



College of
Respiratory Therapists
of Ontario

Optimizing Respiratory Therapy Services

A Continuum of Care from
Hospital to Home

Final Report

June 2010

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A copy of the Training Manual
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West Park Healthcare Centre

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Section 1
Project Overview

Organization Name: College of Respiratory Therapists of Ontario
Application number: OCF0809117
Organization Sector: Community, Long-Term Care, Home Care, Acute Care, Rehabilitation
Organization Category: College or Respiratory Therapists of Ontario *(to be completed by Recipient - 250 characters max)*
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Title of Project:
Optimizing Respiratory Therapy Services: A Continuum Of Care from Hospital to Community

Part 1

Please give a brief summary (2-3 paragraphs) of your entire project. What was the purpose of your project? Did you accomplish your objectives? What was produced from your project? What outcomes did your project have and who will be impacted by these outcomes?

Project purpose: to develop an evidence-based, practice-driven, interprofessional model of care in order to facilitate a safe & timely transition for patients with complex respiratory needs (e.g. long-term ventilation (LTV) &/or airway management), from acute care into the community, by utilizing the full scope of respiratory therapy (RT) competencies.

Project objectives were met: 30 patients were successfully & safely transitioned to the community. Patients & their families have improved quality of life (QOL). Healthcare providers (HCPs) are more confident in their care with the ongoing clinical support of the RT. Overall satisfaction with the program was high. The project team provided all participants with tools & knowledge for risk management & when required, direct support in their home. This was accomplished by establishing an interprofessional communication link between hospital & community HCPs, including patients & families. In addition, tools were developed, based on evidence found in the literature & by experts.

Gaps & barriers were evaluated along with solutions for future transitions. Finally, a process flow map was developed to provide interprofessional teams & patients with a course of action for transitioning.

A project outcome: a RT Model of Care that supports & augments services currently provided through paid registered nurses (RNs), registered practical nurses (RPNs), & personal support workers (PSWs) in transitioning patients & maintaining them in the home with consistent & continued RT support/training. This model can be replicated throughout all the Local Integrated Health Networks (LHINs) in Ontario. In addition, this report presents ways in which this model can be sustained beyond the funding of this project. This model includes (for both acute care & community settings) communication links, consistent support/teaching, identification & educational tools, a process care map & risk management tools.

Other outcomes: enhancement of RT competencies, principally in the community setting, resulting in 1) improved patient support, resource utilization & RT job satisfaction; 2) an increased awareness of the community based RT role. Patients' QOL & satisfaction improved with the RT role in their care; the entire healthcare team articulated benefits of having RT expertise on the team. Both facts providing evidence of the optimization of RT competencies. Patients were offered a much higher level of expertise & provided enhanced knowledge of LTV & airway management. The rest of the healthcare team utilized the RT skills in care enabling individual focus on optimizing their own competencies. The project team transitioned appropriate patients, reducing length of stay (LOS) & increasing availability of acute care beds. Continuous community RT support also allowed for more efficient use of resources e.g. reduction in Emergency Room (ER) visits, hospital admissions with overnight stays, doctor or other health professional visits, tests & procedures & unanticipated morbidity.

This RT model impacts patients with complex respiratory needs who are in acute care & able to transition to the community. It assists the patient, their families &/or caregivers achieve a higher degree of independence, live in a safer environment & improve QOL. Utilizing this model also has a positive impact on resource allocation. Fiscal costs are optimized when these patients are supported in the community vs. acute care setting. Finally the outcomes of this project will impact the HCPs involved in the care of these patients. With this model complex respiratory needs of patients in the community are provided by the experts in the field – the RTs. This optimizes the occupations of both RTs & other HCPs in both the acute care & community setting.

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Section 2 Project Summary

Part 2

Input Summary

- a) Describe the resources used to complete the project (Financial, Human, Equipment, Infrastructure, Other).

Note: a reference list for this Main Report document can be found in the Appendix

- Financial – HealthForceOntario Fund
- Human – individuals from all project partnering organizations worked on a part-time basis and volunteered time and expertise. In addition, individuals not identified on the original proposal also consulted or volunteered their time. See Appendix A for specific names, roles and organizations.
- Equipment – no equipment was purchased for the project. Costs of equipment utilization were on a cost recovery basis only: telecommunication, computers, printers, Microsoft Office software and project manager mileage for home visits.
- Infrastructure – at no additional costs, specifically CRTO office, Professional Respiratory (ProResp) offices, home offices of project managers, various acute care facilities, patient homes.

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- b) Explain the roles and responsibilities of each organization participating on this project and whether or not these roles and responsibilities were appropriate and/or adequate. Why or why not?

The role & responsibilities of all the organizations involved in the project were more than appropriate &/or adequate.

- CRTO – oversaw the project by ensuring the involvement of adequate personnel/staff & adherence to timelines & reporting. They also: organized finances, contracts & meetings; acted as a communication link between all organizations, project members & the Ministry &; disseminated knowledge regarding the project via their membership, web site, face-to-face

Note: All fields are mandatory.

meetings & conferences. This project involved multiple partners, team contributors & locations. The CRTO organized all those involved & provided a "home base" to which everyone attended. Total estimated in-kind hours: 1075. Please see Appendix B for details regarding in-kind contributions.

- Professional Respiratory – provided the community RTs. The community RTs provided the physical means to transition patients from the acute care setting into the home. A more detailed description of their roles & responsibilities can be found below (Part 2, c)) & in Appendix C. This organization also carried out economic analyses as part of the resource utilization outcome measurements. This contributed to the building of the RT Model of Care.
 - Central CCAC – provided consultations regarding the care of patients in the community & provided awareness of RT services to community healthcare providers. The CCAC connects patients with the care they need, at home & in the community.(1) They provide & coordinate care in the home & community, including specialized support services.(1) This project did this for patients with complex respiratory needs. Learning from the experiences of an organization knowledgeable about the process was invaluable. In addition, since September 18th 2009, the Long Term Care Act (LTCA) was amended to include RT services as one of those that can be provided through CCACs in homes, congregate settings or a long term care facility. This includes persons who are ventilator-dependent, have artificial airways or receiving home oxygen services under the Assistive Devices Program administered by the Ministry. Working with the Central CCAC helped bring awareness of this amendment, providing for sustained funding for the RT Model of Care beyond this project.
 - West Park Healthcare Centre – provided consultations regarding LTV & other complex respiratory practices. This included the education of patients, caregivers & healthcare providers; they were involved with the development of the tools. In 2007 West Park was designated the Long-term Ventilation Centre of Excellence. Many programs across the Province have collaborated with the one currently at West Park. They have developed web based e-modules which are accessible to anyone & are a valuable supplement to the RT model presented in this project.
 - The RTSO – is a voice for the RT profession & promotes the leadership & direction in the expansion of the role of the RT in response to the changing health needs of the community.(2) Together with the CRTO, they helped bring awareness of this project to the RT community. As a result, RTs in similar practices were able to share their knowledge by relating their successes & challenges. This helped inform the project, especially with the tools & process care map.
 - Others (non-project team) – RTs from other institutions, experienced in community LTV & other complex respiratory management, provided their expertise toward this project. They helped create & develop the various tools & educational materials. Other professionals such as proofreaders & a plain language reviewer enabled refinement & accessibility of the tools.
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c) Explain the roles and responsibilities of each health care provider and whether or not these roles and responsibilities were appropriate and/or adequate. Why or why not?

The role and responsibilities of all the health care providers (HCPs) involved in the project were more than appropriate and/or adequate. Without their contributions, this project would not have been successful. RT competencies were optimized because of the collaboration with all the HCPs involved. The reasons are described below.

- Acute care RTs – provided direct patient care for in-patients requiring all types of ventilation and airway management. Together with the community RTs, their roles and responsibilities in this project included: identifying patients who are at-risk of becoming ventilator-dependant and recommending weaning strategies; assessing patients who are already on LTV to determine if they are able to transition into the community; coordinating with resources both inside and outside the acute care facility to assist in the placement or repatriation; coordinating the initial education for the patient and caregivers.
- Other acute care HCPs such as physicians (MD), nurses, occupational therapists (OTs), physical therapists (PTs), dieticians, and social work (SW) were involved with the

discharge of the patient

- Community RTs – roles and responsibilities included: collaborating with the acute care team, the patient, his/her family and other caregivers to determine the best care plan for each individual; transitioning patients into the community (organizing trial runs, home respiratory equipment set up, education); instruction and training in the home setting; 24/7 support at home (clinical, equipment, initial and ongoing education, risk management); instruction of adjunct therapy (inhaled medication, pulmonary function, oxygen) and; communication with patients' physicians and other HCPs. More details can be found in Appendix C.
- Patient's caregivers e.g. family, PSWs – contributed toward the individual care plan and subsequent care of the patient in the community (together with the patient and other HCPs involved with his/her care). They identified any barriers and challenges and worked together with the community RTs and other HCPs to overcome them. They were the communication link between the patient and the HCPs.
- Other HCPs such as MDs and nurses (RN and RPN) helped provide medical care to the patient while they were in the community. OTs and PTs were involved on an as needed basis.

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Part 3

Activities Summary

a) What tasks did you do? (processes, programs, work).

- Training tools (see Training Manual & Appendix O)–developed to ensure consistency in the delivery of best practice in LTV and other complex respiratory needs in the community. Documents were based on what was found in the literature and existing training tools. A working group of many RTs who work in the area of community LTV gathered this information and developed the tools. Prior to finalizing the material, several subgroups, consisting of an additional group of experts in the field, reviewed and provided feedback on these documents. The documents were proofread and the material intended specifically for patients & caregivers was revised to ensure an appropriate reading level (plain language).
- Knowledge translation – The CRTO and RTSO announced to its members the existence of the project by email, newsletters and their web sites. Team members promoted the project, by word-of-mouth, at conferences and through their individual network of professionals. RT/nurse/ICU managers/other persons in charge of discharge from hospitals in the Greater Toronto Area (GTA) were telephoned and/or visited face-to-face and mailed flyers to describe and discuss the project and ways to work together. Poster presentations and talks were given at a number of conferences. Furthermore, outside of the funding of this project, further knowledge dissemination is planned through a conference, organized by the project team for Sept. 16, 2010.
- Transitioning patients into the community – We were made aware of potential patients either directly or via the CRTO. Being involved from discharge planning to support in the home with all new admissions, the time invested by the RT was patient and care team centred and varied with each patient. Please see Appendix C for details on the Community RT role.

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b) Explain any factors that affected the timelines of your project. How would you deal with these factors in the future?

- Knowledge translation. Creating awareness of this project in order to help patients transition from the acute care facilities to the community took longer than anticipated (more in

Note: All fields are mandatory.

Appendix J). Fortunately this delay will be avoided in future because the outputs of this project have established a network with many practitioners in the area of LTV in the community.

- Development of training tools. Ideally this would have occurred before patients were transitioned into the community setting. Having these resources up front would have heightened awareness with the HCPs in the acute care settings of the project & their opportunity to identify appropriate patients, giving them consistent information & education tools. Although there are several educational & identification materials in existence there are no consensus documents. Training tools were developed as part of this project in order to incorporate the experience of experts, best practices & evidence, & provide consistent information. This process took time & as a result these tools were only used near the very end of the project. These tools will prevent future delays from occurring; RTs, other HCPs, patients & their caregivers will be able to use them when transitioning their patient with complex respiratory needs into the community. In addition clinical practice guidelines on home mechanical ventilation are currently in progress in Canada (through the Canadian Thoracic Society).
- Staff changes. The community care team remained consistent & effective. Project coordination was accomplished by 3 different people throughout the project & all remained as an ongoing resource to the team. Although the coordination was effective, each new coordinator required some orientation to the project, which took time.
- Integration with CCACs. As RT involvement in the discharge of patients on LTV from hospital into the community is new to the CCACs, it took time to establish the proper processes & lines of communication.

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Part 4

Output Summary

a) What was produced, delivered and learned from your project?

An RT Model of Care – transition complex respiratory patients from hospital to home. This model can be replicated throughout all Ontario LHINs. Sustainability of the model is achievable with the revised LTCA. This model included all the project deliverables: a communication capacity between acute care & the community, identification & educational tools (acute care & community), a process care map, risk management tools, direct patient care assessments, evaluation of resource utilization, & gap & barrier analyses.

Learning of utmost importance is individuals with complex respiratory needs benefit measurably from adequate RT services in achieving independence & quality of live in the community. This can be accomplished by utilizing the existing competencies of RTs already working in the community setting & using a consistent process & tools that are evidence-based & practice-driven, all within an interprofessional team. In addition, this process allows the system to be more efficient because there is reduced LOS & increased availability of beds within acute care facilities. Effectively caring for this patient population in the community has resulted in a reduced demand on the healthcare system, such as decreased physician visits &/or readmissions to hospital.

Although we learned patients lead a better QOL in the community, we also noticed the burden placed on the family was very high. Families & caregivers are willing to make sacrifices in order to have their family member in the community setting. The objectively measured burden is financial: the lack of funded resources available to the patient in the community versus in acute care. In the acute care setting, all equipment, staff, rehabilitation, diagnostics & accommodations were available at no cost to the family. However, once they are discharged into the community, the amount of financial support available for these individuals varies widely & often requires families to self-pay to cover necessary expenses.

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b) Explain how you disseminated the knowledge obtained by your project. Who did you share this knowledge with?

Knowledge of this project was disseminated in several ways (see also Appendix D):

- The CRTO and RTSO announced to its members the existence of the project by email, newsletters and their web sites. This allowed for RTs to make contact and ask questions and/or contribute their knowledge and experiences. Continuous updates were provided through the web site and newsletters. All tools produced from the project are available on the CRTO web site. Hardcopies of the tools have been distributed to LHINS, CCACs, RT departments and other community partners.
- The project manager contacted individuals (within organizations) who have experience in this area. In addition to making these individuals aware of the project, discussions regarding processes, challenges, and successes from their own practice were related. Please see Appendix D for the names of the individuals and organizations.
- Other Team members promoted the project, by word-of-mouth, at conferences and through their individual network of professionals. For instance, RT/nurse/ICU managers/other persons in charge of discharge from hospitals in the GTA were telephoned and/or visited face-to-face and mailed flyers to describe and discuss the project and ways to work together.
- Poster presentation and talks were given at local conferences (2008 Ontario Interprofessional Health Collaborative, 2009 Ontario Association of CCAC, and 2010 Ontario Lung Association Better Breathing; 2009 RTSO Fall Forum) and National conferences (2009 & 2010 Canadian Society of Respiratory Therapy, 2009 Canadian Home Care Association Home Care Summit)
- Furthermore, outside of HFO funds, a conference is organized for the Fall of 2010 in order to disseminate the information resulting from this project. It will be geared toward health care professionals, patients and caregivers. Hardcopies of the tools will be made available to all conference participants. Funding of this conference will be provided by the CRTO. An application to an external grant will also be made (The Canadian Lung Association's Regional Respiratory Health Education Workshops Grant).
- A copy of both the adult and paediatric educational packages will be sent to all the hospitals that ventilate patients in Ontario. They will also be available to download from the CRTO website.

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Part 5

Outcomes/Evaluation Summary

a) What results have your outputs produced?

An RT Model of Care for transitioning patients from hospital to home

- This Model gives patients & their families improved community support & QOL & greater independence. The patients & families as well as their HCPs all speak to high levels of satisfaction with the program. The Model supports & augments the care team. All participants were provided with tools & knowledge for risk management & when required, were provided direct support in their home. This process was more cost effective because there was reduced LOS & increased availability of beds within acute care facilities.
- This Model utilizes RTs currently employed in a community respiratory care role. This team of people already has the competencies to provide the necessary care & support but has previously not been able to utilize these skills in the home care setting.
- After consulting with experts & literature (3) we learned that a funded role for RTs that support community-based complex respiratory care already exists in Ontario but in an inconsistent & informal manner. This has also been found in European countries.(4) For instance the North Simcoe Muskoka CCAC provides in-home visits by a RT for individuals on LTV, under an arrangement with the Royal Victoria Hospital. A RT, as part of a Geriatric Rapid

Response Team, also works with these patients in the Erie St. Clair CCAC. Tertiary centres with LTV services follow VAs primarily through their outpatient clinics & offer hospital admissions for reassessment as needed e.g. McMaster's Children's Hospital, London Health Sciences Centre (with ProResp), Ottawa Rehabilitation Centre, & West Park Healthcare Centre. The experience & knowledge of complex respiratory needs in the community is not lacking, but funding for the services has always been. Overall this project provided a consistent RT Model of Care that includes: consistent identification, education, follow-up & funding.
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b) What are the performance measures to indicate these results?

Descriptive data on all patients will be provided (Appendix E). This includes baseline quantitative items such as age, complex respiratory need, and days in hospital.

To gain more insight into the successes, challenges, satisfaction levels and how their QOL was affected, patients' personal stories were collected (Appendix F).

Satisfaction. Caregivers were administered the Zarit Burden Interview (5) (Appendix H). Patients with the Patient Satisfaction Questionnaire Short-Form (PSQ18) (6) (Appendix G).

Evaluation of project. Several surveys created for this project to evaluate the project e.g. what worked or did not work, what was learned. This included one for: project participants (Appendix I); CRTO members as an online survey (Appendix J) and; the audience at the talk given at the 2010 Ontario Lung Association Better Breathing Conference (Appendix K).

Gap Analysis (Appendix L). The gaps, barriers and solutions regarding complex respiratory care in the community were collected from patients and their caregivers, the project community RTs, RTs outside the project and RTs from West Park Healthcare Centre.

Health care resource utilization (Appendix P & Q). Utilization of health care resources was continually being monitored through the project by the community RTs. This included: unanticipated calls to or visits from the community RT, ER Visits, hospital admissions with overnight stays, Doctor's visits, other health professional visits, tests and procedures, unanticipated morbidity and unanticipated mortality. In addition the Project Manager met with each patient and/or caregiver and was asked to describe unplanned hospital or physician visits and what may prevent such visits in the future. At the end of the project the estimated cost of providing care to patients in the community was compared with an estimated cost of remaining in acute care. Different funding models were calculated for the different types of complex respiratory need.

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c) How are the participants and stakeholders impacted?

The outcomes of this project impacts patients. The RT Model of Care enables patients & their families &/or caregivers to achieve a higher degree of independence, to live in a safer environment, & improve their QOL.

The outcomes positively affect the community RTs. Adding the role of the RT into the care of these complex patients offers the right expertise complement to the patient, optimizes the competencies of the RTs in the home care practice setting, & effectively supports other HCPs in the community setting. The RT Model of Care, in augmenting & supporting community health care services, assists with consistent identification, education, support, follow-up & funding. This Model can be put into practice by community based RTs whether they are experienced or naïve to the process.

Expanding the community-based RT role to supporting & caring for complex respiratory needs

in the community will benefit the CRTO & RTSO. Both organizations will be able to guide their members in this area by providing them with a consistent, evidence-based, practice-driven model of care. Experts in the field will be able to network with those who are seeking more information.

The outcomes of this project will help the LHINs & CCACs offering them an effective care model to provide the best service for patients. Fiscal costs are optimized when these patients are supported in the community versus the acute care setting. Current RT educational programs provide extensive education in resuscitation, mechanical ventilation & airway management including technical knowledge to make improvements & adjustments to the technology.(7) They do not require additional training that other healthcare providers would need. This available expertise provides better continuity of care: RTs in acute care facilities initiate the process & allow for earlier discharge; community RTs provide initial & ongoing education & clinical support as needed to avoid adverse events such as readmissions.

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d) What are the immediate impacts of the project?

The immediate impacts of the project are:

- Improved satisfaction and QOL for the patient, family and caregivers
- Optimization of RT competencies in the community, especially LTV and airway management
- Augmentation and support of patients, families and current community care providers by utilizing RT competencies
- Reduced LOS in intensive care units for patients with complex respiratory needs who are able to transition to the community
- Increased availability of acute care beds

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e) What are the medium term impacts of the project?

The medium term impacts of the project are:

- More efficient use of health care resources including a reduction in: ER visits; unplanned physician visits; hospital readmissions, specifically related to non-emergency ventilation issues and tracheostomy care
- Increased awareness of the skills and competencies of RTs in the role of patients in the community with complex respiratory care needs
- Improved and consistent support for and knowledge of complex respiratory management (e.g. LTV, tracheostomy care) for patients, family and other caregivers

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f) What are the long-term impacts of the project?

- For patients, HCPs and organizations: a consistent, evidence-based, practice-driven RT Model of Care for transitioning patients on LTV into the community.
- Increased access to RTs in the community for complex respiratory care needs to enhance and support continuity of care. RTs can initiate, execute and provide continuous follow-up.
- Consistent, funded RT Model of Care enhancing RT job satisfaction and marketability.
- Increased utilization of RT competencies to a broader patient population which further enhances RT job satisfaction and marketability.
- Enhanced job satisfaction for the rest of the health care team: access to RTs for their expertise and experience with these complex patients.

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g) How did you approach optimizing health providers' competencies, while:

Note: All fields are mandatory.

- remaining within the current legislative and regulatory framework;
- ensuring patient safety;
- supporting team-based care; and
- reflecting current or needed educational requirements.

Legislative framework:

- The Respiratory Therapy Act provides authorization for RTs to perform the controlled acts procedures necessary to provide complex respiratory care. The Regulated Health Professions Act allows for this care to be provided in the community as part of the "routines of daily living" exception by RTs, RNs, and non-regulated HCPs such as PSWs.
- Since September 18 2009, the LTCA was amended to include RT services provided through CCACs in homes, congregate settings or a long term care facility. This includes persons who are ventilator-dependent, have artificial airways or receiving home oxygen services under the Assistive Devices Program administered by the Ministry.

Patient safety:

- Providing a consistent, evidence-based, practice-driven RT Model of Care for transitioning patients from hospital to community and; for ongoing support of their respiratory needs.
- During the development of this model: 1) gaps and barriers in the process were continuously monitored along with ways to rectify them; 2) patients were provided hands-on care & education in the hospital and community; 3) home caregivers learned how to care for the patient and manage problems; 4) patients were provided with an emergency plan and 24/7 access to a RT; 5) patients were followed up in the community by the RT

Team-based care:

- The successful transition of a patient with complex respiratory needs requires a team-based approach. The team includes HCPs, the organizations and most importantly the patient and his/her caregivers. This project incorporated all of these elements not only in the physical transition, but also during the building of tools for identification, education and risk management

Educational requirements:

- Much of the knowledge and skills required for this project are already a part of the current curriculum in RT educational programs. Other more advanced skills such as assisted cough and lung volume recruitment are practiced and taught mainly by RTs.(8, 9)

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h) What is the rationale or evidence base for these activities/processes/approaches?

The rationale and evidence for this project is based mainly on previous investigations by the Ministry of Health and Long-Term Care (MOHLTC). In 2004/05, a Critical Care Transformation Strategy found many intensive care unit (ICU) beds in Ontario were occupied by ventilator assisted individuals (VAIs) who were medically stable and did not need the critical care services. In 2005, an Ontario Chronic Ventilation Strategy Task Group identified short-term strategies to facilitate the transfer of these individuals out of the ICUs and into a more appropriate care setting and to prepare a care strategy for this population.(7) In spring 2007, the MOHLTC developed and implemented a provincial LTV strategy. Part of their action plan included an inventory and gap analysis of services and educational opportunities.(3) Two main issues identified in these 2 reports were: 1) a lack of funded and highly skilled health care professionals – especially RTs. This gap severely limits the ability to provide safe and cost-effective care close to or in the home (3, 7) and; 2) the lack of a province-wide formal training program for physicians and HCPs.(3, 7)

This project addressed concerns, related to RT services, identified by these task groups. First, RT competencies were optimized in this practice area; available RT services allow patients to leave the acute care setting and live in the community. Second, an RT Model of Care that includes identification, support, education and care for these patients was utilized. This model can be implemented province-wide and includes evidence-based and practice-driven tools. Finally, this project marries well with the amendments made to the Provision of Community

Services regulation (O. Reg. 250/09 under the LTCA) which now lists RT services as one of those that can be provided through CCACs, another recommendation identified by these task groups.

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- i) How was the project new/innovative in the specific care context in which it occurred?
This project was innovative because it provided an RT Model of Care for transitioning patients from hospital to home. Individuals requiring LTV have in the past transitioned into the community either directly from an acute care facility or via institutions like the Long-Term Ventilation Program at West Park Healthcare Centre. What was previously missing in both these care paths was the community-based provision of RT services on an on-going basis for the individual and his/ her family and caregivers. This model, which utilized RTs already working in the community, can be consistently replicated throughout all the LHINs in Ontario. RTs working in the community have the necessary core competencies to support and augment the respiratory care and training needs of patients, families and caregivers in the community setting. Developing the Model of Care utilized these competencies and also collaborated with 1) the experience of experts, including those who already provide these services 2) information from previous MOHLTC reports (3, 7) and 3) the literature (10-14). In addition, ways in which this model can be sustained beyond the funds of this project were developed.

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- j) How did the project address/improve patient care or population health needs, and improve health outcomes? How did the project address/support a patient-centred approach to care?
In a survey of CCACs, it was reported that only 7% of patients invasively ventilated at home received in-home RT services, mostly on an "as needed" basis.(7) Patients and caregivers continually identified the need for in-home RT services.(3, 7) The first 2 objectives of this project addressed these gaps in patient care and population health needs: 1) to facilitate a safe and timely transition for patients requiring complex respiratory care, from the acute care setting into the community and; 2) to support patient and family centered care by ensuring their involvement at all stages of decision-making. The primary motivation for this project was in support of a patient-centred approach to care. Thirty patients were successfully and safely transitioned from acute care to the community. Patients and their families experience improved QOL and, along with their healthcare providers, were satisfied with the program. All participants were directly supported in their home and provided with tools and knowledge for risk management and when required.

Overall when asked (by project managers during their home visits) all patients and caregivers were positive and grateful for the RT services they received – especially when they had questions or concerns and/or needed in home in-services and on-going support. All the patients who took part in this project were happier to be home. Most felt they were healthier at home e.g. access to RTs helped avoid hospitalizations for illnesses such as pneumonia. In addition, those who were able to have their trachs changed at home really appreciated it. All the caregivers indicated they were happy to have the patient at home. They felt the patient was better off at home because they (the patient) were happier and healthier.

Please see Appendix F for more details on the project affected specific patients. Please see Appendices G and H for results from the satisfaction questionnaires.

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- k) Why was this project necessary? What current or emergent gap(s) did the project address?
Necessity: Complex respiratory patients need ongoing support of a RT in the community.
Current gaps addressed:
1. RT support – outside of this project, the community RT has not been consistently

available due to a lack of funding. Patients & caregivers consistently identified the need for in-home RT services.(3, 7) RTs currently have an active role in community respiratory care however their role has been limited to non-complex chronic disease management & palliative care. RTs possess a high level of expertise clinically & technologically e.g. mechanical ventilation & airway management.(7) The availability of RT support & services is believed to be an important predictor of success for VAls & contribute to a lower rate of readmissions.(7)

2. Training Tools – MOHLTC task groups recommended the development & implementation of province-wide formal training programs for physicians & HCPs. These programs would help identify, educate & care for these patients in the acute care & community setting.(7) This program might be more effective if it focussed on the wider-spread use of 1 discipline, like RTs, to work with these patients & to support the other clinicians caring for them. This would have the potential to effectively address staff turnover & duplication of training, & access to services across the province.(7)

3. Resource allocation - people who need on-going care, should receive that care in the most appropriate location.(15) This is key for delivering quality & efficient care, from both the patient's point of view & the health care systems.(15) Appropriate allocation of care impacts costs: 1% of the population accounts for 49% of combined hospital & home care costs; 5% for 84%.(15) Although the report did not say who made up the 1 & 5%, it is likely many are VAls: chronically critically ill patients account for fewer than 10% of those receiving mechanical ventilation, but consume between 20% & 40% of ICU bed days & other critical care resources (USA).(16)

2,000 character max.

- l) Describe the overall evaluation of your project. Who evaluated your project? How was it evaluated? How were the evaluation findings used?

The overall evaluation of the project was based on the results from our performance measures (Part 5, question b). This included 1) descriptive data; 2) patient/caregiver stories; 3) satisfaction questionnaires (patients, caregivers); 4) surveys created for this project to evaluate the project (patients, RTs); 5) gap analyses and; 6) health care resource utilization. The majority of these measures were collected by the project manager directly from the patients, caregivers and RTs. A survey evaluating the project was posted on the CRTO web site and its results collated by the project manager. The community RTs collected measurements on health care utilization after the patient transitioned into the community e.g. unanticipated calls to or visits from the community RT, ER visits, hospital admissions with overnight stays, doctor's visits, other health professional visits, tests and procedures, unanticipated morbidity and unanticipated mortality. At the end of the project the estimated cost of providing care to patients in the community was compared with an estimated cost of remaining in acute care. Different funding models were calculated for the different types of complex respiratory need. All this data was analyzed and summarized for the final report by Mika Nonoyama. These evaluation findings provided a description of a sample of patients with complex respiratory needs whom were able to transition into the community. These findings also conveyed the positive impact the patients, caregivers and RTs experienced when given access to community-based RTs for education and care. Finally, the findings also provided evidence of the cost effectiveness to the overall health system when patients are transitioned from the acute care setting into the community. Overall, the evaluation findings were used to support the success of the RT Model of Care and tools developed and implemented within this project.

2,000 character max.

- m) Please provide a comparative analysis of your project, comparing what was originally proposed in your application and your final results.

All of the project original objectives were met. Thirty patients were successfully and safely transitioned from acute care settings to the community. All participants were provided RT support/teaching in their home and tools and knowledge for risk management. This was accomplished by establishing an interprofessional communication link between hospital and

community health care providers, including patients and their families. In addition, identification and educational tools were developed, based on evidence found in the literature and by experts. Gaps and barriers were evaluated throughout the process along with solutions for future transitions. Finally a process flow map was developed to provide interprofessional teams and patients with a course of action for transitioning successfully into the community.

Project deliverables:

- 1) Identification Tools for patients currently on LTV were developed with the help of experts in the field and based on previous evidence (3, 7, 10-14) – as originally proposed (see Training Manual section #2). The identification tools for individuals at-risk were developed with the help of The Ottawa Rehabilitation Centre since they have the specialized expertise in this area.(3)
- 2) Gap & Barrier Analysis (Appendix I) and Process Flow Mapping (Appendix O) were developed with the help of experts in the field and based on previous evidence (3, 7, 10-14) – as originally proposed. Gaps and barriers were collected from the HCPs, patients and caregivers involved in this project. A more broad spectrum gap and barrier analysis has previously been investigated.(3, 7, 14)
- 3) Educational tools were developed with the help of experts in the field and based on previous evidence (3, 7, 10-14) – as originally proposed (see Training Manual).
- 4) Communication Capacity tools. Instead of existing in one document, the communication capacity was divided into several areas. The majority of the initial communication links are found in the process care map (Appendix O). After the patient was transitioned into the community, the communication capacity was mainly through the community based RT.
- 5) Risk Management Tools were developed with the help of experts in the field and based on previous evidence (3, 7, 10-14) – as originally proposed e.g. troubleshooting, emergency contacts and planning (see Training Manual).
- 6) Direct Patient Care Needs Assessment. Patients in this project were provided direct care by the community RT when they needed it, as originally proposed. A detailed description of the community RT role can be found in Appendix C.
- 7) Evaluation of Health Care Utilization. Utilization of resources was continually being monitored through the project by the community RTs and project manager, as originally proposed (Appendix P & Q). At the end of the project the estimated cost of providing care to patients in the community was compared with an estimated cost of remaining in acute care. Different funding models were calculated for the different types of complex respiratory need.

It was anticipated that the development, testing & piloting of project tools occurred before patients were transitioned into the community setting. This would have allowed HCPs in the acute care settings to identify appropriate patients and provide consistent information toward education. Training tools were developed as part of this project in order to incorporate the experience of experts, best practices and evidence and provide consistent information. This process took time and as a result these tools were only available nearer the end project term.
3,800 character max.

n) What worked? What did not work? What could be changed or done differently?

There were many aspects of this project that worked well. The experiences, knowledge and time offered by the patients who transitioned into the community because of this project were invaluable. The experts in the field were amenable to collaboration and enthusiastically volunteered their experience, expertise and time. This enabled us to develop the various tools and products within the project. The acute care facilities that housed the patients, were open to hear about our project and work as a team to help them transition into the community.

As the project built momentum in effectively transitioning patients home, the number of qualified patients grew. Hospitals now see getting these LTV patients directly home from their ICU as a very viable solution. The project has tipped the ice berg of patients who can and should be transitioned home.

There were a few challenges with this project. First creating awareness of this project took longer than anticipated. The development of the training tools was not finished before patients were transitioned into the community setting. This process took time and as a result these tools were not available until the end of the project.

Identifying and communicating with patients already in the community to make them aware of RT services was a challenge. For instance CCAC's coding system made it difficult for us to determine who would benefit from RT services for complex respiratory care. In addition, we were unable to connect with those patients who did not utilize CCAC services. Only about 5% of VAIs living in the community receive services from a CCAC.(3)

A reality outside of the project's direct realm but clearly identified, is the measured burden of care placed on the families. Financial burden is a key component primarily due to a disconnect between funding freed up when the patient leaves acute care and the funding available when they are discharged into the community.

2,000 character max.

- o) How will the findings/best practices/learning etc. of this project be sustained beyond the project funding?

Sustainability of the RT Model of Care in the community can be achieved through the CCAC paying for RT support as they do for other professional patient services in the community. The revision to the LTCA that includes RT services creates the avenue for ongoing funding to support this important aspect of care and support for the complex respiratory patient in the community. The RT Model of Care developed with the funds from this project show patient advantage and cost-effectiveness: the RT Model enables direct transition home from any ICU and the LHIN model enables allocation of health care dollars from a common source. The fact that CCAC has a \$250,000 discretionary fund that does not require a Request for Proposal (RFP) process enables efficiency in implementation of the RT Model of Care in any community in Ontario.

There are other programs that successfully transition patients to the community and provide continuing care.(3) For instance the North Simcoe Muskoka CCAC has established this mechanism for several years by contracting and funding RT services through the Royal Victoria Hospital. The South East CCAC simply needs to continue to utilize a program that already exists at London Health Sciences Centre (with ProResp) by adding funding for the RT role in the community.

Shifting of services and funding from hospital to community has recently been recommended as a way to "bend the health care cost curve".(15) They state the need to "reduce reliance on hospital care to free up hospital capacity with targeted investments elsewhere in the system" (15). By increasing funding to existing MOHLTC community based programs there could be a greater number of discharges to home than are currently possible. "Every 10% shift of alternate level of care (ALC) patients from acute care to home care, results in a \$35 million savings"(15). For patients with complex respiratory needs, this would likely result in greater savings since most are located within ICUs.

2,000 character max.

- p) Comments.

The essence of the proposal, that of optimizing health care providers' competencies, is not only demonstrated in the RT Model of Care and clinical outcomes achieved with this project but is also fully sustainable: 1) Ontario communities are already equipped with RTs with the required competencies working in local communities; 2) The revised LTCA includes RT services in the funding model of the CCACs. Ontario communities have the expertise and funding model to implement the RT Model of Care now. These stable yet complex respiratory patients no longer

need to remain in an ICU bed indefinitely or until a bed becomes available at a specialized rehabilitation unit. Additionally, the corresponding training and education materials developed through the project funds means that each site working to transition these patients into the community has readily available the important training tools.

VALs are currently unable to reside in long-term care facilities because ventilators are not funded in these care sites. Many patients who transition into the community suffer from progressively degenerative neuromuscular diseases. A long-term care facility is a viable option and would allow them to stay out of an acute care facility once their condition deteriorates. Currently this is not an option because there is no funding for the ventilator through the Ventilator Equipment Pool (VEP). These individuals are required to return to an acute care facility and re-occupy an ICU bed, often for no other reason than that they are on a ventilator. This is a gap that needs to be addressed in order to make the best possible use of all available resources.

3,800 character max.

Section 3 Project Detail – Objectives and Deliverables

Part 6

Objective #1

Facilitate Transition into the Community

To facilitate a safe and timely transition, for patients requiring long-term ventilation and/ or airway management, from the acute care setting into the community. It is anticipated, this will improve the quality of life for these patients and also reduce length of stay (LOS) and avoid hospital readmissions.

1st Quarter Activities

Develop tools for identification, gap analysis, education and communication in the hospital sector

Current Status

(Please indicate the status of the activity. If “Not Completed” or “Other” is selected additional detail is required in the “Comments” section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

Tools for identification and education in the hospital have been complete and were developed

Note: All fields are mandatory.

by RTs with expertise in the field of LTV in the community. The VEP also provided their assistance in ensuring that the tools reflected current practices and processes. The communication tool is included within the identification and education tools and the process care map. Both the adult and paediatric tools (13 in total) can be found in The Training Manual, the process care map in Appendix O. A gap analysis, based on patient and RT experiences were collected and can be found in Appendix L.

1,000 character max.

2nd Quarter Activities

Pilot test tools

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

All tools were reviewed by an additional set of RTs expert in the field of home mechanical ventilation and by representatives from the VEP. In addition, they were proof read and the patient/lay caregiver resources and educational material was put into plain language to enhance readability.

1,000 character max.

3rd Quarter Activities

Refine tools

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Accumulate data on length of stay, and acute care bed availability.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

After all the tools were reviewed in the pilot test phase, they were printed, bound & provided in a print format with a CD version included. This same material was also prepared in an electronic format & is available for download on the CRTO web site. Hardcopies of the tools have been distributed across the province to LHINS, CCACs, RT departments & other community partners.

Utilization of resources was continually being monitored through the project by the community RTs. In addition the Project Manager met with each patient &/or caregiver and was asked to describe unplanned hospital or physician visits & what may prevent such visits in the future. (Appendix P, Q)

30 patients were transitioned successfully into the community utilizing the RT Model of Care. Six patients have since passed away as a result of the progression of their disease process. The remaining patients have all been able to remain in their homes with the benefit of the RT support for both patient/family & caregivers.

1,000 character max.

4th Quarter Activities

Final pilot testing of the overall practice model.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Develop funding models that include a proposal for sustainable resources

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

At the end of the project the estimated cost of providing care to patients in the community was compared with an estimated cost of remaining in acute care. Different funding models were calculated for the different types of complex respiratory need. (Appendix P & Q)

1,000 character max.

Objective #2

Support Client-Centered Care

To support client/family centred care by ensuring their involvement at all stages of decision-making. All of the tools developed will focus on optimizing client and family quality of life and satisfaction.

1st Quarter Activities

Develop tools for educational needs, risk management guidelines and direct patient care assessments.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed

- Not Completed
 Other

Researching and choosing quality of life and satisfaction Questionnaire.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

Tools for education, risk management and direct patient care assessment have been complete and can be found in The Training Manual (tools) and Appendix and C (direct patient care).

QOL and satisfaction was described by asking patients, their families and caregivers to relate their experiences with complex respiratory needs and their transition into the community or home.

Satisfaction was further evaluated by questionnaires. Caregivers were administered the Zarit Burden Interview (5) (Appendix H). Patients with the Patient Satisfaction Questionnaire Short-Form (PSQ18) (6) (Appendix G).

1,000 character max.

2nd Quarter Activities

Pilot test tools

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

All tools were reviewed by RTs expert in the field and by representatives from the VEP. In addition, they were proof read and put into plain language.

1,000 character max.

3rd Quarter Activities

Refine tools.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Evaluate patient and caregiver quality of life.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

On-going monitoring of resource utilization e.g. physician visits, ER visits, hospital

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

After all the tools were reviewed in the pilot test phase, they were printed. They are available on the CRTO web site. Hardcopies of the tools have been distributed to LHINS, CCACs, RT depts & other community partners.

Patients, their families & caregivers related their experiences with complex respiratory needs & their transition into the community & how it impacted their QOL (Appendix F).

Analyses of the satisfaction surveys for patients (PSQ18) & caregivers (ZBI) (Appendices G & H) were done.

Utilization of resources was continually being monitored through the project by the community RTs (Appendix P & Q). This included: unanticipated calls to or visits from the community RT, ER visits, hospital admissions, doctor's visits, etc. In addition the Project Manager met with each patient and/or caregiver and was asked to describe unplanned hospital or physician visits and what may prevent such visits in the future.

1,000 character max.

Objective #3

Support Best Practice

To support evidence-based best practice by reviewing medical literature and collaborating with health care professionals currently providing services for these individuals in the community (both regulated and non-regulated) and investigating other programs that have successfully implemented these services.

1st Quarter Activities

Search the literature and consult other programs and other jurisdiction who have successfully initiated similar services

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Note: All fields are mandatory.

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

RTs from other institutions, experienced in community LTV and other complex respiratory management, provided their expertise toward this project. They helped create and develop the various tools and educational materials. Other professionals such as a RT with expertise in patient education completed a plain language review of some of the tools, which allowed for better accessibility for the patient and his/her lay caregivers. In addition information from previous MOHLTC reports (3, 7) and the literature (10-14) was considered.

1,000 character max.

2nd Quarter Activities

Collaborate with West Park Hospital and Ontario's Ventilator Equipment Pool to ensure consistent best practice standards.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

Experts from West Park Healthcare Centre and the Ontario VEP provided their expertise toward this project. They helped create and develop the various tools and educational materials. In addition, the VEP also helped review the tools developed for this project to ensure consistency and accuracy.

1,000 character max.

Objective #4

Competency Utilization

To utilize the full scope of respiratory therapy competencies related to long-term mechanical ventilation and airway management, both in the hospital and the community setting. The optimal way to ensure this is to create an exclusive community-based RT who specializes in long-term ventilation. It is anticipated this will improve staff work life satisfaction for the RT specialist and the health care workers who currently are involved with providing the service. This will also create efficient continuity of care.

3rd Quarter Activities

Develop policies and practice guidelines in collaboration with the CRTO and other relevant regulatory health colleges (e.g. CPSO, CNO, CASLPO)

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

Note: All fields are mandatory.

As a result of this project the role of a community-based RT has been expanded and their competencies optimized. The RT's involvement with complex respiratory needs, such as LTV, has been described (Appendix C). This will form the basis of an official CRTO professional and clinical best practice guidelines regarding this role. These guidelines can then be used by RTs, other HCPs and organizations who provide the same care in the community. Consultation with other health regulatory colleges will continue on an on-going basis, as the provision of home care services continues to evolve.

1,000 character max.

Objective #5

Support Interprofessional Collaboration

The overriding principle that runs through this initiative is interprofessional collaboration and the concept of bringing the right skill set to the client.

1st Quarter Activities

Create a stakeholder team in order to determine the needs to all the HCP and to develop a strategic plan.

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

Each patient transitioned into the community setting had an interprofessional team working with him/her as well as family members. Since each patient had different needs, the membership on each team differed. For instance if a patient had special dietary needs, a registered dietician would be present.

1,000 character max.

2nd Quarter Activities

Implement action items from the plan

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

The interprofessional team worked together to discuss the patient's needs and goals. A care plan was developed with each team member utilizing their specific competencies e.g. RT taking care of ventilation; OT taking care of wheelchair. A detailed description of the discharge process can be found in the in The Training Manual, section #2.

1,000 character max.

3rd Quarter Activities

Meet with team to evaluate process and make adjustment in plan as required

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

The interprofessional team would have subsequent meetings as required e.g. to identify any barriers and to develop a resolutions. This would allow the team to keep informed on the patient's progress. Often the community RT would act as the communication link between the patient and the team.

1,000 character max.

4th Quarter Activities

Evaluate successes and opportunities for improvement

Current Status

(Please indicate the status of the activity. If "Not Completed" or "Other" is selected additional detail is required in the "Comments" section below).

- Completed
 Not Completed
 Other

Comments (Challenges, Difficulties, Problems or Opportunities, Timelines, etc.)

A gap analysis, based on patient and RT experiences was collected and can be found in Appendix L.

1,000 character max.

Part 7

Deliverable #1

Identify clients at risk of ventilator dependence. Certain disease processes predispose individuals to requiring LTV and if they are provided with information about their disease in advance they can better participate in advance decision making and appropriate interventions

Current Status

(Please indicate the status of the deliverable. If "Not Completed" or "Other" is selected additional details are required below).

- Completed
 Not Completed
 Other

If "Not Completed" or "Other", please explain:

500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)

This deliverable was achieved with the expertise of The Ottawa Hospital Rehabilitation Centre (TOHRC), who have an interdisciplinary program aimed at identifying patients at risk of ventilator dependence, while introducing preventive respiratory strategies & elective, entirely outpatient non-invasive ventilation.(3, 17) TOHRC provides follow up care to 150 patients requiring primarily non-invasive ventilation – 18% are non-invasively ventilated 24 hours a day & remain in the community.(18)

500 character max.

Activities: What tasks did you do? (processes, programs, work)

- Consulted Carole LeBlanc, RRT and Dr. Doug McKim at The Ottawa Hospital Rehabilitation Centre
- Consulted the literature (3, 17)

500 character max.

Outputs: What was produced, delivered, learned?

Use of TOHRC's e-resources: under "Respiratory Protocols for SCI and Neuromuscular Diseases" at www.irrd.ca/education or by CD-ROM.(8) We learned the Ontario population of individuals who are at-risk of ventilator dependence are not adequately being identified. They need to be referred to appropriate services for counselling on their disease course and care options so they can make informed decisions.(3) Incorporating this front-end approach to care will optimize health care resources.

500 character max.

Outcomes: What results have your outputs produced?

As a result of the program at The Ottawa Hospital Rehabilitation Centre, there have been reduced health care utilization and; improved critical care access and maintained independence in the home.(3, 17) The incorporation of the resource material created by TOHRC into this project provides the full spectrum of patient care; from prevention strategies to a plan of care for those individuals where LTV could not be avoided.

500 character max.

What are the performance measures to indicate these results?

- Health care utilization: avoiding inpatient admissions and delaying or preventing invasive ventilation e.g. since 2007 over 40 patients were placed on non-invasive ventilation (almost double since 2005). Of 403 ALS patients, 125 are on non-invasive ventilation, and only 10 are on invasive ventilation.(3, 17)
- An example of the RT role and a case example with two treatment options (invasive or non-invasive ventilation), including costs for both (Appendix M and N)

500 character max.

How were the participants and stakeholders impacted?

As a result of the program at The Ottawa Hospital Rehabilitation Centre, there have been reduced health care utilization and; improved critical care access and maintained independence in the home.(3, 17) A case example can be found in Appendix N presenting two treatment options (invasive or non-invasive ventilation), including costs and impact

500 character max.

Deliverable #2

Identify clients able to successfully transition into the community

Current Status

(Please indicate the status of the deliverable. If "Not Completed" or "Other" is selected additional details are required below).

- Completed
 Not Completed
 Other

If "Not Completed" or "Other", please explain:
500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)
RTs from other institutions, experienced in community LTV and other complex respiratory management, provided their expertise toward this deliverable. They helped create, develop and review the Identification Tools (Training Manual, section #2). In addition, evidence from the literature was utilized. (3, 7, 10-14) Other professionals such as proofreaders and a plain language reviewer allowed for the tools to be refined and more accessible.
500 character max.

Activities: What tasks did you do? (processes, programs, work)

- First draft of identification tools created based on existing tools from other institutions and the literature
 - A group of RT experts reviewed the documents and suggested changes. Documents amended.
 - Document sent to another group of expert RTs and the VEP for final review. Documents amended.
 - Documents put into plain language, and reviewed by proofreaders.
 - Final amendments made and tools were prepared in a print, CD and electronic format.
- 500 character max.***

Outputs: What was produced, delivered, learned?

Evidence-based and practice-driven identification tools were produced. They have been delivered to RT departments in all Ontario hospitals and also available on the CRTO and RTSO web site. We learned when patients with complex respiratory needs (who are able to transition) are identified earlier they are able to go into the community earlier, accomplished with the proper tools and accessibility to RT support.
500 character max.

Outcomes: What results have your outputs produced?

The result of early identification (and subsequent discharge) is enhancement of QOL and satisfaction for the patient, caregivers and health care providers involved in the care. With early discharge into the community it also provides more efficient use of health care resources e.g. decreased LOS, increased acute care availability.
500 character max.

What are the performance measures to indicate these results?

- QOL & satisfaction (patient/family/caregiver experiences)
 - Satisfaction surveys (Zarit Burden Interview, PSQ18)
 - Project evaluation surveys
 - Health care resource utilization: LOS, acute care availability, estimated cost of providing care to patients in the community compared with an estimated cost of remaining in acute care, different funding models for the different types of complex respiratory need
- 500 character max.**

How were the participants and stakeholders impacted?

Patients in the ICU identified appropriately & timelier were able to transition earlier and more efficiently. Residing at home helped them achieve more independence, a safer environment (less infection) & QOL. Family did not have the burden of traveling significant distances to the hospital. HCPs were provided with a “starting point” for identifying patients. Fiscal costs were optimized: patients were able to transition earlier.

500 character max.

Deliverable #3

Provide initial education to the client, family and all caregivers (regulated and non-regulated)

Current Status

(Please indicate the status of the deliverable. If “Not Completed” or “Other” is selected additional details are required below).

- Completed
 Not Completed
 Other

If “Not Completed” or “Other”, please explain:

500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)

The initial education to the patient/family/care team was a collaborative effort of the RTs working in the acute setting and the community-based RT's. The Education Tools (Training Manual, section #3) were used as available to support the training/education efforts. The community RT team also provided the necessary education and support for patients requiring RT support and already residing in the community.

500 character max.

Activities: What tasks did you do? (processes, programs, work)

- Weaned the patient from unnecessary monitoring in preparation for the home setting
- Trained the family at the patient's ICU bedside, using tools and practical technique
- Administered training session(s) for the community based care team – training tools and hands on training

500 character max.

Outputs: What was produced, delivered, learned?

We proved that a stable patient with complex respiratory needs can transition home from the ICU effectively with an interprofessional care team that has a very active RT component. The education provided by the RT team facilitated getting the patient into the community earlier. In addition adequate and consistent education enabled the patient and family to make informed decisions more independently.

500 character max.

Outcomes: What results have your outputs produced?

RTs providing the initial education for the patient and their caregivers specific to their respiratory care allowed for direct/earlier discharge into the community. This resulted in a more efficient use of health care resources e.g. decreased LOS, increased acute care availability. Initial education also allowed patients to make informed decisions, be more independent and live in a safer environment.

500 character max.

What are the performance measures to indicate these results?

- 30 patients supported in the home effectively and efficiently. Made possible via the RT Model of Care that utilized training/education tools
- Satisfaction (patient experiences, Zarit Burden Interview, PSQ18)
- Project evaluation surveys
- Health care resource utilization: LOS, acute care availability, estimated cost of providing care to patients in the community compared with remaining in acute care, different funding models for the different types of complex respiratory need.

500 character max.

How were the participants and stakeholders impacted?

Patients and caregivers who were initially educated appropriately and timelier were able to transition to the community earlier. This helped improve their confidence, make better informed decisions, achieve a higher degree of independence and allow them to live in a safer environment. Fiscal costs were optimized because these patients were able to transition earlier to the community versus staying in the acute care setting.

500 character max.

Deliverable #4

Develop a communication bridge between the acute care facility and the community setting

Current Status

(Please indicate the status of the deliverable. If "Not Completed" or "Other" is selected additional details are required below).

- Completed
 Not Completed
 Other

If "Not Completed" or "Other", please explain:

500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)
The communication bridge between acute care and the community was generally led by the RTs. Patients were able to transition home due to the communication between the acute care and community RTs. Tools supported this communication bridge, specifically the process care map (Appendix O).

500 character max.

Activities: What tasks did you do? (processes, programs, work)

- Direct communication of acute care & community RT
- 1st draft of communication tools were created based on existing tools from other institutions & the literature
- A group of RT experts reviewed the documents & suggested changes. Documents amended.
- Document sent to another group of expert RTs & the VEP for final review. Documents amended.
- Patient/ caregiver documents put into plain language & all material reviewed by proofreaders.
- Final amendment, graphic design & printing of tools.

500 character max.

Outputs: What was produced, delivered, learned?

Evidence-based and practice-driven tools with essential communication links were produced. They have been delivered to RT departments in all Ontario hospitals and also available on the CRTO and RTSO web site. We learned with a good communication capacity, acute care facilities, health care providers, patients and their caregivers were able to start the process of transition earlier, be more informed, have greater independence and live in a safer environment.

500 character max.

Outcomes: What results have your outputs produced?

Patients transitioned into the community earlier directly from ICU when the acute care facilities were informed about who to contact about the process. Once in the community a communication link with the acute care facility, the VEP and the community HCPs allowed patients to be more independent and live in a safer environment. Health utilization was optimized because patients are able to stay at home for non-emergency situations or for assessment when their health condition changed.

500 character max.

What are the performance measures to indicate these results?

- QOL & satisfaction (patient/family/caregiver experiences)
- Satisfaction surveys (Zarit Burden Interview, PSQ18)
- Project evaluation surveys
- Health care resource utilization: LOS, acute care availability, estimated cost of providing care to patients in the community compared with an estimated cost of remaining in acute care, different funding models for the different types of complex respiratory need.

500 character max.

How were the participants and stakeholders impacted?

Good communication built confidence throughout the discharge process and helped patients stay in the community. They along with their families and/or caregivers were able to achieve a higher degree of independence, live in a safer environment and improve their QOL. Acute care facilities and other HCPs were provided with a consistent means to communicate with knowledgeable and appropriate resources. Fiscal costs were optimized: these patients were able stay at home for their care.

500 character max.

Deliverable #5

Provide ongoing education. The RT in the community will work with family and existing health care providers to determine their educational needs. On going education prevents the deterioration of knowledge over time and allows for changes in the clients condition.

Current Status

(Please indicate the status of the deliverable. If "Not Completed" or "Other" is selected additional details are required below).

- Completed
 Not Completed
 Other

If "Not Completed" or "Other", please explain:

500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)

The community-based RT provided ongoing training/education by working with the patient, family and care team to ensure ongoing needs were met e.g. training new staff. The ongoing support of the RT with the specific respiratory expertise is essential in maintaining confidence in respiratory care and ensuring all care members are fully trained. This is provided directly in the home. Educational resources and tools stay in the home as a backup resource to the in-person training.

500 character max.

Activities: What tasks did you do? (processes, programs, work)

Community RTs:

- Were utilized. Their role was to teach and educate patients and caregivers in respiratory care management
- Built relationships with the patient, family & care team by being actively involved in the care/support of the patient
- Identified needs for further training/education
- Were apprised of new care team members before they meet the patient – training and education was arranged for the new staff's first shifts
- Training was supported by educational tools

500 character max.

Outputs: What was produced, delivered, learned?

An effective, efficient, responsive, 24/7 model for ongoing support and training. The RT providing training when needed meant that every patient had a trained, full team complement

consistently and at all times. There was no lag time in getting staff trained, alleviating issues resulting from the high turnover rate among community care providers.(3) We learned patients with complex respiratory needs are more apt to stay in the community, be more independent and live in a safer environment.

500 character max.

Outcomes: What results have your outputs produced?

Providing ongoing education for the patient and their caregivers allowed them to remain in the community. This resulted in a more efficient use of health care resources e.g. decreased readmissions to acute care. Available ongoing education also decreased the burden placed on the patient, family and caregivers to train new providers.

500 character max.

What are the performance measures to indicate these results?

- 30 patients in the community – not admitted back to the ICU
- QOL & satisfaction (patient/family/caregiver experiences)
- Satisfaction surveys (Zarit Burden Interview, PSQ18)
- Project evaluation surveys
- Health care resource utilization: LOS, acute care availability, estimated cost of providing care to patients in the community compared with an estimated cost of remaining in acute care, different funding models for the different types of complex respiratory need.

500 character max.

How were the participants and stakeholders impacted?

Confidence & security in staying home & knowing how to access support & training. Patients were more apt to stay in the community, be more independent & live in a safer environment (reduced risk of infection). High turnover rate among community care providers results in a need for frequent training.(3) Available ongoing education alleviated burden on the patient &/or family to train new providers. Fiscal costs optimized: these patients were able to remain in the community & avoid acute care.

500 character max.

Deliverable #6

Provide risk management. This will include technical service, troubleshooting equipment and providing the necessary training or retraining. By managing technical problems in the community, this may help avoid unnecessary readmissions to hospital

Current Status

(Please indicate the status of the deliverable. If "Not Completed" or "Other" is selected additional details are required below).

- Completed
 Not Completed
 Other

If "Not Completed" or "Other", please explain:

500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)

The community RT provided much of the risk management related to technical service, troubleshooting equipment & ongoing training/retraining. The support/resource of the community RT mitigated unnecessary readmissions to hospital. Risk Management tools were developed with the help of RTs experienced in community LTV & complex respiratory management & the literature.(3, 7, 10-14) (Training Manual section 3). Other professionals such as proofreaders allowed for the tools to be more accessible.

500 character max.

Activities: What tasks did you do? (processes, programs, work)

- Utilized qualified community RT's in the role of ongoing support and teaching of respiratory care
- RTs taught and supported troubleshooting; technical function
- Risk management tools supported the role of the RT in risk management

500 character max.

Outputs: What was produced, delivered, learned?

Ongoing training and education achieved the desired outcome of avoiding hospital readmission in all patient instances. Patients with complex respiratory needs were more apt to stay in the community, be more independent and live in a safer environment. They were able to solve many technical and non-acute health issues in the community.

Evidence-based and practice-driven risk management tools were produced and available on the CRTO and RTSO web site.

500 character max.

Outcomes: What results have your outputs produced?

The ongoing support role of the community RT provided very effective risk management for all of the patients and their caregivers. The risk management tools further supported the ongoing training. Confidence in having 24/7 support managed risk as well. They were able to solve many technical and non-acute health issues on their own, over the phone or in-person with the community-based RT resulting in more efficient use of health care resources e.g. decreased re-admissions to acute care.

500 character max.

What are the performance measures to indicate these results?

- Evidence of readmission rates in the population served in the project
- QOL & satisfaction (patient/family/caregiver experiences)
- Satisfaction surveys (Zarit Burden Interview, PSQ18)
- Project evaluation surveys
- Health care resource utilization: LOS, acute care availability, estimated cost of providing care to patients in the community compared with an estimated cost of remaining in acute care, different funding models for the different types of complex respiratory need.

500 character max.

How were the participants and stakeholders impacted?

Confidence in care and support accompanied by ongoing training enabled patients, their families and care team to solve many technical and non-acute health issues in the community setting. They were able to achieve a higher degree of independence, live in a safer environment and improve their QOL. Fiscal costs were optimized because they were able to remain in the community and avoid acute care. HCPs had greater confidence because of the support & resource of the RT expertise.

500 character max.

Deliverable #7

Provide direct patient care as required. This may involve non-invasive monitoring (e.g. SpO2, EtCO2) download compliance and efficacy data from ventilators and bi-level devices, make ventilator parameters changes as prescribed, pulmonary hygiene, cough assist and volume augmentation, frog breathing, infection prevention and control and tracheostomy care

Current Status

(Please indicate the status of the deliverable. If “Not Completed” or “Other” is selected additional details are required below).

- Completed
- Not Completed
- Other

If “Not Completed” or “Other”, please explain:
500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)

The ProResp community RT Team provided direct patient care for invasive, non-invasive and trached patients in the community. ProResp uses a primary RT model for each patient. Primary equipment for invasively and non-invasively ventilated patients came from the VEP. Accessories and adjuncts were procured by the community RT through the ADP. All services were provided from the community RT offices – no additional infrastructure was needed.
500 character max.

Activities: What tasks did you do? (processes, programs, work)

The community RTs

- Were actively involved in procuring the necessary equipment in conjunction with the VEP;
- Provided direct care, teaching and support for the patient, family, and care team for the respiratory care needs;
- Sought ventilator order changes as necessary;
- Taught and demonstrated: pulmonary hygiene; use of the cough assist and breath stacking; infection prevention techniques.
- Taught trach care
- Performed trach changes, in the community with a doctor’s order **500 character max.**

Outputs: What was produced, delivered, learned?

Patient centred care was delivered consistently. 24/7 support in all instances was available to the patients.

We learned patients with complex respiratory needs are more apt to stay in the community, be more independent and live in a safer environment when they are provided with direct care in that setting (rather than in acute care).

500 character max.

Outcomes: What results have your outputs produced?

Direct care and ongoing support helped patients feel comfortable and safe to remain in the community. Confidence was built and consistent practices were developed. These helped prevent acute events from occurring e.g. clean technique; lung volume recruitment; infection control. To facilitate on-going assessment of patients' clinical course, diagnostics such as non-invasive oximetry was performed in the community. All this resulted in a more efficient use of health care resources.

500 character max.

What are the performance measures to indicate these results?

- QOL & satisfaction (patient/family/caregiver experiences)
- Satisfaction surveys (Zarit Burden Interview, PSQ18)
- Project evaluation surveys
- Health care resource utilization: LOS, acute care availability, estimated cost of providing care to patients in the community compared with an estimated cost of remaining in acute care, different funding models for the different types of complex respiratory need.

500 character max.

How were the participants and stakeholders impacted?

Patients, families and caregivers were supported by the community RT giving them direct respiratory care while they remained in the community setting. They were able to achieve a higher degree of independence, live in a safer environment and ultimately improve their QOL. Fiscal costs were optimized because these patients were able to remain in the community and avoid acute care. The patient's HCPs had greater satisfaction because care was provided by the experts in the community.

500 character max.

Deliverable #8

“Evaluation of Health Care Utilization of Clients Post-Transition into the Community - Analysis of health care utilization post transition for respiratory / ventilatory related issues such as unplanned physician visits, ER visits and hospital readmissions for non-emergency ventilation issues and tracheostomy care”

Current Status

(Please indicate the status of the deliverable. If “Not Completed” or “Other” is selected additional details are required below).

- Completed
 Not Completed
 Other

If “Not Completed” or “Other”, please explain:

500 character max.

How did you achieve this deliverable?

Inputs: Resources utilized (financial, human, equipment, infrastructure, etc)

The project team members developed the health care utilization variables to track throughout the project.(3, 7, 10-14) These were monitored throughout the project by the community RTs and project manager (Appendix P & Q). An accountant from Professional Respiratory estimated the cost of providing care to patients in the community compared with an estimated

cost of remaining in acute care. He also calculated different funding models for the different types of complex respiratory need.

500 character max.

Activities: What tasks did you do? (processes, programs, work)

- Project team members developed and finalized the variables to track
- Community RTs and project manager tracked the activities and 24/7 support that enabled patients to avoid unplanned healthcare utilization
- Final report writer analyzed the variables and provided a summary
- Accountant estimated cost of providing care to patients in the community compared with cost of remaining in acute care and calculated different funding models for the different types of complex respiratory need

500 character max.

Outputs: What was produced, delivered, learned?

A description of health care utilization for patients with complex respiratory needs, who were able to transition. The costs for these patients to remain in the community were compared with the cost if they had stayed in acute care. We learned that a system that helps patients stay in the community promotes QOL for these patients and helps optimize resources and efficiencies of the overall health care system. One stumbling block is the limit to funds available for these patients.

500 character max.

Outcomes: What results have your outputs produced?

A description of the type and costs of health care utilization for patients with complex respiratory needs who were able to transition into the community was produced. In addition this was compared with the cost if they had stayed in the acute care setting.

500 character max.

What are the performance measures to indicate these results?

Health care resource utilization: LOS, acute care availability, estimated cost of providing care to patients in the community compared with an estimated cost of remaining in acute care, different funding models for the different types of complex respiratory need.

500 character max.

How were the participants and stakeholders impacted?

This deliverable provided evidence to the LHINs and CCACs that patients with complex respiratory needs who are able to transition, are fiscally best served in the community. Financial costs were optimized when these patients were educated and supported in the community versus the acute care setting. Funds are then available to meet the needs (direct care, expertise, beds) for patients more appropriate for acute care settings.

500 character max.

Section 4 Financial Report

Part 8 Table 1 – Financial Statement

Note: All fields are mandatory.

2008/2009 Financial Report October 1, 2008 – March 31, 2010					
	\$				
Revenue (Ministry Funding received to Date)	\$225,000.00				
Total Interest	\$1,636.00				
Other funding (please specify)	0				
Total	\$226,636.00				
Expenditures	Total Proposed Budget (\$) to project end	Actual Expenditures (\$) from October 1, 2008 to September 30, 2009	Actual for other sources of funding (\$) from October 1, 2008 to September 30, 2009	Variance (\$)	Description of variance (if applicable)
Personnel Salaries and Benefits	\$74,000.00	\$69,465.84	\$0.00	\$4,534.16	Revised budget is 70,000 (\$4,000 transferred to Dissemination & Evaluation)
Consulting and Subcontracting	\$123,000.00	\$122,651.01	\$0.00	\$ 348.99	The actual total proposed amount in this line should be \$126,500, as \$16,500 was transferred out from an initial budget of 143,000 (on approval of HFO in April 2009) into the Travel & Accommodation.
Audit	\$1,000.00	\$787.00	\$0.00	\$ 213.00	Revised budget is \$2,000 (\$1,000 transferred from Travel & Accommodation). *At the time of printing the total cost of the audit was not available (total cost is included in the attached final audited statement).
Travel and Accommodation	\$18,500.00	\$5,396.56	\$0.00	\$13,103.44	Revised budget \$17,500 (\$1,000 transfer to Audit)
Telephone/Fax/Mail/Postage	\$2,500.00	\$2,227.92	\$0.00	\$ 272.08	
Rentals and Utilities	\$0.00	\$0.00	\$0.00	\$ 0.00	
Dissemination and Evaluation	\$25,000.00	\$28,022.49	\$0.00	(\$3,022.49)	Revised budget 29,000 (\$4,000

Note: All fields are mandatory.

					transfer from Personnel Salaries & Benefits)
Supplies and Equipment	\$2,500.00	\$653.39	\$0.00	\$1,846.61	
Overhead Costs	\$0.00	\$0.00	\$0.00	\$ 0.00	
Other (please specify)	\$0.00	\$0.00	\$0.00	\$ 0.00	
Total Expenditures	\$246,500.00	\$229,204.21	\$ 0.00	\$1,846.61	
Total Funding Variance	(\$2,568.21)				

**Section 5
Deliverable Documentation**

Part 9

Submit any materials (manuals, evaluations, reports, etc.) related to the deliverables/products as stated in section 2, question 5 of your application.

**Section 6
Audited Financial Statement**

Part 10

Submit Audited Financial Statement as of September 30, 2009 (1 document max.)
Note: the audited financial statement must conform to the Generally Accepted Accounting Principles of Canada (GAAP) and includes project information only.)

**Section 7
Comments**

Part 11

We do what we do because there is no place like home. We end this report with a patient (pt) story.

The date of discharge finally came & plans fell into place. The ICU & community care teams stood with the pt near the ICU nursing station. The ICU team took pictures & said their warm goodbyes & good luck wishes. The smile on his face graced by tears & his arm lifting slowly in a wave goodbye brought tears to all of our eyes (his diagnosis made moving his arm difficult). My RT colleague & I had the privilege of rolling the pt out of ICU to the transport van. With every roll of his wheelchair & every breath delivered by the ventilator, the hope in his eyes remained strong. As we rolled across the threshold of the door of his home, the smile on his face made it all worthwhile. He was home at last! What a genuine privilege to be part of the difference made for this pt. He has remained at home without incident since discharge. His smiles are frequent; his pleasure in being home palpable.

1,000 character max.

**Section 8
Signatures**

Part 12

I certify that the information given on this form is, to best of my knowledge, accurate and complete.

<u>Christine Robinson</u> Name: Recipient (President, CEO, Project Manager or Lead, or designated equivalent)	<u>[Signature]</u> Signature
<u>Registrar</u> Title	<u>JUNE 21, 2010</u> Date

<u>Amelia MA</u> Name: Chief Financial Officer or Equivalent	<u>Amelia MA</u> Signature
<u>Finance + Office Manager</u> Title	<u>JUNE 21, 2010</u> Date

The above 2 names (Recipient, CFO & Project Manager or Lead) are mandatory.

Health Force Ontario Optimizing Use of Health Provider's Competencies Fund FINAL REPORT APPENDICES

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Tables 10 and 11 can be found on pages 3 and 4 of Appendix P Financial Analysis

Table 10: Overall Cost of Care per Day Comparison – Home care versus Hospital

Table 11: Individual Example Cost of Care per Day Comparison – Home care versus Hospital

List of Figures (pages 5 to 9 of Appendix P Financial Analysis)

Figure 1: Total Cost of Long Stay Invasively Ventilated Patient

Figure 2: Cost of Care per Day of Invasively Ventilated Patients

Figure 3: Cost of Care per Day of Nocturnally Ventilated Patients

Figure 4: Cost of Care per Day of Non-Invasively Ventilated Patients

Figure 5: Cost of Care per Day of Complex Tracheostomy Patients

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Appendix A: Project Human Resources – Names and Roles

For question in Part 2 Input Summary: a) Human resources: Names of individuals and Roles

Project Team

- Carole Hamp (HealthForce Ontario (HFO) project contact, College of Respiratory Therapists of Ontario (CRTO))
- Mary Bayliss (CRTO staff)
- Brenda Andrachuk (Community Care Access Centre (CCAC) advisor)
- Carlos Bautista (contributor, West Park Healthcare Centre)
- Patrick Nellis and Robert Bryan (contributors, Respiratory Therapy Society of Ontario (RTSO))
- Miriam Turnbull (manager of community RTs, Professional Respiratory)
- Project management team: Mika Nonoyama, Rosanne Leddy and Dianne Johnson

Community-based Respiratory Therapists

- Alisa Brubacher
- Antonio Guglietti
- Dave Jones
- Jean (John) Lefebvre
- Jean Demars
- Joseph Lyle
- Julia Ball
- Kristine McGregor
- Sarah Gauthier
- Scott Taylor
- Sandra Mohr
- Tammy Rimmington
- Todd McGivern

Advisory Group

Contributors

- Janet Fraser (West Park Healthcare Centre)
- Noreen Chan (RTSO)
- Adrienne Leach (Ventilator Equipment Pool (VEP))
- Terri Haney (Royal Victoria Hospital)
- Chris Harris (London Health Sciences Centre)
- Jeannie Kelso (Hamilton Health Sciences Centre)
- Gail Lang (Credit Valley Hospital)
- Faiza Syed (Sick Kids)
- Margaret Oddi (St. Michael's Hospital)
- Regina Pizzuti (VEP)

Reviewers

- Melissa Heletea (Children's Hospital of Eastern Ontario)
- Ginny Myles (Royal Victoria Hospital)
- Renata Vaughan (Hamilton Health Sciences Centre)

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- Karen Martindale (Hamilton Health Sciences Centre)
- Regina Pizzuti (VEP)
- Raymond Milton (VEP)

In-Kind Services

- Christine Robinson (registrar, CRTO)
- Janice Carson-Golden (communications co-ordinator, CRTO)
- Ania Walsh (co-ordinator of Registration, CRTO)
- Amelia Ma (finance and office manager, CRTO)
- Accountant: Brian Marshall (Professional Respiratory)

Others

- Melva Bellefontaine (plain language review of tools)
- Vinay Raja (Clarke Henning auditor)
- Terry Coulson (TAC Associates Inc., printer)
- Valerie Gust (TAC Associates Inc., graphic designer)

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Appendix B: Project Lead's activities and CRTO In-Kind Contributions

Project Lead's Activities

Sept. 11/08

- Preliminary meeting with Mika to discuss next steps
 - Business plan
 - Insurance
 - Signing of contract (Sept 19th)
 - Meeting of the group
 - Press release
- Arrange banking with Chris and Amelia.

Sept. 13/08

- Contacted partners and collaborators for face-to-face meeting (must be held part time Oct. 1st)
- Potential dates provided (later confirmed to be Sept 19th from 1 – 4 with Mika, Brenda, Miriam, Mary, Chris and myself in attendance).

Sept. 19/08

- First official team meeting.
- In addition to those mentioned above, Carlos & Patrick Nellis joined via teleconference.
- Discussed outcome measurements, catchment area, contacts in the community, respiratory therapy (RT) resources and the development of tools and care mapping.

Sept. 24/08

- Spoke with Carole LeBlanc at Ottawa Rehab regarding the educational tools that they have already developed.
- Circulated minutes of Friday's meeting and provided team members with distribution list.

Sept. 26/08

- E-mailed Mika and suggested she contact Carole directly to discuss possibly sharing Ottawa's tools

Sept. 29/08

- Received e-mail from Ontario Interprofessional Health Collaborative requesting that we submit an abstract and present early finding to their January 09 conference.
- Contacted Mika and she will develop the abstract and then circulate it to the group
- Sent CRTO press release to HFO for their approval

Sept. 30/08

- Abstract was reviewed by CRTO staff and submitted by Mika

Oct. 1/09

- Official start date of project
- Consulted Chris and Amelia in the development of Mika's contract and confidentiality agreement.

Oct. 4/08

- Rosanne Leddy volunteered to assist with the project and I sent her contact information to Mika. Sent Rosanne a copy of the original proposal.

Oct. 6/08

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- Contacted Kerri Tam re: when money would be coming from HFO. She said it would not likely be until the end of October.
 - Drafted a letter of introduction about the project for hospitals, CCAC's etc.
- Oct. 15/08
- Arranged date and contacted participants for next face-to-face meeting (Oct. 29).
 - Drafted agenda and circulated it.
- Oct. 29/08
- Project team meeting (Mika, Miriam, Mary & myself).
 - Circulated minutes post meeting.
- Nov. 14/08
- Team meeting at CRTO office and formation of advisory group (Mika, Mary, Miriam, myself, Chris Harris, Gail Lang, Jeannie Kelso & Carlos Bautista). This advisory group is a sampling of RTs in Ontario who currently have successful transitioning processes for patients requiring LTV at their hospitals.
 - Circulated minutes post meeting.
- Nov. 18/08
- drafted outline of Project Managers accountability requirements and circulated to CRTO staff for edits.
- Nov. 20/08
- finalized accountability document and gave to Mika.
- Nov. 25/08
- arranged meeting for Miriam and Mika with staff at Humber River Regional Hospital.
- Dec.1/08
- arranged meeting for advisory group Mika Nonoyama (Miriam Turnbull, Jeannie Kelso, Carlos Bautista, Rosanne Leddy, Chris Harris, Mary & myself) at the CRTO office. Adrienne Leach and Regina Pizzuti were also invited and Adrienne was able to join via teleconference.
 - Provided Brenda Andrachuk with an update on the status of the project. She relayed that they have identified that Central CCAC has 9 long term ventilator clients receiving services in our CCAC and community.
 - Prepared agenda and other material for December meeting.
- Dec. 4/08
- Prepared and sent information on the project to go out with the CRTO December e-bulletin.
 - Worked with Janice to add information about our project to the CRTO website.
- Dec. 5/08
- Advisory group meeting (met with Mika in advance of meeting to review her quarterly report and the work done to date).
 - Drafted minutes and circulated post meeting.
- Dec.7/08
- Worked with project team on handout for Scarborough Grace presentation.
- Dec. 10/08
- Presentation at Scarborough Grace Hospital to ICU team and discussion of project and potential collaboration (Mika, Miriam & myself).
 - Made announcement of Rosanne taking over Project Manager position.

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Dec. 16/08

- Worked with Chris & Mary to revise the contract & confidentiality agreement for Rosanne.

Dec. 17/08

- Meeting with Mika in order to prepare for the handover of the Project Manager position to Rosanne and to review the current financial status with Amelia.
- Arrange detail of the ending of Mika's contract with Chris.
- Discussed experiences of VEP service provider (Kelly Vallencort).
- Consulted with Kerri Tam about reporting requirements and when the template for the report could be expected.
- Worked to arrange a meeting between our project team and representatives from the Central East Local Health Integrated Network (LHIN).

Dec. 18/08

- Meeting with Christine Dalglish (Director of Operations, Responsive Health Management), Linda Calabrese (Manager, Lincoln Place), Margaret Oddi (Manager, respiratory Therapy Services St. Michael's Hospital), Mary, Miriam & myself.
- Discussed the possibility of collaborating on long-term ventilation (LTV) initiative by having a patient transition from hospital into their long-term care facility. They would need addition funding to "staff up" in order to accept the increase acuity.

Dec. 29/09

- Prepared material and sent out teleconference information of the Jan. 8/09 meeting.

Jan. 6/09

- Handover meeting for Project Manager (Mika, Rosanne, Mary & myself)
 - Organized tools developed to date
 - Discussed activities in process (e.g., care map for high risk group).
 - Discussed what still needs to be done (e.g., gap analysis tool)
- Sent out agenda, minutes, CCAC announcement, Table of contents for tools, all 12 tools developed and a copy of Mika's poster to the project team for the Jan. 8/09 meeting.
- Updated information on project for January e-bulletin.

Jan. 8/09

- Advisory group meeting (Marg, Carlos, Janet Fraser, Patrick Nellis, Miriam, Mary, myself, Mika, Jeannie, Regina, Adrienne, Brenda and Chris Harris).
- Sent out minutes post meeting.

Jan. 9/09

- Teleconference with Carol Shelton (intensive care unit (ICU) Manager, The Scarborough Hospital – General site) and Dr. Clasky (Central East LHIN Lead for critical care). The purpose of this call was to identify who would need to be at the preliminary meeting with representative from the Central East LHIN hospitals (The Scarborough Hospital – General & Grace, Rouge Valley Health System – Centenary & Ajax Pickering and Lakeridge – Oshawa site).
- Determined that the following representative were required:
 - Senior planner for LHIN
 - Nurse educator
 - Physician lead
 - RT lead

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- After meeting sent Carol the intro piece we shared at our initial meeting at TSH and she said she would get back to me with a meeting date.
- Contacted Kerri Tam (re: reallocation of funds). She said to draft a letter of request along with the rationale.

Jan. 12/09

- Discussed with project team and Chris the possibility of shifting some money from one budget line to another (\$20,000 from consulting and subcontracting to travel/accommodation). This would allow for travel within our expanding catchment area.
- Drafted a letter a circulated it to the group.

Jan. 13/09

- Had Janice set up web office access for Miriam and Rosanne.
- Continued to working with project team to finalize the letter to Kerri Tam.

Jan. 7/09

- Submitted an abstract for a poster presentation to the Ontario Association of Community Care Access Centres (OACCAC) upcoming conference, June 3 – 5, 2009 in Toronto.

Jan 12 – 15/09

- Prepared poster for upcoming presentation.

Jan. 19/09

- Mika and I took part in a poster presentation at Ontario Interprofessional Health Collaborative conference at the University of Toronto Conference Centre on Monday January 19th.
- Submitted an abstract to the 12th annual International Mechanical Home Ventilation Conference, March 27 -28, 2009 in Barcelona, Spain.

Jan. 23/09

- Miriam, Rosanne & myself meeting with Janice Wood and Frances Reinholdt at Humber River Regional Hospital to discuss patient that they have in their ICU. Helen Booth was also there from the local CCAC to provide a community perspective. It was determined at the meeting that this particular patient would unlikely transition into the community in the foreseeable future due to multiple psycho-social issues and lack of family support. However, we would continue to work with them to determine what assistance we might be (e.g., RT support for day trips) and to see if Complex Continuing Care would be an option. As a follow up, I sent them a draft of our Identification tool for their input.
- In the afternoon, Miriam, Rosanne and I met with Faiza Syed and Diane Soares, both RRTs involved with the home ventilation program at Sick Kids. The purpose of this meeting was to gain an understanding of the work they currently do and to see how we can tap into their expertise in neo/paed home ventilation. They were eager to assist in any way possible in the development of educational tools.

Jan. 26/09

- Developed article for The Exchange on the project.

Feb. 02/09

- In order to articulate to the CCACs what the RT role in the community could be, I drafted a cover letter, took excerpt from Respiratory Therapy Act on scope of practice, and took the competencies from the NCP that would be relevant to the provision of RT services in the community. Circulated this around and then sent it to Brenda Andrachuk.

Feb. 10/09

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- Project team meeting to discuss tools and list of “gaps” to be identified in final report.
- March 11/09
- Project team teleconference to discuss potential patients (Chatham-Kent, Southlake & Hamilton Health Science Centre), plans for final dissemination (interprofessional practice guideline for LTV, conference) and conferences where we may want to present. Plan made to ask HFO for project extension to Oct. 1, 2010.
- March 18/09
- Request drafted and send to request reallocation of funds from Consulting & Subcontracting to Travel & Accommodation.
- March 25 – 30/09
- Barcelona International Home Ventilation Conference.
- April 6/09
- Received Rosanne’s draft of the interim report and circulated to project team for review.
- April 9/09
- Project team meeting regarding patient (Bob) review of training manuals and the Chronic Respiratory Disease Questionnaire.
- April 16/09
- Letter sent to HFO requesting extension
- April 29/09
- Face-to-face project team meeting to review and finalize the interim report. Patients, tools, outcomes measurements and dissemination plans was also discussed.
- April 30/09
- Submitted first interim report.
- May – June/09
- Work done on reviewing and formatting adult tools.
- May 4/09
- Letter with further rationale for extension sent to HFO.
- May 9/09
- Began work obtaining permission for all illustrations in tools.
- May 14/09
- E-mails with HFO regarding additional project deliverable.
- May 26/09
- Spoke with Rosanne re: outstanding issues for the project (e.g., Paediatric tools, non-invasive ventilation (NIPPV) manual from Kingston and Assistive Devices Program (ADP) manual).
- May 27 – 31/09
- Project Poster presentation at Canadian Society of Respiratory Therapists (CSRT) conference
- June 3/09
- Adult tools posted tools on WebOffice.
- Late June/09
- Prepared poster for CCAC Home Care Summit.
- July 3/09
- Project team meeting to discuss possible patient form Hamilton, paediatric tools and quality of life (QOL) survey.

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Mid July/09

- Edits done on NIPPV tools and then posted on website. Requests for permission to reproduce was updated.

July – August/09

- Revision done with HFO to budget based on amended completion date.

July – August/09

- Review, revision and formatting of paediatric tools.

Sept/09

- Project team works of 2nd interim report.

Sept. 15/09

- Meeting at West Park regarding project deliverables (Chris, Rosanne, Mary & Carole).

Sept 26/09

- Oral presentation on the HFO project at RTSO forum.

Sept.29/09

- 2nd interim report submitted.

Oct. 20/09

- Established final date for patient intake.

Mid November

- Posted and received applications for project Coordinator position.

Nov. 23/09

- Mary and Carole met with Dr. Goldstein re: interviews with patients d/c'ed from West Park.

Early December

- Conducted interview for project coordinator (PC) position.

Dec. 7/09

- Finalized Dianne's contract & confidentiality agreement and met with her to hand over the project.

Dec. 9/09

- Development action plan for meeting with Mika.

Dec. 18/09

- Consulted with HFO re: audit & template for final report.

Dec. 18/09

- Teleconference with project team regarding process flow map, gap analysis, surveys & Better Breathing conference.

Early January

- Worked with Dianne to develop abstract submission to 2010 OACCAC conference.

Jan. 22/10

- Consulted with Dianne on strategies and educational material.

Jan. 30/10

- Presented on project at the 2010 Better Breathing Conference.

Early February

- Worked with Dianne to establish a group of content expert to review the tools.

Feb. 12/10

- Project Team teleconference to discuss plans for fall conference (date, price, potential speakers).

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Feb. 18/10

- Met with Dianne & printer (Terry Coulson) regarding the printing of the educational material.

Early March/10

- Began discussions with various individuals re: plain language review.

March 3/10

- Sent disclaimer to CRTO legal counsel for recommendations.

March 10/10

- Conference call with Member currently working with a CCAC.

March 11/10

- Signed back contract with Delta Meadowvale for fall conference.

March 18/10

- Met with Dianne to discuss hotel contract & plain language review.

March 24/10

- Request and reviewed work plan from Melva Bellefontaine re: plain language review.

March 25/10

- Project team teleconference re: final report

March 30/10

- Met with Dianne, Terry Coulson & Valerie Gust regarding the graphic design of the educational material.

April 15/10

- Met with Dianne to draft agenda for conference. Circulated to group.
- Discussed with Rob the RTSO's role in the registration process for the conference.

CRTO Staff In-kind Project Contribution

- Carole Hamp (CRTO Project Lead) – approximately 700 hours (average of 2 hours/ day over 17.5 months)
- Mary Bayliss (CRTO staff & Project Team member) – 250 hours
- Janice Carson-Golden (CRTO Communications Coordinator) – 25 hours
- Amelia Ma (CRTO Financial Officer) – 100 hours

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Appendix C: Detailed role of Community Respiratory Therapist

The following is a general description of the tasks the community RT did during the project. The type and number of tasks completed differed according to the patient. This depended on the complexity of the patient's diagnosis and respiratory management, amount of support by other services and home/family circumstances. For instance those patients on invasive ventilation required more care than those on non-invasive ventilation; those with minimal funding support required more hours of care than those with greater funding support. Please see Table 1 and 2 for a description of RT experiences with two patients (one whom had minimal funding and one with full funding support).

Collaborated with the acute care team

- Identified patients who are at-risk of becoming ventilator-dependant and recommended weaning strategies
- Determining the best care plan for each patient:
 - Assessed patients who are already on LTV to determine if they are able to transition into the community
 - Coordinated with resources both inside and outside the acute care facility to assist in the placement or repatriation
- Coordinated and carried out or assisted with the initial education for patient, family, caregivers and/or community healthcare providers (HCPs). Sometimes this training was very intensive and took a lot a time. This included:
 - Ventilator training
 - Tracheostomy tube ("trach") care and changes
 - Manual ventilation
 - Suctioning
 - Lung volume recruitment/breathstacking
 - Cough assist
 - Feeding tube
 - Medication delivery (method & timing)
- Organized trial runs in the home

Transitioned patients into the community

- Were actively involved in procuring and delivering the necessary equipment in conjunction with the VEP
- Home respiratory equipment set up
- Met the patient at the home
- The RT usually spent time (often several hours) with each caregiver for their first shift to:
 - Reinforce the education provided
 - Build relationships within the team
 - Create the confidence in the RT back-up support

Support for patients in the community

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- For the initial transition period (6 to 8 weeks), the RT visited and/or called the home frequently to ensure the care team was confident with the routine patient care. The frequency depended on the needs of the specific patient, on average 1 to 2 times a week but sometimes daily.
- After the initial period, the RTs would visit the home for regular follow-up visits about once a month unless their situation mandated more intense support.
- Identified needs and provided for further training/education (for patients, family, caregivers and/or community HCPs). This included:
 - Ventilator training
 - Trach care & change
 - Manual ventilation
 - Suctioning
 - Cleaning of equipment
 - Infection control
 - Troubleshooting of equipment
 - Troubleshooting of symptoms e.g. when to go to hospital etc.
 - Lung volume recruitment/breathstacking
 - Cough assist
 - General respiratory care
 - General safety
 - Smoking cessation
- Provided education on any adjunct therapy e.g. inhaled medication (by metered dose inhaler or aerosol via compressor), pulmonary function, oxygen (including safety), oximetry, humidification
- Were apprised of new care team members before they meet the patient – training and education was arranged for the new staff's first shifts
- Acted as communication link between the patient and their home and external healthcare team
- Risk management – technical service, troubleshooting equipment and ongoing training/retraining:
 - 24/7 support (“on call”) in the home
 - Taught and demonstrated: pulmonary hygiene; use of the cough assist and breath stacking; infection prevention techniques.
 - Trach changes
 - Ventilator circuit changes
- Direct patient care
 - Sought ventilator order changes as necessary
 - Made ventilator parameter changes, including assessment
 - Weaned patient from ventilator
 - Speaking valve trials
 - Taught trach care
 - Performed trach changes, in the community with a doctor's order

Project specific tasks

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- Collected measurements on health care utilization after the patient transitioned into the community e.g. unanticipated calls to or visits from the community RT, emergency room (ER) visits, hospital admissions with overnight stays, doctor's visits, other health professional visits, tests and procedures, unanticipated morbidity and unanticipated mortality

Table 1: Example of Community RT role – Patient 1 (minimal funding support)

Patient details: A 52 year old male with multiple sclerosis on continuous invasive ventilation with tracheostomy. He was discharged from an intensive care unit. This patient receives 21 hours a week of PSW care; 1 hour, twice a week of RN care and; a monthly visit by a community care nurse for trach changes. The wife took a leave of absence from work and supports his direct care 60 to 80 hours a week. They have 2 school aged children.

Notes: Many of the tasks prevented the patient from going into the hospital e.g. troubleshooting the equipment and tracheostomy tube and home trach tube changes. In addition training of new staff occurred 6 times over the year. Each time provided in a consistent manner – by the same RT staff and same information.

Date discharged	April, 2009
# hours seen	7
1st home day	
# days seen/called	8
1st week home	9 visits
April 2009	<ul style="list-style-type: none"> • Ventilator (vent) training • Troubleshooting suction machine
	9 visits
	<ul style="list-style-type: none"> • Assessment & clinical support • Oximetry • Vent circuit change/clean
May 2009	<ul style="list-style-type: none"> • Support after hospital discharge • Support after new O₂ prescription • Equipment review – follow up (FU) from overnight call (equipment trouble)
	1 call
	<ul style="list-style-type: none"> • Discussed caregivers and lack of support
	10 visits
	<ul style="list-style-type: none"> • Assessment & clinical support • Support post new O₂ prescription • Training new staff
June 2009	<ul style="list-style-type: none"> • Troubleshooting the vent
	3 calls
	<ul style="list-style-type: none"> • Troubleshooting the vent • Informed that patient (pt) hospitalized

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	9 visits	<ul style="list-style-type: none">• Assessment & clinical support• Vent maintenance• Support after hospital discharge• Tracheostomy tube (trach) troubleshooting• Vent circuit change/clean
July 2009	2 calls	<ul style="list-style-type: none">• Nursing staff unable to inflate trach cuff (improper syringe)• Informed that pt hospitalized
	9 visits	<ul style="list-style-type: none">• Assessment & clinical support• Vent circuit change/clean
August 2009	2 calls	<ul style="list-style-type: none">• Informed that pt hospitalized• Informed pt back home
	12 visits	<ul style="list-style-type: none">• Assessment & clinical support• Vent circuit change/clean
September 2009	11 visits	<ul style="list-style-type: none">• Assessment & clinical support• Vent circuit change/clean
	13 visits	<ul style="list-style-type: none">• Assessment & clinical support• Trach troubleshooting –pilot balloon ruptured, sent to hosp for new trach• Training new staff
November 2009	12 visits	<ul style="list-style-type: none">• Assessment & clinical support• Vent circuit change/clean• Training new staff
	13 visits	<ul style="list-style-type: none">• Assessment & clinical support• Vent circuit change/clean• Training new staff• Switching vents• Trach troubleshooting (pilot balloon leak, sent to hosp for new trach)• Home trach change on order of a physician
January 2010	11 visits	<ul style="list-style-type: none">• Assessment & clinical support• Vent circuit change/clean• Training new staff• Helped transfer pt to new bed
	12 visits	
February 2010		
March 2010		

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- Assessment & clinical support
 - Home trach change
- 6 visits
- April 2010**
- Assessment & clinical support
 - Support after fire in home & hospitalization

Table 2: Example of Community RT role – Patient 2 (full funding support)

Patient details: A 78 year old male with Amyotrophic Lateral Sclerosis (ALS) on continuous invasive ventilation with tracheostomy. He was discharged from an intensive care unit. He had initial support from a CCAC Case Manager, the CCAC area director, the CCAC supervisor and the CCAC manager of clinical practice. He receives ongoing CCAC RN and PSW care. In addition he is supported (by insurance/private pay) with a RN, dietician, pharmacist, social worker and 3 physicians (GP, Respirologist and one whom does trach changes in the home). He also has strong family support from his wife and 2 adult sons.

Date discharged	January, 2010
# hours seen	3
1st home day	
# days seen/called	7
1st week home	3 visits
	<ul style="list-style-type: none"> • Patient transfer with ventilator • Education and training
Jan-10	1 call
	<ul style="list-style-type: none"> • Patient was short of breath – the RT instructed the HCP to instil and suction. The RT also recomended lung recruitment treatments.
	3 visits
	<ul style="list-style-type: none"> • Education and training (repeated & new staff) • Monitored patient transfer with ventilator
Feb-10	2 calls
	<ul style="list-style-type: none"> • Regarding patient transfer and bathing issues
	2 visits
	<ul style="list-style-type: none"> • Routine follow up • Patient pain investigation • Monitored ventilator circuit change • Ventilator troubleshooting • Re-training new staff
Mar-10	

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Appendix D: Knowledge Dissemination Summary

A description of the activities, methods or strategies that were used to communicate and disseminate information, and transfer knowledge about the project to inform others.

- The CRTO and RTSO announced to its members the existence of the project by email, newsletters and their web sites. This allowed for RTs to make contact and ask questions and/or contribute their knowledge and experiences. Continuous updates were provided through the web site and newsletters. All tools produced from the project are available on the CRTO web site. Hardcopies of the tools have been distributed to LHINS, CCACs, RT departments and other community partners.
- The project manager contacted individuals (within organizations) who have experience in this area. In addition to making these individuals aware of the project, discussions regarding processes, challenges, and successes from their own practice were related (see below).
- Other Team members promoted the project, by word-of-mouth, at conferences and through their individual network of professionals. For instance, RT/nurse/ICU managers/other persons in charge of discharge from hospitals in the greater Toronto area (GTA) were telephoned and/or visited face-to-face and mailed flyers to describe and discuss the project and ways to work together.
- Poster presentation and talks were given at local conferences (2008 Ontario Interprofessional Health Collaborative, 2009 Ontario Association of CCAC, and 2010 Ontario Lung Association Better Breathing; 2009 RTSO Fall Forum) and National conferences (2009 & 2010 Canadian Society of Respiratory Therapy, 2009 Canadian Home Care Association Home Care Summit)
- Furthermore, outside of HFO funds, a conference is organized for the Fall of 2010 in order to disseminate the information resulting from this project. It will be geared toward health care professionals, patients and caregivers. Hardcopies of the tools will be made available to all conference participants. Funding of this conference will be provided by the CRTO. An application to an external grant will also be made (The Canadian Lung Association's Regional Respiratory Health Education Workshops Grant).
- A copy of both the adult and paediatric educational packages will be sent to all the hospitals that ventilate patients in Ontario. They will also be available to download from the CRTO website.

A list of individuals and organizations with whom the Recipient communicated and to whom the Recipient disseminated information and transferred knowledge regarding the Project.

Information and knowledge was disseminated through the project team, advisory groups and others. This list can be found in Appendix A.

The project manager contacted individuals (within organizations) who have experience in this area. In addition to making these individuals aware of the project, discussions regarding processes, challenges, and successes from their own practice were related. The individuals included:

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West Park Healthcare Centre

- Dr. Roger Goldstein, Respiriologist
- Dr. Monica Avendano, Respiriologist
- Carlos Bautista, RT

Royal Victoria Hospital

- Ginny Myles, RT

Trillium Health Centre

- Rosanne Leddy, RT

The Ottawa Hospital Rehabilitation Centre

- Carole Leblanc, RT
- Dr. Doug McKim, Respiriologist

London Health Sciences Centre

- Chris Harris, RT
- Jane Montgomery, RT
- Mike Keim, RT

Toronto East General

- Krisztina Weinacht, Physical Therapist

Provincial Respiratory Outreach Program in British Columbia (PROP)

- Gillian Harney, RT
- Simon Cox, Executive Director

St. Joseph's Hospital, Thunder Bay

- Shelley Prevost, RT

Hamilton Health Sciences

- Renata Vaughan, RT
- Karen Martindale, RT
- Jeanne Kelso, RT

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Appendix E: Descriptive Patient Data

For question in Part 5: Outcomes/Evaluation Summary: b) What are the performance measures to indicate these results?

Table 3 to 5 below provides specific details about each patient who took part in this project.

The average (standard deviation) age of patients in this study was 44 (26) years with a range from 3 months to 81 years (6 were children). Six patients (3 children, 3 adults) passed away due to their underlying illnesses. One patient lived in the Central LHIN, 1 in Central East, 3 in Erie St. Clair, 4 in Hamilton Niagara Haldimand Brant, 3 in Mississauga Halton, 6 in South East, 9 in Toronto Central and 4 in Waterloo Wellington. Fifteen were on invasive ventilation, 12 on non-invasive ventilation and 2 had a tracheostomy only. All patients except 2 were transitioned to a private residence; 1 went to a long-term care facility and the other to an attendant care facility. Diagnosis included neuromuscular disorders, respiratory disease, and quadriplegia. Twelve of the 30 had changes in healthcare provider staff. The coverage and/or funding varied widely from none (only family or self care) to 24 hours 7 days a week (24/7). Most had some support by CCAC (which decreased over time) and did not have 24/7 care. The average length of stay in acute care was 138 (146) days. The average number of ER visits was 1.0 (2.1), unplanned hospitalizations 0.9 (2.2) and doctor visits 0.9 (2.0).

Table 3: Descriptive Patient Data – Demographics

Age (years)	LHIN	Diagnosis	Vent type	Trach?	Acute care team	Community team
1 70	South West	<ul style="list-style-type: none"> • Kyphoscoliosis • Hypoventilation syndrome 	IV	yes	RTx2, RN, MD, Respiriologist, PT, OT	RT, CCAC RN, CCAC PSW
2 67	South West	<ul style="list-style-type: none"> • COPD 	IV	yes	RT, RN, MD, Respiriologist, PT, OT	RT, CCAC RN, CCAC PT
3 64	South West	<ul style="list-style-type: none"> • Kyphoscoliosis • Diaphragmatic paralysis • COPD 	IV	yes	RT, CNS, RN, MD, PT, OT, RD	RT, CCAC CM, CCAC RN, private NM, GP, private RN (EC), private PT, private PSW
4 45	South West	<ul style="list-style-type: none"> • Quadriplegic 	NIV	no	RT, Respirologist	RT, CCAC RN,

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5	72	South West	<ul style="list-style-type: none"> Respiratory insufficiency COPD 	NIV	no	NA-admitted through outpatient clinic	private PSW RT
6	32	South West	<ul style="list-style-type: none"> Quadriplegic 	NIV	no	RT, MDx2	RT, CCAC CM, MD, 2 HCP from insurance company
7	18	Waterloo Wellington	<ul style="list-style-type: none"> DMD 	NIV	no	RT, MD	RTx3
8	48	Toronto Central	<ul style="list-style-type: none"> Myotonic Dystrophy 	IV weaned	yes	RT, Intensivist x3, GP, discharge coord, SW	RT, CCAC RN, CCAC PSW
9	52	Central	<ul style="list-style-type: none"> Multiple Sclerosis 	IV	yes	RT, ICU manager, Respiriologist, SW	RT x 2
10	34	Toronto Central	<ul style="list-style-type: none"> Muscular Dystrophy 	NIV	no	RT, Respiriology team	RT
11	58	Toronto Central	<ul style="list-style-type: none"> Hypoventilation syndrome 	NIV	no	RT, MD, RN	RT
12	54	Toronto Central	<ul style="list-style-type: none"> Multiple Sclerosis 	NIV	no	NA-admitted through outpatient clinic	RT
13	50	Toronto Central	<ul style="list-style-type: none"> ALS 	IV	yes	MD (ALS), MD (pain), Respiriologist, GP, discharge CC	RT, CCAC RN, CCAC PSW, private RN
14	68	Toronto Central	<ul style="list-style-type: none"> Marfans syndrome 	NIV	no	RT, MD, RN	RT
15		Central East	<ul style="list-style-type: none"> Quadriplegic 	NIV	no		
16	51	Toronto Central	<ul style="list-style-type: none"> ALS 	IV	yes	NA-admitted through outpatient clinic	RT
17	56	Toronto Central	<ul style="list-style-type: none"> Complex neuromuscular disease 	IV	yes	RTx2, MD, RN, practice leader, SW, RD, CCAC, PT, OT	RT, RPN, OT, PT, RD, CCAC
18	60	Erie St. Clair	<ul style="list-style-type: none"> ALS 	IV	yes	NA-after doing a few home trials patient felt home care would be too much for caregiver	

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								(wife)	
19*	28	Erie St. Clair	• DMD		IV	yes		RTx4, intensivist, OT, SW	RTx2
20	3mo	Mississauga Halton	• SMA Type 1		NIV	no		NA-admitted through outpatient clinic	RT, CCAC RN, CCAC OT, CCAC PT, MD
21	1	Waterloo Wellington	• SMA Type 1		NIV	no		RT, MD	RTx3
22*	5	Waterloo Wellington	• Ondine's Curse		IV	yes		RT, MD	RTx2
23	10	Waterloo Wellington	• BPD		IV	yes		RT, MD, RN	RTx2, paediatrician
24	7mo	Hamilton Niagara Haldimand Brant	• Multiple congenital anomalies • Seizure disorder		None	yes		RT, MD, paediatrician, RN	RTx2, CCAC RN, CCAC RPN
25	13mo	Hamilton Niagara Haldimand Brant	• Hydrocephalus • Post ischemic stroke • Chronic lung disease		IV	yes		RT, MDx2, RN	RTx2, CCAC RPN
26	81	Hamilton Niagara Haldimand Brant	• Hypoventilation syndrome • Chronic respiratory failure • Parkinson's disease • Congestive heart failure		NIV	no		RT, MD	RTx2, LTCF MDx2, LTCF RN, LTCF PSW
27	78	Hamilton Niagara Haldimand Brant	• ALS		IV	yes		RT, Respiriologist, RNx2, PT, OT, RD	RTx2, Respirologist, GP, MD, CCAC CM, CCAC director, CCAC clinical manager, CCAC RN, CCAC PSW

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							(discontinued after 2 nd month), private RN, RD, SW, pharmacy
28	55	Erie St. Clair	• Quadriplegic	IV	yes	RT, Respiriologist, RN, PT, CCAC CM	RTx2, Respirologist, GP, RN, PSW, PT, RD
29	63	Mississauga Halton	ALS	IV	yes	NA-admitted through outpatient clinic	RT, CCAC RN
30	57	Mississauga Halton	ALS	IV	yes	NA-admitted through outpatient clinic	RT, CCAC RN

Blank spaces=data not reported

*Patient had been living at home prior to project commencement – information pre & post project included.

ALS= Amyotrophic Lateral Sclerosis; BPD=bronchopulmonary dysplasia; CC=care coordinator; CCAC=community care access centre; COPD=chronic obstructive pulmonary disease; CM=case manager; CNS=clinical nurse specialist; DMD= Duchenne's Muscular Dystrophy; GP=general practitioner; HCP=healthcare provider; ICU=intensive care unit; IV=invasive ventilation; LHIN=Local Health Integrated Network; LTCF=long term care facility; MD=medical doctor; NIV=non-invasive ventilation; NM=nurse manager; OT=occupational therapist; PSW=personal support worker; PT=physical therapist; RD=registered dietician; RN=registered nurse; RN(EC)=registered nurse extended class; RPN=registered practical nurse; RT=respiratory therapist; SMA=spinal muscular atrophy; SW=social work; Trach=tracheostomy; Vent=ventilation.

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Table 4: Descriptive Patient Data – Caregiver Changes and Coverage/Funding

	Caregiver changes	Caregiver change frequency	Caregiver change reason	Coverage/Funding
1	RN, PSW		<ul style="list-style-type: none"> • Role changes 	<ul style="list-style-type: none"> • CCAC RN: one 1 hr/wk then D/C • CCAC PSW: three 1 hr/wk then D/C
2	RN	<ul style="list-style-type: none"> • Several times 	<ul style="list-style-type: none"> • Schedule & role change 	<ul style="list-style-type: none"> • CCAC RN: one ½ hr/wk, then monthly, then D/C • CCAC PT: limited visits several weeks after discharge then D/C
3	None	NA	NA	<ul style="list-style-type: none"> • CCAC RN: three 1 hr/wk • CCAC PT: 1-2 visits/wk then D/C
4	None	NA	NA	<ul style="list-style-type: none"> • CCAC RN: occasional wound care appointments • Private PSW: morning & evening to get in/out of bed & meals (1hr/wk)
5	None	NA	NA	<ul style="list-style-type: none"> • CCAC RN: one 2 hr/wk
6	PT	<ul style="list-style-type: none"> • Added 	<ul style="list-style-type: none"> • Chest physiotherapy required 	<ul style="list-style-type: none"> • CCAC RN: weekly • CCAC PT • Insurance 9 hr/night, 6 days/wk
7	None	NA	NA	<ul style="list-style-type: none"> • CCAC 40 hr/wk
8	PSW, GP, RT	<ul style="list-style-type: none"> • PSW initially >once • GP once • RT once 	<ul style="list-style-type: none"> • Staff changes stopped at request of caregiver • GP: upon discharge • RT: left company 	<ul style="list-style-type: none"> • CCAC PSW: 21 hr/wk • CCAC RN: two 1 hr/wk & once month trach change
9	RN, PSW, RT	<ul style="list-style-type: none"> • RN, PSW regular basis 	<ul style="list-style-type: none"> • RN, PSW: money conflicts, scheduling, personality 	<ul style="list-style-type: none"> • Per wk • Private pay (spouse) 62 hours

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		<ul style="list-style-type: none"> • RT once 	<ul style="list-style-type: none"> • differences, maternity leave • RT: left company 	<ul style="list-style-type: none"> • Other 47 hours • CCAC 43 hours • Insurance 16 hours
10	None	NA	NA	<ul style="list-style-type: none"> • None – cared for by family member
11	None	NA	NA	<ul style="list-style-type: none"> • None – self care
12	None	NA	NA	<ul style="list-style-type: none"> • None – self care
13	PSW, RT	<ul style="list-style-type: none"> • PSW 2-3 times • RT once 	<ul style="list-style-type: none"> • PSW agency changed • RT: company provided supply services only-respiratory care support also required 	<ul style="list-style-type: none"> • CCAC & insurance provides 24/7 care • Private pay for feeding tube, trach care, others
14	None	NA	NA	<ul style="list-style-type: none"> • None – self care
15	None	NA	NA	<ul style="list-style-type: none"> • None – self care
16	None	NA	NA	<ul style="list-style-type: none"> • None – self care
17	RPN, RT	<ul style="list-style-type: none"> • RPN 8 times • RT 2 times 	<ul style="list-style-type: none"> • RPN: unable to cover shifts 	<ul style="list-style-type: none"> • CCAC: 53 hr/wk • Insurance: 115 hr/wk • Private pay for feeding tube, trach care, others
18	NA	NA	NA	NA
19*	PSW, GP, RT	<ul style="list-style-type: none"> • GP 2 times • RT added 	<ul style="list-style-type: none"> • PSW: Employee turnover • GP: illnesses • RT: continuity of care 	<ul style="list-style-type: none"> • CCAC: 2 assessments (pre & post discharge); 1 visit each by RD & PT • March of Dimes PSW: 3 hr/day • RT volunteer (pre-project): four 1.5 hr/yr visits; 3-4 as needed calls/visits
20	None	NA	NA	<ul style="list-style-type: none"> • Insurance for portion
21	None	NA	NA	<ul style="list-style-type: none"> • None – cared for by family
22*	None	NA	NA	<ul style="list-style-type: none"> • CCAC: 43 hr/month • Private pay: 16 hr/month
23	RN	<ul style="list-style-type: none"> • Several times 	<ul style="list-style-type: none"> • Staffing availability & turnover 	<ul style="list-style-type: none"> • CCAC RN: 196 hr/month • Private pay: 24 hr/month

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24	None	NA	NA	<ul style="list-style-type: none"> • CCAC RPN: three 7hr/wk
25	RPN	<ul style="list-style-type: none"> • once 	<ul style="list-style-type: none"> • RPN injured; nursing care time decreased due to lack of nurses in their CCAC zone trained on the ventilator 	<ul style="list-style-type: none"> • CCAC RPN initially 40 hr/wk, decreased to 16 hr/wk
26	None	NA	NA	<ul style="list-style-type: none"> • All care in Long term care facility
27	RN		<ul style="list-style-type: none"> • Case too much for staff 	<ul style="list-style-type: none"> • CCAC, private pay and insurance
28	PSW, GP	<ul style="list-style-type: none"> • PSW once • GP once 	<ul style="list-style-type: none"> • PSW added for vacation and caregiver assistance • GP to one closer in proximity 	<ul style="list-style-type: none"> • Attendant care facility: 24/7 PSW • CCAC RN 7hr/wk for 4 mo then 4 hr/wk • CCAC PT 5 hr total • CCAC RD 1 hr/4-6wks
29	None	NA	NA	<ul style="list-style-type: none"> • CCAC and insurance
30	None	NA	NA	<ul style="list-style-type: none"> • CCAC and insurance

Blank spaces=data not reported

*Patient had been living at home years prior to project commencement – information pre & post project included.

CCAC=community care access centre; D/C=discontinued; hr=hour; NA=not applicable; PSW=personal support worker; PT=physical therapist; RN=registered nurse; RPN=registered practical nurse; RT=respiratory therapist; Trach=tracheostomy; wk=week.

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Table 5: Descriptive Patient Data – Length of Stay, Health Utilization

	Acute LOS (days)	ER visit #	ER visit reason	Hosp stay #	Hosp stay reason	Doctor visit #	Doctor visit reason
1	210	0	NA	0	NA	3	<ul style="list-style-type: none"> • Routine check up • Arrythmia • Stoma closure preparation
2	365	0	NA	0	NA	6	<ul style="list-style-type: none"> • Routine check up • Trach change
3	150	2	<ul style="list-style-type: none"> • Febrile • Increased secretions • SOB 	2	<ul style="list-style-type: none"> • Febrile • Increased secretions • SOB 	8	<ul style="list-style-type: none"> • Routine check up
4		0	NA	0	NA	0	
5	0	0	NA	0	NA	1	<ul style="list-style-type: none"> • Routine check up
6	2	1	<ul style="list-style-type: none"> • Chest infection 	0		4	<ul style="list-style-type: none"> • Routine check up
7	60	0	NA	1	<ul style="list-style-type: none"> • Pt went home temporarily for 12 days and then readmitted (planned) 	0	NA
8	180	3	<ul style="list-style-type: none"> • Trach tube change x2 • Aspiration Pneumonia • Respiratory Failure (req. ventilator) 	1	Admitted from ER <ul style="list-style-type: none"> • Aspiration Pneumonia • Respiratory Failure (req. ventilator) 	1	<ul style="list-style-type: none"> • Routine check up • B12 injection
9	450	9	<ul style="list-style-type: none"> • Pneumonia • Chest infection • Trach tube change x3 • Fire in home (precaution) 	11	<ul style="list-style-type: none"> • Same as ER reasons • Anxiety-HCPs & family not yet comfortable • Family and caregiver 	0	NA

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10	270	0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
11	14	0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
12	0	0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
13	90	5	<ul style="list-style-type: none"> • Trach tube change x2 • Pneumonia • GI related x2 • Respiratory distress • Sepsis 	3	<ul style="list-style-type: none"> • Pneumonia • GI related • Sepsis 								
14	0	0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
15													
16	0	0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
17	270	0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
18	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
19*	365	0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
20	0	1	<ul style="list-style-type: none"> • Cardiac arrest 	1	<ul style="list-style-type: none"> • For palliation/death to help family cope 								
21		0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
22*		0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
23	300	3	<ul style="list-style-type: none"> • Bronchitis • Aspiration x2 	0	NA	0	NA	0	NA	0	NA	0	NA
24		0	NA	0	NA	0	NA	0	NA	0	NA	0	NA
25		0	NA	4	<ul style="list-style-type: none"> • Chest infection • Feeding tube issues • Primary caregiver hospitalized (C-section) 	0	NA	0	NA	0	NA	0	NA
26		0	NA	0	NA	0	NA	0	NA	0	NA	0	NA

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27	120	0	NA	0	NA	0	NA
28	195	5	<ul style="list-style-type: none"> • Trach change (cuff leak) x3 • GI tube reinsertion 	1	<ul style="list-style-type: none"> • Chest infection 	3	<ul style="list-style-type: none"> • Switch to new GP and medication review
29	0	0	NA	1	<ul style="list-style-type: none"> • Evaluate ventilation (planned visit): vent parameter changes 	0	NA
30	0	0	NA	0	NA	0	NA

Blank spaces=data not reported

*Patient had been living at home prior to project commencement – information pre & post project included.

ER=emergency room; GI=gastrointestinal; LOS=length of stay; NA=not applicable; hosp=hospital; HCP=healthcare professionals; SOB=shortness of breath; trach=tracheostomy.

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Appendix F: Patient & Caregiver Stories – Impact of Transitioning Home

The following descriptions were provided by patients, families and caregivers in the community. The project managers (RL and DJ) and community RTs listened and took note of these stories during their visits. These stories provide valuable insights into the lives of those living with complex respiratory issues in the community and how this project affected them.

Overall impressions

All the patients who took part in this project were grateful and happier to be home. Most felt they were healthier at home, despite the fact that some had to return to the hospital. For example access to RTs helped avoid hospitalizations for illnesses such as pneumonia. In addition, those who were able to have their trachs changed at home really appreciated it and those who did not wish they had this service. All the caregivers indicated they were happy to have the patient at home. They felt the patient was better off at home because they (the patient) were happier and healthier.

Overall when asked about RT involvement all patients and caregivers were positive and grateful for the help they received. Everyone especially appreciated being able to connect with a RT when they had questions or concerns and/or needed in home in-services and on-going support.

Individual Stories

The joys, burdens, worries and concerns of these patients are similar for all those involved this project. These stories are a chosen few.

Patient 1

She greeted me with a smile and led me downstairs to their apartment where her baby lay sleeping. His “blankey” was clutched tightly and held close to his face. As he rolled over in his sleep that “blankey” moved with him, as did his ventilator tubings. He can sit up now and can move forward. It seems he understands cause and effect at only 18 months of age – as the ventilator tubing resists his forward movement, he turns and gives a tug and then continues forward with a smile. Yes, he is in command of his tiny world. His caregivers are both overwhelmed by the 24/7 care required and the physical, emotional and social impact of that care. But at the same time they are filled with joy at being able to have their son home. This much-loved child is a part of their extended family too and will attend family gatherings such as weddings. They worry about his future but are filled with optimism and pride. From a practical point of view, the mom asks why they not have the option to hire respiratory therapists to care for him. Their child is not “sick”, he only has respiratory issues.

Patient 2

When I arrive, I am greeted by a nurse, who has been with the family for months now and oversees the patient's care. After I introduce myself, the nurse gives me a brief report on the patient's status. Like all the other patients I have interviewed, this person is optimistic. With

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every question, he considers his answers carefully. He and his spouse believe he has received the very best of care. The room is remarkably cheerful despite the ventilator, suction machine and associated supplies. Underneath his bed I see three large balloons with hand painted faces – compliments of young grandchildren. These are remnants of the large family party held in honour of his birthday last weekend. His spouse admits to being stressed but says that she is sleeping a little better now after sorting out the routine and nursing schedule (this took some duration). She smiles as she tells me that she assists the nurses with morning and evening care and the once-a-week “treat” that her husband looks forward to – a real bath in warm water. She is also grateful for the support of the Respiratory Therapists who have come to the home to check set ups and give in-service talks to the new nurses, on the ventilator and related equipment. She says she finds it reassuring knowing that she can get support from them whenever she needs.

Patient 3

I think that my most poignant visit was with the extended family that lost a young child. They were an immigrant family whose belief is that the entire family should be present when someone dies. Enabling this family to bring home their wee one gave them the comfort of knowing that they had done everything possible for this child. He was able to die surrounded by his parents, grandparents, aunts and uncles. The project enabled a dignified death.

Patient 4

It was the kids that upset me most because their parents were going to miss the joy of watching them meet milestones. I met with a Mom one day who described the joy of having her daughter at home. Unfortunately this joy was also accompanied with great struggle. After approximately half an hour, I asked if I could meet baby E. I wasn't sure what to expect, but when I entered the bedroom and saw this absolutely beautiful cherub lying on the bed, I was couldn't help but smile. I got very close to her (under the watchful eye of their very large cat) and spoke in a soft, whispering voice. I was surprised when baby E. started to track my voice and "laugh" in response to her Mom. Mom and Dad were told that baby E. probably wouldn't live much longer than 11 months. Mom told me that every day since the baby's 11 month birthday they would get up and peer into her crib, fully expecting her to have died. Baby E. was 15 months old when I met her. I can't imagine the pain of waking up every day and expecting my child to no longer be living. The family decided that they wouldn't invasively ventilate the baby, and chose to have non-invasive ventilation instead. They cherish each moment with their beautiful daughter. This family was grateful they could live in their home, surrounded by family and friends rather than "living" in a hospital. Mom did express the need for more professional help, but said that they wouldn't dream of leaving baby E. in the hospital just because "the system" didn't provide them with adequate care. How dreadful to make a family feel that they had to make this choice.

Patient 5

She is tired, isolated and fearful about her husband's future, her own and that of their children. She has taken a leave of absence from her job and will need to return to work within the next year. What will happen to her husband then? He is ventilated and his condition deteriorates as the weeks fly by. She has learned to read lips in order to understand what he is trying to say to

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her.

She sometimes wonders why in the hospital all supplies were free of charge and trained professional staff were there to care for him 24/7. At home her coverage averages 66/168 (hours per week). Her RT homecare coverage is "great". She wonders too why she can't pick and choose the services she needs and arrange her own home service from a variety of providers, instead of a select few.

She and her husband have two children, one teenage son and a daughter, not yet a teenager. Her son is "acting out" and she feels badly because she hasn't had as much time to spend with him as she would have liked to. She worries too about her daughter not getting the individual attention she needs to thrive.

Time and money are in short supply and the house she is struggling to keep- the family home -is in need of some TLC. This will have to wait as she has more pressing issues to deal with.

She feels she is being punished for caring for her husband at home and there is no fallback position for her. The stress is taking its toll on her health. Should she become seriously ill, the coverage provided by her CCAC and her other private insurer totals 66 of the 168 hours in a week and there would be no-one to fill in the other 102 hours in the week that she covers. In addition there would be no one to "manage" his daily care, ordering of supplies, arranging tracheostomy changes, conferring with physicians and healthcare providers, filling out forms and refilling prescriptions. He husband would then be institutionalized.

She doesn't like the options and is desperate for more support- physical, emotional and social.

Patient 6

The date of discharge finally came and plans fell into place perfectly. The ICU team and the community care team stood with the patient near the nursing station in the ICU. The ICU team took pictures and said their warm goodbyes and good luck wishes. The smile on the patient's face graced by tears and his arm that lifted slowly in a wave goodbye brought tears to all of our eyes. (His complex neuromuscular disease made moving his arm very difficult). My RT colleague and I had the absolute privilege of rolling the patient out of ICU and down to the patient transport van. We were taking him home! With every roll of the wheels of his chair and every breath that was delivered by the ventilator, the hope in the patient's eyes remained strong. As we rolled across the threshold of the door of his home, the smile on his face made it all worthwhile. He was home at last! What a genuine privilege to be part of the difference made for this patient. He has remained at home without incident since discharge. His smiles are frequent; his pleasure in being home palpable. We do what we do because there is no place like home!

Patient 7

In this story, the patient was forced to quit his job, leaving his family with one income. His spouse acts as caregiver and continues to work (flexible hours) – her insurance covers 24/7

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nursing care. Although this family is covered financially, the caregiver sleeps an average of 3 hours per night and helps with both morning and evening care (requires 2 people). In addition she is often the sole provider ("nurse") over long weekends, holidays etc. In addition to her job and caring for her spouse, this caregiver manages the household. Her tasks include ordering supplies & medications, negotiating with ADP over coverage of required supplies, arranging staff shifts, organizing hospital and clinic visits and paying the bills. This family's out of pocket costs for supplies is approximately \$2000.00 per month (after 75% ADP coverage), their savings are depleting and they are living pay check to pay check.

Patient 8

Similar to patient 1, this patient was forced to quit his job. The patient's spouse acts as caregiver and had to return to her work as an allied health care professional in order to retain coverage for her husband's nursing care. Unfortunately the coverage is not 24/7 so she arranged nursing care when she is at work and covered many shifts herself. In addition, she wakes every night to suction her husband. After a follow-up visit, the project manager found out that the caregiver's employer changed insurance carriers. The family no longer has nursing coverage and she has forced to take a leave from work to find a solution. This family already lived pay check to pay check and is at risk of losing their home.

Patient 9

This patient, a medical professional, became bed ridden and invasively ventilated within 12 months of being diagnosed. He was the sole support for his family of 6. He has no insurance to cover the loss of income, adequate staff (beyond the 44 hours covered by CCAC) and out of pocket equipment and supplies expenses. His 4 children are all University students and help physically and financially. His spouse is very stressed, emotional and worried about not being able to carry on. In addition, this family experiences problems finding reliable staff who are able to cover the 2 hours (each) in the morning and evening routines.

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Appendix G: Satisfaction – Patient – The Short Form Patient Satisfaction Questionnaire (PSQ18)

To assess patient satisfaction with the care provided in this project we supplemented information gathered from patient visits (Appendix F) by using the Short Form Patient Satisfaction Questionnaire (PSQ-18)(1). The PSQ-18 assesses seven dimensions of satisfaction with care, including general satisfaction (two items) and satisfaction with six specific aspects of care: technical quality (four items), interpersonal manner (two items), communication (two items), time spent with the doctor (two items), accessibility and convenience (four items), and financial aspects (two items). For this study, we modified item wording by changing “doctor” to “healthcare provider” and “medical” to “health” (questionnaire attached in next 2 pages). Scores on the PSQ-18 are on a 5-point Likert scale ranging from "Strongly Agree" to "Strongly Disagree". The scores were weighted from 1 to 5 depending on the question asked.(1) A higher score reflects greater satisfaction. Subscale scores for the seven satisfaction dimensions were obtained by averaging the items within each subscale.

Table 6 shows the results at 2 different time points, 6 to 8 weeks after and 12 to 18 months after patients transitioned into the community. The lowest average score early in the transition period (corresponding to the lowest level of satisfaction) was for financial aspects with a mean (SD) of 3.1 (1.3). The highest average score was for the interpersonal manner of health care providers: 4.0 (0.9). **After a year in the community there was no appreciable change in patient satisfaction** in any subscale. The lowest satisfaction score was still financial aspects at 3.0 (0.8), the highest for interpersonal manner of health care providers at 4.1 (0.3).

Table 6: Results of the PSQ18 (patient satisfaction)

Category	Scores 6-8 wks after transition Mean (SD) N=24	Scores 12-18 mo after transition Mean (SD) N=11
General satisfaction	3.3 (1.2)	3.6 (0.4)
Technical quality	3.6 (0.9)	3.6 (0.2)
Interpersonal manner	4.0 (0.9)	4.1 (0.3)
Communication	3.9 (0.9)	3.9 (0.6)
Financial aspects	3.1 (1.3)	3.0 (0.8)
Time with health care provider	3.8 (1.0)	3.8 (0.5)
Access & convenience	3.4 (0.8)	3.7 (0.3)

Abbreviations: wks=weeks; mo=months; SD=standard deviation; N=sample size

Notes: 1) missing data was scored as 3 “uncertain”. This occurred for 6 questions, initial questionnaire; for 1 question, final questionnaire. 2) At 6-8 weeks after transition 4/30 questionnaires not complete due to unknown reasons; 2/30 due to scheduling issues. At 12-18 months after transition 19/30 questionnaires not complete: unknown=5; died=4; hospital readmission=3; children/infant=3; scheduling issues=3; patient weaned=1.

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Appendix G (con't)

The Short Form Patient Satisfaction Questionnaire (PSQ18)

INSTRUCTIONS FOR PATIENT/CLIENT

- On the following pages are some things people say about healthcare. Please read each one carefully, keeping in mind the healthcare you are receiving now.
- We are interested in your feelings, good and bad, about the medical care you have received.

How strongly do you AGREE or DISAGREE with each of the following statements?

(Circle One Number on Each Line)

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1) Healthcare providers are good about explaining the reason for healthcare tests	1	2	3	4	5
2) I think my healthcare providers' offices have everything needed to provide complete healthcare	1	2	3	4	5
3) The healthcare I have been receiving is just about perfect	1	2	3	4	5
4) Sometimes healthcare providers make me wonder if their diagnosis is correct	1	2	3	4	5
5) I feel confident that I can get the healthcare I need without being set back financially	1	2	3	4	5
6) When I go for healthcare, they are careful to check everything when treating and examining me	1	2	3	4	5
7) I have to pay for more of my healthcare than I can afford	1	2	3	4	5
8) I have easy access to the healthcare specialists I need	1	2	3	4	5
9) Where I get healthcare, people have to wait too long for emergency treatment	1	2	3	4	5
10) Healthcare providers act too businesslike and impersonal toward me	1	2	3	4	5

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11) My healthcare providers treat me in a very friendly and courteous manner	1	2	3	4	5
	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
12) Those who provide my healthcare sometimes hurry too much when they treat me	1	2	3	4	5
13) Healthcare providers sometimes ignore what I tell them	1	2	3	4	5
14) I have some doubts about the ability of the healthcare providers who treat me	1	2	3	4	5
15) Healthcare providers usually spend plenty of time with me	1	2	3	4	5
16) I find it hard to get an appointment for healthcare right away	1	2	3	4	5
17) I am dissatisfied with some things about the healthcare care I receive	1	2	3	4	5
18) I am able to get health care whenever I need it	1	2	3	4	5

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Appendix H: Satisfaction – Caregiver – The Zarit Burden Interview

Caregiver burden “refers to people's emotional response to the changes and demands of giving support to another”(2). It was important to measure both patient and caregiver perspectives on care because studies have shown that caregivers with higher levels of burden often have less agreement with patients’ own ratings of quality of life (2, 3). To assess caregiver satisfaction with the care provided in this project we supplemented information gathered from patient visits (Appendix F) by using The Zarit Burden Interview (ZBI) – a 22 item, 5-point Likert scale used widely to assess caregiver burden (4). Scores on the ZBI are on a 5-point Likert scale ranging from "never" to "nearly always" corresponding from a score of 0 to 4 (respectively). The total burden is calculated obtained by adding the scores for all items with a range of 0 to 88, higher scores indicating greater burden.

Table 7 shows the results at 2 different time points, 6 to 8 weeks after and 12 to 18 months after patients transitioned into the community. Early in the transition period (corresponding to the lowest level of satisfaction) total average burden was at the lower end at 23.3 (13.4) out of a maximum 88. **After a year in the community the average score (total caregiver burden) increased** to 31.3 (10.7).

Table 7: Results of the Zarit Burden Interview (caregiver satisfaction)

Score 6-8 wks after transition Mean (SD) N=21	Score 12-18 mo after transition Mean (SD) N=13
23.3 (13.4)	31.3 (10.7)

Abbreviations: wks=weeks; mo=months; SD=standard deviation; N=sample size

Notes: 1) missing data was scored as 0 “Never”. This occurred for 1 question, initial questionnaire; for 3 questions, final questionnaire. 2) At 6-8 weeks after transition 9/30 questionnaires not complete: unknown reason=5; patient did not have a caregiver=2; scheduling issues=2. At 12-18 months after transition 17/30 questionnaires not complete: unknown=5; patient died=3; patient readmitted to hospital=3; patient had no caregiver=2; scheduling issues=3; patient weaned=1.

See next 2 pages for the questionnaire

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**Appendix H (con't)
The Zarit Burden Interview**

INSTRUCTIONS TO CAREGIVER

1. The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers

	Never	Rarely	Sometimes	Quite frequently	Nearly always
1) Do you feel that your relative/child/client asks for more help than he/she needs?	0	1	2	3	4
2) Do you feel that because of the time you spend with your relative/child/client, that you don't have enough time for yourself?	0	1	2	3	4
3) Do you feel stressed between caring for your relative/child/client and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4) Do you feel embarrassed over your relative/child/client behaviour?	0	1	2	3	4
5) Do you feel angry when you are around your relative/child/client?	0	1	2	3	4
6) Do you feel that your relative/child/client currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7) Are you afraid what the future holds for your relative/child/client?	0	1	2	3	4
8) Do you feel your relative/child/client is dependent on you?	0	1	2	3	4
9) Do you feel strained when you are around your relative/child/client?	0	1	2	3	4
10) Do you feel your health has suffered because of your involvement with your relative/child/client?	0	1	2	3	4

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11) Do you feel that you don't have as much privacy as you would like because of your relative/child/client?	0	1	2	3	4
12) Do you feel that your social life has suffered because you are caring for your relative/child/client?	0	1	2	3	4
13) Do you feel uncomfortable about having friends over because of your relative/child/client?	0	1	2	3	4
14) Do you feel that your relative/child/client seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15) Do you feel that you don't have enough money to take care of your relative/child/client in addition to the rest of your expenses?	0	1	2	3	4
16) Do you feel that you will be unable to take care of your relative/child/client much longer?	0	1	2	3	4
17) Do you feel you have lost control of your life since your relative/child/client's illness?	0	1	2	3	4
18) Do you wish you could leave the care of your relative/child/client to someone else?	0	1	2	3	4
19) Do you feel uncertain about what to do about your relative/child/client?	0	1	2	3	4
20) Do you feel you should be doing more for your relative/child/client?	0	1	2	3	4
21) Do you feel you could do a better job in caring for your relative/child/client?	0	1	2	3	4
22) Overall, how burdened do you feel in caring for your relative/child/client?	0	1	2	3	4

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Appendix I: Project Evaluation Survey – Patient Experiences

In addition to the stories related to the project managers during their home visits (Appendix F), patients were asked to fill in a survey about their experiences with the transition process. This survey was left with the patient (along with a self-addressed envelope) after the project manager's last visit (12 to 18 months after transitioning). Multiple choice answers were "Yes" and "No" with a free text option to "provide details".

17 out of 26 people mailed the surveys back (response rate: 65%). **In general** respondents were positive about the transition from hospital to home. They were also positive about the care provided by the healthcare professionals. Most also felt happier and healthier in the home compared to the hospital. All respondents needed to contact the project community RTs (ProResp) with the majority having a positive experience. Almost half of respondents required re-hospitalization during the first month following discharge for acute illnesses (infection, pneumonia) or non-acute issues e.g. trach tube change, G-tube falling out.

Note: some caregivers completed the survey and answered according to their experience rather than the person they were caring for. It is unknown how many surveys this was since no personal details were included.

Table 8 on next page presents the results: sample size (%).

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Table 8: Results from the Project Evaluation Survey – Patients

Yes	No	Not answered	Details
<i>Did you feel safe in being discharged from the hospital to your home?</i>			
15 (88.2)	2 (11.8)		No, felt scared
<i>Did you feel prepared to be discharged?</i>			
17 (100.0)			
<i>Did you feel that the care provided by the professionals (e.g. RT, RN, RPN, PSW) met your needs?</i>			
16 (94.1)	1 (5.9)		
<i>Did you feel that your relatives and friends were provided with adequate teaching prior to your discharge home?</i>			
13 (76.4)	1 (5.9)	3 (17.6)	No, training not offered other than spouse
<i>Was all of the necessary equipment delivered to your home prior to your arrival?</i>			
14 (82.3)	2 (11.8)	1 (5.9)	
<i>Have you had the need to contact the home care company (e.g. ProResp) since your discharge?</i>			
17 (100.0)			
<i>If you have had the opportunity to contact the home care company, was your call answered promptly?</i>			
16 (94.1)	1 (5.9)		
<i>Was the service that you received from the home care company professional?</i>			
16 (94.1)	1 (5.9)		
<i>Was there any time when you wished that you were back in the hospital, instead of being at home?</i>			
3 (17.6)	14 (82.3)		Yes, felt frustrated with trach/vent and felt would have breathed better in hospital
<i>Were all of your needs met at home?</i>			
14 (82.3)	3 (17.6)		No, need 24/7 support
<i>Did you have to return to the hospital for any reason during the first month following your discharge home?</i>			
8 (47.1)	9 (52.9)		Yes: infection; pneumonia; trach change; G tube change
<i>Did you feel discouraged or frustrated during the first month following your discharge home?</i>			
4 (23.5)	13 (76.4)		Yes, lack of support Yes, physically when on right side
<i>Did you feel comfortable enough with the professional staff (e.g. RT, RN, RPN, PSW) to let them know how you felt?</i>			
14 (82.3)	3 (17.6)		
<i>Do you feel as rested at home as you did in the hospital?</i>			
14 (82.3)	2 (11.8)	1 (5.9)	
<i>Did you feel as healthy at home as you did in the hospital?</i>			
13 (76.4)	3 (17.6)	1 (5.9)	No, better food at hospital
<i>Do you worry about your family or friends having to care for you at home?</i>			
7 (41.1)	8 (47.1)	2 (11.8)	Yes, lack of family support
<i>Are you happier at home than in the hospital?</i>			
15 (88.2)	1 (5.9)	1 (5.9)	
<i>Were the professionals entering your home respectful of your needs and your environment?</i>			
16 (94.1)	1 (5.9)		
<i>Is there anything more that the professionals could have done to make your transition from the hospital to home easier?</i>			
3 (17.6)	14 (82.3)		

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Appendix J: Project Evaluation Survey – Project Awareness and Participation amongst RTs

To determine project awareness and if respiratory therapists from acute care hospitals were participating in the project, a survey was created and posted on the CRTO web site. This survey was distributed (via a link to the web site) to active and inactive CRTO members (a total of 2718) by email newsletter, March 1st, 2010. The questions and results (in red: sample size (%)) are presented below. A total of 42 (response rate=1.5%) people answered the survey but the number of people who answered each question varied (number are indicated).

In general for those who answered the survey, most were aware of the project but the majority did not refer patients. Of those who did refer patients, most found the referral process easy. Respondents identified several suggestions and barriers. The following are the specific results: sample size (%).

- A. Where you aware of the HFO project designed to support the movement of individuals on LTV from acute care to their own homes? N=42
Yes 29 (69.0) No 13 (31.0)
- B. Have you referred patients to the program? N=42
Yes 5 (11.9) No 37 (88.1)
- C. If yes (to question 2), how many patients have you referred? N=6
One 4 (67.7) two 0 (0.0) three 1 (16.7) four 1 (16.7) five 0 (0.0) six 0 (0.0)
- D. If yes (to question 2), how would you describe the referral process? N=7
1. Easy 5 (71.4)
 2. Complicated 0 (0.0)
 3. Slow 0 (0.0)
 4. Other 2 (28.6)
- E. If you were aware of the project but have not referred patients, please tell us why not. Please identify the barriers you encounter. N=23
1. No suitable patients 9 (39.1)
 2. Patient & Family unable to assume responsibility 2 (8.7)
 3. Lack of physician support 1 (4.3)
 4. Lack of management support 0 (0.0)
 5. Lack of community support 4 (17.4)
 6. Inadequate support in the home 2 (8.7)
 7. Financial concerns 0 (0.0)
 8. Inadequate housing 0 (0.0)
 9. Other – please elaborate (free text): 5 (21.7)
- F. What improvements do you recommend for the program (open ended):
- How are you making health care providers aware this program exists? I was under the impression it was still a pilot.
 - Have government take over where the project will leave off
 - Need respiratory services in all LHINs

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- Perhaps better awareness and advertising of the HFO project to not only RRTs but Interprofessional teams such as critical care physicians, managers, Social Workers, RNs. In addition, teaching tools and checklists available to the staff at the acute care hospital to assist in family and patient training.
 - Increased awareness of the program? Not sure if my professional practice lead is aware of it. I work in acute care, but we have sent at least one patient home on a ventilator in the last 2 years. I will research this project further...sounds like a fantastic initiative!
 - Broader communication.
 - I have not accessed it to know what improvements are needed. I know in preparation for sending a patient home recently was a lot of work even after accessing West Park's education binder, coordination with the home care company and home support workers. The major burden of the education fell on the respiratory department who had little previous experience.
 - I believe the program was not available in the Champlain area. Please implement project ASAP
 - Need additional education in the hospitals and additional support hours in the home.
 - Needs more publicity!
 - Additional information for hospital social work manager, ICU manager/director, intensivist, and hospital administrator responsible for length of stay
 - local CCAC failed to accept any involvement for claim of no funds - unsure how funding was to be applied
 - The greatest concern is lack of funding to CCACs to assist with these patients in the community. While our CCAC recognizes that they can use funds for RT support, they claim that there are not enough funds to accommodate. While the government continues to recognize LTV and trach patients in the community, it still has not resolved the issues regarding lack of support.
 - Our experience in more rural areas with smaller hospitals (Chatham-Kent) is that the availability of information and such services required is harder to access. We do not have the physician support either required for such patients. West Park was very good with giving us information but we really felt on our own. We do not have the resources found in larger cities like Toronto and surrounding area and London. If more co-ordination/information could come from a well known central location, like the Ventilator Equipment Pool for smaller rural areas. The larger cities, e.g. Toronto, are far more ahead than us when it comes to this type of co-ordination of services and supports. Even trying to accommodate a chronic vent in a more rural hospital is challenging with what we have available.
 - Educating RT population on available resources.....PR++
 - Provide more information for patients
- G. General Comments (open ended):
- I'm very hopeful that this valuable support can be continued.
 - Great idea! love to know more
 - My hospital is typically involved with patients who are eligible for services provided by Toronto East General and West Park.
 - Did this committee have any chronic ventilator patients outside of the Toronto and surrounding area?

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Appendix K: Project Evaluation Survey – Project Tools Following The 2010 Ontario Lung Association Better Breathing Conference Talk

After providing a presentation at the 2010 Ontario Lung Association’s Better Breathing Conference, the audience was asked to fill out a survey regarding the tools developed during this project. The audience was provided a general description of the tools and draft hard copies were distributed (for the session only).

In general the majority of respondents were RTs (83%) and strongly agreed (50 to 67%) that the tools will improve the efficiency and process of transitioning patients with complex respiratory needs from acute care into the community.

The survey asked “How strongly do you AGREE or DISAGREE with each of the following statements?”

1. The availability of these new LTV tools will encourage the transitioning of more LTV patients from hospital setting to home or community.
2. These tools simplify the transitioning process.
3. These tools will expedite the transitioning process.
4. Patients and caregivers will appreciate having user friendly resources available.
5. These tools will improve consistency in the transitioning process.
6. These tools will improve consistency in education for both patients and caregivers.
7. The potential for involvement in the transitioning process will improve job satisfaction of RTs. (only RTs answered this question)

Twelve out of approximately 20 people (exact number not known) answered the survey; 10 were RTs. Table 9 presents the results: sample size (%).

Table 9: Results from the Project Evaluation Survey – project tools

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1	7 (58.3)	3 (25.0)	0 (0.0)	1 (8.3)	1 (8.3)
2	7 (58.3)	2 (16.7)	0 (0.0)	2 (16.7)	1 (8.3)
3	7 (58.3)	2 (16.7)	0 (0.0)	2 (16.7)	1 (8.3)
4	8 (66.7)	3 (25.0)	0 (0.0)	0 (0.0)	1 (8.3)
5	7 (58.3)	2 (16.7)	0 (0.0)	1 (8.3)	1 (8.3)
6	7 (58.3)	4 (33.3)	0 (0.0)	0 (0.0)	1 (8.3)
7	5 (50.0)	1 (10.0)	3 (30.0)	0 (0.0)	1 (10.0)

Open ended comments:

- The biggest barrier being lack of caregivers, support in the community –CCAC
- Great presentation

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Appendix L: Gaps, Barriers and Solutions

The gaps and barriers and solutions regarding complex respiratory care in the community were collected from various sources. A previous LTV report also provides an overall gap analysis.(5)

- A. Patients and their caregivers were asked to relate their major concerns during the project manager's home visits. Some potential solutions are provided.
- B. The project team, especially the community RTs continually noted the gaps and barriers they experienced through the project's duration.
- C. RTs outside the project were asked to relate gaps and barriers from their own experiences via an online survey (see Appendix J). Recommendations are also provided.
- D. RTs from West Park Healthcare Centre also related very specific examples of real problems encountered in the community and the solutions.

A. Patients and Caregivers

Caregiver burnout and health issues, lack of respite

- The most often reported problem was lack of community caregiver support. Patients require 24/7 support or 168 hours per week for round the clock coverage.
- CCAC provides 14 hours of PSW weekly— usually 1 hour in am and 1 hour in p.m.
- In some cases, more hours are provided up to a maximum of 46 per week for nursing care.
- If there is no other nursing coverage available from insurance policies, this leaves the home caregiver alone 73% of the time to cover the 108 hours.
- Only those fortunate enough to have insurance coverage or those well educated in navigating the system are receiving enhanced hours of coverage

Despite feeling happier, many caregivers felt they were being "punished" caring for their family member at home. They felt there was a double standard: all equipment and around-the-clock costs were covered in hospital but very little in the home. In addition many caregivers experienced sleep deprivation, depression and constant worry. They felt they were in real danger of burnout resulting in the long term re-hospitalization of their patient/family member. They felt they had no control over their lives and had no free time. After transitioning home, 3 of the patients were readmitted to the hospital for long-term care. Although the caregivers found this distressing they also felt it was a much needed physical and emotional break from the 24/7 vigilance.

Respite care was a serious issue and the caregivers were exhausted. In addition, the complexities of travel precluded many patients and caregivers to interact socially and with other family members e.g. weddings. Many felt isolated and wished to have periodic in-home respite care or RT travel assistance to allow them to go out for an evening or to their child's recital or even out to a family wedding.

- ✓ Potential solution: 1) This issue was brought to the CCACs: they would like to provide more coverage but unfortunately budgets do not allow; 2) This issue should be reiterated to the attention of LHINs

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Financial Burden

- In hospital, 24/7 nursing care and all equipment and supplies for the patient are financially covered
- At home, patients must pay 25% of the cost of some supplies and equipment provided by ADP. In some cases this can add up to as much as \$2,000.00 per month. Should they use more of a particular item than is approved by ADP protocol, such as suction catheters and gloves, they must pay for these out-of-pocket.
- Many patients must pay out of pocket for additional PSW or nursing support.
- Often caregivers must leave their jobs to become full time caregiver for their family member thus increasing the financial burden on the family.
- Caregiver savings diminish and many go into debt
- Many caregivers are retirees on fixed incomes

For example this was the out-of-pocket expenses for one patient. The caregiver is the patient's mother and the family lives in a basement apartment in the grandparent's home:

- Nursing for March 2010: \$1,750
 - Medication, February to April 2010: \$671.76 (after Ontario Drug Benefit and Insurance)
 - Inline infant suction Catheters, February to April 2010: \$275.00
 - Tracheostomy tubes, February to April 2010: \$515.00 (approx 1 per month)
- ✓ Potential solution: Provide a cost benefit ratio statement to hospital CEOs. Patients who are discharged home free up an acute care bed meant for a true critically ill patient e.g. in the Emergency Room.

Staffing Turnover and Type

- Many caregivers did not understand why CCAC organized nursing care when a) there is a shortage of nurses; b) other qualified staff at less cost could be substituted.
- Many patients and caregivers found the high staff turnover problematic because of the time and money required to train staff. When patients and caregivers have the same and routine care, their quality of life is much better.

(see Table 4 for details on caregiver changes for each patient)

- ✓ Potential solution: allow caregivers and patients the option to choose the type of service they need for their patient/family member. This would help save costs and optimize the expertise of the healthcare providers. For example one caregiver was provided a registered nurse costing \$43.20 per hour; a registered practical nurse would cost \$19.00 per hour. Two other caregivers felt RN care was unnecessary because their child was not acutely ill; an RT would have met the needs of the child. Related to this issue is the reliability of care.

Equipment Cleaning in the Home

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- The caregivers are responsible for ventilator circuit changes and the cleaning of these circuits. This is often done in the kitchen sink. This is time consuming for the already overburdened caregiver. This not optimal infection control
- ✓ Potential solution: Advocate that disposable circuits be provided free of cost to all home ventilated patients.

At-home Tracheostomy changes

Children with complex respiratory needs had their trachs changed at home by their caregivers (usually parents). Those who did not have this service did not understand why it was not made available.

Psychosocial Impact

Families are negatively affected as they struggle to provide care

B. Project team Community RTs

Lack of ongoing care providers in the home outside of the Community RT

- Patient was unable to be discharged with support that CCAC offered, but was able to be discharged with RT support from this project
- CCAC nursing visits
 - Example (twice): One ½ hour visit per week to start, decreased to monthly then discontinued
 - Example: occasional wound care appointments, no regular nursing
- CCAC PT – limited visits several weeks after discharge then discontinued
- CCAC PSW – 3 visits per week initially then discontinued

Temporary hospital admissions

One RT noted there was a large amount of interest from the hospital to be able to initiate non-invasive ventilation for patients without admitting them for 2-3 nights.

C. Non-Project RTs (via online survey – Appendix J)

For those RTs who answered the survey and had experience with transitioning patients on LTV, the following barriers were noted:

Close ended/multiple choice answers – barriers

- Patient and family were unable to assume responsibility (2/23 or 8.7%)
- A lack of physician support (1/23 or 4.3%)
- A lack of community support (4/23 or 17.4%)

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- Inadequate support in the home (2/23 or 8.7%)
- Other (no specific barriers noted) (5 or 21.7%)

Open ended answers – barriers

- Lack of knowledge and experience
 - “In preparation for sending a patient home recently was a lot of work even after accessing West Park's education binder, coordination with the home care company and home support workers. The major burden of the education fell on the respiratory department who had little previous experience”.
- Lack of accessibility to expertise
 - “Our experience in more rural areas with smaller hospitals (Chatham-Kent) is that the availability of information and such services required is harder to access. We do not have the physician support either required for such patients. West Park was very good with giving us information but we really felt on our own. We do not have the resources found in larger cities like Toronto and surrounding area and London. If more co-ordination/information could come from a well known central location, like the Ventilator Equipment Pool for smaller rural areas. The larger cities, e.g. Toronto, are far more ahead than us when it comes to this type of co-ordination of services and supports. Even trying to accommodate a chronic vent in a more rural hospital is challenging with what we have available”.
- Lack of or no CCAC funding
 - “Local CCAC failed to accept any involvement for claim of no funds - unsure how funding was to be applied”
 - “The greatest concern is lack of funding to CCACs to assist with these patients in the community. While our CCAC recognizes that they can use funds for RT support, they claim that there are not enough funds to accommodate. While the government continues to recognize LTV and trach patients in the community, it still has not resolved the issues regarding lack of support”.

Open ended answers – potential solutions

- Government mandate
 - “Have government take over where the project will leave off”
 - “Respiratory services in all LHINs”
- Education for RTs and patients
 - “Have teaching tools and checklists available to the staff at the acute care hospital to assist in family and patient training”
 - “Need additional education in the hospitals and additional support hours in the home”.
 - “Educating RT population on available resources.....PR++”
 - “Provide more information for patients”
- Communication
 - “Broader communication”.

D. West Park Healthcare Centre RTs (Interview)

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Problems with ventilator

- Caregivers had trouble setting the sensitivity and were unsure if it was set appropriately. Family member & caregiver were in conflict over correct “setting”.
- ✓ Solution: Family & caregivers needed educational support – could not be easily explained over telephone.

Incorrect ventilator settings

- Ventilator was auto-cycling continuously for unknown period of time
- ✓ Solution: Required hospital admission for a few days to allow CO₂ to rise. Follow-up visit to ensure settings were adhered to

Trouble-shooting regarding ventilator battery not holding charge

- External battery would only power spare ventilator for approx. 1 hour. This was 2nd battery & cable given to the patient from VEP. Patient was told to purchase another since he already had “used up 2 batteries”
- ✓ Solution: Able to loan hospital equipment (charger) in order to identify that the charger was the problem. (Biomed examined the patient’s charger). Liaised with VEP to arrange replacement charger for patient.

Assistance with identifying old/damaged equipment

- e.g. Bi-level mask, replacement filters
- ✓ Solution: Informing patient re: eligibility for ADP funding for new equipment & supplies

Non RT issues

- Wheelchair
 - Modifications to accommodate ventilator
 - Changes to seating that was worn or no longer meeting patients needs
- Assistance with recommending appropriate commode
- ✓ Solution: utilize the healthcare providers who are experienced in LTV rather than a general CCAC healthcare provider like an OT. For example: a Seating Clinic for wheelchair modifications or an OT who specialized in LTV.

Assistance with recommending appropriate medical/community services

- ✓ Solution: 1) Appropriate communication: findings upon chest assessment led to advice to contact physician; report from one family regarding swallowing issues led to advice to contact family MD and/or CCAC for SLP referral 2) Accessing CCAC for additional PSW support

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Appendix M: The At-Risk Patient Population – The RT Role

Provided by Carole LeBlanc from The Ottawa Hospital Rehabilitation Centre (TOHRC)
This RT role is patient centred and entirely outpatient

Preventative RT interventions

- Performs neuromuscular diagnostic tests to identify patients at risk and monitor patient progress during return to clinic (neuro pulmonary function tests (PFTs) including end tidal CO₂, overnight oximetry)
- Provides education to patients, family members and other members of the care team (lung volume recruitment with a modified resuscitation bag, CoughAssist, choices of ventilation education session, bilevel and mouthpiece ventilation with a volume ventilator)
- Commences clinical ventilation trials and initiates breathing support set up (bilevel initiation and titration followed by overnight oximetry - no polysomnography (PSG) however could perform home level III sleep studies if required)
- Establishes patient equipment needs and links to durable equipment providers (circuits, interfaces filters)
- Ensures appropriate follow up (bilevel performance download and parameter changes) including home visits if required
- Initiate mouth piece ventilation (outpatient basis), educate and assist with mounting the ventilation to the wheelchair (home visit may be required to reinforce education and home set up)
- Evaluates and incorporates distance monitoring technologies
- Participates in the compilation of clinical indicators for research purposes
- Presents ventilation clinical outcomes to the scientific community.

Education and/or health care provider education

- Perform and interpret a neuromuscular pulmonary function test
- When to initiate or discontinue lung volume recruitment
- When to initiate or discontinue the CoughAssist
- When to initiate or discontinue manual assisted cough manoeuvre
- How to initiate and follow up bilevel ventilation without a PSG
- Bilevel performance downloads and interpretation
- Overnight oximetry interpretation
- How to initiate and mount mouthpiece volume ventilation
- Education to health care providers (RN, RPN, Physio, PSW)
 - Lung volume recruitment
 - CoughAssist
 - Assisted cough manoeuvre
 - Care of bilevel devices and interface application
 - Care of the mouthpiece volume ventilator

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Appendix N: The At-Risk Patient Population – Case Example, 2 Treatment Options & Costs

Provided by Carole LeBlanc from The Ottawa Hospital Rehabilitation Centre (TOHRC)

Note: cost rates used were provided by TOHRC's finance department in 2008.

Patient

- Name: Peter Jones (Alias)
- Age: 22 years old
- Diagnosis: Duchene Muscular Dystrophy
- Presenting Symptom: Increasing Shortness of Breath, Weight Loss
- Other Symptoms: Expectorates a fair amount of viscous white sputum throughout the night and experiences frequent spontaneous awakening with morning headaches
- Test Results: pulmonary function tests (PFTs) have since declined and the high carbon dioxide levels confirm further decline with impending respiratory failure even with nocturnal breathing support and previous sleep studies. Note: this is when most centres would advocate tracheostomy, elective or emergency.
- Other: nutritional supplements required to maintain body weight of 42kg; wheelchair assisted but socially active; attends school full time and lives at home with parents

Invasive ventilation: Treatment Plan A

Step 1: Tracheotomy

The patient undergoing invasive ventilation will be transferred to an inpatient unit and undergo a tracheostomy procedure in the operating room. They would be transferred to the ICU for ventilator management additional testing and care. After weeks of recovery, confirmation of ventilation requirements and the availability of a rehab bed they would be transferred to a rehabilitation unit for a 30 day inpatient stay.

Step 2: Rehab Recovery

The patient would then be transferred to a rehab unit where they would continue post surgical recovery and receive education about care of the tracheostomy and about living life after having a tracheostomy. On average patients would stay in the inpatient rehab facility for 60 days.

Step 3: Complex Continuing Care

After receiving a tracheostomy, and awaiting an available bed, patients would be transferred to a chronic care facility where they would normally live out the rest of their lives. Nursing care in these facilities would assist the patient in living as normal a life as possible with the invasive ventilation. Many patients with a tracheostomy are unable to return home due to the complexity of care and the physical and financial resources required.

The total nursing costs for Treatment Plan A, an elective tracheotomy procedure, over one year would be as follows (cost of operation, diagnostic tests, follow up visits and acute exacerbation (requiring ER visits) are not included in this cost estimation):

- 1 month in ICU and/or Acute care Facilities at \$1688/day= \$88,114
- 2 months in the Inpatient Rehab Facility at \$424/day= \$25,440

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- 9 months in Complex Continuing Care Facility at \$424/day= \$116,388
TOTAL COSTS FOR TREATMENT PLAN A = \$229,942

Non invasive ventilation: Treatment Plan B

The alternative treatment option for this patient was to receive the Non Invasive Ventilation (NIV) program at TOHRC. Here the patient underwent the following treatment:

- Referral to TOHRC Respiriologist to investigate candidacy for non invasive ventilation
- Outpatient medical/clinical assessment (5 hrs including education)
- Supported initiation of non invasive 24 hour ventilation including a chair-mounted mouthpiece ventilator and airway clearance techniques
- Return to TOHRC two months later to receive his day time ventilator and final education (4 hr session)
- A telephone follow up call was done after each visit

The annual operational costs of the NIV Program are anticipated to be \$4,034 per patient. It is important to note that on average, patients who are on non-invasive ventilation in the community receive 15 hours of nursing support per week at home. Thus the total costs of option B is as follows:

- NIV education, equipment, diagnostic tests and follow up = \$4,034
- 15 hours of nursing care per week at \$35.80 per hour = \$537 times 52 wks = \$27,924
TOTAL COSTS FOR TREATMENT PLAN B = \$ 31,958

Final Outcome

As demonstrated above, the 22 year old patient outlined in this example would have had two very different treatments at two different costs. In treatment A, the patient would have undergone a tracheotomy for invasive ventilation, long term hospital stay and expected to remain in complex continuing care for the remainder of their life. This treatment option costs approximately \$230,000 per year.

To validate this number, case costing data was used to find the total care costs for a patient who had a Neuromuscular disorder with bulbar dysfunction. The patient was ventilated in the ICU from the onset of his disease and underwent a tracheotomy at an early stage. The length of stay for this particular patient was 90 days and according to case costing data, the total cost for care was \$289,404.

Alternatively, the patient who underwent treatment B would have had non invasive ventilation education, training with the equipment use, nursing care at home and follow treatments with the respiratory team at TOHRC. In this case, the patient would be able to remain in the comfort of their home, receive quality care at a cost of approximately \$31,958 per year - a difference of almost \$200,000 per patient per year. The cost differential would be considerably greater if a patient who might have benefited from an elective NIV approach presents with acute respiratory failure due to pneumonia or other complication and is intubated in the ER. Not only are all of the costs of invasive ventilation (above) incurred but the critical care admission is more prolonged due to the acute illness.

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Appendix O: Process Flow Care Map

Action	Most Responsible Person (MRP)	Date	Comments
COMMUNICATION			
1. Interdisciplinary Team created: Discharge Planner, RN, OT, PT, Lead RT, RD, Respiratory Specialist, CCAC member, SW, Community RT & others as required. Meeting planned to: a) identify MRPs b) determine suitability of patient for LTV at home and c) collaborate with community care team			
2. Notify the VEP at Kingston General Hospital 640 Cataraqui Woods Drive, Unit 6 Kingston, Ontario K7P 2Y5 Tel: 613-548-6156 or 1-800-633-8977 Fax: 613-548-6157 Email: vep@kgh.kari.net Website: www.ontvep.ca	As determined by the Interdisciplinary Team (ideally the RT – best understanding of the ventilator needs)		
3. Notify Assistive Device Program 7th Floor- 5700 Yonge Street Toronto, Ontario M2M 4K5 Tel: 416-327-8804 or 1-800-268-6021 Fax: 416-327-8192 Website: www.health.gov.on.ca/english/public/program/adp/adp_mn.html	Same person as notifies VEP		
4. Follow-up with local CCAC and Case Manager. Tel: 310-CCAC Web site: http://www.ccac-ont.ca/	As determined by the Interdisciplinary Team		
5. Contact RT Home Care Company	As determined by the Interdisciplinary Team		
6. Identify GP 7. Identify “Home Base” hospital* for ongoing medical outpatient needs and in the event of readmission.	Respiratory Specialist *Ideally hospital from which patient has been discharged		
EQUIPMENT ISSUES, INCLUDING ADP			
1. Mobility – ADP covers 75%.	OT or PT		
2. Mechanical Ventilators – VEP covers 100%	Hospital RT		
3. Respiratory supplies including airway management – ADP covers 75%	Community RT		

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4. Other medical supplies	Pertinent Expert (e.g. RT, OT, PT, RD & other as required)		
5. Application to ADP may be required e.g. enteral feeds (ADP covers 75%)	Pertinent Expert		
EDUCATION AND TRAINING			
1. Schedule education & training sessions	Collaborative effort with the hospital "champion" and the community RT team		
2. Utilize standardized training packages	Collaborative effort with the hospital "champion" and the community RT team		
3. Provide hands on training <u>with equipment to be used in home</u>	Collaborative effort with the hospital "champion" and the community RT team		
4. Provide all checklists	Collaborative effort with the hospital "champion" and the community RT team		
5. Plan car ride and take trial ride	Team effort with community care team		
6. Emergencies Preparedness <ul style="list-style-type: none"> ✓ Provide Emergency situation planning ✓ Provide Emergency contact numbers ✓ Provide a template for Emergency Contact Numbers 	Collaborative community team, client/family and hospital interdisciplinary team		

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Appendix P: Health Care Resource Utilization – Financial Analysis

The next 9 pages contain the financial analysis completed by Brian Marshall (accountant at Professional Respiratory). It includes an overall description (pages 1, 2), 2 tables (pages 3, 4) and 5 figures (pages 5 to 9).

Table 10: Overall Cost of Care per Day Comparison – Home care versus Hospital

See page 3 of the financial analysis

Table 11: Individual Example Cost of Care per Day Comparison – Home care versus Hospital

See page 4 of financial analysis

Figure 1: Total Cost of Long Stay Invasively Ventilated Patient

See page 5 of financial analysis

Figure 2: Cost of Care per Day of Invasively Ventilated Patients

See page 6 of financial analysis

Figure 3: Cost of Care per Day of Nocturnally Ventilated Patients

See page 7 of financial analysis

Figure 4: Cost of Care per Day of Non-Invasively Ventilated Patients

See page 8 of financial analysis

Figure 5: Cost of Care per Day of Complex Tracheostomy Patients

See page 9 of financial analysis

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PROJECT RESULTS – FINANCIAL ANALYSIS

Average HealthForceOntario Project Actual Results

- Represents a mix of staffing: RN, RPN, PSW, PT Visits, and Respiratory Therapists visits
- All clients had a minimum 100 hours of professional care paid for by a mix of CCAC funding, insurance funding, and self-pay
 - Some had 24/7 care
- Includes \$50 per day for supplies and medications (high average for the patients served)

Respiratory therapist support is intensive in the first 6 to 8 weeks home and decreases once all of the care team is comfortable with the respiratory aspects of caring for the patient in the home

- First week visits are 1 to 3 times daily (and occasionally for entire shifts)
- Second week visits are daily
- Third and fourth week visits are 2-3 times each week
- Fifth and six week visits are at least once a week
- Thereafter while stable, the RT visits are every 1 to 3 months
- New staff training requires increased visits until the new staff is competent in the respiratory care
 - New staff training is ongoing while the patient is home due to vacation coverage, staffing changes, etc.

Costs of homecare were modeled with 24/7 professional care with RN care representing costs for the chronic LTV patient who needs more nursing interventions and RPN care for the chronic LTV patient who needs minimal and basic nursing interventions.

Costs in the community (inclusive of travel, documentation et al) as per CCAC (Private Insurance rates are the same):

- RN visit in the community costs \$55/visit; shift nursing is \$47 (higher number of \$45-47)/hour
- PSW costs \$28/hour
- RPN \$36-38/hour for shift nursing
- Physiotherapist: \$110 per visit
- Respiratory therapist \$110/visit

Cost of an ICU Bed taken from Ontario Cost Initiative Data 2004/05 as reported in the Chronic Ventilation Task Group Report. Includes direct and indirect costs.

Cost savings with these chronic long-term ventilated patients in the home not only represents dollars saved but also an opportunity cost savings to the health care system when the ICU bed is freed up to be utilized by a patient who *needs* intensive care.

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The **24 hour invasively ventilated** patient needs 24/7 professional care and the costs of care do not drop off as dramatically over time although there is some drop in costs as RT time decreases. Whereas, the **non-invasively ventilated patients'** cost of care drop off to minimal dollars until there is a decline in clinical status that mandates increased care.

Homecare costs per day where the patient is fully supported 24/7 with paid professional care are similar to that of complex continuing care or chronic assisted ventilatory care beds.

- The reality is that private residences already exist (for the majority) providing the necessary “infrastructure” to care for these patients – all that is needed is the care support and supplies.

HealthForceOntario Home Ventilation Project Financial Results

	Home Care Cost per Day	Cost of ICU Bed		Savings Using Homecare	
		Academic Hospital Cost per Day *	Community Hospital Cost per Day *	Academic Hospital	Community Hospital
Invasively Ventilated 24/7					
Average HFO Project Actual Results (RNs, RPN's, PSW's Care Team + RT Support**)	808	3,745	2,024	(2,937)	(1,216)
24/7 Care Utilizing Registered Nurses + RT Support**	1,243	3,745	2,024	(2,502)	(781)
24/7 Care Utilizing Registered Practical Nurses + RT Support**	987	3,745	2,024	(2,758)	(1,037)
Nocturnally Invasively Ventilated					
Average HFO Project Actual Results	273	3,745	2,024	(3,472)	(1,751)
Non Invasively Ventilated					
Average HFO Project Actual Results	133	3,745	2,024	(3,612)	(1,891)
Complex Tracheostomy					
Average HFO Project Actual Results	136	3,745	2,024	(3,609)	(1,888)

* Cost of an ICU bed: Ontario Cost Initiative Data 2004/05 as reported in the Chronic Ventilation Strategy Task Group Report. Includes Direct and Indirect Costs

** RT Support includes visits, care team training and 24/7 on call support

HealthForceOntario Home Ventilation Project Financial Results

This schedule shows savings realized for one client, as a specific example. This patient would not have gone home, if not for the project.

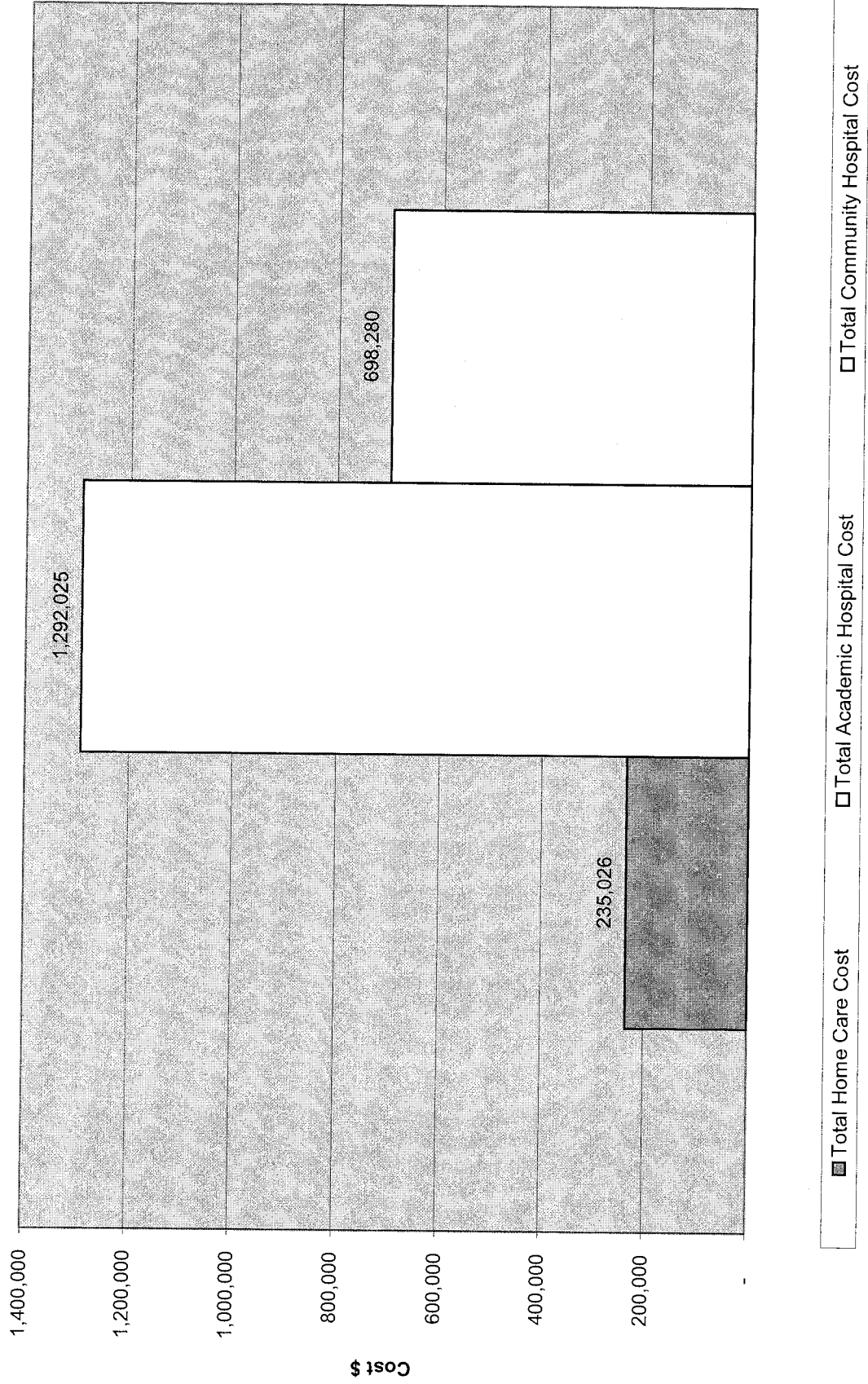
He was not a suitable candidate for other programs that had potential to get him home.

	Total Home Care Cost	Cost of ICU Bed		Savings Using Homecare	
		Total Academic Hospital Cost	Total Community Hospital Cost	Academic Hospital	Community Hospital
HFO Actual Average Cost of Care for 345 days (RN's, RPN's, PSW, PT, Supplies + RT Support**)	235,026	1,292,025	698,280	(1,056,999)	(463,254)

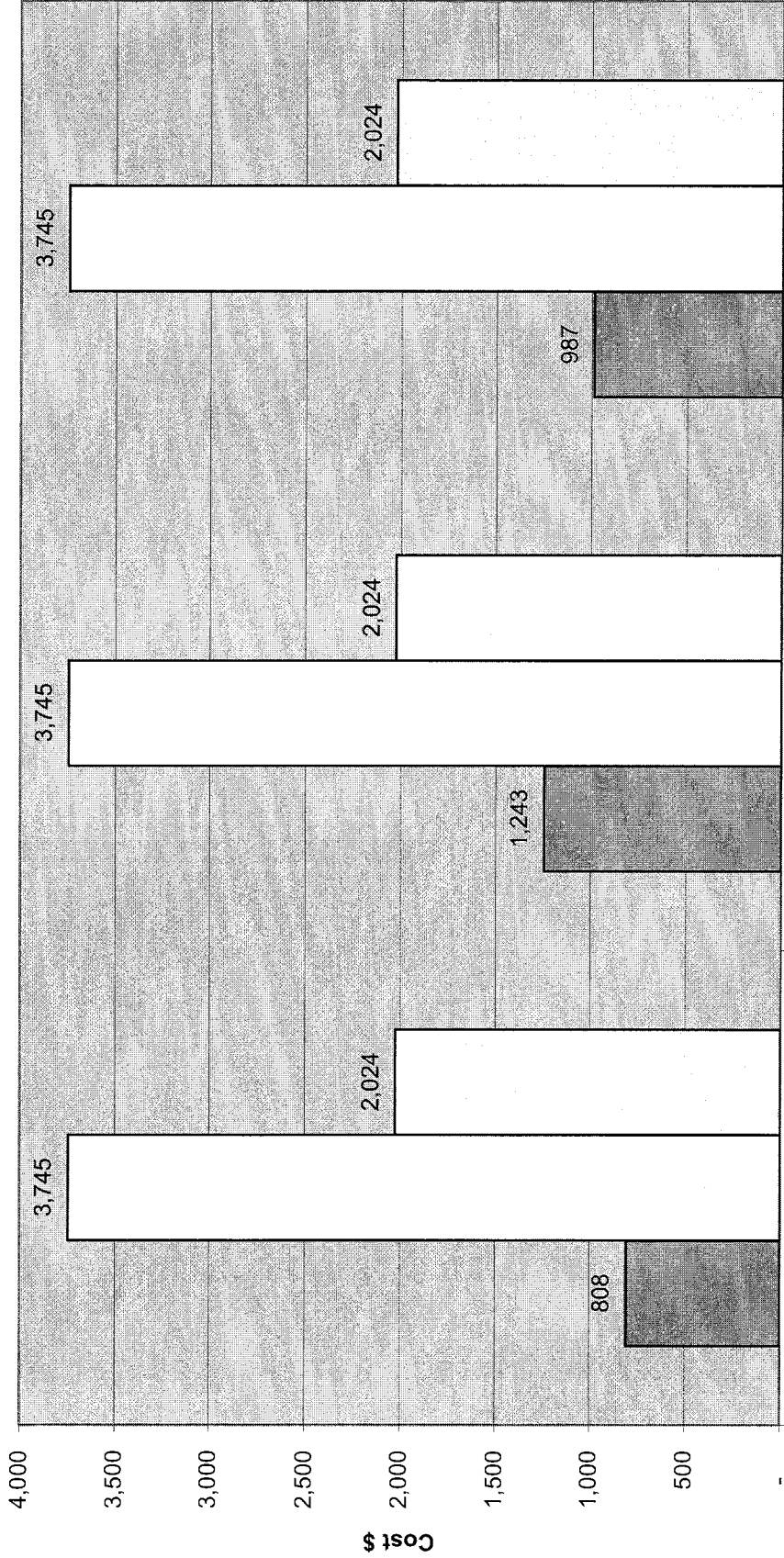
* Cost of an ICU bed: Ontario Cost Initiative Data 2004/05 as reported in the Chronic Ventilation Strategy Task Group Report. Includes Direct and Indirect Costs

** RT Support includes visits, care team training and 24/7 on call support

Total Cost of Long Stay Invasively Vented Client



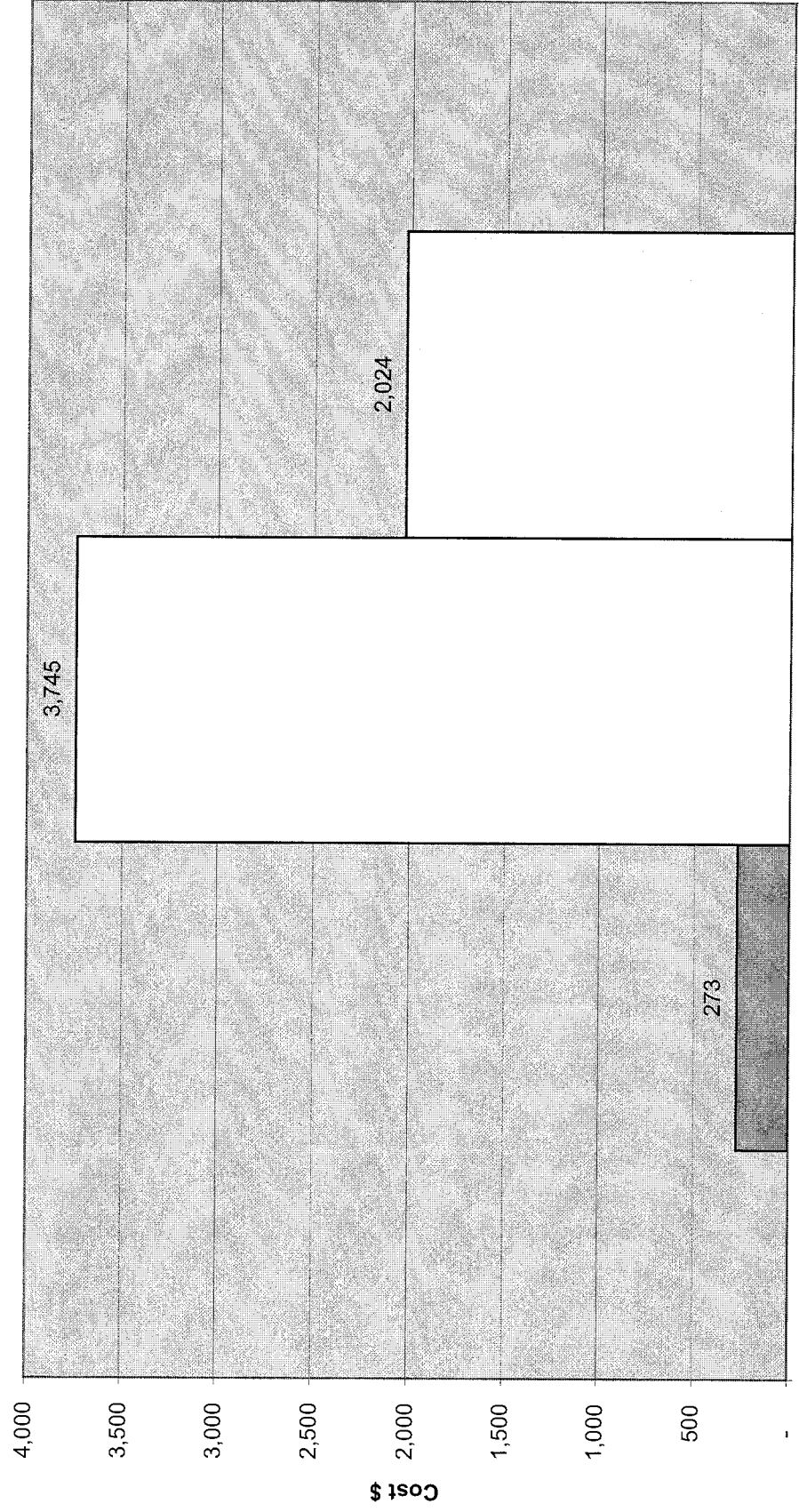
Cost of Care - Invasively Ventilated



HFO Project Actual Results (RN's, RPN's, PSW's Care Team + RT Support**) Utilizing Registered Nurses + RT Support** Utilizing Registered Practical Nurses + RT Support**

- Home Care Cost per Day
- Academic Hospital Cost per Day *
- Community Hospital Cost per Day *

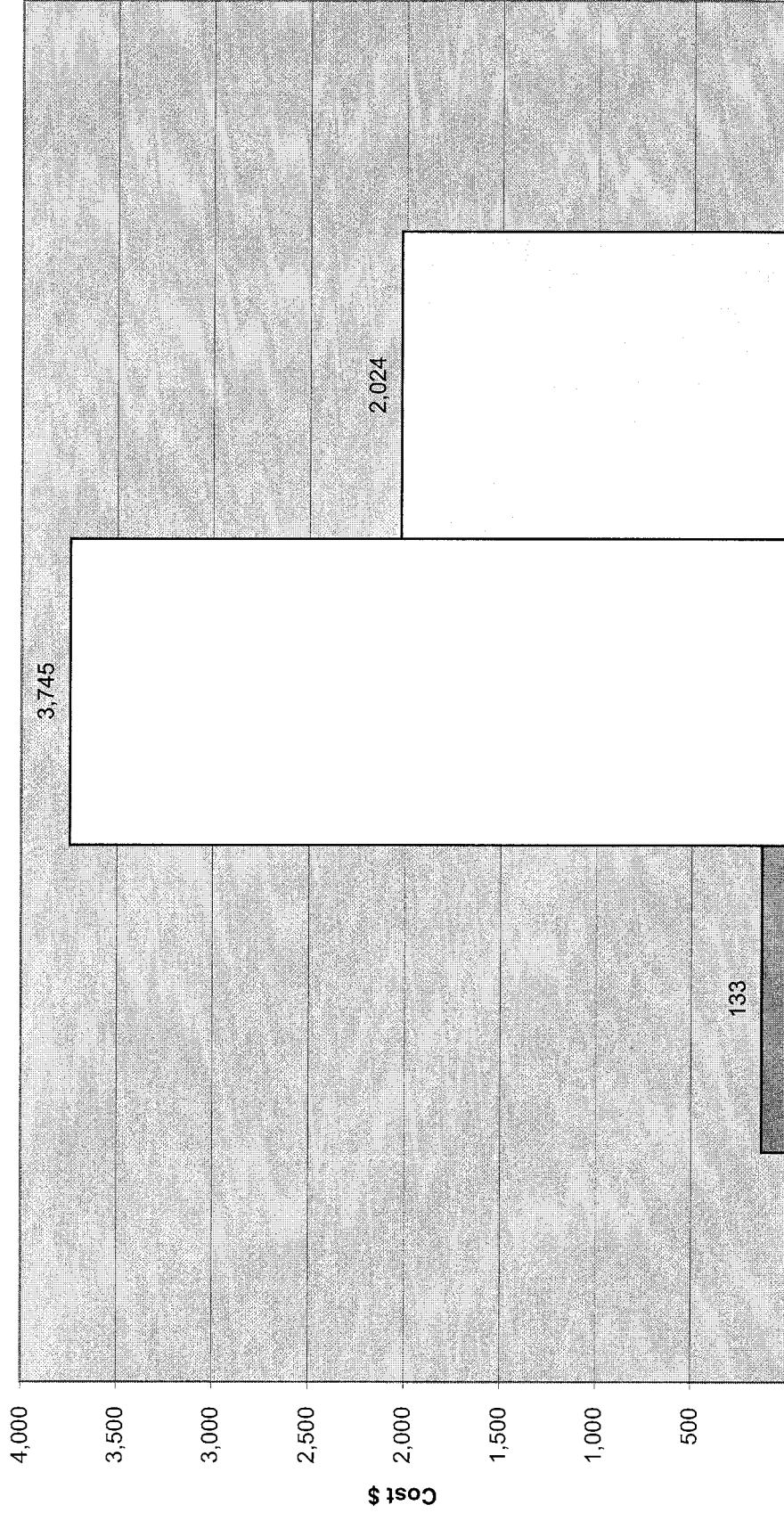
Cost of Care - Nocturnally Invasively Ventilated



HFO Project Actual Results

- Home Care Cost per Day
- Academic Hospital Cost per Day *
- Community Hospital Cost per Day *

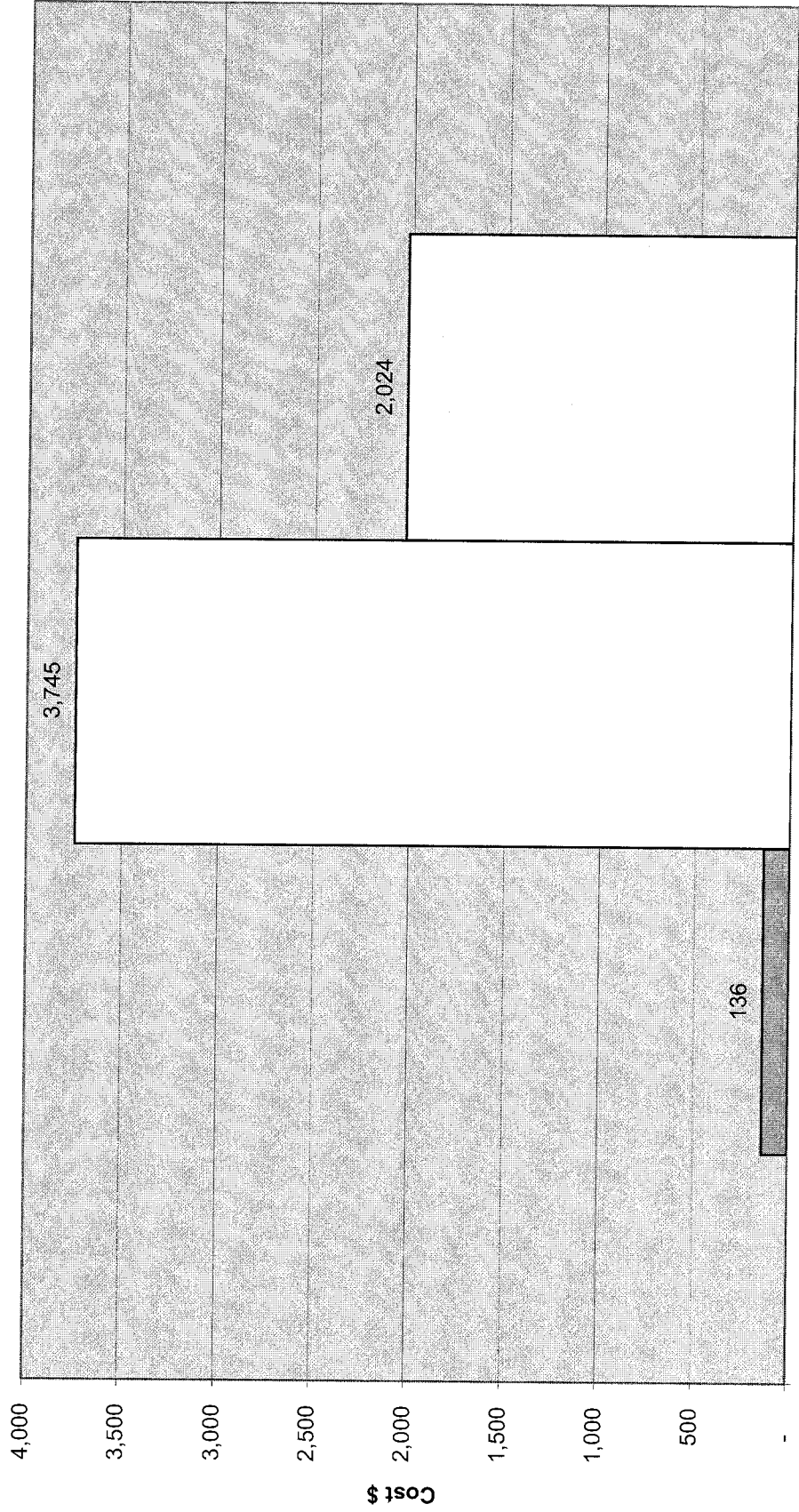
Cost of Care - Non Invasively Ventilated



HFO Project Actual Results

- Home Care Cost per Day
- Academic Hospital Cost per Day*
- Community Hospital Cost per Day*

Cost of Care - Complex Tracheostomy



HFO Project Actual Results

- Home Care Cost per Day
- Academic Hospital Cost per Day *
- Community Hospital Cost per Day *

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Appendix Q: Health Care Resource Utilization – Examples

See Table 5 for details on ER visits, hospitalizations and doctor visits for each patient.

Patient LHSC1

- RT visits
 - Regular visits and calls maintained the family's ability to keep the patient at home. Ongoing education and support likely prevented ER visits
 - One urgent visit in middle of night due to repeated high pressure alarm: Multiple suctioning and troubleshooting helped resolve the situation in the home; patient did not have to go to ER or have an outpatient appointment to resolve issue.

Patient LHSC3

- RT visits
 - In home assessments and visits allowed changes in therapy (vent changes, antibiotics) that prevented the patient from going to the hospital
- Issues resolved over the phone
 - Several calls through the night - community RTs avoided problems associated with increased secretions and with ventilator issues

Patient LHSC4

- RT visit
 - Initiated Bilevel at home for chronic ventilatory support. Able to find suitable mask, learn system with staff support and prevent any admission for trial or titration.

Patient LHSC5

- Issues resolved over the phone
 - Patient called RT regarding equipment issues

Patient LHSC6

- Issues resolved over the phone
 - Patient called RT regarding ventilator alarm issues during the night

Patient GTR1

- RT visits
 - During a visit the RT assessed the patient who appeared lethargic and hypoxic (SpO₂ 79% on room air). Patient was placed back on O₂: SpO₂ improved to 94% at rest and patient's level of awareness. Strongly recommended to the patient and father that O₂ be worn 24hrs. RT also reviewed oxygen therapy and signs of hypoxemia.

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- MD requested the RT reassess the patient in the home. There was concern she was non compliant with her O₂ prescription. The RT met with the patient and father and reviewed oxygen therapy including risks of not following her prescription.
- Issues resolved over the phone
 - Caregiver (father) phoned office with concerns about blood in patient's (daughter) trach. It was determined this was a result of suction trauma; there was no active bleeding source in and around trach. Bleeding had stopped; the patient was in no respiratory distress.

Patient GTR2

- RT visits: routine visits three times per week, consistent support and assessments
 - Helped maintain the patient clinically
 - Ensured staff training is done consistently since the team changed frequently
 - Helped catch infections in early stages
 - Decreased the anxiety of the care team
 - Allowed better understanding of the patient
- Standing orders
 - For trach changes at home and performed by RT
 - For antibiotics to treat at first sign of infection
- Hospitalizations for the above reasons were likely prevented

Patient GTR3

- Patient was able to go home 2 weeks before VEP equipment was shipped. The RT set up equipment (lend) and trained the patient and caregiver in the home.

Patient GTR6

- Issue resolved over phone
 - Spouse phoned on-call service. Patient had complaints of shortness of breath. The RT determined patient was experiencing anxiety with pain and recommended he/she be given scheduled or prn pain medications. Patient was alert and all vitals stable.
 - Spouse phoned during the day. Patient had complaints of shortness of breath. The RT found the patient to have no apparent respiratory distress, was awake and alert with an oxygen saturation of >92% and other vital signs stable. RT determined patients discomfort due to lack of bowel movements for 5 days. RT scheduled a visit – patient had large bowel movement before arrival, relieving pain and SOB
 - Spouse phoned on-call service. RT determined the patient was experiencing anxiety due to pain in his extremities. The RT recommended the pt be given prn pain medications, suctioned and repositioned. PT was alert, vital signs were stable.

Patient CHAT2

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