

Documentation and Analysis of GASHA Hospice Palliative Care Delivery Processes

By

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Acknowledgement and Endorsement

I have written this internship report in partial fulfilment of the requirements for the Master of Health Informatics programme at Dalhousie University. This report has not received any previous academic credit at Dalhousie University or any other institution.

I would like to thank Dr. Wendy MacCaull for providing me with this internship opportunity, and the chance to work on such a dynamic and exciting project. I would like to thank Ms. Heather Jewers for her understanding, patience and unwavering support while I trying to learn the ins and outs of hospice palliative care and come to grips with such concepts as the subtle distinction between hospice palliative care and continuing care. I would also like to thank Ms. Madonna MacDonald for her patience and collaboration as we learned together about “Ontologies”. Thanks goes out to so many more people at StFX and GASHA, including Janet Norgrove, Keith Miller, Fahim Imam, Ethel Gunn, Danielle Murphy, and the PNN, for freely sharing their ideas and experience, and enhancing my internship experience.

Ene Ann Euloth

Executive Summary

The internship placement took place at the StFX Centre for Logic and Information (CLI) in Antigonish, NS, and reported directly to the director of CLI, Dr. Wendy MacCaull, professor of Mathematics, Statistics and Computer Science at StFX University. The internship work was performed over a thirteen-week period from May 7, 2008 through to August 1, 2008.

The internship work was focused on Hospice Palliative Care and contributed to two major projects at the Centre: 1) 'Building Decision-Support through Dynamic workflow Systems for Healthcare' funded by ACOA through the Atlantic Innovation Fund (AIF) and 2) 'Decision Support and Information Management for the Policy Maker focusing on Patient-Centered Palliative Care in GASHA. The objectives for the internship were twofold

- 1) To map the Canadian Hospice Palliative Care Association (CHPCA) Norms of Practice for the Care Delivery Process to the Guysborough Antigonish Strait Health Authority (GASHA) processes of delivering hospice palliative care services.
- 2) To develop a domain ontology at the GASHA Decision and Policy Maker (i.e. Strategic and System) level for provision of Hospice Palliative Care (HPC) services.

Objective 1 was accomplished by first documenting the GASHA Care Delivery processes, and to a level of detail that allowed a comparison to the CHPCA norms. A Gap Analysis was then conducted to identify any missings or required enhancements. This analysis revealed that enhancements needed to be made to the Medication Reconciliation, Fall prevention, Setting of Care, and Essential Services processes. This work was further developed to then map these norms to the CCHSA standards for Palliative Care and End of Life Services. This ensured that not only were the GASHA processes standardized to the 2002 CHPCA Model to Guide Palliative Care, but that there was also a direct correlation to the CCHSA standards. The CCHSA indicators could then be used to measure the performance of the processes at meeting the norms. Another Gap Analysis was conducted to identify any required data that was not being collected through the processes.

Objective 2 was accomplished by superficially documenting processes at the Strategic and System (Senior Management) level of GASHA. From there a Use Case was developed and then a diagrammatic representation of Palliative Care Ontology Flow was created.

Key recommendations from this internship:

- Because of the truly interdisciplinary nature of Hospice Palliative Care, development of common processes and language for GASHA PC services and Continuing Care is a must.
- Document remaining GASHA HPC services processes in the same manner as Care Delivery processes.
- Further develop GASHA processes for medication Reconciliation, Fall Prevention, Setting of Care and Essential services, to meet all the CHPCA Norms of Practice for the Care delivery step.
- Develop ontology to inform GASHA Health Administration policies at the Manager and Director (Operational) level, and not at the Senior Management (Strategic and System) level.

The internship proved to be a valuable learning experience for the author and provided an opportunity to gain an in-depth understanding of Hospice Palliative Care, the 2002 CHPCA National Model, the NS provincial model and the GASHA/Continuing Care Integrated model, as well as the CCHSA standards for Palliative Care and EOL Services. These exciting and relevant projects afforded the author the chance to put health informatics theory, techniques and solutions into practice.

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1. Introduction

Palliative care has come a long way from its earliest roots in special institutions of religious orders in the 19th century, through the first ‘modern’ hospice founded by Dame Cicely Saunders in the UK in 1967 [1], and the concept of ‘total pain’, its management and focus on care of the dying, to its present day evolutionary state. Palliative care, as coined by Balfour Mount, a Canadian physician, in 1974, [2] and hospice care have merged into one movement, with the same set of principles and norms of practice. Today Hospice Palliative Care (HPC) is an approach that strives to help patients and families living with or at risk of developing a life-threatening disease, deal with issues that arise in major areas of their lives as a consequence of the illness or disease.

The 2002 Canadian Hospice Palliative Care Association (CHPCA) National Guide defines Hospice Palliative Care as ‘care that aims to relieve suffering and improve quality of life throughout the illness and bereavement experience, so that patients and families can realize their full potential to live even when they are dying’.

HPC strives to help patients and their families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectation, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement [3]

Hospice Palliative Care Programs have been around in Canada since the 1970s, and since then multiple programs have been put in place to deliver hospice palliative care, with considerable variability in quality and services. In 1997 alone, there were over 600 listed in a Canadian directory. [4] In Canada the population aged 65 or older will rise from 11.6% in 1991 to 16% in 2016 and will reach 23% in 2041. [5] As the number of people older than 65 years increases, and with a strong correlation between aging and chronic illness and an increased need for palliative care services, the healthcare system will face numerous challenges. In the US, the total cost to the federal government, which pays for 85% of hospice care costs, was 8 billion U.S. dollars, in 2006.” [6]

In an effort to standardize the practice of hospice palliative care and to address the variability and inconsistency of services and care across Canada, the CHPCA developed a national model to guide all activities related to Hospice Palliative Care. [7] It was developed using a consensus building process through consultation with experts from the HPC community all across Canada, and based on a Patient/Family centered approach. (Please see Appendix A – CHPCA HPC Model – Square of Care and Organization) This model is based on norms of practice developed by the CHPCA Standards Committee over a nine-year period. ‘The model provides one or more norms of practice for each step in the process of providing care and each aspect of an organization’s function.’[3]

This internship focused on Hospice Palliative Care in Nova Scotia and specifically HPC and the processes to deliver this care at Guysborough Antigonish Strait Health Authority (GASHA), and directly contributed to two projects being undertaken by the StFX centre for Logic and Information, as described in the next section.

This report first describes the StFX Centre for Logic and Information, where this internship was performed; the two major projects that were worked on, the objectives of the internship and the deliverables. It also describes the work performed in the accomplishment of these objectives, through the application of health informatics philosophies and solutions.

2. Description of Organizations and Projects

This internship was performed at the StFX Centre for Logic and Information, located in Antigonish, Nova Scotia, under the direction of Director Dr. Wendy MacCaull, Professor of Mathematics, Statistics and Computer Science at StFX University, Antigonish, NS. The Centre was established in 2007 to promote and support research into modeling and reasoning about complex and distributed processes, which may then be used in the development of

software for verifiable, dynamic, adaptive software for process management, information exchange and data integration.¹

The major project of the Centre, “Building Decision-Support through Dynamic Workflow Systems for Health Care” [8], funded by Atlantic Canada Opportunities Agency (ACOA) through the Atlantic Innovation Fund (AIF), seeks to research and develop innovative and adaptive workflow systems for case management in the areas of hospice palliative care and public health – early childhood. This project has an end goal of developing a prototype for a hospice palliative care workflow system using GASHA processes in the development of this prototype. Another project “Decision Support and Information Management for the Policy-maker focusing on Patient-Centered Palliative Care in GASHA”, [9] seeks to develop a model of an integrated management system and workflow system to provide data and information to support high-level decision making for palliative care. Both of these projects are joint collaborations between the Centre, GASHA, the StFX School of Nursing and a private industry partner.

The work performed for this internship was in relation to these two projects, with the majority of work being done for the AIF project in the hospice palliative care arena. Because of the involvement of the private industry partner, some of the work performed through this internship is proprietary and the property of the Centre and its industry partner. In these cases, deliverables derived from this work are only briefly described in the report and do not accompany the report.

GASHA is one of the 9 District Health Authorities (DHAs) established by the Nova Scotia Department of Health (DOH) on January 1st 2001, by Bill 34, the Health Authorities Act. This bill served to replace the old Regional Health Board system. GASHA is DHA 7 and is comprised of 700 employees, 61 medical staff, 5 hospitals and 2 programs. Please refer to Appendix B for a map showing the DHAs of NS.

¹ www.logic.stfx.ca

The contact for GASHA for these projects was Madonna MacDonald, Vice President of Community Health Services. Madonna has experience in program management, planning and evaluation in community health, in particular, service delivered using an integrated or interagency approach across a variety of care settings. [9]

The contact for the StFX School of Nursing for the projects was Heather Jewers, Assistant Professor. Heather has extensive experience as a nurse consultant for palliative care at St. Martha's Regional Hospital. [9]

3. Internship Work Performed

3.1 Objectives

Initially, the focus of this internship placement was to “Inform Health Administration Policies through Ontology Development” for the “Decision Support and Information Management for the Policy-maker focusing on Patient-Centered Palliative Care in GASHA” project. [9] The job description read as follows:

This position offers a graduate student the opportunity to work on a focused component of a larger project. The overall project will develop a specific ontology related to palliative care provision and workflow systems. This intern position will focus on linking ontology development to administrative policies, to evaluate policy outcomes, and to adapt/develop policies based on results from the ontology development. Key activities will:

- Assist in the development of a model of integrated information management and workflow system which will support high level decision making for patient-centered palliative care
- Flesh out policy planning and decision maker needs
- Collect information and begin development of CIHR grant submission regarding Administrative needs for policy planning, implementation, and measurements of success.
- Assist in Knowledge Translation and Dissemination related to policy implications of improved workflow and information management

- Research the impact of the recommendations within the Provincial Health Services Operational Review (PHSOR) on the larger ACOA AIF Project Streams; Patient-Centered Palliative Care and Healthy Beginnings
- Collaborate on peer-reviewed journal papers targeting policy/decision making and/or presentations at conferences and/or workshops if applicable.
- Assist in the identification of funding opportunities/grant applications which support research on policy development and technological applications/information management

Due to diminished availability of the main contact for this particular project, because of unforeseen circumstances and an imminent project deadline for the AIF project deliverable - *Care delivery protocol of the Palliative Care Program in GASHA is formalized* [8] - the focus of this internship and majority of work was shifted on accomplishing Objective 1.

Objective 1) - AIF Project Stream To map the *Issues Log* to the Canadian Hospice Palliative Care Association (CHPCA) Norms of Practice for the Care Delivery Step, in order to determine whether the AIF project deliverable “Formalize Care Delivery Step” was complete. The *Issues Log* is a form that was developed by Jewers and Miller, to capture any patient and family issues associated with hospice palliative care in all the various domains defined by the 2002 CHPCA Model – Disease Management, Physical, Psychological, Social, spiritual, Practical, end of Life Care and Death Management, and Loss/Grief. A software prototype of the *Issues Log* has also been built by Miller, which incorporates assessments such as ESAS and PPS. (Please refer to Appendix C GASHA Definition of Terms and Glossary of Acronyms) Since the *Issues Log* was meant to embody the delivery of hospice palliative care in GASHA, this became an exercise in mapping the Norms of Practice to GASHA processes of delivering hospice palliative care services.

Objective 2) - Inform Policy Maker Stream To start development of a domain ontology at the GASHA Decision and Policy Maker (i.e. Strategic and System) level for provision of Hospice Palliative Care (HPC) services.

Common Processes - Both objectives required the author to gain a thorough understanding of Hospice Palliative Care in general, and HPC at St. Martha's Regional Hospital (SMRH) specifically. This was accomplished by:

- Information and data gathering interviews with Heather Jewers and Madonna MacDonald
- Attendance at meetings of the Palliative Nursing Network (PNN) and Palliative Care Rounds at St. Martha's. Please see the Glossary of Terms for a more detailed description.
- Becoming very familiar with numerous reports on HPC including:
 - the 2002 CHPCA National Model [3]
 - the GASHA/CC Guide [10]
 - the Rural Palliative Home Care Model [11]
 - the Provincial Hospice Palliative Care Project [12]
 - the PHSOR report [13]
 - the Canadian Council of Health Services Accreditation manual for Hospice Palliative and End-of-Life (EOL) Services
- Attendance at and Facilitation of Roundtable Discussion at the Technology and Palliative Care Workshop ²

To meet these objectives, a scope of work was defined in the form of a Project Proposal and from which a Project Plan was created. (Please refer to Appendices D and E for Project Proposal and Project Plan). Project progress was reported through weekly status reports and discussed at weekly status meetings with Dr. MacCaull and Janet Norgrove, Project Manager for the AIF project. Project presentations were given at mid-term of the internship and at the conclusion. (Please see Appendix F for Final Presentation)

² StFX CLI. Technology & Palliative Care Workshop on Social, Cultural, Ethical and Technical Implications in a Rural Setting. Held May 2008.

3.2 AIF Project Stream

This objective was to map GASHA Care Delivery processes to the norms of practice from the CHPCA model. Once the norms were mapped to the processes, a gap analysis was conducted to reveal any missings or required enhancements. A side benefit of doing this mapping process is to help standardize GASHA processes to the CHPCA model, and a standardization of the terms and language. (Please refer to Appendix C for GASHA Definition of Terms and Glossary of Acronyms) In Nova Scotia alone there are 3 models in use: a Provincial model which was developed from the Provincial Hospice Palliative Care Project (2005) [12]; A Rural Palliative Home Care Model developed in Nova Scotia and PEI in 2001 [11]; and a GASHA/CC Integrated Palliative Care Services Manual (2006). [10] GASHA has decided to follow the national model and standardize their processes using these norms of practice. As a consequence of this work, the AIF prototype workflow system for palliative care will be developed according to these standards.

The Canadian Council on Health Services Accreditation (CCHSA), now known as Accreditation Canada, covers several areas of health care and service areas, one of which is Hospice Palliative and End-of-Life Services. CCHSA develops standards for each of these areas and also Performance Indicators and Measures by which an organization can be adjudicated for compliance to these standards. “Indicators are the way we measure whether the Norms are being met.”³ The CHPCA Norms of Practice for the Care Delivery step were matched to the CCHSA Standards, Indicators and Measures from the Hospice Palliative and EOL Services accreditation standards. This was done to ensure that by standardizing GASHA processes to the model, there was a direct correlation to CCHSA standards, and that the CCHSA Indicators could be used to measure the performance of these norms. Any data required for these indicators was identified as well, in this step.

CCHSA also has accreditation standards at the organizational level. Two of these are Proactive and Supportive Organization, and Governance. Some of these standards and indicators were cross-mapped to the norms of the Care Delivery step, producing a truly

³ Quote from Heather Jewers, Associate Professor, StFX School of Nursing, 2008
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integrated view of the CHPCA Model and GASHA processes, and a way to measure compliance of GASHA as an organization as well as its processes.

CHPCA also provides Norms of Practice for the HPC organization. Some of these norms were mapped to these accreditation standards, separate from Care Delivery but on a strategic and system level.

3.3 Inform Policy-Maker Stream

The first step here was to come to a common understanding of *Ontology* with Madonna. Definitions of ontology are quite straight forward, but what this actually entails and how to go about creating one in practice, were more difficult concepts to grasp. Fahim Imam's demonstration of his Palliative Care ontology work greatly helped to clarify matters. Processes at the System and Strategic level were documented to a superficial degree, and a Use Case was developed. This exercise served to elucidate the fact that documenting processes at the mid-manager and director level (Operational level) would be more beneficial to achieving this goal. The last step was to develop a visual representation of Palliative Care Ontology Flow. (Please refer to Appendix F Final Presentation for a copy of this diagram).

3.4 Evaluation of Internship Work

“I was very pleased to have these students work with my team”, said MacCaull, “and their research will be very valuable to the eventual success of the project”. “Euloth's work on developing a specific knowledge base related to palliative care provision and workflow systems,.....has provided a lot of information critical to attaining our first milestone of the project , care delivery protocol of the palliative care program in GASHA is formalized”, explained MacCaull.⁴

⁴ Summer Interns Present Final Reports – A Press release to the Casket July 24, 2008, from the StFX Centre for Logic and Information, Antigonish, NS
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3.5 Description of Deliverables

- *Context Diagram* – Visio diagram showing scope of work. Documentation of the Care Delivery step from the Square of Care of the CHPCA Model
- *High Level Process Diagram* – Visio diagram showing GASHA Care Delivery process and its sub-processes
- *GASHA HPC Care Delivery Processes* – documentation of GASHA Care Delivery processes in narrative form
- *Compilation of all forms (both digital and paper copies) used in GASHA HPC Care Delivery Processes.* (Appendix G lists these forms)
- *Norms_Processes_Gap_Analysis_Final* workbook has 5 spreadsheets:
 - CD Norms Mapped to CCHSA* – this spreadsheet lists and maps the Norms of Practice to the CCHSA Standards, Indicators and Measures from the HP and EOL Services guide. This spreadsheet also identifies any data requirements for these indicators.
 - CD Norms Mapped to Processes* – this spreadsheet maps the Norms of Practice to GASHA Processes. It also captures PC Service Provider, PC Service Receiver, PC Delivery Vehicle or Location and Tools used in the delivery of PC services (i.e. the forms and information that are collected and used in the delivery of these services).
 - Gap Analysis* – this spreadsheet identifies any gaps or missings between the GASHA Processes, the GASHA HPC Issues Log, the Norms of Practice, and the Indicator Data Requirements. Recommendations on what is needed to bridge the gaps and possible ways to achieve them are provided.
 - CD & Org Norms Mapped to CCHSA* – this spreadsheet maps GASHA Care Delivery Processes to the Norms of Care Delivery, to the Norms for Operations and to the Norms for Quality Management. It also cross-references the CCHSA Organization Standards, Indicators and Measures and Data Requirements for the CCHSA HPC & EOL, Organization, and Governance Indicators, and GASHA/CC Indicators.
 - Org Process/Norms Mapped CCHSA* – this spreadsheet maps the CHPCA Organizational Processes to the Norms of Practice for the Organization and to the

CCHSA Standards, Indicators and Measures for the Proactive and Supportive Organization, and for Governance.

- *Use Case for Policy Maker* – processes for the Policy Maker were documented in the form of a Use Case.
- *Hospice Palliative Care Ontology Flow Diagram* – depicts how the Strategic and System Structure and its functional processes direct the Operational Support Structure and its functional processes, which in turn guides and informs the Care Delivery processes, which in turn delivers Patient/Family centered Palliative Care services. Appendix F Final Presentation
- *Final Presentation of Project, Findings and Recommendations* – Appendix F

4. Relationship with Health Informatics

This internship involved understanding Hospice Palliative Care in general and GASHA processes for delivering that care, in detail. It provided the opportunity to learn about national standards and accreditation, and to develop system requirements based on or incorporating these standards. It gave the intern the opportunity to do business process, information and workflow modeling and conduct gap analyses, similar to the Health information: Its Flow and Use course. The intern was also provided the opportunity to practise project management skills, through the creation of a project proposal and a project plan, and the provision of weekly progress reports.

This internship also involved understanding and working with *Ontologies*; different types of knowledge and its capture, which drew heavily on material and concepts from the Course on Healthcare Knowledge Management.

5. Health Informatics Problems and Solutions

Both objectives provided opportunities to implement Health Informatics solutions. The first objective – to map the Issues Log to the CHPCA norms of practice for the Care Delivery Step - presented the problem of how to map a *document* to a *norm*. The proponents of the Issues Log stated that it covered off all these Norms of Practice. The Health Informatics solution was to explicitly show by means of documenting GASHA Care Delivery processes, and by performing a gap analysis, what they implicitly knew to be true.

The second objective – to develop an ontology at the HPC Policy-maker level; employed Health Informatics solutions of transforming implicit knowledge inherent in processes and relationships; into use case type scenarios, which provided the basis of the ontology. Again, only through documentation of these processes was it possible to show that the real information or knowledge that was being sought, was not to be found at the Strategic and System level, but at the Organizational level.

6. Conclusions

- It was possible to map a *Form* to a *Norm*. Initially this was like comparing *Apples* to *Oranges*, but by first documenting the GASHA Care Delivery processes and capturing all the informational flows, it was possible to then show if the CHPCA Norms of Practice for the Care delivery step were being met, through use of the *Issues Log*.
- Mapping GASHA Care Delivery processes to these norms allowed a gap analysis to be carried out on these processes and to identify any missings or required enhancements.
- Documentation of GASHA Care Delivery processes allowed for a standardization of vocabulary and terms used with the 2002 CPHCA Model to Guide Palliative Care.

- Mapping CHPCA Norms of Practice for the Care Delivery step to the CCHSA Performance Indicators and Measures for the Palliative Care and End of Life Services standards ensured that by standardizing the GASHA process to the Model, there was also then a direct correlation to the CCHSA standards. The CCHSA indicators could then be used to measure the performance of the norms and thereby the processes. This also allowed data to be identified that was required for the indicators and measures but was not already being collected through the processes.
- Mapping CHPCA Norms of Practice for Care Delivery to CCHSA measures and indicators for the Proactive and Supportive organization, and Governance produced a truly integrated view of the Model and GASHA processes. This provides a way to measure compliance of GASHA as an organization as well as its processes.
- Definitions of *Ontology* are not hard to understand in principle. Understanding enough about Ontologies in order to develop one, is harder to do in practice.
- The jury is still out on whether ontology can be used to inform a workflow, and how they will work together.

7. Recommendations

- 7.1 When doing similar projects in future, it is important to spend a far amount of time on planning and defining work to be accomplished. It is a good practice to document all high level processes at the very beginning of the project and to develop a Context diagram for each scope of work. Once these tools were employed for this project, it could readily be seen that starting with the care delivery processes might not have been the best option. The integrated nature of the preceding steps with the care delivery step and the interdisciplinary nature of Palliative Care services by various professionals, made documentation of the Care Delivery step very hard to do in isolation. The preceding processes collect the information necessary to lay the groundwork for how and what Palliative Care services will be provided in this step. If

the preceding processes had been documented first, then about 80-90% of Care delivery processes would have already been documented.

- 7.2 Document remaining GASHA HPC processes in the same manner in which the care delivery processes were done. This would keep language and terms consistent, and ensure that all processes incorporate norms of practice for each step of the CHPCA Model.
- 7.3 GASHA's processes for Medication Reconciliation, Fall Prevention, Setting of Care, and Essential services need to be enhanced to meet all the Norms of Practice.
- 7.4 Currently Continuing Care Department of Health captures data called MDS-HC (Minimum Data Set – Hospice Care). The data that is collected needs to be integrated with the data collected by Palliative Care. GASHA is trying to design an integrated Palliative Care/Continuing Care model. But until the two sides collect and have access to the same data and information, this will not be possible.
- 7.5 HPC is truly interdisciplinary – many disciplines work together to provide these services. In order for them to truly effective, it is the author's opinion that a new entity be created, comprised of CC and GASHA PC, with a common set of goals, mission statement and lines of responsibility. The GASHA/CC HPC manual needs to be revamped with collaboration from both camps to devise a common set of processes for referral, assessment and delivery of PC services.
- 7.6 It is the author's opinion that the Issues Log could easily become an Electronic Medical Record for each PC patient. Any further development of the Issues Log should be done with the NS – iEHR in mind. It should conform as much as possible to the standards being developed for the iEHR, with a view to some day integrating or interfacing with it.

- 7.7 In order to develop an ontology which will inform GASHA Health Administration policies, Operational –level processes need to be documented and analysed, and not at the Strategic and System level. The processes around decision-making, data collection, policy implementation and evaluation are the domain of middle managers and directors.
- 7.8 Currently the majority of patient and family information flowing through the GASHA HPC processes is paper-based. Integration and/or interfacing these informational flows with existing workflows and systems like Meditech, MDS-HC and the proposed NS IEHR should be paramount.

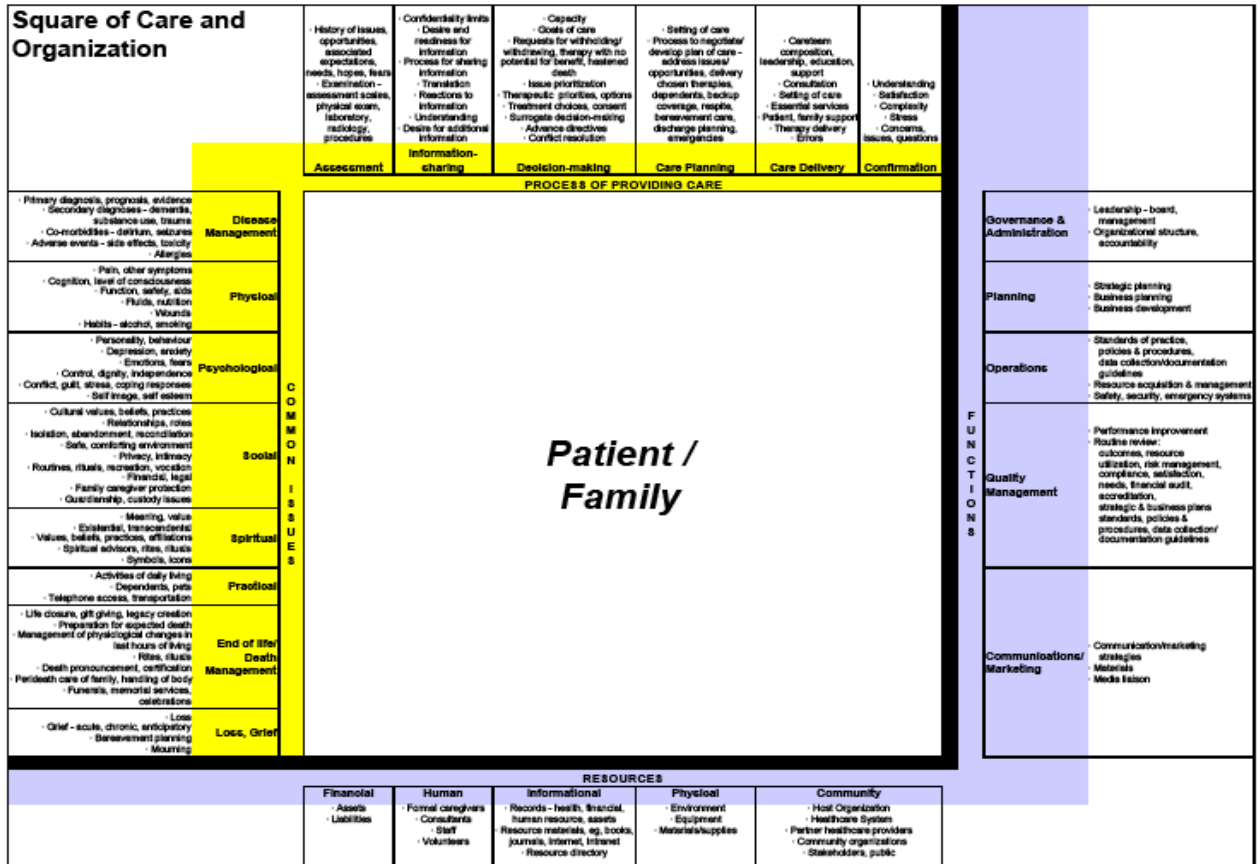
8. References

- [1] Saunders C. A personal therapeutic journey. *BMJ* 1996 Dec 21-28;313(7072):1599-1601.
- [2] Graham F, Clark D. The changing model of palliative care. *Medicine* 2008 2;36(2):64-66.
- [3] Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, et al. A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of practice. 2002.
- [4] Fainsinger RL. Canada: Palliative Care and Cancer Pain. *Journal of Pain and Symptom Management* 2002 8;24(2):173-176.
- [5] Chertkow H. Diagnosis and treatment of dementia: introduction. Introducing a series based on the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia. *CMAJ* 2008 Jan 29;178(3):316-321.
- [6] Cost of hospice care. *J.Palliat.Med.* 2008 Mar;11(2):147.
- [7] Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, et al. A model to guide patient and family care: based on nationally accepted principles and norms of practice. *J.Pain Symptom Manage.* 2002 Aug;24(2):106-123.
- [8] MacCaull WD. Building decision-Support through Dynamic Workflow Systems for Health Care. 2007.
- [9] MacCaull WD. Decision Support and Information Management for the Policy-Maker focusing on Patient-Centered Palliative Care in GASHA. 2008.
- [10] Guysborough Antigonish Strait Health Authority / Continuing Care Integrated Palliative Care Services Guidelines. 2006 September 12 and April 19 versions.
- [11] A Rural Palliative Home Care Model: The Development and Evaluation of an Integrated Palliative Care Program in Nova Scotia and Prince Edward Island. 2001.
- [12] Provincial Hospice Palliative Care Project *Final Report and Recommendations*. 2005 October 4.

[13] Corpus Sanchez International Consultancy. Changing Nova Scotia's HealthCare System: Creating Sustainability through Transformation System-Level Findings and Overall Directions for Change from the Provincial Health Services Operational Review (PHSOR). 2007 December.

APPENDIX A

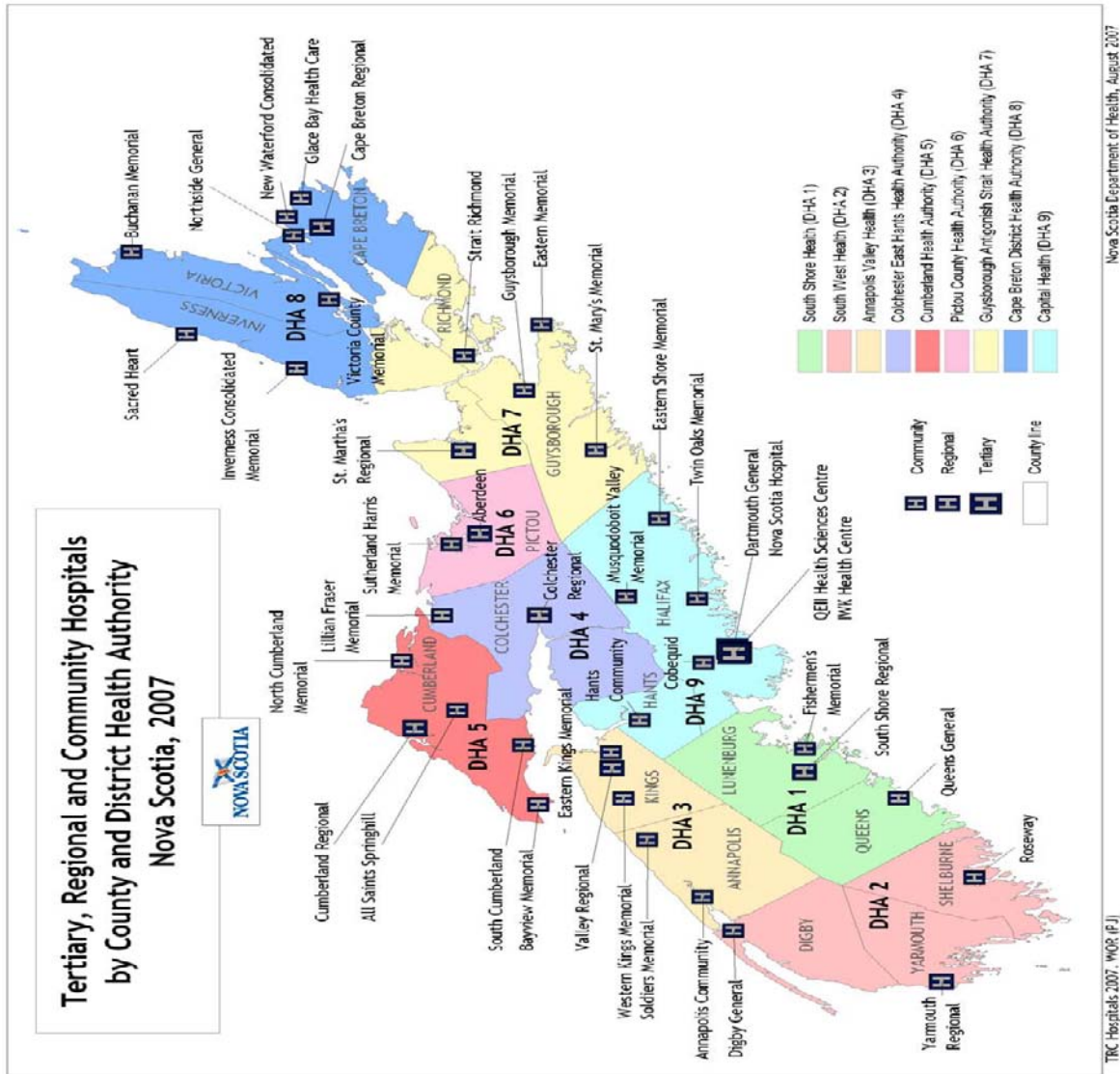
CHPCA HPC Model - Square of Care and Organization



From: Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lemontagne C, Lundy M, Syme A, West P. A Model to Guide Hospice Palliative Care. Ottawa, Canada: Canadian Hospice Palliative Care Association, 2002.

APPENDIX B

Map of NS District Health Authorities



APPENDIX C GASHA Definition of Terms and Glossary of Acronyms

APPENDIX D Project Proposal

APPENDIX E Project Plan

APPENDIX F Final Presentation

APPENDIX G Listing of GASHA HPC Forms and Inputs

Form F1.1 - GASHA/CC Integrated Palliative Care Service: Patient Data Form

Form F1.2 - MDS-HC (Minimum Data Set – Home Care) (Some subset – still to be determined)

Form F1.3 - SMRH Palliative Care Consult Form

Form F1.4 - GASHA Ambulatory Care Record (if a Dr. refers a patient after seeing them in OPD) (4 copies)

Form F1.5 - FAMCARE Satisfaction Survey Questionnaire

Form F1.6 - Cancer and Supportive Care – Nursing Documentation Record “the Yellow Sheets”

Home Chart – The concept of an integrated home chart for GASHA/CC PC services was introduced in 2006, but has not been applied consistently. Its use is currently being reviewed by the Interagency HPC workgroup. Although not consistent in use, the following forms might be included in the Home Chart:

Form F1.7 - Integrated Hospice Palliative Care Service Consent for Sharing Information

Form F1.8 - GASHA Hospice PC Assessment form (4 Pages, includes PPS - Palliative Performance Scale assessment)

Form F1.9 - Drs’ Orders

Form F1.10 - Medication Review

Form F1.11 - Medication Calendar

Form F1.12 - Care Plans (both Initial Plan of Care - IPOC and Continuing Plan of Care – CPOC (unable to get copies)

Form F1.13 – GASHA Communications Sheet / Rounds Report

Form F1.14 - Flow Sheets (Integrated Hospice Palliative Care Services Signature Sheet)

Form F1.15 - Multi-Disciplinary Progress Notes

Form F1.16 - Home Support Flow Sheet (Home Support Worker Supervisor Report Sheet)

Form F1.17 - St. Martha’s Regional Hospital – HITH & Cancer and Supportive Care – Residence Assessment and Pre-Risk Screening (2 Pages)

Form F1.18 - Cancer and Supportive Care – St. Martha’s Regional Hospital – Contact Record

Form F1.19 - ESAS – Edmonton Symptom Assessment System

Form F1.20 - PAINAD (Pain Assessment in Advanced Dementia) Scale Assessment

Form F1.21 - Pain Assessment and Plan for Cognitively Intact Patients – BRHC (Brandon Regional Health Centre)

The Home Chart may also contain a DNR/AND (Do Not Resuscitate/Allow Natural Death) consent form (**Form F1.22**) and a Physician DNR order form (**Form F1.23**); a copy of a Living Will/Advance Directives, and an Enduring Power of Attorney.

Form F1.24 – GASHA Incident Report Form

GASHA/CC Integrated PC Services Manual:

Page 20 – Explanation to Patient/Client re: Palliative Care Services

Page 22 – Explanation to Patient/Client re: Home Chart

Page 30 – Palliative Care Front-Line Education Listing of Courses

Pages 39-40 – List of Informational PC Resources