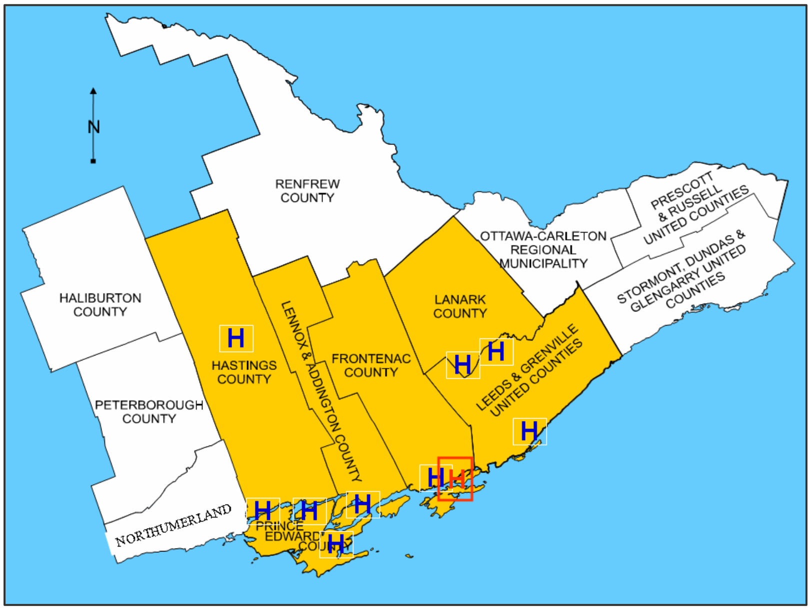
FINAL REPORT

The Stroke Rehabilitation Pilot Project of Southeastern Ontario



Submitted to The Ministry of Health and Long-Term Care
by The Regional Stroke Steering Committee of Southeastern Ontario
November 2004

EXECUTIVE SUMMARY

In June 2000, the report of the Ministry of Health and Long-Term Care (MOHLTC) and the Heart and Stroke Foundation of Ontario (HSFO) Joint Stroke Strategy Working Group, *Towards an Integrated Stroke Strategy for Ontario*, recommended that:

"The MOHLTC and the HSFO should promote the development of regional stroke rehabilitation systems. These systems would be linked to other sectors in the continuum of stroke care and be consistent with the Ministry's Rehabilitation Reform Initiative. Through a collaborative approach and with linkages to community-based services, the system would provide timely, appropriate, client-centred rehabilitation by specialists with stroke expertise." (P24)

Subsequently, the MOHLTC Ontario Stroke Strategy funded rehabilitation needs assessments and rehabilitation pilot projects across Ontario.

Incorporating the results of a 2001 Southeastern Ontario (SEO) regional rehabilitation needs assessment and recognizing the MOHLTC recommendations, the Regional Stroke Steering Committee of SEO developed a proposal entitled *"The Southeastern Ontario Stroke Rehabilitation Pilot Project"* and submitted it to the MOHLTC in November of 2001. Approval was received in May 2002 to conduct the two-year study.

From 2002 to 2004, the Stroke Rehabilitation Pilot Project of SEO investigated ways to improve the rehabilitation system for stroke survivors, their families and for healthcare providers. The project had three components, each addressing different sectors of the stroke care continuum.

- Community Rehabilitation Services following Inpatient Stroke Rehabilitation
  The Discharge Link Project investigated the impact on client recovery, client and provider satisfaction, and health care system utilization of providing timely and enhanced community rehabilitation services following inpatient rehabilitation for individuals with new disability subsequent to a stroke.

- Information across the Care Continuum
  The Diary of Stroke Care piloted a client-centred method of communicating client information across the continuum of care to clients, caregivers and health care providers.

- Stroke Functional Data In Acute Care
  A feasibility study of the Alpha-Functional Independence Measure (AlphaFIM™[1]) instrument was conducted with acute care sites in SEO. The AlphaFIM™ instrument is administered to patients within the first 72 hours of admission to acute care and again prior to discharge. It is a reliable tool for predicting function and burden of care post stroke and correlates strongly with the full Functional Independence Measure (FIM).

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[1] The AlphaFIM™ is a product of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc., Buffalo NY.

The project results include the following:

- Discharge Link Project

  - There is a significantly greater improvement in function in the stroke client group that receives timely enhanced professional community-based therapy in the first 2 months after discharge from a rehabilitation unit. This improvement is maintained for a year, the length of the study. The intensity and timing of professional community rehabilitation therapy is a critical factor in promoting stroke client recovery.
  - Shorter waiting time for community service is associated with faster functional recovery in the first 2 months and this recovery is maintained for the first year following discharge from inpatient rehabilitation.
  - Timely, enhanced professional community-based therapy in the first 2 months after discharge from a rehabilitation unit reduces costs to the healthcare system. There is a decreased burden of care associated with the improved functional recovery in the enhanced therapy group. The group receiving the enhanced community service had a shortened inpatient rehabilitation stay. Clients who received enhanced therapy in the community were 50% less likely to be readmitted to hospital and their readmission stay was shorter than those receiving usual care.
  - Models of community care in SEO differ.
  - Providers experience a higher level of satisfaction with their ability to provide service when resourced with time to collaborate with colleagues across the care continuum.
  - Providers are frustrated with system barriers that make it difficult to provide a coordinated team approach to care in the community and across the care continuum.
  - There are constant critical shortages of rehabilitation therapists in community and inpatient settings. Issues of retention and recruitment are of significant concern in SEO.
  - Caregivers of stroke survivors are overwhelmed with the burden of care.

- Diary of Stroke Care

  - The Stroke Diary is a useful aide to communication during the recovery process for stroke clients and their families.
  - Healthcare providers unanimously support the usefulness of the Diary, but they are not consistently able to make use of this aide due to time constraints.

- The Alpha-FIM™

  - The Alpha-FIM™ is a feasible means of collecting standard reliable data on the functional status of stroke survivors in the acute setting.

The project team recommends the following:

1. Provide timely appropriate intensive home-based professional therapy to meet the community rehabilitation needs of stroke clients being discharged from inpatient rehabilitation with moderate and severe strokes. This is particularly important when these clients are unable to access ambulatory services in the community.

2. Priority setting for community service for this client group may need to be re-considered to ensure that appropriate and timely levels of service are provided. This study provides new evidence about what newly disabled stroke survivors require in terms of appropriate service levels to meet their needs and to promote savings across the care continuum.

3. Increase system responsiveness and flexibility to allow for meeting the particular rehabilitation needs of recovering stroke clients in the community.

4. Promote models of community-based care that best promote stroke client recovery. Timely provision of adequate professional service is an important factor in the model for community care.

5. Create and resource a formal process to support inter-provider communication and coordination of care between the hospital inpatient rehabilitation setting and community-based care.

6. Investigate strategies to recruit and retain professional services to prevent shortages and to promote a stable provider workforce. Frequent change in service provider agencies leads to difficulty with human resource recruitment and stability, impacting on continuity of care.

7. Provide stroke rehabilitation education to professional staff of provider agencies and to case managers. The personal support worker requires education regarding rehabilitation principles and functional activities in the provision of stroke care in the home. Consider designating a CCAC staff member to focus on stroke and serve as an expert resource to other staff.

8. Explore the role of the physiotherapy assistants, occupational therapy assistants and communication disorder assistants in the community rehabilitation of stroke survivors. Provide rehabilitation training to support personnel. (The project demonstrated that service from untrained support personnel does not have an impact on recovery of function post stroke.)

9. Support caregivers with increased respite, education about stroke and by linking clients with the services provided through community support agencies.

10. A triage system to set priorities for enhanced community services for recovering stroke survivors will maximize the provision of appropriate therapy services at adequate levels to meet client needs. Regional planning mechanisms will be sustainable only if an infrastructure is in place to promote this.

11. Include the Stroke Diary as part of a standard patient education and communication tool already in use by patients and providers (e.g., “Let’s Talk about Stroke” by HSFO) in order to facilitate uptake and usage.

12. Re-design the Stroke Diary to meet the special needs of stroke clients (e.g. those with aphasia, visual deficits or limited arm function).

13. Accompany use of the Stroke Diary with a thorough education program for the potential users, addressing privacy issues. There is a need to educate care providers about privacy of information and about patient rights to access clinical information.

14. Continue to trial the Alpha-FIM™ in its present web-based format.

15. Fiscal and human resources are needed to encourage collection of standardized outcome measures (such as the Alpha-FIM™) in acute stroke care, to encourage application of the data to practice, and to incorporate them into a regional system for stroke rehabilitation triage.

ACKNOWLEDGEMENTS

Many stakeholders are acknowledged for their assistance in this study. This project was one of 6 rehabilitation pilot projects funded by the Ministry of Health and Long-Term Care (MOHLTC), Ontario Stroke Strategy. The Heart and Stroke Foundation of Ontario provided assistance in coordinating provincial meetings of the leaders of the 6 projects. The Rehabilitation Subcommittee of the Regional Stroke Strategy Steering Committee of Southeastern Ontario (see Appendix A) directed the project from the proposal phase through implementation to completion.

The project was conducted with the cooperation of many health care agencies throughout Southeastern Ontario including: Brockville General Hospital, Kingston General Hospital, Lennox and Addington County General Hospital, Perth and Smiths Falls District Hospital, Providence Continuing Care Centre (St. Mary's of the Lake Hospital and St. Vincent de Paul Hospital sites), Quinte Health Care (Bancroft, Belleville, Picton and Trenton sites), the Access Centre for Hastings & Prince Edward Counties, the Access Centre for Community Care of Lanark, Leeds and Grenville, the Community Care Access Centre of Kingston, Frontenac, Lennox and Addington counties, and Community Care provider agencies.

The project team wishes to acknowledge and thank the numerous health care providers throughout the region who were involved in the project, such as case managers, health care professionals, and personal support workers. The Canadian Institute for Health Information (CIHI) worked collaboratively with the project team to enable use of rehabilitation data. Dr. Arthur Sweetman, Director of Queen's University School of Policy Studies provided helpful advice on research design and natural experiments early on in the project. Jeff Bakal assisted in statistical analysis and Cornelia Brack assisted in qualitative analysis of key informant interviews.

Sincere thanks are extended to the clients and their caregivers who agreed to be a part of this study and who live with the reality of stroke every day.

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INTRODUCTION

Stroke represents the leading cause of adult disability and a leading cause of death[2] in Canada. The annual direct and indirect costs of stroke care are estimated to approach one billion dollars in Ontario[3]. Inpatient stroke rehabilitation has been shown to be effective in reducing disability post stroke, reducing on-going care costs and improving quality of life for stroke survivors[4]. However, community based rehabilitation for stroke survivors, has received limited attention in scientific literature. There is a limited body of knowledge relating to best practice in stroke rehabilitation in the community setting beyond the hospital or rehabilitation centre.

Development of the Project:

In June 2000, the report of the Joint Stroke Strategy Working Group[3], *Towards an Integrated Stroke Strategy for Ontario*, recommended that:

"The MOHLTC and the HSFO should promote the development of regional stroke rehabilitation systems. These systems would be linked to other sectors in the continuum of stroke care and be consistent with the Ministry's Rehabilitation Reform Initiative. Through a collaborative approach and with linkages to community-based services, the system would provide timely, appropriate, client-centred rehabilitation by specialists with stroke expertise." (p24)

Subsequently, the MOHLTC, as part of its rehabilitation reform policy, developed the following goals for the creation of an Ontario-wide rehabilitation strategy:

- Provide outreach services to support enhanced consultation in rural, northern and remote areas of the province;

- Identify best practices to strengthen and improve coordination of stroke rehabilitation, especially in the case management of the transition between hospitals and from hospital to community-based care;

- Identify best practices for home-based stroke rehabilitation, including community ambulatory programs;

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[2] Heart and Stroke Foundation website, www.heartandstroke.ca

[3] Towards an Integrated Stroke Strategy for Ontario, Report of the joint Stroke Strategy Working Group, MOHLTC and HSFO June 2000, p.2

[4] Evidence-Based Review of Stroke Rehabilitation, prepared for the MOHLTC and the HSFO, by R. Teasall, T. Doherty, N. Foley. S. Bhogal, University of Western Ontario, London, Ontario, http://www.ebrsr.com

- Improve quality of life for Ontarians by improving access to and quality of rehabilitation for stroke patients;

- Avoid future projected major stroke costs by significantly reducing wait times for rehabilitation services; and

- Promote smooth and effective coordination between various parts of the continuum of stroke services.

In the spring of 2001, following its participation in the demonstration phase of the Stroke Strategy, Kingston General Hospital was designated a Regional Stroke Centre for Southeastern Ontario by the MOHLTC. In 2001 the MOHLTC funded a needs assessment of rehabilitation services for stroke clients in SEO. The Regional Stroke Steering Committee of SEO (see Appendix A) and Kingston General Hospital led the assessment with regional partners. The Regional Stroke Steering Committee is a subcommittee of the Health Care Network of SEO, a voluntary partnership of health care organizations in SEO. The Regional Stroke Steering Committee is responsible for overseeing the work of the Stroke Strategy in SEO. The needs assessment revealed several interrelated deficiencies with the current stroke rehabilitation system. This report was submitted to the MOHLTC in November 2001 and noted the following:

- Stroke survivors experience long wait times to see a rehabilitation professional in their home after their discharge from inpatient rehabilitation;

- Professionals from the inpatient and community rehabilitation settings feel that this delay contributes to the survivor's loss of function and independence achieved during the intensive inpatient rehabilitation phase and may contribute to re-admissions to acute care or placement in the long-term care setting;

- The loss of functional independence is further compounded by the demands on in-home personal support workers, who, in their attempt to see numerous clients, may encourage dependency by completing the activities of daily living for the client;

- Caregiver stress is particularly high during this initial phase and the caregivers reported a need for services to support them during this transition period;

- Women stroke survivors may be less likely to return home due to factors such as age and lack of caregiver support. In this region, this trend may be exacerbated by the current long delays with in-home therapy;

- Stroke survivors from rural and remote areas in Southeastern Ontario do not have equitable access to follow-up outpatient rehabilitation because of large travel distances and a lack of transportation. Adequate follow-up in the home is critical for this group;

- Community care therapists require information on rehabilitation techniques and best practices for stroke clients;

- A working tool is needed to facilitate communication of information across the region as patients move through various care settings/organizations; and

- There is a need for a common outcome measure to describe patient function and to determine eligibility for rehabilitation. A similar tool to communicate function across the acute and rehabilitation settings is needed, however, there is concern regarding the feasibility of using outcome measures in the acute setting.

Incorporating the results of this needs assessment and recognizing the MOHLTC rehabilitation reform goals, the Regional Stroke Steering Committee of SEO developed a proposal entitled "*The Southeastern Ontario Stroke Rehabilitation Pilot Project*" and submitted it to the MOHLTC in November of 2001. Approval was received in May 2002 to conduct the two-year study. This report outlines the results of that study.

The Regional Stroke Rehabilitation Committee of the Regional Stroke Steering Committee directed the study. The resource staff included the Regional Stroke Rehabilitation Pilot Project Coordinator, and the Regional Stroke Program Manager, (see Appendix A) who implemented the study in partnership with regional stakeholders.

This project investigated ways to improve the rehabilitation system across the continuum for stroke survivors, their families and for health professionals. The overriding goal was to improve the flow of information and service provision across the care continuum. The project was designed to address the provincial objectives for the stroke rehabilitation pilot studies. Specifically the project objectives were as follows:

1. To identify best practices for community-based stroke rehabilitation;

2. To implement and evaluate methods of improving coordination of service and communication of information from inpatient to community rehabilitation for stroke clients;

3. To investigate the impact on client recovery, client and provider satisfaction, and health care system utilization of providing timely and enhanced community rehabilitation services following inpatient rehabilitation for individuals with new disability subsequent to a stroke;

4. To examine models of home-based rehabilitation service provision, equity in service provision and impact on health outcomes of stroke clients and their caregivers living in the rural and remote areas of SEO;

5. To develop and test a client-centred communication tool for use across the continuum of stroke care; and

6. To assess the feasibility of using the Alpha-FIM™ in the acute care setting.

The project had three components:

Part 1	The Discharge Link Project (DLP)
Part 2	The Stroke Client Profile (SCP), or, "My Diary of Stroke Care"
Part 3	A Feasibility Study of the Alpha FIM™ assessment tool in acute care.

Each component of the project is outlined in separate sections of this report.

Part 1 – The Discharge Link Project (DLP)

1.1 Objectives of the DLP

The DLP investigated best practices for community-based stroke rehabilitation. It tested a process to improve the transition from inpatient rehabilitation to community discharge destination. The objectives were:

- To implement and evaluate methods of improving coordination of service and communication of information from inpatient to community rehabilitation for new stroke clients (e.g. through discharge link meetings between the inpatient rehabilitation therapist, the community-based therapist and other community service providers);
- To investigate the impact on client recovery, client and provider satisfaction, and health care system utilization of providing timely and enhanced community rehabilitation services following inpatient rehabilitation for individuals with new disability subsequent to a stroke; and
- To examine models of home-based rehabilitation service provision, equity in service provision and impact on health outcomes of stroke clients and their caregivers living in the rural and remote areas of SEO.

1.2 DLP Methods

The Southeastern Ontario Region:

The Southeastern region of Ontario (SEO) provides some unique challenges for health care provision in the community. The region has a 46.0% rurally based population[5], one of the largest rural populations in Ontario (See Figure 1). Most acute care health services are located in the southern part of the region, requiring some patients to travel over 2 hours to obtain services. The region has an acute shortage of rehabilitation practitioners, especially in the more remote areas.

Approvals and Consents:

The project received initial written approval from all partner organizations (CCAC and hospital sites) through the Regional Stroke Steering Committee and the Health Care Network of SEO. Following MOHLTC approval it received approval from the Queen's University Health Sciences Research Ethics Review Board in January 2003 (see Appendix B). Written consent was received from all rehabilitation hospitals for the sharing of CIHI NRS data. Written patient consent was obtained from all project participants (see Appendix C for the consent forms used).

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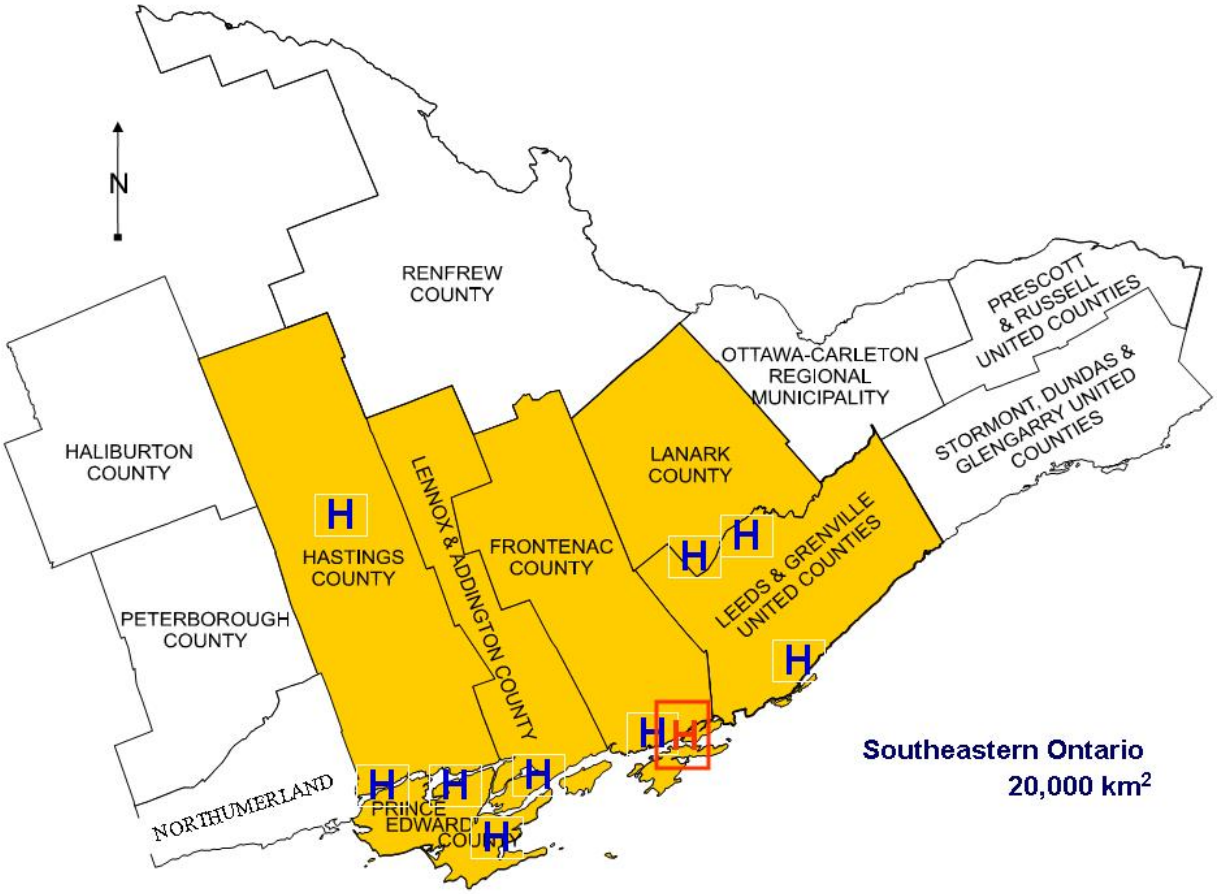
[5] MOHLTC 2003 Estimated Urban/Rural Ratios Based on Statistics Canada, 2001 Census.

Figure 1 – Map of Southeastern Ontario



Sample:

The participants included adults living in SEO who had sustained a recent stroke, had been admitted to an inpatient rehabilitation program and were being discharged to the community with CCAC services as they were unable to access ambulatory outpatient services (because of living too far way from the outpatient services, inability to travel, low physical tolerance, lack of transportation, etc). The project included those clients being discharged to a residential care setting (retirement home) but excluded those who were discharged to a Long Term Care (LTC) facility (nursing home, home for the aged). Participants were divided into either a control "*usual care therapy*" group, or a study "*enhanced therapy*" group based on the time at which they were referred to the DLP and the ability of the local CCAC to provide the enhanced service. All three CCAC's began by providing the usual level of service. When the CCAC had the human resources in place to enable provision of the enhanced service, clients recruited to the study were placed in the enhanced therapy group. Hence, assignment to the enhanced or usual care groups was not random, but was based on the realities of the real life context of this study: on human resource factors that were extrinsic to the clients. A total of 61 people consented to participate in the DLP, 24 in the *usual care* group and 37 in the *enhanced* group.

The Intervention:

The *usual care* study group received no special intervention from the DLP but was subject to usual CCAC therapy services. The *enhanced* study group received 2 interventions as part of the DLP. First, the participant's inpatient and CCAC Occupational Therapists (OTs) met face to face for a Discharge Link Meeting prior to inpatient rehabilitation discharge to discuss the client's recovery, goals and treatment program. Secondly, the participant received an enhanced amount of service above and beyond that which he or she would usually receive from the CCAC providers. This enhanced community service was initiated in the week following discharge, with a minimal wait time. The project was designed to allow the clients in the enhanced group to receive the same amount of therapy as would be available in a Day Hospital or ambulatory team setting. Personal support service was also enhanced with the aim of helping to carry over therapy goals in the home. One of the extra OT visits in the first week was to be used to meet with the Personal Support Worker (PSW) and his or her manager to review the recovery goals and treatment program emphasizing client independence in the home following patient discharge.

In the first month after inpatient rehabilitation discharge, the actual amount of enhanced therapy amounted to a maximum of 2 extra visits per week of PT, OT and/or SLP, and up to 5 extra hours per week of PSW time. In the second month after inpatient rehabilitation discharge, half the levels of enhanced therapy could be provided, i.e. up to one extra visit per week of OT, PT and/or SLP (see Appendix D for details). The actual amount and combination of enhanced professional therapy provided was decided upon by the CCAC case manager in consultation with the rehabilitation team and varied according to the client's needs.

The project also made available an Equipment Fund of up to $200 per enhanced participant to be used towards the purchase or rental of any resource that might assist the attainment of therapy goals in the home (see Appendix D).

See Appendix E for a full description of the DLP methodology and a 2-year work plan.

Evaluation

The assessment tools used for the DLP evaluation are listed below. For a full list of the data elements collected see Appendix F. See Appendix G for copies of the forms and assessment tools used.

- **The Functional Independent Measure (FIM):**
  The FIM is a standardized reliable and valid functional status measurement tool used in stroke care[6]. The FIM assesses domains of self-care, transfers, locomotion, sphincter control, communication and cognition, assessing physical and cognitive function in the

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[6] Dodds TA, Martin D, Stolov W, Deyo R, A Validation of the Functional Independence Measurement and its Performance Among Rehabilitation Inpatients. Arch Phys Med Rehabil 1993;74: 531-536.

context of burden of care. This tool gauges the amount of assistance and resources a person with disability will require in their living environment. In October 2002, as part of the Canadian Institute for Health Information's National Rehabilitation Reporting System (CIHI-NRS), the MOHLTC mandated use of the FIM to measure client function at admission and discharge from all Ontario rehabilitation inpatient centres. Rehabilitation personnel were trained to use the instrument per CIHI standards. The CIHI-NRS is also available in a telephone follow-up format for use after discharge from inpatient rehabilitation and administers the FIM by telephone interview. The FIM phone follow-up interview tool has been found to be valid and reliable[7,8]. With patient consent, the project obtained CIHI-NRS inpatient data (rehabilitation admission and discharge assessments) on each participant. The project coordinator monitored the participant's functional outcome over time by administering the follow-up CIHI-NRS assessment tool by telephone interview at 3, 6 and 12 months.

- CIHI-NRS Data:
  Along with the FIM, CIHI-NRS collects numerous other data elements, for example, living arrangements, vocational status, general health, co-morbidities, length of stay, waiting times, etc. The project collected applicable data after discharge for comparison purposes (see Appendix G).

- The Reintegration to Normal Living Index (RNL):
  The RNL is a standardized assessment tool that assesses global functional status, stroke survivors' perceptions of their own capabilities, and objective indicators of physical, social and psychological performance. It provides an index of client progress towards community re-integration[9]. The DLP collected this information during the follow up telephone interviews. It was not collected in the inpatient setting (see Appendix G).

- Workload Data:
  The project partner CCACs provided the DLP with workload data describing the dates and amount of therapy received by each participant. This data included a record of professional rehabilitation therapy (OT, PT and SLP) and non-professional personal support (PSW/homemaking) services.

- The Client Satisfaction Survey - SEO Version:
  This tool was developed from the CCAC Evaluation Survey obtained with the approval of Smaller World Communications of Toronto. At the start of the project in 2002, no community-based satisfaction tool was in common use, but the CCAC tool was under development by Smaller World Communications. We were permitted to base our survey on the device, as it existed in December 2002 (see Appendix G).

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[7] Ottenbacher KJ al. The Reliability of the FIM: A Quantitative Review. Arch Phys Med Rehabil 1996;7:1226-32.

[8] Smith P et al. Intermodal Agreement of Follow-up Functional Assessment using the FIM in Stroke Patients. Arch Phys Med Rehabil 1996;77:5.

[9] Wood-Dauphinee SL et al, Assessment of Global Function: the Reintegration to Normal Living Index. Arch Phys Med Rehabil 1988;69:583-590.

- Health Care Utilization:
  Participants were asked (at the 3, 6 & 12 month follow-up assessment interviews) to report on any return overnight visits to hospital, how long they were readmitted and for what reasons. Assessment findings were validated with family members.

- Focus groups:
  The coordinator conducted several focus groups with providers throughout the region, recorded the feedback and integrated the results into this report. See Appendix H for a listing of the focus groups and a summary of the information collected.

- Key Informant Interviews:
  Participants and providers were contacted and asked to take part in individual in-depth interviews. A representative sample of 14 people across the region was interviewed; interviews were audio-recorded and then transcribed. The data was analyzed with NVIVO software (a program to assist with the qualitative analysis of large amounts of text) and then reviewed for key themes by a panel of experts in community-based rehabilitation. See Appendix H for a listing of the Key Informants and Appendix I for a summary of the information collected.

Data Analysis: Both the quantitative and qualitative data were analyzed with the support of evaluation analysts. Quantitative data were analyzed using comparative statistics and multiple regression analysis. Qualitative data were analyzed using NVIVO software.

1.3 DLP Results

1.3.1 A Description of the DLP Participants

Participant Characteristics:

The project recruited 61 participants across the region between May 2003 and June 2004: 24 were given “usual” levels of therapy and 37 received the “enhanced” level of therapy. The participants were fairly evenly distributed by region (see Table 1). Statistical analysis of general demographics (Table 2) indicated no significant differences between groups. Only one client was transferred to a LTC facility during the course of the project. 36% (22) of the participants lived more than 20 kms from the inpatient rehabilitation site. Our interviews revealed that, after discharge, some people moved closer to the urban areas (to live with family for example) to be closer to rehabilitation and health services.

Table 1 – Regional Distribution of the DLP Participants

SEO Region Counties	Usual (U) therapy group	Enhanced (E) therapy group	Totals
Hastings and Prince Edward (HPE)	6	12	18
Kingston, Frontenac, Lennox & Addington (KFLA)	8	13	21
Lanark, Leeds and Grenville (LLG)	10	12	22
Totals	24	37	61

Table 2 – Demographics of the DLP Participants

	Usual (n=24)	Enhanced (n=37)
Mean Age (range) in years	72.1 (50-85)	72.7 (48-93)
	N (%)	N (%)
Gender n, % male	10 (42%)	19 (51%)
Living Arrangements: with spouse or partner	12 (50%)	17 (46%)
with family	5 (21%)	6 (16%)
alone	4 (17%)	8 (22%)
in a LTC facility	0	1 (3%)
In a retirement home	3 (12%)	5 (14%)
Vocational Status: Retired for age	19 (79%)	30 (81%)
Retired for disability	4 (18%)	4 (11%)
Working part-time	1 (3%)	0
Unemployed	0	3 (8%)
Distance of residence from rehabilitation centre: (mean =17.8 kms, SD ± 24.1 kms) <5 kms	9 (37%)	18 (49%)
6 – 19 kms	4 (17%)	8 (22%)
>20 kms	11 (46%)	11 (29%)

SD = Standard Deviation

Medical Condition and Self-Reported Health Status of the Participants:

Information on the participant's type of stroke (Responsible Health Condition- Rehabilitation Client Group, and Diagnostic Health Condition) and on co-morbid conditions was provided through the CIHI-NRS data (see Table 3a). There were no significant differences between groups. Seven (11%) of the participants had received thrombolytic therapy (t-PA) in acute care. When asked to describe their own health at 3 months using the CIHI follow-up self-reported health status assessment (Table 3b), no clients responded, "excellent", however the number of positive responses (very good and good) outweighed the negative (fair and poor). No client in the enhanced group described his or her health as poor at 3 months following discharge.

Table 3a – DLP Participants' Medical Conditions

Condition (From CIHI-NRS)	Usual (n = 24)	Enhanced (n = 37)
Responsible Health Condition – Rehabilitation Client Groups (RCG's):	N (%)	N (%)
Left Body Stroke – Right Brain (RCG 01.1)	10 (42%)	11 (30%)
Right Body Stroke – Left Brain (RCG 01.2)	12 (50%)	21 (57%)
No Paresis (RCG O1.4)	0	1 (3%)
Other stroke (RCG O1.9)	1 (4%)	3 (8%)
Other orthopaedic (RCG O8.9)	0	1 (3%)
Surgical complications (RCG 17.8)	1 (4%)	0
Diagnosis:		
Sub-arachnoid, subdural, extra-dural haemorrhage (J17)	1 (4%)	1 (3%)
Intracerebral haemorrhage (J18)	3 (13%)	3 (8%)
Occlusion or stenosis, precerebral arteries (J20)	5 (21%)	9 (24%)
Occlusion cerebral arteries (J21)	12 (50%)	17 (46%)
Acute Ill-defined cerebrovascular disease (J23)	2 (8%)	5 (13%)
Status post vascular surgery (J39)	1 (4%)	0
Chronic Ischemic Heart Disease (J8)	0	1 (3%)
Anoxic Brain Damage (G28)	0	1 (3%)
Comorbid Conditions: (grouped into related areas)		
Cardiac conditions	23(96%)	33 (89%)
Diabetes/Thyroid conditions	11 (46%)	14 (38%)
Musculo-skeletal conditions	18 (75%)	25 (68%)
Number receiving t-PA	3(12%)	4 (11%)

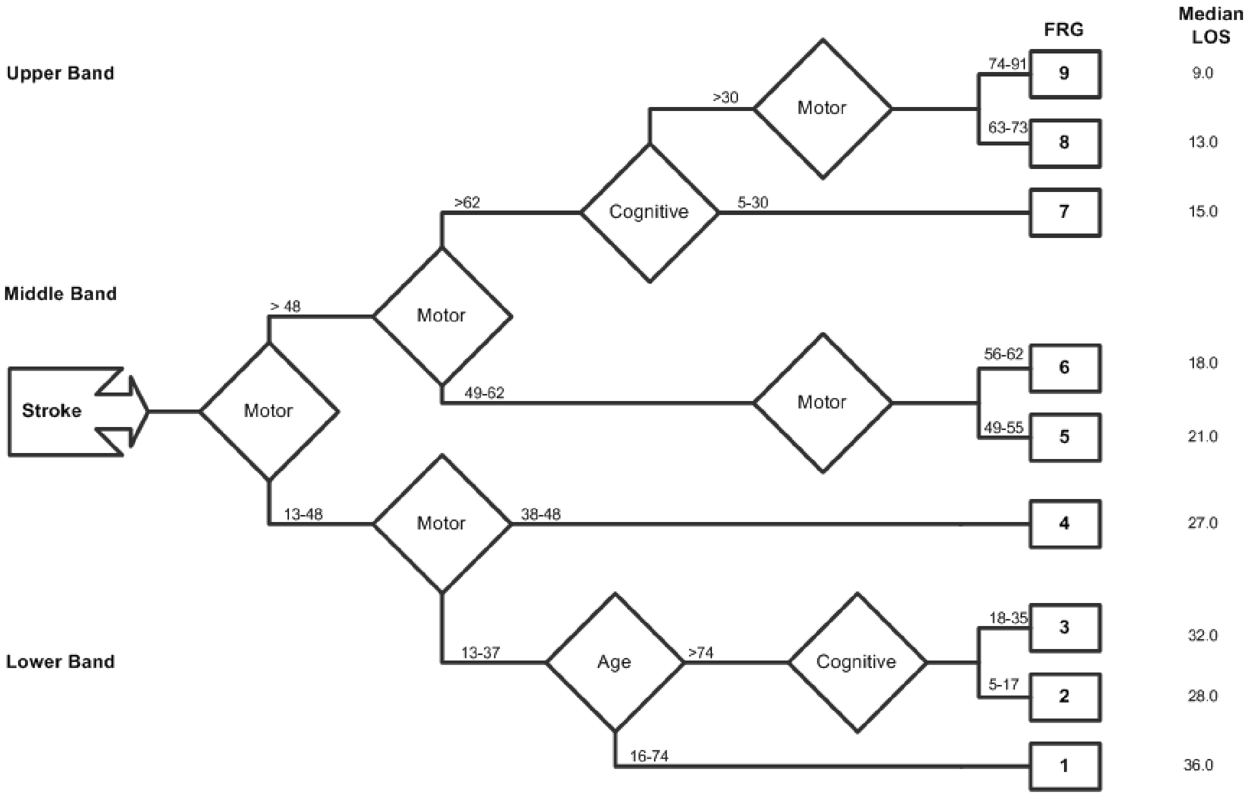
Table 3b – DLP Participants' Self-reported Health Status (from CIHI-NRS at 3mos)

When asked at +3 months, "How would describe your health?' Participants rated themselves as:		
Excellent	0	0
Very good	8 (33%)	15 (40.5%)
Good	11 (46%)	14 (38%)
Fair	3 (13%)	8 (20.5%)
Poor	2 (8%)	0

Severity of Stroke using Functionally Related Groups (FRGs)

Based on years of FIM data collection and research, a system has been devised to use FIM scores and age to designate nine Functionally Related Groups (FRGs)[10] that are predictive of stroke severity and potential for recovery. The patient's rehabilitation admission FIM score is subdivided by motor and cognitive components and groupings are made using motor FIM score, cognitive FIM score and age according to the algorithm in Figure 2. The resulting scores are used to assign the patient to one of the nine FRG's, with 1,2 & 3 considered the "lower band" (more severe strokes), FRGs 4 to 6 considered the "middle band" and levels 7 to 9 called the "upper band" or mild strokes (see Figure 2). FRG's are useful for determining the severity of a stroke, for predicting patient outcomes and for planning the client's level of care.

Figure 2 – Graphic of FIM-FRGs



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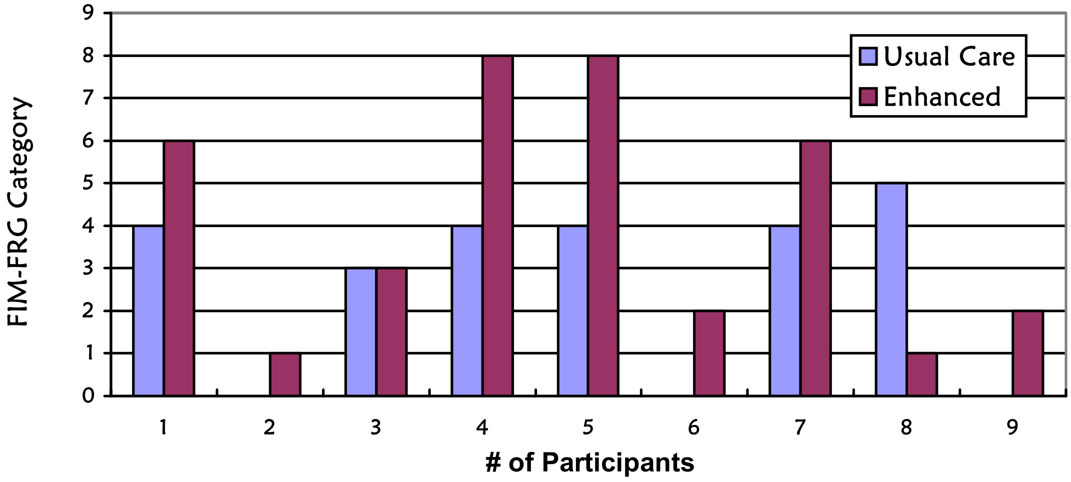
[10] Stineman MG et al, Functional Task Benchmarks for Stroke Rehabilitation, Arch Phys Med Rehabil 1998;79:497-504

Figure 3 indicates the distribution of the DLP's 61 participants into FRGs. More than half of the people in both the usual care and enhanced groups were FRGs 4, 5, 6 & 7, groups to which inpatient rehabilitation services are directed, with the most potential for recovery. There were also significant numbers in both groups in FRG 1, also a group that has been shown to benefit from rehabilitation but is more severely involved with respect to motor function. An anomaly is noted at the 8th FRG level, with a high count of 6 from the usual care group. This group is less severely disabled. Overall, these data indicate that the enhanced group is somewhat more severely disabled than the usual care group.

Figure 3 – DLP Severity of Stroke –FIM-FRG's



1.3.2 System Utilization

Hospital Length of Stay and CCAC Waiting time:

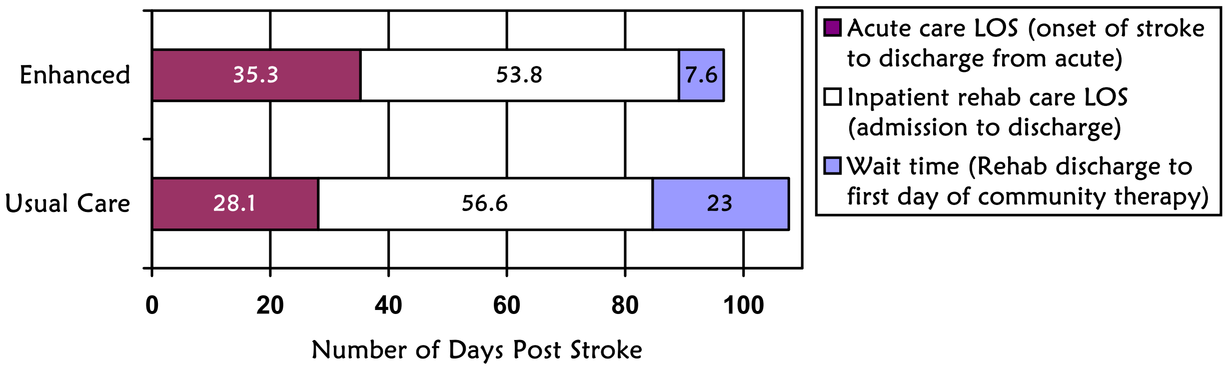
The project recorded acute and rehabilitation hospital Lengths of Stay (LOS) and wait time for CCAC therapy services as participants moved through the continuum of care. These are recorded in Table 4 and Figure 4. The lengths of stay for each episode of hospital care were not significantly different between the usual care and enhanced groups, although there was a slightly shorter LOS in acute care for the usual care group and a slightly shorter LOS in rehabilitation for the enhanced group. There was a statistically significant difference between the CCAC wait times for the two groups, as expected due to the explicit design of the project to provide timely therapy for the enhanced group (mean wait of 7.6 days). This shorter time was also reflected in the overall time from onset of stroke to the start of CCAC therapy (mean of 96.7 days). Of note is the usual care group's wait time of 23 days for CCAC therapy.

Table 4 – Hospital Lengths of Stay and CCAC Waiting times

Time Period	Usual care Days (range)	Enhanced Days (range)
Acute care Mean LOS (stroke onset to discharge from acute)[1].	28.1 (4-90)	35.3 (5-199)
Inpatient Rehab care Mean LOS (rehab admission to discharge)[2]	56.6 (8-156)	53.8 (22-150)
CCAC Therapy Wait time (rehab discharge to first day of community therapy)	**23.0** (0-96)	**7.6*** (1-31)
Stroke Onset to First day of Community Therapy (total of three above)	107.7 (23-224)	96.7 (42-285)
* Significant at p<.05		

1. Combined Acute LOS (E & UC) range was from 4 to 199 days
2. Combined Rehab Inpatient LOS (E & UC) range was from 8 to 156 days

Figure 4 – LOS and CCAC Wait Times (days) for the 2 Study Groups



Community Services Workload:

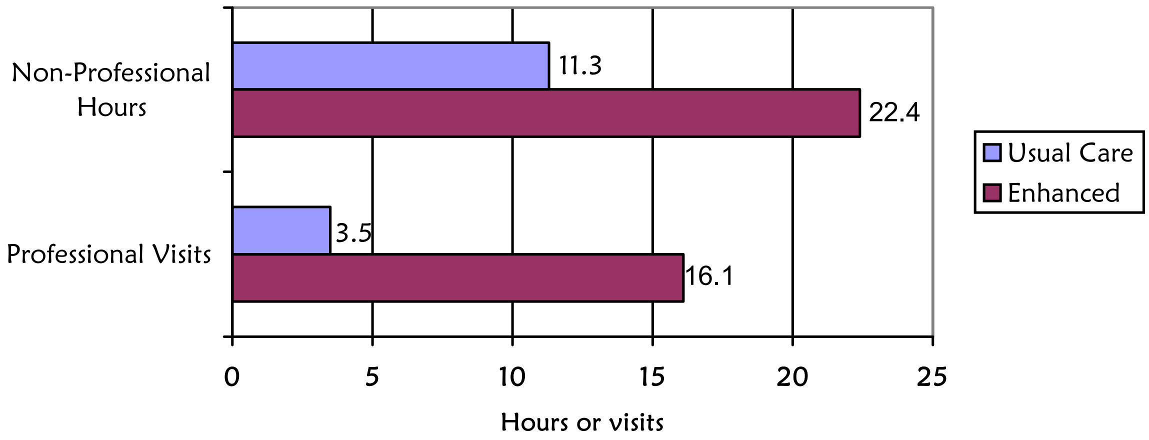
The three SEO CCACs provided the project with the details of the therapy and PSW services provided to each DLP participant in the first two months following discharge from inpatient rehabilitation, as noted in Table 5 & Figure 5. A significant difference is indicated in both professional and non-professional service levels, as designed by the project. However it is interesting to note that newly disabled stroke clients discharged to the community in SEO normally receive less than 4 rehabilitation therapy visits in the first 2 months of CCAC service.

Table 5 – Community Services Workload in first Two Months

Provision of Community Services (first 2 months)	Usual Care	Enhanced
Professional Therapy (OT, PT & SLP), mean number of visits/client (Standard deviation or SD)	3.5(3.4)	16.1(9.4)*
Non-professional (PSW) services, mean number of hrs/client (SD)	11.3(22.8)	22.4(33.5)#

* Significant at p<.05 # Evidence of a difference, 0.05 <p<0.17

Figure 5 – Provision of Community Services in First Two Months



Discharge Link Meetings:

One of the strategies to improve communication was the face-to-face Discharge Link Meeting to be held between inpatient and community therapists prior to patient discharge (see Appendix E iii for details). Unfortunately, most providers found this requirement too difficult to schedule, so only 12 such meetings took place for the 37 enhanced clients taking part.

Re-hospitalizations:

Participants were asked at 3, 6 and 12 months following discharge from their inpatient rehabilitation stay about any readmissions to hospital, the reasons for these, and how long they were admitted. The results in Tables 6a and 6b indicate a considerable difference in the number of readmissions between the groups. Almost half (46%) the clients in the usual therapy group were readmitted, whereas just under l in 4 (24%) of the enhanced therapy clients were readmitted. The 73 bed days utilized by the enhanced group was almost half of the 133 bed days utilized by the usual care group.

It is impossible to assume a causal relationship between the enhanced therapy and the readmission rate, however, it is interesting to note the reasons for readmissions presented in Table 6b. Two of the participants in the usual care group experienced fractures from falls. There were no fractures from falls in the enhanced group. Three of the participants in the enhanced group received elective surgeries (knee, hip replacements, bypass surgery) that might not have been performed had the clients not been recovering well.

Table 6a and Figure 6 present the total cost of re-hospitalizations of the DLP participants during the project study period. The Ontario Case Cost Distribution Methodology direct cost per diem in an acute care bed in 2003 for the East MOHLTC Region was $658/diem. This rate was used to calculate the costs of the readmissions to acute care as noted in the table. The total costs of readmission in the usual therapy group approached twice the costs of the readmissions in the enhanced therapy group, despite the lower numbers of only 24 in the usual care group versus 37 in the enhanced group. The cost per client of readmissions in the usual therapy group was $3,646 versus $1,298 in the enhanced group.

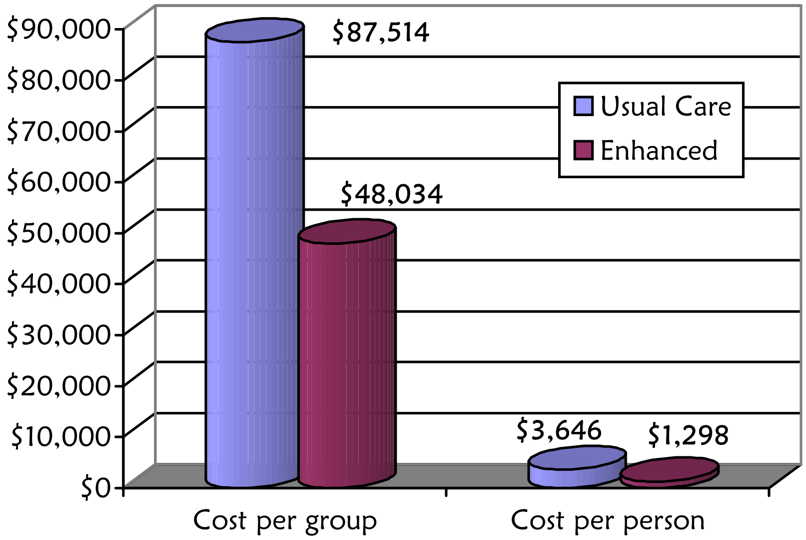
Table 6a – Hospital Readmissions after Discharge to the Community

Event	Usual Care (24)		Enhanced (37)	
	n	%	n	%
Number of clients with Readmission to hospital (at least one night)	11	46	9	24
Number of times readmitted Once	7	29	6	16
Twice	3	13	3	8
Three times	1	4	0	0
Total number of visits	16		12	
Total # of bed-days	133		73	
Average number of days of readmission per visit	8.3		6.1	
Total cost to the acute care system (#bed days x $658/day)	$87,514		$48,034	
Average cost of acute readmissions per patient in each study group (total cost / total N per group)	**$3,646**		**$1,298**	

Table 6b – Reasons for Hospital Readmissions after Discharge

	Usual care group	Enhanced Group
	Number of admissions (number of days)	
TIA	3 (4 days)	2 (5 days)
Seizure	6 (50 days)	1 (1 day)
Pneumonia	1 (14 days)	1 (14 days)
Multiple fractures from fall off bicycle	1 (4 days)	
Pelvic Fracture	1 (45 days)	
Total Knee replacement		1 (14 days)
Total Hip replacement		1 (6 days)
Gastro-intestinal tube complications	2 (8 days)	
Coronary Bypass surgery		1 (7 days)
Dehydration		1 (1 day)
Heart conditions	1 (5 days)	1 (1 day)
Infections	1 (3 days)	1 (2days)
Kidney Stones		1 (15 days)
High Blood Pressure & Urinary tract infection		1 (7 days)
Total number of readmissions	**16 (133 days)**	**12 (73 days)**

Figure 6 – Cost of Re-Hospitalizations



Cost of CCAC Rehabilitation and PSW Services

Table 7 presents the costs for CCAC services derived from the workload data submitted to the project by the CCAC's. They may not reflect total costs to the CCAC such as administrative costs, and costs incurred beyond the 2-month study period used in this project. Excluded from these costs were the DLP funds used to provide equipment for enhanced participants, of up to $200 per person. Approximately half the enhanced clients accessed these funds.

Averaged across the three CCAC's, clients in the usual care group received $509 worth of service, ranging from a $259 to $875 depending on the region. Client cost in the enhanced group, averaged across the three CCAC's, was $2146 per person, ranging from $1591 to $2849. Note that these enhanced costs include the cost of BOTH the usual level of service PLUS the enhanced level of service. Therefore it cost an average of an extra <u>$1637</u> per client to provide the enhanced therapy. It is interesting to note that the added cost of service in the enhanced group is less than the added cost of the readmissions of <u>$2348</u> in the usual care group. The difference in readmission costs cannot be directly linked to the treatment intervention, however there ARE savings directly attributable to the enhanced therapy related to improved client function to be noted in section 1.3.3.

Table 7 – Regional Breakdown of Services and Costs (first 2 mos of CCAC service only)

Service Costs for Usual Care Group (N=24)				
SEO Region	# of Professional therapy visits (ave/client/2mos)	Non-professional hrs of service (ave/client/2mos)	**Total 2 month Service Costs**	**Average cost per client**
A (n =6)	5 (0.8)	55(9.2)	$1,555	$259
B (n =8)	23 (2.9)	0 (0)	$3,155	$394
C (n =10)	57 (5.7)	215 (21.5)	$8,747	$875
TOTAL	84 (3.5)	270 (11.3)	$13,457	**$509 averaged across 3 CCAC's***
Service Costs for Enhanced Group (N=37) – includes usual care plus enhanced service				
SEO Region	# of Professional therapy visits (ave/client/2mos)	Non-professional hrs of service (ave/client/2mos)	**Total 2 month Service Costs**	**Average cost per client**
A (n=12)	127 (10.6)	407 (33.9)	$19,095	$1,591
B (n=13)	259 (19.9)	20 (1.5)	$37,039	$2,849
C (n=12)	211 (17.6)	402 (33.5)	$23,968	$1,997
TOTAL	597 (16.1)	829 (22.4)	$80,102	**$2,146 averaged across 3 CCAC's***

*This is the cost that would be incurred if referral numbers were equal from each region. Actual average costs were $561 for the usual care group and $2165 for the enhanced group due to uneven referral patterns and different costing parameters in the three CCAC's.

Models of Therapy Care in SEO

Table 7 also provides information about the varying models of rehabilitation care provided in the community across SEO. When comparing the nature of service provided for the enhanced group, the data illustrate the following:

- Areas A and C provided less professional therapy and more non-professional services, at a ratio of approximately 1:3 for area A and 1:2 for area C (one therapy visit per 2 to 3 hours of PSW service); and
- Area B provided mostly professional therapy but limited non-professional services, at a ratio of approximately 13:1 (13 therapy visits per 1 hour of PSW service).

The reasons for these variances are thought to be primarily because of human resource availability in each region, contracting transitions with the CCAC RFP process, and long wait lists. Some areas experienced changes in service providers in the middle of the project. Area B reported a long wait list for PSW services, so participants in both the usual care and enhanced care groups may have received PSW support, but not until after the 2 month "window" of the project timelines. These "models" become significant when patient functional recoveries are compared, in the next section.

1.3.3 Functional Outcomes

Each participant's functional ability was assessed using the FIM as part of the CIHI-NRS at least 3 and up to 5 times, for up to a year following discharge. The codes used in Table 8 (and tables to follow) are explained below.

- ADM: At admission to the rehabilitation inpatient hospital (n = 61)
- DIS: At discharge from the rehabilitation inpatient hospital (n = 61)
- +3: At 3 months after discharge from the rehabilitation hospital (n = 58)
- +6: At 6 months after discharge from the rehabilitation hospital (n = 48)
- +12: At 12 months after discharge from the rehabilitation hospital (n = 23)

Three participants were unable to be assessed at +3 months, but were included in the +6 month's group. Not all participants could be assessed at +6 and +12 months, depending upon the date of referral to the project. There were two withdrawals from the project due to one death and one major illness.

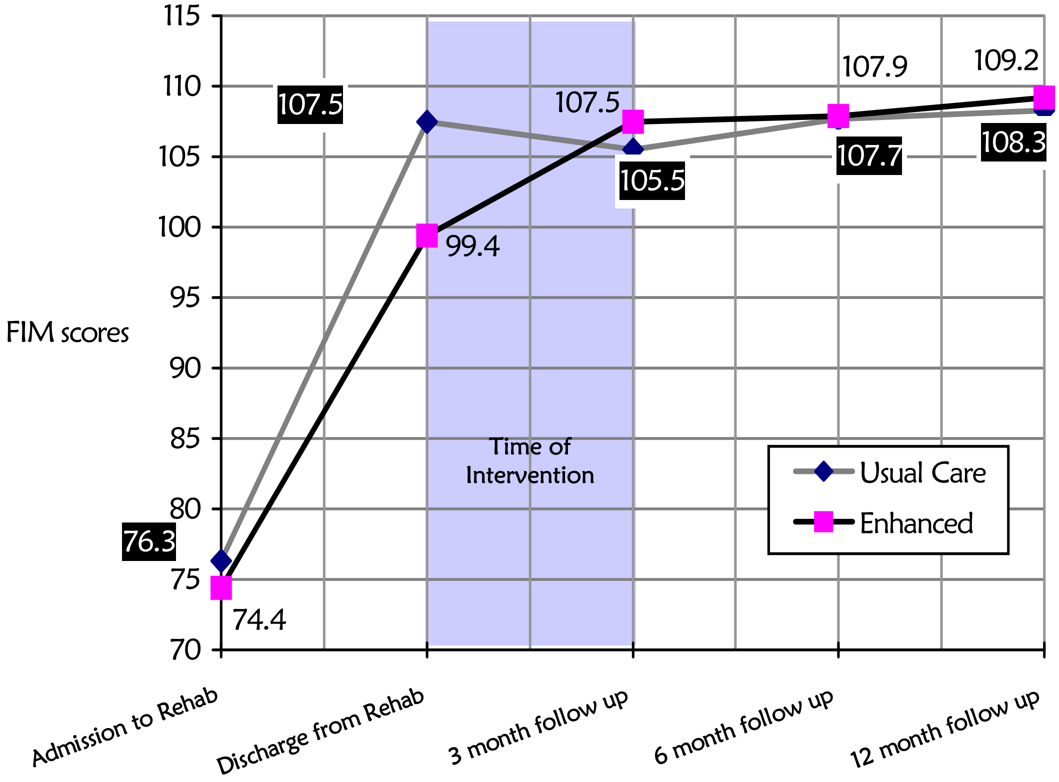
Table 8 and Figure 7 indicate that participants in both therapy groups (usual care and enhanced) were admitted to inpatient therapy rehabilitation with similar FIM scores. (Recall however, that the enhanced group had a one week longer stay in acute care and was noted to be a slightly more involved group with respect to FIM-FRGs per Figure 3.) The actual FIM scores are similar between the usual care and enhanced groups at all time periods except for discharge when a significant difference is observed (p=0.054). The enhanced group is discharged at a lower level of function than the usual care group, with a slightly shorter length of rehab stay. The reason for earlier discharge may have been related to the fact that the rehabilitation team was aware when the enhanced therapy was available in the community, or may have been due to this group simply being a somewhat more involved/disabled group. Despite the lower level of function at discharge, the enhanced group FIM score exceeds the usual care FIM score at 3 month follow-up.

Table 8 – FIM scores (maximum score is 126)

Assessment time (#N,#E)	Usual therapy group		Enhanced therapy group		Test Statistic	p-values
	FIM score	SD	FIM score	SD	t	Significance
ADM (24,37)	76.25	20.78	74.41	20.04	0.35	0.730
DIS (24,37)	107.54	13.77	99.38	19.39	1.79	0.054#
+3 (24,34)	105.46	19.48	107.50	14.54	-0.46	0.809
+6 (22,26)	107.68	19.40	107.92	14.84	-0.05	0.961
+12 (17,6)	108.29	20.53	109.17	14.39	-0.10	0.925

* significant at p<.05 SD = Standard Deviation # = evidence of a difference, .05<p<0.17

Figure 7 – Functional Recovery



Change in Function

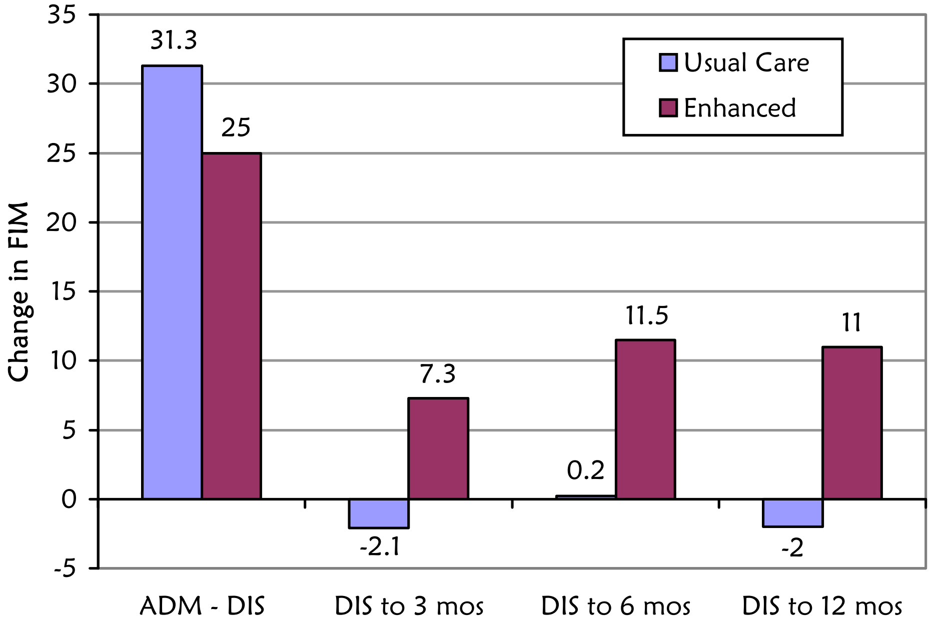
Table 9 and Figures 7 and 8 indicate that, between discharge and the 3-month follow up, there is a significant difference in the functional recovery of the two groups. This increased change occurred specifically in the time period in which the project provided the intervention of the enhanced therapy services. The usual care group actually dropped in function (-2.08 units) and the enhanced group advanced by +7.32 units on the FIM scale. A change in one unit is clinically significant in this score, especially at this point in the recovery curve. This improvement in function is maintained at 12 months for the enhanced group. The changes in FIM scores in the enhanced group between discharge and the 3, 6, and 12 month follow-ups are all significantly different from those in the usual care group.

Table 9 – *Change* in FIM scores

Change in FIM	Usual mean	Usual SD	Enhanced mean	Enhanced SD	Mean difference	Significance 2-tailed T test P value
DIS - ADM	31.29	15.67	24.97	13.12	1.70	0.084#
+3 - DIS	-2.08	15.21	7.32	11.14	-2.72	0.009*
+6 - DIS	0.23	15.24	11.46	12.45	-2.81	0.007*
+12 - DIS	-0.24	17.29	11.00	11.88	-1.46	0.158#

* significant at p<.05 SD = Standard Deviation # = evidence of a difference, .05<p<0.17

Figure 8 – *Change* in FIM Scores



1.3.4 Reintegration to the Community (RNL)

The CIHI-NRS follow-up battery of tests included the "Reintegration to Normal Living Index" (RNL) in which participants are asked a variety of questions concerning their return to the home and community (See Appendix G). The results are shown in Table 10. The maximum score is 22. There was no significant difference between the usual care and enhanced groups' scores. Both groups' scores indicated greater community integration as time passed.

Table 10 – Reintegration to the Community (max score 22)

Participant Groups	RNL score at +3 months	RNL score at +6 months
Usual therapy group (n = 24)	15.7	16.5
Enhanced therapy group (n = 37)	14.5	15.4

1.3.5 Participant and Caregiver Satisfaction

All participants were asked questions based on the modified CCAC Satisfaction Survey (see section 1.2 Methods, and Appendix G). The questions related to satisfaction with the services provided through the CCAC, and focused on coordination of service, timeliness and intensity of service provision, and overall satisfaction. Questions were divided by therapy service provision and PSW service provision. If a caregiver was present and willing, he or she was also asked a brief series of questions.

Table 11 demonstrates that the enhanced group was more satisfied with professional services, but not as satisfied with the non-professional services as were the usual care group. Overall satisfaction was marginally better in the enhanced group. Statistical analysis did not reveal significant differences. Relatively few caregivers were available to answer the caregiver section, however, see the Key Informant Section 1.3.6 for qualitative data that may help to explain these results.

Table 11 – Participant Satisfaction

Question	Usual	Enhanced
Overall, how would you rate the care you received from the Therapist(s)? (score out of 28)	23.73	25.11
Overall, how would you rate the quality of service provided by the PSW or homemaker? (score out of 24)	20.42	16.18
Overall, how would you rate the services you are receiving? (score out of 8)	6.22	6.46

1.3.6 Client and Provider Interviews

Focus groups:

The results of the focus groups conducted across SEO with providers are included in Table 12.

Key Informant Interviews:

To gain a more in-depth and thorough perspective on the DLP, a regional cross-section of DLP participants (5) and providers (9) were individually interviewed (see Appendix H). The participants included clients and their caregivers, and the providers were community therapists and case managers directly involved in the project. Interviews were transcribed and analyzed for significant themes and then reviewed by a panel of experts to ensure validity. These intensive interviews results are summarized in Table 12 and a more detailed and extensive record of findings can be found in the Appendix I. Figure 9 provides some quotes that were felt to be representative of key themes.

Table 12 – Key Informant Interview and Focus Group Findings

Issue	Comments
Intensity of service	Providers were very positive as extra time permitted therapists to provide more focused rehabilitation service, communicate with other therapists, involve the family and see progress over time
Client Independence	Providers felt that client independence and functional abilities were facilitated by the enhanced therapy noting the improved emphasis on recovery in the home. Some therapists worried about the transition back to usual service levels after the first 2 months. There was some concern regarding the value of enhanced PSW time in promoting

Issue	Comments
	recovery. The concern related to the fact that these individuals are largely untrained in rehabilitation principles.
System Flexibility	An important issue with most providers was that they see the present system as restrictive to encouraging full recovery. They felt some clients progress best at different times, perhaps beyond the first 2 months. Some clients may require therapy months later, or re-visits.
Rural Equity	The time required to travel to these clients poses a significant barrier to service given limited community human resources. It is difficult to provide enhanced therapy at the intensity outlined by the project without a significant increase in both fiscal and human resources. Yet, these rural clients cannot access this level of intensity of rehabilitation service through ambulatory settings such as day hospitals.
Transition	Providers unanimously agreed that the Discharge Link Meetings that took place between the community and inpatient Occupational Therapists were invaluable as a means of sharing client information and treatment goals and meeting the family, and therefore easing the transition to home. However, only 12 such meeting took place. Providers noted the difficulties met in attempting to schedule theses meetings and the need to prepare well ahead. System barriers, such as the inability of the CCAC to bill for services until after the client is discharged from inpatient care, hinder the provision of coordinated care across the continuum.
Treatment vs Assessment	This is an important issue, especially for OTs who feel their skills are underutilized in the community. Due to cost and time restrictions, their usual role has been to provide assessments for adaptive equipment in the home. With the enhanced therapy they were able to provide active therapy to promote functional recovery post stroke, something they note is now rarely resourced for this population in community settings.
Staff Turnover	Providers felt that the widespread turnover in community providers is related to low salaries, limited job security, poor job satisfaction and conflicts over client service goals related to limited resources.
Communication, Collaboration and Education	Generally it was felt that all levels of communication and collaboration were improved by the project. This included communication between providers at the same agency, or between providers from one setting to another, between therapists and PSWs and between providers and clients/family. It was observed that this improved communication also led to a greater understanding of providers' roles in the community care system, in particular, improved understanding between therapists and case managers. Therapists and Case Managers noted the need for education with respect to the particular needs of stroke clients and therapy roles.
System Priorities and Financial Barriers	Most providers and some clients stated that the priorities of clients and therapists are at odds with the CCAC system, which is concerned with its financial bottom line.
Client's need for education	Clients voiced the opinion that they were thrust into a new situation about which they knew nothing. Caregivers found they were

Issue	Comments
	unprepared as to what to expect in dealing with the stroke survivor at home. Despite education provided in the inpatient setting, the reality of discharge was overwhelming for caregivers.
Expectations of Caregivers	All caregivers expressed extreme frustration and exhaustion, and the need for support and respite. They expressed feeling overwhelmed with the care expectations placed them especially given that many are elderly and frail. This places undue stress on marital relationships. If the caregiver is still working, employers have a variable degree of understanding.

Figure 9 – Voices (Direct quotes from the Key Informant Interviews)

Provider Voices

"You get so used to working within a system that you … you forget that there might be something better out there..."

"I finally get to do real OT!"

"The system is a cycle of discontinuity"

Client and Caregiver voices

"I am totally overwhelmed"

"Horrific"

"Hell on earth"

"It was hard. It was tough"

"if spouses become therapists… it really degrades and demises the personal relationship." ***"What do you do?"***

1.3.7 Summarizing the Findings

In summary, the DLP revealed some interesting findings:

- Usual care in the community setting in SEO varies across CCAC's but on average, involves less than 4 professional rehab visits over the first two months and involves over a 3 week wait for professional rehabilitation service. The enhanced group received community therapy much sooner than the usual care group, waiting on average only a week and this group received a significantly greater level of therapy and PSW service.

- Participants in the enhanced therapy group made significantly greater change in functional recovery than those in the usual care group, especially in the 3-month period of time immediately after discharge from the rehabilitation inpatient setting. This recovery was maintained for one year following discharge.

- Models of service provision in the community varied with respect to ratios of professional visits and non-professional hours of service.
- There were fewer readmissions to hospital in the enhanced community therapy group during the first year following inpatient discharge.
- Providers were positive about the improved care and change in function observed in their clients in the enhanced therapy group. They were also positive about their ability to provide service that met client rehabilitation goals and about having time to educate clients and family members.
- Providers are frustrated with what they perceive as system barriers in the provision and coordination of community care.
- Caregivers are overwhelmed with the demands of caring for their spouses, family or friends.

1.3.8 Explaining the Findings: Regression Analysis

The DLP collected a large amount of data on all the participants. Multiple linear regression analysis was used to help understand the most important predictors for the significantly different change in functional outcomes between the enhanced and usual care groups. With this technique, a model is proposed that attempts to explain the variability in the dependent outcome variable, in this case, the greater change in the enhanced group's FIM over the first 3 months of community therapy, using a group of potential independent predictor variables. Different models were tested in an attempt to explain what was most predictive of the change in function during the period of the intervention.

The Full Model: A regression analysis was performed taking a broad approach to answering the question, "What explains the variability between the change in function of the two groups?" Any suspected predictors were included in the model:

- FIM score at Discharge;
- Whether or not the Discharge Link Meeting took place;
- Whether or not the client was given t-PA;
- Gender;
- Age;
- Total time (days) from stroke onset to first CCAC therapy visit;
- Number of Rehabilitation Care Professional Visits; and
- Non-Professional Service Hours.

This initial analysis noted that age, gender, the discharge link meeting, time post stroke onset, and tPA delivery were not contributing to the model predicting the change in FIM score.

A Reduced Model: By discarding the predictors that appeared to have little or no influence on the variability of the change in FIM score, a "reduced" model was produced that reflected on those predictors with greater significance. This "reduced" model is presented in Table 13 and highlights the contribution of *FIM scores at Discharge*, *Total time (days)* from stroke onset to first CCAC therapy visit, and *Number of Rehabilitation Professional Visits*. The total time post onset was kept in this model as it was important to know if this had a significant impact on FIM change.

Table 13 notes an R^2 of 0.23 indicating that about 23% of the variability in *Change in FIM* score in the 3 months following discharge for the enhanced group can be explained by the predictive variables used in this model. This is a reasonable R^2 given the many variables impacting on this sociological study. The regression results indicate that two factors showed evidence of explaining the variability: the *Rehabilitation Care Professional Visits* (at p=0.169), the number of professional visits made to each enhanced participant, and the *FIM score of the participant at discharge* (p=0.004). Of clinical significance is the B coefficient of 0.25 for *Rehabilitation Care Professional Visits* in the first column of Table 13. This indicates that for every 4 visits from rehabilitation professionals, one can expect a 1 point change in the FIM score over the 2 month period.

Of note is that the *Time from stroke to CCAC service* was NOT a significant variable. The enhanced participants showed significant change in function in the first three month period post discharge from rehabilitation regardless of the length of time post-stroke. Hence, regardless of the particular point in the natural progression of recovery, enhanced therapy *at the transition point to home* seems to be important in enhancing functional change in the community.

Further regression analyses did not provide evidence for the *Non-professional Hours* contributing to the predictive model for FIM Change score.

In summary, this regression analysis provides evidence supporting the intensity of rehabilitation professional therapy visits as a predictor of change in function post stroke following rehabilitation discharge to the community. The number of hours of non-professional visits (PSWs) does not predict change in function.

Table 13 – Regression Model (R^2 =0. 23) Dependent Variable: 3 Month Change in FIM

Predictors	Unstandardized Coefficients		Standardized Coefficients	t	**significance**	95% CI for B	
	B	Std. Error	Beta		**p-value**	Lower Bound	Upper Bound
(Constant)	35.22	13.51		2.61	0.012	8.14	62.3
FIM at Discharge	-0.32	0.11	-0.40	-2.98	**0.004***	-0.53	-0.10
Time from stroke onset to CCAC service	-0.02	0.03	-0.07	-0.56	0.581	-0.09	0.05
Rehab Care Prof. visits	0.25	0.18	0.18	1.40	**0.169#**	-0.11	0.61

*** significant at p<0.05** # evidence of a difference at 0.05<p<0.17

1.4 Discussion of DLP Results

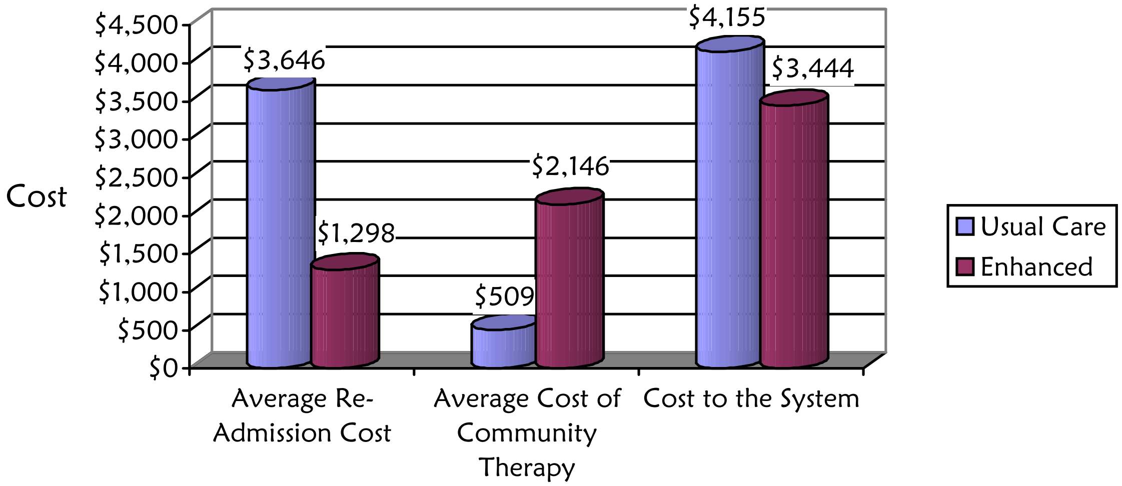
1.4.1 System Utilization, Costs, and Access to Services

The DLP results reveal that providing a stroke client with timely and enhanced professional rehabilitation therapy in the community on transition from the rehabilitation hospital setting may decrease his or her utilization on other parts of the health care system. It is impossible to assume a causal relationship between the enhanced therapy and the readmission rate but it is important to note that almost half (46%) the clients in the usual care group were re-admitted to acute care hospitals, whereas only 1 person in 4 (24%) from the enhanced group was re-admitted. A person in the enhanced group of the study cost an average of $1298 in re-admission costs to the acute care settings (assuming $685/day in acute care per the East Region 2003 rate using the Ontario Case Cost Distribution Methodology), but the survivors who did not receive intense and timely community service cost $3646, three times as much to the system. The difference in the costs of readmissions in the usual care group compared to the enhanced group is $2348 per person.

Table 7 noted that the average cost of providing community therapy and PSW services in SEO over the first 2 months since discharge for the usual care group was $509 per client, whereas the *enhanced* therapy & PSW services amounted to $2146 per client, or an increase of $1637 per client. The **net difference** in these two sets of costs is over $700 per client. See Figure 10.

The enhanced community service may have provided an opportunity for proactive management of patients with more severe disabilities. The client and provider key informant interviews underlined the importance of time availability for client and family education in the home. Preventative management including client and family education, increased safety in mobility, fall prevention, improved understanding of the implications of cognitive and perceptual deficits on safety in the home environment may be potential reasons for the decreased admissions in the enhanced community therapy group. Certainly, the admissions related to fractures from falls were in the usual care group, and the admissions for elective procedures were in the enhanced group.

Figure 10 – Cost Comparisons: Enhanced Community Therapy versus Usual Care



In addition to the cost differences presented in Figure 10, it should be noted that the improved and sustained functional recovery of the enhanced clients may translate into decreased service costs over time. The FIM is a measure of burden of care. If the FIM score improves, the burden of care and associated resources are reduced. The usual care study group did not show improved function in the community, and in fact, lost function over time, while the enhanced study group improved in function and maintained the improvement for a year. Providing an adequate *intensity* of rehabilitation services *at the right time* for this group of recovering stroke survivors is critical to ongoing independence in the home and a reduced long term burden of care.

Another important cost implication is that the length of stay in rehabilitation was slightly reduced for the enhanced group, despite their lower functional level at discharge. If more intensive expert community rehabilitation services were available for stroke clients, rehabilitation units might well discharge these patients sooner, knowing the expert service would continue at home. Currently, without the DLP enhanced therapy services, if a patient undergoing stroke rehabilitation is to be discharged home to a rural part of SEO, the inpatient team tends to delay discharge, knowing that limited stroke rehabilitation services are available in the more remote community settings.

Those who were able to access day hospital stroke rehabilitation services were excluded from participating in this study. There is some inequity across the region as to the ability to access ambulatory day hospital rehabilitation services, due to the rural geography and due to a lack of day hospital services in some parts of the region. A coordinated team approach is necessary in the rehabilitation of stroke survivors due to the complex range of disabilities experienced. For those who live too far away from the day hospital or are too disabled to travel, timely coordinated expert team community services need to be made available. The lack of change in the FIM score in the usual care group has underlined the important long term implications of not providing adequate rehabilitation service levels following discharge. The enhanced costs of the DLP services included a travel subsidy to allow providers to reach clients in remote areas of SEO at an increased level of service. This is an important consideration for facilitation of service delivery closer to home in remote regions.

1.4.2 Client Functional Recovery and Access to Services

The project has shown that stroke client function significantly improves with enhanced community rehabilitation therapy following inpatient therapy. The functional levels of the participants in the enhanced therapy group improved faster and to a greater extent than their usual therapy group counterparts despite being a somewhat more disabled group from the perspective of FIM-FRG's and discharge FIM scores. People with stroke are **able** to recover significant function when an appropriate level of professional rehabilitation therapy is provided. As the usual care group findings show, stroke clients actually lose function after they leave the inpatient rehabilitation unit and go home if appropriate levels of service levels are not provided. It is important to maintain the benefits of inpatient rehabilitation services as recovering stroke survivors transition to the home setting.

The DLP results also underline the importance of the timeliness of enhanced rehabilitation services following discharge. Timely and appropriate levels of rehabilitation have been shown to be important in inpatient rehabilitation care. This study showed that this is also true in the community setting. The enhanced group waited only 7.6 days for service, whereas the usual care group waited over 3 times as long (23 days). Unfortunately, this long waiting period has been a fact of life for newly discharged stroke clients in parts of SEO for many years. The rehabilitation needs assessment performed in 2001 in the area revealed that inpatient providers in some areas had stopped referring stroke clients to community care because the wait time for service was so long that the service was unreliable for transition management. The potential reasons are related to low staffing levels, insufficient community funding and system barriers complicating coordination and communication between health care settings. The DLP results have shown that it is possible to decrease these wait times, and to make a significant improvement in a stroke client's recovery if the system is adequately resourced to provide priority services to those with potential for further recovery. The key informant interviews of both providers and clients/caregivers noted the critical need for service at the time of transition to home. Caregivers noted that despite education received in the hospital setting, they were unprepared for the overwhelming permanence of stroke survivor care needs at the time of transition to home. The providers noted the benefits of having more time for education. This is an important role of the community rehabilitation team.

Setting priorities for care for stroke survivors in the community warrants further attention in light of these findings. Although the numbers of moderately and severely disabled clients unable to access community outpatient or day hospital follow up service may be low, their needs are high and this group stands to benefit from intense and timely community therapy.

The regression analysis indicated the importance of professional (OT, PT, SLP) therapy care in the recovery of a stroke client. The number of professional visits in this time period showed evidence of predicting change in client function. People in the usual care group received less than 4 (3.5) professional visits during their first 2 months home, and usually one of those visits was an assessment for adaptive equipment. The enhanced therapy group received 16 visits in the same time period. At the same time, the analysis noted that the amount of PSW time made no difference to the functional recovery of stroke clients. However, the project team does not want to discount the value of this service as many caregivers rely heavily on the homemaker for relief, respite and social contact. The key informant interviews with clients and caregivers noted the important role of the personal support worker for caregiver relief. The provider interviews also underlined concern regarding the limited expertise of the PSW in reinforcing rehabilitation principles though daily activities. The study results raise the issue of the role of the PSW in rehabilitation of stroke clients in the home. With further education and training in rehabilitation principles, it is possible that the PSW's might have had a more important impact on actual recovery of function.

1.4.3 Satisfaction: Patient, Caregiver & Provider

Coordination and Collaboration:

The DLP provided increased opportunity for providers to communicate and collaborate on issues of stroke client care through the Discharge Link Meeting held between inpatient and community therapists prior to patient discharge. Unfortunately, most providers found this requirement simply too difficult to schedule in the limited timeframe provided (only 12 such meetings took place for the 37 enhanced clients taking part). Nevertheless, as noted in the key informant interviews, when the meetings did occur, providers were very positive about the effects of this meeting. They felt that everyone benefited from these encounters: providers, case mangers, clients, and caregivers. A few participants from the enhanced group commented in the interviews on how the therapists were working as a team and on how smoothly the transition went from hospital to home.

Community providers also commented on the usefulness of simply being involved in the project, including the process training sessions held early on, to the focus groups held toward the end of the project. They were emphatic about how these sessions improved communication between the providers with whom they worked. They emphasized the benefits of learning more from their rehabilitation unit colleagues. Sharing of provider expertise in stroke rehabilitation was important.

The key informant interviews revealed some discomfort regarding the interaction of case managers and providers. Some providers felt the case manager did not always understand stroke client goals and the skills the therapists were able to provide, and therefore did not appropriately allot enough rehabilitation time for certain stroke clients. The DLP appears to have bridged some of those knowledge gaps as providers and case managers had the opportunity to interact more closely and to base care provision on client goals rather than being constrained to CCAC resource limitations. Again the study points to an issue around priorities for stroke care in the community setting.

Provider Satisfaction:

Providers stated that they were more satisfied when working with clients in the enhanced therapy group. Improved functional recovery was easy to observe, client-provider compliance increased, familiarity with the client and his or her family assisted therapy, and as a result, providers were more satisfied with their work.

OTs in particular noted a significant change in the nature of their work with the clients in the enhanced group. According to the interviews, normally, due to fiscal restraints, OT visit allocation is largely limited to conducting an assessment of the home environment for adaptive equipment or alterations. With the clients in the enhanced therapy group, OTs had the time to be able to provide therapy to enhance functional recovery, often in conjunction with the PT or SLP. This was very satisfying to the OTs and in many cases was corroborated by clients' statements concerning the effectiveness of the therapy sessions.

Caregiver Satisfaction:

More often than not, the people who provided care for stroke clients were exhausted, emotionally unstable, ill themselves or simply overwhelmed. Whereas stroke survivor satisfaction appeared to improve over time as he or she became accustomed to life with a stroke, caregivers saw their role as a "life sentence", with no relief. In several situations, the project interviews revealed that a caregiver's attitude and exhaustion actually impeded the stroke client's recovery.

1.5 DLP Sustainability and Costs

The findings of the DLP provide new information related to best practice in the provision of community based stroke rehabilitation for recovering stroke survivors. The costing information provided throughout the report underlines the sustainability of adequately resourcing community stroke rehabilitation services. *The provision of enhanced community service is cost-effective and sustainable because enhanced and timely therapy improves client function and may also decrease* *system utilization by recovering stroke survivors.* The study has noted that resourced transition planning can improve long term recovery from stroke disability. The differences in the costs of enhanced therapy compared to acute care readmissions support the importance of adequately resourcing the community setting to provide continuing professional care in the home.

It should be noted that a triage system to set priorities for enhanced community services for recovering stroke survivors will maximize the provision of appropriate therapy services at adequate levels to meet client needs. Consistent regional planning mechanisms for client selection, triage, and priority setting for community service delivery models will maximize service delivery to the right stroke client at the right time. Regional planning mechanisms will be sustainable only if an infrastructure is in place to promote this. This study, and the work of the Stroke Strategy of Southeastern Ontario in other parts of the continuum of care, have successfully demonstrated the benefits of working regionally on the planning and delivery of stroke care across the continuum. Support for a Regional Rehabilitation Stroke Strategy staff member would assist in further sustaining the work begun in this project.

1.6 DLP Transferability

The results of the DLP could be transferable to people who:

- live at home, anywhere in Ontario whether it is in the rural or urban environment
- have new disability and have received inpatient rehabilitation related to that new disability
- are unable to access ambulatory outpatient services
- have the potential for further recovery

The study results might be transferable to the long term care setting but this was not explicitly studied in this Pilot. This certainly warrants further investigation, as many recovering stroke survivors are being discharged to long term care without having received the benefits of intensive rehabilitation services.

1.7 DLP Recommendations

The project team recommends the following:

1. Provide timely appropriate intensive home-based professional therapy to meet the community rehabilitation needs of stroke clients being discharged from inpatient rehabilitation with moderate and severe strokes. This is particularly important when these clients are unable to access ambulatory services in the community.

2. Priority setting for community service for this client group may need to be re-considered to ensure that appropriate and timely levels of service are provided. This study provides new evidence about what newly disabled stroke survivors require in terms of appropriate service levels to meet their needs and to promote savings across the care continuum.

3. Increase system responsiveness and flexibility to allow for meeting the particular rehabilitation needs of recovering stroke clients in the community.

4. Promote models of community-based care that best promote stroke client recovery. Timely provision of adequate professional service is an important factor in the model for community care.

5. Create and resource a formal process to support inter-provider communication and coordination of care between the hospital inpatient rehabilitation setting and community-based care.

6. Investigate strategies to recruit and retain professional services to prevent shortages and to promote a stable provider workforce. Frequent change in service provider agencies leads to difficulty with human resource recruitment and stability, impacting on continuity of care.

7. Provide stroke rehabilitation education to professional staff of provider agencies and to case managers. The personal support worker requires education regarding rehabilitation principles and functional activities in the provision of stroke care in the home. Consider designating a CCAC staff member to focus on stroke and to serve as an expert resource to other staff.

8. Explore the role of the physiotherapy assistants, occupational therapy assistants and communication disorder assistants in the community rehabilitation of stroke survivors. Provide rehabilitation training to support personnel. (The project demonstrated that service from *untrained* support personnel does not have an impact on recovery of function post stroke.)

9. Support caregivers with increased respite, education about stroke and by linking clients with the services provided through community support agencies.

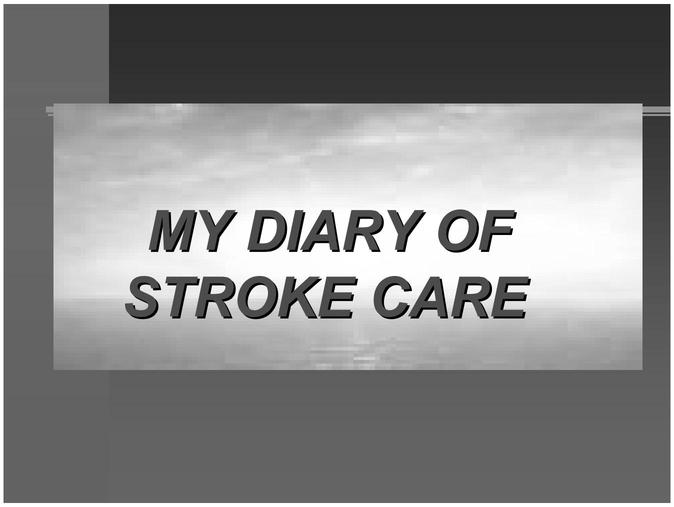
10. A triage system to set priorities for enhanced community services for recovering stroke survivors will maximize the provision of appropriate therapy services at adequate levels to meet client needs. Regional planning mechanisms will be sustainable only if an infrastructure is in place to promote this.

Part 2 – The Stroke Client Profile “*My Diary of Stroke Care*”

2.1 Objective of the Stroke Client Profile “*My Diary of Stroke Care*”

The Diary of Stroke Care (Figure 11) piloted a client-centred method of communicating client information across the continuum of care to clients, caregivers and health care providers. The study aimed to develop, trial and assess a stroke information tool designed to share timely and consistent information, including patient goals, as the patient moves through various care settings and organizations in the continuum of care and across the region.

Figure 11 – My Diary of Stroke Care Cover



MY DIARY OF
STROKE CARE

2.2 Diary Methods

2.2.1 Distribution of the Stroke Client Profile “*My Diary of Stroke Care*”

With input from many stakeholders involved in the provision of stroke rehabilitation across SEO, stroke survivors and caregivers, the project staff developed a booklet entitled, “*My Diary of Stroke Care*”. The Diary contained a brief outline of client information and therapy goals so that health care providers and patients across the stroke care continuum could have straightforward access to patient-centred information. The Diary was distributed at four acute care sites in SEO (Table 14) beginning with patients who were receiving acute inpatient care for a new stroke. The strategy was to distribute as many diaries as possible to stroke clients and to track the use of the Diary as the client took it through the full spectrum of stroke care settings. The Diary was owned by the patient/client, but written consent was still obtained from each client using the diary to ensure that the patient was willing to participate in the evaluation of its use. Sessions were held with care providers at the acute, rehabilitation and community settings to describe the diary goals and to encourage its use. See Appendix J to view the Diary.

Table 14 – Distribution of the Stroke Diary

Acute Care Distribution Site	Numbers of Diaries distributed	Numbers of users interviewed
Kingston General Hospital (Regional Stroke Centre) - 454 beds	48	25
Quinte Health Care - Picton site (Community Hospital) – 38 beds	7	4
Quinte Health Care - Trenton site (Community Hospital) – 64 beds	2	2
TOTAL	**57**	**31**

As Table 14 illustrates, it was difficult for the smaller sites in SEO to recruit many clients, for a variety of reasons. Primarily, this was related to a lack of time on the part of busy health professionals. KGH, as a Regional Stroke Centre, has a Best Practice Stroke Team with an Advanced Practice Nurse designated to stroke care who ensured that use of the Diary was initiated and explained to the patient, family and care team. Smaller community hospitals are not resourced in this manner. One other reason for less use in the community hospital settings may have been that smaller sites tended to keep patients with more severe strokes, while higher functioning patients would often be moved to another site with more opportunity for rehabilitation. According to the staff that requested consent from the patients to participate in the Diary project at these centres, these more disabled patients tended to be less able to use and less interested in using the Diary.

2.2.2 Evaluation of the Diary

Client Feedback:

After 2 to 3 months, the project coordinator attempted to reach every diary user by telephone, and of those contacted, 31 agreed to a brief interview.

Provider Feedback:

Care providers in the region provided feedback at focus group sessions and by returning a tear-out evaluation form contained in each Diary. The project received 25 responses.

2.3 Diary Results

2.3.1 Summary of Stroke Survivor and Caregiver Feedback

Of the 31 clients contacted, 74% could still locate the Diary but only one person was still using it. All users found it easy to complete, but some spouses commented that they were often too busy providing care to take the time to complete the Diary. Several people commented that they were disappointed by the lack of interest shown in the Diary by the health care professionals. It appears the usage of the Diary decreased as the client moved through the continuum of care, as several people stated that the Diaries were lost in transit. One third of the users felt it did assist with their recovery, usually because it gave the stroke client or caregiver an awareness of personal therapy goals and progress made. Suggestions included:

- Reviewing how to use the Diary with the patient and family after the stroke survivor is out of the acute stage, and more able to focus on its use,
- Making it easier to read,
- Encouraging professionals to use it more; and
- Including more information on stroke recovery.

For a full listing of user's comments see Table 15 and Appendix K.

Table 15 – Summary of Stroke Survivor and Caregiver Diary Feedback (n = 31)

Question	Number answering Yes	Number answering No
Can you still locate your Diary?	23	3 (5 unsure)
Do you still use it? (2 to 6 mths post discharge)	1	30
Was it easy to complete?	14	0 (4 unsure)
Was it too much work to fill out?	2	18 (2 unsure)
Were you comfortable disclosing confidential information?	29	2
Did the Diary assist in your care?	9	6 (1 unsure)
How did you use the Diary?		
Only briefly at first	6	
Daily, to monitor improvements	6	
To keep track of exercises	1	
To keep track of appointments/important dates	3	
Therapists used it to track goals and progress	3	
For information	2	
For Medical history	2	
Did not use it	9	
What part of the Diary was most useful to you?		
1. Information about me	2	
2. Information about My Stroke	8	
3. History of my care	1	
4. My Goals	3	
5. My Diary (blank section)	7	
All of it	3	

2.3.2 Summary of Provider Feedback

The project coordinator received comments on the Diary from 25 stakeholders across the region, either by fax, email or in person. These included nurses, therapists, care managers and administrators at different settings along the continuum of care, including Long Term Care. Most respondents made comments and completed a brief checklist using a 1 to 7 Likert scale, see Table 16. Comments were positive about the Diary size and format, the amount of information it included, the ease of use and the need met by this tool. Reservations included the lack of time available to health care professionals to initiate its use, to write in the diary or to use it. This led to difficulties gaining compliance of health care professionals (especially physicians). Confidentiality concerns were expressed during the development of the Diary, but were no longer of concern once the Diary was evaluated. Suggestions were to make it easier for clients with sight problems to read, to make it more aphasia friendly, to include more pages for the client's own Diary section and to make it more available for use in Long Term Care settings. Several providers commented that some clients might find it overwhelming to use the Diary due to its complexity, and also that the information might sometimes be discouraging for clients who are slow to recover due to the emphasis on functional abilities.

Table 16 – Provider Responses to the Diary Questionnaire (N=25):

		Not at all						Yes, very
Question		1	2	3	4	5	6	7
1	Was the Diary useful to me?				3	3	19	
2	Was it easy to use?					9	16	
3	Did this Diary help to improve my, or my client's, knowledge about my stroke and my recovery?				3	6	12	4
4	Did you feel comfortable disclosing the information in this Diary to others?					7	14	4
5	Was the information completed by other providers helpful in my treatment of the client?					12	13	
6	Did information in this Diary prompt me to contact other providers to discuss the client's care?				7	4	7	7

2.3.3 Summary of the Diary Results

Providers and clients in the SEO region and beyond have expressed a great deal of interest and a sense of relief that the Diary was created and used. Creating the Diary was a thorough yet complicated process as all stakeholders had a different vision as to what would be most important to include in the Diary. Although there is little doubt that the Dairy has met a need, the problem remains one of implementation. The project was fortunate to have been strongly supported by the timely creation of a "Stroke Team" at KGH, with an Advanced Practice Nurse who made it her priority to ensure patients and caregivers were given the Diary. However, it took about an hour of her time to fill in the medical information and to familiarize each patient with the Diary.

The original purpose of the Diary was to provide a tool for providers to share and access information about the person with a stroke, *across the continuum*. This objective was met with limited success, as it was difficult to raise awareness of the Diary in all locations to all possible contacts. If the Diary were included in a standard information tool already in use, this would facilitate uptake. Clients and their caregivers seemed to embrace the Diary as a useful personal aide to record their journey through the healthcare system.

2.4 Diary Sustainability/Costs/Transferability

The Dairy could be sustainable and transferable to all stroke survivors in Ontario by inclusion of the document in existing patient HSFO resources such as "Let's Talk about Stroke" for stroke survivors or in the "TIA workbook" for those who have sustained a TIA.

2.5 Diary Recommendations

1. Include the *Stroke Diary* as part of a standard patient education and communication tool already in use by patients and providers (e.g., *"Let's Talk about Stroke"* by HSFO) in order to facilitate uptake and usage;

2. Re-design the *Stroke Diary* to meet the special needs of stroke clients (e.g. those with aphasia, visual deficits or limited arm function); and

3. Accompany use of the *Stroke Diary* with a thorough education program for the potential users, addressing privacy issues. There is a need to educate care providers about privacy of information and about patient rights to access clinical information.

Part 3 – Alpha-FIM Feasibility Study

3.1 Objective of the Alpha-FIM

The Alpha FIM Feasibility Study investigated the feasibility of implementing the Alpha FIM in acute care settings of Southeastern Ontario (SEO) as a standardized means of communicating information regarding stroke survivors' functional recovery across the continuum of care from acute to rehabilitation settings.

Overview:

The AlphaFIM™ is administered to patients within the first 72 hours of admission to acute care and again prior to discharge. It uses only a few items of the FIM instrument that can be collected reliably in the acute hospital setting. These are: eating, grooming, bowel management, toilet transfer, expression and memory. It has been shown to correlate well with the full FIM used in the rehabilitation setting (see Appendix L for a full description).

3.2 Alpha-FIM Methods

1. In September 2003 the project purchased 6 of the Alpha-FIM tools in CD format and distributed them to participating acute care sites across SEO.
2. The project obtained administrative approval to initiate the study at the relevant sites.
3. Stroke care professionals examined the device and provided feedback to the coordinator.
4. A few acute care key personnel were identified to administer the device with patients.
5. These key personnel were oriented to the use of the AlphaFIM™. The device came in a self-training CD format. Formal certification was not required.
6. The Alpha-FIM was administered to people admitted to acute care with a stroke, first within 72 hours of admission, and then just prior to discharge.
7. The usefulness and feasibility of the Alpha FIM was discussed with practice teams.
8. Users completed a survey regarding the use of the AlphaFIM™ device (Appendix L).

Effective December 2003, the company responsible for the Alpha FIM changed the format of the Alpha FIM from a CD available for purchase to a web-based device available by subscription only. As well, the CDs that were purchased automatically expired on Dec 31, 2003 so the CDs were impossible to use. The project was able to negotiate access to the new web-based system.

3.3 Alpha-FIM Results

All practice teams noted that the instrument was easy to learn to use. Lennox and Addington County General Hospital staff noted that the instrument required about 15 to 20 minutes to administer per patient. The Kingston General Hospital enhanced acute stroke team used the instrument to collect standardized information on some stroke patients. The team found that this process assisted in goal setting and in communication of functional abilities within the hospital setting and amongst the rehabilitation team members. As the acute stroke best practice team and the Stroke Strategy Case Manager position become more established, the hope is to use the Alpha-FIM as a standard outcome measure with all stroke clients moving through the acute care system. The Brockville General Hospital discharge planner used the instrument to assess function and to communicate standardized functional information on rehabilitation referrals. She noted that the Alpha FIM reports saved her time, as they provided a summary of functional information in a standard format. Some acute hospitals chose not to participate in the study due to other competing priorities and the timing of other projects.

3.4 Alpha-FIM Transferability & Sustainability

1. The assessment tool could be easily trialed in many acute care settings across Ontario. The web-based format makes it easily accessible and easy for health care providers to use.

2. The predictive properties of the assessment tool and its correlation with the full FIM make it useful for planning care for stroke survivors and for communicating functional information as part of a standardized triage system for rehabilitation care.

3. Although there is a subscription cost to accessing the web site, use of the device was noted to save time in describing stroke functional recovery and to assist discharge planning. In settings where a stroke team is in place in acute care use of this instrument would not require significant extra human or fiscal resources. Without this team, it might be possible to sustain use of the instrument by having a staff member assigned the role of administering this assessment as part of discharge planning. However, resources are needed to analyze findings and to apply the data as part of a regional system of triage to rehabilitation services.

3.5 Alpha-FIM Recommendations

1. Continue to trial the Alpha-FIM™ in its present web-based format.

2. Fiscal and human resources are needed to encourage collection of standardized outcome measures (such as the Alpha-FIM™) in acute stroke care, to encourage application of the data to practice, and to incorporate the data into a regional system for stroke rehabilitation triage.

APPENDIX A:

A(i) The Regional Stroke Steering Committee Membership and Resource Staff – Southeastern Ontario

A(ii) Stroke Rehabilitation Sub-Committee of Southeastern Ontario

Appendix A(i)
The Regional Stroke Steering Committee Membership and Resource Staff – Southeastern Ontario

NAME	INSTITUTION	TITLE
Helen Cooper, Chair	Volunteer from the community	Consultant
Pat Avery	Access Centre for Community Care in Lanark, Leeds and Grenville	Client Service Manager
Dr. Stephen Bagg	Providence Continuing Care Centre St. Mary's of the Lake Hospital	Physiatrist, Stroke Rehabilitation Team Dept of Rehabilitation Medicine
Carolyn Beatty	Ministry of Health and Long Term Care	MOH Hospital Consultant
Rose Bell	Rideaucrest Long-term Care Facility	Director of Nursing
Wilf Clarke	Resident – Stroke Survivor	Consumer Rep
Sally Cowan	HPE County HSFO	Volunteer, Health Promotion Committee
Catherine Crain	Brockville General Hospital	Discharge Planner
Bill Detlor	Hotel Dieu Hospital, Base Hospital	Program Coordinator
Paulette Jamieson	Quinte Healthcare Corporation	Director of Medicine, Critical Care and Oncology
Cynthia Johnston	Southeastern Ontario District Health Council	Senior Planner, Integrated Planning
Allan Katz	Health Care Network of SEO	Director
Eleanor Plain	KFLA Community Care Access Centre	Director, Community Care Services
Shari Sampson	Lennox & Addington County General Hospital	Director, Clinical Services and Informatics
Colleen Small	Kingston General Hospital	Director, Neurosciences, Mental Health, Transitional Care and Medicine

NAME	INSTITUTION	TITLE
Dr. Adam Steacie	Brockville General Hospital and Family Practice	Family Physician and Chief of Staff, BGH
Dr. Kate Stolee	Perth &Smiths Falls District Hospital	Physiatrist
Mark Walden	Access Centre for Hastings Prince Edward	Director, Client Services
vacant	Kingston General Hospital	Medical Director

Corresponding Members

Maureen McGuire	PCCC, St. Mary's of the Lake Hospital	Director, Rehabilitation Services
Nicole McKinnon	Hastings Prince Edward Health Unit	Director, Healthy Lifestyles Program
Eleanor Rivoire	Kingston General Hospital	Vice President Patient Care Services and Chief Nursing Officer Vice Presidents' Offices Watkins 2
Micheline Turnau	Heart and Stroke Foundation of Ontario (HSFO)	Regional Hospital Specialist, Ontario East
Sandra Zambon	Heart and Stroke Foundation of Ontario	Manager, Stroke Care Delivery

SEO Regional Stroke Program, Resource Staff

Pamela Bart	Regional Stroke Program. KGH	Advanced Practice Nurse, Acute Stroke
Paula Christie	Regional Stroke Program. KGH	Clinical Nurse Specialist, Stroke Prevention Clinic
Elizabeth Hill	Regional Stroke Program. KGH	Advanced Practice Nurse, Acute Stroke
Cally Martin	Regional Stroke Program. KGH	Regional Stroke Program Manager
John Paterson	Regional Stroke Program. KGH	Regional Stroke Rehabilitation Pilot Coordinator
Sue Saulnier	Regional Stroke Program. KGH	Regional Stroke Education Coordinator
Sue Veitch	Regional Stroke Program. KGH	SEO LTC/Community Specialist

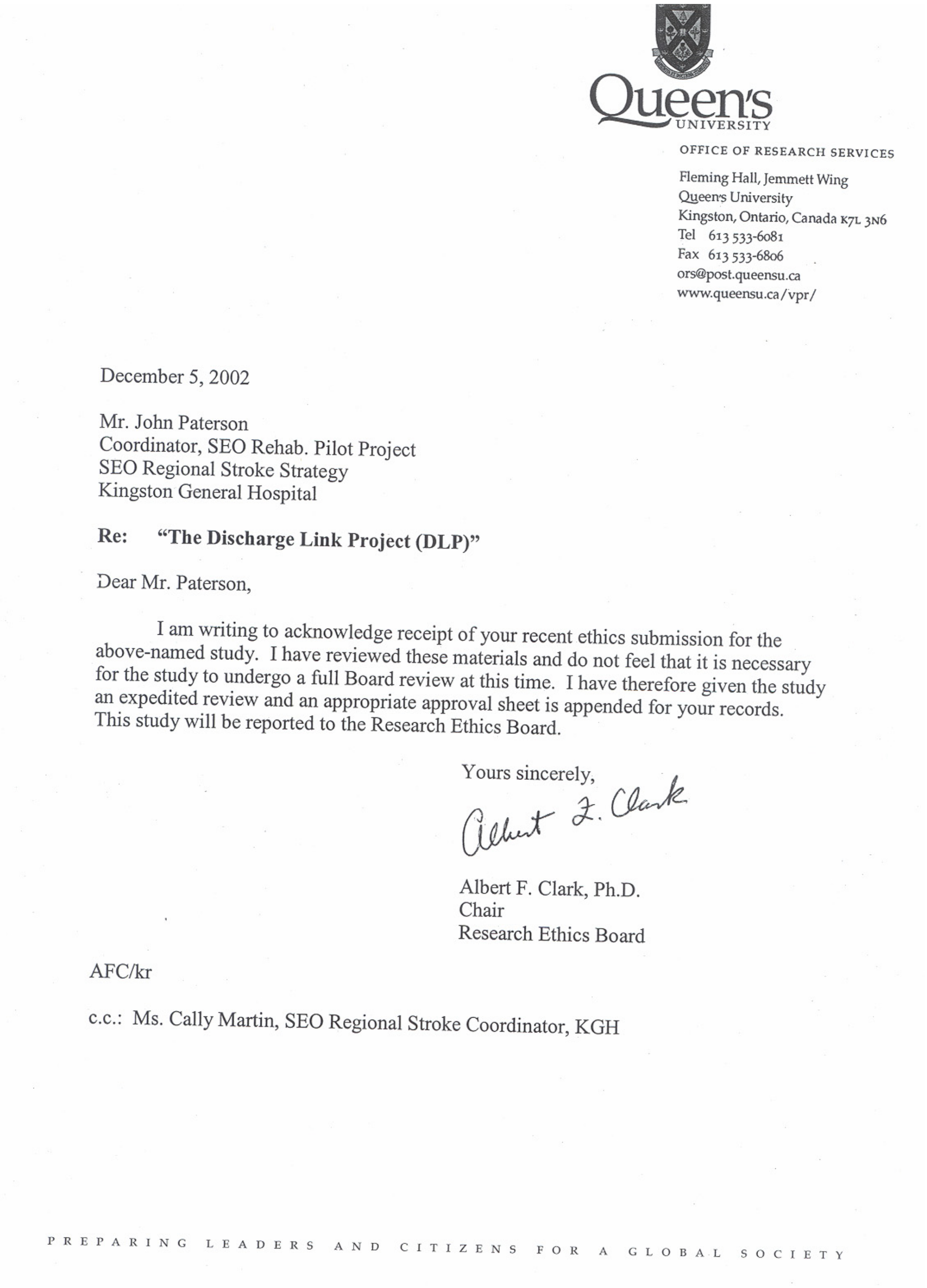
Appendix A(ii)
Stroke Rehabilitation Sub-Committee of Southeastern Ontario

NAME	INSTITUTION	TITLE
Pat Avery	Access Centre for Community Care in Lanark, Leeds and Grenville	Client Service Manager
Dr. Stephen Bagg	Providence Continuing Care Centre St. Mary's of the Lake Hospital	Physiatrist, Stroke Rehabilitation Team, Dept of Rehabilitation Medicine
Catherine Crain	Brockville General Hospital	Discharge Planner
Dr. Kate Stolee Velma Desjardins (Alt)	Perth & Smiths Falls District Hospital	Physiatrist Patient Care Unit Manager, Complex Continuing Care & Rehabilitation Services
Kathy Flegg	Providence Continuing Care Centre St. Mary's of the Lake Hospital	Manager, Rehabilitation Services
Nancy Jones	Quinte Healthcare Corporation	Manager, Rehabilitation Services
Eleanor Plain Jo Mather	KFLA Community Care Access Centre	Director, Community Care Services Manager, Community Care Services
Shari Sampson	Lennox & Addington General Hospital	Director, Clinical Services and Informatics
Mark Walden	Access Centre for Hastings Prince Edward	Director of Client Services
Cally Martin	Kingston General Hospital	Regional Stroke Program Manager
John Paterson	Kingston General Hospital	Regional Stroke Rehabilitation Pilot Project Coordinator

APPENDIX B:

Queen's Research Ethics Board Letter of Approval

Appendix B:
Queen's Research Ethics Board Letter of Approval



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December 5, 2002

Mr. John Paterson
Coordinator, SEO Rehab. Pilot Project
SEO Regional Stroke Strategy
Kingston General Hospital

Re: "The Discharge Link Project (DLP)"

Dear Mr. Paterson,

I am writing to acknowledge receipt of your recent ethics submission for the above-named study. I have reviewed these materials and do not feel that it is necessary for the study to undergo a full Board review at this time. I have therefore given the study an expedited review and an appropriate approval sheet is appended for your records. This study will be reported to the Research Ethics Board.

Yours sincerely,

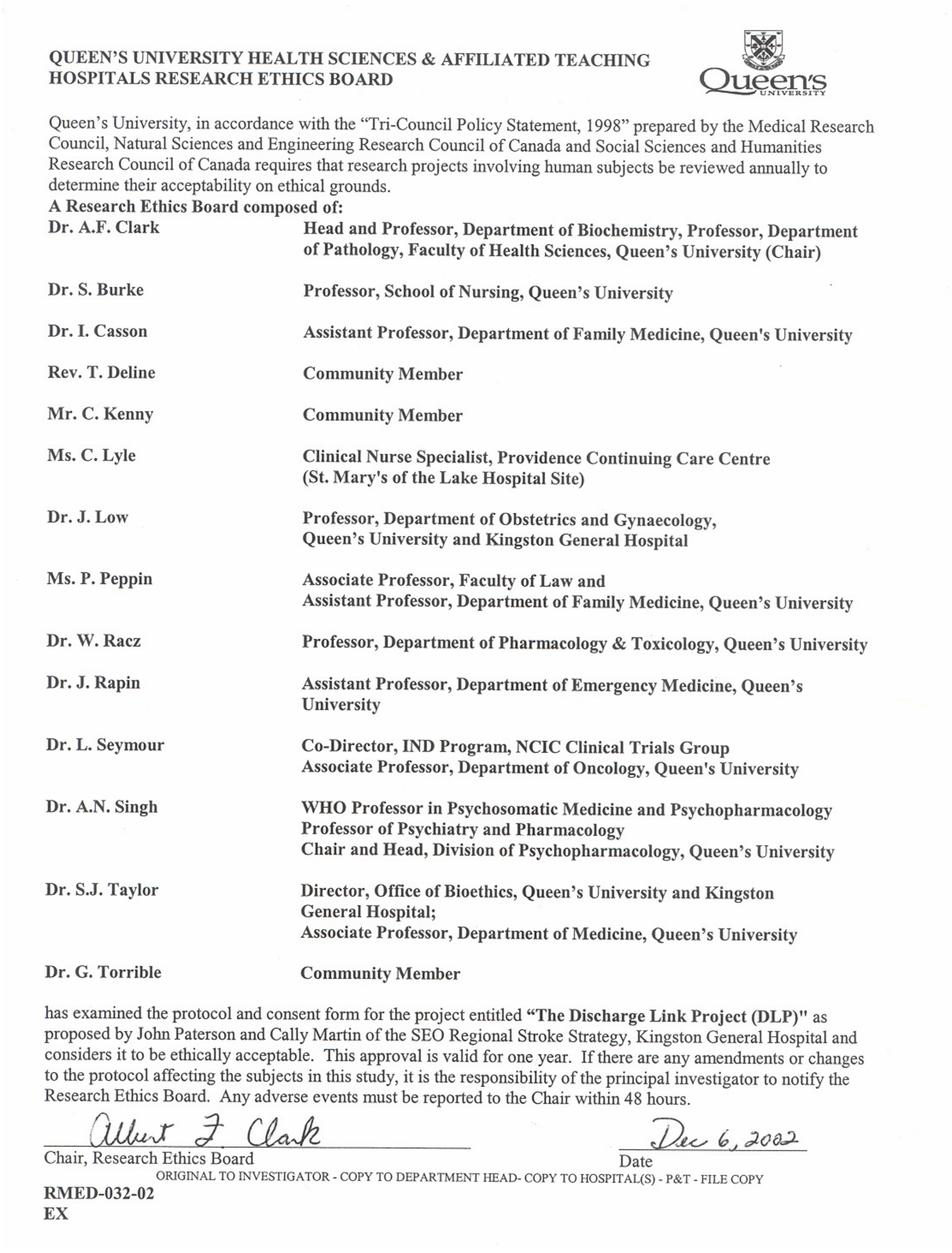
Albert F. Clark

Albert F. Clark, Ph.D.
Chair
Research Ethics Board

AFC/kr

c.c.: Ms. Cally Martin, SEO Regional Stroke Coordinator, KGH

PREPARING LEADERS AND CITIZENS FOR A GLOBAL SOCIETY



QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

Queen's University, in accordance with the "Tri-Council Policy Statement, 1998" prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

Dr. A.F. Clark	**Head and Professor, Department of Biochemistry, Professor, Department of Pathology, Faculty of Health Sciences, Queen's University (Chair)**
Dr. S. Burke	**Professor, School of Nursing, Queen's University**
Dr. I. Casson	**Assistant Professor, Department of Family Medicine, Queen's University**
Rev. T. Deline	**Community Member**
Mr. C. Kenny	**Community Member**
Ms. C. Lyle	**Clinical Nurse Specialist, Providence Continuing Care Centre (St. Mary's of the Lake Hospital Site)**
Dr. J. Low	**Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital**
Ms. P. Peppin	**Associate Professor, Faculty of Law and** **Assistant Professor, Department of Family Medicine, Queen's University**
Dr. W. Racz	**Professor, Department of Pharmacology & Toxicology, Queen's University**
Dr. J. Rapin	**Assistant Professor, Department of Emergency Medicine, Queen's University**
Dr. L. Seymour	**Co-Director, IND Program, NCIC Clinical Trials Group** **Associate Professor, Department of Oncology, Queen's University**
Dr. A.N. Singh	**WHO Professor in Psychosomatic Medicine and Psychopharmacology** **Professor of Psychiatry and Pharmacology** **Chair and Head, Division of Psychopharmacology, Queen's University**
Dr. S.J. Taylor	**Director, Office of Bioethics, Queen's University and Kingston General Hospital;** **Associate Professor, Department of Medicine, Queen's University**
Dr. G. Torrible	**Community Member**

has examined the protocol and consent form for the project entitled **"The Discharge Link Project (DLP)"** as proposed by John Paterson and Cally Martin of the SEO Regional Stroke Strategy, Kingston General Hospital and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol affecting the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any adverse events must be reported to the Chair within 48 hours.

Albert F. Clark
Chair, Research Ethics Board

Dec 6, 2002
Date

ORIGINAL TO INVESTIGATOR - COPY TO DEPARTMENT HEAD- COPY TO HOSPITAL(S) - P&T - FILE COPY

RMED-032-02
EX

APPENDIX C:

Discharge Link Project Consent Forms:
C(i) Client
C(ii) Substitute Decision Maker

Appendix C(i)
Discharge Link Project Consent Form - Client

The Stroke Rehabilitation Project
Of Southeastern Ontario

Information and Consent Form - Client

The Discharge Link Project

(Part of the Stroke Rehabilitation Pilot Project Of South Eastern Ontario)

You are being invited to take part in a study that is examining ways to improve the after-hospital therapy for people who have had a stroke. Please read this form carefully, and ask ____________ to answer any questions you may have.

Aim of the Study

To learn more about the way we deliver therapy at home and how it might affect your recovery and your ability to cope with living at home.

Why are we doing this study?

Stroke care experts believe that it is best to provide an increased level of therapy for people with recent strokes, not just in hospital but also after they return home. For the next 2 years, the Ministry of Health and Long Term Care (MOH-LTC) has given the Stroke Strategy extra money to provide more therapy for some people who have had strokes in Southeast Ontario.

Who is doing this study?

The Regional Stroke Strategy of Southeastern Ontario at Kingston General Hospital is doing this study with the financial help of the MOH-LTC. Also participating in this study are the three Community Care Access Centres (CCACs) of Southeastern Ontario, and the inpatient rehabilitation sites at Providence Continuing Care Centre (St. Mary's of the Lake Hospital in Kingston, and St. Vincent de Paul Hospital in Brockville), Perth and Smiths Falls District Hospital and the Belleville General site of Quinte Healthcare. The study ends in October 2004.

How does the study work?

Everyone who takes part in this study will get a regular level of therapy, but half of the people will get increased therapy as well. If you are in the group that gets the increased therapy, it will be the same as your regular therapy; there will just be more of it for two months after you get home. The decision to get the increased therapy has nothing to do with you or your health. That decision will be made by the researchers and the CCAC case manager and will be based upon a number of things, such as: having enough therapy staff, where you live, and when the increased therapy program is available in your area.

What do I have to do?

To be in this study;

- You must be 16 years of age or older and live in Southeastern Ontario,
- You have had a stroke,
- You were getting rehabilitation therapy at an in-patient or day hospital program and,
- You will be getting further therapy from the CCAC at home.

If you agree to take part in this study, an interviewer will phone you three times after you have left the hospital (about 3 months, 6 months and 12 months later). You will be asked questions about your health, how you are coping at home, and some other questions such as the number of visits you may have made to a hospital or to your doctor. It should take about 20 minutes to answer the questions.

You will not be taking any extra drugs or getting any unusual treatments as part of this study. You will still be doing whatever therapy you, your family, your doctor and your therapists have already decided you should have. You should know that the study investigators would be getting some of your records from your stay in inpatient rehabilitation.

What are the risks and benefits of being in this study?

There are no risks to you. If you would like to try and help us find out whether the way we provide increased therapy is best for people who have a stroke and want to return home, then you should sign this form. The information we get from you during the phone interviews will be very useful in helping us write the final report of the study that will be sent to the Ministry of Health in October of 2004.

Your therapy is covered under normal CCAC liability policies. If you sign this consent form, you are not giving up any of your legal rights, and you are not releasing the investigators from meeting their legal and professional responsibilities regarding the use of your information for this study.

What if I have difficulty answering the questions?

It is possible that your stroke caused you to have some thinking or communication problems in which case someone close to you could help answer the questions for you.

Will my name and information be kept confidential?

Yes. All the information obtained in this study is strictly confidential and your privacy will be protected at all times. Only the study coordinator and the CCAC case manager will know who you are (because we have to phone you for the interviews). This information will be kept in locked files in the research offices at KGH and at the CCAC. Your name will be coded and that code is all that will be used when the information is entered into a secure computer at KGH, which can only be used by Stroke Rehabilitation Pilot Project staff.

You should know that the researchers for this project will ask for information from the Canadian Institute for Health Information (CIHI). CIHI is an independent, national, not-for-profit organization that coordinates and develops health information in Canada that is used to support management of the health care system and to educate Canadians about good health. CIHI collects basic coded information about hospital procedures such as the rehabilitation therapy provided during your hospital stay. With your consent the researchers will request this information from CIHI and combine it with the information collected during your interviews.

The information about you will be combined with information from the other 120 people in the study, and checked to see if the way we delivered the increased therapy has helped people who have had a stroke. However, your name will never be revealed in any way, for example: in reports, presentations or publications about this study.

Will I be paid?

Sorry, no. We are asking you to volunteer your time. If you agree to take part by signing this form, then you will not get any money for participating in this study.

Can I withdraw from the study?

Yes, you can withdraw from this study at any time and, if you do, your therapy will continue as it would have if you were on the regular therapy program.

Participant's Statement and Signature

1. I have read this consent form, or someone has read it for me.
2. I understand what taking part in this study means.
3. I had the purposes, procedures and technical language of this study explained to me.
4. I have had enough time to think about the above information, and have had enough time to seek advice, if I wanted to.
5. I had the chance to ask questions and they were answered to my satisfaction.
6. I am voluntarily signing this form, or instructing someone else to sign for me.
7. I will get a copy of this consent form for my own records.

If I have any further questions, concerns or problems, I can contact:

John Paterson	**Cally Martin**	**Dr Stephen Bagg**
Coordinator	Coordinator	Physiatrist
Rehab Pilot Project	Regional Stroke Strategy	St Mary's of the Lake Hospital
Rm 301, Doran 3, KGH	Rm 313, Doran 3, KGH	Providence Continuing Care Centre
613 549 6666 x 6350	613 549 6666 x 3562	613 548 7222 x 2209

You can also contact the following person at your CCAC with your questions:

Name: ______________________ Phone: ______________

If I have questions regarding my rights as a research subject, I can contact **Dr Albert Clark**, Chair, Research Ethics Board, Queen's University, 613 533 6081.

I agree to participate in this study, and am willing to sign this form.

___________________________________ __________________
Signature of participant Date

___________________________________ __________________
Signature of witness Date

Please fax the signed form to: **John Paterson,** Stroke Rehab Project Coordinator,
Room 313 Doran 3, KGH, 76 Stuart St, Kingston, ON, K7L2V7
Phone 549 6666 x 6350, email patersoj@kgh.kari.net
FAX 613 548 2454

Appendix C(ii)
Discharge Link Project Consent Form - Substitute Decision Maker

The Stroke Rehabilitation Project
Of Southeastern Ontario

Information and
Consent Form - Substitute

The Discharge Link Project
(Part of the Stroke Rehabilitation Pilot Project Of South Eastern Ontario)

As the substitute decision maker for ___________________ you are being invited to allow his/her voluntary participation in a study, known as the Discharge Link Project. This study is examining ways to improve the after-hospital therapy for people who have had a stroke. You will need to know enough about the study's risks and benefits so that you can make an informed decision to let him/her take part. This form contains detailed information about the study. Your family member's case manager will discuss the study with you, and ask you to sign for him/her. You will be given a signed copy of this form to keep as a record. For the purposes of this form, we refer to the client as "your family member". The researchers realize this is not always the case.

Aim of the Study
To learn more about the way we deliver therapy at home and how it might affect the recovery and ability of people who have had a stroke to cope with living at home.

Why are we doing this study?
Stroke care experts believe that it is best to provide an increased level of therapy for people with recent strokes, not just in hospital but also after they return home. For the next 2 years, the Ministry of Health and Long Term Care (MOH-LTC) has given the Stroke Strategy extra money to provide more therapy for some people who have had strokes in Southeast Ontario

Who is doing this study?
The Regional Stroke Strategy of Southeastern Ontario at Kingston General Hospital is doing this study with the financial help of the MOH-LTC. Also participating in this study are the three Community Care Access Centres (CCACs) of Southeastern Ontario, and the inpatient rehabilitation sites at Providence Continuing Care Centre (St. Mary's of the Lake Hospital in Kingston, and St. Vincent de Paul Hospital in Brockville), Perth and Smiths Falls District Hospital and the Belleville General site of Quinte Healthcare. The study ends in October 2004.

How does the study work?
Everyone who takes part in this study will get a regular level of therapy, but half of the people will get increased therapy as well. If your family member is in the group that gets the increased therapy, it will be the same as his/her regular therapy; there will just be more of it for the first two months after he/she gets home. The decision to get the increased therapy has nothing to do with his/her health. That decision will be made by the researchers and the CCAC case manager and will be based upon a number of things, such as: having enough therapy staff, where your family member lives, and when the increased therapy program is available in his/her area.

What do I have to do?

To be in this study, your family member must,
- Be 16 years of age or older and live in Southeastern Ontario,
- Have had a stroke,
- Have been getting rehabilitation at an in-patient or day hospital therapy and,
- **Be getting further therapy from the CCAC at home.**

If you agree to allow your family member to take part in this study, an interviewer will phone you three times after your family member has left the hospital (about 3 months, 6 months and 12 months later). You will be asked questions about his/her health, how he/she is coping at home, and some other questions such as any visits he/she may have made to a hospital or to the doctor. It should take about 20 minutes to answer the questions.

Your family member will not be taking any extra drugs or getting any unusual treatments as part of this study. He/she will still be doing whatever therapy he/she, the family, the doctor and the therapists have already decided. You should know that the study investigators would be getting some of your family member's records from his/her stay in inpatient rehabilitation.

What are the risks and benefits of being in this study?

There are no risks to your family member. If you would like to try and help us find out whether the way we provide increased therapy is best for people who have a stroke and want to return home, then you should sign this form. The information we get from you during the phone interviews will be very useful in helping us write the final report of the study that will be sending to the Ministry of Health in October of 2004.

The therapy is covered under normal CCAC liability policies. If you sign this consent form, you are not giving up any of your legal rights, and you are not releasing the investigators from meeting their legal and professional responsibilities regarding the use of your family member's information for this study.

Who cannot take part in this study?

It is possible that some people who have had a stroke are suffering from some difficulties with thinking or communicating in which case you, as a substitute decision maker, will be asked to sign this form on the patient's behalf.

Will the names and information be kept confidential?

Yes. All the information obtained in this study is strictly confidential and your family member's privacy will be protected at all times. Only the study coordinator and the CCAC case manager will know your family member's name (because we have to phone for the interviews). This information will be kept in locked files in the research offices at KGH and at the CCAC. Your name and your family member's name will be coded and that code is all that will be used when the information is entered into a secure computer at KGH, which can only be used by Stroke Rehabilitation Pilot Project staff.

You should know that the researchers for this project will ask for information from the Canadian Institute for Health Information (CIHI). CIHI is an independent, national, not-for-profit organization that coordinates and develops health information in Canada that is used to support management of the health care system and to educate Canadians about good health. CIHI collects basic coded information about hospital procedures such as the rehabilitation therapy provided during a client's hospital stay. With your consent the researchers will request this information from CIHI and combine it with the information collected during the interviews.

Your family member's information will be combined with information from the other 120 people in the study and checked to see if the way we delivered the increased therapy has helped people who have had a stroke. However, your name and your family member's name will <u>never</u> be revealed in any way, for example: in reports, presentations or publications about this study.

Will I, or my family member, be paid?

Sorry, no. We are asking you and your family member to volunteer your time. If you agree to allow him/her to take part by signing this form, then neither you nor your family member will get any money for participating in this study.

Can I withdraw my family member from the study?

Yes. You can withdraw your family member from this study at any time and, if you do, his/her therapy will continue as it would have if he/she were on the regular therapy program.

Substitute's Statement and Signature

1. I have read this consent form, or had someone read it for me.
2. I understand what allowing my family member to take part in this study means.
3. I had the purposes, procedures and technical language of this study explained to me.
4. I had enough time to think about the above information, and have had enough time to seek advice, if I wanted to.
5. I had the chance to ask questions and they were answered to my satisfaction.
6. I am voluntarily signing this form.
7. I will get a copy of this consent form for my own records.

If I have any further questions, concerns or problems, I can contact:

John Paterson	**Cally Martin**	**Dr Stephen Bagg**
Coordinator	Coordinator	Physiatrist
Rehab Pilot Project	Regional Stroke Strategy	St Mary's of the Lake Hospital
Rm 301, Doran 3, KGH	Rm 313, Doran 3, KGH	Providence Continuing Care Centre
613 549 6666 x6350	613 549 6666 x3562	613 548 7222 x 2209

You can also contact the CCAC Case Manager with your questions:

Name: ________________________ Phone: _______________

If I have questions regarding my family member's rights as a research subject, I can contact **Dr Albert Clark**, Chair, Research Ethics Board, Queen's University, 613 533 6081.

By signing this form I am indicating that I agree to allow my family member to participate in this study.

____
Participant's Name

____________________________________ ______________________________
Substitute Decision Maker's Name Relationship to Participant

____________________________________ ______________________________
Signature of Substitute Decision Maker Date

____________________________________ ______________________________
Signature of witness Date

Please fax the signed form to: **John Paterson,** Stroke Rehab Project Coordinator,
Room 313 Doran 3, KGH, 76 Stuart St, Kingston, ON, K7L2V7
Phone 549 6666 x 6350, email patersoj@kgh.kari.net
FAX 613 548 2454

APPENDIX D:

Guidelines for Provision of the "ENHANCED" Therapy

Appendix D
Guildelines for Provision of the "ENHANCED" Therapy

The Discharge Link Project is supplying the funds for enhanced therapy; that is, therapy **above and beyond** the level of therapy that a CCAC would normally provide. The amount of enhanced therapy will be determined by the client's therapy goals. The funding covers the following activities:

a) The Discharge Link meeting (OT to OT)
b) The OT - PSW initial consultation.
c) Provider visits (see guidelines below).
d) Additional PSW time (see guidelines below).
e) Equipment needs.

A "basket" of funding that represents an average amount for each of the Project's 60 clients in the "enhanced" therapy group will be transferred to the CCAC. The CCAC case manager and/or the rehab team, will determine the most appropriate use of these funds, as long as they are used for some form of therapy provision or equipment purchase (to a maximum of $200.00). Any surplus will be applied to accepting additional participants into the project.

Pre-Discharge:	The CCAC-contracted "community "OT attends the **Discharge Link Meeting** with the inpatient OT, the client, and/or caregiver(s), in the inpatient setting.
First Week:	The CCAC-contracted "community" OT meets with the PSW(s) and the PSW supervisor to communicate client goals and treatment plans, at the client's home.
First 4 weeks:	Up to: 2 extra visits/wk of OT and PT, 1 extra visit/wk of SLP. Up to an extra 5 hrs/wk of PSW
4-8 weeks:	Up to: 1 extra visit/wk of OT and PT, 1 extra visit/2wks of SLP.
Equipment:	Up to $200.00 per client.

Guidelines for Use of the Equipment Fund

There is a $200.00 per participant (enhanced therapy group only) available to be used at the discretion of the case manager and the professional therapy team. Examples of appropriate use would be: to upgrade standard equipment, to extend rental periods, or to buy devices to enhance treatment.

APPENDIX E:

Discharge Link Project Methodology:

E(i) Detailed Discharge Link Project Methodology

E(ii) Discharge Link Project Protocols and Flowcharts
(Case Managers, Therapy Providers, Personal Support Workers)

E(iii) Guidelines for the Discharge Link Meeting

E(iv) Project Workplan

Appendix E(i)
Detailed Discharge Link Project Methodology

The Discharge Link Project (DLP)

Overview of the DLP

The Discharge Link Project (DLP) is investigating the impact of providing an enhanced level of rehabilitation therapy at home, the process of how it is delivered, how it affects the function of people who have had a stroke, and how they are able to cope with living at home.

Objective of the DLP

To test a process to improve the transition from inpatient rehabilitation to community discharge destination.

This project tests methods of linking therapists in the rehabilitation setting with therapists and care providers in the home setting to ensure a visit within the last week of discharge, and tests front-end loading of community service delivery. It investigates issues around timely and appropriate levels of intensity of service, as well as the effective coordination and communication of care across the continuum.

Stakeholders in the DLP

There are many people and organizations involved in the DLP, each with their own specific responsibilities.

- **Inpatient Rehabilitation Centres/Units**
  These include the inpatient Rehabilitation Units and Day Hospitals at Providence Continuing Care sites (St Vincent de Paul, Brockville, and St Mary's of the Lake, Kingston), Quinte Healthcare Corporation (Belleville Hospital site), and Perth and Smiths Falls District Hospital. The major responsibility of these sites is to identify potential clients, to gather informed consent from the potential clients, and to participate in the Discharge Link meeting. These facilities have authorized CIHI to permit the Project Coordinator to gain access to the inpatient CIHI-NRS data on the project participants. This will allow the client's pre- and post-discharge results to be compared with the results of the follow up surveys, conducted as a part of this study.

- **Project Participants**
  The DLP is seeking as many participants (people who have had a stroke) as possible, to be equally divided between the three CCAC regions. Half of the clients will receive the enhanced therapy intervention. The client or a substitute decision maker must provide informed consent.

- **CCACs of SEO**
  These include the Access Centre for Community Care for Hastings and Prince Edward Counties (HPE), the Kingston, Frontenac, Lennox & Addington (KFLA) Community Care Access Centre, and the Access Centre for Community Care in Lanark, Leeds and Grenville (LLG) counties. Their roles involve: participating in the development and planning of the project, providing the therapy interventions through contracted therapists and personal support workers (PSWs), submitting workload data and costs, and participating in the overall evaluation of the Project.

- **CCAC Providers**
  The providers of the Project's therapy interventions are the CCAC-contracted Occupational Therapists, Physical Therapists, Speech Language Pathologists, and Personal Support Workers. The OT's are expected to attend the Discharge Link meeting that occurs prior to client discharge. Some CCAC providers will be asked to participate in the overall evaluation of the Project

Methods

1. The project participants must be over 16, have had a recent stroke, have been recipients of a day hospital or inpatient rehab program, and be eligible for therapy from the local CCAC, at home.
2. After gaining consent of the client or family member, the participants are assigned to either a "normal" therapy group or an "enhanced" therapy group, depending upon the availability of therapy personnel in each CCAC region.
3. The "normal therapy" group serves as a baseline and receives the usual level of therapy from CCAC contracted providers, whereas the "enhanced therapy" group, or the study group, receives an *enhanced* amount of therapy (from the same therapists) during their first two months at home.
4. Participants in the enhanced therapy group also participate in a Discharge Link meeting. This meeting occurs immediately prior to discharge and includes the hospital-based inpatient occupational therapist (OT) and the Access Centre community-based OT, with the goal of having a face-to-face consultation about the participant's goals and treatment plans.
5. In addition, once the "enhanced therapy" participant has returned home, a consultation between the community OT and PSW(s) takes place to facilitate the transfer of patient goals between therapy and support providers.
6. Study investigators obtain the participant's inpatient rehabilitation Functional Independence Measure (FIM) results from CIHI-NRS data (taken at admission and discharge), and obtain the participant's follow-up FIM functional levels using a validated telephone FIM interview.
7. The (FIM) telephone follow-up and the CCAC Client Satisfaction Survey are being used to assess the post-discharge functional levels and satisfaction of the participants in both study groups. The study investigator conducts the follow up interviews by phone at 3, 6 and 12 months, post-discharge from the inpatient rehab or day hospital site.
8. The study investigator is also conducting focus groups/satisfaction surveys with participants, caregivers and providers.
9. Data on participant utilization of the health care system is being collected in order to ascertain overall impact of the enhanced therapy on the system.
10. Data will be analyzed.
11. Initial results will be presented to select group of stakeholders
12. The final report will be written and submitted to the MOH.

Appendix E(ii)
Discharge Link Project Protocols and Flowcharts
(Case Managers, Therapy Providers, Personal Support Workers)

The Stroke Rehabilitation Project
Of Southeastern Ontario

Case Manager Protocol
(Discharge Link Project)

Protocol for Case/Care Managers (or designate):

These are the people who make the decision regarding client eligibility for CCAC service upon the client's discharge from the inpatient rehabilitation or day hospital setting to the community. The decision concerning the placement of consenting clients into either the normal or increased therapy group will be determined through regular contact between John, the rehab project subcommittee representatives and the case managers for each CCAC.

(Note: A flowchart accompanies this document.)

Actions: (these may vary to meet the administrative procedures of different settings)

1. "Flag" potential clients. They could be identified at the usual CCAC case management assessment to determine if the client is eligible for CCAC services, (and therefore, to become a potential participant in the Discharge Link Project).

2. Approximately 2 weeks prior to discharge approach the potential client and caregiver (if applicable) and inform the client about the Discharge Link Project (DLP). Answer the client's questions about the DLP as best as you can. Refer the client to John if you are unable to answer all their questions.

3. If the potential client or caregiver is willing, ask the appropriate person to sign the consent form. (2 copies are needed: one copy for the client and one for you). Leave one of the signed copies with the client or caregiver.

4. If the client or caregiver is unprepared to sign at this time, leave the information and consent form with him/her and make it clear that he/she may contact yourself or John with further questions. A day or two later, return to see if the client is ready to sign. If the client is unwilling to sign, thank them for his/her consideration and make it clear their decision does not affect the level of his/her rehabilitation service. If the client signs, leave a signed copy with the client.

5. Complete a "client tracking form" for every client who has consented. (Contains name, address, family and phone numbers). This will enable John to phone the client for the phone interviews.

6. Fax (548 2454) BOTH the signed consent form (last page is sufficient) and the client tracking form to John.

7. If the client is in the **NORMAL THERAPY** GROUP: Proceed as usual. (Client does <u>not</u> have a Discharge Link Meeting)

8. IF CLIENT IS IN THE **INCREASED THERAPY** GROUP:

   a) Inform the CCAC case manager (if different than the inpatient case manager) of the imminent discharge of a client who will be in the "increased" therapy group. Pass on the

a) name of the client's **inpatient OT** to the **CCAC OT** who will be providing the client's therapy in the community.

b) Inform the client's **inpatient OT** that the client will be participating in the increased therapy group, and that therefore the **CCAC OT** will be in touch to coordinate a time for the **Discharge Link Meeting** to take place at least 2 weeks before, but preferably within 72 hours of discharge. Please give the OT a copy of the "Guidelines for the DLM" (separate document).

Eligibility:

To be eligible for inclusion in either project group, clients will:

- be 16 years of age or older and live in Southeastern Ontario,
- have had a recent stroke,
- will be receiving intensive rehabilitation therapy *for the recent stroke* at an inpatient or day hospital program and,
- will be eligible for CCAC follow up therapy at home or in a residential care facility (not a LTC facility or nursing home).

Note 1: Withdrawals: If a client has to withdraw from the Project for unforeseen reasons, he/she can inform any of his/her providers. The provider will inform the CCAC case manager, who will then inform John.

Note 2: Normal vs Increased therapy group: The decision about the group in which the client is to be placed will be based on the availability of CCAC staff to provide the therapy and the amount of project funding remaining. This information will be communicated to John through the CCAC Regional Stroke Strategy Steering committee representatives.

Guideline for the "Increased" Therapy Group:

The Project is supplying the funds for increased therapy; that is, therapy **above and beyond** the level of therapy that a CCAC would normally provide. The amount of increased therapy will be determined by the client's therapy goals. The funding covers the following activities:

a) The Discharge Link meeting (OT to OT).
b) The OT - PSW initial consultation.
c) Provider visits (see guidelines below).
d) Additional PSW time (see guidelines below).
e) Equipment needs.

A "basket" of funding that represents an average amount for each of the Project's 60 clients in the "increased" therapy group will be transferred to the CCAC. The CCAC case manager and/or the rehab team, will determine the most appropriate use of these funds, as long as they are used for some form of therapy provision or equipment purchase (to a maximum of $200.00). Any surplus will be applied to accepting additional participants into the project.

Pre-Discharge:	The CCAC-contracted "community "OT attends the **Discharge Link Meeting** with the inpatient OT, the client, and/or caregiver(s), in the inpatient setting.
First Week:	The CCAC-contracted "community" OT meets with the PSW(s) and the PSW supervisor to communicate client goals and treatment plans, at the client's home.

First 4 weeks:	Up to: 2 extra visits/wk of OT and PT, 1 extra visit/wk of SLP. Up to an extra 5 hrs/wk of PSW
4-8 weeks:	Up to: 1 extra visit/wk of OT and PT, 1 extra visit/2wks of SLP.
Equipment:	Up to $200.00 per client.

Guideline for use of the Equipment Fund:

There is a $200.00 per participant (increased therapy group only) available to be used at the discretion of the case manager and the professional therapy team. Examples of appropriate use would be: to upgrade standard equipment, to extend rental periods, or to buy devices to enhance treatment.

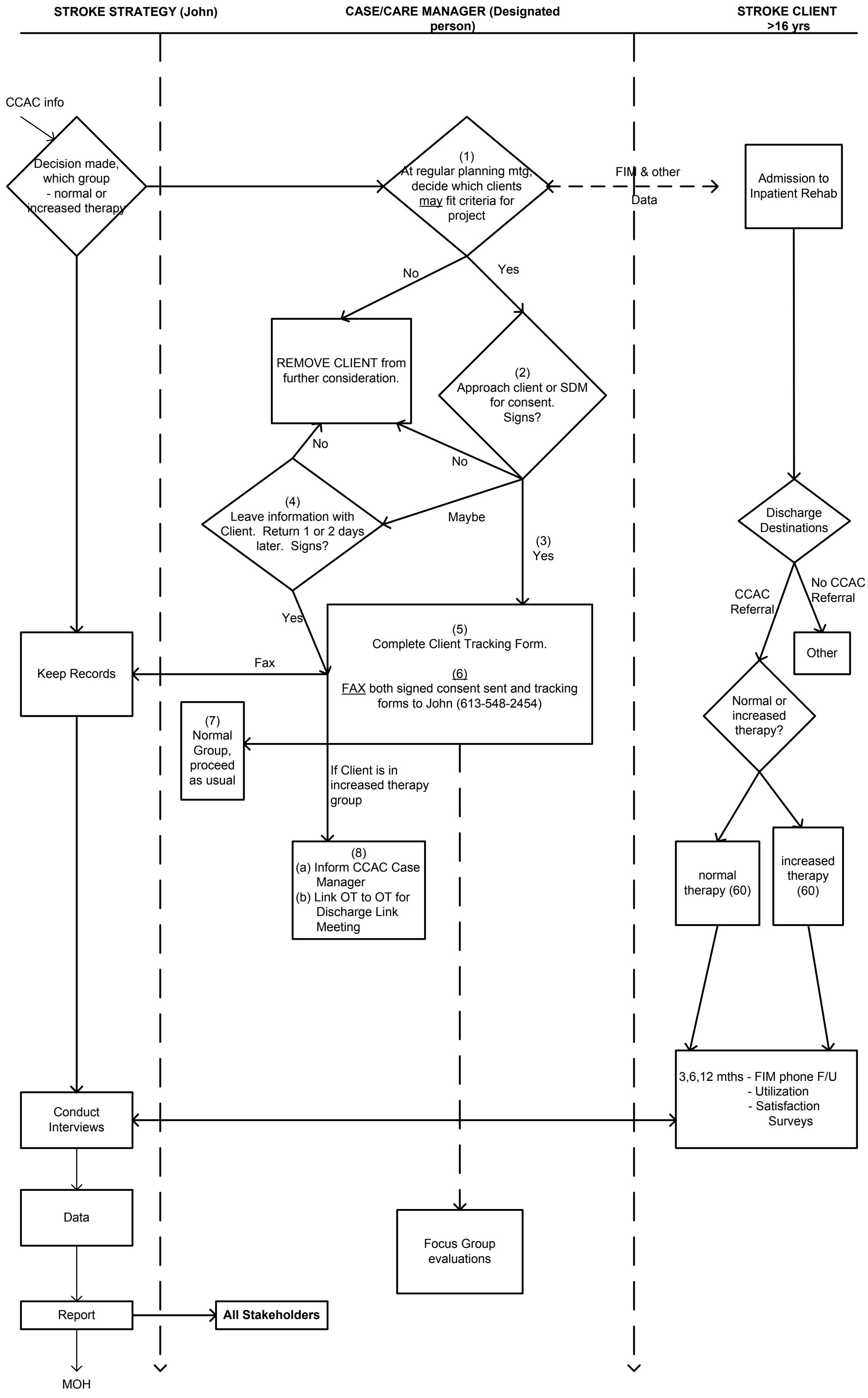
Optimal Distribution of Participants (n=120)

For further Information, contact:

John Paterson
Stroke Rehab Project Coordinator
Room 313 Doran 3, KGH, 76 Stuart St, Kingston, ON, K7L2V7
Phone 549 6666 x 6350, email patersoj@kgh.kari.net
FAX 613 548 2454

For detailed description of procedures, see "Case Managers Protocols"

CASE MANAGER ROLE



The Stroke Rehabilitation Project
Of Southeastern Ontario

Therapy Providers Protocol
(Discharge Link Project)

Protocol for Therapy Providers:

The providers are the Occupational Therapists, Physiotherapists, and Speech Language Pathologists contracted by the CCACs to provide rehab service.

(Note: A flowchart accompanies this document.)

Actions: (these may vary to meet the administrative procedures of different settings)

1. Obtain a new stroke client's referral in the customary way. The referral will indicate whether or not the client is a participant in the Discharge Link Project (DLP), and whether or not the client is in the normal or increased therapy groups. Consenting clients are <u>not</u> aware which group they are in, but some may be able to figure it out. This is not a problem.

2. IF CLIENT IS IN THE **NORMAL THERAPY** GROUP: Therapy will be provided at the normal level. The only difference is that John Paterson will telephone these clients 3,6 and 12 months after discharge for the CIHI-NRS follow up evaluation, and 2 months after discharge for the client/caregiver satisfaction survey. You may be asked what these calls are about.

3. IF CLIENT IS IN THE **INCREASED THERAPY** GROUP:

   Your case manager will inform you that your new client will be receiving the increased therapy, and what that will entail in terms of the increased amount of therapy.

   a) **If you are an OT:**

      i) Your CCAC case manager will give you the name and number of the client's **inpatient OT**. Please contact him/her immediately and arrange a time for the **Discharge Link Meeting (DLM)**, which should take place at least 2 weeks before, but preferably within 72 hours of discharge. (see Guidelines for the DLM – separate document).

      ii) Either you or your Case Manager (determine who) are to arrange a consultation between the PSW(s), the PSW supervisor (if possible) and yourself, at the client's home during their first week home. (See "Guideline for the PSW Consultation" – separate document).

   b) **All Providers**: You will provide the "increased" level of therapy as determined by the client's treatment plan and continue to communicate care plans in the usual way.

4. John Paterson will ALSO telephone this group of clients 3,6 and 12 months after discharge for the CIHI-NRS follow up evaluation, and 2 months after discharge for the client/caregiver satisfaction survey.

5. Towards the end of the Project you will be asked to participate in a "provider satisfaction survey" and perhaps a focus group to evaluate the effects of the Project on client's rehabilitation in the community.

Guideline for the "Increased" Therapy Group

The Project is supplying the funds for increased therapy; that is, therapy **above and beyond** the level of therapy that a CCAC would normally provide. The amount of increased therapy will be determined by the client's therapy goals. The funding covers the following activities:

a) The Discharge Link meeting (OT to OT)
b) The OT - PSW initial consultation.
c) Provider visits (see guidelines below).
d) Additional PSW time (see guidelines below).
e) Equipment needs.

Pre-Discharge:	The CCAC-contracted "community "OT attends the **Discharge Link Meeting** with the inpatient OT, the client, and/or caregiver(s), in the inpatient setting.
First Week:	The CCAC-contracted "community" OT meets with the PSW(s) and the PSW supervisor to communicate client goals and treatment plans, at the client's home.
First 4 weeks:	Up to 2 extra visits/wk of OT and PT, and 1 extra visit/wk of SLP. Up to an extra 5 hrs/wk of PSW
4-8 weeks:	Up to 1 extra visit/wk of OT and PT, and 1 extra visit/2wks of SLP.
Equipment:	Up to $200.00 per client.

Guideline for use of the Equipment Fund:

There is a $200.00 per participant (increased therapy group only) available to be used at the discretion of the case manager and the professional therapy team. Examples of appropriate use would be: to upgrade standard equipment, to extend rental periods, or to buy devices to enhance treatment.

Note 1: Withdrawals: If a client has to withdraw from the DLP for unforeseen reasons, you will probably be the first to know. Please inform your CCAC case manager ASAP.

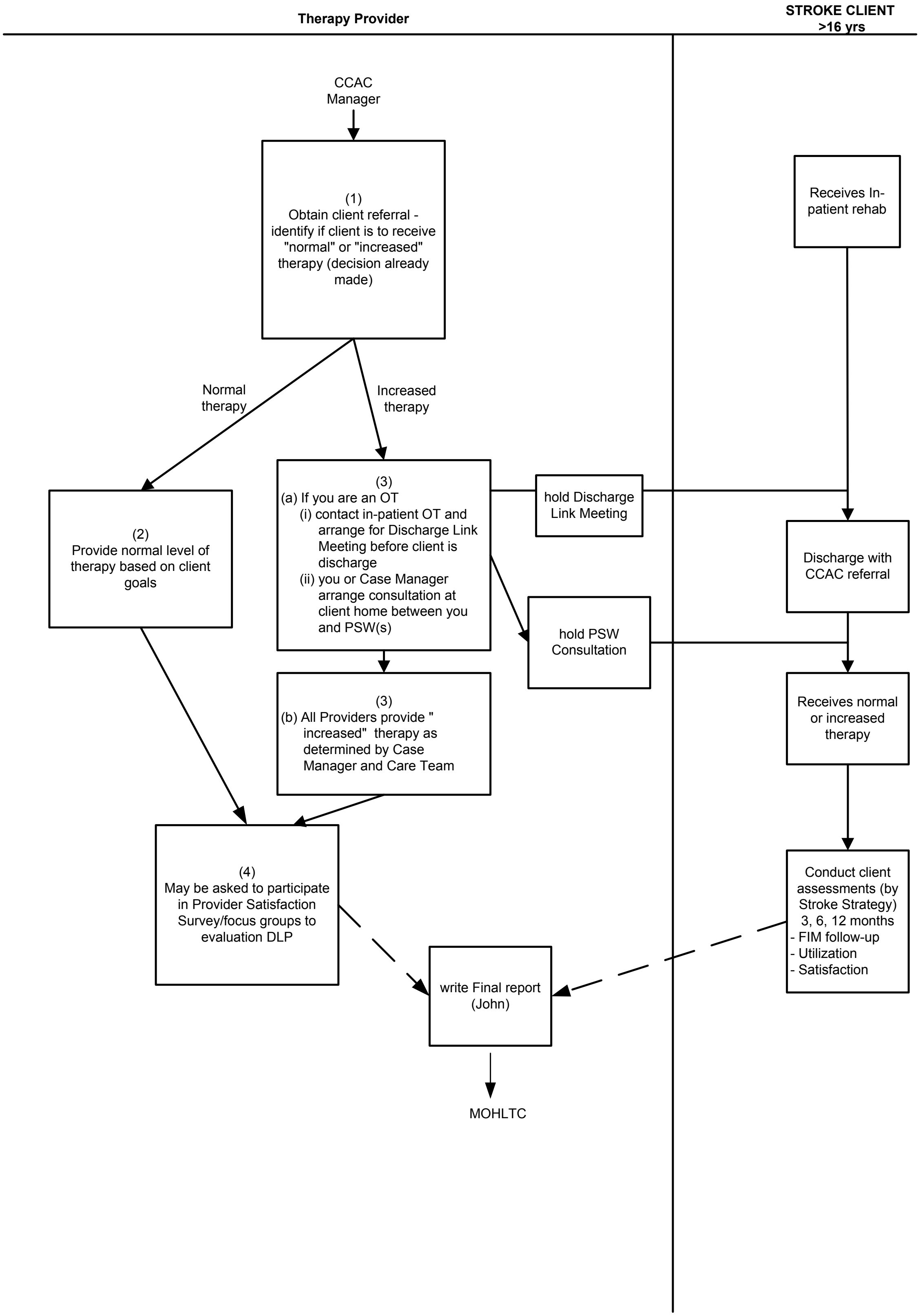
Note 2: Normal vs. Increased Therapy group: The decision about the group in which the client is to be placed is NOT based on any of the client's medical conditions or living situation. It will be based on the availability of CCAC staff to provide the therapy, and the amount of project funding remaining.

For further Information, contact:

John Paterson, Stroke Rehab Project Coordinator
Room 313 Doran 3, KGH, 76 Stuart St, Kingston, ON, K7L2V7
Phone 549 6666 x 6350, email patersoj@kgh.kari.net
FAX 613 548 2454

****For detailed description of procedures, see "Therapy Provider's Protocols"***

THERAPY PROVIDER'S ROLE



The Stroke Rehabilitation Project
Of Southeastern Ontario

PSW Protocol
(Discharge Link Project)

Protocol for Personal Support Workers:

These are the Personal Support Workers (Homemakers) contracted by the CCACs to provide personal support in the home.

(Note: A flowchart accompanies this document.)

Actions: (these may vary to meet the administrative procedures of different settings)

1. Obtain a new stroke client's referral in the customary way. The referral will indicate whether or not the client is in the Discharge Link Project (DLP), and whether or not they are in the normal or increased therapy groups. Consenting clients are <u>not</u> aware which group they are in, but some may be able to figure it out. This is not a problem.

2. IF THE CLIENT IS IN THE **NORMAL THERAPY** GROUP: Support will be provided at the normal level. The only difference is that John Paterson will telephone these clients 3,6 and 12 months after discharge for the CIHI-NRS follow up evaluation, and 2 months after discharge for the client/caregiver satisfaction survey. You may be asked what these calls are about. Refer the client to your supervisor or the CCAC case manager for answers.

3. IF THE CLIENT IS IN THE **INCREASED THERAPY** GROUP:

   Your supervisor will inform you that your new client will be receiving increased home support, and what that will entail in terms of the number of hours per week.

   a) You will be asked to attend a consultation between the PSW(s), the PSW supervisor (if possible) and yourself, at the client's home during their first week home. (see " Guideline for the PSW Consultation – separate document).

   b) You will provide the "increased" level of home support as determined by your supervisor.

   c) John Paterson will ALSO telephone this group of clients 3,6 and 12 months after discharge for the CIHI-NRS follow up evaluation, and 2 months after discharge for the client/caregiver satisfaction survey.

4. Towards the end of the Project you may be asked to participate in a "provider satisfaction survey" and perhaps a focus group to evaluate the effects of the Project on client's rehabilitation in the community.

Guideline for the "Increased" Home Support Group

The Project is supplying the funds for increased therapy; that is, therapy **above and beyond** the level of therapy that a CCAC would normally provide. The amount of increased therapy will be determined by the client's therapy goals. The funding covers the following activities:

a) The Discharge Link meeting (OT to OT)
b) The OT - PSW initial consultation.
c) Provider visits (see guidelines below).
d) Additional PSW time (see guidelines below).
e) Equipment needs.

First Week:	The CCAC contracted "community" OT meets with the PSW(s) and the PSW supervisor at the client's home to communicate client goals and treatment plans.
First 4 weeks:	Up to 5 extra hrs/wk of PSW.

Note 1: Withdrawals: If a client has to withdraw from the Project for unforeseen reasons, you may be the first to know. Please inform your supervisor ASAP.

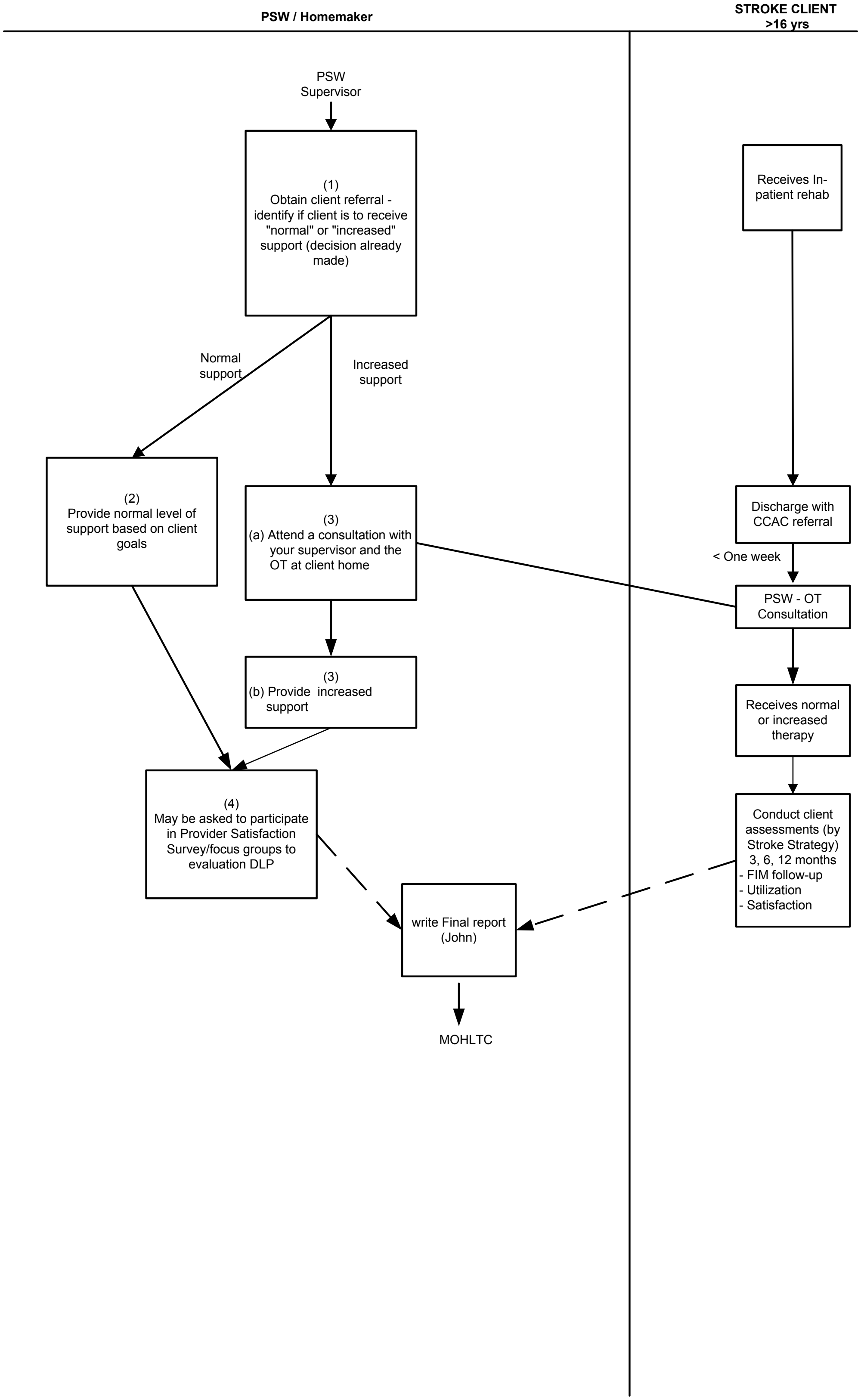
Note 2: Normal vs. Increased Therapy group: The decision about the group in which the client is to be placed is NOT based on any of the client's medical conditions or living situation. It is based on the availability of staff to provide the therapy and the amount Project funds remaining.

For further Information, contact:

John Paterson, Stroke Rehab Project Coordinator
Room 313 Doran 3, KGH, 76 Stuart St, Kingston, ON, K7L2V7
Phone 549 6666 x 6350, email patersoj@kgh.kari.net
FAX 613 548 2454

Personal Support Worker's Role

For detailed description of procedures, see "Personal Support Worker's Protocols"



Appendix E(iii)
Guidelines for the Discharge Link Meeting

I Background Information:

The Discharge Link Project (DLP) is investigating the impact of increased levels of rehabilitation therapy at home, the process of how it is delivered, how it might affect the function of people who have had a stroke, and explore how they are able to cope with living at home. To be eligible, clients must be over 16, have had a recent stroke, have been recipients of a day hospital or inpatient rehab program, and be eligible for therapy from the CCAC.

Two Groups: After gaining consent of the client and/or their family, the clients will be assigned to either a “normal” therapy group or an “increased” therapy group, depending upon the availability of therapy personnel in each region.

Therapy Interventions: The “normal therapy” group of clients (60) will act as a baseline and receive the usual level of therapy from CCAC contracted providers; the “increased therapy” group (60), or the study group, will receive an increased amount of therapy (from the same therapists) especially during their first two months at home.

The Discharge Link (DL) Meeting: Clients who are in the second group will also participate in a Discharge Link meeting. This meeting occurs between the hospital inpatient occupational therapist (OT) and the Access Centre community OT prior to discharge. (Physiotherapists and Speech Language Pathologists will continue to exchange treatment information in the usual way). The purposes of the Discharge Link meeting are:

- To improve the communication of client goals, therapy plans and treatment techniques through a face-to-face meeting of the inpatient OT and the Community OT.
- To increase client involvement by allowing the client to be part of the process.

II Guidelines for Arranging the Discharge Link Meeting

1. The CCAC case manager (or designate) will inform both the inpatient and community OTs of the imminent discharge of a stroke client to the community.

2. The CCAC OT will contact the hospital OT and coordinate the DL meeting to take place just prior (at least 2 weeks and preferably less than 72 hours) to the client’s discharge from the inpatient setting.
3. The inpatient OT will arrange for the client, and his/her caregivers to be present at the DL meeting.

4. The DL meeting takes place.

Appendix E(iv)
Project Workplan

WORKPLAN: SOUTHEASTERN ONTARIO REHAB PILOT PROJECT Updated Sept 2003

Activity	Task	Accountability	Timelines X = completed													
			Jul-Oct'02		Nov'02-Feb'03		Mar-Jun'03		Jul-Oct'03		Nov'03-Feb04		Mar-Jun'04		Jul-Oct'04	
PROJECT 1	Recruit Rehab Pilot Project Coordinator	Regional Coordinator	X													
Stroke	Meet with Rehab SubCmtee of the Regional Stroke Steering Committee, discuss design	Project Coordinator and Regional Coordinator	X													
	Investigate use of similar tools	Project Coordinator	X	X												
Information Tool	Meet with Stroke providers to develop information needed	Project Coordinator		X	X											
	Write draft Tool, circulate for feedback, make revisions	Project Coordinator			X											
	Establish trial of revised Tool	Project Coordinator			X	X	X	X								
	Educate users & establish processes for use of Tool	Project Coordinator			X	X	X	ON GOING	ON GOING	ON GOING						
	Implement tool in predetermined sub group	Project Coordinator							KGH	other sites	▨	▨				
	Evaluation, see next page	Projector Coordinator with Ministry Consultant		X	X	X	X	X	X	▨	▨	▨	▨	▨		
PROJECT 2	Recruit Rehab Pilot Project Coordinator	Regional Coordinator	X													
	Meet with Rehab SubCmtee of the Regional Stroke Steering Committee, discuss design	Project Coordinator with Regional Coordinator	X													
	Gain ethics approval (Queen's)	Project Coordinator			X	X										
	Gain pre-project support (partners) and approvals to access data (CIHI)	Project Coordinator			X	X										
Discharge Link Project	Meet with CCAC & inpatient rehab providers to establish administrative procedures, such as referral and follow up	Project Coordinator		X	X	X										
	Establish test and control sites	Project Coordinator		X												
	Establish CCAC tool for patient satisfaction	Project Coordinator			X	X	X									
	Database development	Project Coordinator			X	X	X	X								
	Educate Stroke providers and managers re: process	Project Coordinator			X	X	ON GOING	ON GOING	ON GOING							
	Implement augmented service in test sites	Project Coordinator					X	X	X	▨	▨	▨	▨	▨		
	Evaluation, see next page	Project Coordinator with Ministry Consultant		X	X	X	X	X	X	▨	▨	▨	▨	▨		

Activity	Task	Accountability	Timelines													
			Jul-Oct'02		Nov'02-Feb'03		Mar-Jun'03		Jul-Oct'03		Nov'03-Feb04		Mar-Jun'04		Jul-Oct'04	
PROJECT SUPPORT	CIHI NRS training & implementation for inpatient rehab	CIHI/Rehab Units	See Note #1 below													
	Alpha FIM feasibility study in acute care	Project Coordinator			L&A					Other	Sites	▨				
	Establish processes for collection of CIHI NRS Data	Project Coordinator			X	X	X	X	X							
	Gain permission from hospitals and CIHI	Project Coordinator			X	X	X									
	Establish processes for phone CIHI NRS follow-up data collection	Project Coordinator				X	X									
	Implement data collection processes	Project Coordinator						X	X	▨	▨	▨	▨	▨	▨	
EVALUATION	Meet other Pilot Project Coordinators and MOHLTC to discuss evaluation of projects	Project Coordinator with Ministry of Health		X		X				▨		▨		▨		
	Develop evaluation of Project 1	Project Coordinator		X	X	X										
	Develop evaluation of Project 2	Project Coordinator		X	X	X										
	Implement evaluation 1&2	Project Coordinator					X	X	X	▨	▨	▨	▨	▨		
	Analyze data	Project Coordinator											▨	▨	▨	
	Prepare interim draft Report, circulate to Regional stakeholders, obtain feedback	Project Coordinator with Regional Coordinator							X	▨						
	Prepare final draft Report, circulate to Regional stakeholders, obtain feedback	Project Coordinator with Regional Coordinator													▨	
	Prepare Final Report for MOHLTC	Project Coordinator with Regional Coordinator													▨	▨

Note #1: Mandated Oct 1/01 for submission by Oct 02. FIM training for SEO occurred in Feb 2002

APPENDIX F:

Discharge Link Project Data Elements

Appendix F
Discharge Link Project Data Elements

1. Client/Caregiver demographics	Source (item #)	Collected at
Patient name	Client tracking form	Pre-discharge
Contact Address	Client tracking form	Pre-discharge
Postal code	Client tracking form	Pre-discharge
Phone number	Client tracking form	Pre-discharge
Caregiver(s) name, contact info	Client tracking form	Pre-discharge
Rehab Client Record # (if different than HC#)	Client tracking form	Pre-discharge
Distance living from hospital (pre-stroke) Kms	Maps	after D/C
Post D/C location, rural or urban	Maps	after D/C
Chart number	CIHI-NRS 4	discharge
HC #	CIHI-NRS 5	discharge
Sex	CIHI-NRS 7	discharge
D.O.B.	CIHI-NRS 8	discharge
Pre-hospital living arrangements	CIHI-NRS 12	discharge
Post Discharge living arrangements	CIHI-NRS 13	discharge
Pre-hospital living setting	CIHI-NRS 14	discharge
Post Discharge living setting	CIHI-NRS 15	discharge

2. Patient Health Characteristics		
Date of (stroke) onset	CIHI-NRS 39	discharge
Rehab client group (RCG) (type of stroke)	CIHI-NRS 34	discharge
Most responsible health condition	CIHI-NRS 35,	discharge
Pre admit co-morbid health	CIHI-NRS 36A	discharge
Post admit co-morbid health	CIHI-NRS 36B	discharge
FIM score total, Admission to inpatient rehab	CIHI-NRS, Admission	admission
FIM score total, Discharge from inpatient rehab	CIHI-NRS, Discharge	discharge
FIM score total, Follow-up, 3 month post DC	CIHI-NRS, Follow up	Discharge +3
FIM score total, Follow-up, 6 month post DC	CIHI-NRS, Follow up	Discharge +6
FIM score total, Follow-up, 12 month post DC	CIHI-NRS, Follow up	Discharge +12
TPA administered? Y/N	Stroke Strategy	After discharge

3. Utilization of Health Care System	Source (item #)	Collected at
a) Acute Care:		
Facility code, acute	CIHI Authorization	Pre-discharge
Adm date to acute care, if same as onset	CIHI-NRS 39	discharge

b) In-patient Rehab Care:		
Facility code, rehab	CIHI-NRS 1A	discharge
Admission class	CIHI-NRS 19A	discharge
Readmission <1 month	CIHI-NRS 19B	discharge
Re-adm planned?	CIHI-NRS 19C	discharge

Date ready for admission known?	CIHI-NRS 20A	discharge
Date ready for admission	CIHI-NRS 20B	discharge
Adm date to rehab	CIHI-NRS 21	discharge
Service interruption, start date	CIHI-NRS 25A	discharge
Service interruption, return date	CIHI-NRS 25B	discharge
Service interruption, reason	CIHI-NRS 25C	discharge
Service interruption, transfer status	CIHI-NRS 25D	discharge
Therapy start date	CIHI-NRS 26	discharge
Therapy end date	CIHI-NRS 27	discharge
Provider type(s)	CIHI-NRS 28A	discharge
Date ready for D/C	CIHI-NRS 29	discharge
D/C date (rehab)	CIHI-NRS 30	discharge
Reason for discharge	CIHI-NRS 31	discharge
Referred to	CIHI-NRS 32	discharge
FIM data (Discharge)	CIHI-NRS 41-70	discharge
Discharge Link meeting? Y/N	Project records	Pre-discharge
Date DL meeting	Project records	discharge

c) Community Rehab Care (CCAC)		
CCAC site providing therapy	Project records	discharge
PSW Consultation meeting? Y/N	Project records	discharge
Date of PSW meeting	Project records	discharge
Follow up assessment date (s)	CIHI-NRS 72	3,6,12 after D/C
Respondent type	CIHI-NRS 74	3,6,12 after D/C
	Source (item #)	Collected at
Follow-up living arrangements	CIHI-NRS 76	3,6,12 after D/C
Follow-up living setting	CIHI-NRS 77	3,6,12 after D/C
Informal support received	CIHI-NRS 16	3,6,12 after D/C
Hospitalization since discharge?	CIHI-NRS 73A	3,6,12 after D/C
Days in hospital (re admission)	CIHI-NRS 73B	3,6,12 after D/C
Hospitalization, reason	CIHI-NRS 73C	3,6,12 after D/C
FIM items (Follow-up)	CIHI-NRS 41-58	3,6,12 after D/C
Impact of Pain	CIHI-NRS 59	3,6,12 after D/C
Meal preparation	CIHI-NRS 60	3,6,12 after D/C
Light Housework	CIHI-NRS 61	3,6,12 after D/C
Heavy Housework	CIHI-NRS 62	3,6,12 after D/C
Presence of Cognitive Impairment, etc	CIHI-NRS 63-69	3,6,12 after D/C
General Health status	CIHI-NRS 70	3,6,12 after D/C
Reintegration to Normal Living Index	CIHI-NRS 75	3,6,12 after D/C
Rehab care, professional (OT, PT, SLP)	Workload measures	3,6,12 after D/C
Rehab care, non professional (PSW) (hrs)	Workload measures	3,6,12 after D/C
Dates of rehab care (days since D/C)	Workload measures	3,6,12 after D/C
Informal support (Community Support, etc)	Client/Caregiver questionnaire	3,6,12 after D/C
Caregiver care (hrs/day)	Client/Caregiver questionnaire	3,6,12 after D/C

d) Other		
Attend prevention clinic? Y/N	Stroke Strategy	3,6,12 after D/C
# Visits to family physician and/or walk in clinics related to the stroke	Client/Caregiver quest	3,6,12 after D/C
# Visits to emergency	Client/Caregiver quest	3,6,12 after D/C
Has there been any use of respite care? #	Client/Caregiver quest	3,6,12 after D/C
Has there been a referral to LTC facility?	Client/Caregiver quest	3,6,12 after D/C

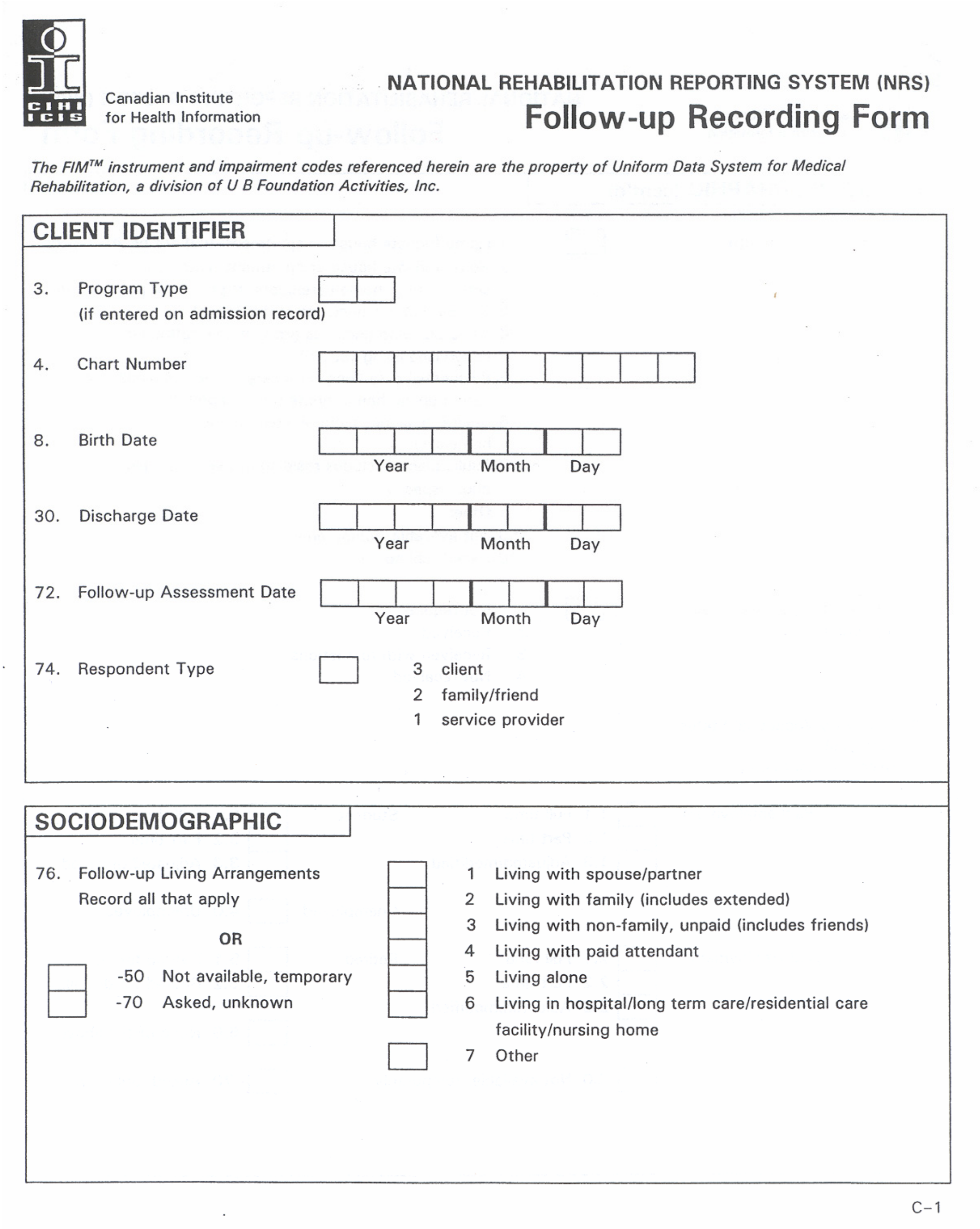
Other Instruments

4. Client/caregiver satisfaction survey (+2 months) (includes a few additional questions on utilization, caregiver support)
5. Provider satisfaction survey (+3,12 months)

APPENDIX G:

Assessment Tools –
G(i) CIHI-NRS (FIM & RNL)
G(ii) CCAC Client Satisfaction Survey – SEO Version

Appendix G(i)
CIHI-NRS (FIM & RNL)



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NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

Follow-up Recording Form

The FIM™ instrument and impairment codes referenced herein are the property of Uniform Data System for Medical Rehabilitation, a division of U B Foundation Activities, Inc.

CLIENT IDENTIFIER

3. Program Type (if entered on admission record) ☐☐

4. Chart Number ☐☐☐☐☐☐☐☐☐☐

8. Birth Date ☐☐☐☐ ☐☐ ☐☐ Year Month Day

30. Discharge Date ☐☐☐☐ ☐☐ ☐☐ Year Month Day

72. Follow-up Assessment Date ☐☐☐☐ ☐☐ ☐☐ Year Month Day

74. Respondent Type ☐
3 client
2 family/friend
1 service provider

SOCIODEMOGRAPHIC

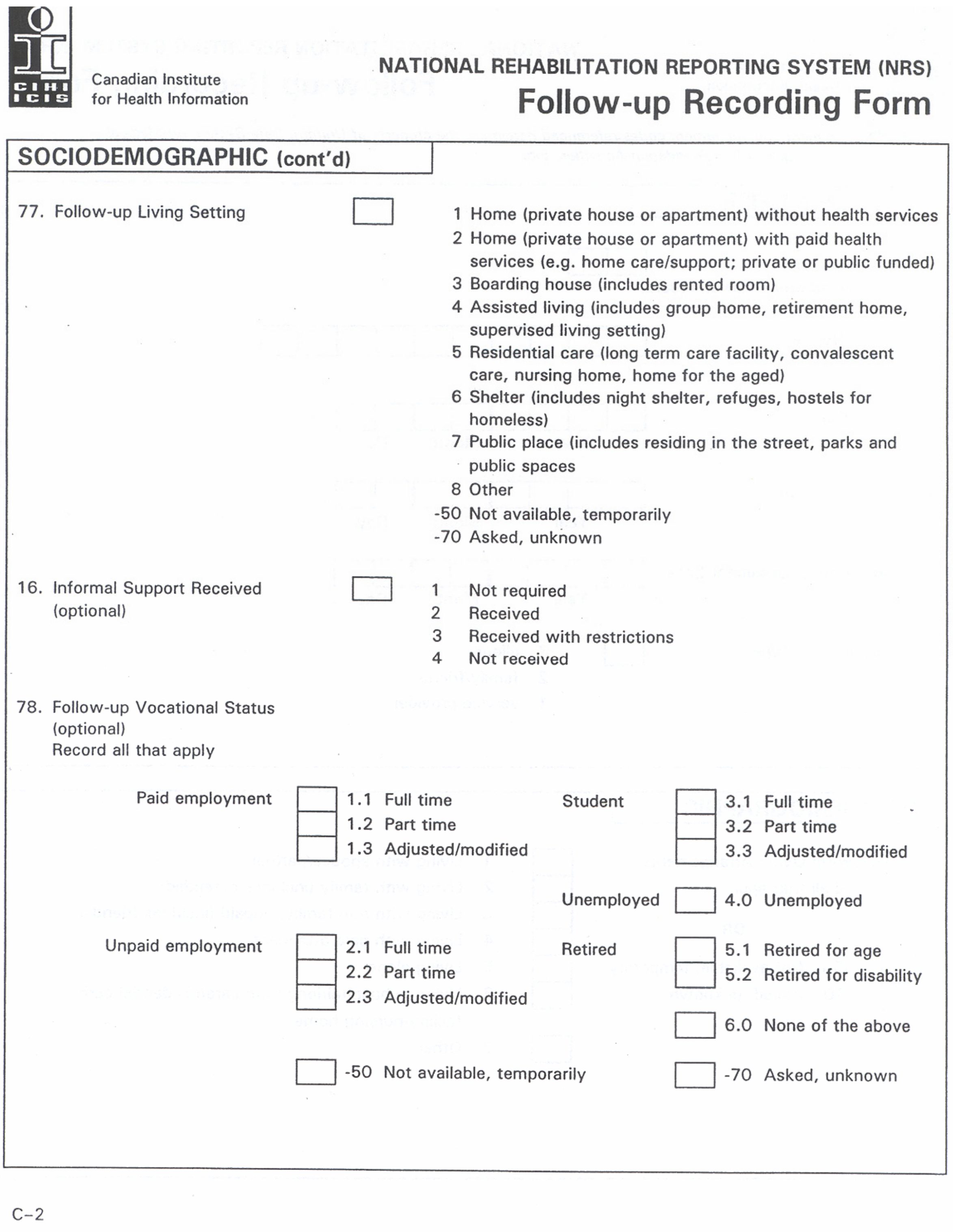
76. Follow-up Living Arrangements
Record all that apply

☐ 1 Living with spouse/partner
☐ 2 Living with family (includes extended)
☐ 3 Living with non-family, unpaid (includes friends)
☐ 4 Living with paid attendant
☐ 5 Living alone
☐ 6 Living in hospital/long term care/residential care facility/nursing home
☐ 7 Other

OR

☐ -50 Not available, temporary
☐ -70 Asked, unknown

C–1



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NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

Follow-up Recording Form

SOCIODEMOGRAPHIC (cont'd)

77. Follow-up Living Setting ☐

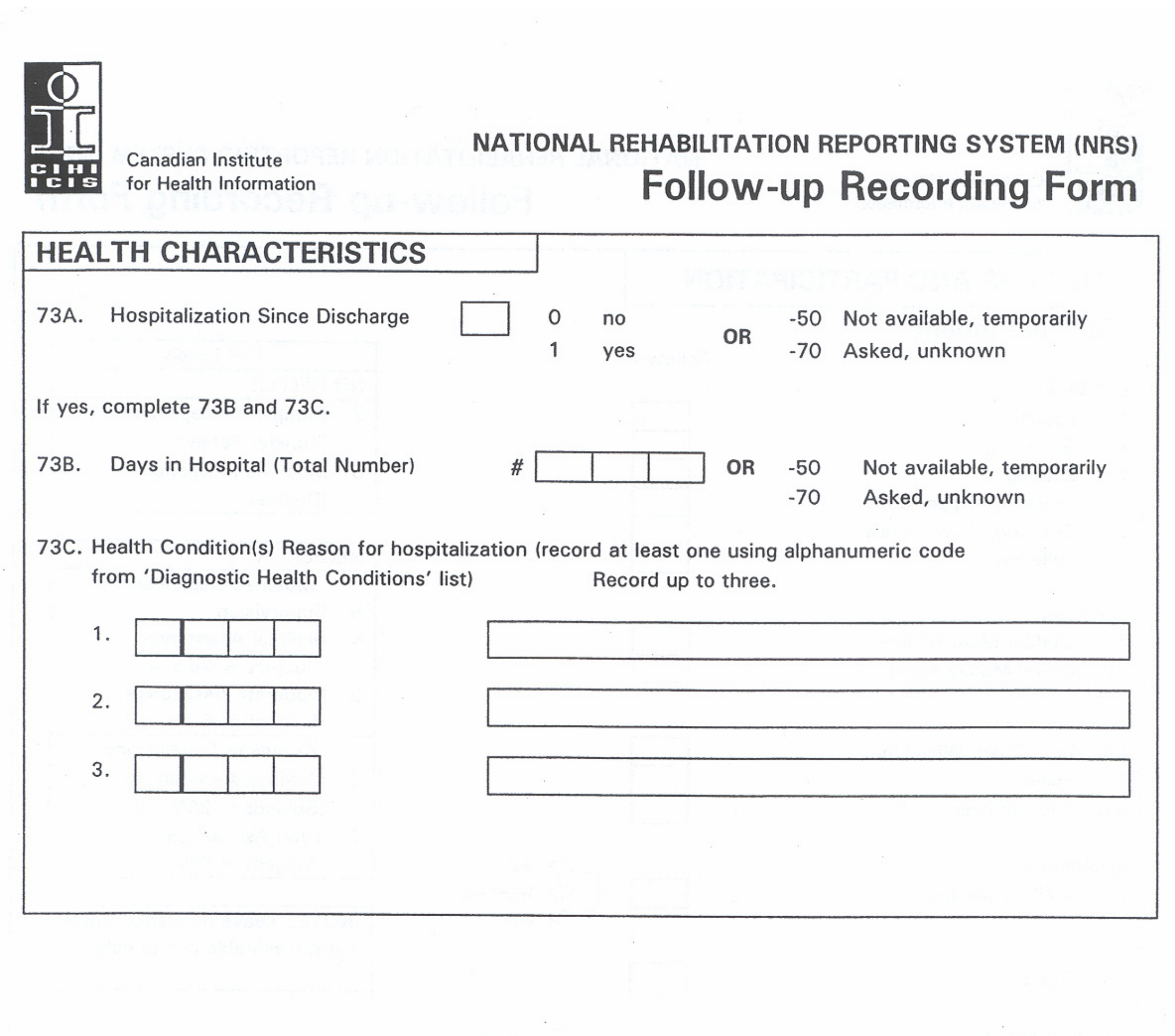
1 Home (private house or apartment) without health services
2 Home (private house or apartment) with paid health services (e.g. home care/support; private or public funded)
3 Boarding house (includes rented room)
4 Assisted living (includes group home, retirement home, supervised living setting)
5 Residential care (long term care facility, convalescent care, nursing home, home for the aged)
6 Shelter (includes night shelter, refuges, hostels for homeless)
7 Public place (includes residing in the street, parks and public spaces
8 Other
-50 Not available, temporarily
-70 Asked, unknown

16. Informal Support Received (optional) ☐

1 Not required
2 Received
3 Received with restrictions
4 Not received

78. Follow-up Vocational Status
(optional)
Record all that apply

Paid employment	☐ 1.1 Full time ☐ 1.2 Part time ☐ 1.3 Adjusted/modified	Student	☐ 3.1 Full time ☐ 3.2 Part time ☐ 3.3 Adjusted/modified
		Unemployed	☐ 4.0 Unemployed
Unpaid employment	☐ 2.1 Full time ☐ 2.2 Part time ☐ 2.3 Adjusted/modified	Retired	☐ 5.1 Retired for age ☐ 5.2 Retired for disability
			☐ 6.0 None of the above
	☐ -50 Not available, temporarily		☐ -70 Asked, unknown



Canadian Institute
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NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

Follow-up Recording Form

HEALTH CHARACTERISTICS

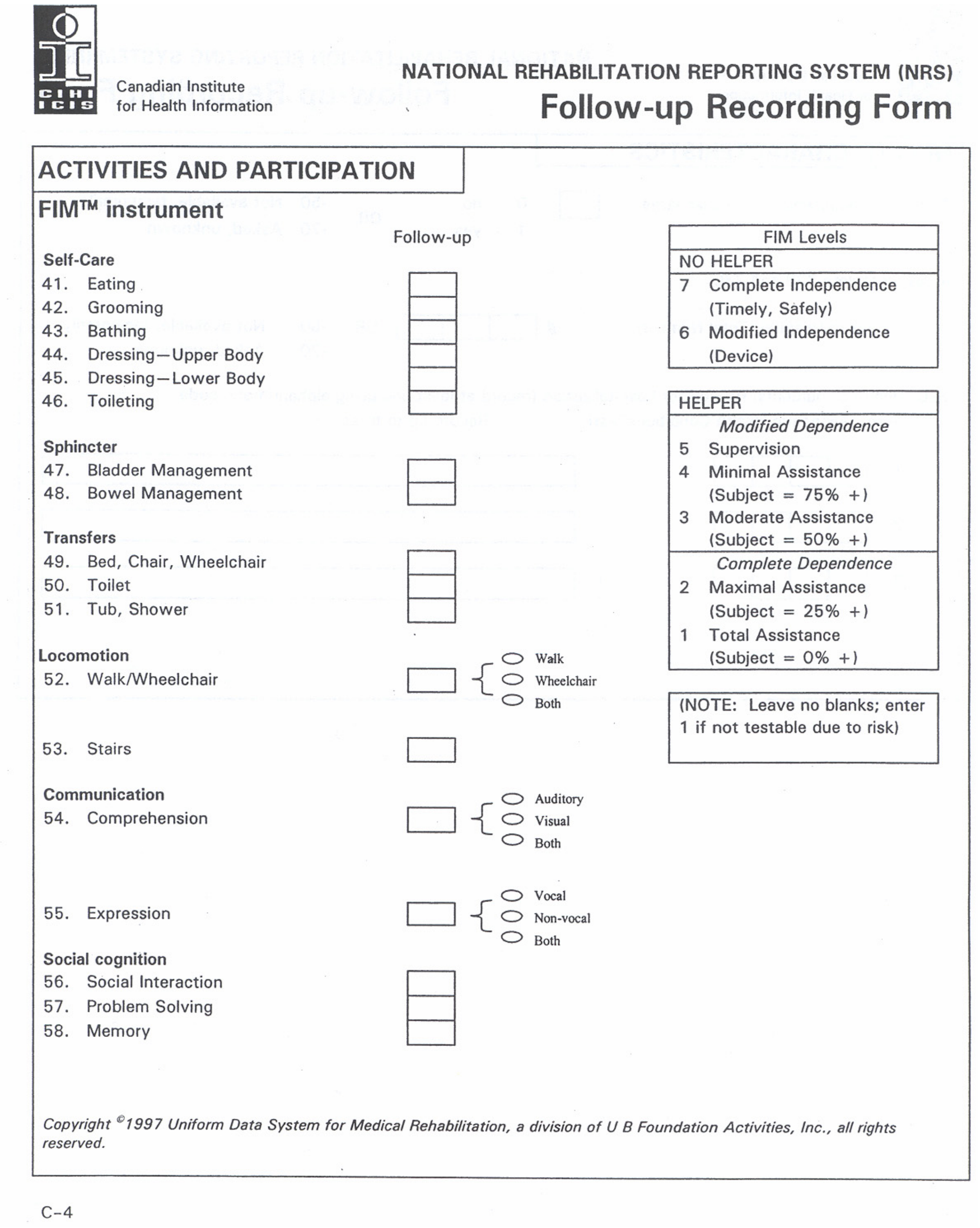
73A. Hospitalization Since Discharge ☐ 0 no / 1 yes OR -50 Not available, temporarily / -70 Asked, unknown

If yes, complete 73B and 73C.

73B. Days in Hospital (Total Number) # ☐☐☐ OR -50 Not available, temporarily / -70 Asked, unknown

73C. Health Condition(s) Reason for hospitalization (record at least one using alphanumeric code from 'Diagnostic Health Conditions' list) Record up to three.

1. ☐☐☐☐ ________________
2. ☐☐☐☐ ________________
3. ☐☐☐☐ ________________



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NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

Follow-up Recording Form

ACTIVITIES AND PARTICIPATION

FIM™ instrument

	Follow-up	
Self-Care		
41. Eating	☐	
42. Grooming	☐	
43. Bathing	☐	
44. Dressing—Upper Body	☐	
45. Dressing—Lower Body	☐	
46. Toileting	☐	
Sphincter		
47. Bladder Management	☐	
48. Bowel Management	☐	
Transfers		
49. Bed, Chair, Wheelchair	☐	
50. Toilet	☐	
51. Tub, Shower	☐	
Locomotion		
52. Walk/Wheelchair	☐	○ Walk ○ Wheelchair ○ Both
53. Stairs	☐	
Communication		
54. Comprehension	☐	○ Auditory ○ Visual ○ Both
55. Expression	☐	○ Vocal ○ Non-vocal ○ Both
Social cognition		
56. Social Interaction	☐	
57. Problem Solving	☐	
58. Memory	☐	

FIM Levels

NO HELPER
7 Complete Independence (Timely, Safely)
6 Modified Independence (Device)

HELPER
Modified Dependence
5 Supervision
4 Minimal Assistance (Subject = 75% +)
3 Moderate Assistance (Subject = 50% +)
Complete Dependence
2 Maximal Assistance (Subject = 25% +)
1 Total Assistance (Subject = 0% +)

(NOTE: Leave no blanks; enter 1 if not testable due to risk)

C-4

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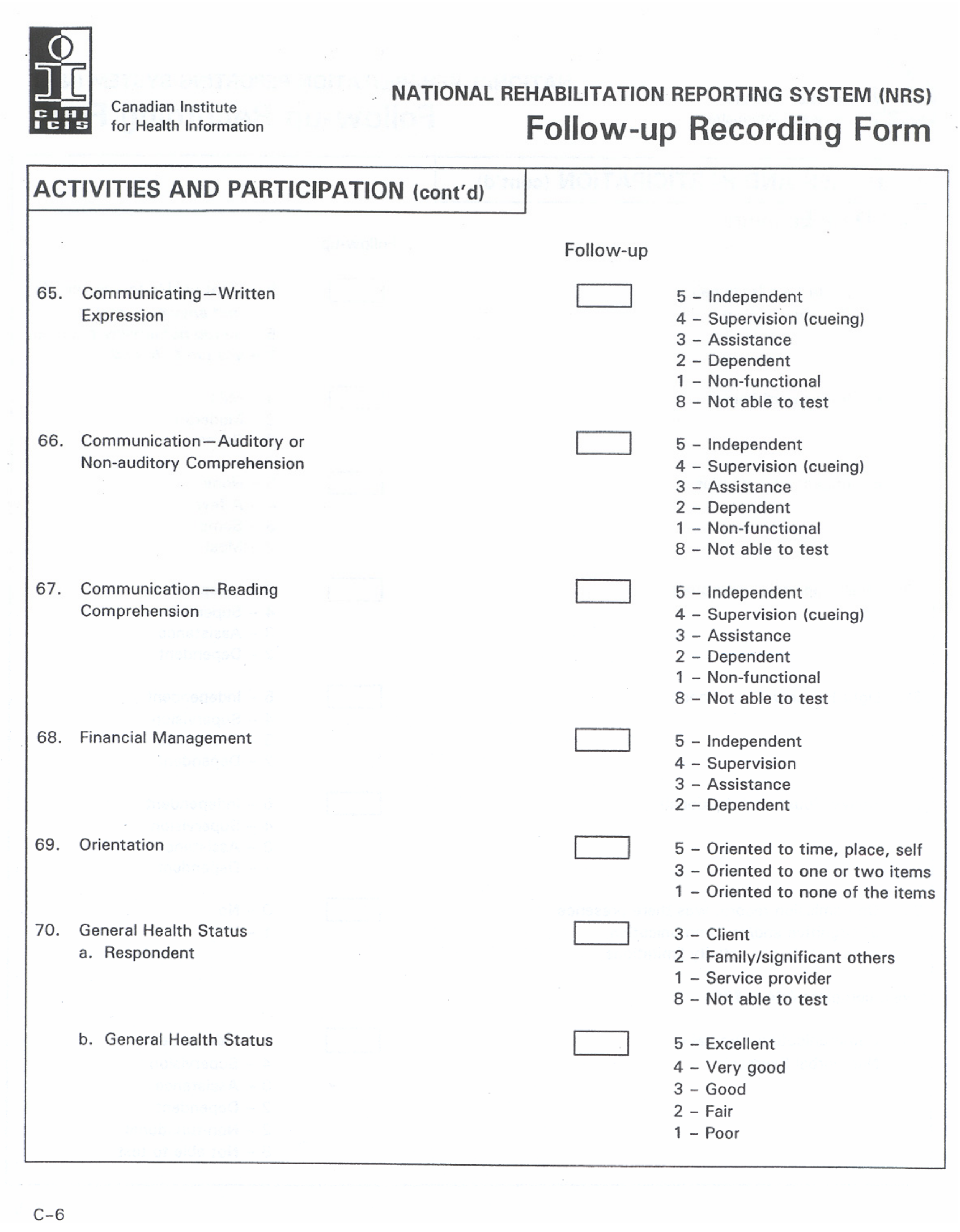
NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

Follow-up Recording Form

ACTIVITIES AND PARTICIPATION (cont'd)

CIHI Data Elements

	Follow-up	
59. Impact of Pain (optional) a. Presence of Pain	☐	8 –Client unable to answer (*do not answer b. and c.*) 5 – no *(do not answer b. and c.)* 1 – yes *(go to b. and c.)*
b. Intensity of Pain	☐	4 – Mild 3 – Moderate 2 – Severe
c. Impact on Activities	☐	5 – None 4 – A few 3 – Some 2 – Most
60. Meal Preparation (optional)	☐	5 – Independent 4 – Supervision 3 – Assistance 2 – Dependent
61. Light Housework (optional)	☐	5 – Independent 4 – Supervision 3 – Assistance 2 – Dependent
62. Heavy Housework (optional)	☐	5 – Independent 4 – Supervision 3 – Assistance 2 – Dependent
63. On admission record, was there presence of cognitive and/or communication impairment(s) or activity limitations	☐	0 – No 1 – Yes
If yes, complete #64 – #69.		
64. Communicating—Verbal or Non-verbal Expression	☐	5 – Independent 4 – Supervision 3 – Assistance 2 – Dependent 2 – Non-functional 8 – Not able to test



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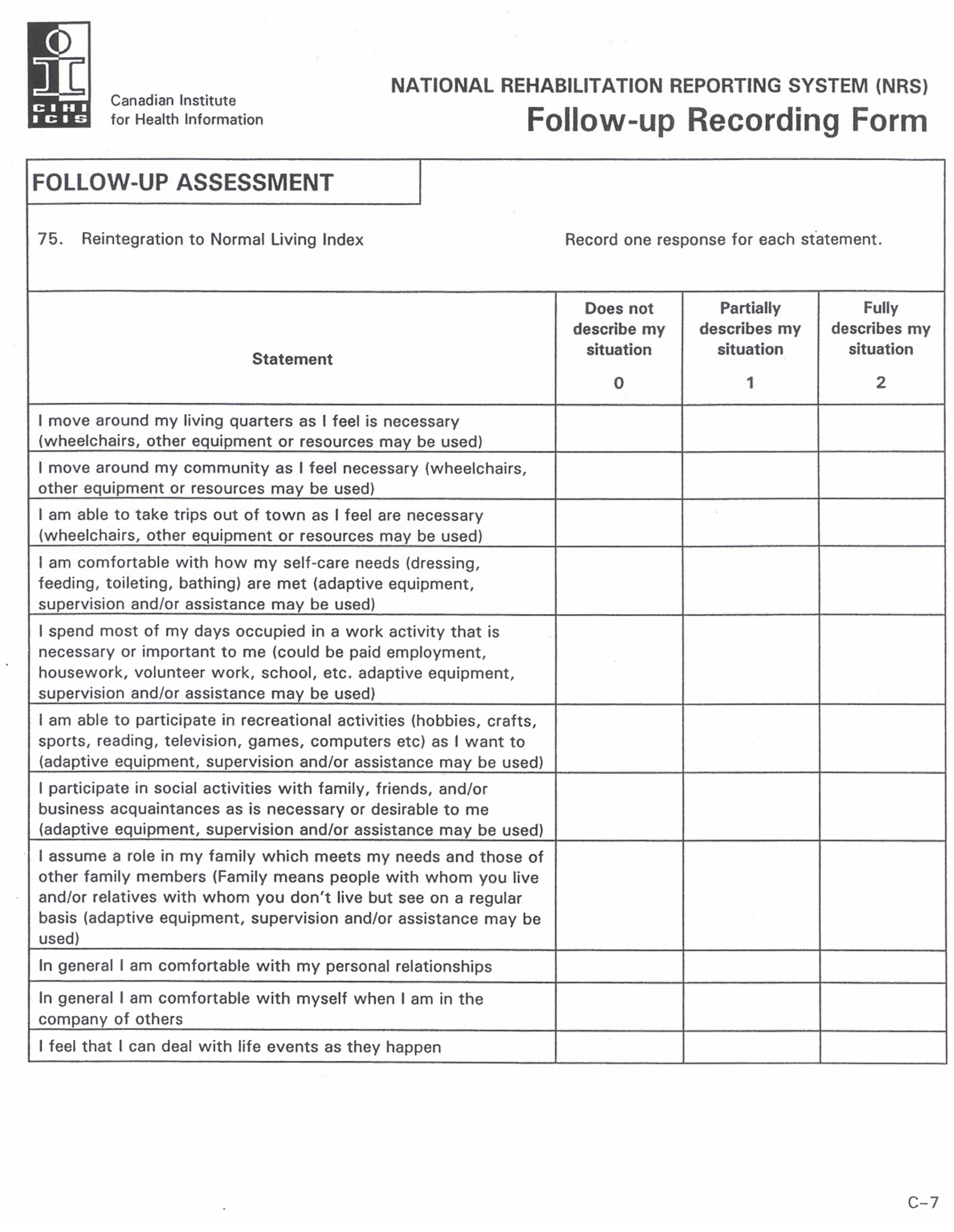
NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

Follow-up Recording Form

ACTIVITIES AND PARTICIPATION (cont'd)

		Follow-up	
65.	Communicating—Written Expression	☐	5 – Independent 4 – Supervision (cueing) 3 – Assistance 2 – Dependent 1 – Non-functional 8 – Not able to test
66.	Communication—Auditory or Non-auditory Comprehension	☐	5 – Independent 4 – Supervision (cueing) 3 – Assistance 2 – Dependent 1 – Non-functional 8 – Not able to test
67.	Communication—Reading Comprehension	☐	5 – Independent 4 – Supervision (cueing) 3 – Assistance 2 – Dependent 1 – Non-functional 8 – Not able to test
68.	Financial Management	☐	5 – Independent 4 – Supervision 3 – Assistance 2 – Dependent
69.	Orientation	☐	5 – Oriented to time, place, self 3 – Oriented to one or two items 1 – Oriented to none of the items
70.	General Health Status a. Respondent	☐	3 – Client 2 – Family/significant others 1 – Service provider 8 – Not able to test
	b. General Health Status	☐	5 – Excellent 4 – Very good 3 – Good 2 – Fair 1 – Poor



Canadian Institute
for Health Information

NATIONAL REHABILITATION REPORTING SYSTEM (NRS)

Follow-up Recording Form

FOLLOW-UP ASSESSMENT

75. Reintegration to Normal Living Index

Record one response for each statement.

Statement	Does not describe my situation 0	Partially describes my situation 1	Fully describes my situation 2
I move around my living quarters as I feel is necessary (wheelchairs, other equipment or resources may be used)			
I move around my community as I feel necessary (wheelchairs, other equipment or resources may be used)			
I am able to take trips out of town as I feel are necessary (wheelchairs, other equipment or resources may be used)			
I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met (adaptive equipment, supervision and/or assistance may be used)			
I spend most of my days occupied in a work activity that is necessary or important to me (could be paid employment, housework, volunteer work, school, etc. adaptive equipment, supervision and/or assistance may be used)			
I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers etc) as I want to (adaptive equipment, supervision and/or assistance may be used)			
I participate in social activities with family, friends, and/or business acquaintances as is necessary or desirable to me (adaptive equipment, supervision and/or assistance may be used)			
I assume a role in my family which meets my needs and those of other family members (Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis (adaptive equipment, supervision and/or assistance may be used)			
In general I am comfortable with my personal relationships			
In general I am comfortable with myself when I am in the company of others			
I feel that I can deal with life events as they happen			

Appendix G(ii)
CCAC Client Satisfaction Survey* – SEO Version
Telephone Interview

(* Based on the CCAC Evaluation Survey, Telephone Interview, from Smaller Worlds, Toronto)

Introduction (SKIP TO S4 IF ALREADY INTRODUCED)

Hello, my name is John Paterson, I am calling from the Regional Stroke Strategy office at KGH to ask you some questions about your recovery. May I speak with [INSERT C1]

YES	1	[SKIP TO BACKGROUND]
NOT ABLE TO	2	[SKIP TO S2]
NOT AVAILABLE	3	[CONTINUE]
REFUSAL	4	[RECORD REASON FOR REFUSAL]

When would be a good time for me to call back? [ARRANGE TIME] ________________

Introduction, continued

I am calling from the Regional Stroke Strategy office at KGH, for the Rehab Pilot project of SEO. You might recall that you agreed to participate in a study called the Discharge Link Project. I am calling to get your feedback on the therapy services [INSERT C1] you received that were arranged by the Community Care Access Centre. Is there another person (like a family member or a friend) I may speak to who participated in arranging the Community Care Access Centre services for [INSERT CLIENT'S NAME].

YES, THAT WOULD BE ME	1	[SKIP TO BACKGROUND]
YES, SOMEONE ELSE	2	[SKIP TO S3]
NO	3	[THANK AND TERMINATE]
REFUSAL	4	[RECORD REASON]

May I speak with [INSERT NAME OF PERSON RECOMMENDED].

YES	1	[SKIP TO BACKGROUND]
NOT AVAILABLE	3	[CONTINUE]
REFUSAL	4	[RECORD REASON]

When would be a good time for me to call [INSERT NAME OF PERSON RECOMMENDED] back? *[ARRANGE TIME IF POSSIBLE AND RECORD NAME OF PERSON].*

____

Background

When correct respondent is reached.
Hello]. My name is John Paterson. I am calling from the Regional Stroke Strategy office at KGH. We would like to get your opinions about the services provided to [IF S1=1 INSERT "YOU"; IF S2=1 OR S3=1 INSERT C1]. Your comments and suggestions will assist us and the MOH with improving their services to all clients. The information you provide is

completely confidential. The interview will only take about 10 minutes. May I interview you now? (If someone is at home right now providing your care, would you prefer I call back?)

YES	1	[CONTINUE]
NO	2	[ARRANGE TIME TO CALL BACK]
REFUSED	4	[RECORD REASON FOR REFUSAL]

*IF RESPONDENT IS CONFUSED ABOUT WHAT THE Stroke Strategy or CCAC IS:

The Stroke Strategy is…..
*The Community Care Access Centre is the organization that arranges services you receive in your home like homemaking, nursing, physiotherapy, etc. not the agency that provides the services.**

***** S4 BEGIN HERE IF YOU HAVE ALREADY ESTABLISHED CONTACT WITH THE CLIENT AND ARE CONTINUING THE ASSESSMENT FROM ANOTHER INSTRUMENT.**

We are about to start another part of the assessment, which has to do with asking you about your level of satisfaction with the therapy and support services you have received at home. The answers you give me are confidential and will not be given to the CCAC or any of the people you have been coming to assist you.

Before we begin I would like to confirm that you received services from the CCAC (ACCC) in the last few months. Did you?

YES	1	
NO	2	[THANK AND TERMINATE]

Are you still receiving services from the CCAC(ACCC)?

YES	1……	GO TO S5_1
NO	2…….	Skip to #

Which type of service(s) did you receive?

S5_1	1	Personal support worker/homemaker*	GO TO SECTION A
S5_2	2	Nurse	
S5_3	3	Physiotherapy*	GO TO SECTION B
S5_4	4	Occupational therapy*	GO TO SECTION B
S5_5	5	Social Worker	
S5_6	6	Dietitian	
S5_7	7	Speech and Language*	GO TO SECTION B
		Not sure	

If 1, 3, 4 or 7 proceed to the appropriate section
If other, go to section C

Section A. Personal Support Worker

Questions Specific to Service Providers

These questions are only asked to those receiving this type of service.

A. Personal Support Worker

A.1 *In the last month or so did you receive services from a personal support worker or homemaker?*

YES; NO; DON'T KNOW] IF YES, continue; otherwise, skip to next section.

A.2 *Approximately how many times* ***<u>in the last month</u>*** *did he/she visit you*?

__/month __/week

For each of the following questions, please rate [T2] the service you received from the personal support worker (homemaker) as Excellent, Good, Fair, or Poor.

INTERVIEWER NOTE: If respondents indicate having multiple providers ask for them to respond on the one who comes most often.

Q#	**Question**	**Scale**			
Communication					
H.5	Understanding [T2] homemaking and/or personal care needs.	Excellent	Good	Fair	Poor
H.7	Taking time to answer your questions.	Excellent	Good	Fair	Poor
	Responsiveness				
H.11	Making sure that [T2] needs are met in a timely fashion.	Excellent	Good	Fair	Poor
Completing Work					
H.15	Showing you how to do activities and use equipment that will help you to maintain [T2] independence.	Excellent	Good	Fair	Poor
H.19	Working independently with minimal supervision.	Excellent	Good	Fair	Poor
H.20	**Overall how would you rate the quality of service provided by [T2] personal support worker/homemaker?**	Excellent	Good	Fair	Poor

Section B. Therapists

B. Therapists

D.1 *In the last month did you receive services from any therapists?*

[YES; NO; DON'T KNOW] IF YES, continue, otherwise skip to next section.

D.2 *Approximately how many times **in the last month** did he/she/they visit you?*

__/month __/week

For each of the following questions, please rate the therapists in general as Excellent, Good, Fair, or Poor.

INTERVIEWER NOTE: If respondents indicate having multiple providers ask for them to respond on the one who comes most often.???

Q#	**Question**	**Scale**			
Communication					
T.6	Understanding [T2] needs.	Excellent	Good	Fair	Poor
T.8	Taking time to answer your questions.	Excellent	Good	Fair	Poor
Responsiveness					
T.12	Ensuring [T2] needs are met in a timely fashion.	Excellent	Good	Fair	Poor
Education					
T.14	Providing information to you about [T2] care.	Excellent	Good	Fair	Poor
T.15	Showing you how to do activities and use equipment that will help you to maintain [T2] independence.	Excellent	Good	Fair	Poor
T.16	Did you receive written instructions to help you with [T2] therapy?	Yes	No, but would have liked to receive instructions	No, not necessary	DK
Completing Work					
T.23	Helping you to stay as independent as possible.	Excellent	Good	Fair	Poor
T.24	**Overall, how would you rate the care you received?**	Excellent	Good	Fair	Poor

Section C. General Questions

Section C General Questions					
2.1a	Did you have any difficulties arranging or getting [T2] services started?	Yes	No	Don't Know	
2.1b	IF YES in Q2.1a. What difficulties did you have?	Open end and code			
2.2	Do you feel you need **other** services in your home [INSERT T3 IF C20a=1]?	Yes	No	Don't Know	
2.3	IF YES in Q2.2. What other services do you feel you need?	Open end and coded			
2.4	Do you feel you need services more often, less often or are you currently receiving the right amount of service?	More	Less	Right Amount	
8.1	How would you rate the coordination of [T2] care between service providers. N/A	Excellent	Good	Fair	Poor
9.2	Have the services you've been receiving allowed [T4] to stay safely in your home?	Yes	No	Don't Know	
9.4	In your opinion are the home care services allowing [T4] to stay as independent as possible?	Yes	No	Don't Know	
9.5	In your opinion has [T2] health been improving, staying the same or getting worse?	Improving	Same	Worse	
9.6	Overall, how would you rate the services [T4] are receiving?	Excellent	Good	Fair	Poor
9.8	Do you receive any other assistance which helps [T4] to stay in your home?	Yes	No	Don't Know	

9.9 *In your opinion what could be done to improve the services you receive from the CCAC? Anything else?*

----

10. *Remembering back to the time of your (his/her) stoke, did you receive tPa in emergency?*
Y N DK

11. *After your stroke, did you take part in the stroke prevention clinic?*

Y N DK

12. *Have you had to go back to see your doctor or go to emergency or a drop-in clinic since your stroke?*
Y N DK
specifically? ____

Section X– Questions for Caregiver (skip to next section if already talking with caregiver)				
10.1a	Is there a family member or someone who lives with you that assists with your care?	Yes	No	Don't Know
10.1b	IF YES in 10.1a. Do you think they would like to provide some feedback?	Yes	No [Go to closing]	Don't Know
10.2	IF YES in 10.1b. May I speak with [INSERT NAME]? THANKS!!!			

When correct respondent is reached. *Hello [INSERT NAME]. My name is [INSERT INTERVIEWERS NAME] I am calling from the Regional Stroke Strategy. We would like to get your opinions about the services provided to [INSERT NAME OF CLIENT]. Your comments and suggestions will assist us and the MOH with improving their services to all clients. The information you provide is completely confidential. Your participation is voluntary but we would really like to know how you feel. I have already interviewed [INSERT NAME OF CLIENT] but I would like to ask you a few questions. May I interview you now?*

Yes	1	[CONTINUE]
No	2	[ARRANGE TIME TO CALL BACK]
REFUSED	4	[RECORD REASON FOR REFUSAL]

Q#	**Question**	**Scale**			
10.3	Did you receive enough information about [C1] progress?	Yes	No	Don't Know	
10.4	How would you rate the support you received to assist with [C1]?	Excellent	Good	Fair	Poor
10.5	Did you receive written instructions to help with [C1] treatment/therapy? IF NO in 10.5: Would it have helped you to receive written instructions?	Yes	No, but would have liked to receive instructions	No, not necessary	DK
10.6	Do you feel that you are expected to do too much, too little or the right amount for [C1]?	Too much	Too little	Right amount	Don't Know
10.7	Overall, how would you rate your ability to cope in your caregiver role? Would you say	Excellent	Good	Fair	Poor

Closing

1. If respondent had voiced some serious concerns (e.g., physical, emotional or financial abuse; suicidal tendencies; or was very upset with the care or service received) please ask them the following:

   The information you provided today is completely confidential. However, you voiced some serious concerns. Would you like me to have someone from the CCAC call you directly?

   YES NO DK

2. If client would like to contact their CCAC please provide them with the phone number of the CCAC in their area.

   That brings us to the end of this interview. I will be calling you back in about 3 months and once more about 6 months later. Is that OK? On behalf of the Regional Stroke Strategy, I would like to thank you for participating.

APPENDIX H:

H(i) Discharge Link Project Key Informant Interview Distribution
H(ii) Distribution of Focus Group Sessions

Appendix H(i)
Discharge Link Project
Key Informant Interview Distribution

HPE	Category
	Client
	OT community
	SLP community
	Spouse of client
	CCAC Case Manager

KFL&A	Category
	PT community
	Spouse
	CCAC Case Manager
	OT Community
	OT Community

LL&G	Category
	OT Community
	CCAC Case Manager
	Client
	Spouse

Appendix H(ii)
Distribution of Focus Group Sessions (Discharge Link Project and Diary)

HPE

Group	Category	Number
QDR	Provider agency	30
QHC- BGH and Trenton	Inpt rehab site	8
Picton*	Acute	2

FLA

Group	Category	Number
Kaymar & CCAC	Provider, Access	6
SMOL	Inpt rehab site	14
KGH, stroke team*	Acute	11

LLG

Group	Category	Number
SVDP	Inpt rehab site	4
PSFDF	Inpt rehab site	7

* sessions concerning the use of the Diary only

APPENDIX I:

Discharge Link Project Summary of Key Informant Interviews

Appendix I
Discharge Link Project
Summary of Key Informant Interviews

Process

A series of 14 Key Informant interviews was held throughout SEO following the completion of the DLP. Their purpose was to unearth further and more detailed information about the effects of the DLP intervention. The participants (14) included 5 people who had had a stroke and his or her caregivers (C1-5), and nine stakeholders (T1-9), including community therapists and case managers directly involved in the provision of the enhanced therapy. These intensive interviews were recorded and analyzed for significant trends and opinions, and then reviewed by a panel of experts to ensure validity. The panel of experts included 2 CCAC rehab directors, the manager of a local rehab provider agency, the Stroke Strategy regional manager, the rehab pilot coordinator and a graduate student in OT.

Factors

The purpose of the DLP was to investigate the effects of the project interventions on certain key factors critical to the provision of home based rehabilitation. These were identified as:

- **Access to Community-based Services:** Intensity, Rural issues
- **Patient Outcomes:** Function, Independence
- **Integration of Service:** Communication, Coordination and Collaboration
- **Client Satisfaction:** Client and Family Caregiving and Coping

Access to Community-based Services

Intensity of Therapy

There are a number of challenges and benefits linked to the increased intensity of therapy and homemaking services as provided to clients in the enhanced group.

The first challenge is from the perspective of the client that there are simply *too many people* coming in and out of the home. Not all therapists reported this as being a problem, but T1 felt that there were too many people coming in and out and that OT was not a priority. She felt it was enough to have the extra PSW support to work with the client. So, in this case the benefit of being in the enhanced group is linked to having increased PSW support, as opposed to more therapy time. The benefit of increased PSW support has increased carry over, practice time and learning of new skills [see memo on independence] for the client according to T1, T2 and T3.

T1 & T2 felt that the increased homemaking support also had an effect on family involvement. They felt that the families were less involved because they were getting extra services and therefore did not need to fill in the gaps. T1 felt this was a positive outcome because the caregivers needed relief. T2 also talks about family members feeling overwhelmed with the care giving duties, but that the increased homemaking support provided to this client, also increased the caregivers stress related to having too many people coming in and out of the home. (So, while respite is necessary, the best way to provide this respite is not necessarily by flooding the home with and endless stream of therapists and support workers). T2 and T3 felt that they had more contact with family members in the enhanced program. T3 felt this was because she was in the home more often and therefore more likely to meet different members of the family. She considered spending time educating the family on how to support the client to be as important as working directly with the client. She was only able to spend time working directly with family members because of the increased intensity of service provision.

T1 feels that a potential draw back of being in the enhanced group is that clients become dependent on the extra services (in this quote T1 also addresses the *transition* of clients from services to no services. This transition only seems to be an issue because services end before the clients stop needing the services) and that the enhanced group may actually lead to a decrease in *independence* once the services come to an end at the predetermined time period. So there is a sense that the increased intensity may be needed for a longer duration for certain clients.

T3 and T2 also talk about *duration* of services, as opposed to intensity. They feel that for some clients an increase in the duration of therapy services would have been more beneficial than an increase in intensity and that recovery after stroke often takes more than a year and that the recovery process is often a slow one. Currently the system is not very flexible in terms of providing extra visits if the client does need services long-term, however some therapists did report that they have found their way around the system in order to get the number of visits that they needed. A benefit of the extra intensity is that it allowed the therapists to do some *hands on therapy* and to address goals that go beyond safety issues. The therapists talk about the case managers not understanding or valuing these other goals or the role of the therapists and that often they simply do not have the time to work on these other goals in the regular therapy. T2 talks a lot about the importance of leisure goals for clients and how she was able to address some of these goals in the enhanced therapy program. T1 states that her greater involvement with clients leads to greater professional satisfaction.

Another drawback to the enhanced program was that some clients simply did not need the enhanced therapy, but in the context of this research project were randomly assigned to the enhanced group whether they needed it or not. At the same time, clients who could have used the enhanced therapy were not assigned to the enhanced group. This points to the need for a system that is *flexible* and able to be *responsive* to the varying needs of people because one program is never going to satisfy everyone's needs. In terms of practical implementation, it just does not seem feasible for therapists to be providing the intensity of services required by the enhanced therapy program, due to a long waiting list and limited number of *staff* covering a huge geographical area, thus making *scheduling* very challenging. This may require more then one therapist of the same profession to be working with the client, which in turn leads to loss of continuity and creates significant communication issues.

An advantage of the increased intensity is linked to individuals living in *rural* areas who are not able to go to the day hospital to receive services there twice a week. The enhanced therapy allowed people living far away from the day hospital to get the same level of service as the people living close by. T3 also feels that it would be nice to have more time to work with clients, especially with people who just recently had a stroke so that you can do a therapy blitz right at the beginning to get therapy going. Another advantage of the increased intensity raised by the therapists and case manager seemed to be that it eased the *transition* to the home, as the client continued to receive intense therapy and to make progress. The increased intensity also allowed for crisis management in the first couple of weeks as the client was adjusting to the home environment. Potential problems were identified earlier and dealt with more effectively in the enhanced group. T4 also felt that a major benefit of the enhanced therapy was being able to tell clients that they would start receiving services within a week, as opposed to having to place them on a waitlist. T2 talks about the client potentially needing more than two therapy visits a week, especially in the first couple of weeks.

The therapists felt that the intensive therapy should be part of the regular system and offered to all people who need it, because what is currently being offered in the community is *not adequate* to meet the needs of stroke clients. T3 also mentions how the research project reminded her that there is something better out there than what is currently being provided.

Community-based services

From the therapist perspective, community-based therapy is 'more real' and better able to address issues that clients face when they come home from the hospital. Therapists feel that they are able to support clients in terms of reintegration at home and in the community. In addition, community services shift the control to the client. According to T6, *"in the hospital it's always the professional who is in charge, but when you, as a professional, go to see a client in their home, the client assumes control."*

Limitations placed on therapy services

There was a strong sense of frustration on the part of the therapists with regards to the limits that are placed on them and the services that they are able to provide. T2 states: *"I really think that what is offered right now in the community is pitiful,... especially with now the research saying that there are … that there are people who just don't finish recovering until a year afterwards if not more,..., why aren't we following these people? I mean, once a week after three months … what do you mean once a week? ... Why can't we do more, why can't we follow them for six weeks or eight weeks or three months, or follow them until eight months post their [stroke]?…"*

In addition, to not being able to follow patients for an adequate amount of time, therapists felt that they were restricted in terms of what they could do. *"It doesn't let the therapists do therapy, it let's them change buildings and add equipment, and doesn't get to the gist of the issue..."* Therapists felt that they were unable to address issues outside of safety & basic mobility concerns, such as the development of motor & perceptual skills and leisure activities. Therapists also felt strongly that services in the community need to do more than assessment, consultation and management, but that there also needs to be room for direct treatment and to work on community re-integration. Several therapists expressed their frustration with some case managers not really understanding what OTs do. T2 felt that one major benefit of participating in the research project was that it allowed the case managers to see how much more occupational therapy can do. T3 felt that it also reminded her that there is something better out there: *"it has been frustrating at times that we are limited sometimes, but you get so used to working within a system that you … you forget that there might be something better out there..."*

Getting more visits for client

In order to be able to address goals that were important to the client (such as leisure activities) or in order to be able to see the client for longer periods of time, therapists have found ways around the system. Some therapists provide clients with their home phone numbers in case there are any problems. T2 stated that she spent a lot of time advocating for clients to get more services by providing scientific evidence to the case manager to back up her request. *"I find that I just have to advocate a heck of a lot more for it, and I have to justify it much more rigorously, and the goals have to be a lot more specific,... I've gotten to the point where sometimes I'll go* *and drop off articles and say this is the evidence, and you're going to tell me no based on this evidence. And now they … they don't question me [laughs] …"* The therapists acknowledge that there will always be a struggle between the case managers trying to stay within their budget and the therapists fighting for what the client actually needs.

Using homemakers to do therapy

At times, securing more services for clients resulted in the client getting more homemaking time, as opposed to increased therapy time. There is an emphasis in the community setting to transfer as much of the therapy program over to the homemaker, as possible. Therapists have been told: *"… well if it's just stretching well the homemaker can do that."* However, homemakers have varying skill levels and motivation to carry out rehab activities. While T2 sees the reasoning behind using homemakers as rehab aids, she emphasizes that they are not rehab aids. The only activities that T1 delegated to the homemakers were the ones she was comfortable having them do, while other therapists did not feel comfortable giving homemakers the responsibility to carry out exercises because they thought homemakers were poorly trained. Homemakers are not trained to be able to adapt the exercises to the clients changing needs or encourage the client to push their limits. Most importantly, however, T2 states that: *"I think of therapy as quality assurance, ..., therapists know what to look for,..., and if you don't have the eye for that, if you're not looking for how the pelvis is working, and the spine, and the trunk and how things are linked together and how they work together then they're missing out."*

Lack of resources

A lack of resources in the community setting was also raised as a challenge. The therapists did not have access to the necessary equipment to deal with more complex issues, such as improving perceptual skills or working on driving skills. Some clients are able to purchase extra equipment or supplies in order to assist in the therapy program, but many families can't afford to do so. In some areas, therapists needed to beg an occupational therapist at the hospital to make splints for them, because they did not have access to the necessary materials.

Lack of specialized care

For community therapists, it is difficult to develop expertise in the area of stroke, because they see very few stroke clients. They also do not have access to other therapists with more experience and continuing education is usually only offered in larger centres, at times far away from where the therapists work. While the therapists make an effort to attend continuing education, it is difficult for them because of the expense and time required to go. Since the community and hospital therapists had little contact prior to this research project, therapists rarely networked with specialized therapists in these settings in order to get more information. Some therapists explained that at one time, it was possible to receive specialized care in the community, but clients are now divided among therapists by postal code and this is therefore no longer possible.

Lack of continuity

In general, the therapists felt that the way community-services are presently being provided are very confusing for clients because the system is complicated to figure out. There are too many different agencies involved and there is high turnover of agencies and staff, leading to a '<u>cycle of discontinuity</u>' for the clients. There was also a concern that certain clients did not receive any therapy services at all depending on the severity of their stroke. For example, clients waiting for placement in a nursing home do not receive therapy services either at the hospital or once they get to the nursing home. T5 felt that all clients could benefit from some rehabilitation. However, the case manager stated that clients in long-term care are eligible for therapy services.

Travel

There are many challenges linked to working in a spread-out community. A major challenge is travelling to the client's homes. Therapists often have large geographical areas that they need to cover and for some therapists more than half their time is spent travelling. Part of this difficulty is related to challenges recruiting staff to work in rural and remote areas. In order to maximize their time with clients, therapists have to be very organized when it comes to scheduling. The flip side to the therapists having to spend much of their time travelling is that they are providing services to clients that live in remote areas that would otherwise not have access to rehab services because they do not live close enough to a day hospital.

Other challenges related to travel include working in someone else's environment, which at times raises issues around personal safety, hygiene and wasting time going to the home and finding that there is no one there.

Patient Outcomes

Function and Independence

Two therapists, T1 and T2, talked about independence and function in great detail, while the other therapists referred to it indirectly.

Client's view on independence

Clients reported that the stroke had a significant impact on their daily functioning, independence and ability to participate in activities of daily living, productivity and leisure. Clients talked about being unable to go on spontaneous trips, drive, read, and work. While being unable to work placed a financial strain on the families, one client was happy to now be retired as a result of the stroke. Other positive outcomes for some clients included having more contact with friends and learning a lot of new information in the past year since the stroke. However, other clients reported a decrease in the contact with friends because of their physical inability to participate in the activities that they used to share as friends. Other physical limitations included difficulties with mobility, such as difficulties getting up out of a chair, being unable to go get something independently and having decreased stamina for walking, therefore requiring a wheelchair and scooter. This raised addition issues regarding environmental accessibility and detailed planning if the client wanted to go on a trip.

The therapists also reported that independence was important to clients. For example, one client became anxious in an attempt to become a fully participating member of the household. This particular client needed to deal with the functional implications of having a stroke, as well as the emotional aspects.

Family involvement and relationship with independence

Family involvement varied greatly from client to client. This is related to the intensity of services (see intensity), the amount of communication between the therapist and the family (see communication) and the ability of families to cope with the client's disability.

Some therapists felt that the enhanced therapy allowed them to take more time with various family members, to meet them informally and exchange information with them. Family members shared information about how things were going in the home and the therapist was able to show them how to support the client and how to put the recommendations into practice. One therapist felt that working with the family was just as important as working with the client because the family is able to support the client in using their newly learned strategies on a daily basis. The therapists encouraged family members to let the client do as much as possible for themselves, this was often difficult for some spouses who were used to just getting things done quickly. The client's loss of independence was often challenging and overwhelming for family members to deal with, especially if clients were unable to be home alone. Some spouses had a difficult time coping with the constant caregiving needs, such as helping with transfers and mobility. For many caregivers the need for respite was apparent and some spouses took advantage of the therapy visits to do chores, run errands or simply relax in front of the TV. T6 & T5 stated that there are not enough support services available for people with stroke and that much of the caregiving duties fall heavily on spouses, who are tired.

Homemaking and relationship with independence

Having increased homemaking was very beneficial in increasing client independence, according to several therapists. The increased homemaking support resulted in the homemakers having more time to work with each client. This allowed them to encourage the clients to do as much as they could on their own, thereby promoting client independence. In the regular system, the homemakers are rushed and do not have enough time to get through all the activities that need to get done, therefore there is no time to let the client participate. The therapists were also able to leave exercises or activities for the homemaker to do with the client on a daily basis, which the therapists felt was beneficial most of the time because the consistent carry over of activities with the clients resulted in the learning of new tasks (this depended on the homemakers skill level and motivation to do rehab type activities with the clients). Having the homemaker work on rehab activities daily was seen as especially important when the client lived alone. Some therapists sought feedback from the homemakers to determine how the recommendations were working on a daily basis and would problem solve jointly with the homemaker. The homemaker meeting (see Communication and Coordination) was helpful in that it allowed the therapist to identify with the client and homemaker what activities could be done by the client independently, thereby setting boundaries with regards to the extent of support provided by the homemaker. The homemakers were generally supportive of the goal to maximize client independence.

While T1 felt that independence was mostly positively influenced by the enhanced therapy program, she was concerned about increased dependence of clients on the greater homemaking support and that the clients would have difficulty transitioning to doing everything on their own once services came to an end. T1 suggests that this is related to a need for increasing the duration of service provision for some clients, as recovery from stroke often takes more than a year (see memo on intensity.

Goal setting and independence

T2 talks about the importance that she places on promoting client independence, not only in the areas of self-care and mobility, but also in the area of leisure because these areas are often significantly impacted by stroke. Clients are often very motivated to reach goals related to leisure activities, so they can get back to doing the activities that they enjoy and this impacts overall motivation during therapy sessions. T2 highlights the importance of recognizing a broader definition of independence, one that includes self-care, productivity and leisure, but she notes that the case managers at the CCAC do often not recognize this.

Other

The discharge meeting at the hospital was also seen as having a positive impact on the client's functioning once they got home. T1 and T2 felt that the discharge link meeting made them aware of some of the issues related to the client's functioning and allowed for them to be dealt with earlier and more effectively. For example, T2 was forewarned that one client could do many more activities then she herself admitted to. This knowledge allowed T2 to push the client, which lead to greater improvements in client functioning. T1 stated that the equipment fund was very helpful in increasing client independence, for example, the purchase of a transfer pole facilitated transfers in and out of bed

Communication, Coordination and Collaboration

The Discharge Link Meeting

All therapists talked about the great benefits of the discharge meeting in improving communication between hospital and community therapists, facilitating the transition home for the client and in improving continuity of care.

Communication between the hospital and community therapists prior to discharge allowed for an exchange of information, passing on of knowledge and an increased awareness regarding the client's current functional abilities, especially regarding transfers and mobility. The discharge meeting was used to discuss the clients therapy program, client goals and potential obstacles or concerns for the client's return home. T1 and T2 felt that the discharge meeting increased their awareness of some of the client's problems therefore allowing them to deal with these problems earlier and more effectively. For example, T2 was forewarned that one client could do many more activities then the client admitted to. This knowledge allowed T2 to push the client, which lead to greater improvements in client functioning (see independence and functioning memo).

The contact with the rehab and medical staff at the hospital was valued by the community therapists because this allowed them to put a 'face to a name' and to learn a lot from the hospital staff, especially for complicated client cases (such as new information on movement patterns). Most of the OTs met with the OT at the hospital, however some therapists also felt that it was helpful to talk with the PTs or physician working with the client. The sharing of goals was seen as important for both the community and hospital therapists. T5 stated that she felt that the meeting increased the hospital rehab staff's awareness of some of the community therapy goals.

Many of the therapists also met with the client and the family during the discharge meeting. The therapists talked about the importance of meeting and getting to know the client and the family prior to discharge. The therapists felt that this eased the transition from receiving services at the hospital to receiving services at home for the clients. Transitions were also facilitated because the OTs were able to clarify issues before the client went home and because they were able to get everyone up-to-date, especially if the family members were present. Overall, it was felt that the discharge meeting allowed for a better preparation for discharge from the hospital, lead to better goal planning and to improved continuity of care.

The increased communication with the hospital staff was seen as very beneficial, but T2 did not feel the on-going communication after the discharge meeting was necessary, because T2 addresses different goals, as the client's needs change. The main challenges with the discharge meeting concerned scheduling. One therapist felt that she had very little time between receiving the referral and the client's discharge to schedule a meeting, while other therapists reported only receiving the referral once the client had already been discharged from the hospital.

The therapists stated that the discharge meeting was very beneficial for them and for the clients and felt that this type of exchange between hospital and community therapists should take place on a regular basis, as it creates a better awareness of client needs and "the client gets much more coordinated, excellent care".

Homemaker Meeting and other contact with the homemaker

Meeting with the homemaker was seen as a positive experience for the therapists. T1 stated that communication with the homemaker was improved after the meeting, as neither person felt intimidated to contact the other. T2 would leave her phone number for the homemaker and encouraged them to call her if a problem came up. Some homemakers would call her, especially once they got to know her. T2 felt that the level of communication between herself and the homemaker depended largely on the homemaker's interest in rehab. T2 felt that some homemakers were very interested and asked many questions while other just went through the motions.

The therapists used the homemaker meeting in order to clearly communicate what activities they wanted the homemakers to do with the client and to set the boundaries between what the homemaker should do and what the client can do on their own. The therapists talked about leaving detailed written instructions for the homemakers. T1 would also leave a grid in order for the homemaker to note when they did the activities so that she could follow up and make sure the activities were being done. At later visits with the homemaker, T3 would problem solve jointly with the homemaker and the client to determine how the activities were working. T3 felt that the close collaboration with the homemaker and client was especially beneficial for clients who lived alone and did not have family support. Overall, the increased collaboration with the homemaker seemed to improve carry over of learning for the clients in the enhanced group (see Function). The therapists did not report any problems with the homemakers taking on the extra therapy activities because it was clear that the extra half hour they had per visit was meant to do the therapy exercises.

Most of the therapists addressed the issue of delegating activities to the homemaker. T1 provided the homemakers only with activities that she was comfortable having them do, but felt that she had to be very careful in doing this. T1 would gauge who the support worker is and their skill level during the meeting. T5-T6-T7 felt that many homemakers were not well trained and therefore did not feel comfortable giving them the responsibility to carry out exercises. T2 stated that she understands the use of homemakers as rehab aids, but emphasized that they are not rehab aids. There is also an on-going problem of high turn over of homemaking staff.

There were also some challenges identified in relation to the homemaker meeting. T1 did not feel that she had enough time to become familiar with the home environment and did not have a lot to teach the homemaker during their first meeting. At some homemaker meetings, she also felt that there were too many different homemakers present from different agencies, which was overwhelming, especially for the client. Coordination with the homemaking agency was also difficult because the agency did not get identified until the day of discharge. T1 would like a standard procedure in place, in order to make the coordination of the homemaker meeting easier for the therapists. There were also difficulties contacting the homemaker because they do not have voice mail and so T1 would leave notes on the fridge for the homemaker, which she was unsure were being read. T1 and T2 coordinated their visits to overlap with the homemaker visit in order to touch base.

Family Members

Communication with family members varied. Some family members were unable to be present during the therapy visits because of work, while others chose to take advantage of the time that the therapist was present to run errands, do chores or to relax in another room. Many family members were present at the therapy visits and this was seen as being very helpful by the therapists. T3 spent more time talking with family members of clients in the enhanced group because she met various members of the family during her frequent visits. She was able to exchange information with them, get feedback from them regarding how suggestions are working, provide education about the client's deficits and show them how to support the client. T3 felt that having as many people as possible supporting the client at home was important and for this reason she liked to spend as much time educating the family as working directly with the client. This was only possibly within the enhanced therapy program. T2 was also able to spend more time getting to know the family better, to learn about what's important to them and therefore provide better services to these clients. T1, on the other hand, felt that she tended to communicate less with family members because she focused on providing suggestions and activities to the homemaker. While she still felt it was important to keep the family in the loop, she thought that less reliance on family members to carry out the therapy program was a good thing because the families needed relief from the care giving duties. T2 agreed that families in the regular therapy group needed to be more involved because she relied on them to carry out the therapy program.

Day Hospital

For two therapists, T1 and T3, communication with another therapist at the day hospital was also discussed at length. Prior to the discharge link project, neither of the therapists had to work with a therapist at the day hospital because clients did not receive services simultaneously through home care and the day hospital. Both of the therapists reported that the communication with the other therapist went well and was beneficial. The therapists contacted each other to decide who is going to work on what, to let the other therapist know what they had worked on, to update each other on client change or if there were any changes in client goals and to discuss differences in client functioning between the home and hospital setting. T3 did not have any difficulties agreeing on the goals with the hospital therapist and actually found it interesting that they had identified similar problem areas and goals. T3 stated that the communication was really good, but that she needed to spend a lot of extra time on the phone to coordinate the care for this client. Coordination of her schedule, so as not to visit on the same day as the day hospital visit, was also challenging. T3 felt that this good communication was possible partially because she has a very good relationship with the hospital and that communication already takes place at times. For example, the in-patient therapists will call T3 prior to discharge to provide an update on the client, which is followed up by the discharge report.

T1 also mentioned a situation where communication between the home care physio and the day hospital physio did not go smoothly. The home care physio decided to discharge the client because it was simply too complicated to coordinate with the hospital physio, as they were both using very different therapy approaches.

Problems with communication before research project

Prior to the discharge link project, there was little or no communication with other professionals on the stroke rehab continuum. Often, client's charts did not even mention that the client received rehabilitation at the hospital and contact numbers for the hospital therapists were never included in the client's chart. T2 stated that she was never contacted by any of the hospital therapists prior to the discharge link project because no one knew who she was or how to contact her. T2 feels that the discharge link project has established a baseline for communication between the hospital and community therapists. She hopes that this communication continues and states that there are often misunderstandings and/or frustrations about the therapists working in the other setting, so continued communication is important.

T5 felt that the "cycle of discontinuity" present in the current system is really hard on the client. There are too many different agencies and groups involved with the client. Many therapists felt that the discharge link project was very beneficial, especially concerning increased communication and collaboration as compared to the regular therapy.

Other

Communication with CCAC

As discussed in the memo on intensity, communication with the case manager is important around goal setting, as the case managers often have different priorities and do not necessarily understand the importance of occupational therapists addressing leisure activities. T2 underlined the importance of clearly explaining the reasoning behind her goals and providing the case managers with information.

Increased intensity

As discussed in the memo on intensity, increases in intensity lead to scheduling difficulties for the therapist. In order to provide the greater intensity, one option is to have two different homecare therapists visiting the client; however this leads to several significant problems, such as loss of continuity and rapport for the client and challenges in communication and coordination between the two therapists. The increased intensity combined with greater communication between hospital and community therapists, ensured that any issues that came up when the client got home, were dealt with much quicker and much more effectively.

Collaboration between therapists in the home

At times, T5, T6 and T7 did joint visits together. This was seen as very beneficial and a great advantage of the discharge link project. However, there were challenges doing these joint visits, as two OTs were not allowed to do a joint visit according to the administration, while a PT and an OT could do a joint visit together. The therapists felt that two OTs could learn from each other during a joint visit.

Client Satisfaction

Family Caregiving and Coping

Primary caregiver's experience of stroke

Two primary caregivers of clients with stroke were interviewed. Their experiences of the care-giving role, coping and searching for support are described. Both describe how the stroke has changed their lives and what changes need to be made in terms of service delivery.

Dealing with more than spouse's loss of independence
All discussion related directly to the clients with stroke (the husbands) tended to focus on the husbands' loss of independence, such as loss of mobility and on changes in their emotional state, such as angry outbursts. The primary caregivers' experiences of the stroke, however, addressed many concerns beyond the loss of function and independence of their spouses. There is a sense of being overwhelmed by the stroke and all the repercussions of the stroke and that it is the primary caregivers who need to address these repercussions, not the individual with the stroke. C1 talked about the first year after the stroke being 'hell on earth', while C2 described the experience as 'horrific'. C1 was overwhelmed by her husband's unexpected stroke, worrying for his well-being and at the same time having to address financial and insurance issues because her husband was no longer able to work. C1 worried about making ends meet, about keeping her home, about just being able to keep going. She describes herself as having been scared to death and not functioning. While things have fallen into place with her husband receiving a pension, their life style has changed significantly, as they do not have the same financial resources as previously.

Living with a stroke is an on-going challenge. C2 states that living with a crisis with no end in sight is the worst part for her. She never knows what tomorrow will bring; yet she needs to plan for the future. She feels that everything is *'like night and day'* and that everything in her life has changed. While C2 feels that she has become stronger by living through all the adversity in the past year, thinking of what lies ahead worries her: *"when you realize it's like I'm 42 years old, do I have what it takes to have my life like this for the next 30 years? Just to have enough willpower to live like this for the next 30 years".*

A major challenge for C1 & C2 was adjusting to their new care-giving role and dealing with the emotional changes in their husbands once they were back living at home. Both husbands had angry outbursts and would yell, shake their fists at their wives or destroy furniture in the home. C1's husband would often scream at her because she did not do things the way the nurses did in the hospital. *"It was hard for me to adjust to that, and it was hard for me to make him understand that it didn't just happen to him, it happened to me too so, you know, when you stand there and you scream at me because I didn't hold the shirt right so you can get your arm in there, I haven't been there for four weeks to learn how to do this, you have to give me time to learn right, and … and it was hard. It was tough."* After a year of violent outbursts, C1 was able to get medication for her husband that turned him back into the man she knew: *"from the first day that he took that pill it's been like … it's been like the same person that he was like from years and years ago, so that issue has now resolved itself, and … and … but it took a long time and it was a tough … it was a tough year."*

For C2, however, the emotional changes in her husband are an on-going challenge. The stroke has also affected is motivation, so it is difficult to get him to get up, go out or to practice any new skills. She feels like she always has to push him to do things and that at times she feels like she is interacting with a child. She also feels that she takes on the role of a therapist: *"I think part of that is the spouse becomes therapist and …if spouses becomes therapists… it really degrades and demises the personal relationship."*

Needing support

To get through such a significant crisis, both C1 & C2 benefited from the support of others, although often there was not enough support available. C1 often struggled on her own, as she was used to relying on her husband for strength, support and advice. She did talk to her now grown-up children, but she also wanted to be strong for them, so she did not rely on them too much. C1 only attended a peer support group a couple of times because she did not feel that she was able to leave her husband alone because he would get angry and start destroying things in the house. C2 also found it difficult to leave her husband alone at home. She worried about his safety and she felt guilty leaving him behind if she went out to pursue a leisure activity. C2 has been getting support from her friends and family. For example, family members check in on her husband when she needs to go away on business. She is also part of a peer support group that she meets up with a couple of times a year. She feels that this is not enough, but that just knowing there are others there is helpful to her. After fighting very hard, C2 has also been able to secure a personal care worker for her husband. At first, her husband was not eligible for support services because he had a spouse. This angered C2, as she works full-time and was not able to cope with taking care of C2's care giving needs, in addition to getting to work on time. C2's employer was supportive of her being absent from work the first couple of months, but then wanted her at work. While fighting for increased services, C2 was made to feel that she was an incompetent wife and that she was crazy, but finally was provided with more support for her husband.

Changes to service provision

Both C1 & C2 would have liked to have more information and warning about the emotional changes in their husbands. While they both acknowledge that they may have been provided with information and that they just weren't ready to process it, they feel that it was a major shock when their husbands came home (and really didn't act like their husbands anymore -so there's a sense of loss of the person that you once knew). *"But it was tough and I think I would have been better served to be told things like, you know, uh your husband is going to be yelling and screaming and calling names and shaking his fist at you. I mean I would have been better served understanding …what do you do when you've had a fight with your husband and he's this close from your face, and you think he's going to hit you, and he doesn't have a violent bone in his body...what do you do?"*

The need for more support and follow-up services after discharge from the hospital was also identified as an area that needed improvement. C2 felt she should have been more involved in the hospital care, in order to better prepare herself for her husband's return home. C2's husband continues to receive services through the day hospital, which C2 feels is beneficial. She thinks it is good for her husband to have to get up and go to the hospital, as opposed to the therapists visiting them at home. However, C2 felt there was a huge gap between when her husband was at the hospital vs. when he came home. There was no support for C2 to help with the transition home or any advice on home adaptations. A home visit was completed almost a full month after discharge from the hospital, but other than that there have been no other therapists that have followed up with C2 or her husband. C2 feels that: *"having a disability doesn't stop after "x"* *amount of years. You are coping or having challenges. For me um I think now, it's funny, it's kind of like surgery. I think you need the support well after the event ...there could be like a three month follow up to come in and do … almost like we do with the doctor for the cholesterol level and the blood work and, you know, there is none of that."* C2 states that it is important to follow up not only on the physical health of the individual, but also on their emotional well-being.

C1 also identified a need for support while her husband was at the hospital and then later on after his discharge. She would have liked a contact person that she could go to or call for support and that would follow up with her husband, as well, to see how he is doing. *"Well I really think if they had someone that you could … that's like sort of like somebody that you could … that was at the hospital that would come up and check and see if you need somebody to talk to, if you need a shoulder, be around, or you know here's a number and if you really need somebody to talk to give me a call, go to the patient and be there for the patient, go in and see them, ... just to be there."* There were no professionals that visited them at home, although they did have homecare support and the help of the cleaning lady that has been helping C1 for years.

In general, C2 felt that there was a need for greater communication, openness and sharing and that what has helped her the most is the contact to other people: *"I don't think there's enough sharing of stories and tools and those types of things..., it shouldn't just be the caseworker saying do you want to share, it should be everybody, everybody trying to connect everybody all the time rather than just in pockets because that's the pocket that sort of traditionally has connected people. I think we need to broaden out that list. Because the most important things I think for me that have made me uh have helped me have been human connections."*

Therapist's perspective on family care giving and coping

From the therapists' perspectives, the client's loss of independence was often challenging and overwhelming for family members to deal with (see independence) especially if clients were unable to be home alone. Some spouses had a difficult time coping with the constant care giving needs, such as helping with transfers and mobility. For many caregivers the need for respite was apparent and some spouses took advantage of the therapy visits, to do chores, run errands or simply relax in front of the TV. Family involvement in care giving for the client varied greatly between each family. In general, T1 and T2 felt that they placed more responsibility on the family to carry out the therapy program (see communication & intensity memos) in the regular therapy and that this responsibility was transferred to the PSW in the enhanced group. T1 thought that less reliance on family members to carry out the therapy program was a good thing because the families needed relief from the care giving duties. However, T2 refers to a case where the primary caregiver was overwhelmed with the care giving duties, but hat the increased homemaking support provided to this client, also increased the caregivers stress related to having too many people coming in and out of the home.

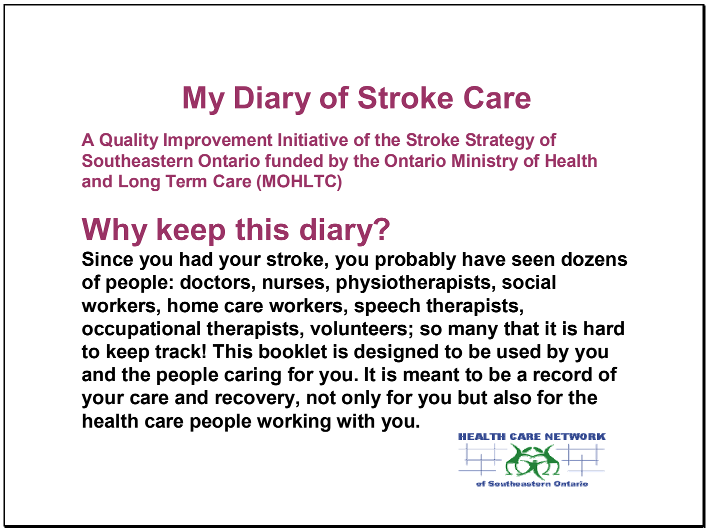
Respite care

The need for respite for this caregiver is obvious, yet the best way of providing it may not be by flooding the home with an endless stream of therapists and support workers. Several therapists address the challenge of providing support services in the community setting: there is a high turn-over of PSW (leading to discontinuity), there are often many different homemaking agencies involved, especially if a lot of support is required (leading to fragmentation of services) and in general, there are many different organizations and people involved leading to confusion and frustration for the client and family who are already struggling to cope. Finally, T5 & T6 stated that there are not enough support services available for people with stroke and that much of the care giving duties fall heavily on spouses, who are tired.

APPENDIX J:

The Diary of Stroke Care (Shortened Version)

Appendix J:
The Diary of Stroke Care - (Shortened Version)



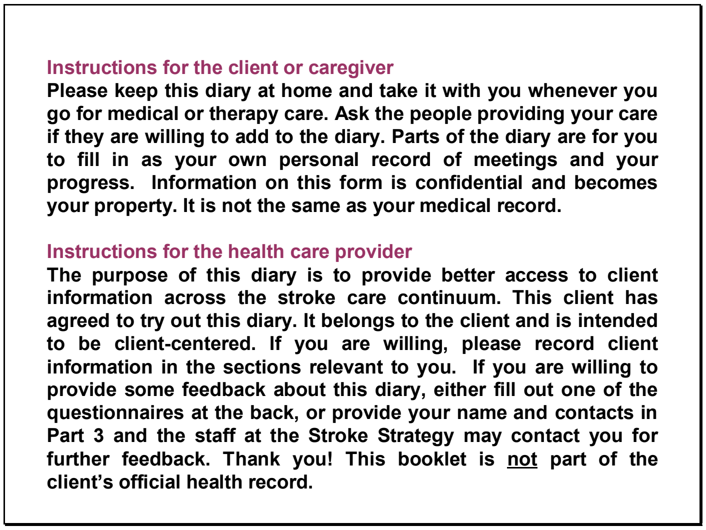
My Diary of Stroke Care

A Quality Improvement Initiative of the Stroke Strategy of Southeastern Ontario funded by the Ontario Ministry of Health and Long Term Care (MOHLTC)

Why keep this diary?

Since you had your stroke, you probably have seen dozens of people: doctors, nurses, physiotherapists, social workers, home care workers, speech therapists, occupational therapists, volunteers; so many that it is hard to keep track! This booklet is designed to be used by you and the people caring for you. It is meant to be a record of your care and recovery, not only for you but also for the health care people working with you.

HEALTH CARE NETWORK of Southeastern Ontario

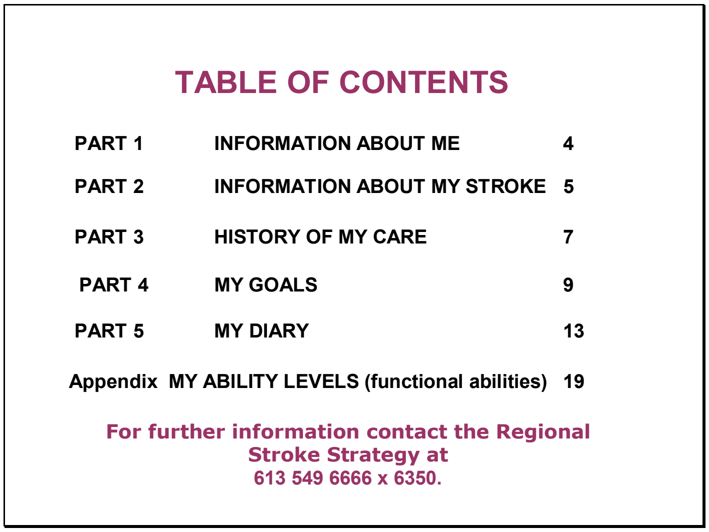


Instructions for the client or caregiver

Please keep this diary at home and take it with you whenever you go for medical or therapy care. Ask the people providing your care if they are willing to add to the diary. Parts of the diary are for you to fill in as your own personal record of meetings and your progress. Information on this form is confidential and becomes your property. It is not the same as your medical record.

Instructions for the health care provider

The purpose of this diary is to provide better access to client information across the stroke care continuum. This client has agreed to try out this diary. It belongs to the client and is intended to be client-centered. If you are willing, please record client information in the sections relevant to you. If you are willing to provide some feedback about this diary, either fill out one of the questionnaires at the back, or provide your name and contacts in Part 3 and the staff at the Stroke Strategy may contact you for further feedback. Thank you! This booklet is <u>not</u> part of the client's official health record.



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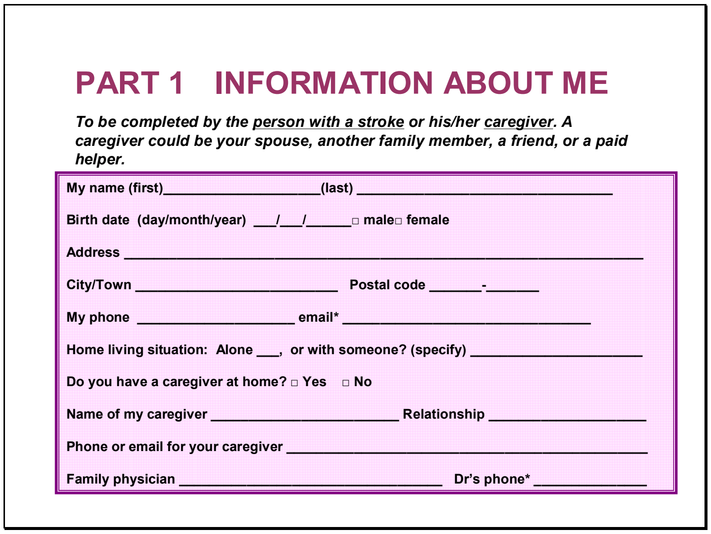
For further information contact the Regional Stroke Strategy at
613 549 6666 x 6350.



PART 1 INFORMATION ABOUT ME

To be completed by the person with a stroke or his/her caregiver. A caregiver could be your spouse, another family member, a friend, or a paid helper.

My name (first)____________________(last) _________________________________

Birth date (day/month/year) ___/___/______☐ male☐ female

Address ____

City/Town __________________________ Postal code _______-_______

My phone ____________________ email* ________________________________

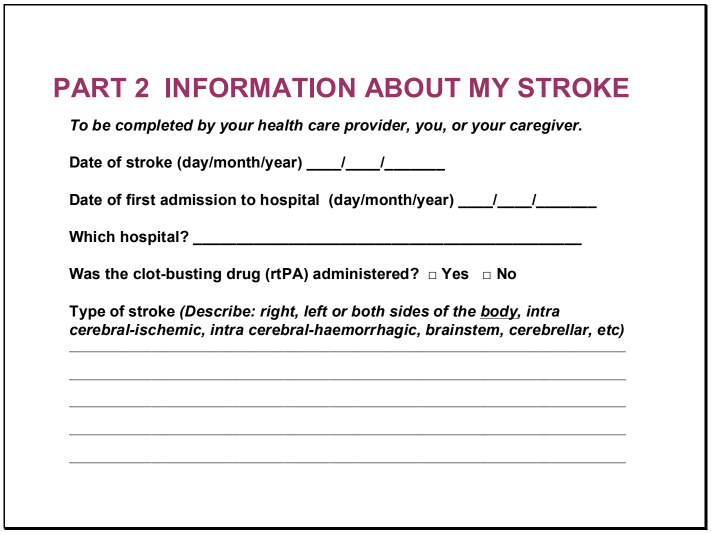
Home living situation: Alone ___, or with someone? (specify) ______________________

Do you have a caregiver at home? ☐ Yes ☐ No

Name of my caregiver ________________________ Relationship ____________________

Phone or email for your caregiver ____

Family physician __________________________________ Dr's phone* ______________



PART 2 INFORMATION ABOUT MY STROKE

To be completed by your health care provider, you, or your caregiver.

Date of stroke (day/month/year) ____/____/_______

Date of first admission to hospital (day/month/year) ____/____/_______

Which hospital? ____

Was the clot-busting drug (rtPA) administered? ☐ Yes ☐ No

Type of stroke *(Describe: right, left or both sides of the body, intra cerebral-ischemic, intra cerebral-haemorrhagic, brainstem, cerebrellar, etc)*

____

____

____

____

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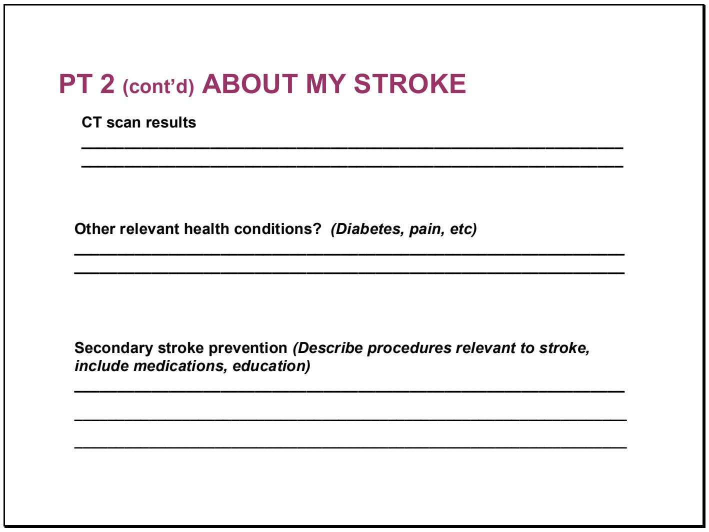


PT 2 (cont'd) ABOUT MY STROKE

CT scan results

____

____

Other relevant health conditions? *(Diabetes, pain, etc)*

____

____

Secondary stroke prevention *(Describe procedures relevant to stroke, include medications, education)*

____

____

____

PART 3 HISTORY OF MY CARE

Instructions: This section is to maintain a record of your path through the stroke care continuum and key health care providers along the way. Please add any information you think appropriate.

Setting	Date	Event	Loc'n	Key Providers	phone
A	*20/04/01*	*Admission to acute*	*KGH*	*B Smith, MD*	*555 5555*

(Setting codes: A=acute, IR=inpatient rehab, OR=Outpatient rehab, DH=day hospital, H=home, RA=readmit to acute, RC=residential care, LTC=nursing home/LTC facility, CCC=complex continuing care)

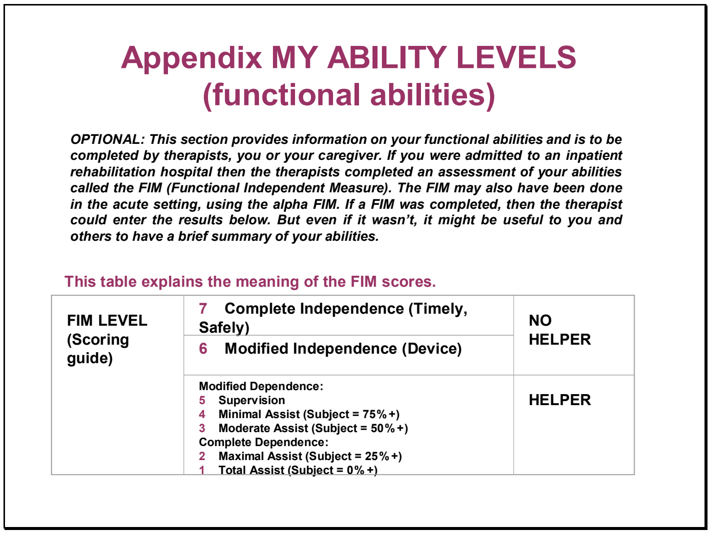
PART 4 MY GOALS

Instructions: You and your therapists have probably decided upon a few goals for your recovery. This section provides a place to record some of the most important goals for you, and to keep track of your progress. See the example below.

Date Written	My Goal	Comments (date)	Attained? Y/N
3/11/01	*I will walk to the bathroom alone.*	*I need to use a walker but I don't need a helper. (3/12/2001)*	*Y*

PART 5 MY DIARY

Instructions: You and/or your caregiver are invited to use the following section in whatever way you see fit. It could be used to record dates of appointments, important phone numbers, administration of medicine, useful pointers, thoughts or impressions.

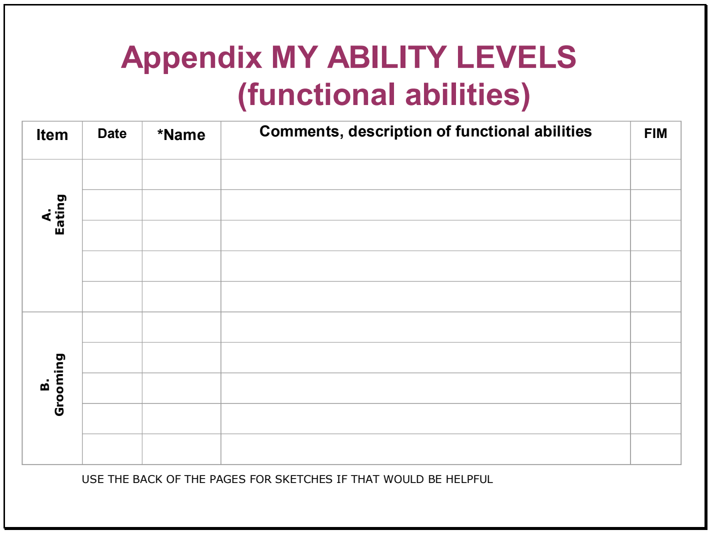


Appendix MY ABILITY LEVELS (functional abilities)

***OPTIONAL:** This section provides information on your functional abilities and is to be completed by therapists, you or your caregiver. If you were admitted to an inpatient rehabilitation hospital then the therapists completed an assessment of your abilities called the FIM (Functional Independent Measure). The FIM may also have been done in the acute setting, using the alpha FIM. If a FIM was completed, then the therapist could enter the results below. But even if it wasn't, it might be useful to you and others to have a brief summary of your abilities.*

This table explains the meaning of the FIM scores.

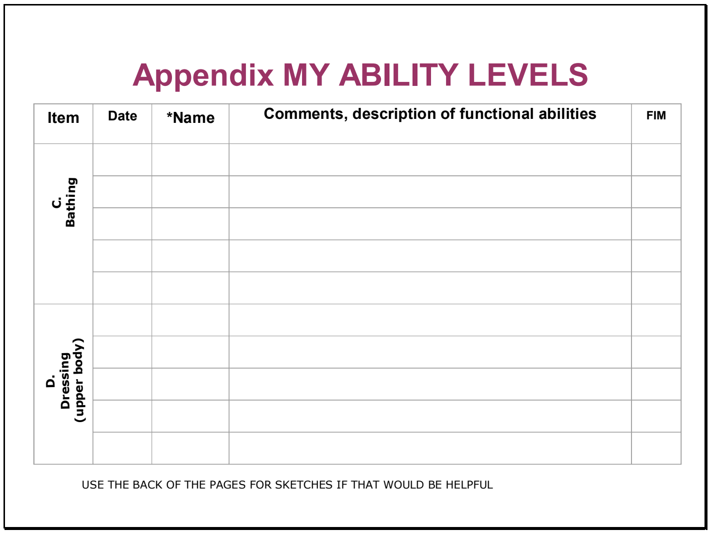
FIM LEVEL (Scoring guide)	**7 Complete Independence (Timely, Safely)**	**NO HELPER**
	6 Modified Independence (Device)	
	Modified Dependence: **5 Supervision** **4 Minimal Assist (Subject = 75%+)** **3 Moderate Assist (Subject = 50%+)** **Complete Dependence:** **2 Maximal Assist (Subject = 25%+)** **1 Total Assist (Subject = 0%+)**	**HELPER**



Appendix MY ABILITY LEVELS (functional abilities)

Item	Date	*Name	Comments, description of functional abilities	FIM
A. Eating				
B. Grooming				

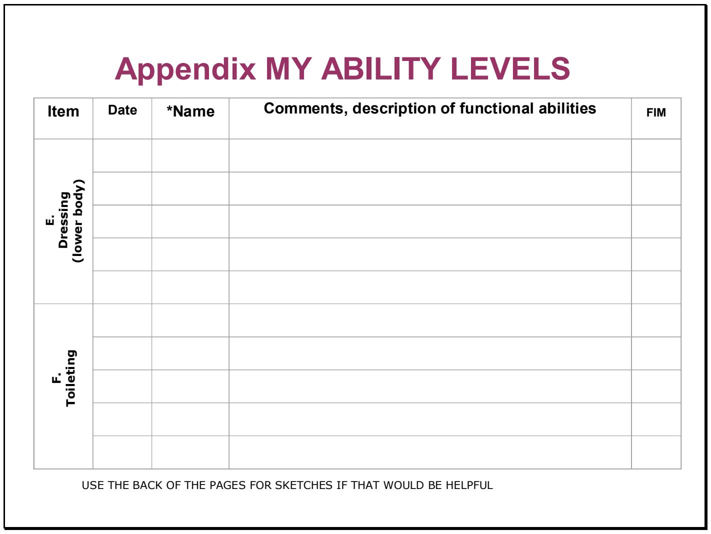
USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL



Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
C. Bathing				
D. Dressing (upper body)				

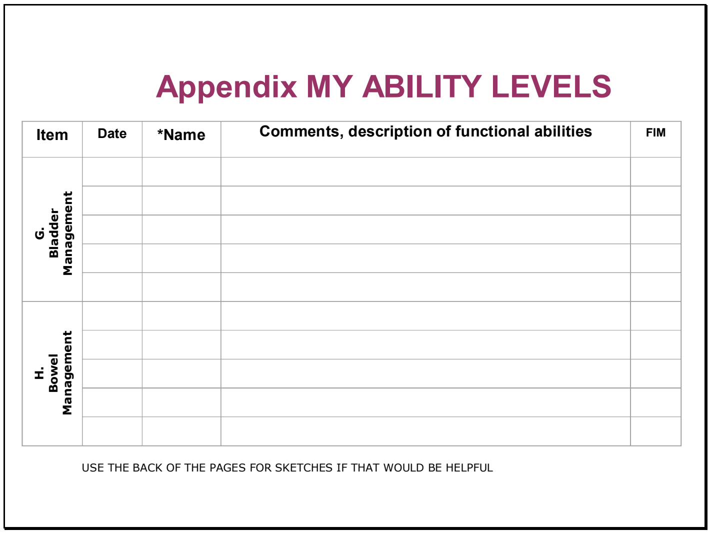
USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL



Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
E. Dressing (lower body)				
F. Toileting				

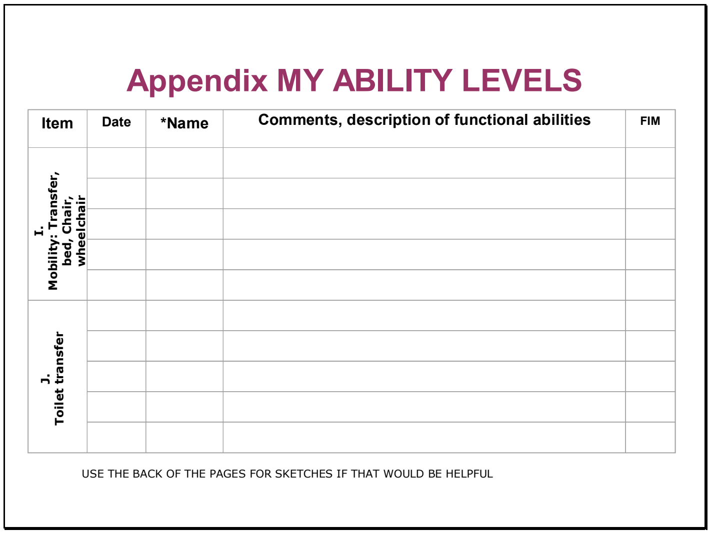
USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL



Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
G. Bladder Management				
H. Bowel Management				

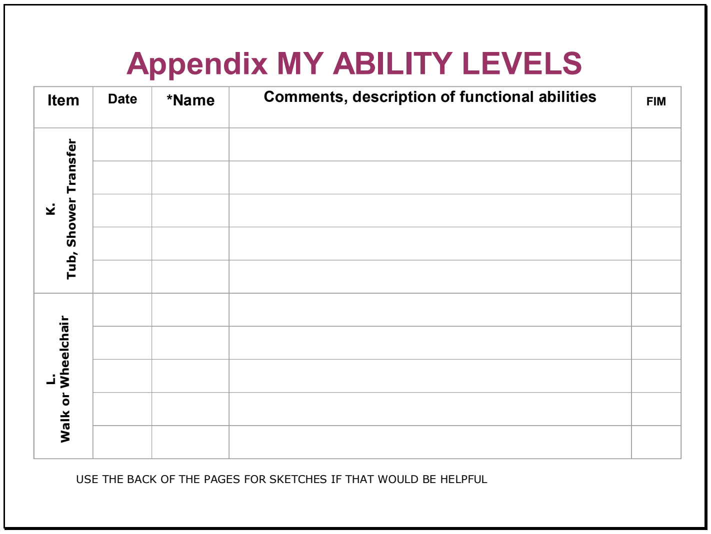
USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL



Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
I. Mobility: Transfer, bed, Chair, wheelchair				
J. Toilet transfer				

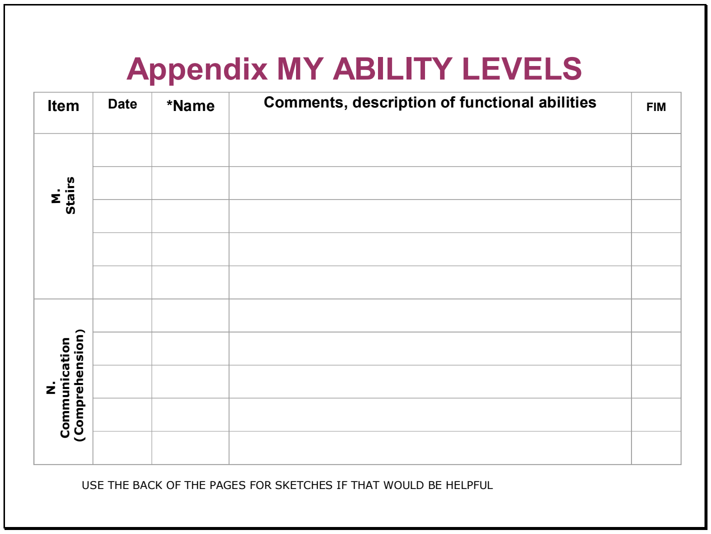
USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL



Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
K. Tub, Shower Transfer				
L. Walk or Wheelchair				

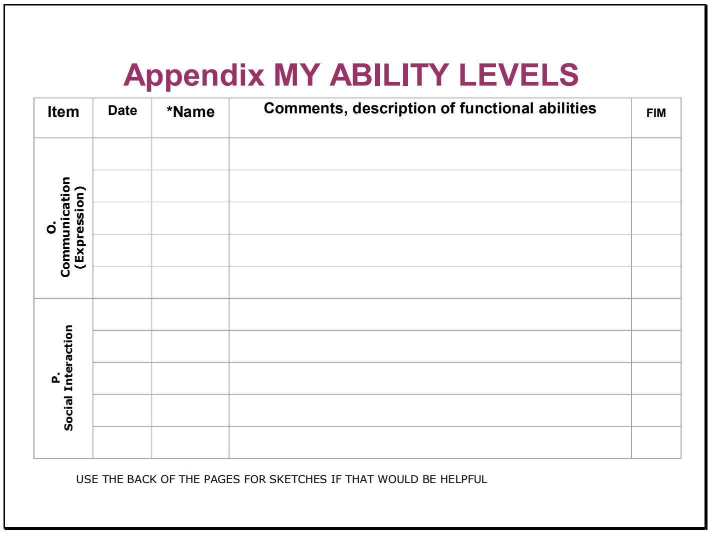
USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL



Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
M. Stairs				
N. Communication (Comprehension)				

USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL



Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
O. Communication (Expression)				
P. Social Interaction				

USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL

Appendix MY ABILITY LEVELS

Item	Date	*Name	Comments, description of functional abilities	FIM
Q. Problem Solving				
R. Memory				

USE THE BACK OF THE PAGES FOR SKETCHES IF THAT WOULD BE HELPFUL

RECOGNIZE THE WARNING SIGNS OF A STROKE

- **Sudden weakness, numbness or tingling**
- **Sudden trouble speaking or understanding speech**
- **Sudden vision problems**
- **Sudden severe headache**
- **Sudden dizziness or loss of balance**

If you think someone you know may be having a stroke, CALL 911 or your local emergency number immediately, or get someone to do it for you. Even if these symptoms appear to go away quickly, seek medical attention IMMEDIATELY.

(Heart and Stroke Foundation)

ABOUT THIS INITIATIVE

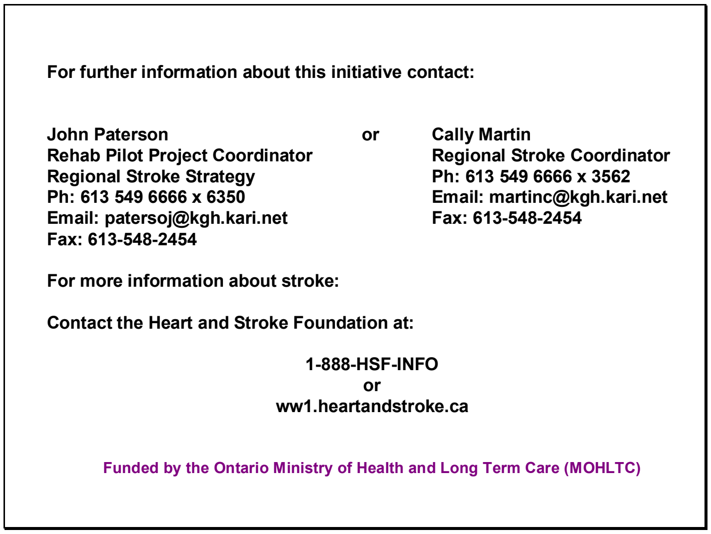
The Stroke Strategy of Southeastern Ontario is part of an Ontario-wide initiative to improve access to best practice stroke care across the entire health care continuum. The Stroke Rehabilitation Pilot Project of Southeastern Ontario is investigating ways to improve stroke rehabilitation across the stroke care continuum. The Stroke Rehab Pilot project has two closely related components:

1. This Diary: (The Stroke Client Profile) A Quality Improvement Initiative

This client-centred diary has been created to improve the communication of a client's key information across the stroke care continuum. It contains a brief outline of the stroke client's information and therapy goals. Stroke clients from selected sites in Southeastern Ontario are being asked to use this diary for one year. These clients are given the diaries during their stay in acute care, and are being asked to maintain the diary while moving through the stroke care continuum.

2. The Discharge Link Project

The Discharge Link Project is investigating the impact of increased levels of rehab service delivered at home, studying how it might affect the function of people who have had a stroke, and exploring the client's ability to cope with living at home. Depending on where the client lives, it is possible that a client could be asked to participate in both the Discharge Link Project and the Diary.



For further information about this initiative contact:

John Paterson
Rehab Pilot Project Coordinator
Regional Stroke Strategy
Ph: 613 549 6666 x 6350
Email: patersoj@kgh.kari.net
Fax: 613-548-2454

or

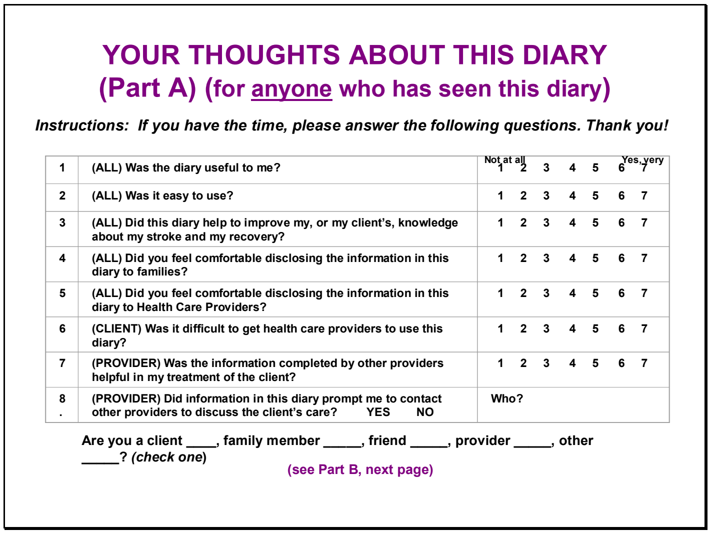
Cally Martin
Regional Stroke Coordinator
Ph: 613 549 6666 x 3562
Email: martinc@kgh.kari.net
Fax: 613-548-2454

For more information about stroke:

Contact the Heart and Stroke Foundation at:

1-888-HSF-INFO
or
ww1.heartandstroke.ca

Funded by the Ontario Ministry of Health and Long Term Care (MOHLTC)



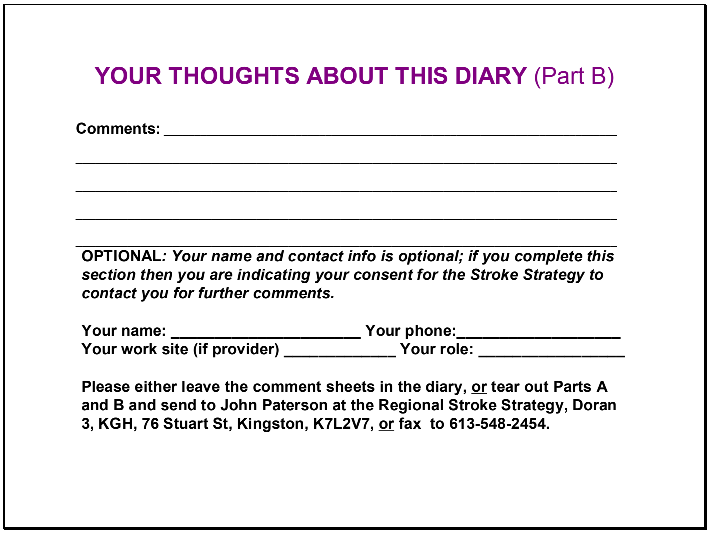
YOUR THOUGHTS ABOUT THIS DIARY (Part A) (for <u>anyone</u> who has seen this diary)

Instructions: If you have the time, please answer the following questions. Thank you!

1	(ALL) Was the diary useful to me?	Not at all 1 2 3 4 5 6 7 Yes, very
2	(ALL) Was it easy to use?	1 2 3 4 5 6 7
3	(ALL) Did this diary help to improve my, or my client's, knowledge about my stroke and my recovery?	1 2 3 4 5 6 7
4	(ALL) Did you feel comfortable disclosing the information in this diary to families?	1 2 3 4 5 6 7
5	(ALL) Did you feel comfortable disclosing the information in this diary to Health Care Providers?	1 2 3 4 5 6 7
6	(CLIENT) Was it difficult to get health care providers to use this diary?	1 2 3 4 5 6 7
7	(PROVIDER) Was the information completed by other providers helpful in my treatment of the client?	1 2 3 4 5 6 7
8.	(PROVIDER) Did information in this diary prompt me to contact other providers to discuss the client's care? YES NO	Who?

Are you a client ____, family member _____, friend _____, provider _____, other _____? *(check one)*

(see Part B, next page)



YOUR THOUGHTS ABOUT THIS DIARY (Part B)

Comments: ____

____

____

____

OPTIONAL*: Your name and contact info is optional; if you complete this section then you are indicating your consent for the Stroke Strategy to contact you for further comments.*

Your name: ____________________ Your phone:_________________
Your work site (if provider) ____________ Your role: ________________

Please either leave the comment sheets in the diary, <u>or</u> tear out Parts A and B and send to John Paterson at the Regional Stroke Strategy, Doran 3, KGH, 76 Stuart St, Kingston, K7L2V7, <u>or</u> fax to 613-548-2454.

APPENDIX K:

Comments from Diary Users

Appendix K:
Comments from Diary Users

Stroke Diary – Summary of Diary Users' Comments

Question 1 – Do you still have the diary?

Total Yes___23______Total No_____3___ Total Unsure____5_______

Question 2 – Do you still use the diary?

Total Yes____1_____ Total No_29_______ Total Unsure___________

Question 3 – How do you still use the diary?

Client reads the diary.

No longer uses the diary because:

- in respite and no longer improving
- has made ++ improvements – no longer relevant
- diary got misplaced when changed hospitals
- diary wasn't used at 2nd hospital
- only used diary for the info on stroke

Did not use the diary because:

- only at hospital for a very short time
- does not remember receiving diary (several spouses were unaware of diary and client was unable to be interviewed)
- keeps own personal diary
- therapists did not keep it updated
- did not understand the purpose of diary and who should be writing in it
- forgot about the diary, but may take a look at it now

Question 4 – How did you use the diary?

- Used diary every day to note daily improvements & monitor progress: 6
- Did not use the diary: 9
- Therapists kept track of client improvements, goals: 3
- Read through diary for information: 2
- Used it a little for first little while at hospital: 6
- Keep track of exercises: 1
- Important dates & appoitments: 3
- Medical history: 2

Question 5 – What parts of the diary were most useful?

- Part 1: 2
- Part 2: 8
- Part 3 :1
- Part 5: 7
- All parts: 2

Question 6 – Who used the diary the most?

Client: 11
Spouse of client: 3
Other relative of client: 2
Professionals: 5
Most interviewees reported very little or no use of the diary by professionals.

Question 7 – Was it easy to fill out?

Total Yes______14___ Total No________ Total Unsure______4_____

Question 8 – Was it too much work?

Total Yes___2______ Total No___18_____ Total Unsure_____2______

Diary was not too much work because:
- spouse filled out diary while watching her husband do the therapy
- client had a lot of time in the hospital.

Diary was too much work because:
- spouse was busy with client care and therefore did not have time to fill it out.
- spouse was ill herself and busy with client care.
- client has difficulty writing due to stroke.
- client was busy with other things

Question 9 – Did it assist in client care?

Total Yes____9_____ Total No____6____ Total Unsure_____1______

Did not improve client care because:
- client had very negative attitude towards care.
- none of the professionals took the time to fill it out

The diary improved client care because:
- it kept the client focused on progress and on therapy goals.

- the client was aware of what was going on.
- the client was able to bring the diary to family doctor.
- it allowed the client to see that she had made progress.
- client has poor memory and it allows him to keep track of medical history.

Question 10 – Do you have any suggestions to improve the diary?

Total Yes_____3____ Total No_16_______ Total Unsure________1___

- Professionals should use the diary more, especially to note assessment or test results.
- Client should be encouraged to use the diary. How to use the diary should be explained to client.
- Not enough space to write in diary section – needed to add pages.

- It was difficult hunting professionals down to write into diary.
- Everybody is different – every individual needs different things
- Professionals need to take more time to talk with spouses and identify their concerns.
- Would have liked more medical information in the diary.
- Would have liked more information on timing of recovery of stroke, symptoms of stroke, etc.

Question 11 – Were you comfortable disclosing medical info in the diary?

Total Yes___20______ Total No______1__ Total Unsure___________

Only one respondent stated that she was not comfortable disclosing her medical information in the diary because she is a private person. Many respondents stated that they would have liked to have more medical information in the diary.

APPENDIX L:

Description of the Alpha-FIM™ Feasibility Study

Appendix L
Description of the AlphaFIM™ Feasibility Study

Objective

- To conduct a feasibility study for the implementation of the Alpha FIM in the acute care setting.

What is the AlphaFIM™? (from http://www.udsmr.org)

Created specifically for the acute care hospital setting, the AlphaFIM™ instrument is the essential first link in the continuum of care. Created by the developers of the FIM™ instrument, the AlphaFIM™ instrument has been validated on more than 2,000 cases over the past three years. (The FIM™ is now mandated for use in all rehab sites in Ontario).

Administered to patients within the first 72 hours of admission to acute care and again prior to discharge, the AlphaFIM™ instrument uses only those items of the FIM instrument that can be collected reliably in the acute hospital setting. The six items are:

1. Eating
2. Grooming
3. Bowel Management
4. Toilet transfer
5. Expression, and
6. Memory

How does it work?

The program comes on a CD and runs on most desktop and laptop IBM-compatible PCs. The system requirements are described in the manual. AlphaFIM Analyzer™ software provides the ability to enter your assessments based on only six FIM™ items in order to predict patient outcomes. You can print forms, view a list of all the patients in your database, view the results of analysis, and create graphs.

Where will it be studied in SEO?

These acute care sites in SEO are taking part in the study: Brockville General Hospital, Kingston General Hospital, Lennox and Addington Hospital, Quinte Health Care corporation at Belleville.

What is involved?

1. Although approval in principal has been granted from all sites in SEO, administrative approval to initiate the study may be required.
2. Identification of acute care key personnel to administer the device.
3. Orientation of key personnel in the use of the AlphaFIM™. The CD is self-explanatory.
4. Administration of the device to people admitted to acute care with a stroke, first within 72 hours of admission, and then prior to discharge.
5. Discussion with practice teams on the use of the Alpha FIM.
6. Completion of a brief evaluation of the use of the AlphaFIM™ device.
7. Sending the evaluation forms to the Stroke Strategy.

Data

There is no need to collect and share client data in this study. The purpose of the study is to evaluate the feasibility and usefulness of this instrument.

Evaluation

The evaluation process will include information gathered from completed survey forms (see attachment) and feedback obtained from the Rehab Pilot Sub Committee. The results will be compiled and included in the final report to the MOHLTC in October 2004.

Number of Clients to be Assessed

- As many as the provider needs to complete in order to assess the feasibility of the instrument.

Timeline

- Approximately 6 months: all evaluations must be completed by May 30, 2004

FAQ

Do I need specialized training to administer the alpha FIM?

- No, the instrument is easy to understand after a few minutes of viewing the CD that contains a self-taught module.

Are different providers needed to complete the 6 items of the instrument?

- Not necessarily, someone familiar with the patient should be able to complete most of the 6 elements. If necessary, other team members could be consulted.

CONTACT INFO

John Paterson, Stroke Rehab Project Coordinator
Room 313 Doran 3, KGH, 76 Stuart St, Kingston, ON, K7L2V7
Phone 549 6666 x 6350, email patersoj@kgh.kari.net
FAX 613 548 2454

Feedback on the Use of the Alpha FIM

Instructions: Each person who uses or examines the Alpha FIM should complete a separate questionnaire. Thank you.

Name ____________________________ Position ___________________________________

Site where used _________________________ Number of patients assessed ____________

Time to become familiar with the Alpha FIM ____ Time to assess a client (average) _______

Please check the box that most correctly reflects your opinion.

1 = No, not at all. 7 = Yes, very positive

Questions	1	2	3	4	5	6	7
1 The Alpha FIM CD was easy to open and understand.							
2 The CD taught me what I needed to know about using the Alpha FIM.							
3 All 6 elements of the Alpha FIM were feasible to measure in the acute care setting. If not, comment below.							
4 The Alpha FIM should be used in your setting.							

5. Which providers are the most appropriate to implement the Alpha FIM in your setting?

6. Describe what you did to assess the Alpha FIM.

7. If your setting were to implement the Alpha FIM, please suggest the process you would use.

8. What are the biggest roadblocks to the implementation of the Alpha FIM in the acute care setting?

9. What support would your setting require in order to implement the Alpha FIM and integrate it with patient care processes?

10. Additional Comments?