term Supportive Care program services.



*Suppressed due to small numbers.

Figure 5.5. Distribution of Days NPT Clients Waited Between Referral and First Service by Core Program and Pilot Site

Service Hours Indicators

Information on the amount of home health and home support service received per episode of care is important for predicting future service utilization and resource use.

To this end, information was collected on the number of home health and home support hours provided by the home care program used during each episode of care for adult clients. Home health services included information and referral services, assessment and case management services, nursing services, therapy services and the provision of drugs and medical supplies and equipment. Home support services included home making, home maintenance, home adaptation, meal provision, personal care, transportation, respite and volunteer services.

The proposed indicators, the average number of home health and home support hours received per episode, were designed to provide information on home health and home support separately. Information is also provided on the total number of services hours.

Although the indicators proposed to use the average (the arithmetic mean), as the distributions of service hours were skewed, median rather than mean hours of service are presented below.

Home Health Service Hours by Core Program

Virtually all home care clients in the NPT received some home health. Figure 5.6 shows the distribution of home health services hours per episode for all adult clients and by core program. The median number of home health service hours per episode was 4 hours and 30 minutes; 55% of clients received a maximum of 5 hours of home health service. A further 23% had between 6 and 10 hours of home health service; 16% between 11 and 25 hours and 6% of clients had more than 25 hours of home health service.

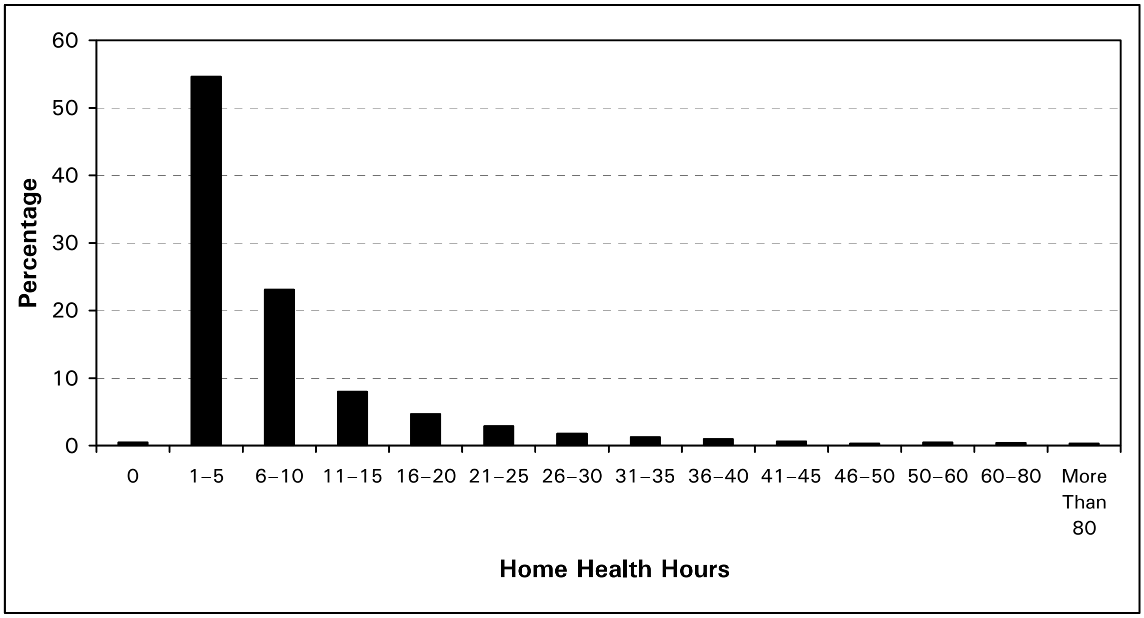


Figure 5.6. Distribution of Home Health Hours Received by NPT Clients

Figure 5.7 also shows the differences in the distribution of home health service utilization across the core programs. Acute Care Substitution tended to have low utilization; 63% had a maximum of 5 hours of home health service. In contrast, End-of Life clients had the highest utilization with a third of clients having at least 16 hours of home health service. The median home health services hours ranged from 3 hours 20 minutes for Acute Care Substitution clients to around 5 hours 45 minutes for Maintenance and Rehabilitation clients, 6 hours and a half hours for Long-Term Supportive Care clients and 9 and a half hours for End-of-Life clients.

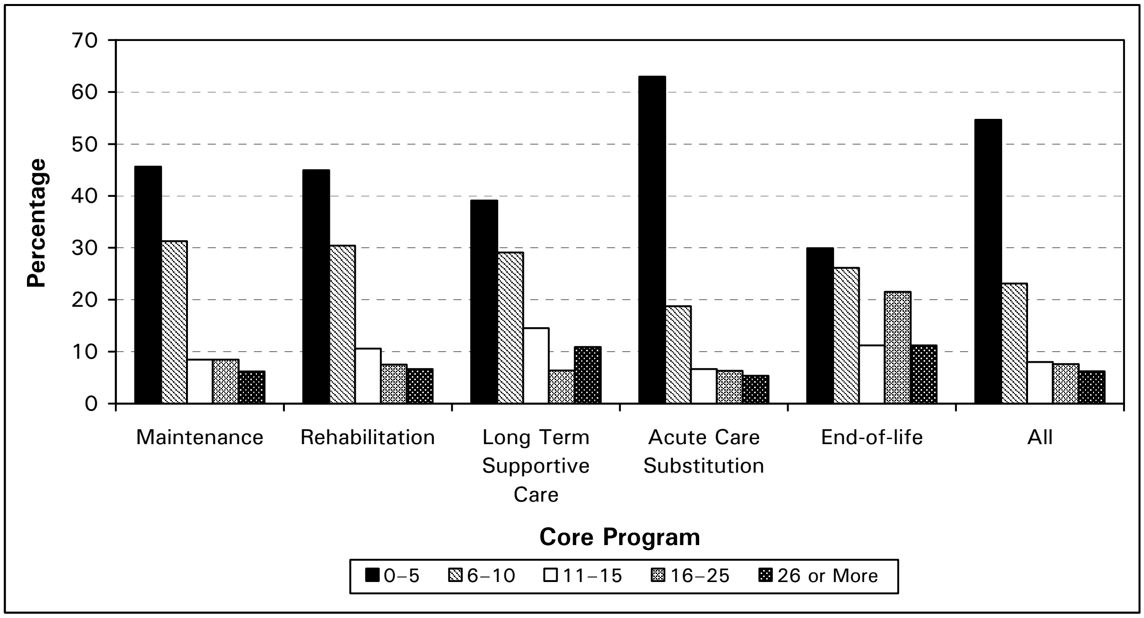


Figure 5.7. Distribution of Home Health Hours Received by NPT Clients by Core Program

Home Support Service Hours by Core Program

By contrast to home health services, only 16% of the home care clients received home support services during their episode of care and the majority of these clients received home support services in addition to home health services. The proportion of clients who received home support varied across the core programs: over half (52%) of Long-Term Supportive Care clients received both home health and home support services as did just under a third of Maintenance, Rehabilitation and End-of-Life clients (31% to 32%). Only 4% of Acute Care Substitution clients received home support services in addition to home health services.

Figure 5.8 shows the distribution of home support service hours per episode by core program.

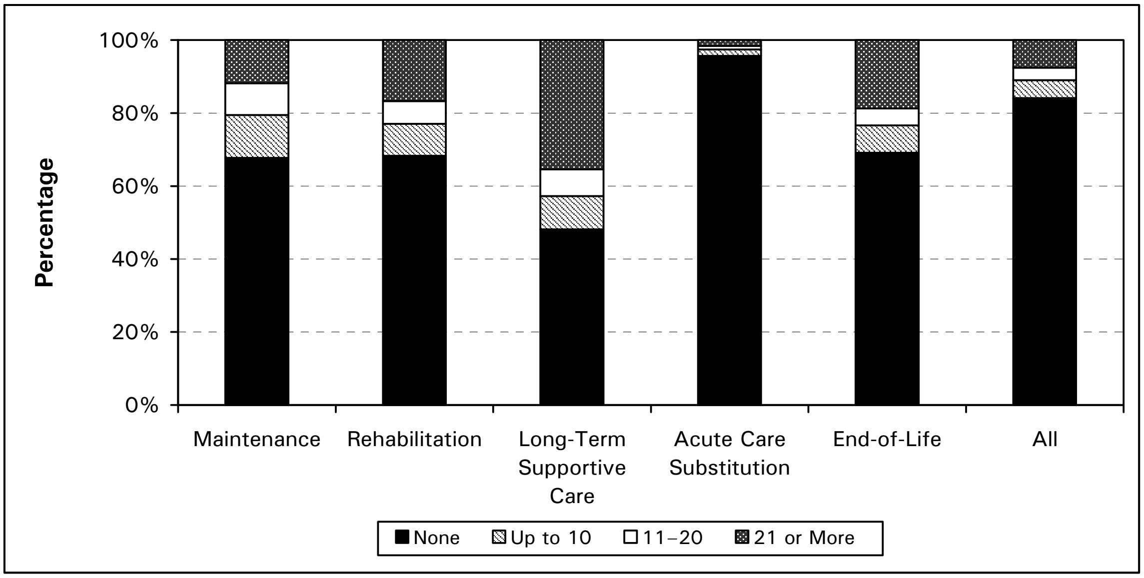


Figure 5.8. **Distribution of Home Support Hours Received by NPT Clients by Core Program**

As more than 50% of clients received no home support service hours, the median number of home support hours for all clients was zero. However, among those clients who had received home support service, the median number of service hours was 19 hours 30 minutes. Median home support service hours for those who received the service was lowest for Acute Care Substitution clients (14 hours) and Maintenance clients (15 hours). Rehabilitation clients received a median 21 hours 30 minutes of home support service and End-of-Life clients received a median 26 hours of home support service. Long-Term Supportive Care had the highest median, 33 home support service hours.

Combined Home Health and Home Support Service Hours by Core Program

As the majority of home care clients only received home health services, the median number of combined home health and home support service hours was very similar to median home health services: 4 hours and 30 minutes for home health services only and five hours for all services. Some 52% of clients had a maximum of five hours of combined service during their episode. A further 19% of clients had up to a maximum of 10 hours services. Five per cent of clients had more than fifty hours of service, with half of these clients receiving over 100 hours. The maximum number of combined service hours was 749 (which were received over a three-month period).

As Figure 5.9 shows, the median number of combined service hours for the different core programs varied from 3 hours 30 minutes for Acute Care Substitution clients to 7 hours 20 minutes for Maintenance and Rehabilitation clients, 12 hours for End-of-Life clients and to 15 hours 24 minutes for Long-Term Supportive Care clients.

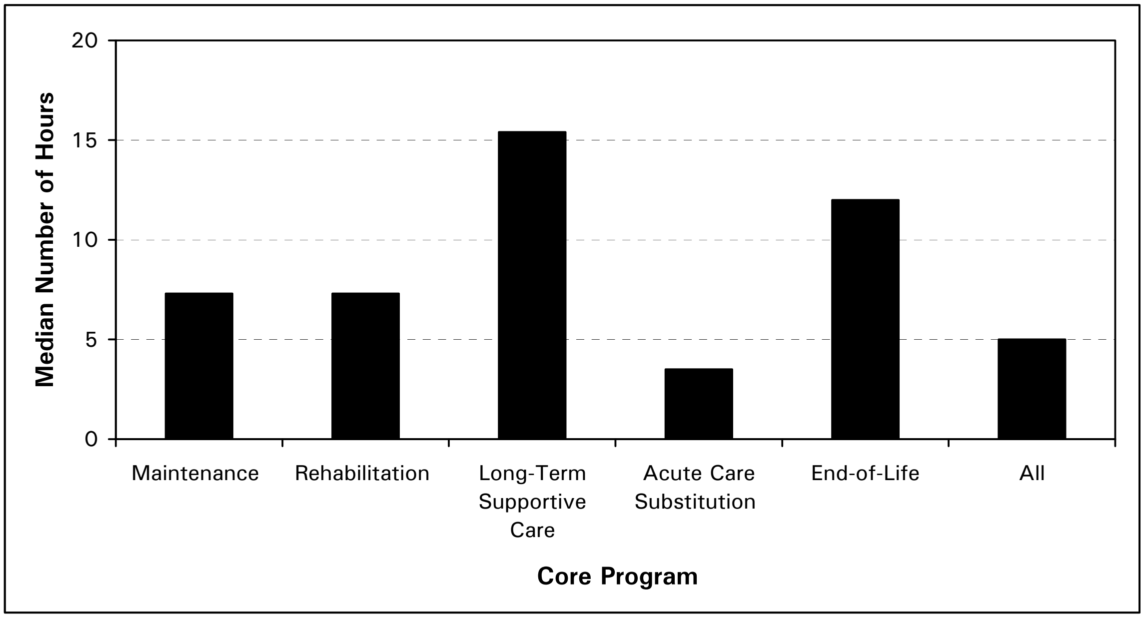


Figure 5.9. **Median Number of Home Health and Home Support Hours Received by NPT Clients by Core Program**

Although only 16% of home clients received home support services, home support accounted for almost half (48%) of the total service hours provided by the home care programs.

Those clients who received home support services in addition to home health services, tended to receive not only more service hours overall but also more home health service hours than those who only received home health services. Those who received home health services only had a median of 3 hours and 45 minutes service per episode. In comparison, those who received both home health and home support services received a median of 9 hours of home health services, 20 hours of home support services and a median of 34 total service hours.

The distribution of total service hours provided by the home care programs to clients in the five core programs showed a different pattern to the distribution of episodes in those programs, reflecting the different care needs of the clients. Figure 5.10 shows that although Acute Care Substitution clients accounted for 62% of episode of care they received only 32% of the total service hours; just over half (53%) of home health service hours and only a tenth (11%) of home support service hours. In contrast, Long-Term Supportive Care clients accounted for only 5% of episodes, but for 19% of the total service hours; 7% of home health service hours and 33% of home support service hours.

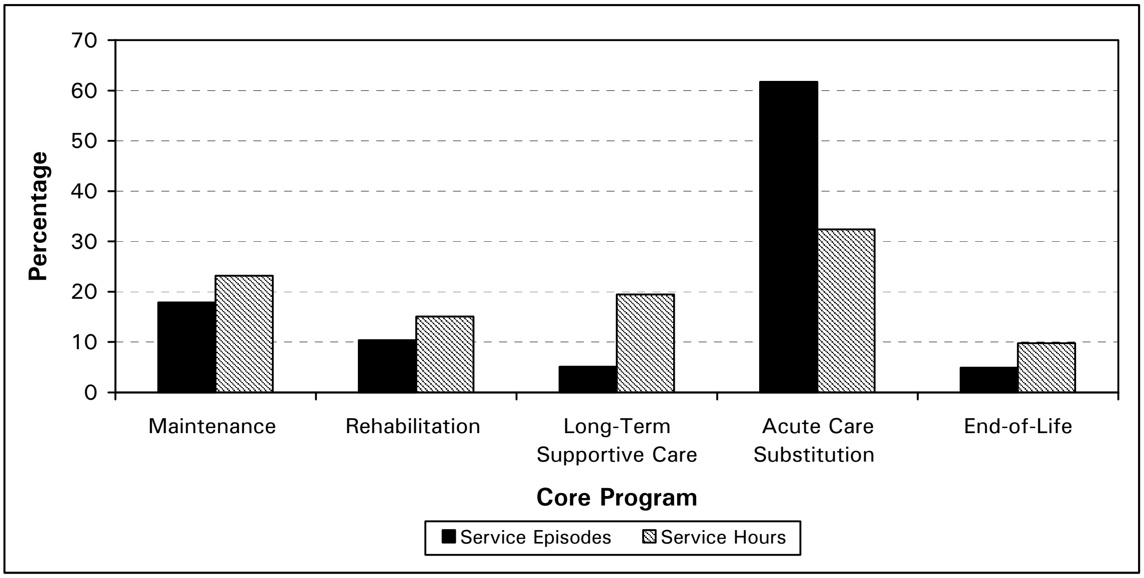


Figure 5.10. Distribution of Service Episodes and Service Hours Across Core Programs

The number of services hours received is related to the care needs of the clients, including their ability to carry out ADL and IADL activities and the duration the care is required for. Acute Care Substitution clients are characterized by having relatively short episodes and have relatively high abilities to carry out ADL and IADL and generally require fewer service hours, mainly home health services. In contrast, Long-Term Supportive Care required longer episode of care and were more dependent in their ADL and IADL activity, hence requiring home support as well as home health services, and requiring more of them.

Primary Service Delivery Setting

Although no indicator was proposed for this data element, the NPT collected information on the principal location where adult home care clients received their home care services. The data element related to the "type" of location the home care services delivered, rather than whether or not the location was the clients' permanent residence.

Primary Service Delivery Setting

Just over three-quarters (78%) of all clients received their home care services in a private home or apartment. These clients accounted for 80% of all the clients who lived in a private home or apartment, although it should be noted the private home where the client received their service may not have been their permanent residence.

The next largest type of service delivery setting was a community-based organization. This category included ambulatory settings provided by home care program, such as wound-care clinics.

Other settings, such as assisted living settings, residential care settings and boarding houses accounted for similar proportions of service delivery settings as they did accommodation setting; suggesting that the majority of the clients living in these settings received their service there. For example, assisted living setting accounted for 4% of both clients' service delivery and accommodation settings.

Primary Service Delivery Setting by Core Program

Almost a quarter (24%) of Acute Care Substitution clients received their home care services in a community-based organisation. These clients accounted for 91% of all episodes delivered in community-based organisations. Acute Care Substitution was the only program to have any clients who received service at work or school.

By contrast, only a small proportion of episodes in the other core programs were delivered in community-based organizations, ranging from 0% (End-of-Life) to 6% (Maintenance). The delivery of service in settings other than private homes reflected differences in the accommodation settings among the core programs. For example, Long-Term Supportive Care had the largest proportion of clients who received their service in an assisted-living setting (16%).

Primary Service Delivery Setting by Pilot Site

The use of community-based organizations as a delivery setting for home care services occurred predominantly in the urban pilot sites—Burnaby, Regina and St. John's pilot sites—and mainly for Acute Care Substitution clients.

In Burnaby and St. John's, Acute Care Substitution episodes accounted for more than four-fifths of all episodes that were delivered in community-based settings in these pilot sites.

However, these episodes only accounted for a portion of all their Acute Care Substitution episodes: 14% in Burnaby and 20% in St. John's. In St. John's, 14% of Maintenance clients had their service in community-based organizations.

In contrast, all of the home care services delivered in community-based organizations in the Regina pilot site were to Acute Care Substitution clients and they accounted for a much higher proportion of their Acute Care Substitution episodes (58%) than in Burnaby or St. John's. However, this figure probably underestimated the proportion of clients in Regina who receive their home care service in a community-based setting. Regina excluded a large number of clients from the NPT, many of whom had only one home care visit; usually suture removal, performed at a treatment centre.

Discharges from Home Care

Although there were no indicators proposed, the NPT collected information about clients' discharges from home care.

The reporting period for the NPT was 90 days. If the episode of care of an adult client ended within this 90-day period, information was collected on the date of discharge and the reason for the discharge/end of service.

Discharges by Core Program

Just under three-quarters (74%) of adult home care clients were discharged from home care before the end of the 90-day period. Figure 5.11 shows that the proportion varied across the core programs. As one might expect, Long-Term Supportive Care clients were least likely to have been discharged; just over a third (36%) of clients were discharged and therefore just under two-thirds (64%) were still receiving home care services after 90 days.

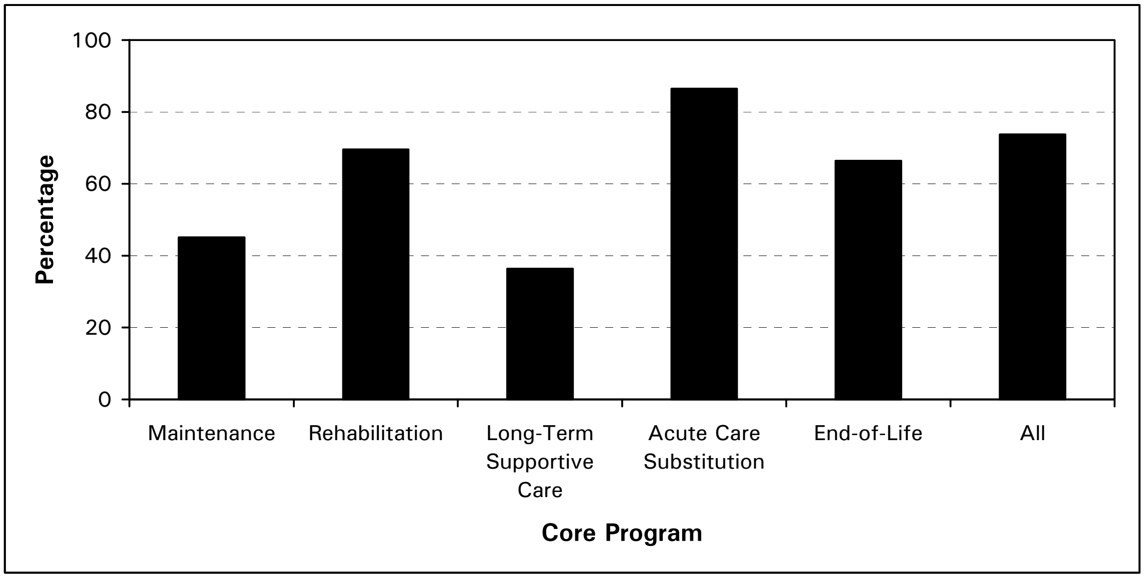


Figure 5.11. Proportion of NPT Clients Discharged from Home Care within 90 Days by Core Program

Just under half of Maintenance clients (45%) were discharged within the 90 days; while around two-thirds of End-of-Life and Rehabilitation clients were discharged (66% and 69% respectively). Acute Care Substitution clients were the most likely to have been discharged within the 90 days (87%).

Reasons for Discharge

Among adult clients who were discharged from home care before the end of the 90-day period, almost four out of every five (79%) had met their service goals at discharge. A further 6% of clients had died and 4% had moved out of the area. Clients who withdrew themselves, referrals to ambulatory or other community based services, and referrals to acute care each accounted for 3% of discharges. Two percent of clients were referred to residential care. The remaining clients' reasons for discharge were recorded as referral to an assisted living setting, no longer eligible for services, or other or unknown reasons (each accounting for less than 1%).

As one might expect, not only did the proportion of clients who were discharged vary across the core programs, the reasons for their discharges also varied.

In all but the End-of-Life core program, the most frequently recorded reason for discharge was the client had met their service goals. The most frequently recorded reasons for discharge for each core program were:

- *Maintenance*: service goals met (60%), client withdrew (10%), and client died (7%).
- *Rehabilitation*: service goals met (63%); referral to ambulatory or community-based care (20%) and client withdrew (6%).
- *Long-Term Supportive Care*: service goals met (38%), referral to residential care (28%), and client died (18%).
- *Acute Care Substitution*: service goals met (89%), client moved out of area (3%) and client withdrew (2%).
- *End-of-Life*: client died (76%) and referrals to acute care (7%).

Service Goals Met

One of the effectiveness indicators proposed was the proportion of home care clients achieving documented service goals by specified target dates, by core program.

Clients, caregivers and service providers ideally work together to set specific goals, plan services and document expected outcomes, which would include specified target dates for meeting these goals. The proportion of home care clients who then attain their documented services goals could be monitored. This information would provide important feedback to program managers for quality improvement initiatives and service planning.

During the NPT, information on service goals was collected during each adult client's reassessment. The service goals measured were those documented in the client's health record with an expected date of achievement less than or equal to 90 days (the length of the data collection period). A service goal was considered met if the goals were met by the expected target date or sufficient progress towards the goal had been made.

The quality of a "service goals met" indicator is predicated on the setting of the services goals at the beginning of the episodes and the quality of the documentation of the goals. Feedback from the pilot sites was that the setting and documentation of services goals was variable and some clients had no goals set, or they were ill defined or not well documented. This made assessing whether the goals had been met difficult or impossible. Therefore the results regarding whether or not service goals were met should be interpreted with caution.

Service Goals Met by Core Program

Overall, 84% of clients had met their service goals for their period of care. As Figure 5.12 shows this ranged from 68% of End-of-Life clients to 88% of Acute Care Substitution clients.

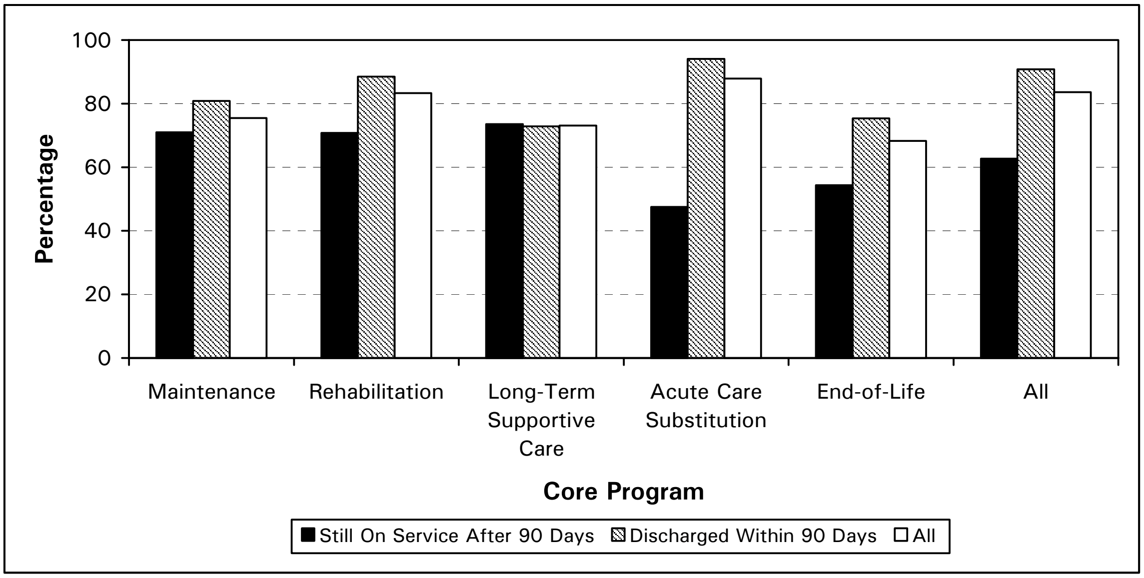


Figure 5.12. Proportion of NPT Clients Who Had Met Their Service Goals by Core Program and Discharge Status

Figure 5.12 also shows that, for most core programs, clients who had been discharged from the home care programs before the end of the 90-day reporting period were more likely to have met their service goals than those who were still receiving home care services at the end of the reporting period. For example, 94% of discharged Acute Care Substitution clients had met their service goals compared with 47% of those who were still receiving home care services at the end of the reporting period. Only Long-Term Supportive Care clients were equally likely to have met their service goals whether or not they were discharged from home care.

These differences may be explained by the fact that those clients who had not been discharged still required more service to attain their service goals. It may also be an indication that home care staff found it easier to set and monitor the shorter-term service goals of Acute Care Substitution clients than to set goals for those clients expected to stay in the home care programs longer than the 90 day period.

Indicators Relating to Health System Characteristics

Two indicators were proposed relating to how home care clients utilize other parts of the health system:

- The proportion of clients who used emergent care services, by core program.
- The proportion of clients who had a temporary transfer to a facility-based (acute and long-term care facilities) short-term and/or transitional bed, by core program.

Use of Emergent Care Services

Use of emergent care services is costly. Organizations responsible for planning and evaluating health services may monitor and trend emergent care use among their home care clients and draw conclusions about the overall health system performance. Jurisdictions could compare their rates over time and their experiences with that of other jurisdictions to identify potential opportunities to improve existing processes of care.

During the NPT, information was collected on whether or not adult clients had used emergent care services, such as hospital-based emergency rooms and/or free-standing emergent care facilities, during the 90 day data collection period (or during their whole home care episode if their episode lasted less than 90 days).

Use of Emergent Care Services by Core Program

Overall, 12% of adult clients had used emergent care services during their episode of home care. As Figure 5.13, shows the proportion of clients who had used emergent care facilities varied across the core programs. Rehabilitation and Acute Care Substitution clients were least likely to have used emergent care facilities (7% and 10% respectively). As one might expect, End-of-Life clients were the most likely to have used emergent care services; three out of every ten clients had used such services during their episode of care.

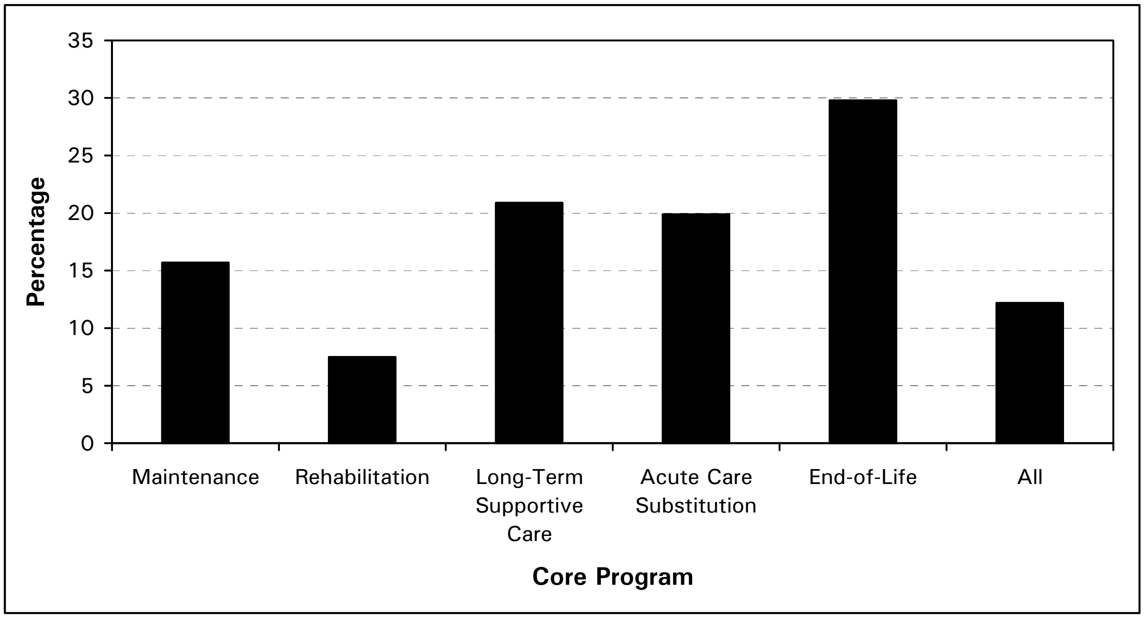


Figure 5.13. Proportion of NPT Clients Who Had Used Emergent Care Services During Their Service Episode by Core Program

Use of Emergent Care Services and Episode Outcomes

There was a strong relationship between whether or not the home care clients had used emergent care services and the outcome of their episode: whether or not they had been discharged by the end of the 90-day period and if so, the reason for their discharge.

Figure 5.14 shows that clients who had used emergent care services were much more likely to have died or been transferred to an acute or a residential care facility than those who had not used such services. For example, 29% of clients who had used emergent care services died compared with only 3% of those who had not used emergent care. Clients who had used emergent care services were also more likely to still be receiving home care services at the end of the 90 day period; 41% compared with 24% of those who had not used such services. In contrast, only 29% of those who had used emergent care had met their services goals and been discharged from home care compared with 62% of those who had not used emergent care.

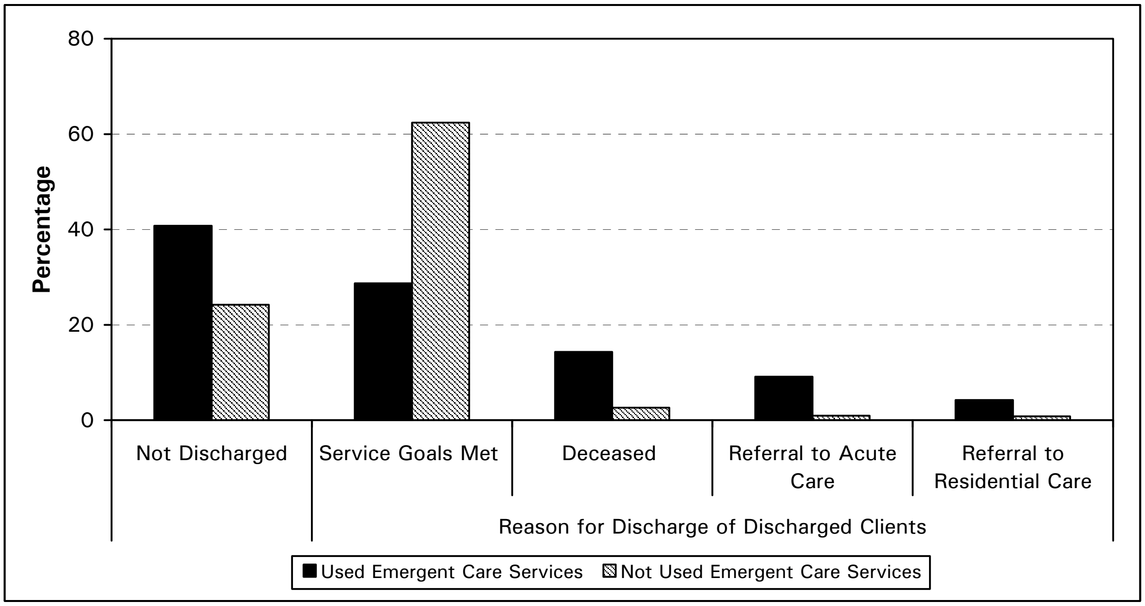


Figure 5.14. Distribution of Episode Outcomes by Clients' Use of Emergent Care Services

Use of Emergent Care Services by Pilot Site

The proportion of home care clients who had used emergent care services during their episode of care varied across the pilot sites: from 6% of clients in St. John's to 15% of clients in Burnaby and to 20% of clients from Capital (NW) and Regina pilot regions (there were too few clients using emergent care services in Whitehorse and Burntwood to provide statistics for these areas individually).

These differences in the use of emergent care may in part be explained by the different distributions of clients in the core programs across the pilot sites and the relative likelihood of using emergent care services. They may also be affected by the fact that only a subset of clients within the pilot sites was included in the NPT data collection.

Temporary Transfers to Short-Term and/or Transitional Beds

Unplanned transfers to a facility-based short-term and/or a transitional bed (either in acute care or long-term care facilities) usually occur as a result of a change in health status of the client and/or the ability or availability of the informal caregiver to provide the required care and supervision.

Information was collected on whether adult clients had an unplanned temporary transfer to such a bed during their home care episode. Planned and scheduled respite services were not included.

It should be noted that feedback from the pilot sites suggested that getting consistent information across Canada on such transfers would be problematic. In particular, they raised concerns surrounding the different service delivery models that may affect the types of beds included in the indicator, and differences in how jurisdictions would decide when a transfer to a facility bed is permanent or temporary.

Temporary Transfers by Core Program

Figure 5.15 shows that, overall, 6% of adult home care clients had temporary transfers to a short-term or a transitional bed. The use of short-term and transitional beds followed a similar pattern with respect to core program: 28% of End-of-Life clients had had a temporary transfer to a short-term or transitional bed compared with only 3% of Acute Care Substitution clients and 4% of Rehabilitation clients.

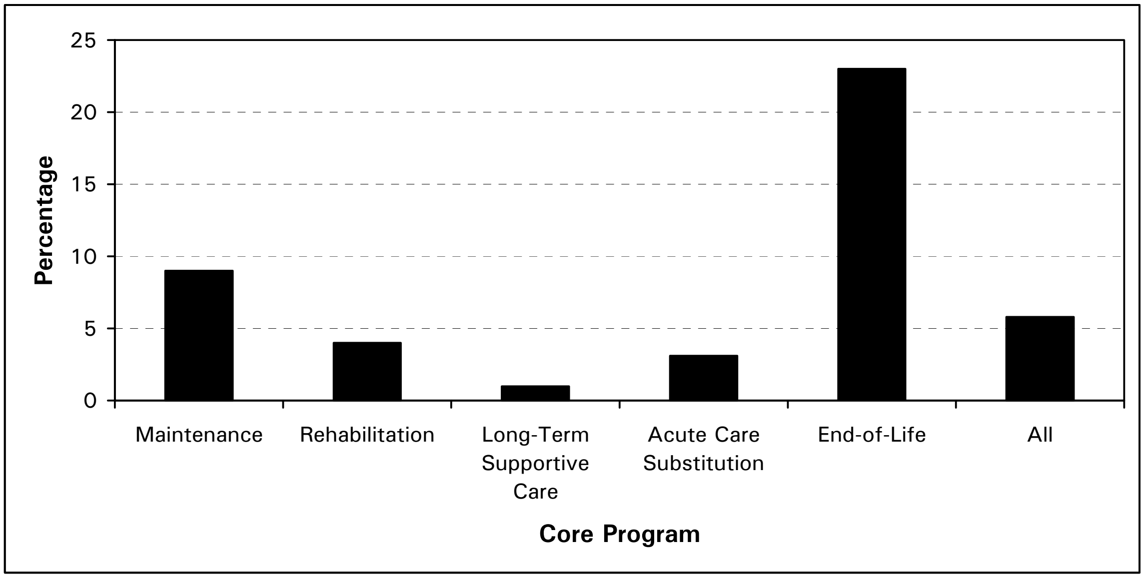


Figure 5.15. Proportion of NPT Clients Who Had a Temporary Transfer to a Short-Term or Transitional Bed During Their Service Episode by Core Program

There were a number of clients who had used both emergent care services and had a temporary transfer to a short-term or transitional bed: three out of every five clients who had had a temporary transfer to a short-term or transitional bed had also used emergent care services. These clients accounted for just over a quarter (28%) of clients who had used emergent care services.

Chapter 6: Lessons Learned

This chapter describes the main "lessons learned" in carrying out the NPT. These relate to three main areas:

- some general points relating to how home care is delivered across Canada;
- issues relating to the collection of data on clients who receive these services; and
- lessons learned relating to indicator development.

The lessons itemized here were illuminated during and/or after the pilot project, in retrospect. Along the way, the CIHI project team supported pilot sites throughout the pilot test with education programs and regular teleconferences, where "trouble-shooting" and information sharing took place. In July 2003, following the NPT data collection, CIHI hosted a two-day meeting in Ottawa, with representatives from each of the pilot sites, to debrief and evaluate the NPT experience. Participants in this event agreed that the National Pilot Test had been an important learning experience and that future initiatives must address the outstanding challenges in standardizing home care information.

The following observations were considered important to document for moving forward, to improve our capacity for comparable pan-Canadian home care reporting. Not all are new revelations, however the NPT has added significantly to our understanding of the issues and clearly illustrates the diversity of the sector and the associated reporting challenges.

About Home Care in Canada

1. Home care programs deliver a diverse set of services

The NPT confirmed the findings of Phase 1 of the project and other studies. These findings include the following:

- The individuals who receive home care have a broad range of service needs;
- How jurisdictions meet those needs varies considerably. The home care services provided by jurisdictions vary with respect to organizational size, types of services provided, eligibility requirements and service maximums; and
- The service delivery models for home care include: services delivered directly through service providers employed by the regional health authorities; through contracted-out services providers; and through self-managed care (where the clients receive funding and are responsible for acquiring the services they require).

Implication: While the characteristics of home care clients were documented in detail to allow for measurement of change (outcomes), the service utilization indicators for the NPT were defined at a relatively high level (that is, home health and home support services). Collection of detailed data elements describing services delivered was out of scope for the NPT given the challenges in achieving consensus on definitions for a common "basket" of home care services, and the work underway at the Federal/Provincial/Territorial (F/P/T) level. This work remains to be done and will require significant collaborative effort.

Action: CIHI will continue to support Federal/Provincial/Territorial processes as they work toward a common understanding of the scope of home care in Canada. The proposed CIHI Home Care Reporting System (HCRS), discussed in more detail in the following chapter, will allow for additional analysis of utilization by the different services received by the client, a step in the right direction toward standardizing all key home care service delivery definitions and concepts.

2. The structure for home care service delivery varies

Some jurisdictions are organized such that their home care programs are integrated into a wider range of home and community-based services across the continuum. These jurisdictions have a central referral and admission system to decide which, if any, service the person who has been referred should receive. (In the NPT, two pilot sites had integrated systems: the Capital Health Region, Alberta and Burnaby in the Fraser Health Authority, B.C.)

Other jurisdictions run their home care services independently of other community-based programs, and sometimes of other home care programs. In the NPT, for example St John's provided data for their two home care programs that operated independently of each other.

Implication: Where there are multiple, separately administered programs within a jurisdiction (as seen in St. John's), there are significant data quality challenges in calculating the financial and population-based indicators where jurisdictional boundaries overlap and definitions differ.

Action: CIHI will work closely with each jurisdiction participating in HCRS reporting to ensure unique identification (that is, single counting) of clients and associated home care activity. This will be particularly important in jurisdictions (such as Newfoundland and Labrador and New Brunswick), where home health and home support services are delivered under different administrative and governance structures. Within CIHI, the Home Care program area will collaborate closely with the MIS Guidelines team to work toward alignment of clinical and financial data to improve comparability across diverse delivery systems.

3. Home care services are not necessarily received at home

In the NPT, home care was defined as *"A range of health and support services received at home …".* However, the NPT found that a number of clients, particularly those receiving acute care substitution, received their home care services in a community-based setting, such as ambulatory clinics run by the home care programs. These clinics have been set up by home care programs to provide certain services more cost-effectively. In some instances, the home care service provider may not have any face-to-face contact with the client, delivering their services (for example, education, counselling and advice) over the telephone.

Implication: The definition of home care has evolved since the launch of the Roadmap project, in keeping with the evolution of home care service delivery during the period. Trends in hospital care have contributed to the changing nature of the home care client population, with increasing numbers of acute home care clients, who are relatively mobile and require short-term services (perhaps only one visit). Efficiencies may be gained for the home care program by serving these clients in settings outside the home, such as community clinics.

Action: In accordance with these findings, CIHI has amended its working definition of home care to reflect that home care services, while not necessarily received at home, enable clients to remain in their homes:

> *"An array of services, which enables clients incapacitated in whole or in part to live at home, often with the effect of preventing, delaying or substituting for long-term or acute care alternatives. These services may be provided by a number of different agencies or individuals."*[21]

4. Programs providing home care services are not necessarily called "home care"

Some jurisdictions, in addition to the services provided under programs explicitly named "home care", have other programs that deliver services that fit CIHI's definition of home care, but are organizationally separate from the jurisdictions' main home care programs. An example of this was the Palliative Care program in Regina, which delivered services to people at home, but was separate from all other home care services delivered in the jurisdiction. Clients in this program were not included in the NPT, and therefore affected the comparability of the data across the pilot sites, particularly for the End-of-Life core program.

Implication: This significant data quality (coverage) issue, particularly for indicators of population access, arises for at least two reasons. There is the ongoing challenge of the basket of specific services that are included in the definition of home care. In addition, as illustrated in the NPT, there may be administrative reasons for a lack integration of the information and/or business processes for clients receiving care at home in a given health region.

Action: The proposed HCRS will capture a profile of each jurisdiction regarding expected submissions by home care client group (see also Lesson #15). Significant education and consultation will be undertaken as plans for data submission are developed. The focus on client characteristics rather than programs will help to mitigate the issue, particularly in jurisdictions with integration across the community portion of the continuum. The comprehensive data quality program planned for the HCRS will also address strategies for assessing and improving coverage.

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[21] FPT Working Group on Home Care, a Working Group of the FPT Subcommittee on Long Term Care, Report on Home Care, Health Canada, 1990.

5. Referral and admission processes vary across and within jurisdictions

As the organizational structure of home care programs varies across Canada, it is not surprising that the referral and admission processes for those programs also vary.

Jurisdictions with integrated home and community-based services had centralized referral systems, which stream individuals at several different points. For example, the first stage of the process would determine whether or not an individual needed home and/or community services and may include an eligibility assessment. If they were eligible for service, a second stage would assess whether the individual should receive home care or facility-based community care. Once an individual was deemed to require home care, a further assessment could be carried out to determine which home care services they required.

Jurisdictions with separate home care programs have different referral and admission processes. Some referrals come through a coordinated system, that is, a general referral to "home care" is made, and a case manager or care coordinator determines which, if any, services an individual should receive/be referred to. Other referrals occur directly to particular programs/services, such as nursing or physiotherapy.

The NPT also found that there were differences in the point at which jurisdictions considered an individual to be a "home care client". For example, in BC, individuals must be admitted onto the home care program (that is, become home care clients) before they received a clinical assessment, whereas in Alberta and Manitoba, a clinical assessment is done as part of the referral process.

Implication: Without standardized definitions for when a referral and admission to home care takes place, these types of differences will lead to problems in comparing data on wait times and admission rates across jurisdictions.

Action: Rigorous ongoing evaluation of the data and feedback from HCRS data suppliers on issues illuminated by the NPT, such as this one, will contribute to the further development of definitions and analytical techniques to optimize comparability of the indicators. For example, should significant variation in waiting times be observed between jurisdictions, clear documentation of referral process differences would be required as context for interpretation. Longer-term options for mitigation may also include adjustments to the indicator definition and/or data sources. For example, survey data on client satisfaction with time waiting for home care might shed more light on the issue than administrative data. CIHI currently collaborates with Statistics Canada on home care information planning for the Canadian Community Health Survey (CCHS)[22] to ensure that key information needs are met through the appropriate data source. With respect to the admission rate indicator, should the definition of admission be problematic through data quality evaluation, the indicator could be modified to count a first service (date to be collected in HCRS), rather than an admission. Such decisions will be made in future in consultation with key stakeholders.

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[22] For further information, see the Statistics Canada Website at <http://www.statcan.ca/english/concepts/health/cycle2_1/cchsinfo.htm>.

6. Discharge processes vary across jurisdictions

The NPT found that discharge processes also varied across jurisdictions. However, there was one commonality across the pilot sites: the date of discharge could be much later than the date of the last service received by the client. There were two main reasons given for this delay. Firstly, the date of discharge may reflect the date the staff complete all the administrative processes and paperwork required to officially discharge the client, which may occur some time after the client received their last service.

Secondly, staff keep clients on their caseload in case they return to home care. Some home care clients require stays in acute care and in many cases, they are expected to return home and begin to receive home care services again. In such instances, case managers do not discharge their clients immediately as they expect clients to return. If the clients do not return, they may discharge them after a certain length of time. However, there was considerable variation in the length of time jurisdictions left clients' cases open; in fact some jurisdictions never officially discharged some of their long-term home care clients, even though they had not received any service for years.

Implication: Differences in discharge procedures will impact on the comparability of admission rates: if some jurisdictions considered clients who have gaps in the home care service as new admissions but others did not, their admission rates would vary considerably. In addition, if a client is not discharged when services are discontinued, there will be no capture of important discharge information including outcomes.

Action: In addition to the administrative dates of admission and discharge, the dates of the first and last service received will be collected in the HCRS. These dates will provide more accurate information on the length of time the client actually received home care services. CIHI will provide clear standards for when a discharge record should be generated for a client.

7. First Nations and Inuit Home Care may be delivered through existing regional structures

The First Nations and Inuit Health Branch (FNIHB) of Health Canada fund Home and Community Care Programs that provide home and community care services to First Nations people and Inuit who live on a First Nations reserve, Inuit settlement or First Nations community North of the 60th parallel.[23]

There are variations in how these programs are delivered: some are delivered through existing provincially-organized regional home and community care programs, while others may be delivered completely separately from these structures. For example, in the Whitehorse pilot site, the First Nations' Homemaking services were excluded as they had a separate service provider.

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[23] For more information, see the Health Canada Website at <http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/phcph/fnihccp/index.htm>.

Implication: Any indicators based on information from provincially-run home care programs would exclude First Nations people and Inuit who receive home care provided directly and solely by the FNIHB. This may impact on the comparability of indicators of population access and admission rates, particularly if First Nations and/or Inuit constitute a significant proportion of a jurisdiction's population, as is the case of the Burntwood pilot site.

In addition, if First Nations or Inuit clients were included in such indicators because they are receiving service through a provincial or territorial program, there could be the potential for duplicate data collection and coverage, as they would be also be included in statistics produced by FNIHB.

Action: CIHI will continue its collaboration with Health Canada, through the CIHI Home Care Forum, to share information on home care initiatives and address data quality issues of mutual concern.

About Collecting Data on Home Care Clients

8. Data for comparative reporting should flow from the process of care

The NPT relied on a standardized set of data elements being collected in addition to the information usually collected by the pilot sites during their referral and admission processes. However, many of the NPT data elements were similar to those already collected through the regions existing processes, and therefore were considered an additional burden, in time, cost and human resources.

Pilot sites felt that it would be more effective and efficient if data for comparative reporting were to flow from the information collected through the process of care. They recognized that these processes would require standardization, for example, through the use of standardized clinical assessment tools. These tools would allow the clinician to plan and deliver effective home care services and would also provide information that could be used for planning and management of the home care programs and that could populate indicators for comparative reporting.

In addition, many jurisdictions are developing integrated health information systems, which have the potential to allow for service utilization data to flow from workload measurement systems on a client-specific basis, which would allow for analysis of the relationships between clients' clinical characteristics and their service utilization.

Implication: The concept of a minimum *reporting* data set to populate high-level indicators will result in either duplication of data collection or the need for manual or electronic "mapping" unless the data elements are identical to those created through the normal process of delivering service. Where there is any opportunity for standardized "foundation" data sets, which will feed into the reporting data set and indicators, data quality will be significantly enhanced.

Action: Harmonization of the applicable elements of the Roadmap Data Standard with the RAI-HC©[24] to address this gap for some client groups has already been undertaken. Further detail may be found in the following chapter.

9. An appropriate amount of data should be collected according to clients' service needs

Although the NPT reporting data set was originally envisaged as a *minimum* data set, feedback from the pilot sites indicated that the burden of collecting all the data elements for certain clients was not justified considering the clients' service needs.

Of particular concern was the amount of data required that was appropriate for Acute Care Substitution clients who received only one or two home care service visits. Feedback from the pilot sites suggested that the collection of information on ADL and IADL performance, or the presence of disruptive behaviours were not necessary for these clients.

Implication: This lesson, among others, highlights both the diversity of home care clients and the impact of data collection on already busy home care providers. It is clear that the benefits of the data must be weighed against the costs (human and financial) to collect it.

Action: The HCRS data standard will reflect this feedback. For Acute Care Substitution clients, jurisdictions may elect to submit basic demographic and administrative information to allow for calculation of access and utilization indicators. Ongoing research and consultation will be incorporated into future enhancements of the data standard, particularly for the short-term home care client groups.

10. Clear, comprehensive and feasible data standards are required

The NPT reaffirmed the need for clear, comprehensive and feasible data standards, which include the intent of each data element, a definition, and valid codes with coding standards. Some of the lessons learned already presented speak to the importance of standards.

The intent or rationale of each data element was considered important particularly where the final use for the data element was not self-evident, or of immediate value, to those collecting the information.

Feedback from the pilot sites identified issues with the definitions of particular NPT data elements or codes that impacted on their usefulness and/or interpretation. Examples include:

- Lack of clarity in the definition of support for informal caregivers, which resulted in assessors not being able to code it reliably.

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[24] Copyright© inter*RAI* Corporation, 2001. Modified with permission for Canadian use under licence to the Canadian Institute for Health Information, 2002.

- Discrepancies, detected during the inter-rater reliability study, in the coding of the most responsible health condition, many of which were the result of one assessor using an "intervention" code and the other assessor coding a specific health condition (which may have been responsible for the intervention coded by the other assessor).

In addition, data standards may be comprehensive, but may not be feasible to assess consistently. For example, for the ADL and IADL data elements, the specified difference between a client requiring "assistance" and being "dependent" was whether or not the client could perform 25% of the task. However, feedback from the pilot sites indicated that it was difficult to determine what proportion of the activity the client had performed.

The NPT also identified the need for standardized, community-based terminology. Many data elements routinely collected on many of CIHI's data holdings reflect the fact they are facility-based or based on medical models. For example, the NPT contained a data element "Chart Number" which was defined as the client's unique identification number as assigned by the home care program. Although the pilot sites assigned such identification numbers, they did not use the term "chart number" to describe them.

An additional example of the need for standardized terminology is the use of the term "assisted living" and other terms used to describe the living settings that provide a spectrum of care from living completely independently through to 24-hour care. The pilot sites used the term "assisted living" to describe a variety of levels of care. Standardized definitions and coding would be required in order to compare information on such settings across Canada.

Implication: There are clearly challenges in the community sector with the use of diagnostic coding, which, in facility-based health care, is managed by professional health records personnel rather than front-line clinicians. Most of the other data elements were developed by CIHI specifically for the NPT, and had been subjected to a small (12-client) pre-test. The feedback highlights the challenges of creating valid and reliable measurement tools and the resources required for development and testing.

Action: The following chapter describes the movement toward the RAI-HC© standardized clinical assessment instrument, which has been internationally validated. Clearly, this strategy alone will not guarantee valid and reliable data. CIHI will design and implement a proactive data quality strategy for the HCRS including targeted education and support for jurisdictions to ensure consistent coding and data capture (see Lesson #11).

11. Support and education are essential to ensure good data quality

The NPT reaffirmed the need to provide jurisdictions with support and education on a continuing basis, in order to achieve and sustain good quality information. In particular, data derived from clinical assessments carried out by home care service providers will require those providers to be able to conduct the assessments accurately and consistently.

Feedback from the pilot sites indicated that CIHI provided good quality education and client support for the NPT, and the items outlined in lesson 10 are some areas where greater emphasis should be placed on education and support. The pilot sites also identified the need to share information and best practice across regions collecting the same data.

Implications: Given the importance of ongoing education to data quality, the resource implications for home care organizations, and the relative isolation of many home care providers, there is an urgent need to explore innovative methods of knowledge transfer.

Action: CIHI is currently developing a comprehensive education and support strategy for the HCRS that will incorporate distance learning, e-learning and communities of practice components to enhance access to information and sharing of experiences across Canada.

12. Ensuring the privacy of clients' health information is essential

As with all other data holdings at CIHI, the NPT reinforced the fact that the privacy and confidentiality of all home care clients must be protected. The pilot sites took various steps to encrypt and de-identify the data they sent to CIHI.

Implications: Ongoing changes in the Privacy landscape will likely impact future data collection across the continuum, as jurisdictions enact legislation to protect client information.

Action: The changing environment will require a proactive approach at CIHI to ensure that all jurisdictions can participate in national comparative reporting for home care while respecting applicable privacy standards and/or legislation. Consultations planned for 2004–2005 between all jurisdictions and the CIHI Privacy Secretariat will assess their current and anticipated privacy requirements and inform the HCRS development process. CIHI processes for data security will incorporate state-of-the-art technology and best practice.

13. Jurisdictions working to standardize client identifiers

While recognizing the need to protect clients' privacy, pilot sites acknowledged that their current information systems required some redevelopment in order to facilitate a more efficient flow of client information across service providers. In particular, several pilot sites had already introduced, or were in the process of introducing/ standardizing province-wide identifiers that would be used for every episode of care a client had in any of the provinces' community-based services. This would allow for more accurate tracking of patients across episodes and services.

Implications: A unique client identifier is clearly critical across the health care system for confident measurement of access and utilization, and subsequent use of the data to inform system planning and funding. In regionalized jurisdictions, integration of information systems across the continuum to allow them to "link" their institutional and community-based data is another driver of this development and clearly supports efficiency and accountability within the regional organization.

Action: The HCRS will be developed to accept province-wide, privacy compliant unique identifiers in the data standard and CIHI will liaise with jurisdictions to facilitate the specifications and related protocols for this identifier.

14. Many jurisdictions may not be ready for point-of-care electronic data collection

Pilot sites were provided with the option of using electronic real-time data collection at the point-of-care. However, no pilot site chose this option, deciding instead to use paper-based recording forms that were subsequently entered into data-entry software provided by CIHI.

It is certainly not surprising that the pilot regions elected to use paper-based data collection, as the pilot test was clearly time-limited. For regions to introduce new software to case managers, who may not have been using computers for assessment, would have required additional investment in training and may have resulted in loss of productivity throughout the learning period. Even in the absence of a pilot test, however, it is understood that not every region may be ready for introducing point-of-care electronic data collection in the near term.

Implications: Moving to point of care electronic data collection represents a very significant business process change requiring investment in both people and infrastructure. Recent experiences in Canadian jurisdictions suggest that there is growing recognition of its benefits in home care, particularly for documentation of comprehensive assessments, such as the RAI-HC©. Still, while the benefits of electronic data collection are well understood, such as improved data quality and real-time production of reports/outcomes, switching from paper to electronic data collection requires significant investments in IT resources and staff training.

Actions: Through the HCRS development process and beyond, CIHI must allow for both electronic and paper data collection and provide opportunities for collaboration and sharing of experiences in electronic data capture and business process change among key home care stakeholders including vendors, provincial ministries and health regions.

15. Core Program data element required revision

The NPT confirmed that there is a need to distinguish, at a high level, the different types of clients who receive home care services in order to facilitate comparative reporting. Feedback from the pilot sites indicated that the “Core Program Component” data element that was used to make this differentiation required revision. In particular, it became clear that such a data element should focus on the characteristics and needs of the clients, rather than the types or level of services provided. While potential home care clients across Canada are likely to be similar, home care programs and service offerings vary significantly across jurisdictions, thereby reducing the usefulness of the Core Program data element.

Implication: This lesson is also related to the challenge of articulating the scope of home care in Canada (Lesson #1). Defining home care programs and services will require further research and consultation.

Action: CIHI has revised the NPT Core Program definitions to reflect client characteristics and renamed the data element accordingly—Home Care Client Groups (see Appendix E). CIHI will continue to work with key stakeholders in evolving standardized definitions for home care programs and services.

16. Clinical discharge data may be difficult to collect

The NPT highlighted the fact that there may be circumstances where clinical assessment data cannot be collected at discharge. The original intention of the NPT was to collect all data elements for all adult clients at initial assessment and at reassessment or discharge. However, some clients did not have their ADL and IADL performance reassessed because they had died, had been admitted into an acute care facility or had moved and could not be traced. While pilot sites attempted to get ADL and IADL information for some of those clients who had died or had gone into hospital, they met with limited success. The NPT also highlighted the fact that there are circumstances when it is not known at the time that the last service visit is in fact the last visit, as services may suddenly stop if the client goes into hospital or dies unexpectedly. In these circumstances, it may only be feasible to collect administrative data about the clients' discharge/end of service.

Feedback from the pilot sites also indicated that while discharge assessments provide information on clinical outcomes and effectiveness indicators, they do not assist with the development or delivery of the client's care plan (as they have or are about to be discharged). Therefore, jurisdictions may decide to focus their resources on ensuring that all initial assessments and any reassessments required while clients are still on service are carried out.

Implications: Resource constraints within home care programs and certain factors beyond the control of the home care service provider may well compromise our ability to measure certain outcomes. In particular, measures such as change in functional status, may not be available given the requirement for an experienced clinician to conduct and record clinical assessments. There are, however, other non-clinical data elements that can help to shed light on client outcomes where comprehensive assessment is not useful or feasible.

Action: For HCRS data standard, CIHI modified the NPT discharge data elements to allow for a basic analysis of whether service goals were met, reason for discharge and referral to other health services. Case managers will be encouraged to document these three items in real time or retrospectively, even where a final clinical assessment has not been conducted due to death or transfer to a facility.

17. Service delivery models may impact the data that can be collected

As mentioned above, jurisdictions employ a variety of models in the delivery of home care services. The amount, quality and comparability of any service utilization data is likely to be affected by the service delivery model(s) employed.

For example, in the NPT, one pilot site that contracted out their home care service delivery provided home support hours based on the number of hours the clients "funded" rather than actual hours they had received. It may also prove difficult to get accurate information on the actual service hours provided to clients who self-manage their care.
The level of aggregation of available data may also depend on the delivery model. For example, if the health region directly employs the service providers, the region may have an IT system that allows the service providers to log details of each client visit they make. However, if information is being supplied by a contracted agency, they may only provide aggregated data for all visits made to the client within the specified time period.

Implication: Private service delivery of publicly funded home care raises issues related to reporting for accountability purposes, an issue not exclusive to home care. There is an inherent challenge in that jurisdictions need to fulfill their need for information accounting for expenditure of public dollars, while private sector service providers face competitive pressures that discourage disclosure of detailed business information.

Action: The HCRS will, in its profile of data suppliers, highlight where there is known deviation from the standard, as in the example of funded rather than actual service hours. CIHI will also continue to develop and refine home care reporting standards that allow for flexibility in the level of detail submitted across jurisdictions while maintaining comparability for higher-level indicators.

18. Pediatric home care clients are a specialized population

The NPT demonstrated that pediatric home care clients are a specialized population of home care clients. Not all provincial/territorial ministries of health are mandated to provide home health and support services to pediatric clients (as some jurisdictions have specific services for children and families). However, for jurisdictions that do have pediatric clients, the NPT showed that their service needs are sometimes different from adult clients and that information collected for adult clients is not necessarily applicable or appropriate to pediatric clients. For example, information on informal support on pediatric clients was difficult to assess. As most of the pediatric clients lived at home with their parents, assessors found it difficult to determine what amount of care that was above and beyond the usual parental or familial care and that was directly related to the condition for which the child was receiving home care services.

In addition, many clinical assessment tools are not validated for use on pediatric populations.

Implication: It is clear that there are challenges in populating all of the recommended indicators for children. However, as for other specialized populations (for example, end-of-life) where there is no consensus on a standardized clinical assessment tool, many important indicators can still be calculated with demographic and administrative data.

Action: The HCRS will accept a subset of data elements for children and will consult with key stakeholders in reporting on this population. The paediatric data will be excluded for analysis of population-based indicators until/unless all jurisdictions submit data for all age groups.

About Home Care Indicator Development

19. The NPT indicators make an important contribution to our understanding of home care client populations, system characteristics, utilization and outcomes

The NPT demonstrated that a relatively small number of data elements can populate a wide range of indicators reflecting the priorities of diverse stakeholders. While the results presented in this report should be interpreted with caution given data quality caveats (mainly related to the extent to which all home care clients were included), many of the findings from the NPT have face validity and represent an important step forward in understanding home care in Canada.

Implication: These indicators represent a significant step in moving toward a balanced set of measures for home care to support accountability. Considerable work remains to build the foundation data sets that will support comparable results.

Action: CIHI will continue to address the need for comparable foundation data to populate the indicators through its plan for the HCRS as described in the final chapter of this report.

20. Indicators used in benchmarking of outcomes for front-line quality improvement require a more comprehensive data set

While the NPT indicators provide valuable information for accountability purposes, their level of detail would be insufficient for meaningful benchmarking at an organizational level in support of continuous quality improvement activities. In particular, many clinical quality indicators require some degree of risk adjustment (beyond age and sex standardization) to facilitate fair comparisons. Additional clinical detail can assist in “levelling the playing field” by identifying clients that are at risk for adverse outcomes.

Implication: Collection of a comprehensive clinical data set where appropriate (for example, RAI-HC©) provides additional opportunities for application to performance measurement and analysis of resource utilization.

Action: The HCRS will provide flexibility to allow jurisdictions to participate in RAI benchmarking and/or Roadmap Indicator reporting (see Chapter 7).

Chapter 7: New Developments and Future Directions

This chapter provides an overview of important developments since the launch of Phase 2 of the Roadmap Project. It provides context for building on the lessons learned presented in the previous chapter and includes emerging health policy directions, provincial/territorial home care initiatives, recent national consultations and progress to-date in CIHI's development of a pan-Canadian Home Care Reporting System (HCRS). The chapter concludes with next steps for the Home Care Roadmap Indicators.

Health Policy Direction

In his 2002 report, Commissioner Roy Romanow identified home care as the "next essential service"[25] and proposed new federal funding of $2 billion over the next two years.

In 2003, the First Ministers recognized the importance of health information for accountability and agreed:

> *"…to prepare an annual public report to their citizens … commencing in 2004. They further agree to use comparable indicators and to develop the necessary data infrastructure for these reports. This reporting will inform Canadians on progress achieved and key outcomes."* [26]

It is clear that much work remains to be done to put into place the infrastructure that will allow for comprehensive, balanced comparative reporting across Canada. However, there is evidence, through the work of the Federal/Provincial/Territorial (F/P/T) committees and through recent commitments at federal and provincial levels, that home care and home care information remain high on the public policy agenda.

Provincial/Territorial Home Care Initiatives

Meanwhile, many Canadian jurisdictions were (and are) in the process of planning or implementing new comprehensive health information systems, integrating client information across health regions and across the continuum of care. In many regions across the country, home care information is now being captured through regional information systems, replacing legacy "stand-alone" or paper-based systems.

Regions and service delivery organizations are also evolving the "business" of home care service delivery, with goals such as improving quality and accountability. There is growing recognition that standardized clinical assessment tools can contribute to improved quality of care and provide a rich foundation set of clinical, social and demographic data.

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[25] Building on Values: The Future of Health Care in Canada, Commission on the Future of Health Care in Canada (November, 2002).

[26] First Ministers Accord on Health Care Renewal, February, 2003.

In 2002, the Ministries of Health in Ontario and Nova Scotia implemented the RAI-HC© clinical assessment instrument for long-term clients in their home care programs. CIHI facilitated a collaborative process for developing a Canadian Version (October 2002) of the RAI-HC© to ensure standardized implementation across the country.[27]

Early in 2003–2004, the BC Ministry of Health (BCMOH) requested a proposal from CIHI to build a RAI data repository for home care, similar to the reporting system in Ontario for the RAI continuing care instrument (MDS 2.0© [28]), collected by CIHI since 1996. BC also wanted to support the movement toward comparable indicator reporting, harmonizing their provincial reporting standards with those of the Roadmap Indicator Data Standard.

Within CIHI, discussions with BC precipitated an updated environmental scan of current home care initiatives and anticipated needs in other jurisdictions.

The table below shows that as of 2003, seven provinces and one territory have inter*RAI* research projects and/or implementations underway to standardize the clinical assessment process, improve service planning and delivery, and acquire consistent data to inform decision-making.

Adoption Status	Province/Territory							
	N.L.	N.S.	Ont.	Man.	Sask.	Alta.	B.C.	Y.T.
Research sites	✓			✓	✓	✓		
Mandate		✓	✓				✓	✓

Some jurisdictions, including Quebec and Prince Edward Island, are using their own data collection tools. For the most part, the information collected is similar, and can be mapped to the proposed indicators, albeit with some comparability caveats. Other jurisdictions, such as Nunavut and remote areas such as Labrador, have few, if any, resources to support automated data collection in the community at this time.

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[27] Copyright© inter*RAI* Corporation, 2001. Modified with permission for Canadian use under licence to the Canadian Institute for Health Information, 2002.

[28] Copyright© inter*RAI* Corporation, 1997, 1999. Modified with permission for Canadian use under licence to the Canadian Institute for Health Information, 2002.

The Role of Clinical Assessment Instruments

CIHI consultations have revealed support for the use of standardized clinical assessment instruments. A standardized assessment, with associated care planning protocols, such as the RAI-HC©, supports quality of care through:

- real-time feedback on client risks and needs for care planning;
- clinical benchmarking using risk-adjusted indicators and outcome scales at regional, national and international levels; and
- a better understanding of the resource needs of diverse home care populations.

There are several reasons why have jurisdictions chosen the RAI-HC© as their standardized clinical assessment tool. Several Canadian jurisdictions/organizations have independently undertaken evaluations of clinical assessment tools and many have selected inter*RAI* assessment tools for their unique features:

- international validation, reliability and comparability;
- the only integrated suite of tools with instruments designed to assess and measure across the continuum; and
- large research consortium facilitates development of case mix tools, quality measures and other value-added outputs.

CIHI Home Care Consultation Process

A comprehensive home care consultation process, conducted between April and December 2003, involved key stakeholders such as Health Canada, Statistics Canada, the Canadian Council on Health Services Accreditation (CCHSA), inter*RAI*, Provincial/Territorial managers and policy-makers, field experts, and the CIHI Roadmap Indicator Expert Working Group. A one-day meeting in December 2003 brought together stakeholders from across the country to discuss the CIHI vision for a pan-Canadian home care reporting system (HCRS).[29]

The key messages from stakeholders were:

- CIHI leadership in setting home care data standards is critical for achieving comparability across the continuum and across the country;
- standardizing the foundation data, captured through a standardized clinical assessment, will improve the quality of the care, as well as the quality and usefulness of the indicators; and
- data for national reporting should be a by-product of the process of care.

The consultations revealed strong support across Canada for CIHI to continue its ongoing development of home care reporting standards to facilitate comparative reporting. Jurisdictions using or about to use inter*RAI* tools also communicated the need for standardized inter*RAI* products and services for Canada, as well as CIHI coordination of research and development activity.

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[29] Canadian Institute for Health Information, *Proceedings of the Home Care Summit 2003,* (Ottawa: CIHI, 2004).

They endorsed the modular concept of the proposed HCRS to support benchmarking of their inter*RAI* quality and outcome measures nationally and internationally and to allow for phased adoption of additional instruments for specialized client groups.

The consultations also revealed the significant challenges being experienced across the country in acquiring the human, financial and technological resources to improve their information systems to support decision-making and front-line care in the community sector.

HCRS Development

In April 2004, CIHI launched the HCRS development project, a two-year initiative to design, build and test a pan-Canadian reporting system for home care, with data collection beginning in BC in 2005–2006. The project also incorporates the development of education and support services for jurisdictions, including e-products and communities of practice, a comprehensive data quality program, and flexible, privacy-compliant reporting.

The Home Care Reporting System (HCRS) will provide comparative longitudinal and cross-sectional statistical reports and analysis relating to clients who receive publicly funded home care. This will include Roadmap Indicators, additional risk-adjusted quality of care indicators, and information on client characteristics, outcomes and resource utilization.

Through the development of the HCRS, CIHI will:

- Provide all provinces and territories with the opportunity to participate in national reporting of Roadmap Indicators.
- Leverage the rapidly growing uptake of the Resident Assessment Instrument for Home Care (RAI-HC©) in Canada to create a repository of comparable clinical, administrative and resource data, collected as a by-product of an improved, standardized process of care. This repository will support quality of care research and benchmarking for best practices in home care.
- Support a new structure and process for CIHI collaboration with national and international inter*RAI* researchers for continuous improvement of validated assessment instruments, case mix and quality indicator tools across the continuum of care.

The principles for HCRS design reflect themes from the Roadmap project:

- HCRS will support the core business of home care service delivery; data are a by-product of an evolving business, not an add-on;
- clinical assessment protocols will reflect best practice, while allowing for phased implementations based on availability of resources;
- KISS—keep it simple—realistic and feasible;
- the system will be flexible in anticipation of future data elements, future clinical assessment instruments, additional client groups;

- timely data inputs and timely, value-added outputs for front-line care planning, continuous quality improvement, planning and policy-making; and
- data quality is everyone's priority.

While comparability of information will always be challenging given the variation in models of service delivery across the country, the HCRS represents a first step in making meaningful comparisons between jurisdictions. These comparisons have been impossible to date given the absence of data standards and a common vocabulary for describing client groups or services delivered.

Beyond the Prototype

A strategic plan for implementation beyond the BC prototype year will be developed in 2004–2005 in consultation with interested jurisdictions. The HCRS will allow for a phased approach to reporting of the Roadmap Indicators depending upon readiness on the front lines to implement standardized clinical assessment instruments and/or the development of integrated information systems.

Jurisdictions electing to submit demographic, administrative and resource elements for all clients, while phasing in their clinical assessment reporting for some client groups, will be able to report on comparable indicators of access and service utilization.

Research is currently underway for development of inter*RAI* assessment instruments for other client groups (for example, acute home care, end-of-life, community mental health). The HCRS will be designed to allow for future development of additional clinical modules as appropriate.

Jurisdictions using standardized clinical assessment tools other than those developed by *interRAI* will also be able to submit to HCRS, through the development of mapping algorithms.

HCRS Collaboration

The HCRS Advisory Committee, formed in April 2004, provides a forum for consultations, dialogue and collaborative efforts. It will ensure that CIHI's work continues to be guided by, and relevant to the needs of the stakeholders. The role of the Committee is to advise and assist CIHI in the implementation of the HCRS, achievement of ongoing data quality and the design of useful products and services.

The Advisory Committee has representation from six Provincial/Territorial ministries that have home care information management initiatives underway—Ontario, Nova Scotia, British Columbia, Alberta, Saskatchewan and Yukon. Field experts, managers and an inter*RAI* Research Fellow provide additional perspectives. A Privacy sub-committee will be struck to give specialized advice in this important area.

The RAI Expert Panel, established in May 2003, brings together expertise from across the country to provide advice to CIHI and inter*RAI* on Canadian standards for inter*RAI* assessment instruments and their outputs. The RAI Expert Panel will identify solutions to technical, coding, data quality, training and operational issues pertaining to the inter*RAI* clinical assessment tools, definitions, care planning protocols, quality indicators and outcome measures.

Collaboration with vendors has begun with the goals of enhancing the vendor specifications process, improving the efficiency and effectiveness of operation processes relating to vendors, and ultimately contributing to optimal data quality.

To further ensure successful implementation and data quality, CIHI will facilitate Communities of Practice to enable colleagues across Canada to learn from one another through discussion of issues and lessons learned, through sharing knowledge, connecting people and collaborating for solving problems and promoting best practice.

Next Steps for the Home Care Roadmap Indicators

In 1999, when the Roadmap project began, there was no consensus across Canada on a single clinical assessment instrument for home care. Given that, at the present time, many jurisdictions are or will be using the RAI-HC© as their foundation data set for their long-term clients, many of the indicators have been modified to allow for harmonization of the Roadmap and inter*RAI* data elements.

The Roadmap Indicator data set now uses, with permission, elements from the RAI-HC© which replace demographic, social and clinical variables originally designed for the pilot by CIHI. A summary and explanation of changes can be found in Appendices F and G.

The Home Care Roadmap project has set the direction for the journey toward comprehensive home care reporting in Canada. Believing that an incremental approach is necessary, based on the very serious challenges of implementing new home care business processes and information systems in the field, CIHI has designed a Home Care Reporting System that recognizes current constraints while preparing for the future.

Populating the current set of indicators represents a goal to strive for in the medium term (three to five years) and, with experience and feedback from our data suppliers, we will have opportunities to evaluate their quality and usefulness. CIHI also recognizes that ongoing health reform and other significant environmental factors may influence the evolution of the indicator set, as new priorities emerge.

In the meantime, the HCRS project continues to build the foundation for home care reporting and supporting front line providers in delivering better home care services. CIHI will continue to provide opportunities for broad consultation, and at key milestones will report on progress, solicit input and welcome feedback from all key stakeholders.

Appendix A
Health Indicator Framework

Health Indicator Framework

Health Status
How healthy are Canadians?
Health Status can be measured in a variety of ways, including well-being, health conditions, disability or death.

Health Conditions	**Human Function**	**Well-Being**	**Deaths**

Non-Medical Determinants of Health
Non-medical determinants of health are known to affect our health, and in some cases, when and how we use health care.

Health Behaviours	**Living and Working Conditions**	**Personal Resources**	**Environmental Factors**

Health System Performance
How healthy is the health care system?
These indicators measure various aspects of the quality of health care.

Acceptability	**Accessibility**	**Appropriateness**	**Competence**
Continuity	**Effectiveness**	**Efficiency**	**Safety**

Community and Health System Characteristics
These measures provide useful contextual information but are not direct measures of health status or the quality of health care.

Community	**Health System**	**Resources**

Appendix B
NPT Indicators

NPT Indicators

Health Status

Health Conditions

Health Status of Maintenance Clients: Distribution of Maintenance clients, by primary functional impairment grouping.

Health Status of Rehabilitation Clients: Distribution of Rehabilitation clients, by Rehabilitation Client Group (RCG)

Health Status of Long-Term Supportive Care Clients: Distribution of Long-Term Supportive Care clients, by primary functional impairment grouping

Health Status of Acute Care Substitution Clients: Distribution of acute care substitution clients, by most responsible health condition.

Health Status of End-of-Life Clients: Distribution of end-of-life clients, by most responsible health condition.

Human Function

Functional Status—ADLs and IADLs: The average functional score of home care clients for activities of daily living (ADLs) and for instrumental activities of daily living (IADLs), at time of initial assessment and reassessment, by core program component.

Cognitive Status of Home Care Clients: The proportion of home care clients who have a cognitive impairment at time of assessment, by age group and core program component.

Presence of Disruptive Behaviours: Proportion of home care clients who exhibit disruptive behaviours, by core program component.

Non-Medical Determinants of Health

Personal Resources

Availability of Informal Caregivers: Percent of home care clients who have a primary informal caregiver who provides regular and sustained assistance/support, by age group and core program component.

Informal Caregiver Burden: Percent of home care clients whose primary informal caregiver expresses inability to continue in caregiving activities, need for more support, or feelings of distress, anger, depression, by core program component.

Living Arrangements: Distribution of home care clients, by type of permanent living arrangement, age group and core program component.

Accommodation Setting: Distribution of home care clients, by type of accommodation setting and core program component.

Health System Performance

Accessibility

Time Waiting for Home Care—Referral to Initial Assessment: Average number of calendar days individuals waited, from date of first referral to the home care program to initial client assessment, by core program component.

Time Waiting for Home Care—Initial Assessment to Service Provision: Average number of calendar days individuals waited, from the initial date of client assessment to the provision of first service, by core program component.

Home Care Access Per Capita: The number of individuals receiving publicly funded home care, by age group and gender, per capita

Effectiveness

Service Goals Met: Percentage of home care clients achieving documented service goals by specified target dates, by core program component.

Functional Outcomes: Distribution of home care clients, by functional outcome and core program component.

Health System Characteristics

Population Utilization—Admissions: Per capita admissions to publicly funded home care, by age group and gender and core program component.

Population Utilization—Service Hours: The average number of service hours received per episode, by type of home care service and core program component.

Use of Emergent Care Services: Proportion of home care clients who used emergent care services, by core program component.

Temporary Transfers to Short-Term and/or Transitional Beds: Proportion of home care clients who had a temporary transfer to a facility-based (acute care and long-term care facilities) short-term and/or transitional bed, by core program component.

Per Capita Regional Expenses for Home Care (Home Health and Home Support): Per capita regional expenditures on home health and home support services, by health region.

Appendix C

Client-Specific Data Elements

Client-Specific Data Elements

Data Element	Collected at/for:			
	Adult Initial Assessment	**Adult Reassessment**	**Pediatric Clients**	**Inter-Rater Reliability**
Chart Number	✓	✓	✓	✓
Health Card Number	✓	✓	✓	
Province/Territory Issuing Health Card Number	✓		✓	
Birth Date	✓	✓	✓	✓
Estimated Birth Date	✓		✓	
Sex	✓	✓	✓	
Postal Code of Residence	✓		✓	✓
Living Arrangements	✓		✓	
Accommodation Setting	✓		✓	
Availability of Primary Informal Caregiver	✓		✓	
Living Arrangements of Primary Informal Caregiver[1]	✓		✓	
Primary Informal Caregiver Burden[1]	✓		✓	
Date of Referral	✓		✓	
Date of First Contact for Client Assessment	✓		✓	✓
Primary Service Delivery Setting	✓			
Core Program Component	✓		✓	✓
(Home Care Program) Support for Informal Caregivers[1]	✓		✓	✓
Primary Functional Impairment Grouping[2]	✓		✓	✓
Rehabilitation Client Group[3]	✓		✓	✓

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[1] Only collected if client had a primary informal caregiver.
[2] For Maintenance and Long-Term Supportive Care clients only.
[3] For Rehabilitation clients only.

Data Element	**Collected at/for:**			
	Adult Initial Assessment	**Adult Reassessment**	**Pediatric Clients**	**Inter-Rater Reliability**
Most Responsible Health Condition[4]	✓		✓	✓
Presence of Cognitive Impairment	✓			✓
Standardized Mini Mental State Examination	✓			
Presence of Disruptive Behaviours	✓			
Date of Acceptance into the Home Care Program		✓	✓	
Date of First Contact for Treatment/Service		✓	✓	
Date of Reassessment		✓		
Discharge from Home Care		✓		
Date of Discharge from Home Care Service Episode		✓		
Reason for Discharge		✓		
Number of Home Health Service Hours		✓		
Number of Home Support Service Hours		✓		
Service Goals Met		✓		
Service Goals Modified		✓		
Temporary Transfer to Short-term and/or Transitional Beds		✓		
Use of Emergent Care Services		✓		
Eating/Drinking (ADL)	✓	✓		✓
Grooming (ADL)	✓	✓		✓
Dressing (ADL)	✓	✓		✓
Bathing (ADL)	✓	✓		✓

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[4] For Acute Care Substitution and End-of-Life clients only.

Data Element	Collected at/for:			
	Adult Initial Assessment	**Adult Reassessment**	**Pediatric Clients**	**Inter-Rater Reliability**
Toileting (ADL)	✓	✓		✓
Transferring (ADL)	✓	✓		✓
Indoor Locomotion (ADL)	✓	✓		✓
Outdoor Locomotion (ADL)	✓	✓		✓
Meal Preparation (IADL)	✓	✓		✓
Light Housework (IADL)	✓	✓		✓
Heavy Housework (IADL)	✓	✓		✓
Managing Medications (IADL)	✓	✓		✓
Shopping (IADL)	✓	✓		✓
Telephone Use (IADL)	✓	✓		✓

Appendix D
Regional Profiles

Regional Profiles

This appendix provides contextual information about the home care programs provided by the health regions included in the NPT:

- the types of home health services offered;
- the types of home support services offered;
- any eligibility requirements or service limits that exist; and
- whether there any co-payment charges to the client.

In addition, information is also provided about the populations living in these health regions, including their demographic, socio-economic and health characteristics. Only two of the six pilot sites were complete health regions (St. John's and Burntwood). The other four sites were only selected offices or areas within their respective health regions. For these pilot sites, demographic and socio-economic information is also provided for the Census Subdivisions with the closest matching geographical coverage to these areas (the City of Regina, the City of St. Albert (Alberta), the City of Burnaby, Whitehorse and Dawson). The data on health characteristics were not available for geographical areas below health region.

Table D1: Home Health Services Offered

Pilot Region	Assessment and Case Management	Information and Referral	Dietitian/Nutrition Services	Nursing	Occupational Therapy	Physiotherapy	Respiratory Therapy	Social Work	Speech/Language Therapy	Medical/Surgical Supplies and Equipment	Prescription Drugs
Health and Community Services—St. John's Region	Y	Y	Y[5]	Y	Y[6]	Y[7]	N	Y	N	N	N[8]
Burntwood Regional Health Authority	Y	Y	Y[9]	Y	Y	Y	Y	Y	Y[10]	Y[11]	N
Regina Qu'Appelle Health Region	Y	Y	N	Y	Y	Y	N	Y	N	Y[12]	N
Capital Health Authority (Alberta)	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	N
Fraser Health Authority	Y[13]	Y	Y	Y	Y	Y	N	Y	N	Y[14]	Y[15]
Yukon Health and Social Services	Y	Y	N	Y	Y	Y	N	Y	N	Y	N

Source: NPT Pilot Sites

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[5] Available on a limited basis mainly in the urban areas.

[6] Available on a limited basis for non-ambulatory clients, mainly in the urban areas.

[7] Available on a limited basis mainly in the urban areas.

[8] Clients who are financially eligible may receive a drug card.

[9] Specific to clients with swallowing difficulties, specialized diets or diabetes.

[10] Available only in Thompson for clients with dysphagia.

[11] Equipment includes high cost items only (beds, commodes, hoyer lifts)

[12] Excludes equipment

[13] For clients 19 years and over with chronic medical conditions

[14] For clients with acute illness or condition, up to 2 weeks supply of medical or surgical supplies. Clients registered on the Provincial Palliative Care Program receive supplies and equipment for the last 6 months of life.

[15] Clients registered on the Provincial Palliative Care Program receive medications listed on a formulary.

Table D2: Home Support Services Offered

Pilot Region	Homemaking	Home Maintenance/ Adaptation	Personal Care	Transportation	Respite	Volunteer Services
Health and Community Services—St. John's Region	Y	Y[16]	Y	Y[17]	Y[18]	N
Burntwood Regional Health Authority	Y	N	Y	N	Y	N
Regina Qu'Appelle Health Region	Y	N	Y	N	Y	Y
Capital Health Region (Alberta)	Y	N	Y	N	Y	Y
Fraser Health Authority	Y	N	Y	N	Y	Y[19]
Yukon Health and Social Services	Y	N	Y	N	Y	N

Source: NPT Pilot Sites

Note: This table does not include other services available within the region but only those that are supplied as part of the home care services.

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[16] Occupational Therapy assessments provided for assistive devices or home modifications.
[17] Funding eligibility required.
[18] Funding eligibility required. Limited funding available for caregivers of palliative and Alzheimer's clients.
[19] Volunteer services only minimally funded by the health region.

Table D3: Eligibility

Pilot Region	Home Health Services		Home Support Services	
	Service Caps/Limits	Income Testing	Maximum Hours Provided	Income Testing
Health and Community Services—St John's Region	Y[20]	Y[21]	Y[22]	Y[23]
Burntwood Regional Health Authority	Y[24]	N	Y[24]	N
Regina Qu'Appelle Health Region	Y[25]	N	Y	Y
Capital Health Region (Alberta)	N[26]	N	N	Y[27]
Fraser Health Authority	N	N	Y[28]	Y[29]
Yukon Health and Social Services	N	N	Y	N[30]

Source: NPT Pilot Sites

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[20] Some limits apply, e.g. clients may not receive more than one visit per service per day.

[21] For medical or surgical supplies that are required for more than two months.

[22] Maximum of 72 hours of service for short-term and crisis intervention.

[23] Clients are assessed for ability to pay if liquid assets are less than $5,000 (single) or $10,000 (double).

[24] Formula used to calculate the maximum hours a person is eligible for per month of all home care services combined.

[25] Dependent on circumstances.

[26] No set maximum hours but all clients are assessed and services authorized must fall within the $3,000 legislated monthly maximum.

[27] Income testing is applied to homemaking based on an established income scale in the Home Care Regulations

[28] Some flexibility based on need

[29] Income testing for clients who are assessed as long term care

[30] Guideline of maximum of 35 hours per week—includes personal care, homemaking and respite.

Table D4: Co-Payment Charges to the Client

Pilot Region	Assessment and Case Management	Information and Referral	Dietitian/Nutritionist Nursing, Occupational Therapy, Physiotherapy, Respiratory Therapy, Social Work, Speech/ Language Therapy Services	Medical/Surgical Supplies and Equipment	Prescription Drugs
Health and Community Services—St John's Region	N	N	N	Y[31]	N/A
Burntwood Regional Health Authority	N	N	N	N	N/A
Regina Qu'Appelle Health Region	N	N	N	N	N/A
Capital Health Region (Alberta)	N	N	N[32]	N	N/A
Fraser Health Authority	N	N	N	N	N/A[33]
Yukon Health and Social Services	N	N	N	N	N/A

Source: NPT Pilot Sites

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[31] Charges to clients for medical equipment and oxygen

[32] Clients are charged only if they are out-of-province or country and require home support or professional services

[33] Palliative clients only—restricted to formulary list

Table D5: Demographic Characteristics of Regional Population

Pilot Region	Population	% of Population Aged 75–84	% of Population Aged 85 and Over	Land Area (km^2)	Population Density (per km^2)
Health and Community Services—St John's Region	181,084	3.7	1.2	3,047	59.4
Burntwood Regional Health Authority	[34]43,103	0.9	0.2	334,028	0.1
Regina Qu'Appelle Health Region	235,775	5.0	1.8	25,775	9.1
City of Regina	178,225	4.7	1.7	119	1,501.9
Capital Health Region (Alberta)	939,648	3.5	1.1	11,314	83.1
St. Albert	53,081	2.2	0.7	35	1,533.7
Fraser North Health Region[35]	516,712	3.9	1.3	2,831	182.5
City of Burnaby	193,954	4.7	1.7	90	2,152.9
Yukon Territory	28,674	1.6	0.5	474,707	0.1
Whitehorse	19,058	1.6	0.5	416	45.8
Dawson	1,251	1.2	0.8	32	38.6

Source: Statistics Canada, 2001 Census Community Profiles[36]

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[34] A substantial proportion of the Burntwood population live on First Nation reserves and therefore would not receive home care services through the Regional Health Authority.

[35] At the time of the 2001 Census, the City of Burnaby was part of the Fraser North Health Region. Since then, the Regional Health Authorities in B.C. have been reorganized and Burnaby is now part of the large Fraser Health Authority, the services of which are described in earlier tables.

[36] Extracted from Statistics Canada's website < http://www12.statcan.ca/english/profil01/PlaceSearchForm1.cfm?LANG=E> on July 10, 2004.

Table D6: Socio-Economic Characteristics of Regional Population

Pilot Region	Employment Rate[37]	Unemployment Rate[38]	Median Total Income[39]	% of Income Which Were Government Transfers[40]
Health and Community Services—St John's Region	55.8	12.1	20,057	14.2
Burntwood Regional Health Authority	49.8	17.5	14,358	15.7
Regina Qu'Appelle Health Region	65.1	6.1	22,239	12.1
City of Regina	69.2	7.3	23,952	11.1
Capital Health Region (Alberta)	67.9	5.4	23,123	9.9
St. Albert	73.4	4.1	30,139	5.8
Fraser North Health Region[41]	61.7	7.3	24,015	10.0
City of Burnaby	57.3	8.3	20,724	11.5
Yukon Territory	70.6	11.6	26,488	8.6
Whitehorse	72.8	10.0	30,348	7.2
Dawson	76.8	9.8	24,026	9.3

Source: Statistics Canada, 2001 Census Community Profiles[42]

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[37] Refers to the number of persons employed in the week (Sunday to Saturday) prior to Census Day (May 15, 2001), expressed as a percentage of the total population 15 years of age and over.

[38] Refers to the unemployed expressed as a percentage of the labour force in the week (Sunday to Saturday) prior to Census Day (May 15, 2001).

[39] Of persons aged 15 and over and who reported receiving an income.

[40] Based on aggregate amounts

[41] At the time of the 2001 Census, the City of Burnaby was part of the Fraser North Health Region. Since then, the Regional Health Authorities in B.C. have been reorganized and Burnaby is now part of the large Fraser Health Authority, the services of which are described in earlier tables.

[42] Extracted from Statistics Canada's website < http://www12.statcan.ca/english/profil01/PlaceSearchForm1.cfm?LANG=E> on July 10, 2004.

Table D7: Health Characteristics of Regional Population

Pilot Region	Self-Reported Health[43]	Obesity[44]	Smoking[45]	Physical Activity[46]	Contact with a Medical Doctor[47]
Health and Community Services—St John's Region	67.3	17.5	21.9	48.3	85.7
Burntwood Regional Health Authority	49.6	26.6	28.9	46.1	73.4
Regina Qu'Appelle Health Region	61.5	17.1	24.2	52.5	84.2
Capital Health Region (Alberta)	63.7	13.8	22.9	52.0	82.1
Fraser North Health Region[48]	57.9	8.6	18.4	56.0	83.0
Yukon Territory	55.1	20.6	27.5	59.6	83.1

Source/Adapted from: Statistics Canada, 2001 Census Community Profiles[49]

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[43] Proportion of the population (aged 12 and over) who rated their own health status as being either excellent or very good.

[44] Proportion of the population (aged 18 and over) who had a body mass index (BMI) 30.0 or more.

[45] Proportion of the population (aged 12 and over) who reported being a current smoker (daily or occasional).

[46] Proportion of the population (aged 12 and over) who reported being at least moderately active, based on their responses to questions about the frequency, duration and intensity of their participation in leisure-time physical activity.

[47] Proportion of the population (aged 12 and over) who have consulted with a medical doctor / pediatrician in the past 12 months.

[48] At the time of the 2001 Census, the City of Burnaby was part of the Fraser North Health Region. Since then, the Regional Health Authorities in B.C. have been reorganized and Burnaby is now part of the large Fraser Health Authority, the services of which are described in earlier tables.

[49] Extracted from Statistics Canada's website < http://www12.statcan.ca/english/profil01/PlaceSearchForm1.cfm?LANG=E> on July 10, 2004.

Appendix E

Definition of Client Groups

Definition of Client Groups

X2 Client Group[50]

Definition

The client group that the home care client is assigned to by the case manager/care coordinator that best reflects client need(s).

1. **Acute Home Care Client**—Client with acute health or post surgical condition(s) with clearly identified and predictable outcomes or expected recovery.
2. **End-of-Life Client**—Client with a health condition that is not responsive to curative treatment. The client and/or family has been informed by a physician that the client is expected to live less than six months.
3. **Rehabilitation Client**—Client with impairments (temporary or permanent), activity limitations and/or participation restrictions who has the potential for significant improvement in functional status and/or participation.
4. **Long-Term Supportive Care Client**—Client with ongoing multiple and/or complex health conditions, who may be unstable, medically fragile or considered by the case manager/care coordinator to be at risk for institutionalization.
5. **Maintenance Client**—Client with a stable chronic health condition or functional limitation who requires augmentation of personal resources for assistance with personal care, activities of daily living and/or instrumental activities of daily living.

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[50] Taken from *Home Care Roadmap Indicators Data Standard,* Canadian Institute for Health Information (Ottawa: CIHI, 2004)

Appendix F

2004 Home Care Roadmap Indicators

2004 Home Care Roadmap Indicators

The CIHI Home Care Roadmap Indicators were developed through a four-year research and consultation project under the auspices of the Health Information Roadmap Initiative. These health region-level comparable indicators will be available for jurisdictions submitting data elements as defined in the *Roadmap Indicators Data Standard*.[51]

Jurisdictions who elect to participate in reporting of Home Care Roadmap Indicators will submit data to the CIHI Home Care Reporting System (HCRS). The HCRS will be a pan-Canadian, bilingual resource of standardized clinical, demographic, administrative and resource information about home care.

The HCRS will accept data, in its prototype year (2005–2006), for five client groups: Acute Home Care, End-of-Life, Rehabilitation, Long-term Supportive Care and Maintenance. One of the aims of the HCRS is to utilize the information that will be collected through jurisdictions' redeveloped processes of care: introducing standardized clinical assessments and developing integrated health information systems.

Jurisdictions may plan for phased implementation depending upon readiness on the front lines to implement standardized clinical assessment instruments, such as the RAI-HC©.[52] To date, implementations of the RAI-HC© are focused on Long-term Supportive and Maintenance clients. Data collected through clinical assessments will be used to populate indicators of health status, determinants of health and health system performance. Indicators that use data elements from the RAI-HC© are identified with **R**.

In addition, jurisdictions may plan for phased reporting of the Roadmap Indicators during the redevelopment of their business processes. Jurisdictions electing to submit demographic, administrative and resource elements for all clients, while phasing in their clinical assessment reporting for some client groups, will be able to report on comparable indicators of access and service utilization. Such indicators are identified with ★.

The HCRS and the Roadmap Indicators will adapt to the evolving home care sector. Future HCRS modules will be developed, as required, to support new standardized clinical assessments and emerging priorities (such as acute community mental health). In parallel, the Roadmap Indicators will adapt to availability of these new standardized data for particular groups of clients: current indicators may become applicable to these clients and/or new indicators may be added.

Jurisdictions using standardized clinical assessment tools other than those developed by inter*RAI* will also be able to submit to HCRS, through the development of mapping algorithms.

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[51] Canadian Institute of Health Information, *Roadmap Indicators Data Standard* (Ottawa, CIHI: 2004).

[52] Copyright© inter*RAI* Corporation, 2001. Modified with permission for Canadian use under licence to the Canadian Institute for Health Information, 2002.

Given differences across regions in the definition of an adult, indicators will apply to home care clients aged 20 years and over. Special analyses may be conducted for pediatric home care clients where feasible. All indicators will be available by Client Group and age, with selected indicators available by sex.

Health Status

Diagnostic Health Conditions: The distribution of home care service episodes by the clients' diagnostic health conditions that, at the time of assessment, were monitored or treated by a home care professional. **R**

Functional Status—Activities of Daily Living (ADLs): The proportion of home care service episodes in which the client, at the time of assessment, was dependent on others for, or required extensive assistance with Activities of Daily Living (ADLs). **R**

Cognitive Status: The proportion of home care service episodes in which the client, at the time of assessment, had a moderate to severe cognitive impairment. **R**

Behavioural Symptoms: The proportion of home care service episodes in which the client exhibited behavioural symptoms that caused distress to themselves or that were distressing or disturbing to others with whom clients lived. . **R**

Determinants of Health

Living Arrangements: The distribution of admissions to home care by the clients' permanent living arrangements. **R**

Living Setting: The distribution of admissions to home care by the clients' permanent living setting. **R**

Availability of Informal Caregivers: The proportion of home care service episodes in which the client had at least one informal caregiver who provided regular and sustained assistance and/or support. **R**

Relationship of Primary Informal Caregivers: The distribution of home care service episodes by the relationships of the primary informal caregivers to the clients. **R**

Living Arrangements of Primary Informal Caregivers: The proportion of home care service episodes in which the primary informal caregiver lived with the client. **R**

Types of Care Provided by Primary Informal Caregivers: The distribution of home care service episodes by the types of care provided to the clients by their primary informal caregivers. **R**

Informal Caregiver Burden: The proportion of home care service episodes in which the client's primary and/or secondary informal caregiver felt unable to continue in their caring activities. **R**

Health System Performance

Time Waiting from Referral to Service Provision: The median number of days between the date home care clients were first referred to the home care program and the date of their first service excluding comprehensive assessment. **R** ★

Population Access to Home Care: The number of individuals who received publicly funded home care per thousand population. **R** ★

Service Goals Met: The proportion of discharges from home care at which the clients had met their expected service goals. ★

Disruptive or Intense Daily Pain: The proportion of home care service episodes in which the clients reported having daily intense pain or pain that disrupted their usual activities on a daily basis. **R**

Inadequately Controlled Pain: The proportion of home care service episodes in which the clients reported pain and that their medications did not adequately control their pain. **R**

Referral to Other Health Services: The distribution of discharges from home care by the health services clients were referred to after discharge. ★

Falls: The proportion of home care service episodes in which the clients had at least one fall in the previous 90 days. **R**

Community and Health System Characteristics

Utilization Rate: The number of admissions to publicly funded home care per thousand population. **R** ★

Service Intensity—Hours: The average number of service hours received by home care clients per home care service episode. ★

Service Intensity—Face-to-Face Visits: The average number of face-to-face visits received by home care clients per home care service episode. ★

Service Delivery Settings: The distribution of home care service episodes by the service delivery settings in which the clients received home care. ★

Visits to an Emergency Room: The proportion of home care service episodes in which the clients visited a hospital-based emergency room. ★

Appendix G

Changes Made to the NPT Indicators

Changes Made to the NPT Indicators

National Pilot Test Indicator	Is it included in 2004 set of Roadmap Indicators?	Details of Changes and Rationale
Health Conditions		
Distribution of Maintenance/ Long-Term Supportive Care Clients by Primary Functional Impairment Grouping	No	In the Pilot Test the health status of these client groups was measured using body function impairments coded to the International Classification of Functioning, Disability and Health (ICF). Feedback from jurisdictions was that this classification duplicated other information collected as part of the RAI-HC© assessment and therefore they could not justify the extra burden of collection. The Roadmap indicators include an indicator that reports on the diagnostic health conditions of Maintenance and Long-Term Supportive Care clients, as captured by the RAI-HC©.
Distribution of Rehabilitation Clients by Rehabilitation Client Group	No	At present, there is no standardized clinical assessment tool applicable to Rehabilitation clients. An indicator reporting the health status of rehabilitation clients will be added when a standardized assessment becomes available.
Distribution of Acute Care Substitution/End-of-Life Clients by Most Responsible Health Condition	No	At present, there is no standardized clinical assessment tool applicable to Acute Home Care or End-of-Life clients. An indicator reporting on the health status of these clients will be added when standardized assessments become available.
Human Function		
Functional Status—ADLs	Yes	At present, this indicator will be applicable only to Long-Term Supportive Care and Maintenance clients. It is envisaged that when standardized clinical assessment tools become available for other client groups a similar indicator of ADL functional status will be available for Rehabilitation and End-of-Life clients. Consultations and feedback from the pilot sites stated that this indicator should not be applicable to Acute Home Care clients as the burden of data collection would be too high, particularly given the high turnover of clients and short duration of service.

National Pilot Test Indicator	Is it included in 2004 set of Roadmap Indicators?	Details of Changes and Rationale
Functional Status—ADLs (cont'd)	Yes	The data elements used to populate this indicator have been harmonized with the ADL elements on the RAI-HC©. The calculation performed has been changed. The National Pilot Test proposed an arithmetic sum of eight ADL activities, including outdoor locomotion. Feedback from pilot sites raised concerns relating to the use of outdoor locomotion in Canada, as some clients' ability to go outside during the winter would be more affected by the weather than on clients' functioning ability. The indicator is now calculated based on four ADLs (eating, personal hygiene, toilet use and locomotion in the home) that are combined into the ADL Self-Performance Hierarchy Scale, devised by interRAI.
Functional Status—IADLs	No	While it was felt an indicator reporting on IADL functioning would be useful, it was also felt that further development of the indicator is required.
Cognitive Status	Yes	At present, this indicator will be applicable only to Long-Term Supportive Care and Maintenance clients. It is envisaged that a similar indicator would be calculated for the other client groups once standardized clinical assessment tools are available. The indicator uses the Cognitive Performance Scale to rate clients' cognitive status rather than the Standardized Mini Mental State Examination that was used in the Pilot Test. The elements that comprise this scale form part of the RAI-HC©.
Presence of Disruptive Behaviours	Yes	The name of this indicator changed to "Presence of behavioural symptoms". This indicator will be applicable only to Maintenance and Long-Term Supportive Care clients—in the pilot the information was collected for all client groups. Consultations and feedback recommended that this information would be most relevant for clients with long-term care needs. The data element used to populate the indicator was amended to that used in the RAI-HC©.
Personal Resources		
Availability of Informal Caregivers	Yes	At present, this indicator will be applicable only to Long-Term Supportive Care and Maintenance clients. It is envisaged that a similar indicator would be calculated for the other client groups once standardized clinical assessment tools are available. The data element used to populate the indicator was amended to that used in the RAI-HC©.

National Pilot Test Indicator	**Is it included in 2004 set of Roadmap Indicators?**	**Details of Changes and Rationale**
Informal Caregiver Burden	Yes	At present, this indicator will be applicable only to Long-Term Supportive Care and Maintenance clients. It is envisaged that a similar indicator would be calculated for the other client groups once standardized clinical assessment tools are available. The definition of the indicator and the data elements used to populate it have been amended to reflect the data collected using the RAI-HC©. The indicator that was pilot tested related only to the primary informal caregiver. In the RAI-HC©, information is collected on up to two informal caregivers. One of the data elements relating to burden (caregiver unable to continue caring activities) does not distinguish which caregiver is unable to continue; the other two burden items relate only to primary caregivers. The indicator was amended to use only the "unable to continue" data element.
Living Arrangements	Yes	At present, this indicator will be applicable only to Long-Term Supportive Care and Maintenance clients. It is envisaged that a similar indicator would be calculated for the other client groups once standardized clinical assessment tools are available. The data element used to populate the indicator was amended to that used in the RAI-HC©. At present, information on clients' living arrangements will be collected at their admission to the home care program.
Accommodation Setting	Yes	The name of this indicator changed to "Living Setting". At present, this indicator will be applicable only to Long-Term Supportive Care and Maintenance clients. It is envisaged that a similar indicator would be calculated for the other client groups once standardized clinical assessment tools are available. The data element used to populate the indicator was amended to that used in the RAI-HC©. At present, information on clients' living setting will be collected at their admission to the home care program.

National Pilot Test Indicator	Is it included in 2004 set of Roadmap Indicators?	Details of Changes and Rationale
Accessibility		
Time Waiting from Referral to Initial Assessment	No	These two indicators have been replaced with a single indicator reporting on the time between referral and service provision. Data from the Pilot Test showed that for the majority of clients, there was no wait between initial assessment and first service provision. In addition, some clients received their first service prior to receiving their assessment that resulted in negative waiting times between initial assessment and service provision. It was therefore felt that an indicator relating to the whole waiting time between the client's referral and receiving service was more appropriate. Data from the Pilot Test also showed that the wait times were highly skewed and therefore it was decided to use a median rather than the arithmetic mean to measure the central tendency of the distribution. Data will still be available to measure the time between referral and assessment and assessment and service provision.
Time Waiting from Initial Assessment to Service Provision	No	
Home Care Access Per Capita	Yes	The name of this indicator has been changed to "Population Access to Home Care". The rates will be produced per thousand population.
Effectiveness		
Service Goals Met	Yes	The name and definition of this indicator has changed. The information on whether the documented services goals have been met will be collected only at discharge from the home care program.
Functional Outcomes	No	While it was recognized that indicators reporting on functional outcomes were needed—consultations revealed that it would be extremely difficult to get the required data due to compliance issues in conducting full RAI-HC© assessments at discharge. While outcome measures could be calculated for those clients for whom a full discharge assessment was carried out, the results would probably not be generalizable to all home care clients. Further development work and consultation is required to determine a feasible method of collecting data on functional outcomes.

National Pilot Test Indicator	**Is it included in 2004 set of Roadmap Indicators?**	**Details of Changes and Rationale**
Health System Characteristics		
Population Utilization—Admissions	Yes	The name of this indicator has been changed to "Utilization Rate". The rates will be produced per thousand population.
Population Utilization—Service Hours	Yes	The name of this indicator has been changed to "Service Intensity – Hours". In the Pilot Test service hours were collected separated into hours providing home health and home support services. The current indicator will provide information for the following service provider categories: case management; nursing; clinical nutrition; occupational therapy; physiotherapy; social work; speech/language pathology; home support/community care worker; and other providers.
Use of Emergent Care Services	Yes	The name of this indicator has changed to "Visits to an Emergency Room".
Temporary Transfers to Short-Term and/or Transitional Beds	No	Feedback from the pilot sites suggested that getting consistent information across Canada on such transfers would be problematic. In particular, they raised concerns surrounding the different service delivery models that may affect the types of beds included in the indicator, and differences in how jurisdictions would decide when a transfer to a facility bed is permanent or temporary. Further development of the data elements would be required before such an indicator could be included.
Per Capita Regional Expenses for Home Care	No	While recognizing the need for financial indicators relating to home care, further development is required before consistent operating expenses for home care can be reported. In particular, there is no current methodology to allocate indirect costs.

In addition to the indicators piloted in the Phase 2 National Pilot Test, the following indicators have been added:

For All Client Groups

- Referrals to Other Health Services;
- Service Intensity—Face-to-Face Visits; and
- Service Delivery Settings.

For Long-Term Supportive Care and Maintenance Clients

- Relationship of Primary Informal Caregivers;
- Living Arrangements of Primary Informal Caregivers;
- Types of Care Provided by Primary Informal Caregivers;
- Falls;
- Disruptive or Intense Daily Pain; and
- Inadequately Controlled Pain.

ten
years
dix
ans
taking health information further
à l'avant-garde de l'information sur la santé