

Identifying Outcome Indicators for Evaluating Services

Provided by Community Care Access Centres (CCACs)*

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Executive Summary

The objectives of this report are to propose a conceptual framework to evaluate the effectiveness of home care services in Ontario, and to identify potentially appropriate measures to assess the effectiveness of such services. The report has benefited from the assistance of an Advisory Committee, the members of which can be found in Appendix 1.

The need to identify outcome and performance measures and a framework for evaluation of home care services arises because of a number of different pressures. Health system restructuring, improvements in drugs and technology, and the aging of the population have dramatically increased the current and future demand and utilization of home care services. As a result, care has shifted into an arena where effectiveness research is in its infancy. Moreover, the decrease in care covered by the *Canada Health Act (CHA)* and the consequent increase in care not covered by the national standards enunciated under the *Act*, necessitate the introduction of some form of accountability for the continued safety and accessibility of care for Canadians. At the same time, a growing distrust of governments and the increase in consumerism has given rise to citizen demands for better public accountability of spending and reporting of service quality. Lastly, Ontario's reformed home care sector which relies on competitive contracting out of services to not-for-profit and for-profit provider agencies requires the identification and development of performance and outcome measures for the fair and effective selection of home care provider organizations by Ontario's Community Care Access Centres.

Home health managers, providers and policy-makers have a need for the development of performance and outcome measures on which to inform and base decisions. They continue to be frustrated by the lack of data concerning the costs and consequences of in-home

services. This lack of evidence means: home care managers are limited in their ability to undertake evidence-based decisions; home care health professional and providers are limited in their ability to practice evidence-based care; and provincial and federal policy makers are limited in their ability to develop evidence-based health policy.

A comprehensive review of the research and grey literature on outcome indicators for services provided in the home, a collation of information on the development of in-home service outcome indicators currently underway in Canada and the U.S., and information gathered from contacts with key individual stakeholders form the information sources for this report.

The report provides a conceptual framework with which to evaluate outcomes of care and the performances of agencies at the micro (individual recipient or service provider), meso (provider agency or CCAC) and macro level (region or province). Definitions of key terms are discussed which include measurement, outcomes, performance, assessment tools and effectiveness.

Five criteria are used to assess the utility of particular tools identified in the literature. Three of these criteria are psychometric properties of the tools; that is, validity (does the tool measure what it purports to measure?), reliability (refers to the stability or consistency of the measure), and responsiveness (the ability of the tool to measure changes in health and social care outcomes or performance over time or across organizations). The last two criteria are feasibility (the administrative burden and financial cost of implementing the tool) and scope (the range of measures that the tool collects).

A number of initiatives in Canada and the US are described. The project, Development of a National Indicators and a Reporting System for Home Care, mounted by

the Canadian Institute for Health Information is the most ambitious one in Canada. While the CIHI initiative is very important, its objective is for the development of indicators for reporting and comparison at the provincial and national level. The framework developed in this paper allows for assessments and comparisons at the micro, meso and macro level.

A summary of assessment tools used to measure and evaluate the health and social care outcomes provided in the home and the performance of agencies providing that care is reported. Each tool is described and assessed against the five criteria where possible.

Although many more assessment tools and indicators have been used in the evaluation of health and social care, this report only focuses on those already applied in the home setting.

This report represents the first step in the development of outcome/performance measures and assessment tools to be used to evaluation home care services in Ontario. It provides the reader with a framework within which to conceptualize the complexities of assessing care provided in the home, and a list of indicators and tools to review. The next steps in the development of tools and measures is the broad dissemination of the report across multiple stakeholder communities. A focus group in early 2001 will be held to discuss the issues raised in the report, to come to a consensus on outcomes and tools to be used in the Ontario context, and to prioritize the development of such tools.

1.0 Introduction

The objectives of this report are two-fold: to propose a conceptual framework to evaluate the effectiveness of home care services in Ontario, and to identify potentially appropriate outcome measures to assess the effectiveness of such services.

Home care has been defined by the Canadian Institute for Health Information as: “A range of health-related, social 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 co-ordination, 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. The range of services provided include prevention, maintenance, rehabilitation, support and palliation.”¹

The need to identify outcome measures and a framework for the evaluation of the effectiveness of home care services has arisen for a number of disparate reasons which are outlined in this section. To begin with, health system restructuring and improvements in drugs and technology have resulted in a shift in the site of care from institutions into the home. These factors along with the aging of the population have resulted in higher actual and projected utilization rates in a sector of care where effectiveness research is in its infancy. The decrease in care covered by the *Canada Health Act (CHA)* and the consequent increase in care not covered by the national standards enunciated under the *Act*, necessitate the introduction of some form of accountability for the continued safety and accessibility of care for Canadians. The growing distrust of governments and the increase in consumerism has

given rise to citizen demands for better public accountability of spending and reporting of service quality. Lastly, the identification and development of performance and outcome measures are required for the fair and effective selection of home care provider organizations in the competition for contracts issued by Ontario's Community Care Access Centres.

Sections 1.1 to 1.5 outlines the context within which the call for outcome indicators has emanated.

1.1 Shifting Site of Care

The restructuring of the health care system and the rapid improvements in medical technologies and pharmaceuticals have led to a dramatic change in the nature and site of health care. As a result, more and more care is being provided in the home and by care providers other than physicians, such as family and friends, community support groups, volunteers, nurses and other allied health providers, and personal support workers.

This shift in the setting for care is also being mirrored in the changing split in public and private financing of Canadian health care. The *Canada Health Act (CHA)*, introduced in 1984, privileged all medically necessary care provided by physicians and in hospitals through public financing of such care. When the *CHA* was introduced in 1984, the expenditures covered under the principles of the Act (i.e., expenditures on physicians and hospitals) represented 57% of total health spending. However, in the last sixteen years, that share has fallen to 45.5%.² As such, the *CHA* now applies to a minority of health spending in Canada. Indeed, it has been estimated that approximately half of the growth in the share of private finance is attributable to service-specific patterns of expenditure (cost shifting or passive privatization) and half to the higher rate of private sector expenditure growth (expanding markets or active privatization).³

Although home care represented less than 4% of national spending in fiscal year 1997 (FY97), the growth rate in home care spending in the last twenty-five years relative to spending in other health care sectors is evidence of its growing importance. Between FY75 and FY92, home care expenditures in Canada grew at an annual rate that was almost double the growth in total health spending (19.9% vs. 10.8%). Since FY92, home care expenditures have continued to grow, but at a rate that was fourfold greater than that for other health spending, 9.0% vs. 2.2%.

In Ontario, while inflation-adjusted per capita Ministry of Health spending fell by 5.6% between FY91 and FY99, these cuts were differentially absorbed across health spending categories. Specifically, inflation-adjusted per capita acute care hospital expenditures fell by 19.7%, and equivalent physician expenditures fell by 16.7%. Meanwhile, home care spending grew by 70.9% compared with only 20.3% growth in all other categories of MOH spending. Indeed, in fiscal year 2000 Ontario is projected to spend \$1.06 billion on home care services.⁴ In most Canadian jurisdictions, the pace in the downsizing and closure of hospitals and the decrease in hospital lengths of stay has occurred at a much faster rate than the planning and organization of home and community based care. As a result, the need for home and community care has outpaced the system's capacity to manage the need effectively.

The development of standardized outcome and performance indicators, moreover, is essential to link home care data and data bases with data bases in other sectors of health care that are already fairly well established. Without these data linkages, planning, management effective service delivery, and evaluation of services within and across defined regions and across the full continuum of care is hindered.

1.2 Demographic and Utilization Projections

Home care is also becoming the new frontier for health care because of demographic pressures. Changes to the age-gender composition of the population are likely to exert a significant upward impact on home care expenditures. Figure 1 portrays information from the Organization for Economic Cupertino and Development (OECD) on two demographic dimensions for member countries. Namely, the proportion of the population over 65 years and the proportion over 80 years. In 1999, Canada had a relatively young population, with residents over 65 years of age accounting for 12.4% of the population, while less than 3% of the population were over 80 years.

Based on population projections to the year 2026 developed by Statistics Canada,¹³ Table 1 reports medium growth projections for the Canadian population. This table demonstrates that the Canadian population is expected to grow at an average annual rate of 0.6% over the next twenty six years, while the population over 65 years of age is expected to increase at an average annual rate of 2.7%. This projection suggests that by the year 2026, 21.5% of Canadians will be over 65 years of age and more than 5% of the population will be over 80 years, as shown in Figure 2. Canada, along with Japan and Australia, are expected to age at a greater and more dramatic rate than other OECD member states.

Home care utilization rates (the number of home care clients per 1,000 population) increase with the client's age and are greater for older women than men. Home care utilization rates by age and gender are shown in Figure 3. While the number of clients under 65 years of age is large, their utilization rate is small, <2%, compared to persons over 65 years. Women exhibit utilization rates that are more than 20% higher than those for men.

The intensity of home care utilization (the number of home care services or level of expenditure per home care client) also varies by the age and gender of the care recipient, as shown in Figure 4. While average provincial home care expenditures per client were substantial at \$2,736, expenditures for clients under 20 years of age were approximately 60% of the provincial average. In contrast, the intensity of home care utilization by clients older than 85 years of age was more than 20% greater than the provincial average. The intensity of home care use increases with the client's age and was higher for women older than 45 years than for men.

Given the changing age-gender composition of the population and the higher utilization rate of the elderly and especially women, the use of home care services in the future are predicted to increase dramatically. Indeed, based on utilization data from Ontario and information from Statistics Canada on the age-gender distribution of the population of Canada for 1999 and 2026, it has been projected that between 1999 and 2026 home care expenditures will increase by a total of 78.4%, or an average annual increase of 2.2%,⁵ even in the absence of further reforms to Ontario's health system.

1.3 Erosion of Medicare

When care covered by the *CHA* (care provided by physicians or in hospitals) shifts into the home setting, there is no guarantee that it need be protected by the principles of the *Act* or to be publicly financed. That is, it no longer needs to be: universally available to all residents; comprehensive; accessible; portable; or publicly administered. While most provinces have chosen to publicly fund some portion of home care, there are considerable private costs in home care. Although there is a lack of information concerning the extent of private financing some estimates have been derived from surveys of household expenditures. One survey estimated that approximately 24.5% of the cost of home nursing care and 59.3% of the cost of home support

services was paid for by private insurance or out of pocket.⁶ Furthermore, a survey conducted by PriceWaterhouseCoopers,^{7 8} based on responses from over two thousand Canadians, indicated that 25% of home care clients report average out-of-pocket expenses of \$407 per month on home care and \$138 on prescription drugs. These home care expenditures represent almost 15% of the average annual public home care expenditures per client in Ontario. Based on public and private sources of revenue, a survey of three national in-home service providers estimated that approximately 20% of their total revenues were derived from private sources.⁹

The shift of care covered by the *CHA* to the home has opened the door to a possible reallocation of health costs from the public to the private sector, with the care recipient absorbing more of the financial costs and families and friends providing more of the care. Moreover, without the protection of the *Act*, the amount of home care that is publicly financed differs considerably across Canada. Indeed there is a four-fold variation in publicly funded home care in this country.¹⁰ Figure 5 reports inter-provincial variations in the share of public sector health expenditures devoted to home care and demonstrates that New Brunswick, Ontario and Newfoundland have the largest shares (at over 5%), while Prince Edward Island and Quebec have the smallest shares, at less than 3%. The growth in home care, without changes to the *CHA* or the introduction of national standards, may herald an erosion of Canada's most cherished social program.

The federal government, on the advice of the National Forum on Health, has explored the possibility of extending public insurance to home care. To advance this extension of federal involvement into areas of provincial jurisdiction, decisions must be made concerning: the terms and conditions of public insurance, including the range of insured services (social/medical), the duration of coverage (acute/chronic), the setting for service provision, and an array of financial

considerations, including the scale of deductibles, the size of co-payments, the level and means by which service providers are reimbursed, and the amount of funding to ensure equitable access to high-quality care. In addition, appropriate methods for allocating public funds for in-home services and mechanisms for the advancement of cost-effective service provision are required.

While provincial and federal governments continue to debate their respective responsibilities and accountabilities in the setting of home care standards, care in the home continues to increase. Meanwhile, there is a lack of information concerning the costs and consequences to individuals and to society of increased home care expenditures and modified patterns of practice. Currently, little is known about the impact of home care services on health and lifestyle outcomes, and the extent to which the burden of care has shifted from institutions to care recipients, families and community agencies.¹¹ While it is clear that expenditures have increased, this increase has occurred without compelling evidence of service cost-effectiveness.^{12 13 14} Moreover, there is a growing perception that unless home care services are targeted towards specific client groups they will not represent a cost-effective alternative to institutional care.^{15 16 17 18}

Two recently heralded studies concerning the use of home care following hospitalization¹⁹ and as an alternative to facility-based long term care²⁰ suggest that home care may lower costs without adversely affecting the health of Canadians. While neither study used randomization to identify the unique contribution of home care services, both studies did suggest that cost savings might occur through modifications to health service delivery and organization. However, before embarking on radical health system change, more evidence is needed to confirm these preliminary results.

1.4 Increasing Consumerism

Since the early 1990s there has been a growing distrust of governments, in particular on their efficient and effective use of public funds, and an increasing faith in markets. Citizens are demanding greater accountability from their elected representatives and are looking to market-type mechanisms to increase efficiency. Commensurate with this paradigm shift is a growth in consumerism. Within health care, consumerism has altered the traditional roles of recipients of care and care providers, especially physicians. The availability of more treatment options for complex conditions with different associated risks, benefits, and outcomes for care recipients, progress in pharmaceutical innovation that require physicians and care recipients working together to determine the appropriate drug choice and dosage, and the differing nature of treatment decision making contexts (for example, emergency, acute, long-term, and palliative) have also necessitated greater care recipient involvement. Care recipient autonomy, care recipient control, and challenges to physician authority, have all resulted in the call for better information. Better information is required to reduce the power asymmetry between care providers and recipients in order that the latter may make informed decisions about treatment and choice of providers. The advancement of evidence-based care and provider report cards is partly a response to this new consumerism.

Concerns about increasing costs associated with inappropriate decision making and the greater availability of information about medical problems, treatments and alternatives to traditional medicine through various media, especially the internet, have also given care recipients a greater role. Lastly, the changing nature of medical practice from acute to chronic illnesses has meant that physicians are becoming more and more managers of illnesses rather than curative agents. As a result, a more active role for care recipients is both desired and has

been recommended. Canadians are demanding greater accountability from governments and from providers on the effective use of public funds. And care recipients are demanding more information about care options, outcomes and the performance of different provider organizations.^{21 22 23 24}

1.5 Competition and Evidence-Based Selection

In Ontario, Community Care Access Centres (CCACs) receive funds from the province to underwrite the cost of in-home services. Since the introduction of organizational reforms in 1996, the CCACs have withdrawn from the direct provision of in-home services. Each regionally-based CCAC is responsible for assessing client eligibility, setting service requirements, selecting service providers through a competitive process, monitoring performance and paying providers. Both professional and non-professional services are contracted by CCACs. Professional services include nursing, physiotherapy, occupational therapy, speech language therapy, social work, dietetic services, and provision of medical equipment. Non-professional services include homemaking and personal support services. Homemaking includes house cleaning, laundry, ironing, essential mending, shopping, banking, paying bills, planning menus, preparing meals and caring for children. Personal support services include personal hygiene activities and routine personal activities of living, including assistance with walking, climbing or descending stairs, getting into and out of bed, eating and dressing.²⁵

One consequence of the divestment of in-home service provision was the introduction of increased competition between in-home service providers for contracts with CCACs. In principle, competition takes place on two dimensions, price and the quality of care,²⁶ with CCACs responsible for selecting and negotiating contractual arrangements with in-home

providers. While one objective of the reforms was to ensure fair and equal access to services across the province, another objective was to lower service costs and improve health and lifestyle outcomes through competition.

Under these arrangements, in-home service providers were expected to have an equal opportunity to competitively bid for service contracts. In the absence of quality indicators, price has been perceived as the default determinant of provider selection. However, price can only be lowered at the cost of quality. Moreover, the ability to lower costs is not equivalent amongst providers, it being dependent, amongst other things, on the unionized status of the organization's employees. Without outcome and performance measures, CCACs are hampered in their ability to choose the best quality service provider at the best price, and provider organizations are denied the level playing field they were promised through competition.

Moreover, the lack of standardized outcome indicators, which would provide measures of accountability, impel CCACs to manage the process by which care is provided by contracted agencies. Some CCACs, anticipating large deficits, are being forced to cut back on service provision, resulting in potential unmet demand and need for their services. Meanwhile, others are in the position to extend services not available in other regions.²⁷ The absence of outcome and performance measures limits the government's ability to make decisions regarding the efficient allocation of resources amongst competing health system stakeholders, including CCACs, and also limits the ability of CCACs to make informed resource allocation decisions amongst service providers and across service categories.

1.6 Conclusion

Home health managers, providers and policy-makers require the development of performance and outcome measures on which to inform and base decisions. They continue to be frustrated by the lack of data concerning the costs and consequences of in-home services.

^{28 29 30 31 32} This lack of evidence means: home care managers are limited in their ability to undertake evidence-based decisions; home care health professional and providers are limited in their ability to practice evidence-based care; and provincial and federal policy makers are limited in their ability to develop evidence-based health policy. Without such information to facilitate evidence-based decision making,^{33 34 35 36} health reform may result in more, not less, costly patterns of practice, and erode, not enhance, health and social care outcomes. The absence of appropriate tools to enhance clinical practice, to manage service provision, to guide policy development, and to evaluate performance, may result in decisions that are neither congruent with the best interests of clients and the cost-effective utilization of scarce health and social care resources.

2.0 Outline of the Report

The report is divided into 9 further sections: 1) a description of the data sources and techniques used to compile information for this report, 2) a description of what we mean by measurement of health and the effectiveness of health and social care, 3) a description of our conceptual framework that categorizes indicators and assessment tools by the level of analysis (care recipient, service provider, provider organization, and regional and provincial health system), 4) a description of the criteria for evaluating indicators and assessment tools, 5) a typology for assessment tools 6) current initiatives in Canada and other countries, and 7) a description of assessment tools that have been used in the home, 8) the conclusions and 9) next steps.

3.0 Data Sources

The data sources for this paper include: 1) a comprehensive review of the literature on outcome indicators for services provided in the home; and 2) a collation of information on the development of in-home service outcome indicators currently underway in Canada. Medline and Healthstar databases were used to identify peer-reviewed journal articles that addressed the development, implementation and evaluation of various assessment tools and outcome measures in the home setting. Keywords used in the search included “outcome measures,” “assessment tools,” “outcomes,” “indicators,” and “home care.” Additional references were identified from the bibliography of articles obtained through the electronic search.

Additional information and reports (grey literature) were obtained by contacting key individuals working on outcome assessment initiatives and through web-based searches on the internet.

4.0 Measuring Health and the Effectiveness of Care

The focus of this report is the identification of outcome measures to evaluate the effectiveness of home care, tools that may be used to measure them, and a conceptual framework for thinking about the effectiveness of home care.

Before we can measure the effectiveness of a particular intervention, we need first to be able to measure health and social states. However, this is a complex task because of the abstract nature of the conditions on which we are seeking information. For example, one cannot measure health directly; rather the process requires a number of steps.

First we need to understand the concept of measurement which can be defined as “the assignment of numbers to objects or events to represent quantities of attributes according to rules”³⁷ or “the process of applying a standard scale to a variable.”³⁸ For example, we use a ruler to measure a person’s height in centimeters. Here height is the variable or attribute, and the ruler marked in centimeters is the standard scale. It must be kept in mind, however, that measurement is an arbitrary process which is useful only when there is consensus or universal agreement on the rules (i.e., guidelines to perform measurement). Originally, a meter was defined as the length of a gold bar stored in Greenwich, England. This standard was replaced by a percentage of the meridian at Greenwich. The current standard for a meter is now expressed as a percentage of the wave length of Krypton. While this is the current standard it may change with new and better knowledge.

Measurements may be classified according to the type of outcome categories used: binary, nominal, ordinal, interval, and ratio. Binary scales have two responses such as yes/no or male/female. Nominal scales have multiple categories with no inherent rank or order, such as categories of religion. Ordinal scales order categories along a hierarchy, for example,

strongly agree, agree, neutral, disagree, strongly disagree. Interval scales have multiple categories that have a rank order but the interval between ranks is not necessarily equal (no absolute zero), such as a Fahrenheit thermometer where degrees represent a ranking, where 50 degrees Fahrenheit is hotter than 25 degrees Fahrenheit but not twice as hot. Continuous or ratio scales are similar to ordinal scales but the interval between categories are equal or there is an absolute zero, for example, temperature on a Kelvin thermometer where 50 degrees Kelvin is twice as hot as 25 degrees Kelvin and zero degrees represent an absence of motion.

Unlike common physical measures, there is no agreed-upon standard scale for health, or indeed for most clinical measures. Moreover, there is no single attribute called health, but rather multiple ones. Health indicators are constantly being developed. Many purportedly measure the same phenomenon yet yielding dramatically different results for the same care recipient.

Measurements of an individual's health may be based on diagnostic tests or they may be based on the care recipient's or care provider's subjective judgment. Many health measures are considered subjective because they are based on self-report rather than direct observation. Typically subjective health measures record general feelings of well-being, or symptoms of illness, or focus on the adequacy of an individual's functioning.

Moreover, indicators are not passive markers of health, but rather are deliberately chosen because of a social or health concern for which improvement is sought. As such, they reflect choices which are usually intended to influence social and political goals. As our notions of health have moved from survival, to an absence of disease, to the ability to

perform daily activities, and finally to general well-being, our indicators of health have evolved and become more complex.³⁹

4.1 Outcome Measures/Indicators

Outcome measures are necessary components for the evaluation of health and social care as well as individual and organizational performance. Outcomes are the results, changes in a given state (which also includes the prevention of decline) attributable to a given intervention. To obtain a measure of an outcome, one needs to take measures at two or more points in time to determine a change or lack of change that may be attributable to the particular intervention, or we take one measure and compare it to some population or condition-based norm. Health outcomes can be defined as “...states or conditions of individuals and populations attributed or attributable to antecedent healthcare. They include changes in health states, changes in knowledge or behaviour pertinent to future health states, and satisfaction with healthcare.”⁴⁰ Others have defined it as “the status of a client’s health at specified intervals of health care.”⁴¹ Health outcomes are not only changes in health states but also include the maintenance or slower rate of decline of health status. Health outcomes provide a measure of the effectiveness of an intervention.

Research on health outcomes emanate from two different paradigms: the biological model that focuses on etiologic agents, pathological processes and biological, physiological and clinical outcomes, and the social science paradigm that focuses on dimensions of functioning and overall well-being and attempts to measure complex behaviours and feelings.⁴²

Outcomes can be measured at the micro level, that is, changes in states for care recipients or for individual informal or formal care provider. They may also be measured at

the meso level, which concerns performance by care provider organizations, or at the macro level which addresses system-wide issues at the regional, provincial or national level.

Hirdes and Carpenter point out that outcomes may be used in several ways to improve health, quality of life and service delivery: 1) to identify interventions that lead to the greatest change in outcome measures; 2) to use selected care recipient characteristics as quality indicators; 3) to increase cost efficiencies by identifying programs and services that attain certain outcomes in a cost-effective manner; and 4) to assess the cost/benefit ratio of the costs of interventions compared with changes in outcomes. They also argue “that different outcomes are relevant for different populations, and different risk factors may need to be addressed as threats to those outcomes.” As strong advocates for the adoption of the minimum data set, Hirdes and Carpenter argue that the implementation of a “standardized assessment can provide information about indicators of need and changes in assessment items can act as indicators of outcome”.⁴³

There are a number of ways to measure health and social outcomes. First, self-report measures provide a direct assessment of care recipients’ views of their condition, but these measures are often thought to contain subjective bias, especially with the frail elderly.⁴⁴ Second, proxy responses are used as ratings, but these practices have also received criticism since it is difficult to calculate the margin of error between the care recipient and the proxy response. Direct care recipient interviews and proxy interviews are commonly used but these can sometimes create an added layer of administrative burden due to the need to collect new data that is not necessarily used in the pursuit of day-to-day activities.⁴⁵ Third, care recipient records can be used by researchers. However, ethical issues must be addressed and concerns about data gaps due to the incompleteness, lack of comprehensiveness, and lack of reliability

and validity of the records arise. The final method for obtaining outcome data is through the use of standardized assessment tools where the psychometric properties (validity, reliability, and responsiveness) of the tools have been tested. With sufficient standardization, the tools may be used to compare different groups of care recipients, service providers, organizations and jurisdictions.

4.2 Performance Measures/Indicators

Performance measures have to do with the workings of the system or to do with the mechanics of providing care, as well as outcomes of interventions. “Performance measures are a broad managerial tool that encompass measurement of inputs (indicators of the resources essential to provide a service), processes or activities (indicators of how the resources are used), outputs (indicators of the services resulting from the use of those resources, and impacts (the effect of these outputs on other variables or factors).”⁴⁶

Performance measures may be quantitative or qualitative measures used to evaluate and improve outcomes and/or the performance of functions and processes at the organizational or regional level, so that intra- and inter-organizational or regional comparisons may be made.

Performance measures serve a number of useful purposes, and are an essential means to assess service provision and the accomplishment of the mission of organizations.⁴⁷ For example, performance measures may be the time it takes to provide a particular intervention, or the time it takes to obtain a particular result. Some performance measures include financial measures, indicators of resource use and outcomes, measures of access and waiting times, and the satisfaction of care recipients with providers.⁴⁸ Performance measures provide yet another measure of the effectiveness of an intervention and are used to increase the effectiveness of an organization’s performance, including quality of care.

4.3 Assessment Tools

Assessment tools are designed to measure outcomes and/or performance. While assessment tools may consist of a single-item, they usually contain multiple items. A multi-item tool may measure the amount of pain experienced by the care recipient, or measure the recipient's physical functioning, e.g., range of motion, or measure the recipient's ability to participate at a psycho-social level, e.g. to participate in leisure activities, or all three. Each item more or less represents an element of the overall concept to be measured. Numerical scores are assigned to the indicators which may be combined to form an overall score. One of the purposes of this paper is to review and appraise assessment tools used to evaluate services provided in the home.

4.4 Effectiveness

Assessment tools can be used diagnostically to measure a particular health state, or to measure the effectiveness of interventions which requires looking at changes or variations in health and social states. As such, the effectiveness of home care services is measured by the change in health and social status of the individual care recipient or population, the effects of service provision on informal and formal caregivers, and the effects on the health system as a whole that may be attributable to the provision of in-home services while holding other factors constant. In measuring the effectiveness of a particular home care service, one would look at both outcome and performance measures. Similarly, effectiveness may be measured at the micro, meso and/or macro level.

To summarize, assessment tools are developed to evaluate: health and social outcomes for care recipients and informal care providers as a result of specific interventions; the performance of individual or groups of provider organizations as defined by some sub-

provincial, geographic catchment area; and the performance of an entire network of home care services that constitute this sector of care in the province.

4.5 Unit of Analysis

In evaluating the effectiveness of services, we need to be clear on the perspective adopted as well as the unit of analysis. Units of analysis in research are the things or persons being studied and may be individuals, groups of individuals, , organizations, or whole systems. For example, we need to ask ourselves, are we measuring the impact on individuals or classes of individuals (all diabetics) or the entire population. In addition, we need to determine whether individual service providers (formal or informal), types of service providers (such as, nurses) or an array of providers are the focus of analysis?

4.6 Level of Assessment

In evaluating the effectiveness of health and social support services in the home, the level of analysis also needs to be explicit. It needs to be clear whether in measuring effectiveness, we are measuring the impact of the services at a micro level (impact on care recipients, informal caregiver, or individual service provider); at the meso level (the level of the provider organization or CCAC); or the macro level (all service providers and CCACs in a given region, or for the entire province).

5.0 Conceptual Framework

The conceptual framework we have developed for the assessment of home care services incorporates the range of in-home professional and non-professional services contracted by CCACs to service the needs of care recipients in Ontario. The framework is sufficiently general that it provides an opportunity to assess outcomes and performance at multiple levels. The three dimensional cube in Figure 6 represents the home care services provided to care recipients under the responsibility of a particular CCAC as represented by CCAC₁. For Ontario there would be 43 “cubes” one for each CCAC as Figure 7 demonstrates.

On the vertical axis of the cube in Figure 6 are all the care recipients cared for by a single CCAC, grouped by health and social conditions, for example, diabetes, oncology, nephrology, etc.. Included in this dimension are informal caregivers since some of the services provided in the home have an impact on them in alleviating the burden of their role.

On the horizontal axis of the cube in Figure 6 are all the home care services provided by CCAC₁, grouped according to type of service, for example, homemaking and personal support care, nursing, speech language therapy, case management, etc. The informal caregiver can technically be considered a provider of care, the impact of whose services theoretically should be assessed and evaluated. However, the purpose of this report is to review and assess outcome and performance measures of care provided by the formal home care system. Therefore, care provided by the informal caregiver is not included as a type of service.

On the third axis of the cube, the depth dimension running from front to back, are all the agencies contracted with CCAC₁ to provide in-home services. Each “slice” of the three

dimensional cube represents a single provider organization that holds a contract with CCAC₁ and the recipients to whom that agency provides care. The whole “cube” represents the particular CCAC, the provider agencies with whom they hold contracts and all the care recipients to whom care is provided. (Note, some residents may receive care from multiple CCACs.)

The Ontario home care system is represented by 43 “cubes”, one for each CCAC, its service agencies and care recipients as shown in Figure 7.

In Figure 6, ‘E_{ns}’ represents the measure of service effectiveness (or outcomes) of services ‘s’ for a particular condition ‘n’ provided by Provider Agency 1. The intersection of the row representing Condition 3 and the column representing nursing would represent the effectiveness of nursing services provided by Provider Agency 1 to care recipients who have Condition 3 (e.g. diabetes).

‘E_n’ represents the measure of the effectiveness of the care provided by entire health and social care team of Provider Agency 1 for Condition ‘n’. E_s represents the measure of effectiveness of a particular type of care (e.g., nursing) provided by Provider Agency 1 across all conditions. Finally ‘E’ represents the measure of effectiveness of all services provided by Provider Agency 1 across all types of care recipients, while ‘E_T’ represents the measure of effectiveness for all services provided by all the agencies contracted by CCAC₁ to all of its care recipients.

In evaluating the effectiveness of services, we need to be clear whether we are assessing the effectiveness of services provided by, and to individuals or groups. For example, ‘E_n’ could represent the effectiveness of services provided by the complete health and social service team of Provider Agency 1 for all care recipients with Condition ‘n’, or it

could represent the effectiveness of the members of a particular health and social service team providing care to a particular care recipient with condition ‘n’.

Similarly, ‘E_s’ could represent the effectiveness of care provided by all care providers ‘s’ in Provider Agency 1 who provide care to care recipients across all conditions, or it could represent the effectiveness of care provided to all care recipients regardless of condition by an individual service provider.

Moreover, Figure 6 allows us to measure the effectiveness of all nursing care provided by all agencies contracted with CCAC₁ for Condition 1, or the team of health and social services provided by all agencies contracted with CCAC₁ for Condition 1. Indeed, the conceptual framework allows us to measure effectiveness of care at the micro (individual) level, the meso (agency or CCAC) level, or the macro (regional or provincial) level.

6.0 Criteria for Evaluating Indicators and Assessment Tools

Five criteria were used to evaluate the assessment tools identified in the literature. They include psychometric properties of the tools (i.e., validity, reliability, and responsiveness), the ease of administering the tools or their feasibility, and the scope of the outcomes measured by the tools. Table 2 summarizes the criteria and provides working definitions for each criterion.

6.1 Validity

Validity of an instrument or tool refers to the extent that it measures what it is supposed to measure. For example, if we use a bathroom scale to measure a person's height, it would not be a valid instrument for measuring that characteristic. The scale may be reliable in that it consistently gives the same measure (e.g. 150 lbs.) each time the person steps on it. Also weight may reflect a person's height in that it is correlated with height but it is clear that a yardstick would be a better instrument for measuring height.

There are several kinds of validity and ways in which they are tested: *face* validity and *content* validity are based on subjective or expert judgments rather than statistical properties of whether the instrument measures what it is supposed to. Face validity is based on an overall judgment as to whether “on the face of it” an instrument measures what it purports to measure. Content validity refers to whether, based on expert judgment, the content or questions of an instrument accurately represent the attribute being measured. *Construct* validity describes a scale or measure according to its predicted correlation with other measures. If you hold a theory that assertiveness correlates with self-esteem and your measures of assertiveness positively correlate with known measures of self-esteem, then your measure of assertiveness is said to have construct validity. This is, of course, predicated on

the correctness of your theory and the validity of measures of self-esteem. *Criterion* validity refers to the ability of an instrument to make accurate predictions. For example, the extent to which university entrance exams accurately predict grades in university is an example of criterion validity.^{49 50}

6.2 Reliability

Reliability refers to the consistency or stability of an instrument in measuring attributes or the ability of a test to obtain the same result when repeated. *Inter-rater reliability* refers to the consistency of results obtained by different individuals who use the same instrument to measure the relevant attribute or variable. If raters A and B obtain different measures in applying a pain instrument scale, the scale is said to lack inter-rater reliability. *Internal reliability* refers to the consistency of items in the instrument in measuring the attribute in question. *Test-retest reliability* refers to the stability of the measure obtained by the instrument in each application. If a particular bathroom scale were to give three different weights in three different weighings, the scale lacks test-retest reliability.

6.3 Responsiveness

Responsiveness is the ability of an instrument to detect change in a state, whether it be a change in health and social outcomes, or a change in the performance of individual providers, provider agencies, services provided for a whole region or province.

Responsiveness is assessed by the effect size, that is, the mean change score relative to the standard deviation of the baseline scores. Consequently, an instrument is said to be more responsive if the mean change score is large and/or the standard deviation of baseline scores is low.

6.4 Feasibility

In evaluating an instrument or assessment tool, the feasibility of administering or implementing the tool has to be a consideration. Feasibility refers to the ease of administration and includes the human and financial costs involved, the ease of interpreting the results, and the tool's compatibility with existing data sets. If training personnel on how to use the tool is too costly, too time consuming or too complex, the tool is not very feasible. Similarly, if administering the tool is too resource intensive in terms of human and other resources, it is not likely to be adopted. Finally, the feasibility of a tool is increased if outcome measures are derived from information that care providers routinely collect or use.

6.5 Scope

Scope of the instrument or tool refers to the breadth of measures that it compiles or the range of populations to which it can be applied. For example, if an instrument measures the clinical, functional and psychosocial capabilities of a care recipient following an intervention, its scope is broader than one that only is capable of measuring clinical changes. Similarly, if an instrument is applicable only for care recipients with a given condition, it has less scope than one that can be applied to a care recipients with a wide range of conditions. A broad scope is not necessarily preferred if one is looking for sensitive indicators for care recipients with a particular condition.

7.0 Typology of Outcome Indicators

The creation of tools for measuring outcomes in long-term care and home care has been underway for a considerable period of time.⁵¹ Assessment tools that are used in the home care setting measure care recipient status at different points in time, the characteristics of the care recipients, the perceived burden experienced by informal caregivers, the effect of a care intervention over time, the costs to the health and social care systems and utilization. Assessment tools can be used in a variety of circumstances that enable care providers, researchers and policy makers to assess the impact of interventions on the health and social status of a care recipient.

According to Shaughnessy et al.⁵² there are three categories of outcome measures that have a relevance for care provided in the home: end-result outcomes; intermediate or instrumental result outcomes, and utilization outcomes.

End-result Outcomes:

These outcomes measure change in a care recipient's health status between two or more points in time.⁵³ The measures that pertain to all care recipients are referred to as global measures while those pertaining to specific care recipient conditions are referred to as focused measures.

Instrumental Outcomes:

These outcomes measure a change in a care recipient's or an informal caregiver's behaviour, emotions or knowledge that can have an influence on the care recipient's end-result; for example, changes in compliance with a treatment regime which facilitate the attainment of end-result outcomes.⁵⁴

Utilization Outcomes:

These outcomes, often thought of as proxy outcomes for a change in the status of a care recipient, may include the use of an emergency department or hospital admission.⁵⁵

The problem with using Shaughnessey's typology is that it is limited to care recipients and informal caregiver outcomes. Outcomes for care provider organizations or the system as a whole may be determined by the aggregate of outcomes for care recipients. However, Shaughnessey's framework does not account of the more process oriented outcomes of provider performance.

We have identified three categories of indicators that are used to assess the effectiveness of in-home services: health and social outcomes for care recipients and informal caregivers; performance outcomes for service provider organizations; and system-level health and social performance outcomes. Table 3 outlines the types of indicators from the perspective of the recipient whether the recipient is the care recipient or the informal caregiver; the service provider organization; or the system as a whole, i.e., at the regional or provincial level.

7.1 Recipient Outcomes

Recipient Indicators refer to the measurable outcomes associated with the provision of health or social care received by either care recipients or informal caregivers. There are a range of indicators used to measure these outcomes. Clinical indicators are “designed to evaluate the processes or outcomes of care associated with the delivery of clinical services...[they] must be condition specific, procedure specific, or address important functions of care recipient care (for example, medication use, infection control, [care recipient] assessment, and so forth)”⁵⁶ Physical functioning indicators reflect the care

recipient's functioning in the physical aspects of daily living. These indicators are usually a component of assessment tools designed to measure *Activities of Daily Living* or *Instrumental Activities of Daily Living*. Cognitive functioning indicators involve the ability to communicate, to understand and to make decisions.⁴² Social functioning indicators refer to quality of life and ability to function within the social environment and the existence of a social network for the recipient. Finally, service utilization indicators refer to the amount of in-home care received in terms of the number of visits and/or hours within a specified time period, as well as the use of other services.

In Ontario, the provisions of the *Long Term Care Act* limit the weekly amount of professional service hours allotted for nursing to 43 hours of service performed by a Registered Nurse, or 53 hours performed by a Registered Practical Nurse, or 48 hours of service performed by a Registered Nurse or Registered Practical Nurse. Excluding exceptional circumstances, homemaker and personal support services are limited to a weekly maximum of 80 hours in the first 30 days that follow the first day of service and then a subsequent maximum of up to 60 hours per week in any subsequent 30 day period.⁵⁷

Informal caregiver indicators are usually collected for family members but may also include neighbours and/or volunteers. These indicators measure changes to the health and social well-being of the caregiver resulting from the level of burden experienced by the informal care provider or relief of that burden through home care services.

7.2 Service Provider Outcomes

Professional Service Provider Indicators measure the level and type of professional services that the care recipient was receiving before admission to home care and the amount

received during the episode of home care.⁵⁸ These indicators measure the outcome of the care intervention, utilization and service intensity, as well as performance measures.

Homemaking and Personal Supports Quality and Effectiveness Indicators provide measures of the number of service hours, the type of activities performed (light housework, paying bills etc.) and changes in the intensity or type of care required. They also include measures of performance outcomes.

Care Provider Organization Performance Indicators measure performance at the level of the care provider organization or agency. These indicators include performance and outcome measures aggregated at the organizational level.

7.3 System Outcomes

Finally, *System Indicators*, Regional Health Management Indicators and System Expenditure and Quality Indicators, measure performance at the CCAC level and province-wide outcomes. These indicators fall into the following categories: performance measurement indicators or system expenditure and quality of care indicators. System expenditure and quality of care indicators include cost per care recipient, cost per capita, quality of care to care recipients etc.

8.0 Current Initiatives

This section outlines a number of initiatives in both Canada and the U.S. to develop indicators for measuring home care outcomes and performance. In Canada, the most ambitious project is spearheaded by the Canadian Institute for Health Information.

8.1 In Canada

8.1.1 Canadian Institute for Health Information: Development of National Indicators and Reports for Home Care

Despite the significant growth in home care spending in the last decade, little data is currently available in Canada on the client outcomes and program effectiveness. For home care services in particular, the lack of standardized terminology, data definitions and data collection processes across jurisdictions and organizations is a major barrier for the cost effective planning, management and evaluation of these services. To address these issues, the Canadian Institute for Health Information (CIHI), with funding from the Health Transition Fund (Health Canada) undertook to develop a core set of national priority indicators to support the evaluation of home care services at the provincial/territorial and regional levels.

The specific objectives of the initiative were:

- to obtain agreement on priority indicators for home care;
- to identify data needed to support indicators, using standardized data definitions and elements; and
- to test and evaluate the recommended indicators.⁵⁹

In May 1999, CIHI surveyed key home care stakeholders in government, regional authorities, and care provider organizations to identify current and emerging health information needs and priorities for the planning, management and evaluation of home care

services. Survey recipients were asked to rate the appropriateness, availability and priority of certain types of information. There was almost complete consensus that all the information proposed in the survey was appropriate. Respondents identified the following information as high priority: health characteristics, achievement of client goals, reason for referral, hours of services provided, proportion of service recipients on waiting list, average period of time on waiting list, profile of interventions provided, level of informal support received, number of visits, average duration of services, symptom control and impact of symptoms on clients, and profile of service providers. However, none of the information that was identified as high priority by respondents was rated as readily available.

Stakeholders were also asked to identify current and emerging issues and priorities within home care that require information to support decision making. Respondents identified the need for data to evaluate the effectiveness and outcomes of home care services, standard classification systems, data on utilization and spending, and information on overall satisfaction of care recipients and their families with provided services. In addition to these issues, respondents also identified the following as emerging issues and priorities: profile of catchment areas, human resources data, and information systems.

Three themes emerged from the survey. There was a clear need for comparative data to demonstrate the cost effectiveness and value of services provided and to report on the health status of individuals as a result of the services provided. Information about the catchment population was necessary for effective planning and evaluation of home care services. Lastly, increased use of technology was identified to facilitate data capture, management and reporting.⁶⁰

Based on findings from a Consensus Workshop with the assistance of the Home Care Expert Working Group, a set of priority indicators were identified and defined. Between April and November 2000, a national pilot test of the draft indicators was conducted in collaboration with 11 regional health authorities across Canada. The objectives of the pilot were to identify and assess data element collected by regional health authorities, evaluate the feasibility of data submission and to calculate and evaluate draft indicators and a prototype home care report. A final report of the pilot is to be completed in 2001.

In June and July 2000, CIHI also conducted an external field review to assess the usefulness, clarity, relevance and breadth of the draft home care indicators. The indicators were grouped and reported based on the high priority information requirements for which data is currently available. The groupings include: functional status of home care clients at time of admission, regional and provincial home care/health expenditures, utilization of home care services, demographics of the home care population, diagnostic and health characteristics of the home care population, assistance/services provided by informal care providers, and the level of satisfaction and burden of informal care providers. Table 4 provides a summary of the indicators that comprise each of the groupings.

Reviewers were on the whole supportive of the initiative and provided favourable responses to the draft indicators. While the set of home care indicators is a good start, relevant and valuable, additional indicators that focus on *outcomes and effectiveness of services* should be developed. In addition, reviewers suggested greater clarity and standardization of definitions so that they are understood by decision makers and stakeholders, and an increased use of technology and resources to facilitate data capture.⁶¹

While the CIHI initiative is a very important undertaking for the development of indicators to be used to plan, manage and evaluate home care services, its objective is for provincial and national reporting and comparison. The conceptual framework developed in this report which will incorporate the indicators and tools developed through the CIHI exercise, goes further by allowing for the assessment of home care interventions at the care recipient, organization, CCAC, regional and provincial levels.

8.1.2 Manitoba's Screening, Assessment and Care Planning Automated Tool (SACPAT)

Manitoba's Screening, Assessment and Care Planning Automated Tool (SACPAT) was developed by the Manitoba Home Care Program with funding from the Health Transition fund. SACPAT is a computerized tool to be used in community and hospital-based home care settings. Its objective is to capture a range of client-based demographic data, and was developed to assess eligibility for home care, assess the client's functional needs and develop appropriate care and service plans for clients. The project encompasses five primary activities: modifying SACPAT to make it functional in a multi-site regional environment; developing a training strategy for the users of SACPAT; developing a strategy to incorporate the required client data which is currently in non-electronic form; creating the required infrastructure and hardware to enable SACPAT to run; and implementing SACPAT on a pilot basis throughout the city of Winnipeg. The tool has been tested at two sites in Winnipeg and will be expanded to include all community and hospital-based Home Care offices in that City of Winnipeg. The tool is currently undergoing evaluation. A report comparing SACPAT to the Resident Assessment Instrument-Home Care (RAI-HC) is expected for release to Health Canada by the end of the 2000. SACPAT is expected to enable more consistent,

responsive and appropriate home care services for clients, as well as greater collaboration and communication between hospital and community care sites.⁶²

8.1.3 Canadian Council on Health Services Accreditation/Comcare Health Services

The Canadian Council on Health Services Accreditation (CCHSA) has standards for the accreditation of home care organizations. These standards allow organizations to monitor and improve their performance on an ongoing basis. The regular survey visits give organizations the opportunity to have their performance reviewed and validated by peers outside their organization.⁶³ The accreditation program is, however, voluntary and many smaller agencies need financial assistance to participate.⁶⁴

Comcare Health Services along with the Canadian Council on Health Services Accreditation has been reviewing the issue of standards and quality of care provided in the home. In a paper presented at their 10th Canadian Home Care Conference, standards were differentiated from quality in that the former is thought to relate to performance. Performance is defined as the objective description of activities toward a stated goal, and quality is the value placed upon performance (i.e., a reflection of expectations and beliefs).

The scopes of standards are dictated by legislation, professional bodies such as the Canadian Nurses Association, associations such as the Canadian Intravenous Nurses Association, organizational and accreditation standards. Federal and provincial associations often determine clinical standards or standards of practice, care paths, or evidence-based care. Organizational standards are guided by by-laws, policies and procedures, etc.

The vision of the Canadian Council on Health Services Accreditation's Achieving Improved Measurement (AIM) Program is to develop a better quality measurement system which allows for consistency of the accreditation process, comparability of results and

sharing of good practice. In the AIM framework, quality is measured by four factors: responsiveness, client/community focus, system competency, and work life. Responsiveness consists of measures of availability, accessibility, timeliness, continuity and equity. System competency takes into consideration appropriateness, competency, effectiveness, safety, legitimacy, efficiency, and system alignment. Client/community focus evaluates communication, confidentiality, participation and partnership, respect and caring, and organizational responsibility and involvement in the community. Lastly, work life measures the openness of communications in the organization, clarity of roles, employee participation in decision-making, and the organization's commitment to a learning environment and the well-being of its staff.

8.2 In the United States

8.2.1 Health Care Financing Administration (HCFA) Home Health Pilot Project

The 1997 Balanced Budget Act required Medicare-certified Home Health Agencies (HHAs) to submit information necessary to develop a reliable case mix system. The purpose was to establish a prospective payment system for HHAs and to achieve broad-based, measurable improvement in the quality of care furnished through Federal programs. Home Health Agencies were to implement the Outcome and Assessment Information Set (OASIS) tool and to collect OASIS outcomes data (approximately 80 items) in order to qualify for reimbursement under Medicare. The HCFA's objective was to ensure quality outcomes for home health care recipients through the collection and use of standardized data.

The OASIS system collects a vast array of information including personal identifiers, demographic information, financial information, health and social conditions, medical

treatment, risk factors, living arrangements, safety hazards in a care recipient's residence, sanitation of residence, identity of people assisting the care recipient, and more.

The Home Health Pilot Project which is funded by the HCFA is designing and implementing an Outcomes Based Quality Improvement (OBQI) model, making use of OASIS outcome information and the Peer Review Organization network. Both the OASIS and OBQI were developed by Peter Shaughnessy and associates at the Center for Health Policy and Services Research, University of Colorado.⁶⁵ The Peer Review Organizations in the five participating states (Rhode Island, New York, Michigan, Virginia and Maryland) will assist HHAs in their state to interpret OASIS outcome reports, target clinical areas for improvement, identify behaviours which will improve outcomes, develop plans of action to implement these behaviours, monitor adherence to the plan, and develop resources for identifying "best practices" linked to "best outcomes".

Outcome-Based Quality Improvement (OBQI) has two stages. The first stage includes the collection of uniform data at uniform time points using a standardized data set (OASIS), followed by data analysis and preparation of agency-level outcome reports. The second stage, outcome enhancement, includes targeting specific outcome measures (in the agency-level report) for improvement or reinforcement. Continued OASIS data collection allows the agency to see whether these targeted outcomes are improved in the next outcome report. The OBQI system allows agencies to compare themselves with a national reference for 41 outcome measures and to streamline many of their processes.

The Outcomes Based Quality Improvement System being developed under this project will eventually extend nationwide as Peer Review Organizations provide technical support in quality improvement efforts of Medicare-certified Home Health Agencies.⁶⁶

8.2.2 Joint Commission on Accreditation of Health Care Organizations (JCAHO)

Project on Home Care Accreditation

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is an independent, not-for-profit organization which accredits nearly 18,000 health care organizations and programs in the United States. The mission of JCAHO is to improve the quality of care provided to the public through the provision of health care accreditation and related services that support performance improvement in health care organizations. It develops its standards in consultation with health care experts, providers, measurement experts, purchasers and consumers.⁶⁷ Accreditation by JCAHO is recognized nation-wide and indicates that an organization meets certain performance standards.

In February 1997 the Joint Commission introduced the ORYX (not an acronym) initiative which integrates outcomes and other performance measurement data into the accreditation process. ORYX is the critical link between accreditation and the outcomes of recipient care, which allows the Joint Commission to review data trends and to work with organizations as they use data to improve care. The goal of this initiative is to create a more continuous, data-driven, comprehensive accreditation process which not only evaluates a health care organization's methods of standards compliance but also the outcomes of these methods. Performance measures will supplement and guide the standards-based survey process by providing a more targeted basis for the regular accreditation process; a basis for continuously monitoring actual performance; and a basis for stimulating continuous improvement in health care organizations.^{68 69}

The ORYX initiative was designed to be implemented in phases. The Joint Commission's intent through this project was to *identify* rather than develop measures that support the objectives of the ORYX initiative and organizational process improvement.

In the initial phase of ORYX, the Joint Commission invited the submission of measurement systems to be part of the future accreditation process. Of the 150 systems submitted, the Commission's Advisory Council on Measurement reviewed each against screening criteria and selected for inclusion those that met criteria. From the list of selected systems, organizations chose the measurement system(s) that best met their overall measurement needs and indicators that were most applicable to the care recipient to whom they provided services. Health care organizations were to submit data through their chosen measurement system at regular intervals to the Joint Commission. The Commission, in turn, would use this information in their survey and accreditation process. When common national measures for the various types of organizations are identified and embedded in the listed systems, it is the intent of the Joint Commission to standardize the measures that each organization submits through their chosen measurement system.

This past May, advisory groups comprised of providers from the home health, hospice, pharmaceutical services and home medical equipment industries met to deliberate issues. Two sessions of Executive Briefings for Home Care were scheduled to take place on November 16, 2000 in Scottsdale, Arizona, and to discuss standards, survey process, fees etc on December 4th, 2000 in Chicago.⁷⁰ During 2000 and 2001, Joint Commission surveyors will assess how home care organizations have integrated and used ORYX performance measurement data in their performance improvement activities.

9.0 Overview of Assessment Tools

The following is a summary of assessment tools that have been used to evaluate care in the home. While there are many more tools that have been administered in institutional settings, we have focused only on those that have been administered to evaluate home care. In each case, we have used the five evaluative criteria (validity, reliability, responsiveness, feasibility and scope) to describe and assess each tool. Although these tools have been administered to measure and evaluate care in the home, their psychometric properties (validity, reliability, and responsiveness) may have only been tested when used in other settings, such as hospitals. As a result, an assessment against the five evaluative criteria may not be complete for all tools.

Tables 5 to 21 provide summaries of most of the tools listed below. Some tools were mentioned in the literature but insufficient evidence was provided to complete a table. A summary of all the tools, indicating what they measure, whether tests of validity and reliability have been conducted, with an indication of responsiveness, feasibility and scope can be found in Table 22.

9.1 Recipient Outcomes

9.1.1 Co-Morbidity

- *Diagnostic Cost Group/Hierarchical Coexisting Category (DCG/HCC) Model*

The DCG/HCC methodology measures an individual's health status by grouping diagnoses found in administrative claims data into a comprehensive set of hierarchies across clinical conditions, capturing both chronic and serious acute presentations of disease processes. The model uses diagnoses obtained from administrative data to summarize health problems and to predict future health care costs of populations. The methodology has been

validated in both the US and the Netherlands and is based on diagnostic information contained in inpatient hospitalizations, outpatient hospitalizations and physician claims.^{71 72 73}

The DCG/HCC Model was recently used to develop prospective, capitated home care funding for CCACs in Ontario.⁷⁴ The assignment of diagnostic health status was determined by using diagnostic information obtained from physician OHIP claims and hospital separation data. The method was found to be both valid, reliable, feasible and responsive for home care recipients. The method has broad scope in measuring a range of conditions. See Table 5.

9.1.2 Physical Functioning

- *Barthel Index*

The Barthel index has been used with orthopedic, neurological, and cardiovascular patients and amputees and is designed to evaluate and predict a care recipient's functional independence. The scale has 15 items that measure self-care, continence and mobility. It uses a 3-point scale (completes task by self, completes task with aid, and cannot do). Both its validity and reliability have been tested. The tool is responsive to changes in patient status from admission to discharge from acute care settings, but may not be responsive to changes resulting from rehabilitation therapy. In terms of scope, the index does not measure social or cognitive functioning. It takes approximately 25 minutes to complete, and the setting in which the test is administered may unduly influence the scores. See Table 6.

- *Stroke Rehabilitation Assessment of Movement (STREAM)*

The Stroke Rehabilitation Assessment of Movement was designed as a clinical measure of motor function for care recipients who have had a stroke. It is used as an outcome

measure to evaluate therapies and to monitor motor recovery. Items involving voluntary movement in four positions (supine, sitting, standing, and standing and walking) are rated by a therapist on a 4-point ordinal scale. It has been shown to be both reliable and valid.

However, additional studies are required to provide an indication of responsiveness.

STREAM takes approximately 10 to 15 minutes to complete. See Table 7.

- *Motoricity Index*

This is a measure of limb function with a maximum score of 100 for normal subjects. Severe paralysis is defined by a score of 0-32, moderate as 33-64 and mild as 65-99.

- *Timed Walk*

Care recipients are made to take a walk (5 metres and 10 metres have been used, as well as a 2-minute walk test) and the speed of the gait is evaluated.

9.1.3 Cognitive Functioning

- *Mini Mental-state Examination*

The test assesses orientation, memory, attention, and the ability of the care recipient to write a complete sentence, name objects, follow verbal and written commands and reproduce a complex polygon.⁷⁵ This measure is widely used as a screening tool for severe cognitive impairment. A score of 23 or less, out of a maximum of 30, is indication of severe impairment.

- *FROMAJE Scale*

This scale, developed in 1981, assesses the care recipient's overall mental function. The scale measures seven parameters of mental status: function, reasoning, orientation, memory, arithmetic, judgement and emotion on a three point scale. The scores range from a

low of 7 to a high of 21. A low score is an indication of no abnormal behaviour while moderate to high scores signify severe dementia or depression.⁷⁶

- *Frenchay Aphasia Screening Test*

This is a screening instrument designed to detect aphasia in care recipients with stroke. Scores of 13 or less out of 20 indicate aphasia.

- *Rivermead Activities of Daily Living Score*

This measure has been validated for use in elderly care recipients with stroke. Scores are from 15 (indicating dependence) to 45 (indicating independence)

9.1.4 Social Functioning

Social Functioning refers to the level of (in)dependence with which a care recipient performs activities of daily living. Some measures also capture the ability of the individual to maintain social activities with family/friends and work roles.⁷⁷ The Activities of Daily Living tools assess bathing, dressing, toilet functions, transfers, continence and feeding.⁷⁸ The following is a list of some of the ADL measurement tools that are available:

- *Katz Activities of Daily Living Index*

This tool measures functions such as bathing, dressing, transfer, toileting, continence and feeding, ambulation and house confinement. Each item is scored on a 3-point scale representing increasing levels of dependence. The scale has been shown to have content, construct and criterion validity, as well as inter-rater reliability. The tool measures self-care and mobility for those living with a disability. Its responsiveness and feasibility have not been reported.⁷⁹ See Table 8.

- *Barthel Index*

This tool only measures ADL. The care recipient is scored out of 100, with a full score showing independence, which is not necessarily an indication that the he or she is able to live alone.⁸⁰ See the listing of this tool under Physical Functioning above.

- *Functional Independence Measure (FIM)*

The FIM measures the severity of disability and outcomes of medical rehabilitation mostly on non-elderly care recipients. It is intended to measure rehabilitation progress. Based on direct observation, the therapist rates the care recipient along a 7-point ordinal scale on 18 items. The 18 items are grouped into 6 subscales which assess self-care, sphincter control, mobility, locomotion, communication, and social cognition. The FIM includes more detail than the Barthel Index as well as measures of social cognition and communication beyond basic ADLs. The FIM has been shown to be both valid, reliable, and somewhat responsive. However, there are some concerns that the cognitive subscales may not detect change with mild to moderate impairments. While it takes 30 minutes to complete, there is no indication of the administrative costs of implementation. See Table 9.

- *Comprehensive Geriatric Assessment (CGA)*

A comprehensive geriatric assessment is a multidimensional tool designed to measure general health as well as function, cognition, and psycho-social aspects of the health of elderly care recipients.⁸¹

Additional tools that are infrequently cited in the literature include: Pace II Physical Function; Rapid Disability Rating Score; Hebrew Rehabilitation Centre for Aged Vulnerability Index; OARS Physical Functioning; Barthel Self-Rating Scales; and Spitzer Quality of Life Index.

Instrumental Activities of Daily Living (IADL) Measurement Tool is different from ADL tools in that IADLs involve the care recipient's ability to cook, clean, use the telephone, write, read, shop, do laundry, manage medications, walk out of the house, climb stairs, perform work outside of the house, manage money and use public transportation.⁸² The following tools measure IADL:

- *PULSES Profile*

This test is similar to the Barthel and FIM tests, but it also assesses “supports” (emotional, family, social and financial) available to the care recipient. There are six subscales which include physical condition, upper limb function, lower limb function, sensory components (speech, vision, hearing), excretory functions and mental and emotional support functions. Each of the subscales receive equal weighting and are measured at four levels of impairment. The scales have been tested for validity, test-retest and inter-rater reliability. The tool has been found to be able to detect change in function in disabled adults between admission and discharge from rehabilitation centres. The scale is designed to measure functional independence only in the activities of daily living of the chronically ill and elderly living in institutions. The tool has also been widely used attesting to its feasibility. See Table 10.

- *Quality of Life Index*

The Quality of Life Index (QL Index) was designed to measure general independence and well-being of care recipients that have cancer or chronic disease. The tool has five subscales measuring activities of daily living, health, support and outlook. The tool has been shown to be both valid and reliable, and can discriminate between healthy individuals and various groups of patients. However, the 3-point scoring system may create a ceiling and

floor effect making it insensitive for extreme scores. No training is required to administer the tool and it takes approximately 2 minutes to complete. The QL Index has been criticized for not being applicable to populations other than those with cancer or chronic disease. See Table 11.

- *Functional Status Questionnaire (FSQ)*

The FSQ was designed to assess physical, psychological and social/role functions and to be a screening tool for functional disability. There are 6 subscales presented in three categories: basic ADLs, intermediate ADLs, mental health, work performance, social activity, and quality of interaction. The tool has been shown to be valid, reliable and although responsive to change in function of elderly patients with cardiac disease at one and three month post surgery, it was less responsive than the Short Form-36 (SF-36). It is a self-administered test and straight forward to score. It, however, is a screening tool that does not measure outcomes. See Table 12.

- *McMaster Health Index Questionnaire*

The McMaster Health Index Questionnaire measures the impact of clinical and health care interventions on quality of life and health status. It has three dimensions which assess physical function, social function, and emotional function. It is used with patients with chronic disease. While the responsiveness of the social and emotional function subscales has not been reported, the physical function subscale has been shown to be responsive in detecting change as a result of a physical therapy intervention. It is a long self-administered questionnaire taking approximately 20 minutes to complete. See Table 13.

In addition to the above mentioned tools, some additional ones, including Pace II: Ability to Carry out IADLs, ROSCOW Functional Health Scale, Brief IADL Measure, and the PGAP Functional Assessment Scale have also been mentioned in the literature.

Many of the ADL and IADL tools were designed to measure the outcome of a rehabilitation intervention. An additional tool referred to in the literature specifically for geriatric care recipients is the Functional Outcome Assessment Measuring Tool. This tool measures bed mobility, feeding and dressing, transfers, grooming and hygiene and homemaking.⁸³

d) Informal Caregiver Outcomes

- *Caregiver Strain Index*

This index measures the burden on the informal caregiver of looking after a care recipient. Originally used to evaluate the burden of informal caregivers of older adults who had received hip and heart surgery, it is now used with those caring for persons with multiple sclerosis, cancer, disabled veterans, and CVA. The effects of caregiving on work, family, finances, physical health, psychosocial demands and emotional health are measured by responses to a 13 item multidimensional questionnaire. Overall stress score is obtained by summing the subjects' ratings across all of the items. The test has been shown to have content and construct validity, and internal consistency. However, the tool is viewed as a subjective tool, and open to bias. It appears to have a low administrative burden, taking only 5 to 10 minutes to complete. It has largely been used to measure the burden of caring for older disabled adults. See Table 14.

9.1.5 Multidimensional Recipient Outcomes

Standard instruments ably capture functional ability, physical dependence and mental state, but, according to discussion groups at a recent European SCOPE conference, measurements of individual coping responses, psychological adjustment, emotional state and perceived quality of life are more difficult to capture in standard instruments.⁸⁴ This section examines tools that assess care outcomes and performance along a number of dimensions.

- *Older American Resources and Services (OARS Questionnaire)*

This tool, developed in 1988 at Duke University, is a multidimensional assessment questionnaire consisting of two parts: Multidimensional Functional Assessment Questionnaire (MFAQ) that examines levels of functioning, and the Services Assessment Questionnaire (SAQ) which examines service utilization. The MFAQ consists of 99 questions representing five dimensions: economic resources, mental health, activities of daily living, instrumental activities of daily living and social function. The SAQ includes 24 different services.⁸⁵ Inter-rater and test-retest reliability were found to be high for the MFAQ, and it was shown to be valid. Reliability and validity have not been tested for the SAQ. The MFAQ and SAQ take 30 and 15 minutes respectively to administer, and a two-day training period is recommended to administer the test. See Table 15.

- *Minimum Data Set - Home Care (MDS-HC)*

For the past decade, a group of 30 international researchers from 16 different countries has been working together on the interRAI project. The objective of this project is the “development, application and evaluation of comprehensive assessment instruments for home care, nursing homes, acute care, mental health and rehabilitation settings”.⁸⁶ The Minimum Data Set (RAI/MDS) is the most well known outcome of this project. In 1995,

interRAI developed an MDS specifically for home care (MDS-HC). This tool is considered to be a promising tool for implementation in Canada, but the Canadian Home Care Association indicates that further consultation, development and expansion are necessary before MDS-HC can be implemented.⁸⁷

The RAI-HC includes an assessment of the medical, social, psychological and environmental factors that affect an individual's ability to function independently in the community. Many outcome measures such as the cognitive performance scale and ADL summary scales are included. In the future, algorithms for quality management will be available. The reliability and validity of this tool has been well tested and established in 1997. Assessment requires direct questioning of the care recipient and family caregiver by clinicians as well as direct observation of the care recipient in the home. While there is an absence of information on the ease of administration for the RAI-HC, approximately 1.5 to 6 hours is required to complete the nursing home MDS for new clients. See Table 16.

- *The Outcome Assessment Information Set (OASIS)*

OASIS was formerly the Shaughnessey et al. Outcomes Measurement Tool.⁸⁸ As indicated earlier, use of the tool has been mandated by the U.S. Health Care Financing Administration for all home care agencies seeking reimbursement under Medicare and Medicaid. Designed as a tool for use with adult home care recipients, it collects information about each care recipient at admission, re-certification and discharge from home health care. This tool includes health status measures such as, functional, physiologic and cognitive status and condition specific measures. Unlike the Omaha system, the outcome indicators are risk adjusted.

The tool collects demographic data, information on living arrangements, support system, sensory, integumentary, respiratory, elimination, neurological, emotional and behavioural status, functional status and management of equipment and medications. While the tool has been tested at more than 200 sites in the US, according at least to one author it is subject to gaming, that is, providers unconsciously deflate initial scores and inflate gains.⁸⁹ One of the problems that has been identified with OASIS is that it was not developed as a comprehensive assessment system and needs to be supplemented with additional client specific measures.⁹⁰ See Table 17.

- *The Omaha System*

The Omaha System, developed by Martin and Scheet,⁹¹ is used to classify outcomes of home health care by measuring the effectiveness of nursing diagnoses and interventions. The system includes: a “problem classification scheme” that measures domains such as environmental, psychosocial, physiological and health related behaviours; the “problem rating scale for outcomes” consisting of three five-point Likert-type subscale measuring knowledge, behaviour and status; and an “Intervention scheme” that is a hierarchy of nursing actions divided into 4 categories of interventions: Health Teaching, Guidance and Counselling; Treatments and Procedures; Case Management and Surveillance.⁹² The outcome indicators are not risk adjusted.

- *Medical Outcome Study Short Form (SF-36)*

The SF-36 was designed as a generic indicator of health status in population surveys. The SF-36 is a validated and reliable tool used to evaluate functional status by assessing relevant health concepts. In particular, the SF-36 measures physical functioning, mental health and health perception, social functioning, role limitation attributed to physical health,

role limitation attributed to emotional problems, bodily pain and energy and fatigue.⁹³ When assessed for reliability and validity for use with home care nursing, it was found that SF-36 “...demonstrated responsiveness to change in health status within a community nursing setting”.⁹⁴ Irvine et al. also noted that many of the SF-36 subscales were specifically associated with nursing intensity. The physical functioning subscale is the most responsive in differentiating between patients with minor versus serious medical conditions. The SF-36 has also been found to be useful in detecting clinically important changes in patients in a cardiac rehabilitation program. The questionnaire, which takes 5 to 10 minutes to complete, can either be completed by patients themselves or can be used with telephone administration, personal or proxy interview. See Table 18.

- *Quality of Life Profile (QOLPSV)*

This tool was developed to plan care and to assess outcomes of health care interventions and health services for older adults living in the community with or without disabilities. It is a self-administered questionnaire, designed to measure a wide range of outcomes: physical well-being, psychological well-being and spiritual well-being; physical belonging, social belonging and community belonging; and finally, practical becoming (activities carried out day-to-day), leisure becoming and growth becoming. Validity has been established. With respect to reliability, the internal consistency for each subscale, and its items, were high. Irvine et al. used QOLPSV to measure the contribution of nurses to health status in a community setting. Several of the subscales reported lower reliability. The authors indicated that the low reliability of some of the subscales could be a contributing factor in the tool’s overall lack of responsiveness to change over time. There is a possibility of interviewer/rater bias if administered by interview. While the completion of the questionnaire

takes only 7 to 15 minutes and can be self-administered, self-administration may present problems for the very elderly. See Table 19.

- *Dartmouth COOP Charts*

The Dartmouth Cooperative Primary Care Practices developed this tool to assess health status in various populations. The tool, developed from the SF-36, measures physical endurance, emotional health, role function, social function, overall health, change in health, level of pain, quality of life and social resources and support. The tool has been shown to be both reliable and valid when tested in diverse primary care settings in the US, Europe and Japan. The COOP Charts have shown similar sensitivity in detecting the effects of several diverse disease conditions, such as heart disease and depression. This tool is easily administered and is comprehensible and acceptable to both practitioners and care recipients in North America. See Table 20.

- *EASY-Care*

This is an initial comprehensive assessment tool for use by community nurses, social care workers and care assistant staff located in primary care settings. It is currently used by the European SCOPE project as one of three assessment instruments/outcome measures for evaluation in field trials.

- *Nottingham Health Profile*

This tool is used to assess subjective health status across six domains: energy, pain, emotion, sleep, social and physical mobility. The maximum total score is 45 with a high score indicating poor health status.

9.2 Service Provider Outcomes

▪ *Goal Attainment Scoring (GAS)*

This scale was developed in 1968 to evaluate community mental health programs. It has been used to assess outcomes for a range of elderly home care recipients. The selection of goals is established through negotiation with the care recipient or a designated family caregiver and is evaluated on a scale from -2 to +2.

A recent study examined the validity and reliability of the Goal Attainment Scoring (GAS) for elderly clients registered in a home health care program in Alberta. The study found that GAS measures some of the same outcomes as other instruments. GAS was found to be more sensitive to change than other instruments that are commonly used in the evaluation of specialized interventions.⁹⁵ Rockwood et al. likewise found that for care recipients of cognitive rehabilitation, GAS was more responsive to change than standard measures such as the Rappaport Disability Rating Scale, the Milwaukee Evaluation of Daily Living, the Instrumental Activities of Daily Living Scale and the Spitzer Quality of Life Index.⁹⁶ Forbes suggests that for a comprehensive assessment of outcomes, other standardized instruments should supplement GAS. Although GAS was criticized during the 1970s, there has been a renewal of interest in the scale for a variety of therapies. Forbes indicates that the strength of the GAS lies in its ability to accurately detect “clinically meaningful change” and to detect a difference when one is present. Moreover, GAS is “an appropriate outcome measurement approach for case managers, who are primarily nurses.”⁹⁷

The administration of GAS takes a substantial period of time and a number of steps. Completion of the tool may require observation of the care recipient performing certain tasks,

using standardized instruments to evaluate skill areas, assessing their environment and identifying their support network. See Table 21.

- *Other Performance Outcomes*

Many of the indicators identified through the exercise spearheaded by the Canadian Institute for Health Information, and shown in Table 4, can be used as measures of agency performance. Indicators of home care expenditures, utilization, waiting lists measured at the provider agency level can supplement the care recipient indicators to provide a measure of an agency's performance over time. These indicators may also be used to compare the performance of an agency with other agencies contracted with the same CCAC, or to compare the outcomes of a particular CCAC over time or against other CCACs.

9.3 System Outcomes

System outcomes are measures of care recipient indicators and provider agency indicators aggregated across CCACs to make comparisons across regions or over time, and to make provincial comparisons over time.

9.4 Challenges to the Implementation of Outcome Measures

There are several difficulties associated with using assessment tools in the home setting. To begin with, home care is carried out in the privacy of an individual's residence, with only the care recipient, care provider and family or other household members present. Moreover, each home is equipped and organized differently introducing a measure of confounding into any evaluation. As a result, assessment of care in a unique home environment is much more difficult than in an institutional setting which tend to be more standardized.

Secondly, the current availability of data is limited. The data that comprise Ontario's Home Care Administration System (OHCAS) are separated into two major components. First, the registration file includes basic demographic data on the care recipient such as age and gender as well as place of residence. This file highlights the initial service and discharge dates. The service advice file tabulates the number of specific provider visits, in the case of professional services, or hours of care for homemaking or personal support services, and the date of service provision. These data are augmented with basic diagnostic information pertinent to the care recipient. However, there is a widely held view that the data collected in the diagnostic information component is unreliable. The OHCAS data enables the analysis of regional variation in the propensity and intensity of home service provision.⁹⁸

Many of the valid and reliable assessment tools that are used to construct outcome measures in the home care setting are based on data collected directly from the care recipient or informal caregiver, or are tied to care recipient level data that is not currently available in OHCAS. By linking OCHAS data to other sources of information, such as hospital discharge records (inpatient and same-day-surgery), physician fee-for-service claims, and drug benefit claims, descriptions and evaluations of current patterns of practice may be gauged within a broad health systems environment.

10.0 Conclusions

The need to develop indicators and tools to evaluate the effectiveness of home care in Canada has been widely identified. Health and social indicators measure change in health status and social well-being at the population and individual level (e.g. mortality rates, re-admission to hospitals, quality of life). Performance indicators relate to those aspects of care (e.g. cost, effectiveness, quality, access, appropriateness and efficacy) that can be altered by service providers, staff, organizations and systems whose performance is being measured.⁹⁹

While many indicators already exist to assess the care provided to acute care patients in institutions, these may not be appropriate for evaluating care in the home. Unlike acute care services provided in hospitals, care provided in the home presents many challenges and complexities. Home care currently lacks identifiable and measurable national or provincial standards. It is provided in a sector where care is funded by a mix of public and private financing, is delivered by not-for-profit and for-profit provider agencies, and where the major allocation of public resources is performed through competitive contracts. Moreover, unlike institutional settings, each home is different, varying in its appropriateness as a setting for care.

Nevertheless, despite these complexities, it is incumbent on governments and providers of home care to ensure the provision of safe, effective, and equitable care. The development of appropriate indicators and tools should guide policy development, evaluate performance, enhance clinical practice, allow governments and agencies to plan and manage service provision.

The absence of valid and reliable outcome (or quality of care) indicators for in-home services in Ontario necessarily implies that the full impact of provider competition falls on

the price of these services. Because the home care sector is labour intensive, a lower price for services entails lower wages and benefits for nurses and other care personnel. Such compensation reductions only add to the current recruitment and retention problems in the sector. Moreover, the erosion of on-the-job moral may adversely affect the quality of in-home care.¹⁰⁰

The system-wide adoption of assessment/measurement tools based on valid, reliable and responsive indicators of health, social and performance outcomes which are feasible and broad enough in scope should inform both practice and policy development.

11.0 Next Steps

The first steps in the development of home care indicators and assessment tools have been provided in this report; namely, the development of a conceptual framework for the evaluation of home care in this province, and a review of the literature pertaining to assessment tools used to evaluate home care outcomes and the performance of home care agencies. However, there are a number of stages that must follow. Because these tools are to be used by a number of different stakeholders for differing purposes, this report will be broadly disseminated to key interests. It is our intention to solicit feedback to further refine our thinking.

In February, a focus group with key stakeholders (home care provider organizations, CCACs, officials from the Ministry of Health and Long-Term Care, care recipient groups, and researchers) will be brought together to discuss the issues raised in this paper. In particular, discussion will focus on the indicators thought to be most useful to include in the evaluation of Ontario home care services and the priority in which these tools should be developed.

Appendix 1**HMRU Advisory Committee****Susan Donaldson**

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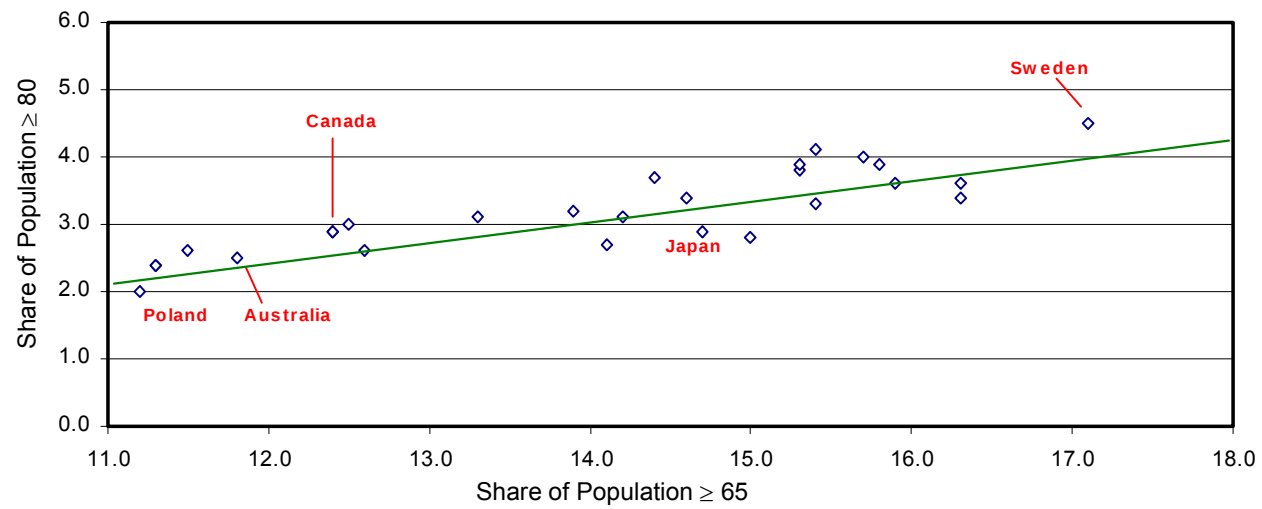
Ontario Community Support Association

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Figure 1: Share of Population ≥ 80 Compared to the Share of Population ≥ 65



Organization for Economic Cooperation and Development (OECD) for 1998 and Canadian Data for 1999

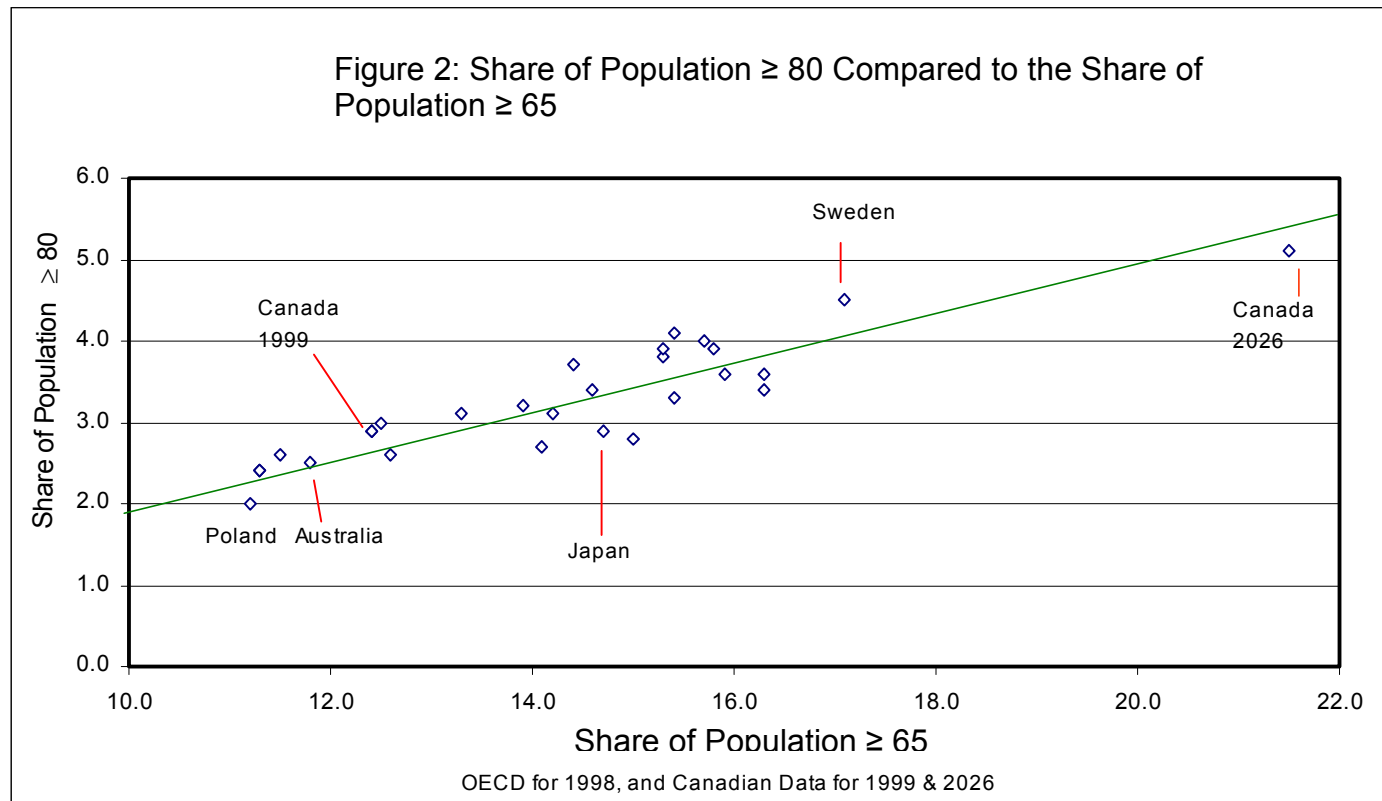


Figure 3: Home Care Utilization Rates by Age and Gender in Ontario, FY95

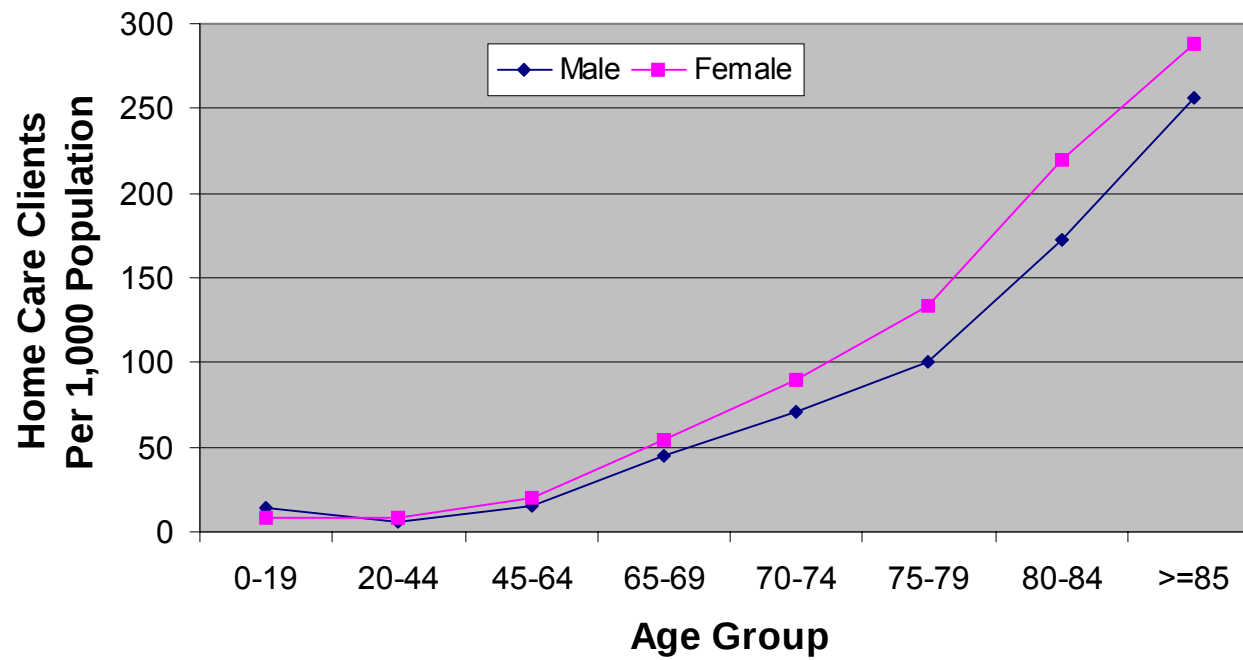


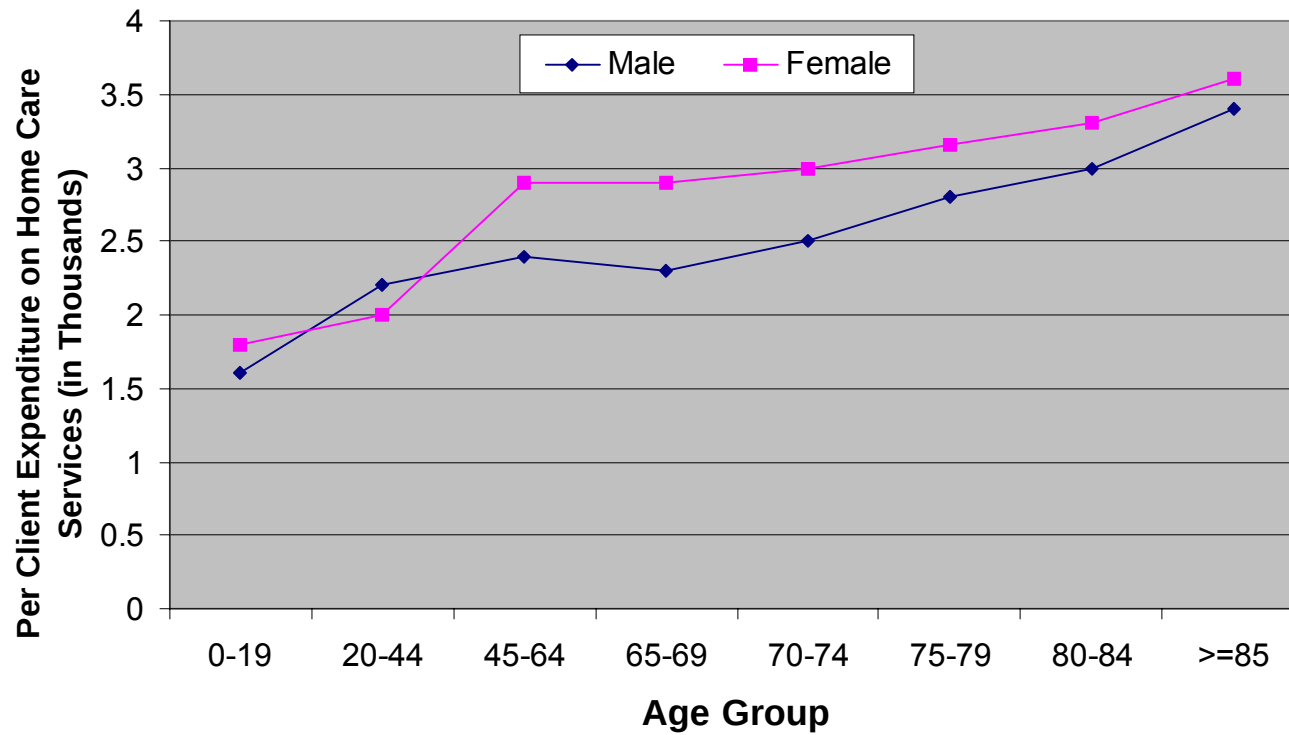
Figure 4: Intensity of Home Care Utilization, FY95

Figure 5: Share of Public Home Care Expenditures in Public Health Expenditures, FY97

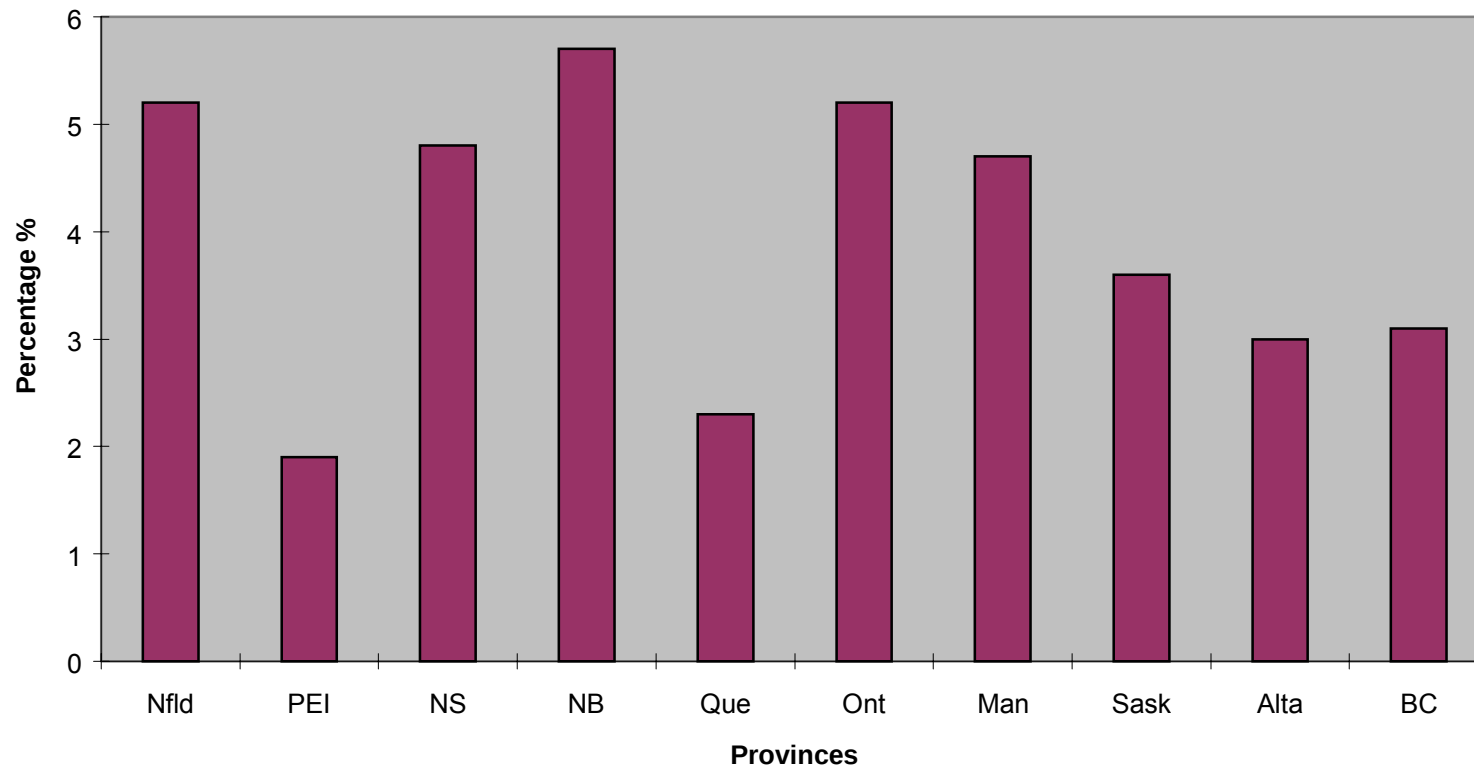


Figure 6: Conceptual Framework for the Evaluation of Home Care Services for Care Recipients and Care Provider Agencies under a Single CCAC

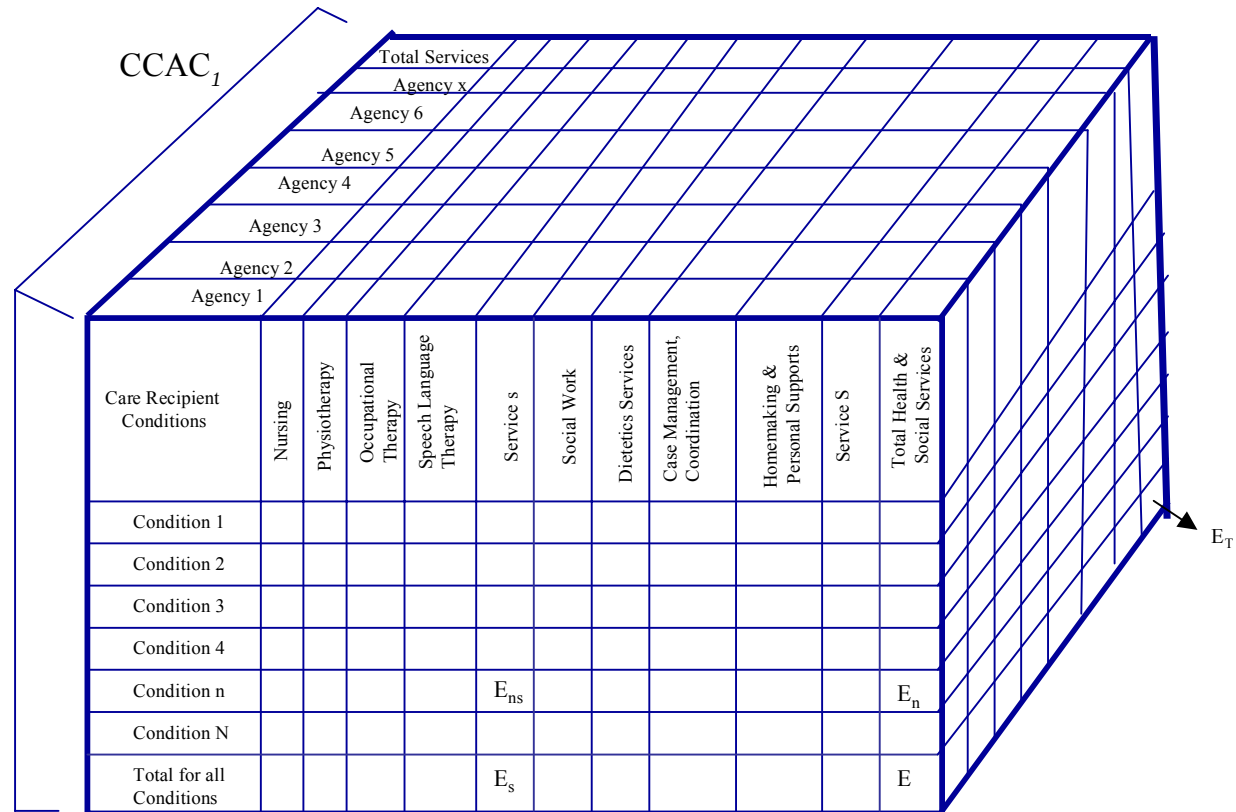


Figure 7: Conceptual Framework for the Evaluation of Home Care Services Across All CCACs

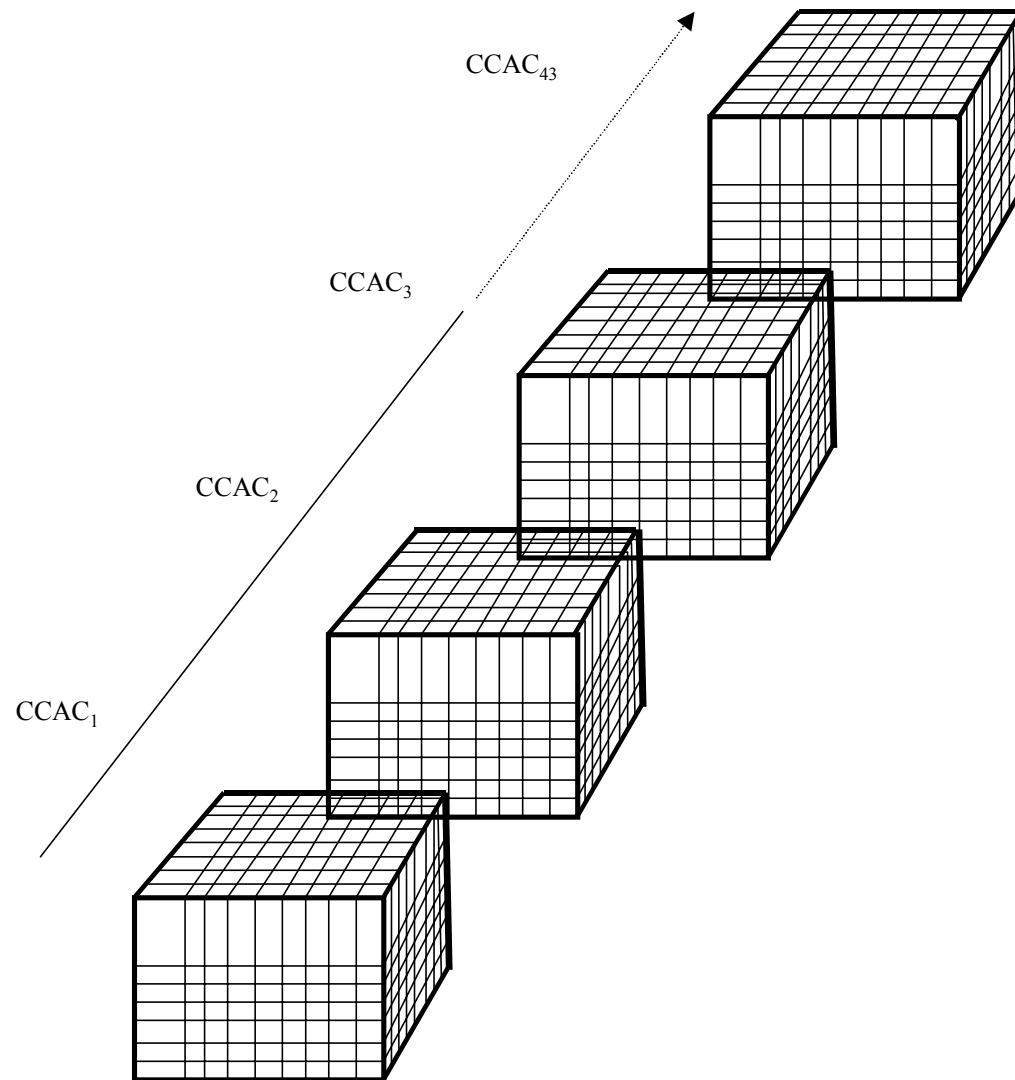


Table 1: Canadian Population Size (000s), Distribution (%) and Rate of Growth by Age Group

Age Group	1999	2026	Average Annual Compound Rate of Growth
0-64	26,700.7 (87.6%)	28,445.6 (78.5%)	0.2%
65-74	2,130.4 (7.0%)	4,383.6 (12.1%)	2.7%
75-84	1,265.1 (4.1%)	2,451.2 (6.8%)	2.5%
≥85	395.1 (1.3%)	924.9 (2.6%)	3.2%
Total	30,491.3	36,205.3	0.6%

Source:

Statistics Canada: Population Projections for 2026, July 1: Medium Growth Projections, www.statcan.ca 2000.

Table 2: Criteria for Evaluating Assessment Tools	
Validity	Validity refers to the ability to measure what is intended. There are four major types of validity: • Face Validity: refers to the appearance that the test is indeed measuring what it intends to measure. • Content Validity: relies on judgements (rather than statistical properties) about whether items accurately represent the thing or universe being measured. • Construct validity: is used to describe a scale, index, or other measure of a variable that correlates with measures of other variables in ways that are predicted by, or make sense according to a theory of how the variables are related. • Criterion Validity: refers to the extent to which the ... measure predicts or agrees with a gold standard for the measure.
Reliability	Reliability refers to the stability or consistency of a measure, i.e., consistency of items within the tool, or the consistency of a measure from one time to another or across raters. • Inter-rater Reliability: examines the equivalence of the information obtained by different data gathers on the same or comparable groups of respondents. • Internal Consistency Reliability: This is used primarily for constructing and evaluating summary scales. It reflects the extent to which individual items of the same scale measure the same thing. • Test-Retest Reliability: reflects the degree of correspondence between answers to the same question asked of the same respondents at different points in time. This measure is less reliable when measuring health outcomes.
Responsiveness	Responsiveness measures the ability of an instrument to measure changes in health and social outcomes over time or in performance outcomes between different providers, organizations, regions or systems over time or in comparison. It can be assessed by the effect size (mean change score / standard deviation of baseline score).
Feasibility	Feasibility identifies the resources (financial, human resources) and complexity (time, ease) involved in administering a particular tool. For example, the type of training that is required to conduct and score the assessment tools and the costs associated with implementing the tool (including the time to complete and the ease of interpreting the tool).
Scope of Outcomes Measured by the Tool	Scope of outcomes reflects the breadth or range of measures that the tool collects. For instance, a generic measure with multiple dimensions or a specific tool relevant to only one population.

Table 3 : Outcome Indicators

Micro Level Outcome Indicators	Macro Level Outcome Indicators
Recipient Outcomes: a) Care Recipient • Co-Morbidity Indicators • Physical Functioning Indicators • Cognitive Functioning Indicators • Social Functioning Indicators • Services Utilization Indicators b) Informal Caregiver • Caregiver Burden Indicators	Service Provider Outcomes: • Professional Service Provider Indicators • Homemaking & Personal Supports Quality and Effectiveness Indicators • Care Provider Organization Performance Indicators System Outcomes • Regional Health Management Indicators • System Expenditure and Quality Indicators

Table 4: Canadian Institute for Health Information Draft Development of National Indicators & Reporting System for Home Care

Canadian Institute for Health Information Roadmap Initiative: Draft Priority Home Care Indicators					
Functional Status Indicators	Home Care Expenditure Indicators	Utilization Indicators	Demographic Indicators	Health Status Indicators	Informal Care Indicators
- level of performance for ADLs (e.g. transferring, locomotion, bathing), - Cognitive ADLs (e.g. decision making and memory) and - IADLs (e.g. shopping, housekeeping, meal preparation).	- Regional home care operating expenses as a percentage of total regional health expenses; - Home care expenses per capita by region; - Home care expenses as a percentage of total provincial health expenses; - Provincial home care expenses as a percentage of total health expenses; - Provincial home care expenses as a percentage of total provincial expenses for facility based acute and long term care services; and - Home care expenses per capita by province.	- umber of admissions/1000; - number of separations/1000; - number of active cases/1000; - number of service hours/1000; and - average number of service hours by type of home care service (e.g. nursing, home support) (All information by catchment area).	- clients by age and gender; - clients by type of living arrangement (e.g. alone, with spouse with family); - percentage of clients living alone, by age and gender; and - clients by accommodation setting (e.g. home, assisted living).	- home care clients by primary diagnosis; - and home care clients by reason of discharge from home care.	% of provincial population who receive assistance from informal care providers; - types of care (e.g. housekeeping, personal care) received from informal care providers; % of provincial population who provide informal service; - average hrs/week of assistance provided by informal care providers; - informal care providers perceived burden; and % of informal care providers who are satisfied with the level of their involvement.¹⁰¹

Table 5: Diagnostic Cost Group/Hierarchical Coexisting Category (DCG/HCC) Model

Diagnostic Cost Group/Hierarchical Coexisting Category (DCG/HCC) Model					
Description	The DCG/HCC methodology measures an individual's health status by grouping diagnoses found in administrative claims data into a comprehensive set of hierarchies across clinical conditions, capturing both chronic and serious acute presentations of disease processes. The model uses diagnoses obtained from administrative data to summarize health problems and to predict future health care costs of populations.				
Population	The Condition Categories in the model are based on all diagnoses from inpatient hospitalizations, outpatient hospitalizations and physician claims.				
Items Subscales	Not available				
Scoring	Not available				
Time To Complete	Not available				
Principles for Evaluation	Reliability	Validity	Responsiveness	Feasibility	Scope
	The method was found to be reliable for home care recipients.	The methodology has been validated in both the US and the Netherlands. ^{102 103 104}	The method was found to be responsive for home care recipients.	The DCG/HCC Model was recently used to develop prospective, capitated home care funding to CCACs in Ontario. ¹⁰⁵ The assignment of diagnostic health status was determined under the model by using diagnostic information obtained from physician OHIP claims, hospital separation data, population registration information from the Ontario Registered Persons Database, and the Ontario Home Care Administration System.	The method has broad scope in measuring a range of conditions.

Table 6: Barthel Index

Barthel Index ¹⁰⁶					
Description	The Barthel Index is designed to evaluate and predict a patient's functional independence.				
Population	Care recipients with orthopaedic, neurological, cardiovascular disease or amputee.				
Items Subscales	The scale has a total of 15 items; 7 in the area of self-care; 2 in the area of continence; 6 in the area of mobility.				
Scoring	A 3-level scale is used (completes task by self, with some aid or can't do). Points are assigned to each level for each item. Sub-total scores are calculated for ADL (self-care), continence and mobility. A total score is also calculated.				
Time To Complete	20 minutes (observation); 5 minutes (verbal report)				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Intra-rater Reliability: established with a kappa value of 0.83 and a correlation coefficient of 0.98. ¹⁰⁷	<u>Criterion:</u> <u>Concurrent</u> The Barthel Index has been found to have a moderately strong correlation with the PULSES profile of independence in life and functioning ($r=-0.79$).¹⁰⁸ A separate study found significant correlations between the Barthel and the Katz Index of ADL, the Kenny Self-Care Evaluation and the PULSES profile.¹⁰⁹ <u>Predictive:</u> Demonstrated effectiveness in predicting discharge destinations,¹¹⁰ length of hospital stay,¹¹¹ vocational status 18 months after discharge¹¹² and the amount of service required from home care when the client is home.¹¹³	The Barthel has been found to be responsive to changes in patient status from admission to discharge from an acute care setting.^{114 115} This index may not be sensitive to changes resulting from rehabilitation therapy.	Setting in which the test is administered and other environmental factors may unduly influence the patient's score. Testing should be completed in a setting similar to that in which the patient will be discharged.	The Barthel Index measures only independence with respect to physical state. Social, emotional and mental well-being are not addressed.

Table 7: Stroke Rehabilitation Assessment of Movement

Stroke Rehabilitation Assessment of Movement					
Description	The Stroke Rehabilitation Assessment of Movement (STREAM) was designed as a clinical measure of motor function for care recipients who have had a stroke. It is intended to be used as an outcome measure to evaluate therapies and monitor motor recovery.				
Population	Care recipients who have suffered from a stroke.				
Items Subscales	30 items are presented in 4 positions: supine (6 items); sitting (15 items); standing (4 items); standing and walking (5 items).				
Scoring	Items involving voluntary movement are scored on a 4-point ordinal scale (0-3); items involving basic mobility are scored on a 3-point ordinal scale (0-2). Descriptions of scoring procedures are located in the test manual.				
Time To Complete	10-15 minutes				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Intrarater reliability was evaluated using videotaped assessments of patients. Interrater reliability was evaluated through direct observation of patients. Reliability for both methods ranged from 0.96-0.99 for subscale scores. Generalizability correlation coefficients for total scores were 0.99. Kappa statistics for individual items ranged from 0.8-1.0.^{116 117} Internal Consistency: was considered excellent for both subscales and total scores, with Cronbach's alpha statistics of greater than 0.98.¹²⁶	Content: Items were originally selected from a number of existing assessment instruments and from clinical experience. Items for the current version of the STREAM were selected based on a content verification survey and review by several panels of physiotherapists.^{126 127}	Additional studies are required to provide additional evidence of the reliability, validity and responsiveness of this instrument.	Therapist rates the patient's performance based on observation.	This tool is intended to be a clinical measure of motor function in stroke rehabilitation patients.

Table 8: Katz Index of Activities of Daily Living

Katz Index of Activities of Daily Living					
Description	The Katz Index of Activities of Daily Living (ADL) is a disability scale measuring the dimensions of self-care and mobility.				
Population	Chronically ill patients				
Items Subscales	6 areas of function are assessed: bathing, dressing, toileting, transfer, continence and feeding.				
Scoring	Each item is scored on a 3-point scale representing increasing levels of dependence. Functional independence is described relative to the total number of tasks the patient is able to complete independently.				
Time To Complete	Not available				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Interrater Reliability: reported in a study involving 100 patients and 2 raters who were nurses. The coefficient of scalability, using a calculation based on maximum number of errors, ranged from 0.74 to 0.88, indicating that the reliability of the Index of ADL is good. ¹¹⁸	Content: Through a series of studies, the authors identified a number of primary ADL functions that were related hierarchically.¹¹⁹ Construct: This scale is based on the assumption that the recovery of function in adults occurs in a pattern of ascending complexity similar to the acquisition of skills by a developing child. The Index of ADL has been found to form a successful cumulative scale.¹²⁰ Criterion: <u>Predictive</u> In a study involving 230 patients who had suffered a stroke, the predictive power of the Index of ADL was examined. The index was able to predict which patients would be living at home within 1 month of the stroke with a positive predictive power of 94-96% and a negative predictive power of 92-96%.¹²¹	The responsiveness of the Index of ADL has not been reported.	Not available	Measures Self-care and Mobility for those who are disabled

Table 9: Functional Independence Measure (FIMSM)

Functional Independence Measure (FIM SM) ¹²²					
Description	The Functional Independence Measure (FIM SM) measures the severity of disability and the outcomes of medical rehabilitation. It is intended to evaluate the rehabilitation progress of patients with disabilities and to act as a multidisciplinary tool for identifying particular problems in rehabilitation ² and to measure the level of independence at the time of discharge as well as the length of hospital stay. ¹²³				
Population	All patients. Scale completed by the therapist based on direct observation				
Items Subscales	A total of 18 items are presented in 6 subscales: self-care (6 items); sphincter control (2 items); mobility (3 items); locomotion (2 items); communication (2 items); social cognition (3 items).				
Scoring	A 7-point ordinal scale (1-7) is used with descriptors provided for each point along the scale with respect to degree of independence or assistance required.				
Time To Complete	30 minutes				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Interrater reliability was established upon admission and discharge with a group of patients. Total FIM score ICC was 0.86 for the initial scores (n=303) and 0.88 for the discharge scores (n=184). ¹²⁴	Content: The items selected for the FIMSM instrument were based, in part, on the Barthel Index. Rasch analysis of the FIMSM items was completed. Item difficulty was found to be consistent between admission and discharge and across types of impairments.¹²⁵ Construct: Items fall into 2 clusters relating to motor and cognitive function respectively.¹²⁶ Criterion: <u>Concurrent</u>: Examined for the FIMSM self-care and mobility areas of function in a study involving 41 spinal-cord injured patients. A single rater assessed the patients upon admission to a rehabilitation program, discharge and 12 month follow-up. Correlations between the FIM subscales and the Barthel Index were as follows: r=0.89-0.94 (self-care); r=0.64-0.76 (mobility); r=0.83-0.89 (total score).¹²⁷ <u>Predictive</u>: Motor and cognitive function measures were used with 27,699 patients undergoing initial rehabilitation. Functional status upon admission, according to the FIMSM instrument, was related to discharge status and length of stay. Motor function was found to be a more accurate predictor of length of stay than was cognitive function.^{128 129}	Sensitivity was examined with a sample of patients with multiple sclerosis. Change in FIM scores from admission to discharge was found to be significant (10.7 +/- 0.9 FIM units).¹³⁰ Some concern that the cognitive subscales of the FIM may be too insensitive to detect mild to moderate impairments¹³¹	The tool takes very 30 minutes to complete.	The tool is focussed on outcomes of medical rehabilitation The scale can be used for all groups of patients

Table 10: PULSES

PULSES					
Description	This is a physical functioning and impairment measurement scale. PULSES is an acronym representing physical condition, upper limb functions, lower limb functions, sensory components (speech, vision, hearing), excretory functions and mental and emotional status.				
Population	The scale is designed to measure functional independence in the activities of daily living of the chronically ill and elderly, institutionalized populations.				
Items Subscales	There are six subscales: P= Physical Condition, U=Upper Limb Functions L= Lower limb functions S=sensory components (speech, vision, hearing), E=Excretory Functions S= Mental and Emotional Status				
Scoring	Four levels of impairment are specified in each of the categories. All of the categories receive equal weighting ranging from 6 (indicating unimpaired independence to 24 indicating full dependence. Category scores are represented by the first letter in the acronym and the numerical score, for instance, “L-3” to indicate a person who is able to walk under supervision.				
Time To Complete	Not available				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Test-retest reliability was reported by Granger et al.¹³² Inter-rater reliability exceeding 0.95 was found by Granger et al	Granger et al reported Pearson correlation coefficients comparing the Barthel and the PULSES and found -0.74 to -0.80 (p<0.001).	In a study examining 307 disabled adults in 10 rehabilitation centres located in the United States, Granger et al. reported that the PULSES was able to detect change between admission and discharge.	PULSES is still used widely.	This scale measures functional independence only.

Table 11: Quality of Life Index

Quality of Life Index					
Description	The Quality of Life (QL) Index was designed to measure general independence and well-being.				
Population	Identified for use with care recipients that have cancer or chronic disease.				
Items Subscales	5 items (activity, daily living, health, support and outlook).				
Scoring	A 3-point ordinal scale (0-2 points for increasing independence). A total QL Index score is obtained by summing the 5 items. The test administrator is asked to rate their confidence in the accuracy of the assessment.				
Time To Complete	2 minutes				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Interrater: Ratings of 2 physicians were compared for reliability purposes. The overall Spearman correlation coefficient was 0.81 ($p < 0.001$) (English version $r = 0.84$, $p < 0.001$; French version $r = 0.74$, $p < 0.005$). Physician ratings were also compared with patient self ratings. The correlations were significant (161 Australian patients $\rho = 0.61$, $p < 0.001$; 51 Canadian patients $\rho = 0.69$, $p < 0.001$).¹³³ Internal Consistency: Cronbach's alpha of 0.77 was calculated for a sample of 91 Australian patients. With a sample of 261 Canadian patients, alpha was 0.78.¹²⁶	Content: Multiple advisory panels consisting of patients, families, health professionals and other professionals provided input regarding factors enhancing quality of life. Two draft versions of the QL Index were pilot tested on a sample of 339 patients. Items were grouped into clinically and socially meaningful clusters with high intra-group correlations. All 5 remaining items were judged to be equally important and were given equal weighting.¹²⁶ Construct: The draft versions of the QL Index were compared with each other and with the QL Uniscale (a visual analogue version of the scale). The following correlations were found: • QLA and Uniscale - Spearman's $\rho = 0.87$ QLA; and ▪ QLB - Spearman's $\rho = 0.86$.¹²⁶ ▪ The predictive validity of this instrument has not been discussed.	Differences in mean scores have been used to suggest that the QL Index discriminates between healthy individuals and various groups of patients.¹²⁶ Sensitivity, specificity and positive and negative predictive values have been reported for QL cut-off scores of 2 to 10.¹³⁴ The 3-point scoring system may create a ceiling and floor effect making it insensitive for extreme scores.¹²⁶	No training is required. Physician or therapist rates the patient based on their most recent assessment.	The QL Index has been criticized for being too general to measure independence and well-being and not applicable with populations other than cancer or chronic disease.¹²⁷

Table 12: The Functional Status Questionnaire (FSQ)

The Functional Status Questionnaire (FSQ) ¹¹³					
Description	The Functional Status Questionnaire (FSQ) was designed to assess physical, psychological and social/role functions. It is intended to be used as a screening tool for functional disability.				
Population	Self-administered questionnaire to be completed by the patient.				
Items Subscales	6 subscales are presented in the 3 categories: basic ADL (3 items), intermediate ADL (6 items), mental health (5 items), work performance (6 items), social activity (3 items) and quality of interaction (5 items). As well, 6 single item questions are included in the questionnaire.				
Scoring	A 5-point ordinal scale (0-4) is used for scoring. Descriptors for each category are provided for points along the scoring continuum. Subscale summary scores are provided, but no total score is obtained. Items that are not applicable to an individual patient are not included in the summary score calculation.				
Time To Complete	15 minutes				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Test Retest: Scores collected on 2 consecutive days reflected good test retest reliability.¹³⁵ Internal Consistency: In a primary care setting, the internal consistency coefficients for the 6 subscales ranged from 0.62 to 0.82. The basic and intermediate ADL and mental health subscales had the highest internal consistency. Internal consistency for the social interaction subscale was particularly low for patients over the age of 65.¹³⁶	Content: Items were selected after a review of a number of existing instruments. 3 of the dimensions of function recommended by the WHO were also included. The items within each subscale are relatively equal in difficulty and importance. The FSQ was pretested on a sample of 1553 ambulatory patients who were regular users of community based internal medicine practices.¹³⁷ Construct: based on a model of functional status. Confirmatory factor analysis using a sample of healthy young adults indicated an acceptable fit to the 6 factor model proposed. The highest factor intercorrelations were between the basic ADL and the intermediate ADL subscales. It was also suggested that a 5-factor model, with the two ADL subscales collapsed into one would also fit.¹³⁸ Criterion: Scores were correlated with a number of instruments designed to measure functional disability (National Health Interview Survey, Rand Health Insurance Study Instruments, SIP).¹¹³	The FSQ was found to be sensitive to change in function of elderly patients with cardiac disease at 1 and 3 month post surgery.¹³⁹ It was less sensitive to change than the SF-36. With respect to psychological function, the FSQ was equal in its responsiveness to change to the SF-36.	Short test that is self-administered by the patient. The administrative burden is low. Scoring of the scale is straight-forward.	Screening assessment tool Does not measure outcomes Comparison across patients using FSQ scores is not feasible because of the small numbers of items in each subscale.

Table 13: McMaster Health Index Questionnaire

McMaster Health Index Questionnaire ¹²²					
Description	The McMaster Health Index Questionnaire was designed to systematically measure the impact of clinical and health care interventions on quality of life and health status. It has been adopted for use in both clinical trials and health evaluations.				
Population	Patients with chronic disease. The scale can either be completed as a self-administered questionnaire or through a telephone or personal interview.				
Items Subscales	3 dimensions are assessed: physical function (24 items), social function (25 items), emotional function (25 items). There are a total of 59 items (some items overlap for the social and emotional dimensions).				
Scoring	Items for the physical function subscale are scored as yes/no responses or self-ratings. The social and emotional subscales are 5-point Likert scales. All responses are interpreted using a good/poor health dichotomy and summed for each subscale. Standardized index values range from 0.0 to 1.0.				
Time To Complete	20 minutes.				
Criteria for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Test retest reliability was examined using a sample of 30 physical therapy outpatients and 40 psychiatry outpatients. The following ICC's were obtained for the subscales for the respective samples: Physical function: 0.53, 0.95; Social: 0.48, 0.66; and Emotional: 0.70, 0.77¹⁴⁰ Internal consistency: was examined with a sample of 40 patients with rheumatoid arthritis. KR-20 coefficients of 0.76, 0.51 and 0.67 were obtained for the physical, social and emotional functions respectively.¹⁴¹	Content: Initial pool of 172 questions was developed by a multi-disciplinary team using extensive literature review, brainstorming and consulting with internal and external experts. After a series of field tests, 59 items were selected based on the responsiveness to change in function and the ability to predict family physician global assessments of physical, social and emotional function.¹²² Criterion: <u>Concurrent</u>: For the physical function dimension, scores on the MHIQ correlated with scores on the Lee Index of Functional Capacity.¹²²	The physical function subscale has been shown to be responsive in detecting change as a result of physical therapy intervention. The responsiveness of the social and emotional function subscales has not been reported	It is a long questionnaire Self-administration reduces administrative burden	Measures clinical, health care interventions for quality of life and health status outcomes

Table 14: Caregiver Strain Index (CSI)

Caregiver Strain Index (CSI) ¹⁴²					
Description	This instrument quantifies the caregivers' burden of caring for a disabled older adult.				
Population	Originally used to evaluate caregivers of older adults that had received hip and heart surgery. The instrument has since been used to measure the strain of caring for persons with MS, CVA, cancer and disabled veterans.				
Items Subscales	13 item multidimensional questionnaire that examines the effect of caregiving on work, family, finances, physical health, psychosocial demands and emotional health.				
Scoring	Dichotomous scoring with each "yes" response assigned the value of 1, "no" responses, 0. The responses are totalled. A scores >7 indicates significant strain.				
Time To Complete	The instrument takes approx 5-10 minutes to complete				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Internal Consistency: A post-operative study evaluated the internal consistency of the 13 items on the questionnaire finding of Cronbach's alpha = 0.86.¹⁴³ The index is viewed as a subjective tool open to unforeseen bias.¹⁴⁴	Content: In a study by Robinson, 49 adult children who were caring for elderly parents were interviewed three times over a five-year period⁴. 10 stressors were commonly identified based on the interviews and were included in the instrument. 3 more items were added after a literature review.¹⁴⁵ Construct: The relationship between CSI scores and a number of criterion variables that theoretically should reflect strain were evaluated, including examining patient characteristics, caregivers' subjective perceptions of the care-taking relationship and measures of physical and emotional health of the caregiver.¹⁴⁶	No available	Low administrative burden due to	Measures burden of caring for a disabled older adult.

Table 15: The Older Americans Resources and Services (OARS) Questionnaire

The Older Americans Resources and Services (OARS) Questionnaire					
Description	This instrument was designed to provide a profile of the level of functioning and the need for services of adults. It is comprised of 2 parts: the Multidimensional Functional Assessment Questionnaire (MFAQ) that examines level of functioning, and the Services Assessment Questionnaire (SAQ) which examines service utilization.				
Population	Seniors (aged 65+)				
Items Subscales	The MFAQ consists of 99 questions representing 5 dimensions: physical health, mental health, social resources, economic resources and ADL. The SAQ includes 24 different services.				
Scoring	A rater scores each dimension by determining a level of function for each section. Level of function is rated on a 6-point scale (1-6 for increasing level of impairment). The summary scores for each of the 5 sections may be presented as a profile or they may be summed to form a Cumulative Impairment Score. Profile scores can be examined over time to provide information on patient change. Alternative scoring procedures are also available.				
Time To Complete	MFAQ - 30 minutes; SAQ - 15 minutes.				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Interrater: 11 raters were asked to score 30 interviews containing the MFAQ portion of the OARS. The reliability obtained for the scores for each of the 5 dimensions was significant at $p < 0.001$. ICC values were as follows: social: 0.82; economic : 0.78; mental health: 0.80; physical health: 0.66; self-care capacity: 0.87.^{147 148} Some of the reliability information available for the MFAQ is drawn from earlier versions of the test. Test-retest: Thirty community residents (age 65+) were interviewed twice (mean time interval 5 weeks, range 3-8 weeks). 98.5% of the items were responded to on both occasions, with 90.7% of responses identical on the two occasions. Agreement was comparable for subjective and objective items, with response being internally consistent.¹²⁴ Reliability and validity not available for the SAQ.	Content: The MFAQ portion of the OARS is based on an earlier version of the questionnaire (the Community Survey Questionnaire). Items were selected based on the judgment of a multidisciplinary team (geriatric researchers, clinicians and service providers), and the discriminatory power of individual items.¹²⁵ Construct: The MFAQ was intended to provide an assessment that would take into account good and poor functioning of patients.¹²⁵ Criterion: <u>Concurrent</u>: Concurrent validity was examined for 4 of the MFAQ dimensions (all but social resources, for which no external criteria were available).¹²⁵	Not available	2-day training session is recommended in order to administer the test. Course offered by Duke University Center for Aging and Human Development.	Measures level of functioning outcomes and provides a services needs assessment

Table 16: RAI-HC

RAI-HC					
Description	The RAI-HC is a standardized assessment tool for use in clinical situations. This tool includes an “assessment of the medical, social, psychological and environmental factors that affect an individual’s ability to function independently in the community”. ⁴⁴ The tool has triggering algorithms in 30 areas to drive care planning.(including pain management and caregiver strain). As well, many outcome measures such as the cognitive performance scale and ADL summary scales comprise part of the instrument. In the future, algorithms will be available for quality management.				
Population	Home care clients				
Items Subscales	There are 223 functional, health status, social environment and service items in the MDS-HC of which 114 were derived from the MDS for nursing homes. Here are two components to the RAI-HC. 1) The MDS-HC assessment component allows the clinician to assess multiple domains of function, health, social support and service use. As well, selected sub-set items called triggers to provide a standardized mechanism to identify those care recipients for whom additional evaluation of specific problems is merited or there is a risk of functional decline. 2) There are 30 Clinical Assessment Protocols (CAPs) to identify potential problems such as pain, health promotion, social isolation, elder abuse and falls. The caps are triggered by clinical algorithms that determine whether various problems are actually or imminently present. ¹⁴⁹				
Scoring	Assessor must weigh available information and use clinical judgement to record weightings for the client.				
Time To Complete	There is not clear information on how long it takes to complete an RAI-HC. Indications are that to complete the nursing home MDS, it takes from 1 ½ to 6 hours (for a new client).				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	The reliability and validity of this tool was established in 1997.¹⁵⁰ Inter-rater: reported in cross-national sample of varying composition.¹⁵¹ Excellent reliability established for IADL (0.79) , IADL self-performance (0.77), IADL difficulty (0.75) and stamina (0.74), memory & decision making (0.79) and communication (0.84), history of falls (0.81), bladder continence (0.81), indicators of elder abuse (0.79), and service utilization assessment (0.75). Depression and anxiety (0.61) rated fair to good inter-assessor reliability. Self-reported health demonstrated good reliability (0.58).¹⁵²	Convergent validity demonstrated by Morris et al¹⁵³	Not available	Assessments require direct questioning of the client and primary family caregiver by the clinician (nurses, social workers, therapists and physicians) as well as observation of the client in the home environment.¹⁵⁴ There are assessment protocols to guide the assessor through best practices to develop a care plan The assessment process could be broken into two parts, where information is gathered on two visits over a 7-14 day period.¹⁵⁵	Standardized assessment tool with many items that can be used as outcome measures. Inter-rater reliability suitable for comparison of groups. There are triggering algorithms to drive care planning in 30 different areas (e.g. pain management, continence and caregiver strain). Also, outcome measures including the cognitive performance scale and ADL summary scales are included.¹⁵⁶

Table 17: OASIS

Outcomes Assessment Information Set (OASIS)					
Description	The OASIS tool Outcome-based Quality Improvement OBQI protocol were developed by Peter Shaughnessey et al at the Centres for Health Policy and Health Services research at the University of Colorado. ^{157,158} This tool is mandated by the Health Care Financing and Administration to be used by all home care agencies seeking reimbursement under Medicare and Medicaid in the United States. Completion of OASIS data has become a requirement for Medicare reimbursement as conditions of participation.				
Population	This is a multidimensional tool designed for use with adult home care recipients. The tool is comprised of a set of core assessment items from which quality-based outcome measurements may be derived				
Items Subscales	The OASIS is designed to collect patient outcomes by requiring health care service providers to respond to a series of 79 questions about each of their patients at admission, re-certification and discharge from home health care. The 79 data elements in OASIS were developed by clinicians. The outcome indicators in the OASIS are risk adjusted. In addition, the care recipient's status is measured for each of the outcome indicators. The start of care and resumption of care items include the following subscales: clinical record items, demographics and patient history, living arrangements, other types of supportive assistance, sensory status, integumentary status, respiratory status, elimination status, neuro/emotional/behavioural status, ADLs/IADLs, medications, equipment management, therapy need,				
Scoring	Not available				
Time To Complete	Not available				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	The OASIS tool has been tested at more than 200 sites in the United States.	According to Irvine et al. the problem with the OASIS is that it is “subject to <i>gaming</i> – a self-enhancing bias, whereby providers consciously or unconsciously, deflate initial scores and inflate gains to present themselves in the most favourable light”. ¹⁵⁹	Measurement of outcomes as change in patient health status over time, most OASIS data items are collected at start of care and every two months thereafter until and including time of discharge. ¹⁶⁰	Home health agencies in the USA are required to transmit computerized, coded OASIS data to State survey agencies using a private network with a direct phone connection. The State then compiles the data and forwards it to the Health Care Financing Administration.	The tool collects demographic data, information on living arrangements, support system, sensory, integumentary, respiratory, elimination, neurological, emotional and behavioural status, functional status and management of equipment and medications. One of the problems that have been identified with OASIS is that it was not developed as a comprehensive assessment system and needs to be supplemented with some client specific measures. ¹⁶¹

Table 18: Medical Outcomes Study 36-item Short-Form Health Survey (SF-36)

Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) ¹⁶²					
Description	The Medical Outcomes Study 32-item short-form health survey (SF-36) is a multidimensional measure of general health status.				
Population	General population				
Items Subscales	The scale includes 36 items measured across 8 health concepts: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/fatigue, bodily pain and general health perceptions.				
Scoring	Item responses in 3, 5 or 6-point ordinal scales or yes/no choices.				
Time To Complete	This instrument takes between 5 and 10 minutes to complete.				
Criteria for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Test Retest: Studies have shown test retest reliability for multiple administrations is high.^{163 164} Internal Consistency: (Cronbach's alpha) the internal consistency consistently exceeds 0.70, with most studies citing an alpha of 0.80 or greater.¹⁶⁵ ¹⁶⁶Item-scale correlations were found in the range of 0.55 to 0.78.	Content: Items selected from the Medical Outcomes Study survey (included 149 questions regarding health status). This original survey was completed by 22,000 individuals. Items were chosen to reflect the 8 health concepts. Construct: A factor analytic study indicated that most of the identified health concepts correlated highly with one of two factors, physical health or mental health.¹⁶⁷ Criterion: <u>Concurrent</u> Scores from the SF-36 were correlated with scores from the Nottingham Health Profile.¹⁶⁸	The most responsive subscale of the SF-36 in differentiating between patients with minor versus serious medical conditions is physical functioning. The mental health subscales were found to be the most responsive in differentiating with respect to psychiatric conditions.⁵ Jette and Downing have found the SF-36 to usefully detect clinically important changes with patients in a cardiac rehabilitation program.¹⁶⁹	Self-administered questionnaire that is to be completed by the patient It can also be used with telephone administration, personal interview, or proxy interview).	The scale measures a wide range of outcomes, including physical functioning, social functioning, role limitations due to both physical and emotional problems, overall mental health, energy levels pain and perceptions of health status.

Table 19: QOLPSV Brief Version

Quality of Life Profile: Seniors Version (QOLPSV) Brief Version ¹⁷⁰					
Description	This tool was developed to plan care and to assess outcomes of health care interventions and health services for community client populations.				
Population	Older adults living in the community (≥55 years of age) with/without disabilities.				
Items Subscales	This instrument is self-administered. There are 27 items in the questionnaire. This tool is designed to measure physical being, psychological being and spiritual being, physical belonging, social belonging and community belonging, and finally practical becoming (activities carried out day-to-day), leisure becoming and growth becoming. The physical, psychological and spiritual dimensions of being, physical, social and community aspects of belonging, and the practical, leisure and growth issues of becoming are evaluated. Each question is scored first for how important it is to the individual then for how satisfied the individual feels in that area of their life. Finally the person evaluates the amount of personal control they have in that area and what opportunities for improvement exist for them.				
Scoring	This scale uses a 5-point ordinal scale. Personal importance and satisfaction scores are totalled separately. QOL score is calculated using the following formula: $QOL = (importance / 3) \times satisfaction$ Control and Opportunity measures are used for descriptive and evaluative purposes only.				
Time To Complete	The brief version of the measure takes between 7 minutes and 15 minutes				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Internal consistency for each subscale and its items were high (Cronbach's alpha = >0.90), Control (alpha = 0.92), Opportunities (alpha = 0.92). An evaluation of the QOLPSV to measure nurses' contribution to health status in the community setting by Irvine et al. noted that several of the subscales in the brief version of the tool register a lower reliability. Possibility of interviewer/ rater differential effort bias if administered by interview.	Content: input from 55+ population, service providers, and literature. Construct: Strong theoretical basis. Concurrent: Items are related to MUNSCH, Social Health Battery (SHB), Life Satisfaction Scale (LSS), and Activity Items (ACT).	Irvine <i>et al.</i> indicate that the lower reliability of some of the subscales could be a contributing factor in the tool's overall lack of sensitivity to change over time.	The brevity of the instrument makes it practical to use Since it is self-administered the tool may present some problems for those that are very elderly.	The scale measures a wide range of outcomes using a conceptual framework based on "being", "belonging" and "becoming".

Table 20: Dartmouth COOP Charts

Dartmouth COOP Charts					
Description	The Dartmouth Coop project was developed and validated by the primary care research network to efficiently assess health status in various populations. The charts were developed from the General Health Outcome Standard Form (SF-36)				
Population	For measurement use with many disease states and for functional health status.				
Items Subscales	The charts are based on the following nine domains of health: 1) physical condition 2) daily work 3) social activities 4) emotional condition 5) quality of life 6) overall condition 7) change in condition 8) pain and 9) social support.				
Scoring	Not available				
Time To Complete	Not available				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	The instrument has shown reliability and validity when tested in diverse primary care settings in the United States, Europe and Japan. ¹⁷¹	The instrument has shown reliability and validity when tested in diverse primary care settings in the United States, Europe and Japan. ¹⁷²	The COOP charts and the Medical Outcomes Study have been compared and show similar sensitivity in detecting the effects of several diseases (e.g. heart disease, depression), and on functional health status. ¹⁷³	These charts have proven to be easily administered and are comprehensible and acceptable to practitioners and patients in North America. ¹⁷⁴	This tool is designed to measure health status in a variety of populations.

Table 21: Goal Attainment Scoring

Goal Attainment Scoring (GAS)					
Description	This tool was developed, by Kiresuk and Sherman, in 1968. The tool was originally developed to evaluate community mental health programs. New research has shown that GAS is being recognized as a valid and reliable outcome measurement approach.				
Population	The GAS has been used for elderly home care recipients, mental health, family therapy, brain injury rehabilitation, stroke rehabilitation, orthopedic surgery, and with frail cognitively impaired older adults in nursing homes.				
Items Subscales	The selection of goals is established through negotiation with the individual or with their designated family caregivers.				
Scoring	Each of the goals is ranked from -2 to 2 with 0 as the middle level that is assigned to goals following effective intervention. Other scale levels are identified for each goal indicating outcomes that are: much less than expected (-2), somewhat less than expected (-1), somewhat more than expected (+1), or much more than expected (+2).				
Time To Complete	The process of evaluation using the GAS may take a substantial period of time given the complexity of the process of establishing goals with the care recipients and their family caregivers.				
Principles for Evaluation	Reliability	Validity	Responsiveness	Administrative Burden	Scope of Outcomes Measured
	Forbes reports that measuring traditional psychometric properties of the GAS are not relevant since the GAS is based on setting individual, client centred goals and not common client goals.¹⁷⁵ Forbes also argues that inter-rater reliability in goal construction is not relevant for GAS since different case managers will likely conceptualize a client's problems in different ways. She notes that the rater issue is the inter-rater reliability of the raters who evaluate the client outcomes at the follow-up interviews.¹⁷⁶	Few studies have reported on the validity of GAS. Content Validity of the GAS has been considered in terms of clinical relevance at the time of goal setting, content appropriate for the client, and realism of goals. Between 77% and 88% of the therapists ratings for each dimension met the criteria for content validity.¹⁷⁷	The GAS has been compared other outcome measures such as the Barthel Index, the Katz Activities of Daily Living Index, and the Spitzer Quality of Life Index to assess responsiveness to change in the health status of the population of frail elderly patients that had been admitted to two geriatric medicine wards. In this situation the GAS was found to be more responsive to change than the other measures that are more commonly used in these situations.¹⁷⁸ The GAS was also found to be more responsive to change in the status of cognitive rehabilitation patients than more common scales such as standard measures such as the Rappaport Disability Rating Scale, the Milwaukee Evaluation of Daily Living.¹⁷⁹	The GAS tool involves 7 steps: 1) the selection of goals, 2) weighting 3) follow-up time selection 4) title and indicator selection for each goal 5) statement of expected outcomes 6) completion of other scale levels and finally 7) follow-up.¹⁸⁰ Completing the tool may require observation of the care recipient performing certain tasks, using standardized instruments to evaluate skill areas, assessing their environment and identifying their support network.¹⁸¹	According to Forbes, GAS has the potential to demonstrate the contribution of home health care programs to the health of clients by measuring changes that have occurred while they are in the care of home health care providers.¹⁸² Forbes reports that the GAS accommodates multiple, individualized goals.

Table 22: Summary of Assessment Tools

Assessment Tools	Reliability	Validity	Responsiveness	Feasibility	Scope	Page Reference
Criteria	✓ = tests have been conducted	✓ = tests have been conducted	✓ = tests have been conducted	Low (too difficult to administer, too difficult to train, too costly, too time consuming etc.) Medium (test is comprehensive but very time-consuming/ average cost/ no real training issues, test does not take too long to administer) High , (test can be used in the home setting – although it may also be used in other settings, easy to train to administer, cost is not too high, test is short)	Micro (limited to specific conditions, examines more than one disease condition, multi-dimensional across disease conditions) Meso (limited to specific organizations, somewhat comprehensive across organizations) Macro (limited to specific organizations, enables system level comparison)	
Diagnostic Cost Group	✓	✓	✓	High	Macro -- enables system level comparison	p. 49
Barthel Index	✓	✓	✓	Medium	Micro –limited to specific conditions	p.50
Stroke Rehabilitation Assessment of Movement	✓	✓	N/A	High	Micro – limited to specific conditions	p. 51
Katz Index of Activities of daily Living	✓	✓	N/A	N/A	Micro – limited to specific conditions	p.52
Functional Independence Measure	✓	✓	✓	Medium	Micro –limited to specific conditions	p.53
PULSES	✓	✓	✓	High	Micro – examines more than one disease condition	p.54
Quality of Life Index	✓	✓	✓	High	Micro –limited to specific conditions	p.55
Functional Status Questionnaire	✓	✓	✓	High	Micro— examines more than one disease condition	p. 56
Mc Master Health Index Questionnaire	✓	✓	✓	High	Micro – examines more than one disease condition	p. 57
Caregiver Strain Index	✓	✓	N/A	N/A	Micro— examines more than one disease condition	p. 58

Assessment Tools	Reliability	Validity	Responsiveness	Feasibility	Scope	Page Reference
OARS Questionnaire	✓	✓	N/A	Low	Micro – Limited to specific disease conditions	p. 59
RAI-HC	✓	✓	N/A	Medium	Micro – multidimensional across disease conditions	p. 60
OASIS	✓	✓	✓	Medium	Micro – multidimensional across disease conditions	p.61
SF-36	✓	✓	✓	High	Micro – multidimensional across disease conditions	p. 62
Quality of Life Profile (QOLPSV)	✓	✓	✓	Medium	Micro – multidimensional across disease conditions	p. 63
Dartmouth COOP Charts	✓	✓	✓	High	Micro – multidimensional across disease conditions	p.64
Goal Attainment Scoring	✓	✓	✓	Medium	Micro – multidimensional across disease conditions	p.65

Bibliography

- ¹ Canadian Institute for Health Information. Development of National Indicators and Reporting System for Home Care: Research Design for National Pilot Test. March 2000.
- ² Canadian Institute for Health Information: National Health Expenditures in Canada, 1975-1999. Ottawa: Canadian Institute for Health Information, 1999.
- ³ Coyte, PC; Passing the Buck. Report for the Dialogue on Health Reform. May, 2000
- ⁴ Coyte, PC; and Young, W; Regional Variations in the Use of Home Care Services in Ontario 1993-1995, Canadian Medical Association Journal. 161: 4, 376-380, 1999.
- ⁵ Coyte, PC; 2000.
- ⁶ Toronto Star: How Would You Pay For Home Care? November 27, 1999, page E2.
- ⁷ Globe and Mail: Home Health Care: Only If You Can Afford It. December 6, 1999, pages A1 and 9.
- ⁸ PriceWaterhouseCoopers Health Care Group: Health Insider: An Indepth Research Report on Consumer Health Issues. PriceWaterhouseCoopers: Toronto, Survey No. 2, November 1999.
- ⁹ Coyte, PC; 2000.
- ¹⁰ Coyte, PC; 2000.
- ¹¹ Parr K; The Cost Effectiveness of Home Care: A Literature Review. Health Services Utilization and Research Commission: Saskatoon, Saskatchewan, March, 1996.
- ¹² Federal/Provincial/Territorial Subcommittee on Long Term Care, 1992. *ibid*.
- ¹³ Parr K., 1996.
- ¹⁴ Price Waterhouse, 1989. *ibid*.
- ¹⁵ Weissert, W; Wan, T; Livieratos BB; Pellegrino J; Effects and Costs of Day-Care Services for the Chronically Ill. Medical Care 1980; 28:6, 567-584.
- ¹⁶ Weissert W; Seven Reasons Why it is so Difficult to Make Community-based Long-Term Care Cost-effective. Health Services Research, 198520:4, 423-433.
- ¹⁷ Weissert WG; A New Policy Agenda for Home Care. Health Affairs 1991; 10:2, 67-77.
- ¹⁸ Weissert WG; Cready CM; Toward a Model for Improved Targeting of Aged at Risk of Institutionalization. Health Services Research 1989; 24:4, 485-510.
- ¹⁹ Saskatchewan Health Services Utilization and Research Commission; Hospital and Home Care Study. Saskatoon, Saskatchewan Health Services Utilization and Research Commission (Report No. 10), 1998.
- ²⁰ Hollander MJ; Substudy 1: Comparative Analysis of Home Care and Residential Care Services: Preliminary Findings. National Evaluation of the Cost-Effectiveness of Home Care, Centre on Aging, University of Victoria, November, 1999.
- ²¹ Charles, C; Gafni, A; Whelan, T; Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). Soc Sci Med, 1997; 44: 681-92.
- ²² Llewellyn-Thomas, H; Patients' Health-care Decision Making: A Framework for Descriptive and Experimental Investigations. Medical Decision Making, 1995; 15:101-6.
- ²³ O'Connor A.; Consumer/Patient Decision Support in the New Millennium: Where should our research take us? Can J Nurs Res, 1997; 29:7-12.
- ²⁴ Dominick, L; Frosch, B; Kaplan, R; Shared decision making in clinical medicine: past research and future directions. Am J Prev Med, 1999; 17:285-94.
- ²⁵ Ontario Association of Community Care Access Centres, Community Care Access Centres, August 1999, pp. 3-4.
- ²⁶ Anonymous; Government Unveils Plan for Speedy Long-Term Care Reform. News Release. Toronto: Ministry of Health, January 25, 1996.
- ²⁷ Personal Communication, Steve Handler, North York CCAC, November 14th, 2000
- ²⁸ Jacobs, P; Hall, E; Henderson; I; Nichols, D; Episodic Acute Care Costs: Linking Inpatient and Home Care. Can J Pub Health 1995; 86: 200-205.
- ²⁹ Richardson, B; Overview of Provincial Home Care Programs in Canada. Health Care Management Forum 1990; Fall: 3-10.
- ³⁰ Parr, K; 1996.
- ³¹ Price Waterhouse; Operational Review of the Ontario Home Care Program, Final Report, Toronto: Price Waterhouse, 1989.

-
- ³² Federal/Provincial/Territorial Working Group on Home Care: A Working Group of the Federal/Provincial/Territorial Subcommittee on Long Term Care: Report on Home Care. Ottawa: Health Services Promotion Branch, Health and Welfare Canada, 1990.
- ³³ Davidoff, F; et al: Evidence Based Medicine. BMJ 1995; 310:6987, 1085-1086.
- ³⁴ Sackett, DL; et al: Evidence Based Medicine: What it is and What it isn't BMJ 1996; 312: January 13, 71-72.
- ³⁵ Sackett, DL; Rosenberg WM: On the Need for Evidence-Based Medicine. Health Econ 1995; 4, 249-254.
- ³⁶ Evidence-Based Medicine Working Group: Evidence-Based Medicine; A New Approach to Teaching the Practice of Medicine. JAMA 1992; 268: 2420-2425.
- ³⁷ Chapman, CR; Measurement of pain: problems and issues. In Bonica JJ, Abe-Fessard D (eds) Advances in Pain Research and Therapy. Vol. 1. New York Raven Press, 1976:345-353.
- ³⁸ McDowell, I; Newall, C; Measuring Health: A Guide To Rating Scales and Questionnaires. New York: Oxford University Press. 1987, p. 12.
- ³⁹ McDowell, I; Newall, C; Measuring Health: A Guide To Rating Scales and Questionnaires. New York: Oxford University Press. 1987, p. 12.
- ⁴⁰ Donabedian, A; The role of Outcomes in Quality Assessment and Assurance", Quarterly Review Bulletin, 1992, 11, 356-360.
- ⁴¹ Marek, KD; in T. Lee and M Mills; Analysis of Patient Profile in predicting Home Care Resource Utilization and Outcomes, in, JONA, Vol 30, No. 2, February 2000, 69.
- ⁴² Wilson, I; and Cleary, P; Linking Clinical Variable with Health-Related Quality of Life: A conceptual model of patient outcomes. JAMA, Vol. 273, 1996, 59-64.
- ⁴³ Hirdes, J; and Carpenter, I; Health Outcomes Among the Frail Elderly in Communities and Institutions: Use of the Minimum Data Set (MDS) to Create Effective Linkages Between Research and Policy, in, Canadian Journal on Aging, Supplement, pp. 53-69, 1997.
- ⁴⁴ Chipperfield, J; Incongruence between Health Perceptions and Health Problems, in, Journal of Health and Aging, 1993, 5,475-496.
- ⁴⁵ Hirdes, J; and Carpenter, I; Health Outcomes Among the Frail Elderly in Communities and Institutions: Use of the Minimum Data Set (MDS) to Create Effective Linkages Between Research and Policy, in, Canadian Journal on Aging, Supplement 1997, 53-69.
- ⁴⁶ Joint Commission on Accreditation of Health Care Services, Facts about the Review of Performance Measurement Systems, in, <http://wwwb.jcaho.org/perfmeas/reviewpm.html> accessed October 2000.
- ⁴⁷ McClure, CR; Performance Measures and Quality Standards. School of Information Studies Syracuse University.
- ⁴⁸ Baker R; et al. Healthcare Performance Measurement in Canada: Who's Doing What? Hospital Quarterly. Winter 1998.
- ⁴⁹ Voigt, P; Dictionary of Statistics and Methodology. Newbury Park, California: Sage, 1993.
- ⁵⁰ Strecher, DL; Norman, GR; Munroe-Blum, H; Epidemiology. Toronto: Decker Inc. 1989.
- ⁵¹ Shaughnessy, PW; Schlenker, RE; and Crisler, KS et al. Home Care: Moving Forward with Continuous Quality Improvement, in, Journal of Aging and Social Policy, 1996; 7: 149.
- ⁵² Shaughnessy, PW & Crisler KS; Outcome-Based Quality Improvement: A Manual for Home Care Agencies on How to Use Outcomes. Washington, DC: National Association of Home Care, 1995.
- ⁵³ Shaughnessy, P; Crisler, K.; Schenkler, R. and Arnold, A. Outcomes Across the Care Continuum: Home Health Care, in, Medical Care, 1997, Volume 35, Number 11, NB115-NS123.
- ⁵⁴ *ibid.*
- ⁵⁵ *ibid.*
- ⁵⁶ Joint Commission on Accreditation of Health Care Services, Glossary Of Terms For Performance Measurement Systems, in, <http://wwwb.jcaho.org/perfmeas/pmgsl/glossry.html> accessed October 2000.
- ⁵⁷ Ontario Association of Community Care Access Centres, Community Care Access Centres, August 1999, p5.
- ⁵⁸ Health Watch, "Developing a Case-Mix Adjuster for Home Care PPS", in Health Watch Spring 2000 Volume IV Number 2.
- ⁵⁹ Canadian Institute for Health Information, "Home Care, National Indicators and Reports Development. www.cihi.ca/Roadmap/Home_Care/star.htm, accessed December 5, 2000.
- ⁶⁰ Canadian Institute for Health Information, Development of National Indicators and a Reporting System for Home Care: External Survey Results. Ottawa:CIHI, September 1999.
- ⁶¹ *Ibid.*

-
- ⁶² Health Canada, Summary of projects in Manitoba Screening, Assessment and Care Planning Automated Tool (SACPAT): Phase II. www.hc-sc.gc.ca/english/archives/releases/1999/9910ebk.htm. accessed December 6, 2000.
- ⁶³ Canadian Council on Health Services Accreditation. Standards for Home Care Organizations: A Client-centred Approach. 1997.
- ⁶⁴ Canadian Home Care Association. Home Care and Health Care System Renewal. August 2000.
- ⁶⁵ Shaughnessey, PW; and Crisler, KS; Outcome-Based Quality Improvement: A Manual for Home Care Agencies on How to Use Outcomes. Washington, D.C.: National Association of Home Care. 1995.
- ⁶⁶ Website of the Home Health Pilot Project to use OASIS data for Quality Improvement in Home Health. http://homehealth.dfmc.org/html/obji_system.html. Accessed December 9, 2000.
- ⁶⁷ Joint Commission on Accreditation of Health Care Services. in <http://www.fmas.com/oryx/default.asp> accessed December 9, 2000.
- ⁶⁸ Joint Commission on Accreditation of Health Care Services, Facts about the Review of Performance Measurement Systems, in, <http://www.jcaho.org/perfmeas/reviewpm.html> accessed December 9, 2000.
- ⁶⁹ Ibid.
- ⁷⁰ Joint Commission on Accreditation of Health Care Services, Home Care Bulletin, April 2000, <http://www.jcaho.org/news/hcb0400.html> accessed October 2000.
- ⁷¹ Ash, AS; Ellis, RP; Pope, GC; Ayanian, JZ; Bates, DW; Burstin, H; Iezzoni, LI; MacKay, E; and Yu, W; Using Diagnoses to Describe Populations and Predict Costs. Health Care Financing Review, In Press. 2000.
- ⁷² Pope, GC; Ellis, RP; Liu, CF; Ash, A; Iezzoni, LI; Ayanian, JZ; Bates, DW; & Burstin, H; Revised Diagnostic Cost Group (DCG)/Hierarchical Coexisting Conditions (HCC) Models for Medicare Risk Adjustment. Final Report prepared for Health Care Financing Administration, February 1998.
- ⁷³ van de Ven, WPM; Van Vliet, RCJA; Barneveld, EM; & Lamers, LM; Risk-adjusted Capitation: Recent Experiences in the Netherlands. Health Affairs 1994; Winter: 120-136.
- ⁷⁴ Hall R. Predicting Home Care Expenditures. Unpublished Doctoral Dissertation, University of Toronto, Toronto, Canada. 2001.
- ⁷⁵ Russo, H; Measurement: The Key to Success, in, Caring Magazine, June 2000 p. 31.
- ⁷⁶ Libow, LS; A Rapidly Administered Easily Remembered Mental Status Evaluation: FROMJE, in, L.Libow and F. Sherman (eds.) The Core of Geriatrics Medicine, St. Louis: Mosby, 1981, 85-91.
- ⁷⁷ Murdaugh, C; Health related Quality of Life as an Outcome in Organizational Research, in, Medical care, 1997 35(Suppl), NS41-NS48.
- ⁷⁸ Russo, H; Measurement: The Key to Success, in, Caring Magazine, June 2000; 30.
- ⁷⁹ Katz, S; Ford, AB; Downs, TD; Adams M; and Insby, D. Effects of Continued Care: A Study of Chronic Illness in the Home, in, DHEW Publication 73-3010. Washington, DC: US Government: Government Printing Office, 1972.
- ⁸⁰ Neal, L; Current Functional Assessment Tools, in, Home Healthcare Nurse, Vol. 16, No. 11, November 1998, 766-772.
- ⁸¹ Stuck, AK; Aronow, HU; Steiner, A; et al. A Trial of Annual In-Home Comprehensive Geriatric Assessment for Elderly People Living in the Community in, New England Journal of Medicine, 1995: 333: 1664-70.
- ⁸² Russo, H; Measurement: The Key to Success, in, Caring Magazine, June 2000 p. 30-31.
- ⁸³ Baum, C; & Edwards, DF; Cognitive Performance in Senile Dementia of the Alzheimer's Type: the Kitchen Task Assessment, in, American Journal of Occupational Therapy, 1993, 47, 431-436.
- ⁸⁴ McCormack, B; Improving the Quality of care for Older People, in, Nursing Times, June 2nd, Volume 95, No. 22, 1999, pp.42-43.
- ⁸⁵ Fillenbaum, G; The OARS Assessment Methodology: Multidimensional Functional Assessment Questionnaire (2nd edition), Duke University Centre for the Study of Aging and Human Development, Durham, N.C., 1988.
- ⁸⁶ ⁸⁶ Hirdes, J; Society's Adaptation to its Own Aging: A New Challenge for Community Based Health Care, in,
- ⁸⁷ Canadian Home Care Association, Home Care and Health Care System Renewal, August 2000.
- ⁸⁸ Shaughnessey, PW; Schlenker, RE; and Crisler, KS et al. Home Care: Moving Forward with Continuous Quality Improvement, in, Journal of Aging and Social Policy, 1996; 7: 149.
- ⁸⁹ Irvine, D; O'Brien-Pallas, L; Murray, M; Cockerill, R; Sidani, S; Laurie-Shaw, B; Lochhaas-Gerlach, J; The Reliability and Validity of Two Health status Measures for Evaluating Outcomes of Home Care Nursing, in, Research in Nursing and Health, 2000, 23, pp. 43-54.

-
- ⁸⁹ Russo, H; Measurement: The Key to Success, in, Caring Magazine, June 2000 pp. 28-33.
- ⁹⁰ Martin, KS; Sheet, NJ; and Stegman, MR; Home Health Clients: Characteristics, Outcomes of Care and Nursing Interventions, in, The American Journal of Public Health, December 1993, Vol. 83, No. 12, 1730 – 1734.
- ⁹¹ ibid.
- ⁹² Russo, H; Measurement: The Key to Success, in, Caring Magazine, June 2000 p. 30.
- ⁹³ Irvine, D; et al. 2000.
- ⁹⁴ Rockwood, K; Stolee, P; and Fox, RA; Use of Goal Attainment Scoring in Measuring Clinically Important Change in the Frail Elderly, in, Journal of Clinical Epidemiology, 1993, 46, 1113-1118.
- ⁹⁵ ibid.
- ⁹⁶ Forbes, D; Goal Attainment Scaling A Responsive Measure of Client Outcomes, in, Journal of Gerontological Nursing, December 1998, 39.
- ⁹⁷ Coyte PC; Young, W; Regional Variations in the Use of Home Care Services in Ontario 193-1995.” Canadian Medical Association Journal, 1999, 161:4, 376-380.
- ⁹⁸ Giuffrida, A; Gravelle, H; Roland, M; Measuring quality of care with routine data: avoiding confusion between performance indicators and health outcomes, in BMJ 1999; 319; 94-98.
- ⁹⁹ Registered Nurses Association of Ontario; Vision Lost: Reform of Long-Term Care Community Services. Registered Nurses Association of Ontario: Toronto, September 1999.
- ¹⁰⁴ Canadian Institute for Health Information, Development of National Indicators and a Reporting System for Home Care, National Pilot Test, Draft National priority Indicators for Home Care Phase I, June 2000, 101. www.cihi.ca/Roadmap/Home_Care/start.htm
- ¹⁰² Ash, AS; Ellis, RP; Pope, GC; Ayanian, JZ; Bates, DW; Burstin, H; Iezzoni, LI; MacKay, E; and Yu, W; Using Diagnoses to Describe Populations and Predict Costs. Health Care Financing Review, In Press. 2000.
- ¹⁰³ Pope, GC; Ellis, RP; Liu, CF; Ash, A; Iezzoni, LI; Ayanian, JZ; Bates, DW; and Burstin, H; Revised Diagnostic Cost Group (DCG)/Hierarchical Coexisting Conditions (HCC) Models for Medicare Risk Adjustment. Final Report prepared for Health Care Financing Administration, February 1998.
- ¹⁰⁴ van de Ven, WPM; Van Vliet, RCJA; Barneveld, EM; & Lamers, LM; Risk-adjusted Capitation: Recent Experiences in the Netherlands. Health Affairs 1994; Winter: 120-136.
- ¹⁰⁵ Hall R. Predicting Home Care Expenditures. Unpublished Doctoral Dissertation, University of Toronto, Toronto, Canada. 2001.
- ¹⁰⁹ Mahoney, F; & Barthel, D; Functional evaluation: The Barthel Index. Maryland State Medical Journal, 1965, 14(2), 61-65.
- ¹¹⁰ Loewen, S; & Anderson, B; Reliability of the Modified Motor Assessment Scale and the Barthel Index. Physical Therapy, 1988; 68(7), 1077-1081.
- ¹¹¹ Granger, C; Albrecht, G; & Hamilton, B; Outcome of comprehensive medical rehabilitation: Measurement by the PULSES profile and Barthel Index. Archives of Physical Medicine and Rehabilitation, 1979, 60, 145-154.
- ¹¹² Gresham, G, Phillips, T; & Labi, M;. ADL status in stroke: Relative merits of three standard indices. Archives of Physical Medicine and Rehabilitation, 1980, 61, 355-358.
- ¹¹³ ibid.
- ¹¹⁴ Granger, C; Sherwood, C; & Greer, D; Functional status measures in comprehensive stroke care program. Archives of Physical Medicine and Rehabilitation, 1977, 58, 555-561.
- ¹¹⁵ Goldberg, R; Bernad, M; & Granger, C; Vocational status: Prediction by the Barthel Index and PULSES profile. Archives of Physical Medicine and Rehabilitation, 1980, 61, 580-583.
- ¹¹⁶ Hasselkus, B; Barthel self-care index and geriatric home care patients. Physical and Occupational Therapy in Geriatrics, 1982, 1, 11-22.
- ¹¹⁷ Granger, C; Dewis, L; Peters, N; Sherwood, C; & Barrett, J; Stroke rehabilitation: Analysis of repeated Barthel Index measures. Archives of Physical Medicine and Rehabilitation, 1979, 60, 14-17.
- ¹¹⁸ ibid.
- ¹¹⁹ School of Physical and Occupational Therapy, McGill University and Physiotherapy Department Stroke Rehabilitation Assessment and Movement (STREAM) test manual .1994, Jewish Rehabilitation Hospital, Montreal, PQ.
- ¹²⁰ Daley, K; Mayo, N; & Wood-Dauphinee, S; Stroke Rehabilitation Assessment of Movement (STREAM) content validity and preliminary reliability. Physical Therapy Canada, 1994, 46, 38.

-
- ¹²¹ Brorsson, B; & Asberg, K; Katz Index of Independence in ADL: Reliability and validity in short term care. Scandinavian Journal of Rehabilitation Medicine, 1984, 16, 125-132.
- ¹²² Katz, S; & Akpom, C; A measure of primary sociobiological functions. International Journal of Health Services, 1976, 6, 493-507.
- ¹²³ Brorsson, B; 1984.
- ¹²⁴ Asberg, K; & Kydevik, I; Early prognosis of stroke outcome by means of Katz Index of Activities of Daily Living. Scandinavian Journal of Rehabilitation Medicine, 1991, 23, 187-191.
- ¹²⁵ Guide for the Uniform Data System for Medical Rehabilitation (Adult FIMSM), Version 4.0. Buffalo, NY 14214: State University of New York at Buffalo; 1993.
- ¹²⁶ Heinemann, A.; Linacre, J; Wright, B; Hamilton, B; & Granger, C; Prediction Of Rehabilitation Outcomes With Disability Measures. Archives of Physical Medicine and Rehabilitation, 1994, 75, 127-132.
- ¹²⁷ Hamilton, B; Laughlin, J; Granger, C; & Kayton, R; Inter-Rater Agreement Of The Seven Level Functional Independence Measure (FIM). Archives of Physical Medicine and Rehabilitation, 1991, 72, 790.
- ¹²⁸ Heinemann, A.; Hamilton, B; Granger, C; Wright, B; Linacre, J; Betts, H; Agunda, B; & Mamott, B; Rating scales analysis of functional assessment measures. 1991, Chicago, IL: Rehabilitation Institute of Chicago.
- ¹²⁹ Guide for the Uniform Data System for Medical Rehabilitation (Adult FIMSM), Version 4.0. Buffalo, NY 14214: State University of New York at Buffalo; 1993.
- ¹³⁰ Roth, E; Davidoff, G; Haughton, J; & Ardner, M; Functional assessment in spinal cord injury: A comparison of the Modified Barthel Index and the adapted Functional Independence Measure. Clinical Rehabilitation, 1990, 4, 277-285.
- ¹³¹ Heinemann, A; Linacre, J; Wright, B; Hamilton, B; & Granger, C; Prediction of rehabilitation outcomes with disability measures. Archives of Physical Medicine and Rehabilitation, 1994, 75, 127-132
- ¹³² Mauthe, RW; Haaf, DC; Hayn, P; & Krall, JM; Predicting discharge destination of stroke patients using a mathematical model based on six items from the Functional Independence Measure. Archives of Physical Medicine and Rehabilitation, 1996, 77, 10-13.
- ¹³³ Granger, C; Cotter, A; Hamilton, B; Fiedler, R; & Hans, M; Functional assessment scales: A study of persons with multiple sclerosis. Archives of Physical Medicine and Rehabilitation, 1990, 71, 870-874.
- ¹³⁴ Granger, C; Cotter, A; Hamilton, B; Fiedler, R; & Hans, M; Functional assessment scales: A study of persons with multiple sclerosis. Archives of Physical Medicine and Rehabilitation, 1990, 71, 870-874.
- ¹³⁵ McDowell, I; Newell, C; Measuring Health: A Guide to Rating Scales and Questionnaires. Oxford: Oxford University Press, 1987.
- ¹³⁶ Spitzer, W; Dobson, A; Hall, J; Chesterman, E; Levi, J; Shepherd, R; Battista, R; & Catchlove, B; Measuring the quality of life of cancer patients: A concise quality of life index for use by physicians. Journal of Chronic Disease, 1981, 34, 585-597.
- ¹³⁷ Addington-Hall, J; MacDonald, M; & Anderson, M; Can the Spitzer QL Index help to decrease prognostic uncertainty in terminal care? British Journal of Cancer, 1990, 62, 695-699.
- ¹³⁸ Soderback, I; Schult, M; & Nordenar, R; Assessment of patients with chronic back pain using the Functional Status Questionnaire. Scandinavian Journal of Rehabilitation Medicine, 1993, 25(3), 139-143.
- ¹³⁹ Jette, A; Davies, A; Cleary, P; Calkin, D; Rubenstein, L; Fink, A; Kosecoff, J; Young, R; Brook, R; & Delbanco, T; The Functional Status Questionnaire: Reliability and validity when used in primary care. Journal of General Internal Medicine, 1986, 1, 143-149
- ¹⁴⁰ Soderback, I; Schult, M; & Nordenar, R; Assessment of patients with chronic back pain using the Functional Status Questionnaire. Scandinavian Journal of Rehabilitation Medicine, 1993, 25(3), 139-143.
- ¹⁴¹ Yarnold, P; Bryant, F; Repasy, A; & Martin, G; The factor structure and cross-sectional distributional properties of the Beth Israel/UCLA Functional Status Questionnaire. Journal of Behavioral Medicine, 1991, 14(2), 141-153.
- ¹⁴² Tedesco, C; Manning, S; Lindsay, R; Alexander, C; Owen, R; & Smucher, M; Functional assessment of elderly patients after percutaneous aortic balloon valvuloplasty: New York Heart Association classification versus Functional Status Questionnaire. Heart and Lung, 1990, 19(2), 118-125.
- ¹⁴³ Chambers, L; The McMaster Health Index Questionnaire: An update. In S. Walker & R. Rosser (Eds.), Quality of life assessment: Key issues in the 1990's. Boston, MA: Kluwer Academic Publishers, 1993.
- ¹⁴⁴ Chambers, L; MacDonald, L; Tugwell, P; et al; The McMaster Health Index Questionnaire as a measure of quality of life for patients with rheumatoid disease. Journal of Rheumatology, 1982, 9, 780-784.
- ¹⁴⁵ Robinson, BC; Validation Of A Caregiver Strain Index. Journal of Gerontology, 1983, 38, 344-348.

-
- ¹⁴⁶ Robinson, BC; Validation Of A Caregiver Strain Index. Journal of Gerontology, 1983, 38, 344-348.
- ¹⁴⁷ Marchi-Jones, S; Murphy, JF; & Rousseau, P; Caring for the Caregivers. Journal of Gerontological Nursing, 1996, 22(8), 7-13.
- ¹⁴⁸ Robinson, BC; Validation Of A Caregiver Strain Index. Journal of Gerontology, 1983, 38, 344-348.
- ¹⁴⁹ ibid.
- ¹⁵⁰ Fillenbaum, GG; Multidimensional functional assessment of older adults: The Duke Older Americans Resources and Services procedures. Hillsdale, NJ: Lawrence Erlbaum Associates, 1988.
- ¹⁵¹ Fillenbaum, G; & Smyer, M; The development, validity and reliability of the OARS Multidimensional Functional Assessment Questionnaire. Journal of Gerontology, 1981, 36, 428-434.
- ¹⁵² Hirdes, J; et al; Integrated Health Information Systems Based on the RAI/MDS Series of Instruments, Healthcare Management Forum, Volume 12 Number 4, 30-40.
- ¹⁵³ Morris, JN; et al. Comprehensive Clinical Assessment in Community Setting: Applicability of the MDS-HC, in, Journal of the American Geriatrics Society, 1997, 45:1017-1024.
- ¹⁵⁴ ibid.
- ¹⁵⁵ Morris, J; et al, Outcome Measures for Use with Home Care Clients: RAI-HC unpublished manuscript, Hebrew Rehabilitation Centre for the Aged, 1999.
- ¹⁵⁶ Morris, JN; Nonemaker S, Murphy K, Hawes C, Fries BE, Mor V, et al A Commitment to Change: Revision of HCFA's RAI Journal of the American Geriatrics Society, 1997; 45: 1011-1016.
- ¹⁵⁷ op. cit.
- ¹⁵⁸ Morris, J; et al. "Comprehensive Clinical Assessment in Community Setting: Applicability of the MDS-HC, Journal of the American Geriatrics Society, 1997, 45(8), 1017-24.
- ¹⁵⁹ Hirdes, J; Society's Adaptation to its Own Ageing: A New Challenge for Community Based Health Care. 205-212.
- ¹⁵⁷ Shaughnessey, PW; & Crisler, KS; Outcome-Based Quality Improvement: A Manual for Home Care Agencies on How to Use Outcomes. Washington, DC: National Association of Home Care, 1995.
- ¹⁵⁸ Ibid.
- ¹⁶² Irvine, D; et al; 2000.
- ¹⁶⁰ Testimony of Peter W. Shaughnessey, Center for Health Services and Policy Research, University of Colorado Health Sciences Center, Evidence On The Value Of Oasis Efficiently Raise Home Care To A New Level Of Quality And Patient Well-Being, accessed on December 13th, 2000.
<http://www.senate.gov/~aging/hr32ps.htm>
- ¹⁶⁴ Russo, H; Measurement: The Key to Success, in, Caring Magazine, June 2000, 28-33.
- ¹⁶⁵ Ware, J; & Sherbourne, C. The MOS 36-Item Short-Form Health Survey (SF-36): Conceptual Framework And Item Selection. Medical Care, 1992, 30(6), 473-481.
- ¹⁶⁶ Brazier, J; Harper, R., Jones, N., O'Cathain, A., Thomas, K., Usherwood, T. & Westlake, L. Validating The SF-36 Health Survey Questionnaire: New Outcome For Primary Care. British Medical Journal, 1992, 305, 160-164.
- ¹⁶⁷ Jette, D; & Downing, J; Health Status Of Individuals Entering A Cardiac Rehabilitation Program As Measured By The Medical Outcomes Study 36-Item Short-Form Survey (SF-36). Physical Therapy, 1994, 74(6), 521-527.
- ¹⁶⁸ ibid.
- ¹⁶⁹ Garratt, A; Ruta, D; Abdalla, M; Buckingham, J; & Russell, I; The SF-36 Health Survey Questionnaire: An Outcome Measure Suitable For Routine Use Within The NHS? British Medical Journal, 1993, 306, 1440-1444.
- ¹⁷⁰ ibid.
- ¹⁷¹ Brazier, J; et al; 1992.
- ¹⁷² Jette, D; & Downing, J; (1994).
- ¹⁷³ Raphael, D; et al. Measuring the quality of life of older persons: A model with implications for community and public health nursing. Int. J. Nurs. Stud., 1997, 34(3):231-239.
- ¹⁷⁴ Bronfort, G; and Bouter, L; Responsiveness of General Health Status in Chronic Low Back Pain: A Comparison of the COOP Charts and the SF-36, Pain, 83: 1999, 201-209.
- ¹⁷⁵ ibid.
- ¹⁷⁶ ibid.
- ¹⁷⁷ Gulliland, S; et al. Adaptation of the Dartmouth COOP Charts for Use Among American Indian People with Diabetes, Diabetes Care Vol. 21(5) May 1998, pp. 770-776.
- ¹⁷⁸ Forbes, D; 1998.

¹⁷⁹ *ibid.*
¹⁸⁰ *ibid.*
¹⁸¹ *ibid.*
¹⁸² *ibid.*
¹⁸³ *ibid.*
¹⁸⁴ *ibid.*
¹⁸⁵ *ibid.*