



## **REGIONAL PALLIATIVE CARE PROGRAM**

### **ANNUAL REPORT**

**APRIL 1, 2002 - MARCH 31, 2003**

**and**

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**Capital Health  
Community Care Services**

***Regional Palliative Care Program***  
*'Improving the Quality of Living and Dying'*

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## **I. OVERVIEW OF PROGRAM**

The Regional Palliative Care Program (RPCP) is a community-based model of care designed to increase access to exemplary palliative care services in the most appropriate setting. A focus of the program is to shift the main area of care from acute care to the home and hospice (in continuing or long term care facilities). The community-based model recognizes that the family, home care and the family physician provide the majority of palliative care. Acute and tertiary level services are available when needed, allowing persons to choose settings such as home and palliative hospice when stable. Persons and their families have access to palliative care consultants regardless of the care setting.

The components of care: home care and family physicians, community nurse and physician consultants, acute care consultants, tertiary palliative care unit, palliative hospice, and access to an oncology outpatient clinic are centrally coordinated by the regional office. The program is outcomes-based with goals set for each area of the program.

## **II. PROGRAM HISTORY**

The RPCP began as a response to the need for a population-based approach in providing palliative care in the Capital Health Region. Two palliative care programs existed, a unit at the Edmonton General Hospital and consult services at the Misericordia Hospital. In 1992, 21% (290 persons), of all persons with cancer dying in the region had access to these services. Palliative home care was also providing care in the community. Access to palliative care services, a main ingredient of a population-based program, was inconsistent and inequitable. The need for a coordinated, integrated palliative care program became apparent in 1993 since more than 78% of people with cancer were dying in acute care hospitals with an average of 20,000 person days per year.

1993: Resources were enhanced in home care and palliative hospices. Community consultation services were created.

Advisory Committee formed. The advisory committee represented stakeholders from the community, home care, continuing care, acute care, Cross Cancer Institute, Alberta Health, and family practitioners provided input into the design and operation of the program

1999: A survey of family physicians was completed. Referral access was identified as a major concern.

September 2001: The Advisory Committee was replaced with the Palliative Care Program Council to provide regional direction.

The philosophy, goals and palliative care definition for the programs were updated and the vision and mission were created. The development of the vision and mission involved consultation with staff representing all areas of the program and the Program Council. Families and palliative individuals from each setting also had opportunity for review. The completed work is consistent with the Canadian Hospice Palliative Care Model to Guide Hospice Palliative Care (March 2002).

October 2001: Access to tertiary care, community consultation and home care was centralized, as Community Care Access became the community referral link.

Palliative Hospices were opened at 4 sites in Capital Health providing timely end of life care. These sites remain at:

- Mel Miller Hospice, Edmonton General Continuing Care Centre,
- St. Joseph's Palliative Care Unit, St. Joseph's Auxiliary Hospital,
- Norwood Hospice, The Capital Care Norwood, and
- Youville Hospice, Youville Home in St. Albert.

### III. VISION, MISSION, PHILOSOPHY

The vision, mission, philosophy and goals are consistent with Capital Health, Caritas Health Group and the Alberta Cancer Board visions and missions.

#### Our Vision

Improving the quality of living and dying

#### Our Mission

Through an integrated program of compassionate and accessible palliative services, care is provided to patients and families within the Capital Health Region. Our caring tradition embraces all aspects of person. As we engage in the work of our mission, we strive to exceed the ordinary, endeavouring always to provide exemplary care.

<b>CARING</b>	being with each individual, providing care that aims to improve the quality of living and dying,
<b>EDUCATION</b>	ongoing learning for patients, families and caregivers,
<b>RESEARCH</b>	the advancement of care through research,
<b>LEADERSHIP</b>	accountability and continuance of program excellence, and
<b>OUTREACH</b>	providing clinical consultation, education and tertiary level care.

#### Our Philosophy

The Regional Palliative Care program recognizes, respects, and incorporates into their practices the following fundamental values based in part on the values and ethical principles identified by the Canadian Palliative Care Association in the document *2001 Proposed Norms of Practice for Hospice Palliative Care*:

#### We believe

- *Access is Foundational* - Palliative care services should be available to all who require care.
- *Care is Patient-Focused* – Palliative care strives to meet the physical, psychological, spiritual and social needs of patients and families. It is sensitive to personal, cultural and religious values, beliefs and practices, developmental state, and readiness to deal with the dying process.
- *People Have the Right To Choice* - Each person is an autonomous and unique individual with the right to participate in informed discussion related to care and to choose the best possible options and outcomes based on that information.
- *Dying is Part of Life* – Palliative care affirms life. Euthanasia and physician assisted suicide are not considered options. Palliative care never intentionally hastens death.
- *Quality of Life Guides Decisions* – Care choices should be guided by quality of life as defined by the patient.

- *Team Work Is Essential* – Palliative care is a network of services most effectively delivered by an interdisciplinary team who rely on shared knowledge, expertise and effective interactions.
- *Service is Coordinated* – A palliative care program should promote continuity of care across settings and coordination amongst all involved caregivers and programs/services.
- *Accountability is Demonstrated Through Outcomes*- We are accountable to ourselves, each other, to our individual sites, to the regional program and to the public we serve. Accountability is demonstrated through measurable goals.
- *Confidentiality is Central* – Patient information is treated with the utmost respect. Team members must adhere to this principle.
- *Care Setting Is Important* – Palliative care is provided in a patient and family-focused environment in the most appropriate care setting such as the home, hospice, continuing care centers, acute hospitals or on a tertiary palliative care unit. The needs and preferences of the patient and family, as well as the resources available, are taken into consideration.
- *Caregiver Well-Being Is Fundamental* – The provision of ongoing support to enhance formal and informal caregivers' well-being is integral to a successful palliative care program.
- *On-going Education is Essential* – Patient, family, caregiver and public education is important to the maintenance and enhancement of the quality of palliative care.
- *Research Leads to Advancement in Care* – The development, dissemination and integration of research are critical to palliative care.
- *Resources Influence Program Quality* – Adequate resources, responsibly managed, are imperative to maintain and advance palliative care programming.
- *Collaborative Leadership is Advantageous*- The development and maintenance of a quality palliative care program requires the active involvement of all stakeholders in the decision-making processes.

#### **IV. PROGRAM GOALS**

##### **Broad Program Goal**

*Access to exemplary palliative care provided in the most appropriate setting.*

**Specific Program Goals** - The goals of the Regional Palliative Care Program are to:

1. Ensure a coordinated, continuous plan of care that minimizes duplication of efforts and is maintained across all settings from referral of the patient to support of the bereaved family.
2. Review and follow relevant norms of practice based on CHPCA guidelines at each site of care.
3. Provide timely access to palliative care services 24 hours a day, 7 days a week, throughout the region.



4. Ensure consultation team availability in all settings to support primary caregivers.
5. Support community based care by providing proactive palliative care in the home and hospice, thereby decreasing the use of emergency and acute care services.
6. Offer tertiary level palliative services to patients with complex care needs that exceed care levels available in other settings.
7. Support the interdisciplinary nature of palliative care emphasizing that the patient and family are key members of the team.
8. Further the development of the bereavement program to ensure that the needs of bereaved family members and caregivers are addressed.
9. Recognize and support the essential role of volunteers on the palliative care team.
10. Offer effective palliative care education, based on norms of practice, to patients, caregivers, health professionals and the public.
11. Facilitate a program of ethically based research, which advances palliative care practice.
12. Develop accountability and program excellence through a collaborative regional leadership model.
13. Increase support for formal and informal caregivers.
14. Advocate for resources to maintain and further enhance a program of excellence.
15. Review and articulate the palliative care needs of non-malignant populations and of cancer patients with needs that arise as treatment options advance.

## V. REGIONAL PROGRAM STRUCTURE

The RPCP reports to Community Care Services and the Vice President Medical Services (see Figure 1). A central office, which includes the program and clinical director, data manager, grief care manager and secretarial staff, coordinates the components of the program. The community nurse and physician consultants also work out of the main office.

Components of the program include: consultation at acute care hospitals and all other regional settings e.g. continuing care and home, palliative home care, family physicians, the tertiary palliative care unit (TPCU) at the Grey Nuns Community Hospital, palliative hospices, and the Division of Palliative Care Medicine. As well, the RPCP works closely with the Cross Cancer Institute (CCI). The regional office maintains a liaison role in the area of standards, guidelines, education, research and program outcomes with all areas of the program.

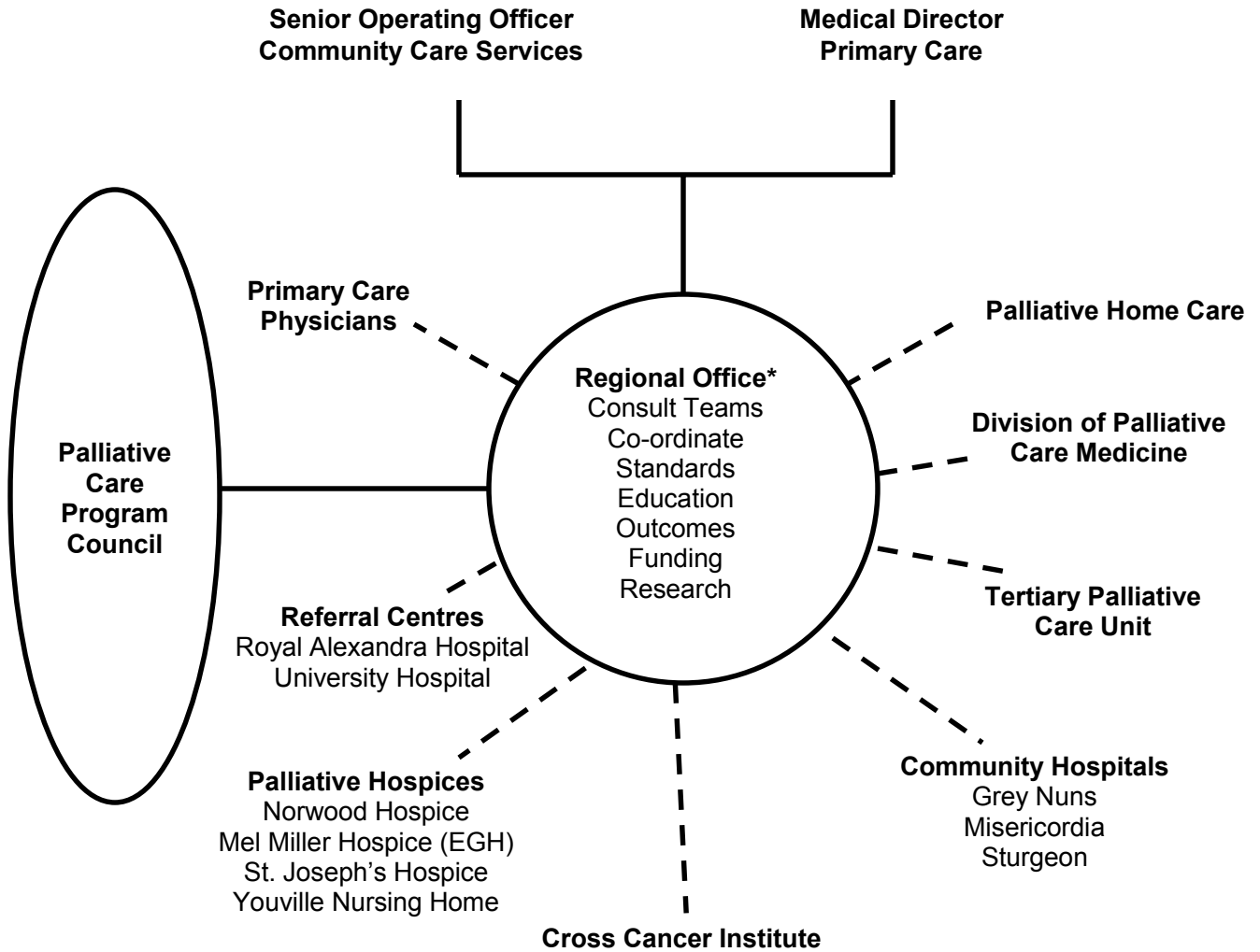
The person and their family is the central focus of the program with the family physician and palliative home care providing the majority of palliative care. Figure 2 and Figure 3 illustrate palliative care services in Capital Health. A person who requires palliative care services can be identified in any setting and referred through a single access number.

If family physicians require assistance managing symptoms of the palliative person they can refer to the Pain & Symptom Control Clinic for persons with cancer at the CCI or to the community nurse and physician consultants who will visit in any setting within the original Capital Health region (home, acute care, continuing care, hospice). If the person is unable or unwilling to remain at home, but does not require acute care services, the family physician can refer to the community consultants to assess for palliative hospice. Since April 2003, new areas to Capital Health are supported by family physicians and local home care with access to palliative hospice, TPCU and telephone consultation by community nurse and physician consultants.

For persons with acute palliative care needs or diagnostic work that cannot be completed on an outpatient basis, any hospital can admit and request a palliative care consultation for symptom assessment and management. Discharge options may include TPCU or palliative hospice. The consultants work with the discharge site to ensure that all necessary information is shared.

A request for admission to the TPCU for management of severe symptoms can originate from any care setting. A palliative care consultant will assess the person and refer to the unit if symptoms cannot be managed in the present setting. The TPCU is a resource to northern Alberta. They will work directly with the attending physician and nursing staff to assess and arrange admission for persons residing in another region.

## Regional Palliative Care Program (RPCP) Structure



\*The Regional Office maintains a liaison role, in the areas of standards, guidelines, education, research and program outcomes with all areas of the program. The program also liaises with the Alberta Cancer Board.

**Figure 1**

## REGIONAL PALLIATIVE CARE MODEL

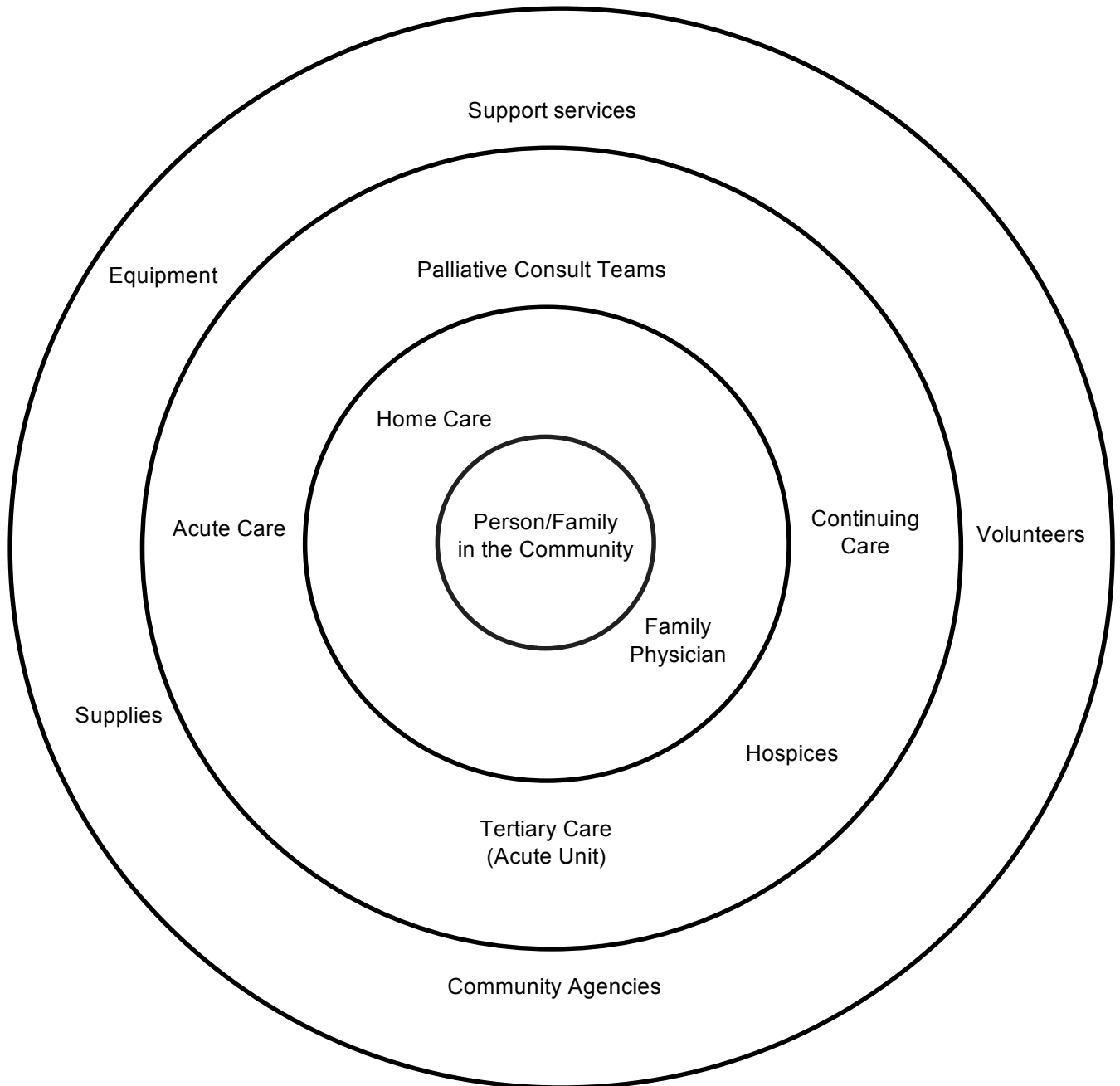
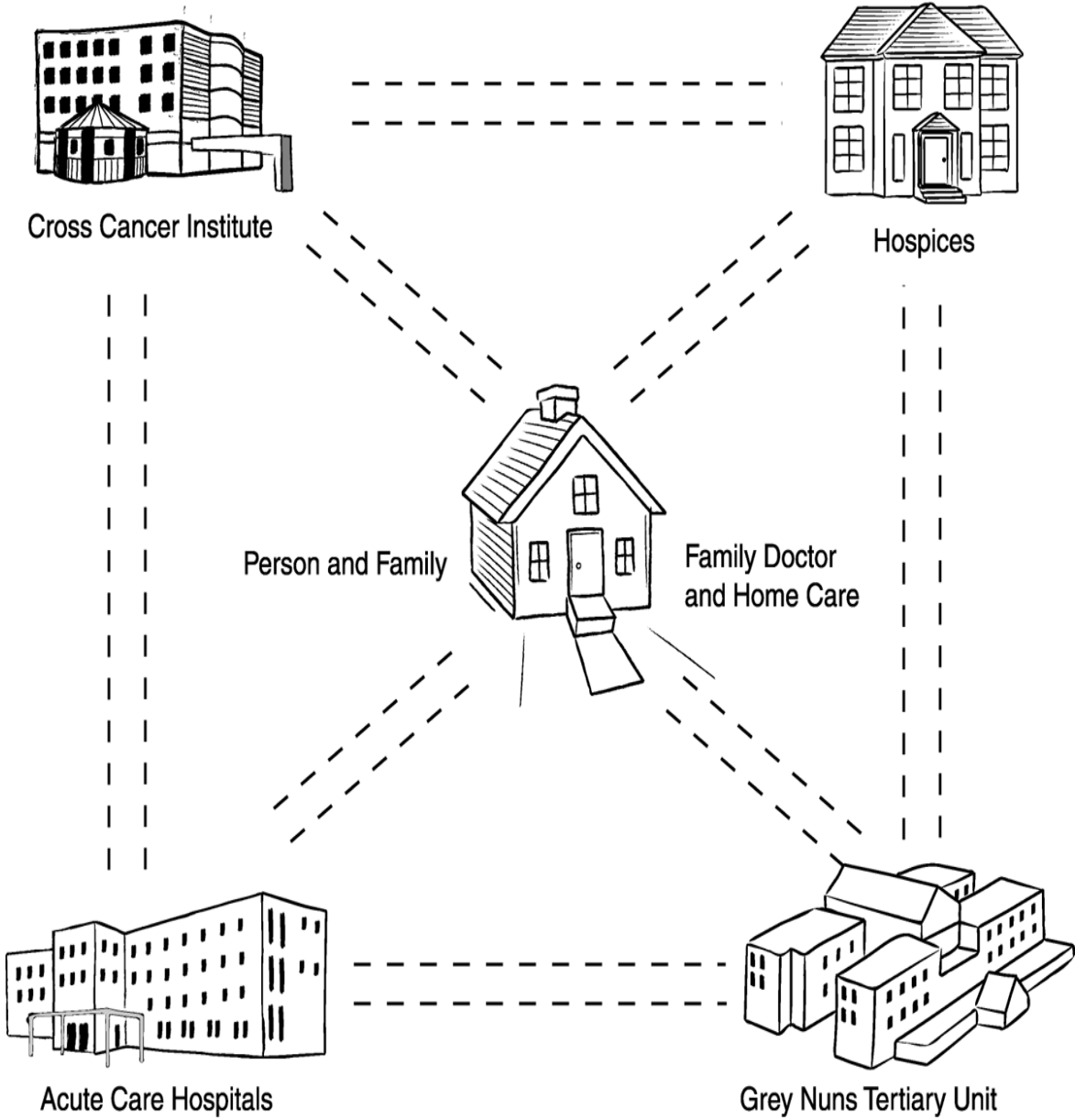


Figure 2

### Palliative Care Services in the Capital Health Region



**Figure 3**

## **VI. REGIONAL PROGRAM COMPONENTS**

### **A. Regional Palliative Program Council**

The Palliative Care Program Council was established in September 2001 to:

- advise Capital Health Executive on physicians work force requirements
- conduct regional program utilization and quality initiatives to produce improvements in service delivery
- collaborate in health technology assessment projects to evaluate drugs, procedures, equipment/technology for use in the region
- recommend to Capital Health Executive Committee standards to advance the provisions of care within the program
- provide input into regional service delivery planning and
- contribute to corporate strategy in areas of research, education and information exchange with clients and public.

The key areas of responsibility of the council are quality improvement, utilization management, health technology assessment, service delivery planning, research and education, and physician workforce planning.

### **B. Regional Palliative Care Office**

The Regional Palliative Care Program office (RPCO) is located at the Grey Nuns Community Hospital. The data manager, grief care manager and secretarial staff report directly to the Program Director. The RPCO:

- Coordinates the delivery of care in the region
- Provides four consult teams (physicians/nurses) to assist primary caregivers in providing care to palliative persons and families at home, in continuing care, community hospitals and other health care institutions in the region
- Is responsible for the development of standards, and common assessment tools.
- Identifies and advocates for funding needs
- Provides education in palliative care for professionals and the public
- Coordinates research with the Division of Palliative Care Medicine and Alberta Cancer Board Palliative Care Research Initiative
- Provides education and support for palliative care volunteers
- Identifies, coordinates and encourages development of grief care services.
- Manages the data and identifies outcomes
- Identifies and plans for the future direction of the program

#### **1. Volunteers**

Volunteers play a crucial role in the interdisciplinary approach to palliative care. All volunteers are required to take 27 hours of palliative care training. This provides them with information relating to the physical, psychological, emotional and spiritual aspects of palliative care, as well as cultural issues, family dynamics and personal wellness. Volunteers help support individuals and their families at all palliative care settings.

Volunteers are provided with support through the volunteer department in each setting where the program operates. The Grief Care Manager provides training and centralized palliative care support through regular newsletters, team meetings and an annual retreat. The Grief Care Manager regularly liaises with site volunteer managers.

## **2. Grief Care**

The term bereavement has been changed to Grief Care as this term encompasses the broader concepts pertaining to grief and bereavement. The Grief Care support program operates as a bridging system for grieving family and friends between the place where palliative care is provided prior to the person's death and community support available after the death.

Following RPCP Grief Care Guidelines, the program strives to support the grieving in a variety of ways depending upon their needs, such as:

- Providing a grief care package that gives them information about grief and ways to help them deal with it.
- Providing a follow-up phone call from a volunteer or staff member to offer appropriate support, and where requested, referrals to agencies and individuals specializing in grief care.

It is important to support staff in the area of grief support. To this end grief care education is provided for hospice and homecare staff, medical students, fellows and family physician residents and in other educational and community care facilities when requested. The 2004 annual meeting focused on grief care and an action plan, with a focus on grief education and identification of complex grief, will unfold in 2004 and 2005.

## **3. Education and Communication**

Basic and continuing education is provided to a wide range of health professionals in a variety of settings to support them in providing quality palliative care to individuals and caregivers. Educational initiatives for persons receiving palliative care and caregivers are also fundamental. Many of the initiatives are completed in collaboration with the Division of Palliative Medicine. Communication and education activities are core components of the RPCP:

Educational resources are available to assist health professionals provide care to the person and caregiver. These resources include:

- The family physician handbook, titled "Alberta Palliative Care Resource" is provided to all medical residents and new physicians (Joint project with the Alberta Cancer Board and Calgary Regional Health Authority). The Alberta Cancer Board now undertakes to provide it free of charge to all family physicians in Alberta.
- Nursing handbook titled "99 common Questions (And More) About Palliative Care: A Nurses' Handbook" (2<sup>nd</sup> edition) is available for nurses in all areas of Capital Health. The handbook is a Capital Health handbook written in collaboration with Clinical Nurse Specialists at Alberta Cancer Board, and East Central, David Thompson and Calgary Regions.
- The "palliative care tips" are updated and sent to all family physicians in the region on a monthly basis and are posted on the website. This is a highly popular method of education for physicians.
- Publications in peer reviewed journals. To review a list of these publications from 2002 to 2004 see Appendix A.

Continuing education is provided to a wide range of health professionals in a variety of settings to support them in providing quality palliative care to palliative persons and their caregivers. Continuing educational opportunities include:

- An Annual Conference, “Palliative Care Education and Research Days” is available to all interested individuals. Conference streams include basic, trends & issues, collaboration in care, psychosocial/spiritual, and research.
- A clinical placement Main-Pro C course on palliative care is available to family physicians (by Dr. Anna Taube).
- A three level palliative care continuing education half-day session to staff in palliative hospices. Created by community nurse consultants with components for Registered Nurses (RN)'s, Licensed Practical Nurses (LPN) and Nursing Attendants (NA). Designed as a continuing education and retainment initiative, these sessions are positively evaluated by staff.
- Education sessions for staff employed by agencies contracted to deliver personal care to persons in their homes is offered by Palliative home care.
- Community Case Rounds occur twice per month and rotate between palliative care sites.
- A monthly city wide round is held at the Grey Nuns Hospital. This round includes presentations by national and international speakers on education and research aspects of palliative care. Weekly palliative care rounds continue to take place. These rounds focus on the continuing education of palliative care health professionals in the region.

The RPCP provides educational opportunities for individuals' new to palliative care. These educational opportunities include:

- The TPCU and RPCP provide educational opportunities to physician trainees and fellows (Table Y). Visitors spend varying amounts of time in other areas of the program, (tertiary, acute care, hospice, community) depending upon their objectives, providing exposure to a regionalized community based program.
- Family medicine residents attend the TPCU for a two-week rotation or arrange a community rotation (see Table 5).
- Two-day home care palliative orientation is open to all RN's working for home care, vendor organizations, all new hospice staff and acute care nurses.
- University of Alberta nursing students can be placed with staff working in various palliative care settings in their 4<sup>th</sup> year.

Educational resources for persons receiving palliative care and for caregivers are also fundamental. These resources include:

- A video about palliative care services for persons and families titled “Palliative Care Services: Helping You Find the Right Place” is available to be shown to new palliative persons and their families and is used in educational opportunities to describe the program (Joint project of the RPCP, CCI and Caritas Health Group).
- A brochure on the program complements the video by describing aspects of the program from wherever site the person is accessing services.



- A handbook for family caregivers “A Caregiver’s Guide: A handbook about end of life care” is provided to every palliative care person at home by palliative home care. (Collaborative project between RPCP and Palliative Care Association of Alberta and Order of Lazarus). The handbook is available free of charge to all palliative caregivers in Alberta. The Caregiver Guide is also installed on the website [http://www.chpca.net/publications/caregivers\\_guide.htm](http://www.chpca.net/publications/caregivers_guide.htm) as part of the Ed Net Project.

Communication strategies which provide access to information pertinent to palliative care have been developed. These strategies include:

- The RPCP website [www.palliative.org](http://www.palliative.org). It contains a description of the program “palliative care tips”, divisional publications, nursing notes, assessment tools, palliative care protocols/clinical guidelines, as well as the annual report.
- The quarterly “palliative care newsletter” by RPCO is a communication tool within the palliative care community. The newsletter is utilized as a wide communication tool to update all staff of what is happening nationally, provincially and regionally including clinical, program, research and wellness notes.

#### **4. Research**

The RPCP, in collaboration with the Division of Palliative Medicine, maintains a strong research program in support of evidenced-based practice. The Alberta Cancer Board has supported a province wide palliative care research initiative since 2000 and this support continues until March 2005.

[http://www.cancerboard.ab.ca/research/research\\_research\\_initiatives.html](http://www.cancerboard.ab.ca/research/research_research_initiatives.html)

### **C. Palliative Home Care**

Consistent with the national norms of practice, palliative home care provides coverage 24 hours per day, seven days per week. Westview area has 24 hour phone access and all other areas have home care coverage by phone with ability to visit 24/7. A centralized community access number is provided to each person and they are encouraged to call home care first. Nurses are available to visit during days and evenings 7 days per week and are on call at night in most areas. Care is provided collaboratively with the family physician and with community consultants available upon request of the physician.

A wide variety of services are available in the home, including case management, professional nursing, rehabilitation services, social work, respiratory therapy, contracted support services (LPN and personal care). Home care has dedicated palliative case managers in the north and south offices of Edmonton, and integrated teams in the surrounding areas. New areas to Capital Health are supported by local home care.

A palliative home care database was created by home care November 2001. The database contains specialized data such as the ESAS, MMSE and Home Death Assessment Tool that the regular home care database does not accommodate. New areas to the region complete the ESAS and MMSE but do not have access to the database. This information is accessed by the RPCO data manager to create reports.

#### **D. Palliative Hospices**

Palliative hospices consist of 57 beds located on four sites:

- Mel Miller Hospice at the Edmonton General Hospital (Caritas) with 22 beds
- Norwood Hospice at Capital Care Norwood with 20 beds
- St. Joseph Hospice at St. Joseph Auxiliary Hospital with 14 beds
- Youville Nursing Home in St. Albert with 1 bed.

Palliative hospices, which focus on end of life care in the last 2-3 months of life, are specialty units located in continuing care facilities. Hospice has enhanced interdisciplinary, nursing and medication support. Family physicians are asked to visit twice per week, and may be called at any time to address symptom issues.

Access to the hospices is centralized through the RPCP community nurse and physician consultants. Assessment is completed wherever the person is located. A primary principle of the program is that the person's family physician is able to provide palliative care in hospices, maintaining the continuum of care. Family physicians are able to receive admitting privileges to any hospice on the same day it is requested. When the referring physician is not able to provide care in palliative hospice, a family physician interested in palliative care is approached to transfer care. An initial consult is completed on admission by a community physician consultant, with follow-up by the community consultants until stable. Community nurse and physician consultants support hospice by attending team meetings and provide consultation at the request of the attending physician.

Tours are offered to prospective hospice individuals and their families. Care at the end of life often requires multiple adjustments to medications, hypodermoclysis to prevent dehydration, individual and family psychosocial support, involving significant staff and volunteer support. Although, according to admission criteria, persons admitted should be "stable", there are multiple needs and expectations for this population, particularly when discharged from acute care to hospice. Transfers from palliative hospice to acute care sites continue to be monitored and remain low (< 3%) suggesting the palliative hospice staff and community consultants continue to deal with symptom issues proactively in the hospice setting.

#### **E. Referral Hospitals**

As large tertiary referral centres, the Royal Alexandra and the University of Alberta Hospitals have full time palliative care nurse and physician consultants. Interdisciplinary support is available at both sites. The referral hospitals tend to see a larger percentage of persons with a diagnosis other than cancer, than other areas of the program. Acute care consultants tend to see persons earlier in the disease trajectory, at times just receiving a palliative care diagnosis. Time is needed to absorb information, address symptoms and consider different options for care. There is an ongoing focus on discharge planning with consultants following the person through their hospital stay until discharge.

#### **F. Community Consultation**

Community nurse and physician consultants who travel to see referred persons in the community, palliative hospice, continuing care, community hospitals and any other health care institutions with the exception of the Royal Alexandra Hospital, University of Alberta Hospital, and the CCI. The primary physician requests consultation on symptom management and/or access to a palliative hospice or tertiary care bed.

The program provides 24 hour, 7 days per week on-call coverage to provide support to the primary caregivers. All areas have a nurse and physician consultant on call by phone. Leduc, Westview, Morinville, Redwater areas do not have nurse-physician teams able to visit and Fort Saskatchewan have halftime coverage.

#### **G. Cross Cancer Institute:**

The RPCP maintains a strong relationship with the CCI and their palliative care services:

- Pain & Symptom Control Clinic: This highly interdisciplinary clinic provides assessment and consultation to persons with cancer from any health care region.
- Consultants: part-time physician consultants, nurse consultant and pharmacist provide inpatient consultations and run the outpatient clinic with the assistance of the interdisciplinary team and a regional physician consultant. Outpatients are followed with telephone calls until stable and are referred to the regional palliative consultants if required.

#### **H. Tertiary Palliative Care Unit (TPCU)**

The 14-bed TPCU is located at the Grey Nuns Community Hospital. The primary focus of the TPCU is to treat persons with the most complex palliative physical and psychosocial issues within Northern Alberta. Persons admitted to the TPCU are younger with increased severity of symptoms, poor prognosis for pain management and difficult family and psychosocial issues. The expected length of stay is 2 weeks, to treat symptoms and discharge to the most appropriate setting. There continues to be a group of people where the most appropriate setting for end-of-life care is the Tertiary Unit, due to the severity of symptoms and psychosocial support needed.

### **VII. MAJOR INITIATIVES / ACCOMPLISHMENTS**

- ⇒ 2002 The two-day home care palliative orientation became open to RN's working for home care vendor organizations.
- ⇒ 2002, May. The RPCP was part of the Northern Alberta Renal Program end of life working group that designed a model supporting advanced care planning and supportive care for symptoms.
- ⇒ 2002, May. The Clinical Practice Committee group began to build on physician and nurse handbooks in areas where specific protocols/guidelines need to be widely available for palliative care people. This group is interdisciplinary, and is connected with the Clinical Performance Information and Research group formed in January 2004.
- ⇒ 2002. Case Rounds replaced the traveling bus rounds as a means to provide education and clinical discussion for the regional consultants, site staff and students.
- ⇒ 2003, January. The program description for palliative hospice was completed and submitted to Alberta Health and Wellness.
- ⇒ 2003, February. Hospice guidelines, *Admission to Palliative Hospice*, were created and distributed region wide with input from the Role of Hospice ad hoc committee of the Program Council. Guidelines, which were developed over a period of four months, provide detail about criteria of admission and limited admission based on what present

staffing levels can provide. This process has begun to identify populations that require care above hospice care but not acute care, e.g. persons requiring platelets or intravenous therapy, as well as those who are now referred to continuing care.

- ⇒ 2003, March. The research study *Economic Evaluation of Two Regional Palliative Care Programs for Terminally Ill Cancer Patient*, funded by the Canadian Health Services Research Foundation was completed. (See program outcomes)
- ⇒ 2003. Two day palliative care training session on palliative care needs in continuing care for non-malignant populations presented by Kathleen Davis, Continuing Care CNS Bethany Centre, Calgary, at the Mewburn Veterans Centre for all staff. RPCP staff attended.
- ⇒ 2003, April. A .5 FTE nurse consultant from Fort Saskatchewan joined the RPCP team.
- ⇒ 2003, May. Clinical Practice binders with seven protocols were distributed to different areas of the program.
- ⇒ 2003, May. The nursing handbook titled *99 common Questions (and answers) About Palliative Care: A Nurses' Handbook* was updated and widely distributed in the region during Palliative Care Week held in May.
- ⇒ 2003, May. The RPCP Website [www.palliative.org](http://www.palliative.org) which is linked to the Capital Health website was reviewed and updated. A website committee will maintain this site on an ongoing basis.
- ⇒ 2003. The focus of the annual staff retreat was education resulting in the development of a strategy document, education model and formation of an education committee.
- ⇒ 2003, August. Per Diem charges for palliative hospice were discontinued.
- ⇒ 2003, September. The *First Balanced Scorecard* was submitted to Community Care Services. The scorecard will be integrated with annual reports.
- ⇒ 2003 Fall. Orientation and discussions on palliative care for new areas to Capital Health was completed.
- ⇒ 2004, January. The focus of the annual staff retreat was grief and bereavement resulting in a renewed strategy for grief care. Prior to the retreat a consultant was hired to complete a review (literature search, benchmark, focus groups, staff input). This strategy has a strong focus on grief education.
- ⇒ 2004, Spring. The Privacy Impact Assessment was completed, which allows the Cross Cancer Institute pain and symptom team to use the RPCP database.

## VIII. PROGRAM EVALUATION

### A. Education

The evaluation of the education component of the RPCP includes keeping track of the types and numbers of education presentations by the Regional Palliative Community Consultants, the number of palliative care rounds, the number of fellows attending palliative care and the number of residents completing a two week elective. This information follows in Table 1 to Table 5.

**Table 1**

Education Presentations by Regional Palliative Community Consultants Team\*  
 April 1, 2002 - March 31, 2003

	In Region	Out of Region	Out of Province
In-services/Lectures/Orientations **	243	6	4
Workshops	14	5	8
Conference presentations or posters	16	3	23

**Table 2**

Education Presentations by Regional Palliative Community Consultants Team\*  
 April 1, 2003 - March 31, 2004

	In Region	Out of Region	Out of Province
In-services/Lectures/Orientations **	305	7	3
Workshops	21	10	5
Conference presentations or posters	21	4	25

\* Does not include Clinical Director

\*\* In-services/Lectures/Orientations include Bus Rounds, Case Rounds, Training Sessions, etc.

**Table 3**

Number of Palliative Care Rounds

2002-2003	36
2003-2004	35

**Table 4**

Number of Fellows Attending Palliative Care

2002-2003	2
2003-2004	4

**Table 5**

Number of Residents Completing 2 Week Elective

2002-2003	38
2003-2004	37

## B. General Program Outcomes

Expected and Actual Outcomes Regional Palliative Care Program, Figure 4 compares the actual outcomes of the TPCU, acute care hospitals, palliative hospices and palliative home care in 1992 and in 2001 and 2002 with the expected outcomes. For example:

- The number of deaths in palliative hospices has consistently been 30-35 % of all cancer deaths, ranging from 480-504 (2002/03–2003/04) meeting the goal of 30% of all cancer deaths.
- The decrease of acute care deaths has been significant and has remained at approximately 40% for several years.
- Home care consistently cares for approximately 15% of all cancer home deaths, which is 30% of the palliative home care population. It is not clear what the optimal number of home deaths could be with an integrated palliative care program that has several options for care. Changes in numbers to home deaths would involve significant increases to resources in home care and further research needs to occur to know if persons and families would make this choice near the end of life.

Access to exemplary palliative care services is the primary goal of the program. Each year an increase of 100-150 persons are seen by the RPCP. In 2003, 1629 persons with any diagnosis were seen by at least one area of the program (region 6 prior to reorganizing regions) and 1872 (region 10, including new area) in 2004. Of note, 143/1628 (9% for 2003) and 1658/1872 (11% for 2004) are patients with a primary diagnosis other than cancer. We are redesigning how access to RPCP is reported an updated version of Figure 5 will be added at a later date. In 2002, based on the study “Economic Evaluation of Two Regional Palliative Care Programs for Terminally Ill Cancer Patients” ([www.chsrf.ca/final\\_research](http://www.chsrf.ca/final_research)), access was reported to be 81% compared with 45% of all cancer patients who died the year of 1993/94, a significant increase from the 290 patients seen in 1992. This high level of access is an important indicator for a population health approach to palliative care services. At this time, we are not able to report on all end-of-life persons receiving care due to the difficulty in identifying the denominator.

*From this study, key implications for decision-makers include:*

- *Access to palliative care services has increased from 45 percent to 81 percent for terminally ill cancer patients' between 1993 and 2000 as a result of introducing comprehensive, regional palliative care programs in two large urban centers.*
- *Comprehensive, integrated palliative care programs can be implemented at no additional cost to the healthcare system in large urban settings. These findings support the introduction and expansion of palliative services where none currently exist. Where services already exist, these findings will help to maintain budgets in the face of increasing demands for shifting resources into other healthcare services.*
- *Acute care continues to account for the majority of costs at the end-of-life. We identified health care services totalling \$28,093 per person, two-thirds of which we provided by hospitals to terminally ill cancer patients in their last year of life. Physician services (10 percent), residential hospice care (8 percent), nursing home (6 percent), home care (6 percent) and prescription medications (3 percent) made up the rest. Age, gender, socio-economic status, cancer diagnosis, disease burden, geographic, and health care system variables are significant predictors of these costs.*
- *Co-ordination of palliative care services meant that terminally ill cancer patients spent less time in hospital between 1993 and 2000, freeing up 74 beds per year between Edmonton and Calgary. A reduction in the demand for acute care beds over this time period was achieved by providing additional palliative home care and residential hospice care.*

- *Decision makers need to continue to develop communication initiatives that will inform the public regarding palliative care so that they can make informed decisions regarding quality end-of-life care for themselves and their families.*
- *Decision makers should continue to invest in management and collecting data in order to generate a strong evidence base upon which to improve decision making in palliative care. (Page 1, [www.chsrf.ca/final\\_research](http://www.chsrf.ca/final_research))*

Utilization of acute care services by persons with cancer is illustrated by Total CHA Hospital and Cross Cancer Institute Deaths, Figures 6; Average Length of Stay, Figure 7 and Total Days in Hospital, Figure 8. In 1992, 87% of oncology patients died in acute care hospitals utilizing 20,000 bed days. The decrease in acute care bed days has been transferred to palliative hospice as well as palliative home care, resulting in decreased costs to acute care services.

**EXPECTED AND ACTUAL OUTCOMES  
 REGIONAL PALLIATIVE CARE PROGRAM**

**TERTIARY PALLIATIVE CARE UNIT**

Outcome	1992	Plan <sup>a</sup>	2002 <sup>b</sup>
#deaths/year <sup>c</sup>	120 (9%)	96 (8%)	111 <sup>d</sup> (7.3%)
ALOS	25	15	23.1 (median 19) <sup>d</sup>
# pts./year	168	273	199 <sup>d</sup>
Criteria	exist	monitor	monitor

**ACUTE CARE HOSPITALS**

Outcome	1992	Plan	2002
#deaths/year <sup>c</sup>	1050 (78%)	265 (22%)	596 <sup>e</sup> (39.1%)
ALOS	25	15	16.4 <sup>f</sup>
Consult Teams	varied	develop	465 <sup>g</sup>
Criteria for Admission	inconsistent/absent	develop & monitor	monitor

**PALLIATIVE HOSPICES**

Outcome	1992	Plan	2002
#deaths/year <sup>c</sup>	62 (< 5%)	360 (30%)	504 <sup>d</sup> (33.0%)
ALOS		66	34.3 (median 17) <sup>d</sup>
Consult Teams		develop	exist
Criteria	varied	develop	exist and reviewed
Continuing Care			76(5.0%) <sup>d</sup>
Died out of region			18 <sup>e</sup> (1.2%)
Other Died			4 <sup>e</sup> (0.3%)

**PALLIATIVE HOME CARE**

Outcome	1992	Plan	2002
#deaths/year <sup>c</sup>	109 (9%)	480 (40%)	213 <sup>e</sup> (14.1%)
ALOS	4 months	3 months	not available
medical care	minimum	↑ education of f.p.	447 distinct MD referrals to RPCP/year; > 901 since July/95
Consult Teams	absent	develop	exist: in home
24 hr. service	absent	develop	present
Criteria	varied	develop	exist
Drugs 24 hour	minimum	24 hour available	5 - 24 hour delivery
Lab service	varied	develop	exists

Outcome	1992	Plan	2002
Died out of region			18 <sup>e</sup> (1.2%)
Other Died			4 <sup>e</sup> (0.3%)

<sup>a</sup> Plan based on 1200 patients/year.

<sup>b</sup> Utilizes calendar year not fiscal year therefore, total death differs on this table.

<sup>c</sup> Percentages based on number of deaths divided by actual 1992 (1341) and 2002 (1525) cancer deaths for region. #deaths/year from Alberta Cancer Board, Division of Epidemiology, Prevention & Screening. Number used in table for 2002 does not include out of region patients who died in region (134) or in region patients who died out of region (18). The numbers provided in the table are provisional as some cases (deaths) may be registered in subsequent years. Methods of coding of cancer on the Alberta cancer Registry have varied through the years; therefore caution should be exercised when comparing data to that of previous years. <sup>d</sup> Regional Palliative Care database, Jan 01, 2002 to Dec 31, 2002. Only Cancer deaths are included in #deaths. ALOS and #pts/year include all diagnosis. (5.9 % are non-cancer patients) <sup>e</sup> Number of deaths at all acute care sites including Cross Cancer Institute (CCI). Data from Alberta Cancer Board, Division of Epidemiology, Prevention & Screening, Jan. 1, 2002 - Dec. 31, 2002.

<sup>f</sup> Evaluation, Information, and Research, Capital Health, Jan 01, 2002 to Dec 31, 2002.

<sup>g</sup> Consultations to RAH palliative care team (UAH data were not available until October, 2002).

Figure 4



**Access to Palliative Care as Measured by Patients Receiving Palliative Care Consultation to Actual 2000 & Predicted 2001 Number of Deaths Due To Cancer for Region 10 Population**

Historic figures

1992	Number of Patients Receiving Palliative Care Services (1)	290	
			21.6%
1992	Actual Number of Deaths Due to Cancer (2)	1341	

NOTE 1- Estimate of patients seen in the Acute Palliative Care Unit and at the Misericordia Hospital in 1992  
 2- Information provided by the Alberta Cancer Board, Epidemiology. Includes Edmonton, St. Albert, and Strathcona County.  
 Subtotals for areas include: Edmonton: 1275 deaths. St.Albert:59 deaths. Strathcona County: 7 deaths

Present figures

2001	Number of Region 10 Cancer Patients Receiving Palliative Care Consultations (3)	1073(4)	
2001	Actual Number of Deaths Due to Cancer (5)	1568	<b>68.4%(6)</b>
2002	Number of Region 10 Cancer Patients Receiving Palliative Care Consultations (3)	1182(4)	
2002	Actual Number of Deaths Due to Cancer (5)		
2003	Number of Region 10 Cancer Patients Receiving Palliative Care Consultations (3)	1322	
2003	Predicted Number of Deaths Due to Cancer (5)	1551	<b>85.2%(7)</b>

NOTE 3- Number of unique admissions/referrals to CHA palliative care consultations from Jan 01, 2002 to Dec 31, 2002 and Jan 01, 2003 to Dec 31, 2003 respectively  
 INCLUDES: unique Region 10 palliative admissions to the Tertiary Palliative Care Unit and Palliative Hospices, and through referrals to the Palliative Consult teams at the Acute Care Hospitals and the Regional Palliative Care Program.  
 DOES NOT INCLUDE unique patients seen at the Cross Cancer Institute, or Home Care.  
 Source: Palliative Care Information System (July 22 06, 2004)

4- UAH Palliative Care team consultation numbers are not available

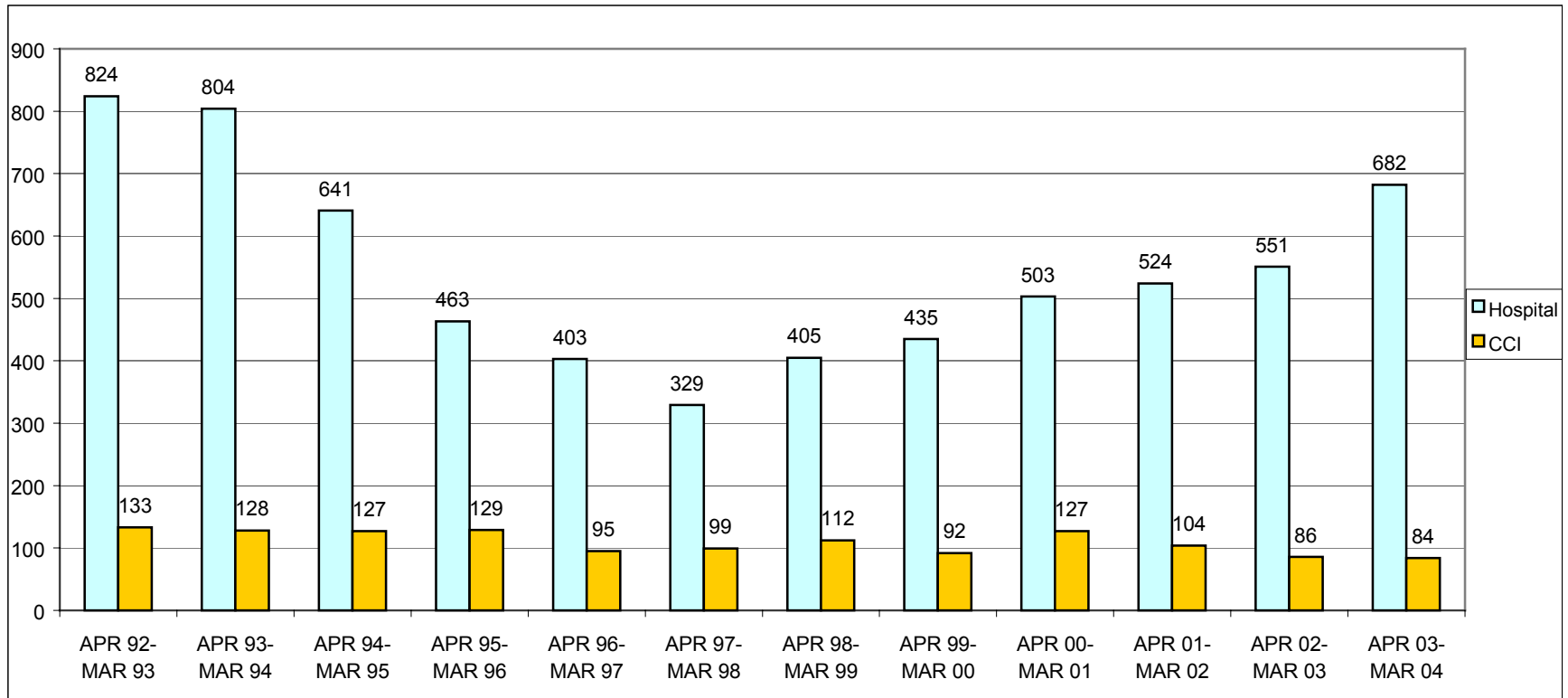
5- Information provided by the Alberta Cancer Board, Epidemiology. Includes Edmonton, St. Albert, and Strathcona County on all regional cancer deaths including out-of-regions.  
 The number is provisional as some deaths may be registered in subsequent years as methods of coding on the Alberta Cancer Registry have varied through the years

6- Actual percentage of cancer patients receiving consultations from Jan 01, 2002 to Dec 31, 2002

7- Predicted percentage of cancer patients receiving consultations from Jan 01, 2003 to Dec 31, 2003

**Figure 5**

**TOTAL CHA Hospital Deaths<sup>a</sup> with a Most Responsible Diagnosis of Cancer,  
 and Deaths at the Cross Cancer Institute<sup>b</sup>**



NOTE: ICD-9-CM diagnostic codes used to determine cancer are 140.\* to 208.\* and 230.\* to 234.\* (malignant neoplasms)  
 ICD-9-CM diagnostic codes used to determine palliative care, chemotherapy or radiotherapy are V58.0, V58.1 and V58.89 (to 97/03/31) and V66.7 (from 97/04/01)  
 with a secondary diagnosis of 140.\* to 208.\* and 230.\* to 234.\*, or V10.\* to V10.9\*

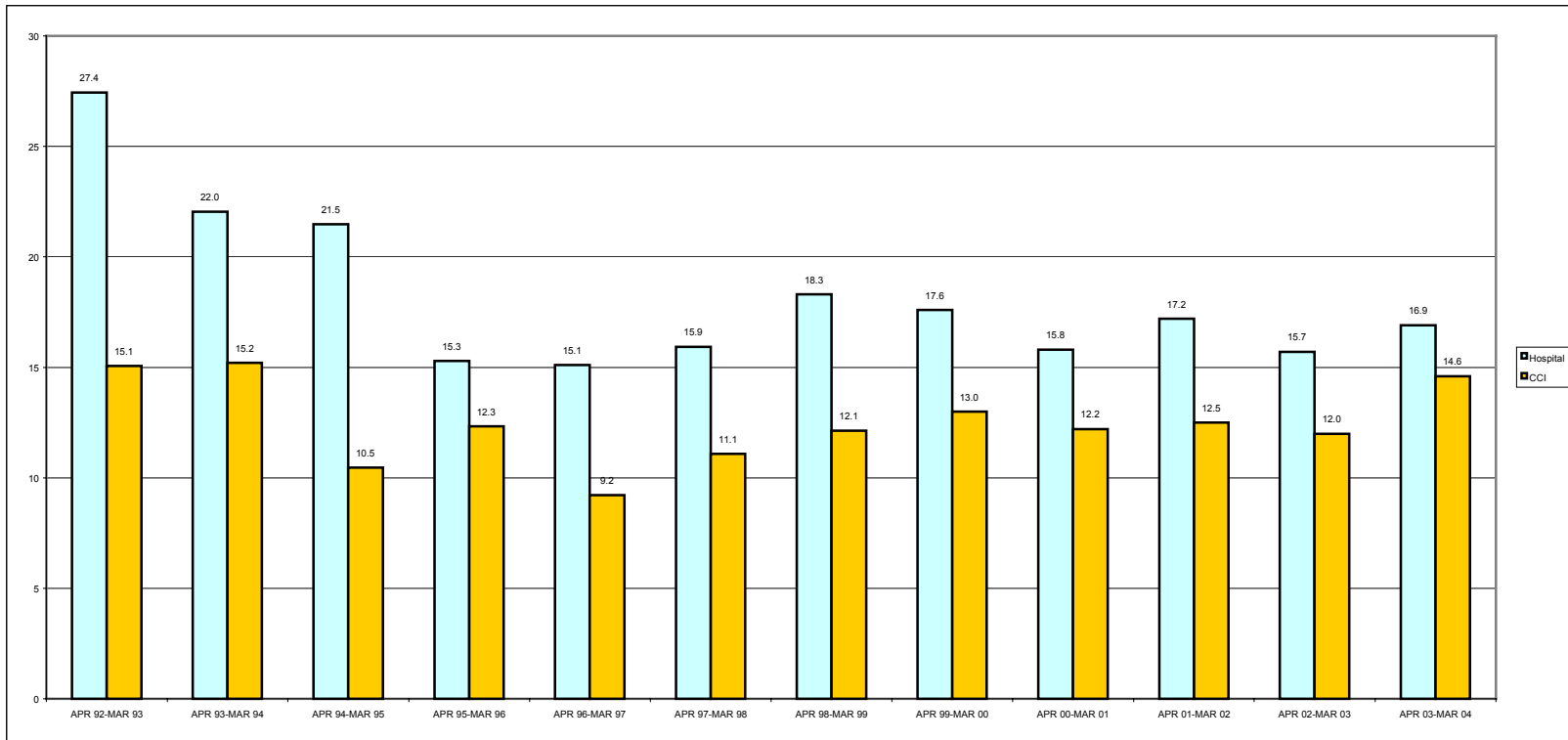
<sup>a</sup>Source: Capital Health Evaluation, Information and Research, April 2002

<sup>b</sup>Cross Cancer Institute April, 2002. The numbers provided in the tables are provisional as some cases (or deaths) may be registered in subsequent years.

Methods of coding of cancers on the Alberta Cancer Registry have varied through the years; therefore, caution should be exercised when comparing this data to that of previous years

**Figure 6**

**Average Length of Stay- CHA Hospital<sup>a</sup> and Cross Cancer Institute(CCI)<sup>b</sup>  
 Deceased Patients with a Most Responsible Diagnosis of Cancer**



NOTE: ICD-9-CM diagnostic codes used to determine cancer are 140.\* to 208.\* and 230.\* to 234.\* (malignant neoplasms)

ICD-9-CM diagnostic codes used to determine palliative care, chemotherapy or radiotherapy are V58.0, V58.1 and V58.89 (to 97/03/31) and V66.7 (from 97/04/01) with a secondary diagnosis of 140.\* to 208.\* and 230.\* to 234.\*, or V10.\* to V10.9\*

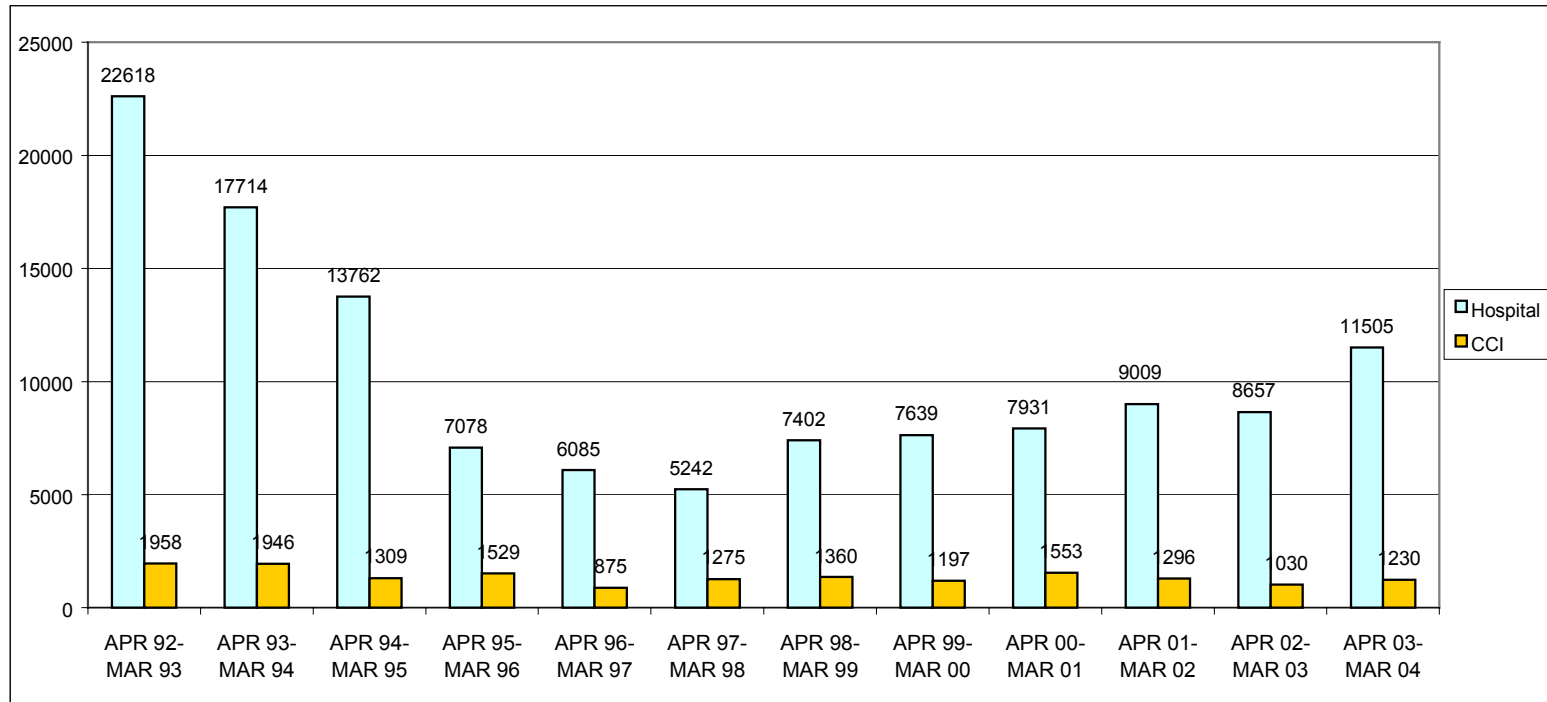
<sup>a</sup>Source: Capital Health Evaluation, Information and Research, April 2002

<sup>b</sup>Cross Cancer Institute April, 2002. The numbers provided in the tables are provisional as some cases (or deaths) may be registered in subsequent years.

Methods of coding of cancers on the Alberta Cancer Registry have varied through the years; therefore, caution should be exercised when comparing this data to that of previous years

**Figure 7**

**Total Days in Hospital- CHA Hospital<sup>a</sup> and Cross Cancer Institute(CCI)<sup>b</sup>  
 Deceased Patients with a Most Responsible Diagnosis of Cancer**



NOTE: ICD-9-CM diagnostic codes used to determine cancer are 140.\* to 208.\* and 230.\* to 234.\* (malignant neoplasms)

ICD-9-CM diagnostic codes used to determine palliative care, chemotherapy or radiotherapy are V58.0, V58.1 and V58.89 (to 97/03/31) and V66.7 (from 97/04/01) with a secondary diagnosis of 140.\* to 208.\* and 230.\* to 234.\*, or V10.\* to V10.9\*

<sup>a</sup>Source: Capital Health Evaluation, Information and Research, April 2002

<sup>b</sup>Cross Cancer Institute April, 2002. The numbers provided in the tables are provisional as some cases (or deaths) may be registered in subsequent years.

Methods of coding of cancers on the Alberta Cancer Registry have varied through the years; therefore, caution should be exercised when comparing this data to that of previous years

**Figure 8**

## C. Balanced Scorecard Report

The Balanced Scorecard is organized according to financial performance, service quality, person and stakeholder satisfaction and employee satisfaction. Selected indicators are included to describe aspects of the program.

### 1. FINANCIAL PERFORMANCE

*“To achieve the desired benefit for patients/ residents/ families/ communities, with the most cost effective use of resources.”*

#### 1.1 Contracted Provider (Hospice) Reported Hours Per Resident Per Day

**Benchmark:** 5.88 hours per resident day (PRD)

**RPCP Goals:** Review and follow relevant norms of practice based on CHPCA guidelines of each site of care.

**CCRMH Goals:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement.

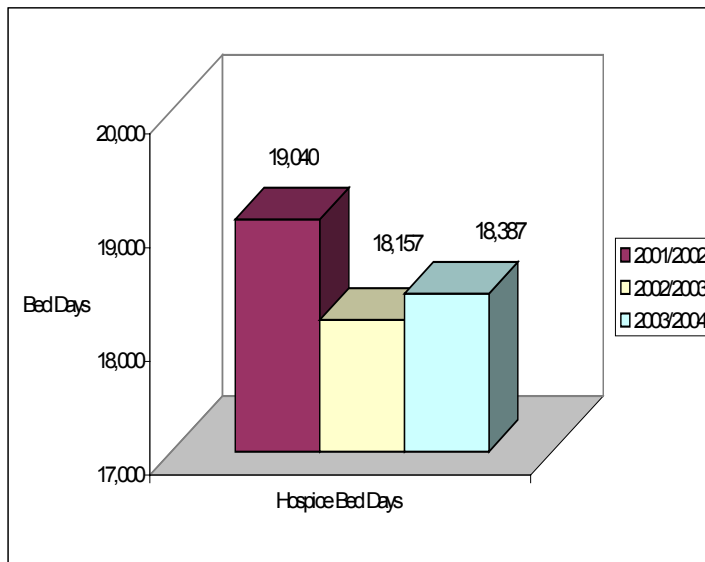
**Definition:** Number of blended nursing hours provided at each hospice site per resident per day.

**Interpretation:** Mel Miller utilizes 2 RN rather than 1 during the day, which is a higher blended nursing rate.

Year	Reported hours per resident per day per site		
	St. Joseph's	Mel Miller Hospice	Norwood
2002*/2003	6.75	4.57	5.92*
2003/2004	6.90	4.63	5.99

\*April – Oct 2002

## 1.2 Acute Care Bed Days Saved Per Fiscal Year



**Benchmark:** 92% occupancy = 19,140 bed days

**RPCP Goals:** Support community based care by providing proactive palliative care in the home and hospice, thereby decreasing the use of emergency and acute care services.

**CCRMH Goals:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement

**Definition:** Number of acute care bed days saved per year. Note: If hospice beds were not available all bed days would occur in acute care facilities.

**Interpretation:** Occupancy was 88.5% with a mean of 33 days and a median of 17 days.

**1.3 Research / Grants Produced By RPCP Staff**

**RPCP Goals:** Facilitate a program of ethically based research, which advances palliative care practice.

**CCRMH Goals:** Partnering with Others.

**Definition:** Number of Research projects and publications produced by staff and/or affiliates of the RPCP in collaboration with the Alberta Cancer Board Palliative Care Research Initiative (ACBPCRI) members within the Capital Health Region. Research activities are categorized under 5 different research streams. *Other includes:* study in proposal phase, pending grant funding, and on hold.

**Interpretation:**

Number of Research projects according to research stream for 2002/2003							
Status	Clinical Trials	Cachexia/Anorexia	Health Services	Opioids/Analgesics	Information Systems	National Collaboration	Education
Ongoing	2	7	5	3	2	2	4
Completed	4	4	4	1	1	2	-
Other	2	4	3	2	1	1	-
<b>Total</b>	<b>8</b>	<b>15</b>	<b>12</b>	<b>6</b>	<b>4</b>	<b>5</b>	<b>4</b>

Number of Research projects according to research stream for 2003/2004							
Status	Clinical Trials	Cachexia/Anorexia	Health Services	Opioids/Analgesic	Fatigue	Other	Others
Complete	2		7	1	1	1	1
Ongoing	1	1	2		2		
Proposal	1	2	1			1	
<b>Total</b>	<b>4</b>	<b>3</b>	<b>10</b>	<b>1</b>	<b>3</b>	<b>2</b>	<b>1</b>

## 2. SERVICE QUALITY

“To respond to the needs and expectations of patients/ residents/ families and to changes in the environment in the best possible way given the current and evolving state of knowledge.”

### 2.1 Availability - Criteria For Admission For Each Site

<p><b>Target:</b> 100%</p> <p><b>RPCP Goal:</b> Ensure a coordinated and continuous plan of care that minimizes duplication of efforts and is maintained across all settings from referral of the patient to support of the bereaved family.</p> <p><b>CCRMH Goals:</b> Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement.</p> <p><b>Definition:</b> Each specific area/site has admission criteria in place. Percent of sites in Capital Health Region that have criteria for admission in place.</p> <p><b>Interpretation:</b> With the new boundary changes effective April 1, 2003 a comprehensive definition of “criteria for admission” is required. A review of all sites admission criteria will need to be completed.</p>
---

Year	Criteria of Admission available at each site
2001/2002	100%
2002/2003	100%
2003/2004	100%



## 2.2 24/7 Palliative Home Care Coverage

24/7 Palliative Home Care Coverage	
Year	Palliative Home Care
2001/2002	100%
2002/2003	100%
2003/2004	88%

**Target = 100%**

**RPCP Goal:** Provide timely access to palliative care services 24 hours a day, 7 days a week throughout the Capital Health Region.

**CCRMH Goals:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement

**Definition:** Availability of 24 hour on call palliative home care services to visit person.

**Interpretation:** Stony Plain, Spruce Grove and Devon area have phone access rather than staff to visit. (# of palliative care clients are estimated in these areas). All other areas have home care coverage by phone with ability to visit 24/7.

## 2.3 24 / 7 RPCP Consultant Coverage

24/7 Consultation Coverage	
Year	Consultant on call
2001/2002	100%
2002/2003	100%
2003/2004	86% home care, 96% acute care

**Target:** 100%

**RPCP Goal:** Provide timely access to palliative care services 24 hours a day, 7 days a week throughout the Capital Health Region.

**CCRMH Goals:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement

**Definition:** Availability of 24 hour on call consultant coverage to visit person.

**Interpretation:** Access to consultants varies since the regional border change. All areas have a nurse and physician consultant on call by phone. Leduc, Stony Plain, Spruce Grove, Devon, Morinville, Redwater areas do not have Nurse / Physician teams able to visit. Fort Saskatchewan has half time coverage.

## 2.4 Continuity Of Care – Use Of Common Assessment Tools

**Target:** 100%

**RPCP Goal:** Exemplary palliative care provided in the most appropriate setting.

**CCRMH Goal:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement.

**Definition:** Are common consultant assessment forms and tools used throughout the Capital Health Regional Palliative Care Program?

**Interpretation:** The palliative consultants utilize a single assessment form and common symptom assessment tools to ensure the most appropriate care setting is selected. Common assessment tools include: Edmonton Symptom Assessment System (ESAS), Mini Mental State Exam (MMSE), CAGE, Edmonton Staging System for Cancer Pain (ESS), Palliative Performance Scale (PPS). All diagnostic categories throughout all areas of the RPCP are consistent with 17 Alberta Cancer Board groupings. Morinville and Redwater home care now use the tools but the new areas to the west do not.

Year	Use of common assessment tools
2001/2002	100%
2002/2003	100%
2003/2004	88% home care, 96% acute care

## 2.5 Service Response Time For The RPCP – Community

**Benchmark:** Appointment booked within 1 day, seen within 1-2 working days. Urgent referral same day.

**RPCP Goal:** Access to exemplary palliative care provided in the most appropriate setting.

**CCRMH Goal:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement.

**Definition:** Time duration between referral call and date of first clinical contact reported as mean, median in the RPCP Community.

**Interpretation:** Response time includes weekends, when only urgent referrals are seen.

	2001/2002	2002/2003	2003/2004
Mean	Not Available	1.6 days	1.7 days
Median	Not Available	1 day	1 day

**2.6 Wait Time For Admission To Hospice And TPCU (GNCH)**

**Benchmark:** 1 day

**RPCP Goal:** Ensure a coordinated continuous plan of care that minimizes duplication of efforts and is maintained across all settings from referral of the patient to support of the bereaved family.

**CCRMH Goal:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement.

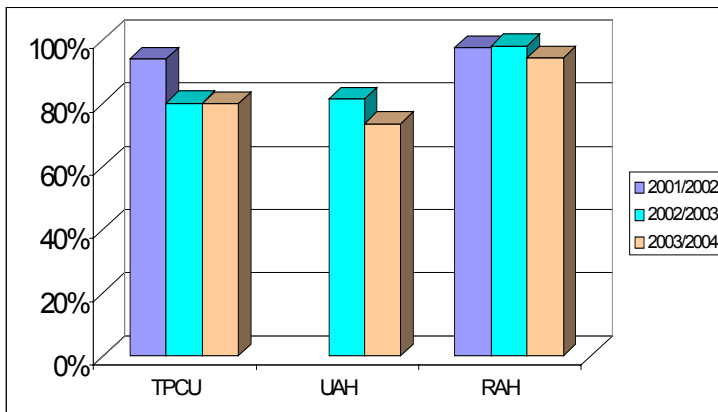
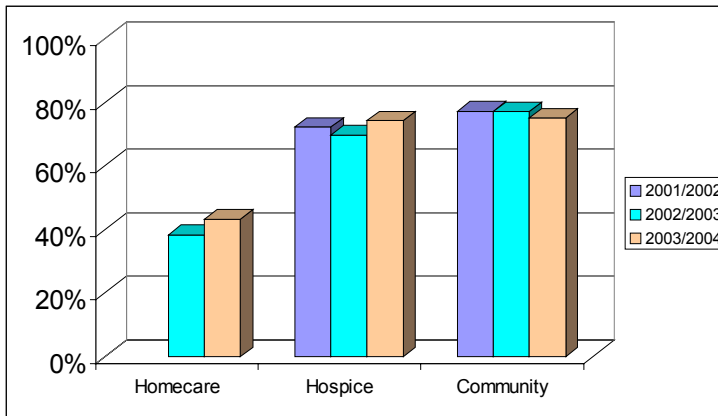
**Definition:** Time duration between date accepted and date person is admitted to hospice or TPCU. Time reported as mean, and median for 2002/ 2003 and 2003/2004.

**Interpretation:** Wait time has increased for 207 persons waiting for TPCU for 874 days and 112 persons not admitted resulting in 292 wait days for hospices. Ways to address this issue are being considered

Wait Time in Days				
	TPCU		Hospice	
	Mean	Median	Mean	Median
<b>2002/ 2003</b>	2.9	2	1.9	1
<b>2003/ 2004</b>	3.9	3	3.7	2

## 2.7 Pain And Symptom Management – ESAS Completed By Site

ESAS: Edmonton Symptom Assessment System – This tool is designed to assist in the assessment of nine symptoms common in people with cancer: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. The ESAS provides a clinical profile of symptom severity over time when graphed. For good symptom management to be attained the ESAS must be used as just one part of a holistic clinical assessment.



**Benchmark:** 100%

**RPCP Goal:** Review and follow relevant norms of practice based on CHPCA guidelines at each site of care.

**CCRMH Goal:** Strengthening Efficiencies

and Efficiency; Develop a System of Quality Improvement

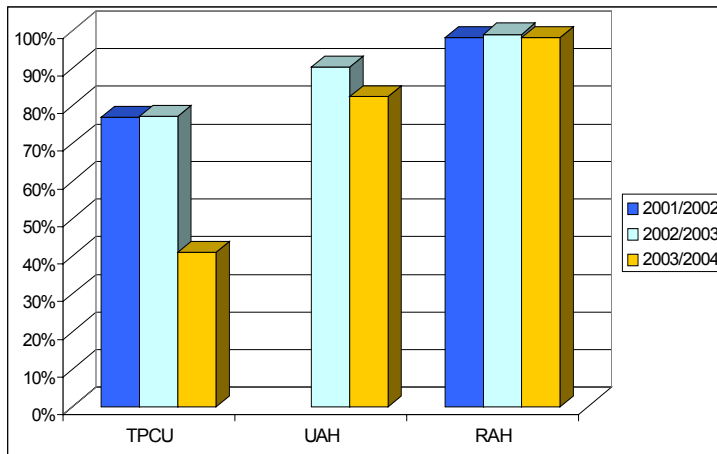
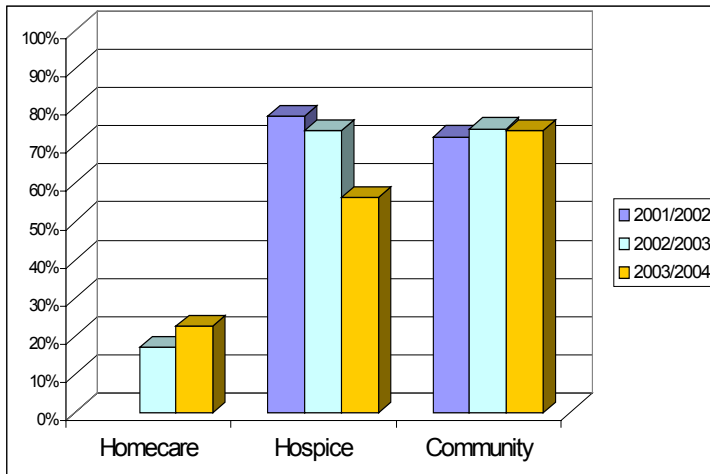
**Definition:** % of persons who have ESAS completed:

- I. Within 24 hours in TPCU, hospice
- II. On first visit in RPCCT (where consult not requested from UAH, RAH, CCI, TPCU or unknown)
- III. Within 48hr for RAH / UAH.
- V. Within 7 days for Palliative Home Care.

**Interpretation:** Discussions are ongoing with Palliative Home Care and TPCU to discuss frequency of ESAS administration.

## 2.8 Pain & Symptom Management MMSE <sup>1</sup>Completed By Site

This is a widely used, well-validated screening tool for cognitive impairment. It briefly measures orientation to time and place, immediate recall, short-term verbal memory, calculation, language, and construct ability.



**Benchmark:** 100%

**RPCP Goal:** Ensure a coordinated, continuous plan of care that minimizes duplication of efforts and is maintained across all settings from referral of the person to support of the bereaved family.

**CCRMH Goal:** Strengthening Efficiencies and Efficiency; Develop a System of Quality Improvement.

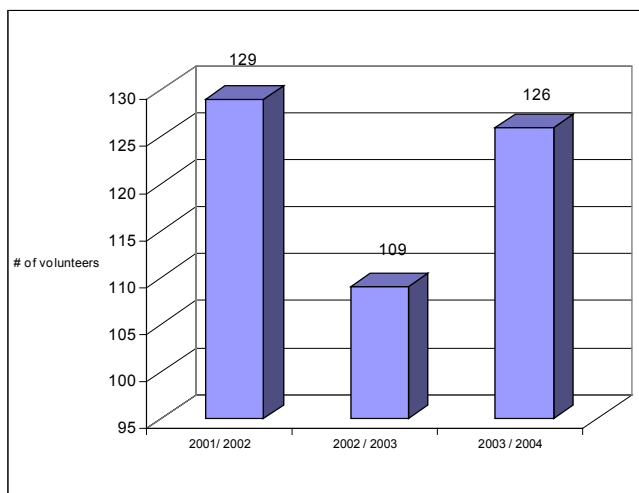
**Definition:** % of persons who have MMSE completed:

- I. Within 24 hours in TPCU
- II. Within 1 week in palliative hospice and Palliative HC
- III. On first visit in RPCP (where consult not requested from UAH, RAH, CCI, TPCU or unknown)
- IV. Within 48hr RAH / UAH.

**Interpretation:** Discussions are ongoing with Palliative Home Care and TPCU to discuss frequency of MMSE administration.

<sup>1</sup> Folstein, M.F., Folstein S., & McHugh P.R: (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.

## 2.9 Number Of PC Volunteers Trained By The RPCP



**Benchmark:**

**RPCP Goal:** Recognize and support the essential role of volunteers on the palliative care team.

**CCRMH Goal:** Partnering with Others.

**Definition:** Number of volunteers trained per year in the program.

**Interpretation:** Volunteers in palliative care are specially trained to help support palliative persons and families at the Hospices, Tertiary Palliative Care Unit, Royal Alexandra, University and Sturgeon Hospital, Cross Cancer Institute and in the home. Training is offered 10 months per year over three sessions.

## 2.10 PC VOLUNTEER HOURS PER LOCATION PER YEAR

Site	2003/2004	2002/2003	2001/2002
Norwood hospice	1750	*	2002
Mel Miller Hospice, EGH	1873	1812	2404
St Joseph's Hospice	484	458	565
Unit 43 Grey Nuns	1558	1338	1308
Royal Alexandra Hospital	596	364	153
University of Alberta Hospital	274	0	0
Home Care	1484	720	720
Sturgeon Hospital	187	89	373
Youville Nursing Home	0	0	52
RPCP	0	0	92
<b>Sub Total</b>	<b>8206</b>	<b>4781</b>	<b>7669</b>
RPCP Training Hours	1134	981	1341
Cross Cancer Institute	8569	7765	6707
<b>Total</b>	<b>17909</b>	<b>13527</b>	<b>15717</b>

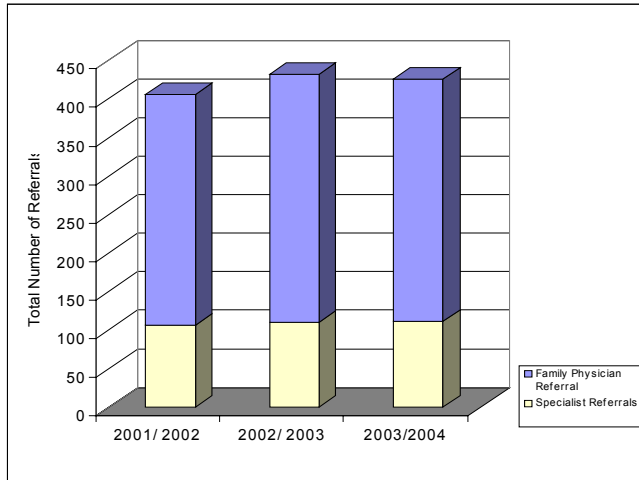
\* Hours unavailable at time of reporting

The UAH started their program in Sept. 2003.

### 3. PERSONS AND STAKEHOLDER SATISFACTION

“Strengthening respectful relationships with persons/ residents/ families/ communities and colleagues”

#### 3.1 Physician Referrals Received By RPCP



Fiscal Year	# MD Referrals	% of referrals received from family physicians
2001/ 2002	406	73.9% (300)
2002/ 2003	432	74.5% (322)
2003/ 2004	426	74.1% (315)

**Benchmark:** N/A

**RPCP Goal:** Support the interdisciplinary nature of palliative care emphasizing that the palliative person and family are key members of the team.

**CCRMH Goal:** Partnering with Others.

**Definition:** Number of physicians referring to the RPCP per year; Percentage of family physicians referring to RPCP = No. of family physicians referring divided by the total number of physicians referring to RPCP.

**Interpretation:** Referrals to the consult team are from the palliative person’s primary care physician, for consultation on symptom management and/or access to palliative hospice beds. It is important to monitor the referral patterns from physicians to ensure a wide number of physicians are aware of the program and are able to refer people when required. Knowledge of the program is essential to access for palliative care persons.

#### **D. Profile of Palliative Person by Site**

Palliative Home Care supports persons requiring symptom management and psychosocial support. There is an increase in the number of persons in this program from 957 (2000/01) to 1197 (2003/04). Diagnosis continues to be primarily cancer and the expected length of stay is 3 to 4 months. The average length of stay of 99.2 days (2002/03) to 81.5 days (2003/04) described in Figure 9a and 9b is within expected parameters for persons requiring active care to alleviate symptoms. Fourteen percent of all persons with cancer (2002) die at home, which represents 30% of the palliative home care population (2002). The steady increase in persons requiring palliative home care is expected to continue as the number of cancer deaths increase by 50-100 per year.

The number of persons who receive end of life care at the Palliative Hospices has stabilized at around 500 persons per year, 515 (2002/03) and 525 (2003/04) Figure 10a and 10b. The average length of stay has decreased slightly in the last few years from 40 days (2001/02) to 33.2 days (2003/04) with the median decreasing from 20 days (2001/02) to 17 days (2003/04). The occupancy rate remains quite stable at 89% (2000/2001) to 88.5% (2003/04) allowing for rapid admissions from home to avoid emergency visits or acute care. An average of 40 discharges to the 57 hospice beds occur every month representing a 70% turnover.

At the RAH the number of referrals has increased from 421 (1999/00) to 466 (2002/03) and 518 (2003/04) Figure 11a and 11b. The number of referrals for the UAH is 407 (2003/04) Figure 12. Diagnosis other than cancer reflecting the broader end of life care population, is over 10% for RAH and UAH. The RAH collects further information which identifies that 50% of the people they see have learned of that they require palliative services on this admission, demonstrating the mixed population in acute care.

The community consultation team is visiting persons in a wide variety of settings, the primary site being the three community hospitals (49-51%). The initial reason for referral to community consultation team continues to be placement for hospice or tertiary unit 56% (2002/04) versus 35% symptom management and 9% both placement and symptom management Figure 13a and 13b. A poor prognosis for pain management 45.4% (2002/03) and 51.2% (2003/04) suggests that the community consultants continue to be involved in complex palliative care problems in the community. Data on referrals to community consultants from within hospices has been an area identified for data collection.



**Table 6** Community Referrals to Palliative Care Cross Cancer Institute

	Capital Health Region		Other Regions		Total	
	2002/2003	2003/2004	2002/2003	2003/2004	2002/2003	2003/2004
<b>Total</b>	238	379	69	68	307	447
<b>Monthly Average</b>	19.8	31.6	5.8	5.7	25.5	37.3

**Table 7** Cross Cancer Institute – Pain & Symptom Statistics

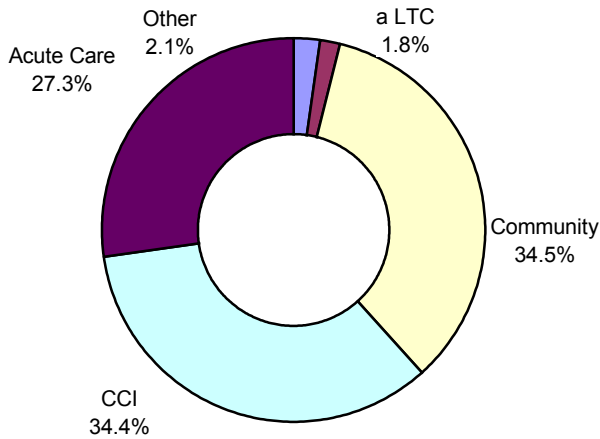
	New		Follow-up		Total	
	2002/2003	2003/2004	2002/2003	2003/2004	2002/2003	2003/2004
<b>Clinic</b>	137	134	94	88	231	222
<b>Referral<sup>a</sup></b>	274	325	277	281	551	606
<b>Total</b>	411	459	371	369	782	828

<sup>a</sup> Referrals to Pain & Symptom team seen outside of clinic.

Palliative persons are referred to the TPCU from anywhere in Northern Alberta. Palliative persons from other regions account for 4% (2002/03) and 8% (2003/04) Figure 14a and 14b. The most common referral site is acute care 43.8% (2002/03) and 44.5% in (2003/04) Figure 14a and 14b. In the past two years the average length of stay has decreased from 27 days to 24.7 days (2002/03) and 25.2 days (2003/04) Figure 14a and 14b with a median stay of 20 and 21 days. The decreased length of stay has allowed an increase in admissions. The number of people who are dying on the unit is slowly increasing due to lack of discharge sites for people with acute care needs. Compared with other areas the population is younger with complicated family situations. People have increased problems with pain management 76% (2002/03) and 81% (2003/04) Figure 14a and 14b.

**Palliative Home Care  
 Patient Profile  
 For Patients Discharged between Apr 01, 2002 and Mar 31, 2003  
 n = 1098**

**Referred from Location**



**Age at Discharge**

Mean	67.4
Minimum	0
Maximum	100

**Gender**

GENDER	PERCENT
Male	48.6%
Female	51.4%
Totals	100.0%

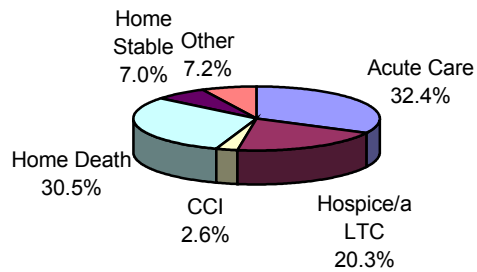
**Diagnosis**

Cancer	83.5%
Non-Cancer-Neuromuscular	1.7%
Non-Cancer-Cardiopulmonary	1.8%
Non-Cancer-Infectious Diseases	0.4%
Non-Cancer-Other	7.9%
Unknown	4.6%
TOTAL	99.9%

**Length of Stay (Days)**

Mean	99.2
Median	52
Mode	1
Minimum	0
Maximum	1519

**Discharge to Location**



a LTC: Long term care

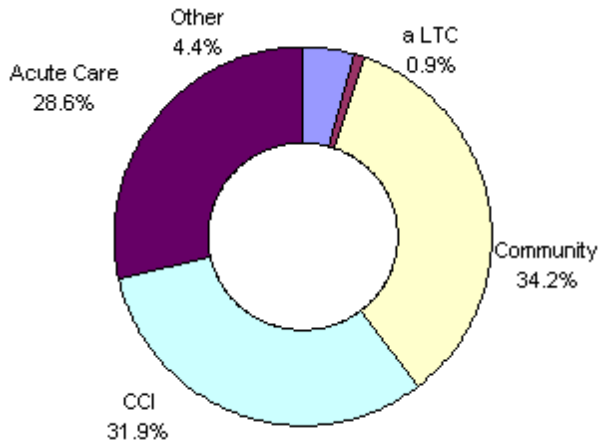
Source: Home Palliative Care Information System

Date: May 28, 2003

**Figure 9a**

**Palliative Home Care  
 Patient Profile  
 For Patients Discharged between Apr 01, 2003 and Mar 31, 2004  
 n = 1197**

**Referred from Location**



**Age at Discharge**

Mean	67.5
Minimum	0
Maximum	101

**Gender**

GENDER	PERCENT
Male	50.5%
Female	49.5%
Totals	100.0%

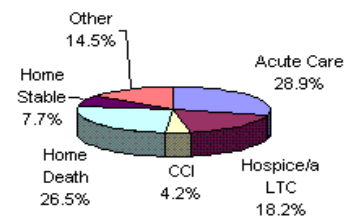
**Diagnosis**

Cancer	87.1%
Non-Cancer-Neuromuscular	0.8%
Non-Cancer-Cardiopulmonary	1.1%
Non-Cancer-Infectious Diseases	1.0%
Non-Cancer-Other	6.1%
Unknown	3.9%
<b>TOTAL</b>	<b>100.0%</b>

**Length of Stay (Days)**

Mean	81.5
Median	41
Mode	1
Minimum	0
Maximum	897

**Discharge to Location**



a LTC: Long term care

Source: Home Palliative Care Information System

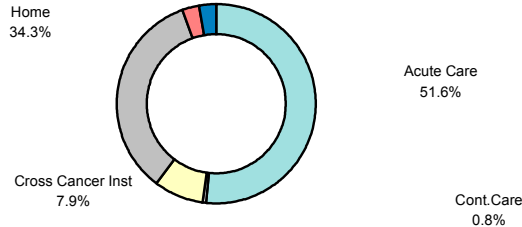
Date: June 08, 2004

**Figure 9b**

**Palliative Hospices  
 Patient Profile: All Sites  
 For Patients Discharged between Apr 01, 2002 and Mar 31, 2003**

n = 515

**Referred From Location**



**Age at Time of Admission**

Mean	73.1
Minimum	30
Maximum	100

**Diagnosis<sup>b</sup>**

DIAGNOSIS	PERCENT
BONE CT	0.8%
BREAST	7.6%
ENDOCRINES	2.9%
EYE, BRAIN, OTHER CNS	2.7%
GASTRO-INT	24.7%
GENITO-URI	14.8%
HEAD&NECK	6.8%
HEMATOLOGY	5.0%
LUNG	25.6%
MELANOMA	1.2%
OTHER CANCERS	3.5%
RETROPERITONEUM & PERITONEUM	0.6%
NON-CANCER-CARDIOPULMONARY	0.8%
NON-CANCER-NEUROMUSCULAR	0.4%
NON-CANCER-OTHER	2.7%
<b>TOTAL</b>	<b>100.0%</b>

**Gender**

GENDER	PERCENT
Male	44.80%
Female	55.20%
<b>TOTALS</b>	<b>100.00%</b>

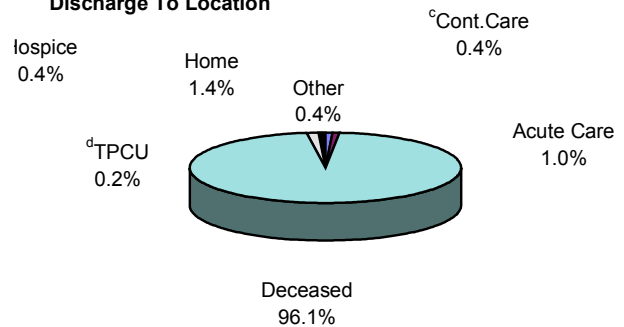
**Length of Stay (days)**

Mean	32.4
Median	17
Mode	n/a
Minimum	0
Maximum	299

**Occupancy Stats<sup>e</sup>**

Number of Beds	57
Days Occupied	18157
Days Available	20805
Occupancy Rate	87.3%

**Discharge To Location**



<sup>a</sup>Cross Cancer Inst - Cross Cancer Institute  
<sup>b</sup>Method of categorizing diagnosis changed year 2002 to be consistent with Alberta Cancer Board diagnosis groupings

<sup>c</sup>Cont Care - Continuing Care

<sup>d</sup>TPCU:Tertiary Palliative Care Unit

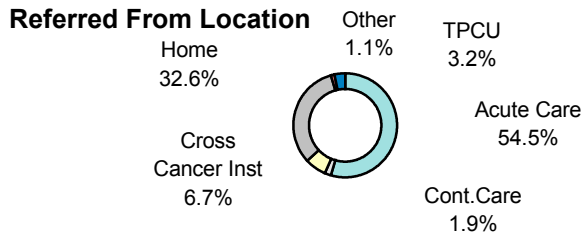
<sup>e</sup>Source: Regional Continuing Care  
 Source: Palliative Care Information System

Date:May 27, 2003

**Figure 10a**

**Palliative Hospices  
 Patient Profile: All Sites  
 For Patients Discharged between Apr 01, 2003 and Mar 31, 2004**

n = 525



**Age at Time of Admission**

Mean	72.7
Minimum	37
Maximum	101

**Diagnosis<sup>b</sup>**

DIAGNOSIS	PERCENT
BONE CT	0.6%
BREAST	8.8%
ENDOCRINES	1.9%
EYE, BRAIN, OTHER CNS	2.1%
GASTRO-INT	29.1%
GENITO-URI	17.1%
HEAD&NECK	5.1%
HEMATOLOGY	2.7%
LUNG	23.8%
MELANOMA	1.3%
OTHER CANCERS	3.6%
RETROPERITONEUM & PERITONEUM	0.4%
NON-CANCER-CARDIOPULMONARY	1.1%
NON-CANCER-INFECTIOUS	0.2%
NON-CANCER-NEUROMUSCULAR	0.2%
NON-CANCER-OTHER	1.9%
<b>TOTAL</b>	<b>100.0%</b>

**Gender**

GENDER	PERCENT
Male	40.90%
Female	59.10%
<b>TOTALS</b>	<b>100.00%</b>

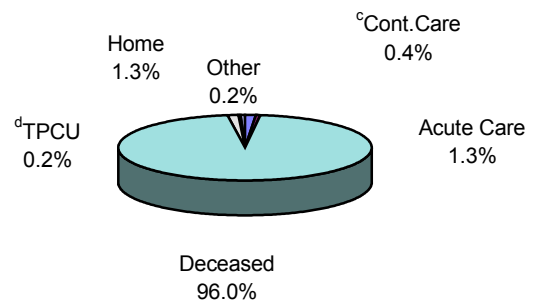
**Length of Stay (days)**

Mean	33.2
Median	17
Mode	1
Minimum	0
Maximum	327

**Occupancy Stats<sup>e</sup>**

Number of Beds	57
Days Occupied	18387
Days Available	20782
Occupancy Rate	88.5%

**Discharge To Location**



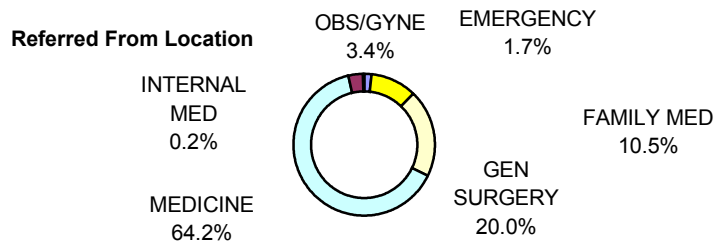
<sup>a</sup>Cross Cancer Inst - Cross Cancer Institute  
<sup>b</sup>Method of categorizing diagnosis changed year 2002 to be consistent with Alberta Cancer Board diagnosis groupings  
<sup>c</sup>Cont Care - Continuing Care  
<sup>d</sup>TPCU:Tertiary Palliative Care Unit  
<sup>e</sup>Source: Regional Continuing Care  
 Source: Palliative Care Information System  
 Date:June 15, 2004

**Figure 10b**

## Referral Hospitals Royal Alexandra Hospital Palliative Consult Team Patient Profile

**For Patients Discharged Between Apr 01, 2002 and Mar 31, 2003**

n = 466



### AGE at Time of Admission

Mean	70.6
Minimum	23
Maximum	100

### Diagnosis<sup>b</sup>

Diagnosis	Percent
BONE CT	1.5%
BREAST	4.9%
ENDOCRINES	0.2%
EYE, BRAIN, OTHER CNS	0.9%
GASTRO-INT	27.3%
GENITO-URI	15.9%
HEAD&NECK	2.1%
HEMATOLOGY	4.1%
LUNG	22.1%
MELANOMA	0.2%
NON-MELANOMA	0.2%
RETROPERITONEUM & PERITONEUM	1.3%
OTHER CANCERS	9.0%
NON-CANCER-CARDIOPULMONARY	4.1%
NON-CANCER-INFECTIOUS DISEASES	0.9%
NON-CANCER-NEUROMUSCULAR	1.9%
NON-CANCER-OTHER	3.4%
<b>Total</b>	<b>100.0%</b>

### Gender

GENDER	PERCENT
Male	50.80%
Female	49.20%
<b>TOTALS</b>	<b>100.00%</b>

### Length of Stay (days)

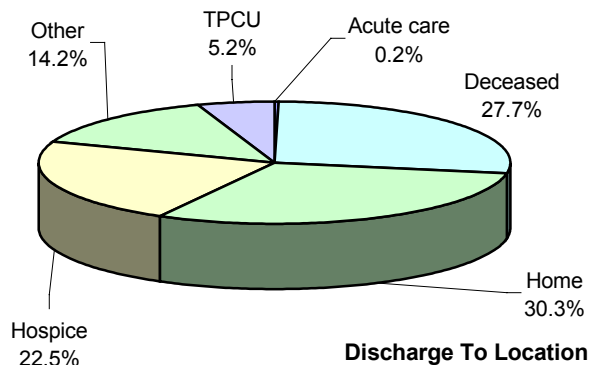
Mean	18.8
Median	14
Mode	14
Minimum	0
Maximum	149

### CAGE Scores(n=257)

SCORE	PERCENT
0 to 1	84.80%
2 to 4	15.20%
<b>TOTALS</b>	<b>100.00%</b>

### Pain Stage(n=355)

STAGE	PERCENT
1	38.60%
2	26.20%
3	35.20%
<b>TOTALS</b>	<b>100.00%</b>



<sup>a</sup>TPCU-Tertiary Palliative Care Unit

<sup>b</sup> Method of categorizing diagnosis changed year 2002 to be consistent with Alberta Cancer Board diagnosis groupings

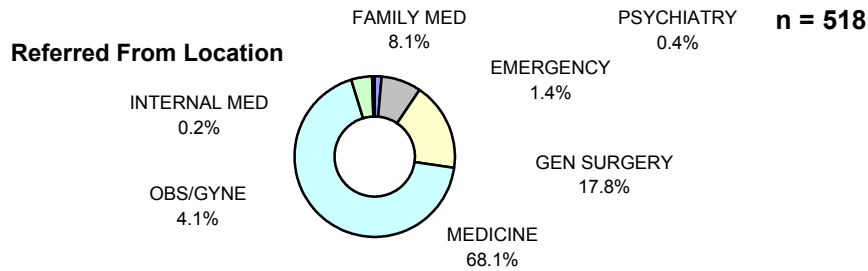
Source: Palliative Care Information System

Date: May 27, 2003

**Figure 11a**

## Referral Hospitals Royal Alexandra Hospital Palliative Consult Team Patient Profile

**For Patients Discharged Between Apr 01, 2003 and Mar 31, 2004**



### AGE at Time of Admission

Mean	69.8
Minimum	21
Maximum	100

### Diagnosis<sup>b</sup>

Diagnosis	Percent
BONE CT	1.7%
BREAST	5.4%
ENDOCRINES	0.2%
EYE, BRAIN, OTHER CNS	1.7%
GASTRO-INT	24.7%
GENITO-URI	15.4%
HEAD&NECK	1.0%
HEMATOLOGY	5.6%
LUNG	23.2%
MELANOMA	1.0%
NON-MELANOMA	0.2%
RETROPERITONEUM & PERITONEUM	0.2%
OTHER CANCERS	8.9%
NON-CANCER-CARDIOPULMONARY	5.4%
NON-CANCER-INFECTIOUS DISEASES	1.0%
NON-CANCER-NEUROMUSCULAR	1.5%
NON-CANCER-OTHER	2.9%
<b>Total</b>	<b>100.0%</b>

### Gender

GENDER	PERCENT
Male	49.80%
Female	50.20%
<b>TOTALS</b>	<b>100.00%</b>

### Length of Stay (days)

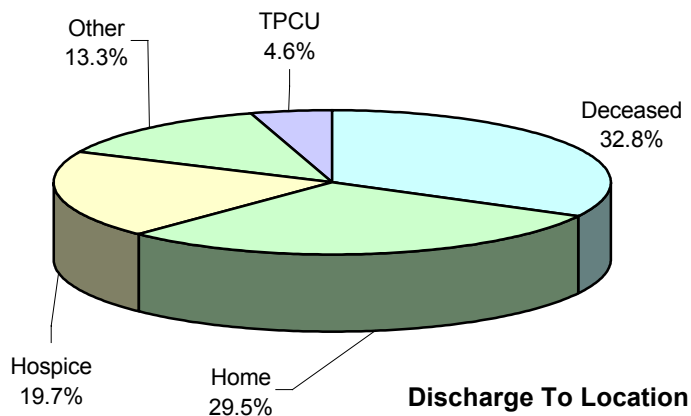
Mean	19.1
Median	14
Mode	13
Minimum	0
Maximum	159

### CAGE Scores(n=308)

SCORE	PERCENT
0 to 1	86.40%
2 to 4	13.60%
<b>TOTALS</b>	<b>100.00%</b>

### Pain Stage(n=368)

STAGE	PERCENT
1	44.60%
2	26.60%
3	28.80%
<b>TOTALS</b>	<b>100.00%</b>



<sup>a</sup>TPCU-Tertiary Palliative Care Unit

<sup>b</sup> Method of categorizing diagnosis changed year 2002 to be consistent with Alberta Cancer Board diagnosis groupings

Source: Palliative Care Information System

Date: June 15, 2004

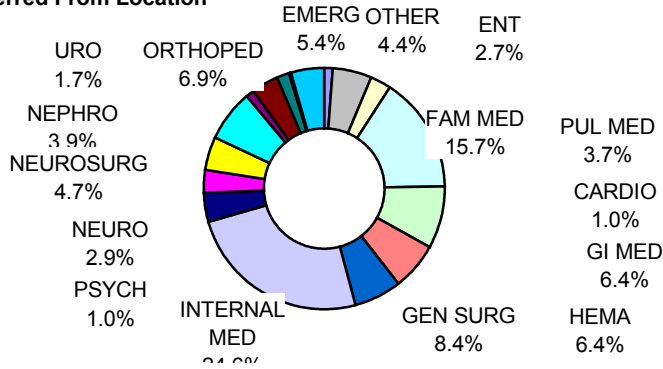
**Figure 11b**

**Referral Hospital: University Hospital Palliative Consult Team**

**Patient Profile n = 407**

**For Patients Discharged Between Apr 01,2003 and Mar 31, 2004**

**Referred From Location**



**AGE at Time of Admission**

Mean	69.8
Minimum	18
Maximum	98

**Gender**

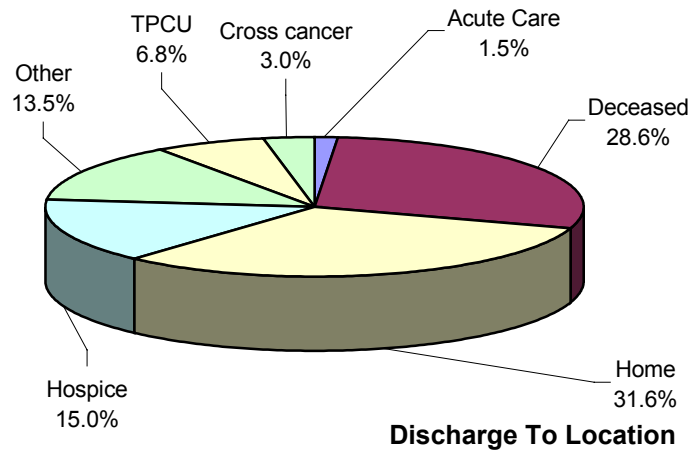
GENDER	PERCENT
Male	55.40%
Female	44.60%
<b>TOTALS</b>	<b>100.00%</b>

**Diagnosis<sup>b</sup>**

Diagnosis	Percent
BONE CT	1.7%
BREAST	7.1%
ENDOCRINES	0.2%
EYE, BRAIN, OTHER CNS	4.7%
GASTRO-INT	22.1%
GENITO-URI	9.8%
HEAD&NECK	3.9%
HEMATOLOGY	11.1%
LUNG	19.4%
MELANOMA	1.0%
CARDIOPULMONARY	2.2%
NON-CANCER- INFECTIOUS DISEASES	0.2%
NON-CANCER- NEUROMUSCULAR	4.4%
NON-CANCER-OTHER	4.9%
OTHER CANCERS	6.9%
RETROPERITONEUM & PERITONEUM	0.2%
<b>Total</b>	<b>100.0%</b>

**Length of Stay (days)**

Mean	19.2
Median	14
Mode	n/a
Minimum	0
Maximum	136



**CAGE Scores( n = 225 )**

SCORE	PERCENT
0 to 1	75.60%
2 to 4	24.40%
<b>TOTALS</b>	<b>100.00%</b>

**Pain Stage( n = 218 )**

STAGE	PERCENT
1	28.40%
2	7.30%
3	64.30%
<b>TOTALS</b>	<b>100.00%</b>

<sup>a</sup>TPCU-Tertiary Palliative Care Unit

<sup>b</sup> Method of categorizing diagnosis changed year 2002 to be consistent with Alberta Cancer Board diagnosis groupings

Source: Palliative Care Information System

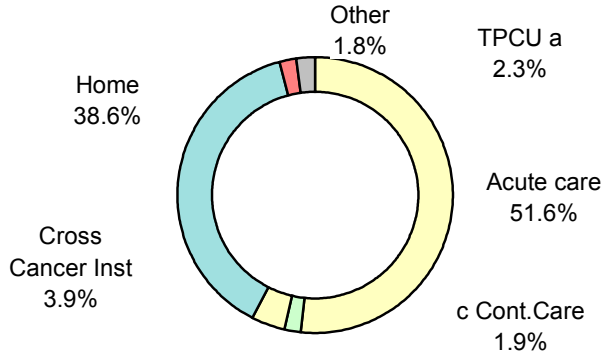
Date: June 15, 2004

**Figure 12a**



**Community Consult Team  
 Patient Profile n = 1085  
 For Patients Referred between Apr 01, 2002 and Mar 31, 2003**

**Referred From Location**



**AGE at Time of Referral**

Mean	70.5
Minimum	16
Maximum	100

**CAGE Scores(n=611)**

SCORE	PERCENT
0 to 1	86.3%
2 to 4	13.7%
<b>TOTALS</b>	<b>100.0%</b>

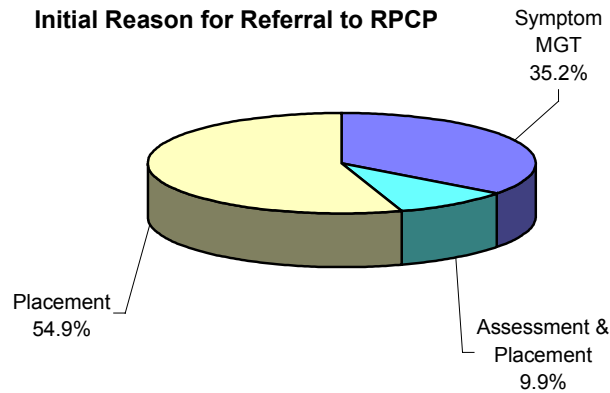
**Diagnosis<sup>b</sup>**

Diagnosis	Percent
BONES & CONNECTIVE TISSUE	0.5%
BREAST	9.6%
ENDOCRINE GLANDS	0.3%
EYE,BRAIN & OTHER PARTS OF CNS	2.3%
GASTRO-INT	25.3%
GENITO-URI	18.8%
HEAD&NECK	3.1%
HEMATOLOGY	5.8%
LUNG	23.8%
MELANOMA	0.9%
NON-MELANOMA	0.1%
OTHER CANCER	5.0%
RETROPERITONEUM & PERITONEUM	1.2%
NON-CANCER-CARDIOPULMONARY	0.8%
NON-CANCER-NEUROMUSCULAR	0.6%
NON-CANCER-OTHER	2.0%
<b>TOTAL</b>	<b>100.0%</b>

**Gender**

GENDER	PERCENT
Male	46.4%
Female	53.6%
<b>TOTALS</b>	<b>100.0%</b>

**Initial Reason for Referral to RPCP**



**Pain Stage(n=141)<sup>d</sup>**

STAGE	PERCENT
1	40.40%
2	14.20%
3	45.40%
<b>TOTALS</b>	<b>100.00%</b>

<sup>a</sup>TPCU - Tertiary Palliative Care Unit

<sup>b</sup> Method of categorizing diagnosis changed year 2001 to be consistent with Alberta Cancer Board diagnosis groupings

<sup>c</sup>Cont. Care - Continuing Care

<sup>d</sup>Pain Stage data collection started June, 2000

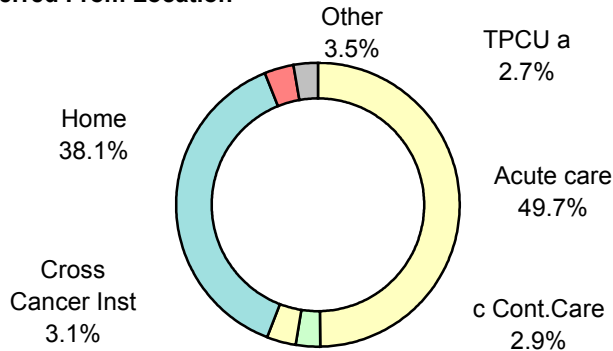
Source: Palliative Care Information System

Date: May 27, 2003

**Figure 13a**

**Community Consult Team  
 Patient Profile n = 1088  
 For Patients Referred between Apr 01, 2003 and Mar 31, 2004**

**Referred From Location**



**AGE at Time of Referral**

Mean	70.8
Minimum	24
Maximum	101

**CAGE Scores(n=607)**

SCORE	PERCENT
0 to 1	82.0%
2 to 4	18.0%
<b>TOTALS</b>	<b>100.0%</b>

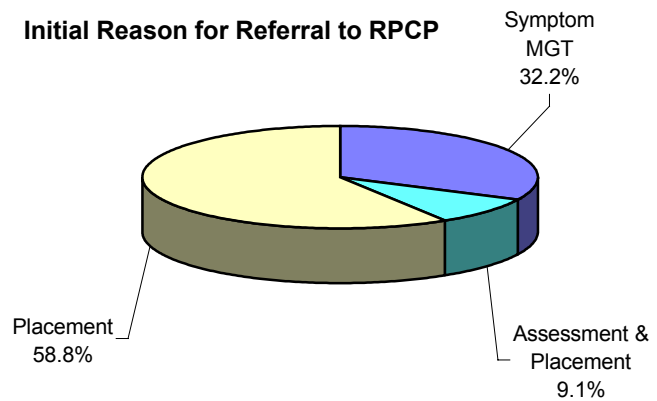
**Diagnosis<sup>b</sup>**

Diagnosis	Percent
BONES & CONNECTIVE TISSUE	1.0%
BREAST	9.9%
ENDOCRINE GLANDS	0.2%
EYE, BRAIN & OTHER PARTS OF CNS	2.6%
GASTRO-INT	28.4%
GENITO-URI	18.7%
HEAD&NECK	1.6%
HEMATOLOGY	5.8%
LUNG	23.6%
MELANOMA	0.7%
OTHER CANCER	3.3%
RETROPERITONEUM & PERITONEUM	0.6%
NON-CANCER-CARDIOPULMONARY	1.1%
NON-CANCER-INFECTIOUS	0.1%
NON-CANCER-NEUROMUSCULAR	0.4%
NON-CANCER-OTHER	2.0%
<b>TOTAL</b>	<b>100.0%</b>

**Gender**

GENDER	PERCENT
Male	44.7%
Female	55.3%
<b>TOTALS</b>	<b>100.0%</b>

**Initial Reason for Referral to RPCP**



**Pain Stage(n=170)<sup>d</sup>**

STAGE	PERCENT
1	36.50%
2	12.30%
3	51.20%
<b>TOTALS</b>	<b>100.00%</b>

<sup>a</sup>TPCU - Tertiary Palliative Care Unit

<sup>b</sup> Method of categorizing diagnosis changed year 2001 to be consistent with Alberta Cancer Board diagnosis groupings

<sup>c</sup>Cont. Care - Continuing Care

<sup>d</sup>Pain Stage data collection started June, 2000  
 Source: Palliative Care Information System

Date: June 18, 2004

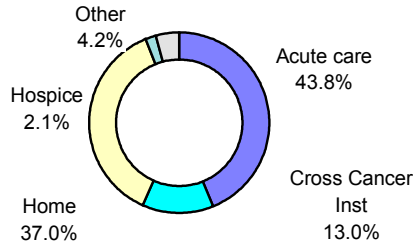
**Figure 13b**

### Tertiary Palliative Care Unit (TPCU) Patient Profile

For Patients Discharged between Apr 01, 2002 and Mar 31, 2003

n = 192<sup>a</sup>

#### Referred From Location



#### AGE at Time of Admission

Mean	60.6
Minimum	20
Maximum	87

#### Gender

GENDER	PERCENT
Male	41.8
Female	58.2

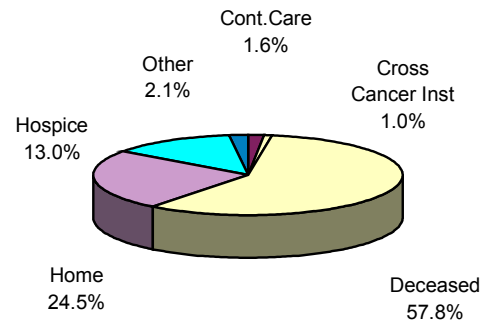
#### Diagnosis<sup>b</sup>

Diagnosis	Percent
BREAST	14.6%
BONE CT	1.1%
ENDOCRINES	0.5%
EYE, BRAIN, OTHER CNS	0.5%
GASTRO-INT	24.0%
GENITO-URI	22.9%
HEAD&NECK	2.6%
HEMATOLOGY	5.7%
LUNG	19.8%
MELANOMA	2.1%
OTHER CANCER	5.7%
RETROPERITONEAL	0.5%
<b>TOTALS</b>	<b>100.0%</b>

#### Length of Stay (days)

Mean	24.7
Median	20
Mode	n/a
Minimum	0
Maximum	392

#### Discharge To Location



#### CAGE Scores(n=154)

SCORE	PERCENT
0 to 1	79.2%
2 to 4	20.8%
<b>TOTALS</b>	<b>100.0%</b>

#### Pain Stage(n=150)

STAGE	PERCENT
1	13.3
2	6.0
3	80.7
<b>TOTALS</b>	<b>100.0</b>

#### Occupancy Stats<sup>c</sup>

Number of Beds	14
Total LOS <sup>d</sup>	4467
%Occupancy(adjusted) <sup>a</sup>	91.10%

<sup>a</sup>excluding non-palliative patients  
<sup>b</sup> Method of categorizing diagnosis changed year 2002 to be consistent with Alberta Cancer Board diagnosis groupings

<sup>c</sup>Grev Nuns Health Records

<sup>d</sup>LOS- Length of Stay

Source: Palliative Care Information System

Date: May 27, 2003

**Figure 14a**

## E. Clinical Data

The RPCP is supported by a regional database where demographic and clinical data is entered from all areas of the program utilizing common assessment tools. The community nurse and physician consultants utilize a single assessment form and common symptom assessment tools to ensure that the most appropriate care setting is chosen. Each assessment tool has guidelines that provide frequency of administration per area:

- Edmonton Symptom Assessment System (ESAS) - designed to assist in the assessment of nine symptoms common in persons with cancer and provides a clinical profile of symptom severity over time.
- Mini Mental State Examination (MMSE) – screens for cognitive impairment.
- CAGE –used for screening persons for alcoholism.
- Edmonton Staging System for Cancer Pain (ESS) - provides a clinical staging system predicting the prognosis for management of cancer pain. Stage 3 indicates poor prognosis for cancer pain.
- Palliative Performance Scale (PPS). - measures the functional/performance status of palliative persons.

As well as providing individual clinical information, the averages of ESAS scores allows the program to review and describe the types of palliative care issues occurring in the different areas of the program.

Palliative Home Care ESAS scores reflect the more stable population of mild symptom profile. Average pain scores are 3/10, Figure 15a and 15b. Cognitive impairment is less common (10% with abnormal MMSE on admission, Figure 16).

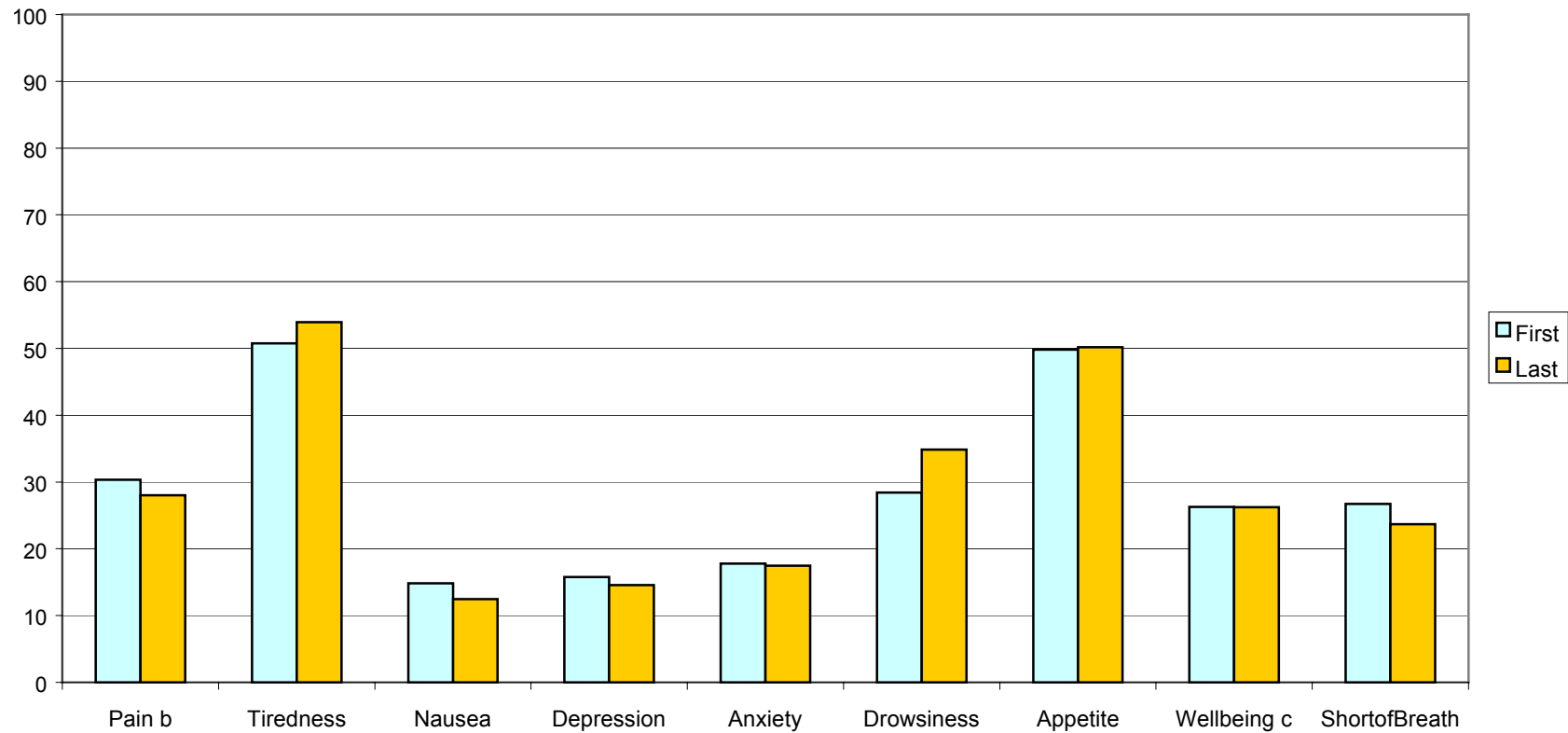
Hospices ESAS scores reflect mild to moderate symptoms, Figure 17a and 17b. The average pain score is 3/10. Higher abnormal MMSE of 50%, Figure 18a and 18b and drowsiness scores of 4/10 begin to describe the nursing care needed to provide safe, quality palliative care.

Consultations to the Royal Alexandra and University of Alberta Hospital appear to demonstrate the more mixed population seen often earlier in the disease trajectory. Average pain scores at the RAH are 2/10 (2002/04), Figure 19a and 19b and 3/10 (2003/04) Figure 21 at the UAH. Cognitive impairment is more frequently noted in this population than for community or TPCU often reflecting the need for referral to Hospice. Discharge planning to the most appropriate setting remains a strong focus for the consultation team.

Scores from the community consultants reflect people assessed in their home, community setting or hospital and demonstrate moderate symptom distress. Average pain scores are more than 4/10, Figure 23a and 23b. Higher symptom scores are expected than Home Care where consultants should be seeing those requiring advice on symptom management.

Clearly the TPCU admits persons with the highest symptom scores, requiring the intense management available from the interdisciplinary team (2002/04) Figure 25a and 25b. The average pain score on admission is more than 5/10 indicating severe pain. Increased psychosocial support is needed for the younger population, as indicated by the higher depression (5/10), anxiety (4/10) and sense of wellbeing (5/10) scores than other areas of the program.

**Palliative Home Care  
 ESAS<sup>a</sup> Scores First and Last Averages  
 Administered between Apr 01, 2002 and Mar 31, 2003**



<sup>a</sup> Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

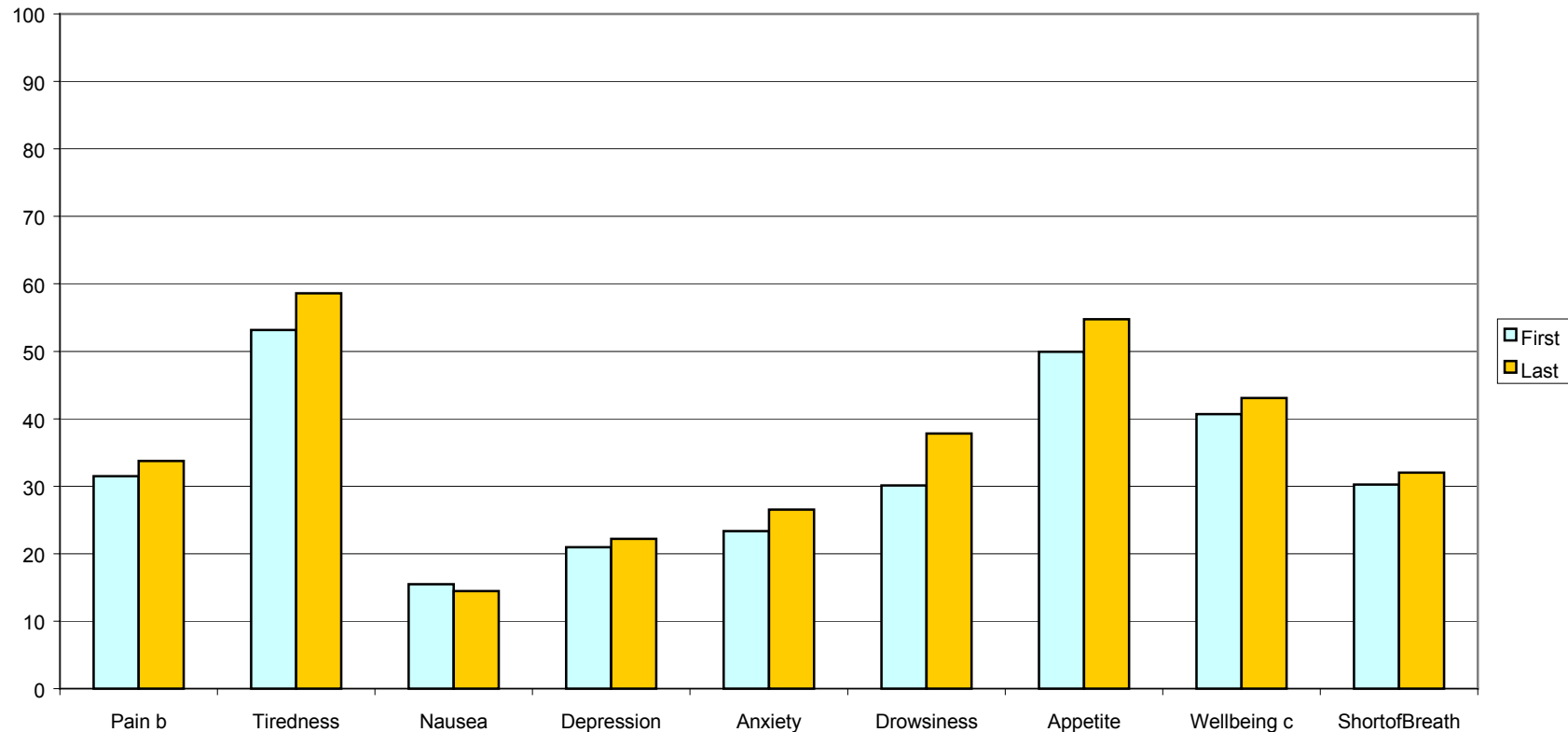
<sup>b</sup> Pain: total First and last Pain assessment counts are 607 and 422 respectively

<sup>c</sup> Wellbeing: total First and Last Wellbeing assessment counts are 568 and 359 respectively

Source: Home Palliative Care Information System

**Figure 15a**

**Palliative Home Care**  
**ESAS<sup>a</sup> Scores First and Last Averages**  
**Administered between Apr 01, 2003 and Mar 31, 2004**



<sup>a</sup> Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup> Pain: total First and last Pain assessment counts are 572 and 354 respectively

<sup>c</sup> Wellbeing: total First and Last Wellbeing assessment counts are 438 and 240 respectively

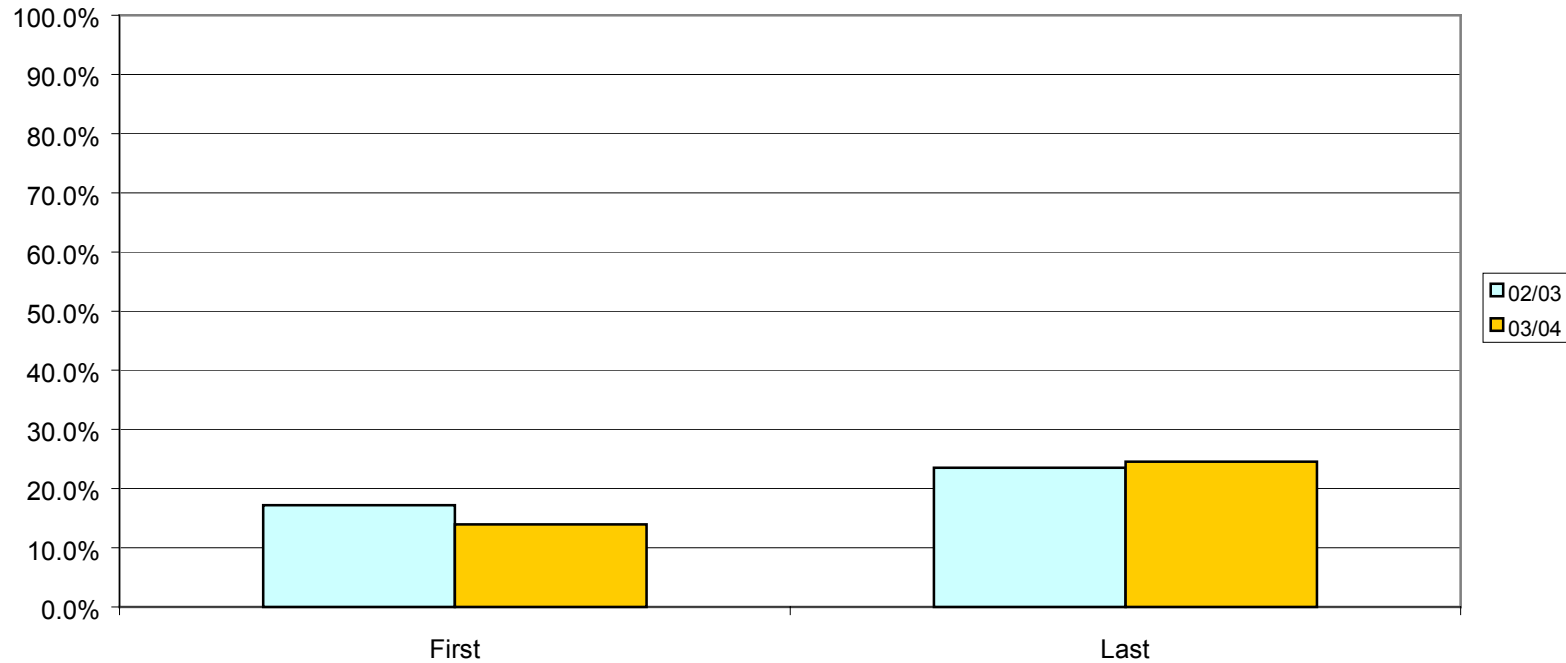
Source: Home Palliative Care Information System

Date: June 08, 2004

**Figure 15b**

**Palliative Home Care  
 Abnormal MMSE Scores<sup>a</sup> - First and Last Measures  
 Administered between Apr 01, 2002 and Mar 31, 2004**

	02/03	03/04
<b>First</b>	49	45
<b>First Total</b>	285	322
<b>Last</b>	20	26
<b>Last Total</b>	85	106



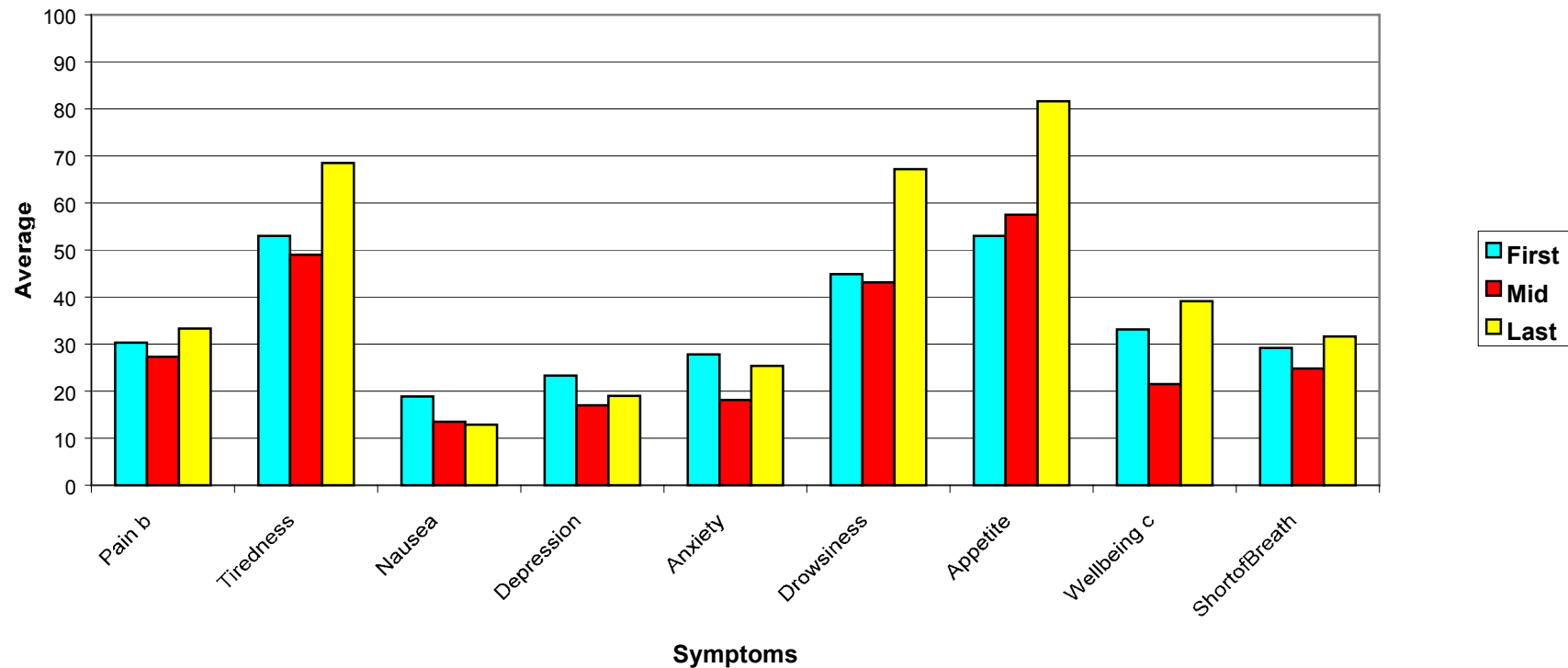
<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment

Source: Home Palliative Care Information System

Date: June 04, 2004

**Figure 16**

**Palliative Hospices**  
**ESAS<sup>a</sup> Scores First Mid and Last Averages**  
**For Patients Discharged between Apr 01, 2002 and Mar 31, 2003**



<sup>a</sup>Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup>Pain: Total First, Mid and Last Pain assessment counts are 457, 408 and 442 respectively

<sup>c</sup>Wellbeing: Total First, Mid and Last Wellbeing assessment counts are 296, 396 and 93 respectively

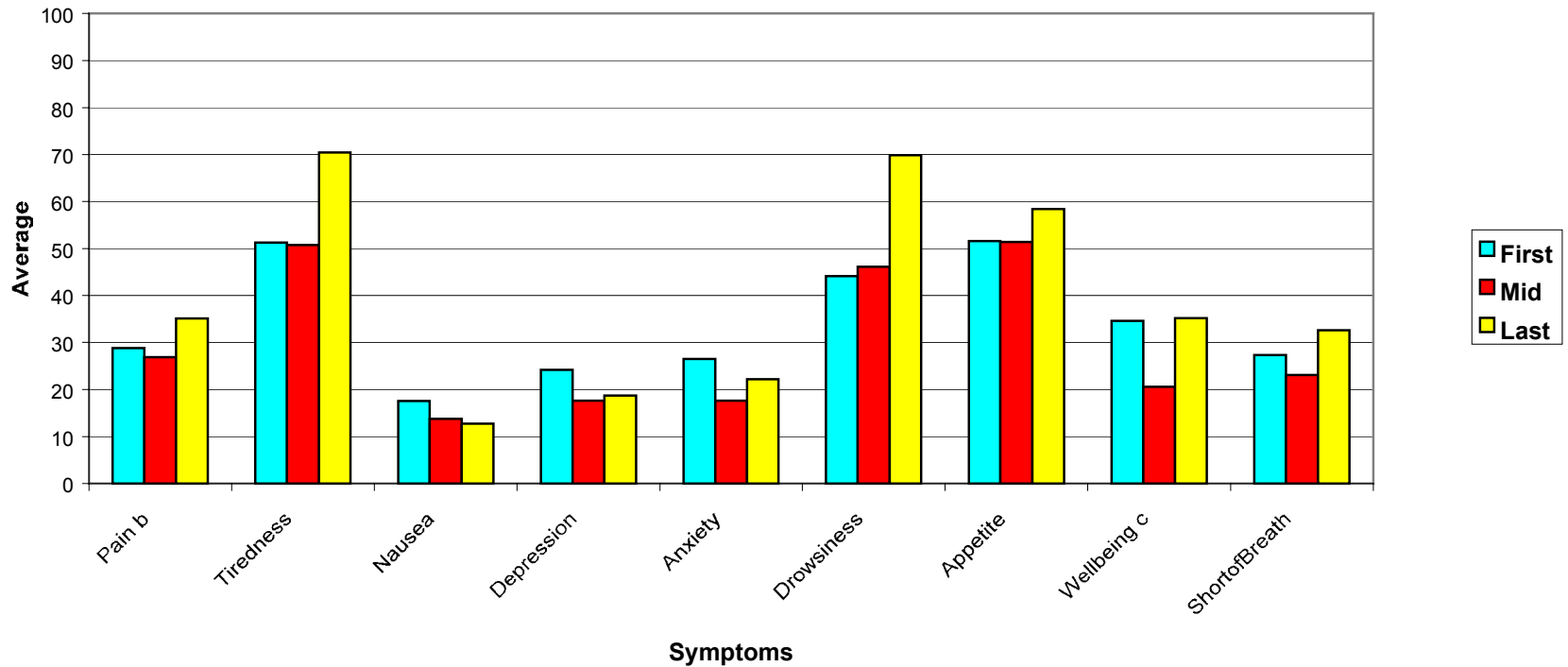
Source: Palliative Care Information System

Date: June 03, 2003

**Figure 17a**



**Palliative Hospices**  
**ESAS<sup>a</sup> Scores First, Mid and Last Averages**  
**For Patients Discharged between Apr 01, 2003 and Mar 31, 2004**



<sup>a</sup>Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup>Pain: Total First, Mid and Last Pain assessment counts are 484, 424 and 460 respectively

<sup>c</sup>Wellbeing: Total First, Mid and Last Wellbeing assessment counts are 328, 408 and 105 respectively

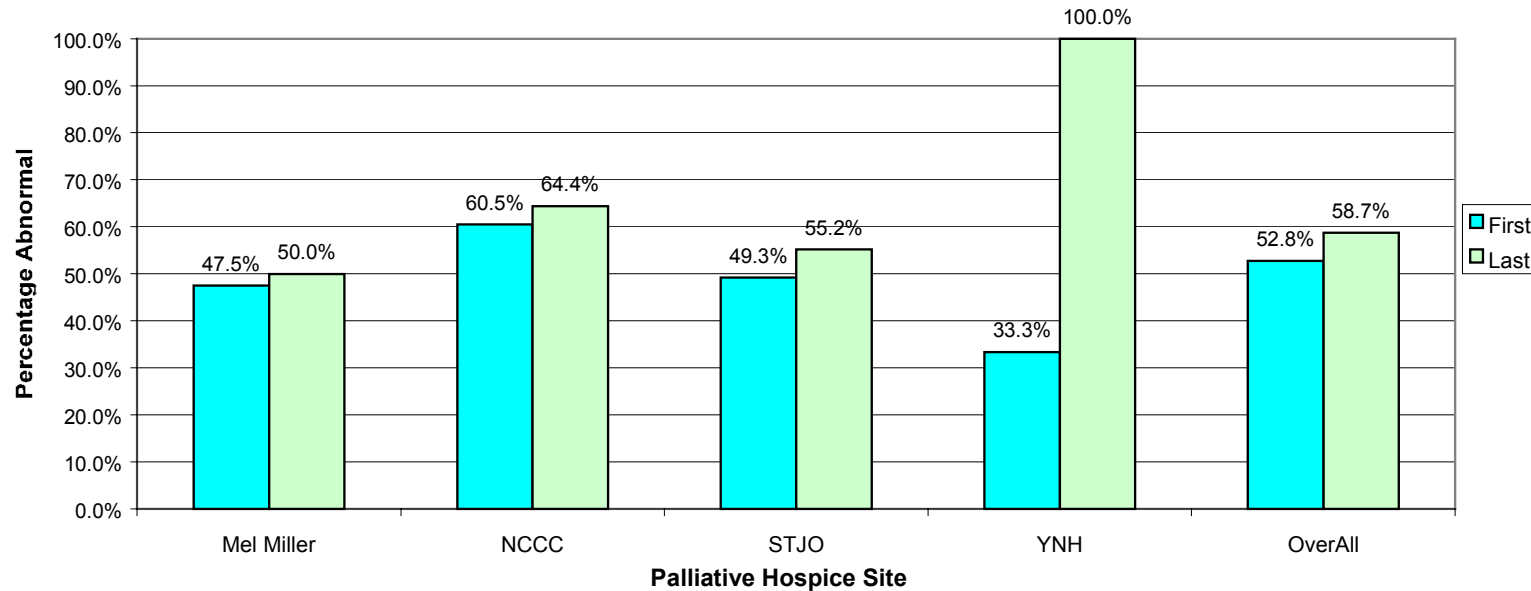
Source: Palliative Care Information System

Date: June 15, 2004

**Figure 17b**

**Palliative Hospices**  
**Abnormal MMSE Scores<sup>a</sup> - First and Last Measures**  
**For Patients Discharged between Apr 01, 2002 and Mar 31, 2003**

Hospices	First(Overall)	Last(Overall)
Mel Miller	120	40
Norwood	119	73
St.Joe	67	29
Youville	3	1
<b>Overall</b>	<b>309</b>	<b>143</b>

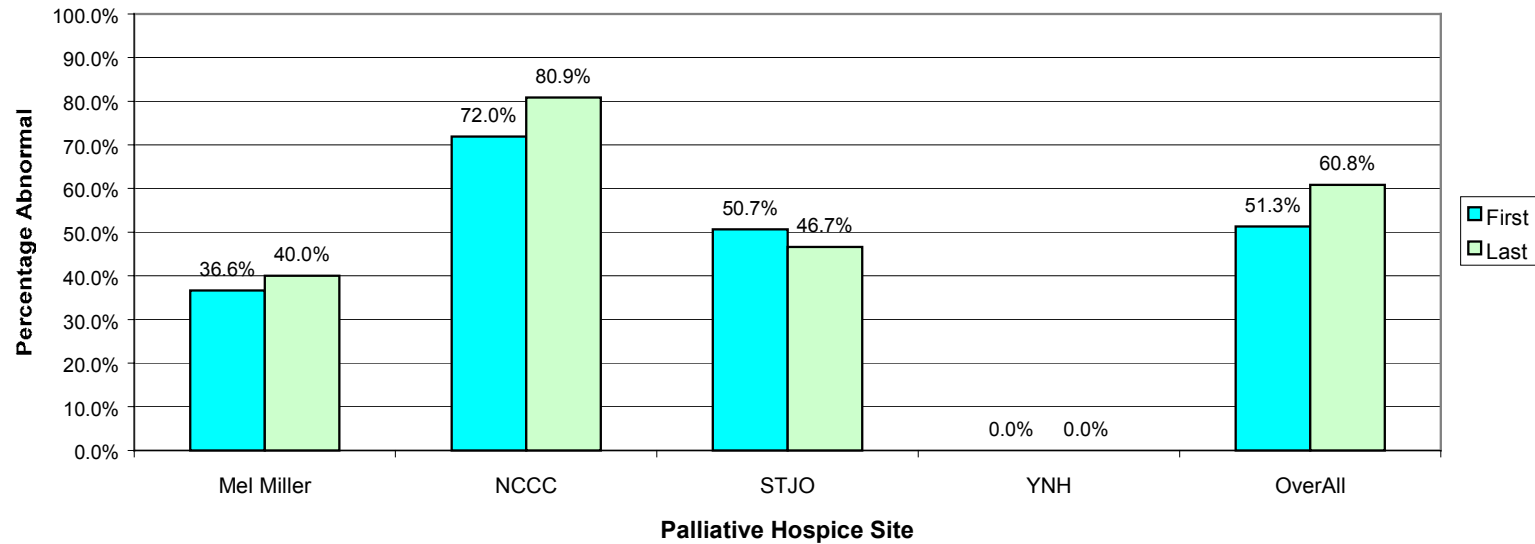


<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment  
 Source: Palliative Care Information System  
 Date: May 27, 2003

**Figure 18a**

**Palliative Hospices**  
**Abnormal MMSE Scores<sup>a</sup> - First and Last Measures**  
**For Patients Discharged between Apr 01, 2003 and Mar 31, 2004**

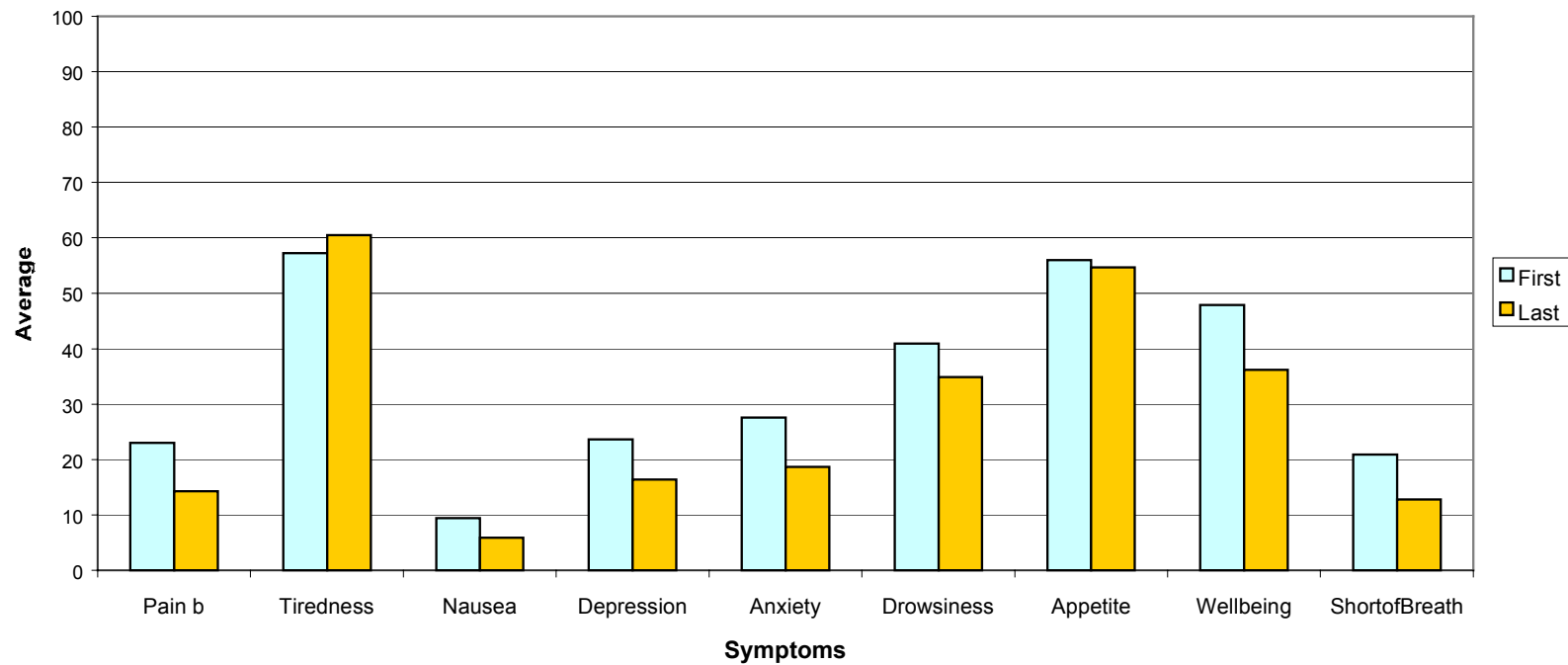
Hospices	First(Overall)	Last(Overall)
Mel Miller	112	35
Norwood	82	47
St.Joe	73	15
Youville	n/a	n/a
<b>Overall</b>	<b>267</b>	<b>97</b>



<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment  
 Source: Palliative Care Information System  
 Date: June 15, 2004

**Figure 18b**

**Referral Hospital: Royal Alexandra Hospital Palliative Consult Team**  
**ESAS<sup>a</sup> Scores First and Last Averages**  
**For Patients Discharged Between Apr 01, 2002 and Mar 31, 2003**



<sup>a</sup>Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup>Pain: Total First and Last Pain assessment counts are 463 and 305 respectively

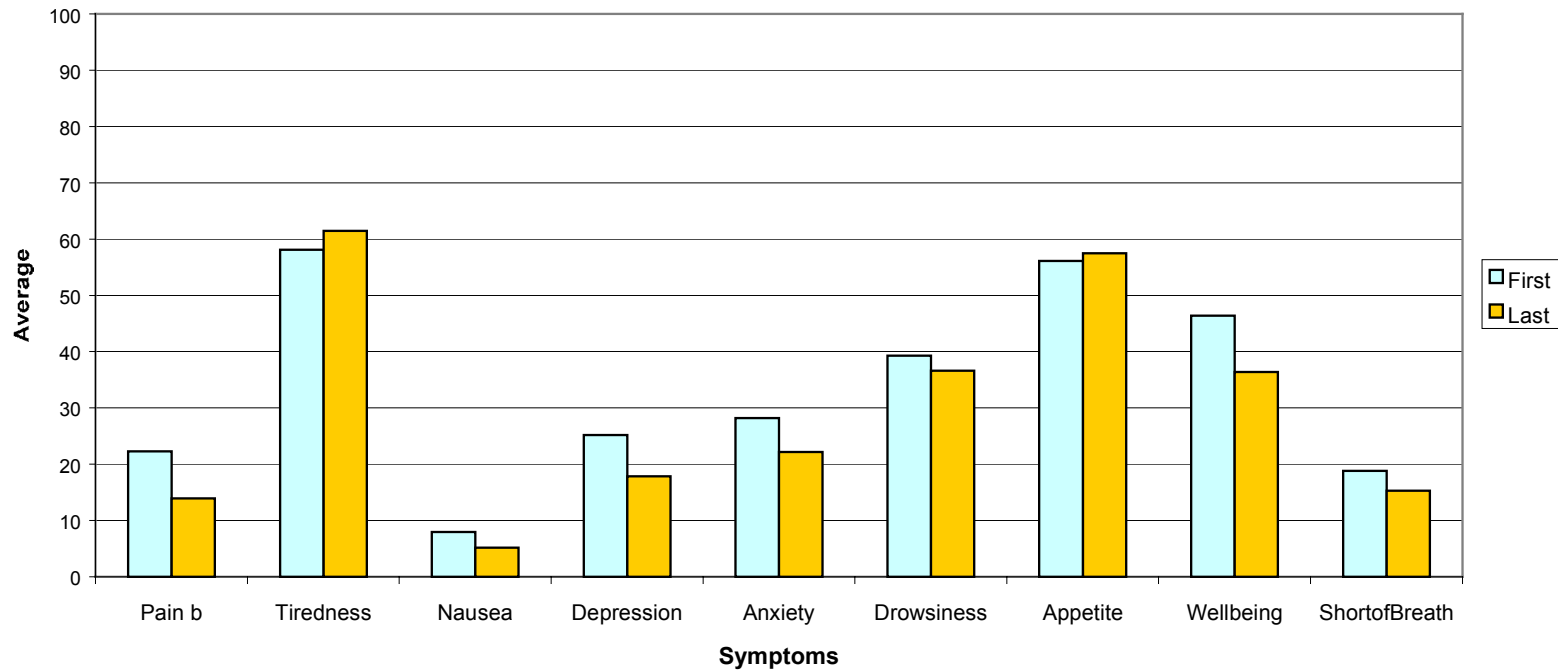
<sup>c</sup>Wellbeing: Total First and Last Wellbeing assessment counts are 298 and 200 respectively

Source: Palliative Care Information System

Date: Jun 03, 2003

**Figure 19a**

**Referral Hospital: Royal Alexandra Hospital Palliative Consult Team**  
**ESAS<sup>a</sup> Scores First and Last Averages**  
**For Patients Discharged Between Apr 01, 2003 and Mar 31, 2004**



<sup>a</sup>Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup>Pain: Total First and Last Pain assessment counts are 507 and 312 respectively

<sup>c</sup>Wellbeing: Total First and Last Wellbeing assessment counts are 322 and 177 respectively

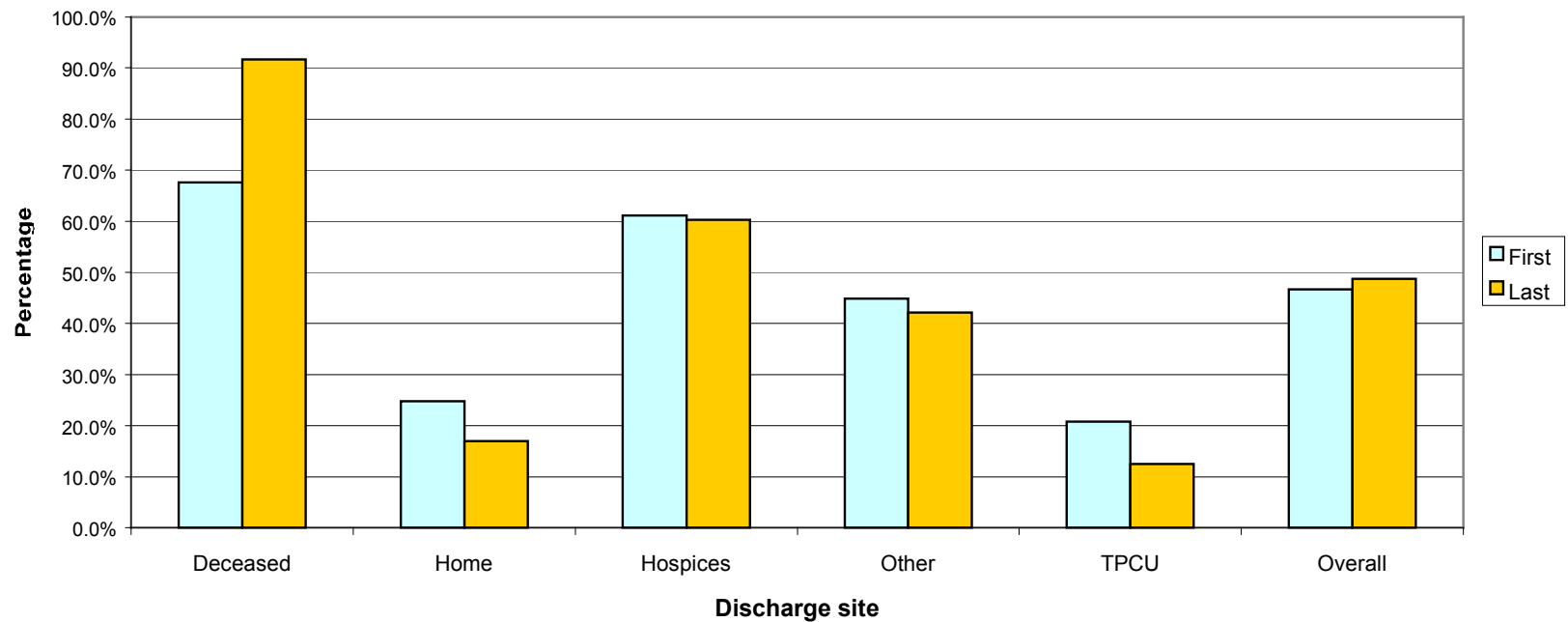
Source: Palliative Care Information System

Date: June 15, 2004

**Figure 19b**

**Referral Hospital: Royal Alexandra Hospital Palliative Consult Team**  
**Abnormal MMSE<sup>a</sup> - First and Last Measures**  
**For Patients Discharged Between Apr 01, 2002 and Mar 31, 2003**

	Overall
<b>First</b>	188
<b>First Total</b>	403
<b>Last</b>	117
<b>Last Total</b>	240

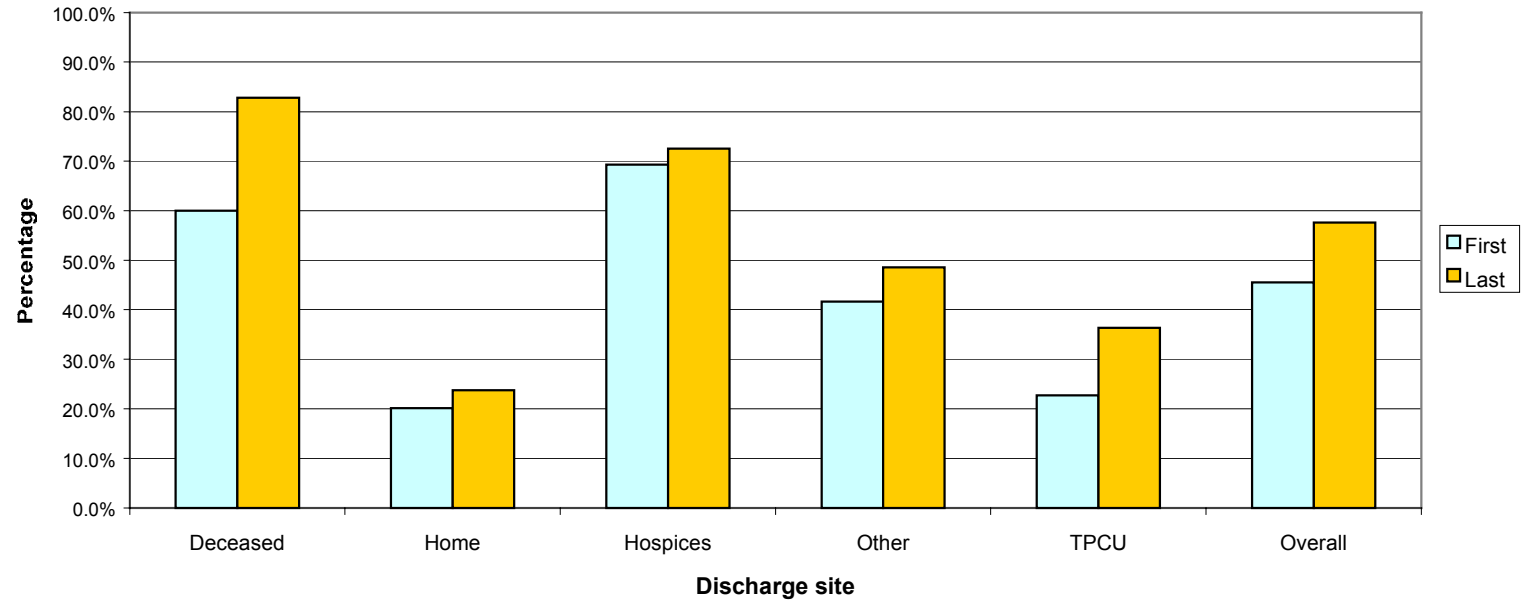


<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment  
 Source: Palliative Care Information System  
 Date: Jun 03, 2003

**Figure 20a**

**Referral Hospital: Royal Alexandra Hospital Palliative Consult Team**  
**Abnormal MMSE<sup>a</sup> - First and Last Measures**  
**For Patients Discharged by Site of Discharge Between Apr 01, 2003 and Mar 31, 2004**

	Overall
First	202
First Total	444
Last	133
Last Total	231



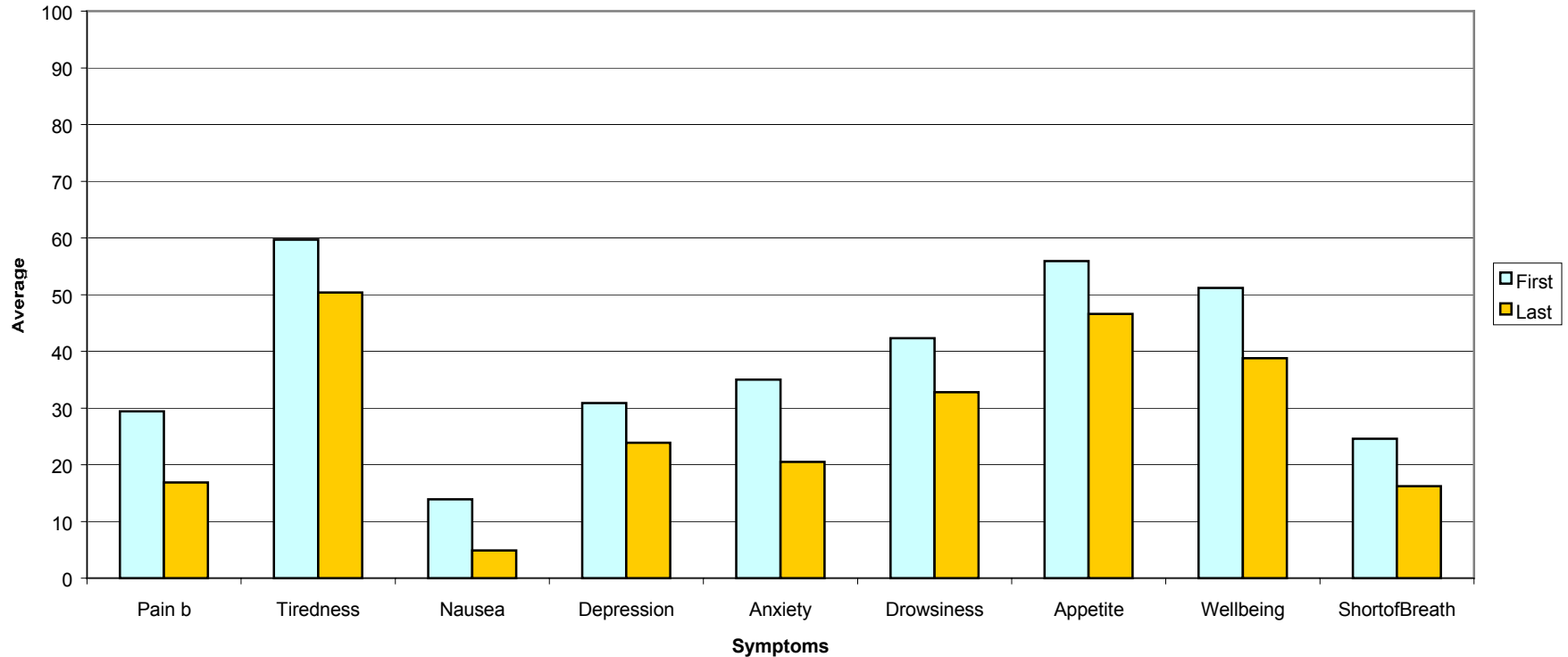
<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment

Source: Palliative Care Information System

Date: June 15, 2004

**Figure 20b**

**Referral Hospital: University Hospital Palliative Consult Team**  
**ESAS<sup>a</sup> Scores First and Last Averages**  
**For Patients Discharged Between Apr 01, 2003 and Mar 31, 2004**



<sup>a</sup>Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup>Pain: Total First and Last Pain assessment counts are 118 and 12 respectively

<sup>c</sup>Wellbeing: Total First and Last Wellbeing assessment counts are 85 and 6 respectively

Source: Palliative Care Information System

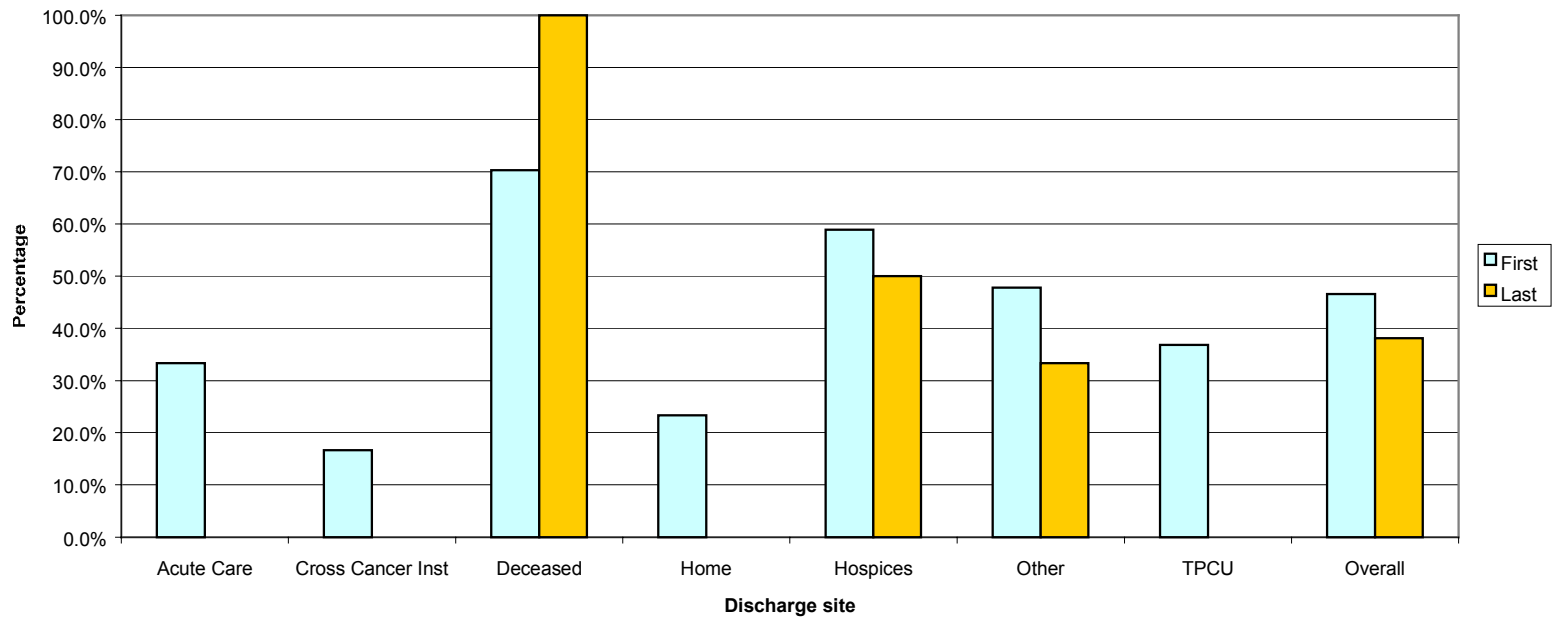
Date: June 15, 2004

**Figure 21**



**Referral Hospital: University Hospital Palliative Consult Team**  
**Abnormal MMSE<sup>a</sup> - First and Last Measures**  
**For Patients Discharged by Site of Discharge Between Apr 01, 2003 and Mar 31, 2004**

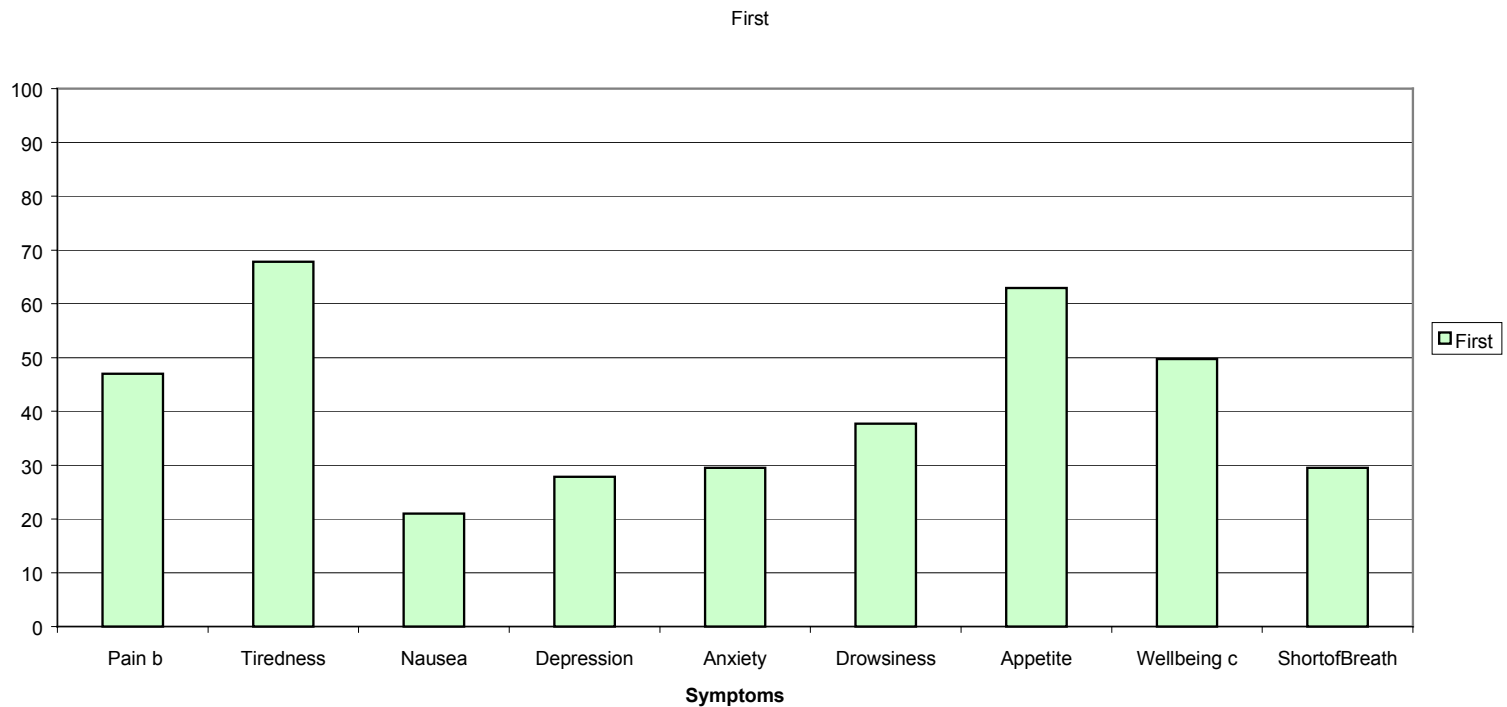
	Overall
<b>First</b>	137
<b>First Total</b>	294
<b>Last</b>	8
<b>Last Total</b>	21



<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment  
 Source: Palliative Care Information System  
 Date: June 15, 2004

**Figure 22a**

**Community Consult Team**  
**ESAS<sup>a</sup> Scores First Averages**  
**For Patients Referred between Apr 01, 2002 and Mar 31, 2003**



<sup>a</sup> Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup> Pain: total First Pain assessment count is 679

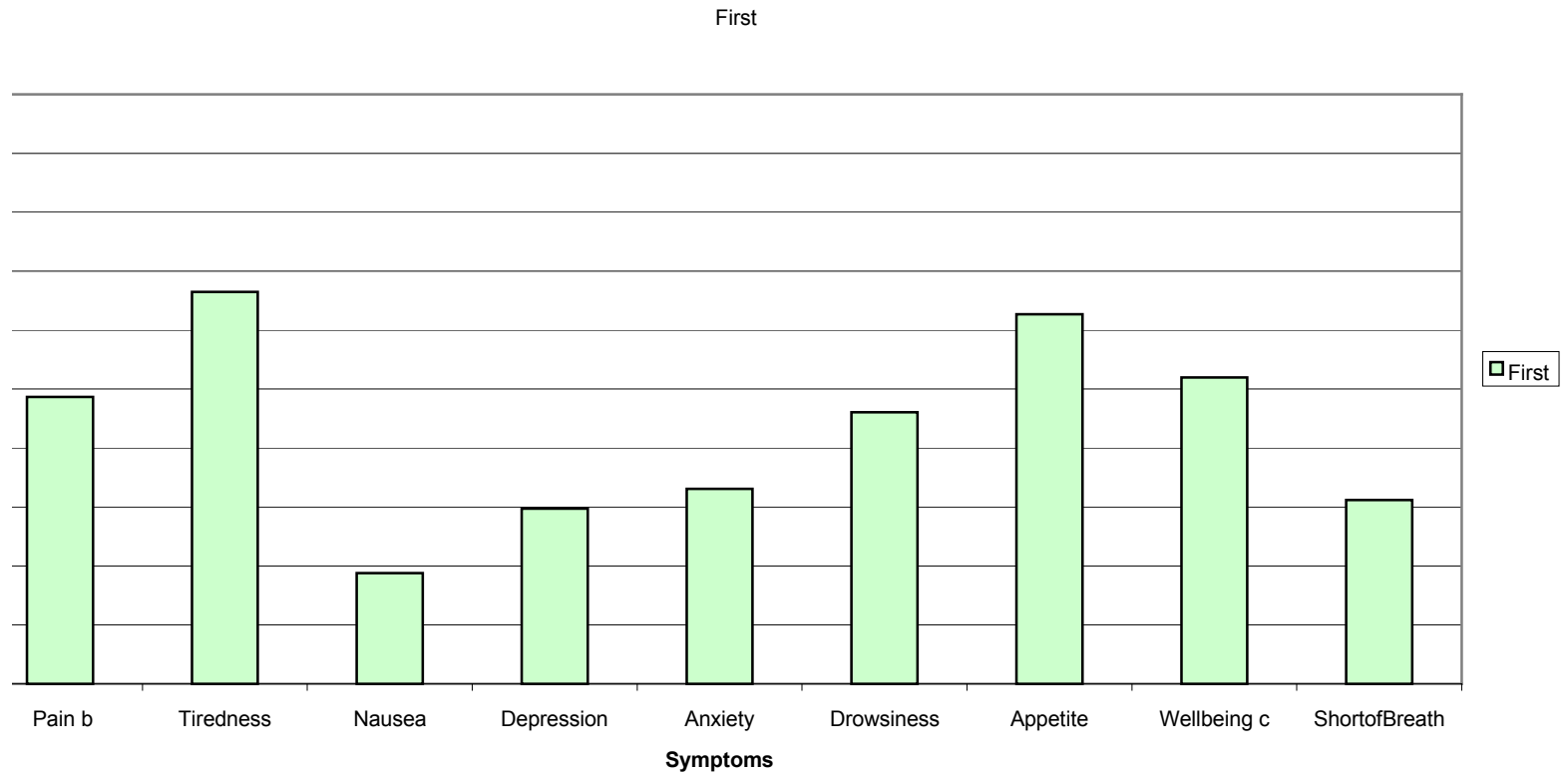
<sup>c</sup> Wellbeing: total First Wellbeing assessment count is 430

Source: Palliative Care Information System

Date: Jun 03, 2003

**Figure 23a**

**Community Consult Team**  
**ESAS<sup>a</sup> Scores First Averages**  
**For Patients Referred between Apr 01, 2003 and Mar 31, 2004**



<sup>a</sup> Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup> Pain: total First Pain assessment count is 647

<sup>c</sup> Wellbeing: total First Wellbeing assessment count is 365

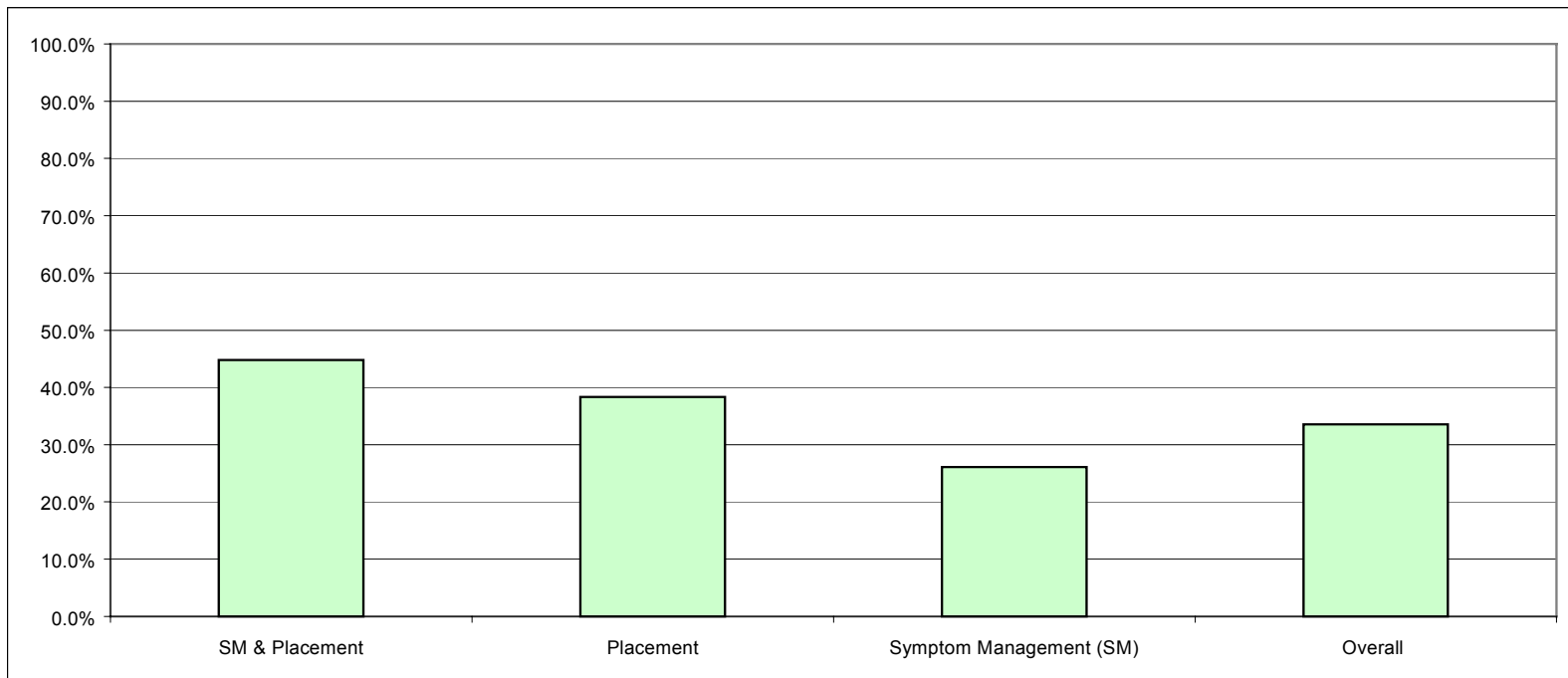
Source: Palliative Care Information System

Date: June 18, 2004

**Figure 23b**

**Community Consult Team**  
**Abnormal MMSE Scores<sup>a</sup> - First Measure by Reason of Referral**  
**For Patients Referred between Apr 01, 2002 and Mar 31, 2003**

	<b>Count</b>	<b>Total</b>
SM & Placement	30	67
Placement	89	232
Symptom Management (SM)	65	249
Overall	184	548



<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment

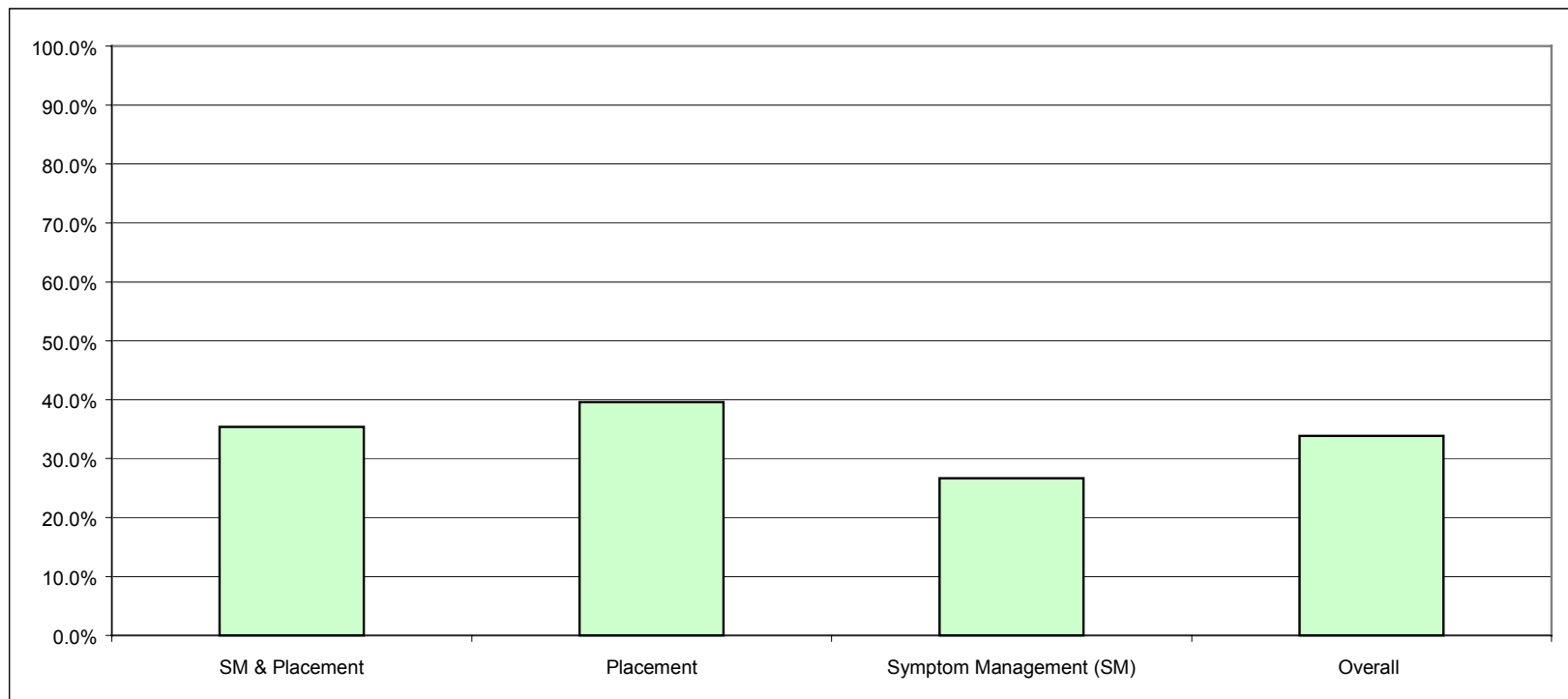
Source: Palliative Care Information System

Date: May 27, 2003

**Figure 24a**

**Community Consult Team**  
**Abnormal MMSE Scores<sup>a</sup> - First Measure by Reason of Referral**  
**For Patients Referred between Apr 01, 2003 and Mar 31, 2004**

	<b>Count</b>	<b>Total</b>
SM & Placement	23	65
Placement	112	283
Symptom Management (SM)	64	240
Overall	199	588



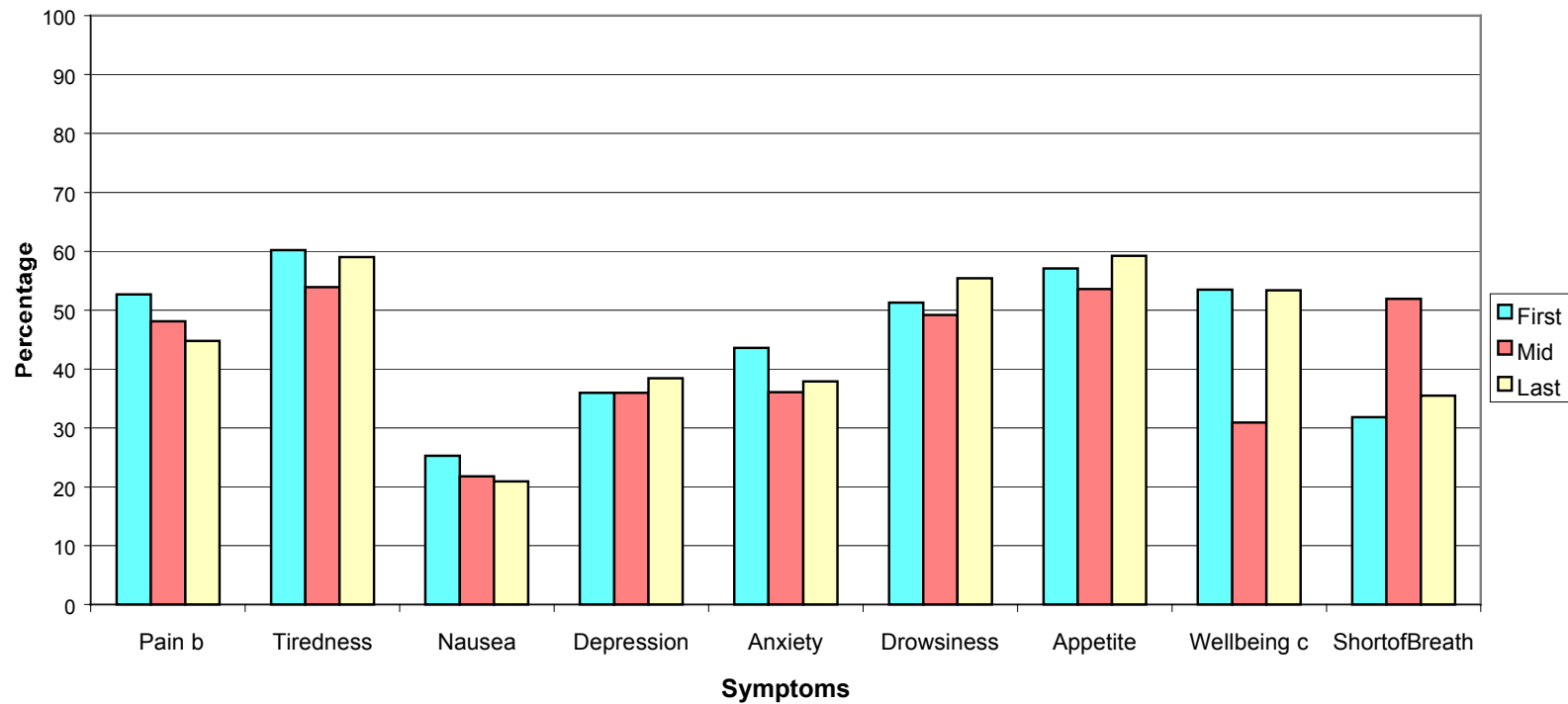
<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment

Source: Palliative Care Information System

Date: June 18, 2004

**Figure 24b**

**Tertiary Palliative Care Unit (TPCU)  
 ESAS<sup>a</sup> Scores First, Mid and Last Averages  
 For Patients Discharged between Apr 01, 2002 and Mar 31, 2003**



<sup>a</sup>Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup> Pain: total First, Mid and Last Pain assessment counts are 171, 154 and 156 respectively

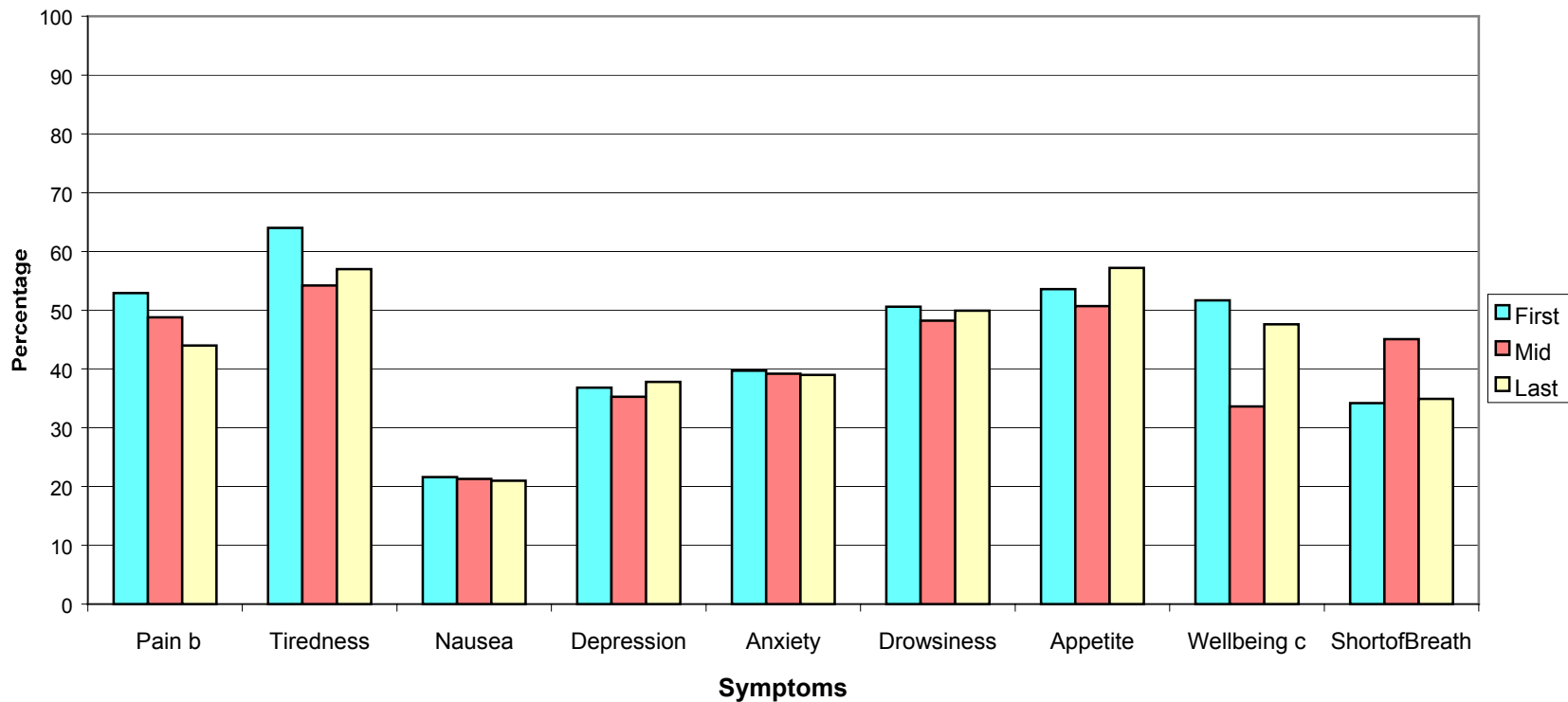
<sup>c</sup> Wellbeing: total First, Mid and Last Wellbeing assessment counts are 162, 153 and 131 respectively

Source: Palliative Care Information System

Date: Jun 03, 2003

**Figure 25a**

**Tertiary Palliative Care Unit (TPCU)  
 ESAS<sup>a</sup> Scores First, Mid and Last Averages  
 For Patients Discharged between Apr 01, 2003 and Mar 31, 2004**



<sup>a</sup>Edmonton Symptom Assessment Scale-scores are patients' ratings of symptoms on 0 to 10 scale

<sup>b</sup>Pain: total First, Mid and Last Pain assessment counts are 162,139 and 151 respectively

<sup>c</sup>Wellbeing: total First, Mid and Last Wellbeing assessment counts are 145, 135 and 122 respectively

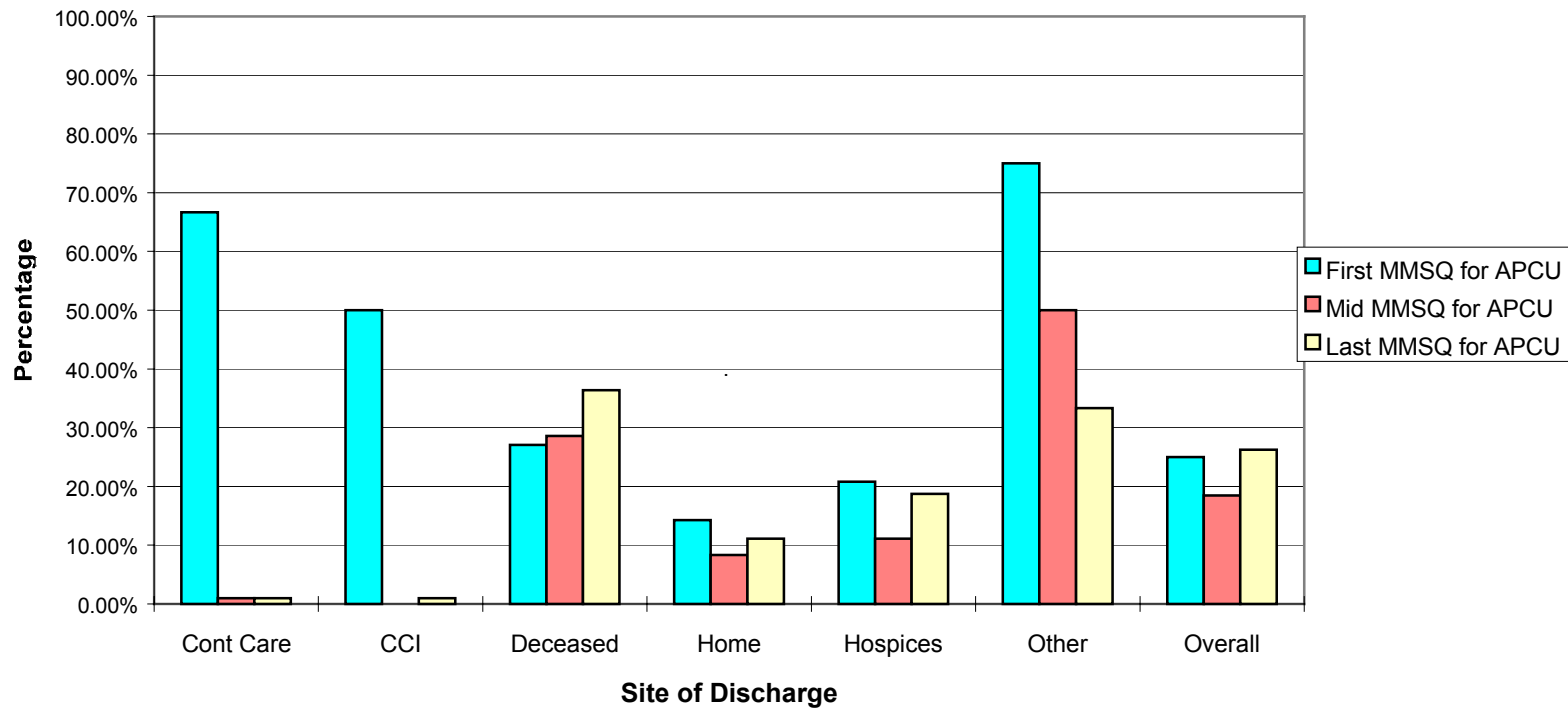
Source: Palliative Care Information System

Date:June 15, 2004

**Figure 25b**

**Tertiary Palliative Care Unit (TPCU)**  
**Abnormal MMSE<sup>a</sup> - First, MidPoint and Last Measures by Discharge Location**  
**For Patients Discharged between Apr 01, 2002 and Mar 31, 2003**

	Overall
<b>First</b>	160
<b>MidPoint</b>	38
<b>Last</b>	84



<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment

Source: Palliative Care Information System

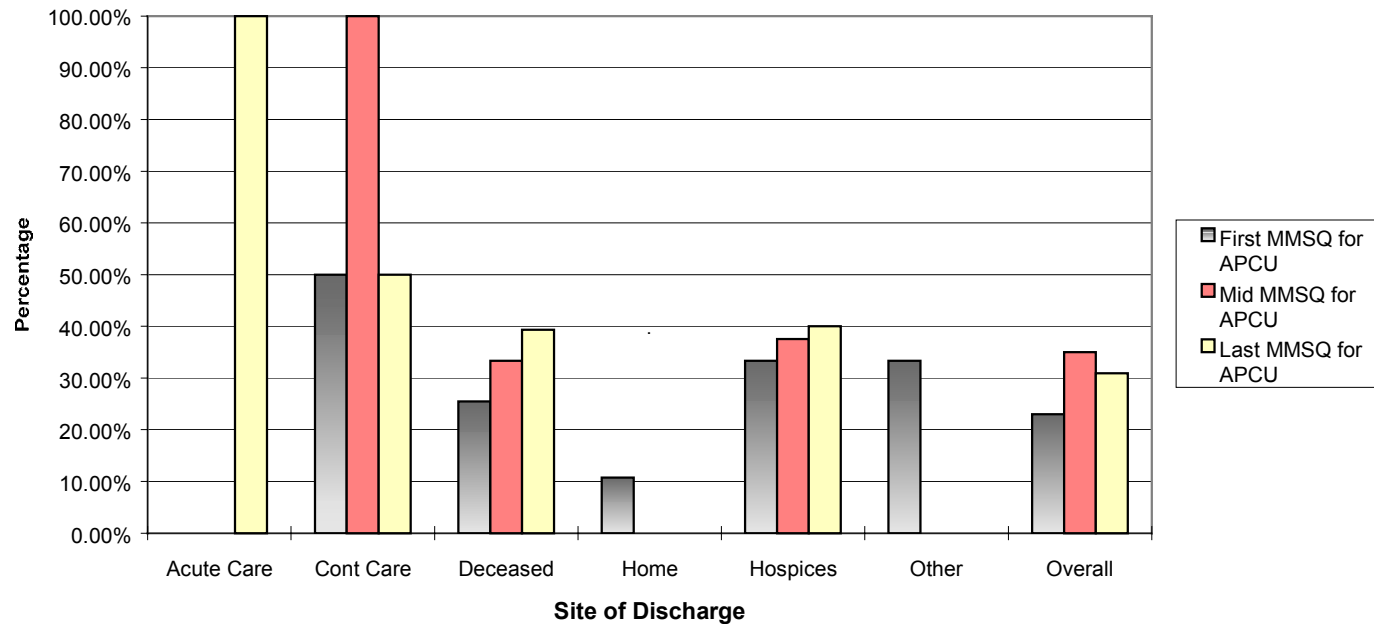
Date: Jun 03, 2003

**Figure 26a**



**Tertiary Palliative Care Unit (TPCU)**  
**Abnormal MMSE<sup>a</sup> -First, MidPoint and Last Measures by Discharge Location**  
**For Patients Discharged between Apr 01, 2003 and Mar 31, 2004**

	Overall
<b>First</b>	100
<b>MidPoint</b>	20
<b>Last</b>	55



<sup>a</sup>Abnormal Mini Mental State Examination: <80% of answers correct is an indicator for cognitive impairment  
 Source: Palliative Care Information System  
 Date: June 15, 2004

**Figure 26b**

## IX. CHALLENGES AND FUTURE DIRECTIONS

- ⇒ The reorganization of Health Regions resulting in an expansion of Capital health boundaries in April 2003 has impacted the RPCP. RPCP will be working with new areas to determine services and gather data for all new areas.
- ⇒ The RPCP is developing relationships with the newly formed Local Primary Care Initiative Groups in Westview area and Southside. The early plans suggest the present model for palliative care is well supported by the groups.
- ⇒ A Clinical Services Strategic Plan is being developed with wide regional input. The goal of the Plan is to prepare for the significant increase in workload expected with the increase in cancer mortality and other areas of end of life care.
- ⇒ Work on the balanced scorecard to determine most appropriate performance indicators are ongoing. The RPCP Program Director is a member of Health Canada Surveillance Working Group for Palliative Care, which is working on identifying palliative care performance indicators
- ⇒ An accreditation team named End of Life/Palliative Care has been formed (2004/05) to involve broader end of life issues for several specialties.

## X. APPENDIX

### Appendix A. Publications 2003/2004

Al-Shahri, MZ, Herrera Molina E, Oneschuk D. Medication-focused approach to total pain: poor symptom control, polypharmacy and adverse reactions. *Am J Hospice & Palliat Care* 2003; 20(4): 307-310.

Barnes EA, Parliament M, Hanson J, Watanabe S, Palmer JL, Bruera E. Palliative radiotherapy for patients with bone metastases: survey of primary care physicians. *Radiotherapy & Oncology* 2003; 67: 221-23.

Barreth A, Fainsinger R, Oneschuk D, Pritchard Z. The challenge of communicating intent of sedation in advanced illness. *J Palliat Care* 2003; 19(3): 217-19.

Bruera E, Strasser F, Palmer JL, Willey J, Calder K, Amyotte G, Baracos V. Effect of fish oil on appetite and other symptoms in patients with advanced cancer and anorexia/cachexia: a double-blind, placebo-controlled study. *J Clin Oncol* 2003; 21(1): 129-134.

Fainsinger RL, Davidson SN, Brenneis C. A supportive care model for dialysis patients. *Palliat Med* 2003; 17(1):81-2.

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