

DESIGNING A CONSUMER CANCER INFORMATION WEB PORTAL:

Cowlitz Cancer Awareness, Resource & Education (C.A.R.E.)

By

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CERTIFICATE OF APPROVAL

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ABSTRACT

Background: The Internet has great potential in assisting cancer patients and their families find relevant information. However, this potential may not be fully realized in Cowlitz County Washington. The goal of this project is to design a cancer information portal that contains three types of information: (1) Web links to cancer literature; (2) Local resource information such as library, support group, child care, counseling, spiritual care, etc, and (3) Special vendor information for a spectrum of products and services, such as prosthetics, nutrition, medical equipment, etc. To maintain the content of this portal (add new information, remove outdated information and update existing information) a relational database was designed and created.

Methods: In order to design a cancer web portal, we must gather and analyze the relevant information. To build a new system, I reviewed the existing system and specified the parts which could be improved. I analyzed local resources, such as the content of the Lower Columbia Regional Cancer Center's New Patient Orientation notebook binder to learn what information the new cancer patient was currently provided. Other Web sites of this type were also studied. Interactions with care providers at Lower Columbia Cancer Center, and my eight years experience serving information needs of cancer patients provided the overall basis of what this web portal should provide. Using gap analysis methodology, we identified the existing cancer resources and opportunities for improvement, in other words, where we are and where we could potentially be. **Results:** A cancer resource web portal presents opportunities to empower cancer patients in Cowlitz County in their journey, enabling cancer patients to find needed information in one convenient place. It could reduce time required to find information that will help them make informed decisions about their health. This could also have immediate practical

impact. To accomplish this, we developed design recommendations for a Cowlitz C.A.R.E. Web Portal. This included content design and database specifications. The new content and organization of material was specifically designed to help patients and their care givers to find useful information such as lodging, spiritual care, child care, local support group meetings and schedules, counseling and other local relevant services.

INTRODUCTION

The routine use of the Internet has become a way of life. In 2009, 1.7 billion people world-wide surf the Internet.¹ During that same period, 128 million Internet users searched MedlinePlus, a consumer health information Web site, a 312 % increase from 408169 in 1999.² The Internet has great potential in assisting cancer patients and their families find relevant information.

However, this potential may not be fully realized. Cancer patients' information needs vary according to factors such as type of cancer, disease stage, education, age, location and ethnicity. By going to the Internet for information, consumers of cancer information, i.e. cancer patients, their family, friends and care givers have to wade through a massive maze of information that may or may not be helpful. Many people go to Internet before and even after diagnosis. More and more people use the Internet as a source of information for cancer, health, and other topics. Cancer patients who search the Internet retrieve a huge amount of information. Some of this information is accurate, some is not.³ What one finds on the Internet can often be a chaotic mess of information that may be something similar to the image by Earley and Associates.

[Figure 1]¹⁴

Figure 1 – Representation by Earley & Associates showing the difficulty in finding critical information



The goal of this project is to design a cancer information web portal framework for cancer patients, their families and their care providers. When built, this portal will provide access to basic cancer information which is most helpful to the newly diagnosed cancer patient. It is hoped that the portal will facilitate patient understanding of their health conditions in a laymen language. This portal eliminates the need to visit many sites for information. Also this portal will empower cancer patients to make the best informed decisions about treatment, local support services, and clinical trials. This cancer patient-centered portal brings together cancer information and resources, making them available in one convenient, easy-to-access place.

Definition of web portal:

A web portal is a web page with links to diverse information sources in a unified way.⁴ There are many cancer web portals already on the net. One of the reasons for building Cowlitz C.A.R.E. is to help people get trusted health information, including local resources.⁵ The main purpose of this project is to design Cowlitz C.A.R.E. - a web portal framework for cancer information with local resources related to cancer in Cowlitz County. Potentially this could be part of Washington Go Local, an initiative to connect local health services to users. However, since National Library of Medicine will no longer support this state initiative, the Cowlitz C.A.R.E. Portal could potentially be valuable resource for cancer patients in this particular geographical area. This portal is designed to be a living entity and can mature and grow in time. It should allow a number of health professionals to manage, contribute, check, and control the quality of the cancer information

BACKGROUND

General level: The emerging modern communications technologies made it possible for health consumers to play an active role in their own healthcare. In 1995 Tom Ferguson described the Information Age healthcare where people with a health concern or problem can begin by managing it themselves, and move on to other resources, i.e., friends and family, self-help networks and health care professionals only as needed. Contrary to the old, obsolete Industrial Age Healthcare, where professional care was the only option and self-help was discouraged thus high healthcare costs, the Information Age Healthcare encouraged self-help with a potential to reduce healthcare costs. A new generation of electronic tools became available to enable patients access to information and “we are beginning to see the equivalent of the toppling of the ‘Berlin wall’ that once separated lay healthcare from professional medicine.”¹³

Figure 2 - Information Age Healthcare

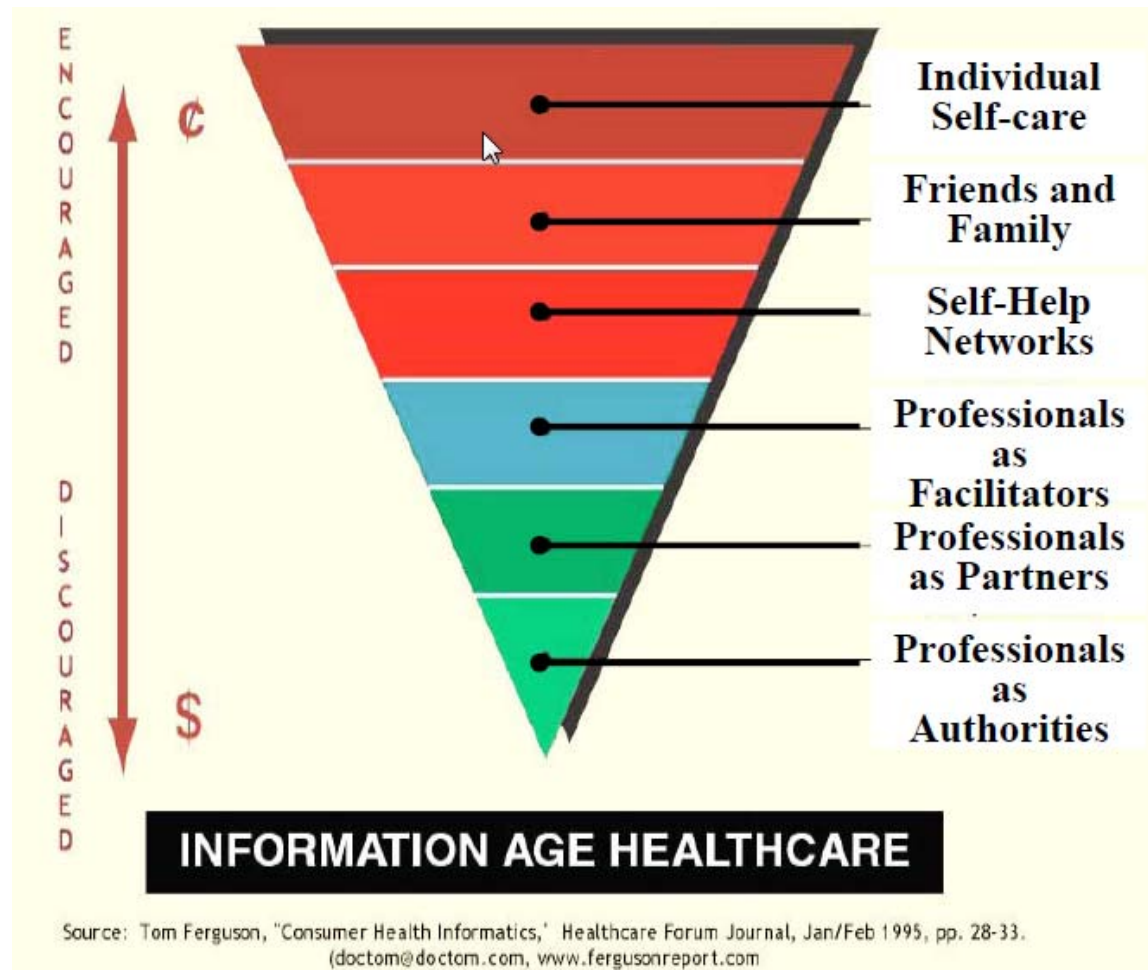


Figure 2 shows Ferguson's up-side-down pyramid, depicting Information Age Healthcare. In this model we see that self-care, care by friends and family, or by self-help networks is greatly encouraged. The value of the Information Age Healthcare model is illustrated powerfully by Anja Forbriger's story.⁶ In her article she talks about the power of support groups, outlining the following priceless points:

1. Her support group responds quickly and calmed her down, gave her emotional strength

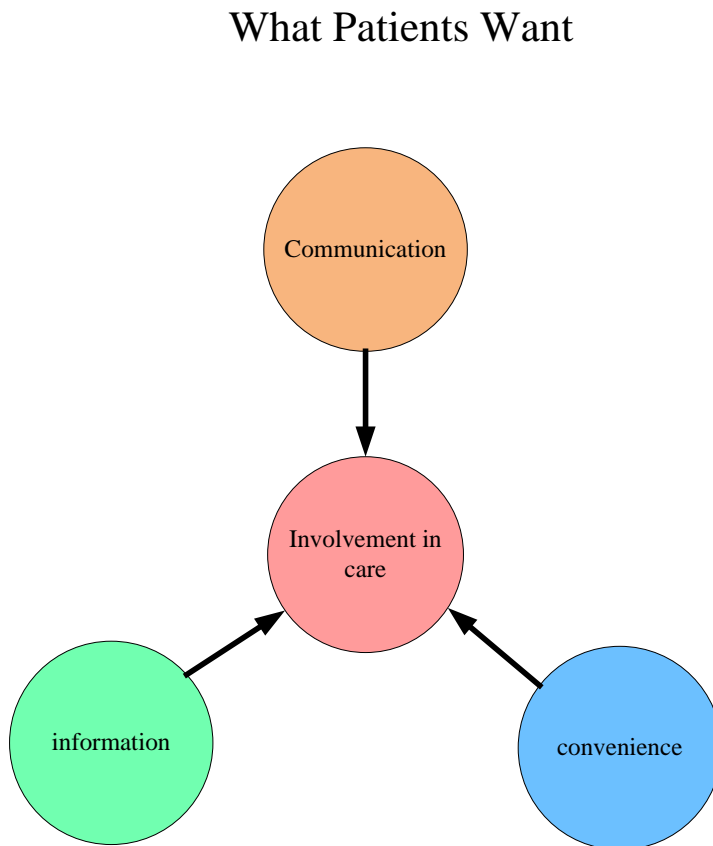
2. A cancer patient wanted to finish the post so he could go skiing - what's on his mind?
Snow, not death.
3. Patients become informed using the Internet, forcing doctors to get up-to-date information.
4. Patients who are informed about their disease play a more active part in their own treatment and have higher expectations of their doctors.
5. Patients are overwhelmed at time of diagnosis – doctors don't have time to explain details of treatment plan, e.g. what CT is and what it does.

According to Dr. Daniel Z. Sands, formerly from the Harvard Medical School and now Senior Medical Informatics Director at Cisco Systems, patients want to be involved in their care.⁷ He advocates that consumer health information systems focus on three main needs:

1. Information - Consumers need timely and easy access to information in order to make informed decisions concerning their medical care.
2. Communication – Consumers need to be able to communicate with the care team, family and friends, and be able to networking with others “in same boat”.
3. Convenience - Consumers should be able to access services, such as child care, counseling, spiritual care, and hospice, as needed.

This concept is depicted in the figure below:

Figure 3 - What Patients Want



Bosworth in his keynote speech at the 2007 American Medical Informatics Association (AMIA) Spring Congress: “Informatics Across the Spectrum” Orlando, Florida May, 22, 2007 described what consumers need in a good health system:⁸

“ ... in a good health system, consumers will have three core abilities:

1. Discovery - Consumers should be able to discover the most relevant health information possible.

2. Action - Consumers should have direct access to personalized services to help them get the best and most convenient possible health support
3. Community - Consumers should be able to learn from and educate those in similar health circumstances and from their health practitioners”

Local Factors

According to the Washington Department of Health, cancer is the leading cause of death in Washington State. In 2004, 10,968 people died from cancer. There were 33,077 new cancer cases in 2007, an 8% increase from 30,541 in 2000. In Cowlitz County, cancer incidence is on the rise. In 2006, there were 592 new cases, a 177% increase from 215 in 2000.⁹ The cancer patients need a variety of practical and support services at local level. According to National Cancer Institute Fact Sheet, people who are undergoing cancer treatment often are unaware of the services available in the community: support group, counseling, advice, financial assistance, transportation to and from treatment, or information about cancer. Support services help cancer patients to deal with any type of problem that might occur.¹⁰ This Web portal aims to provide comprehensive list of services available to cancer patients. The following list describes these services:

Counseling – having someone to talk to reduces stress and helps patients both mentally and physically.

Medical Treatment Decisions –information about hospitals and physicians will help patients make complicated medical decisions.

Prevention and Early Detection – prevention services such as smoking cessation; early detection services such as mammograms, Pap Smear, prostate exams, or colon cancer screening.

Home Health Care – for patients who no longer need to stay in a hospital or nursing, but still require professional medical help can get skilled nursing care, physical therapy, social work service, and nutrition counseling at home.

Hospice or Palliative Care – this is for terminally ill cancer patients and focuses on providing comfort, controlling physical symptoms, and giving emotional support. This service can be done in various settings, including the patient’s home, hospice centers, hospitals, skilled nursing facilities.

Advocacy – this type of service offer assistance with legal, ethical, medical, employment, legislative, or insurance issues.

Financial – information about government and nonprofit organizations that help cancer patients with problems related to billing, insurance coverage, and reimbursement issues. Some patients may need help with collecting entitlements from Medicaid, Medicare, and the Social Security Administration.

Housing/Lodging - Some health care organizations provide lodging for the family of a patient undergoing treatment. This information can be found in the Web portal.

Children’s Services - A number of organizations provide services for children with cancer, including summer camps, make-a-wish programs, and help for parents seeking child care.

The Lower Columbia Cancer Center at St. John Medical Center in Longview, Washington gets its patients from Cowlitz County and surrounding areas. The patient demographics include a large Spanish and Russian speaking populations. Patient educational materials in Spanish and Russian are not readily available.

This C.A.R.E patient-centered Web portal is intended to provide easy access to cancer information and local resources in English as well as non-English languages. Once built, it will be a valuable resource that the medical library can offer in support of the hospital's mission, "We carry on the healing mission of Jesus Christ by promoting personal and community health, relieving pain and suffering, and treating each person in a loving and caring way", and its promise that "every patient receives safe, evidence-based, compassionate care: every time, every touch."

Currently a newly diagnosed patient visits the library and asks for information. The librarian asks a few questions to learn what is needed, searches in MedlinePlus on the topic, and prints out a few articles, usually at the patient's choosing.

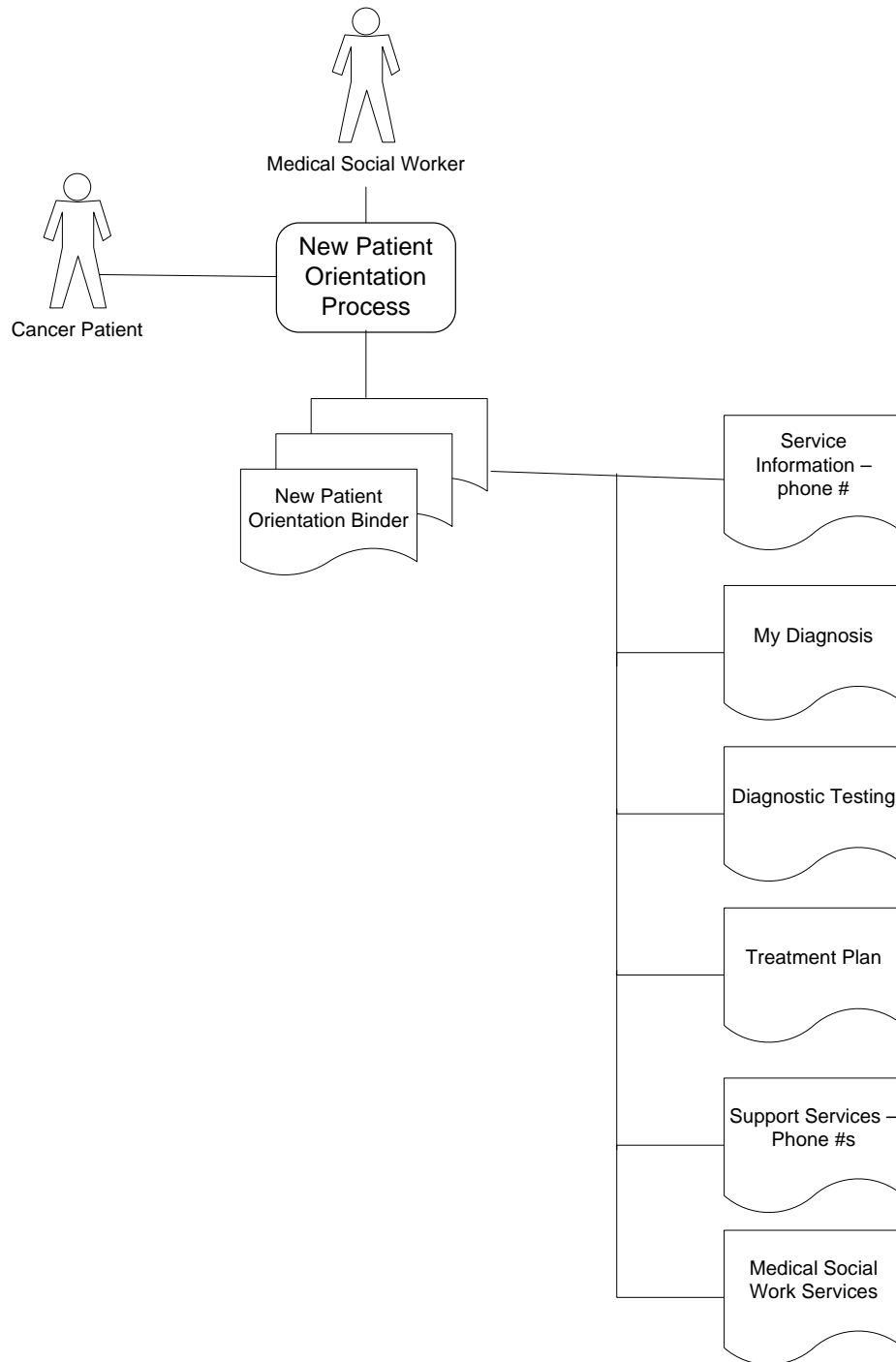
At a difficult time such as this, patients may want to be left alone to browse and print on their own and have privacy. What do they need at this time? They need to learn about their disease, in their native language, and find a physician for second opinion, and find support groups, counseling, financial assistance, care assistance, transportation, networking, etc.

METHODS

System Analysis of Existing System

The goal of system analysis is to understand the existing system, specifically how the informational, emotional, spiritual, practical needs of the cancer patients are met. Each newly diagnosed cancer patient receives a “New Patient Orientation” notebook binder. The content of this binder is analyzed in detail, to get an overall picture of available resources in Cowlitz County. The detailed information about each resource or service includes the name, type, description and contact information of the service. This binder serves as the main source information for the local resource portion of the Cowlitz Cancer Awareness, Resource & Education (C.A.R.E) Web Portal. To analyze the existing system we use the context diagram¹¹ that depicts the actors outside the system - cancer patients and medical social worker. After meeting with the medical social worker and receiving the binder at the New Patient orientation, the cancer patient can choose to act on the information in the binder and any additional information from the medical social worker.

Figure 4 - Use Case Context Diagram of Current System



This diagram was created based on the information contained in the SJMC LCCC new patient orientation binder.

Gap Analysis

Gap analysis is a technique for determining the steps to be taken to move from a current state to a desired future state.¹² This gap analysis process for the existing system involves three steps:

1. Describe service provided and current practice
2. Identify issues (gaps)
3. Identify opportunities for improvement (what should be)

The Cowlitz C.A.R.E. portal is aimed to align with the Information Age Healthcare as depicted in Figure 2, where individual self-help is highly encouraged.

Currently the cancer patients rely on the medical social worker to get the information they need. For example, if the patient needs low or no cost child care, he or she would call the medical social worker, who then contact child care agency and arrange child care for the patient. This could be problematic when the medical social worker is not immediately available and the need is urgent. The red parts in the information age healthcare pyramid (self-care, friends, etc) are not emphasized. There are opportunities for improvement in the areas of self care, family networks, self-help networks. In Table 1 we identified areas of improvement that will empower patients and their families & friends to be an active part of the medical care.

Table 1 - Gap Analysis

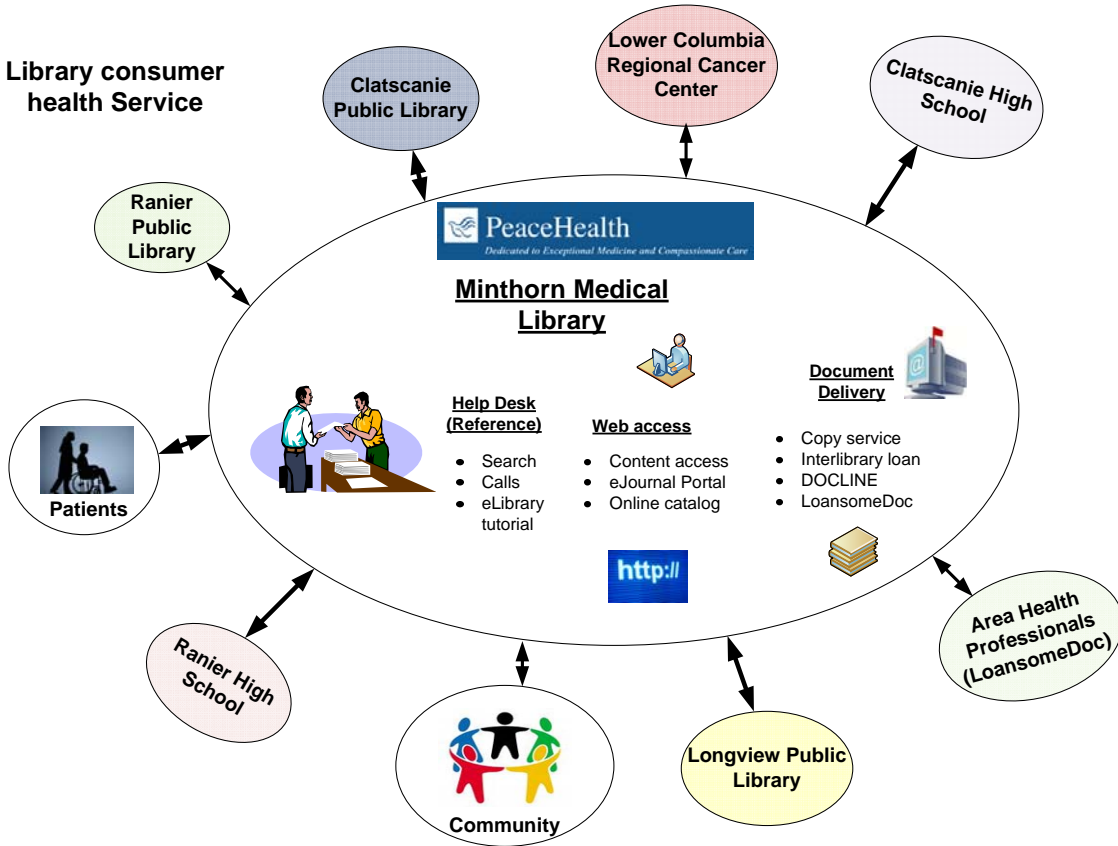
SERVICE PROVIDED	CURRENT PRACTICE	ISSUES (GAPS)	IMPROVEMENT OPPORTUNITIES
Service Information – phone #	Important Phone numbers are listed: Oncology Clinic and Infusion Services, Clinic Nurses Desk, Social Work Services, Radiation Therapy, Longview Surgical Group, Columbia Regional Breast Center, St. John Medical Center, Emergency Dept.	After hours message can be left at any of the phone numbers and calls are returned the next working day. Patients do not feel comfortable leaving message. Messages may be difficult to understand.	Collect questions and publish FAQ and inform patients of it. With an FAQ it is possible to provide patients with instant answer to frequently asked questions.
My Diagnosis	Physicians and nurses are the primary source of information.	Get second opinion. Missing from the orientation packet are Internet and library resources.	Need a resource to educate patients about their disease, this should be online.
Diagnostic Testing	A comprehensive list of common procedures and imaging exams and tests is included in the orientation packet. This information is used to help diagnose, monitor and assist in treatment planning.	Patients have many questions most of which are answered at the encounter by the care provider, but in-depth follow up is not done.	Online resources for specific diagnostic testing are readily available would be very helpful for cancer patients.

Treatment Plan	Customized according to the needs and specific circumstance of each individual patient.	The current system does not provide information about non-conventional treatment.	Evidence-based medicine literature is available but patients could use some hand-holding in using the resource to help them make informed decisions about their medical care.
Medical Social Work Services/ Support Services	A long list of local resources is included in the orientation packet.	The list, although comprehensive, is static and it is cumbersome to update.	We need a database of local resources that can be updated on regular basis.

Librarian's Experience

The Minthorn Library at St. John Medical Center supports the cancer patient's information needs. The care provider at the cancer center calls the librarian and requests specific cancer information in a particular language. The librarian then searches for the relevant information and delivers it to the provider. Sometimes the patients come to the library and request assistance with searching and locating relevant information. As an outreach community service, we provided C.A.R.E. collection to the public library and high school of two neighboring rural communities, Ranier and Clatskanie.

Figure 5 - SJMC Library's Consumer Health Service



Cancer Care Providers' Insights

Through eight years of working relationship with cancer care providers at Lower Columbia Cancer Center, I gained a good understanding of informational needs of the cancer patients they serve. Some examples include the following:

- A medical social work asked me to find a book that a cancer patient can read to her small children about her cancer.
- Sign language was required
- Cancer information in non-English language

- Local sources for look good/feel good – wigs, hats, make-up, manicure, pedicure
- Locate specialists
- Information about cancer treatment clinical trials

Examine other Websites

I explored numerous consumer cancer information Web sites to get ideas for the look and feel of the Cowlitz C.A.R.E. Web portal. Appendix A shows some of the Web sites the will be linked from the portal.

RESULTS

There is a wealth of cancer information on the Web at national level, such as MedlinePlus, andcancer.org, but the information found in these sites is overwhelming. These sites will be linked in the Cowlitz C.A.R.E. portal, which has basic cancer information and local resource information. In this project we discovered that the information in Cowlitz County are scattered, and therefore hard to be kept up to date. There is not a unified collection of cancer information.

There are opportunities for improvement in satisfying patient needs to discover the relevant information they need, act on their healthcare decisions, and share with others. There is a need for building a database that contains local information as well as links to cancer literature that is basic. A cancer resource web portal presents opportunities to empower cancer patients in Cowlitz County in their journey. It enables cancer patients find needed information in one convenient place. It will reduce time required to find information that will help them make informed decisions about their health. This will also have immediate practical impact. Patients

and their care givers will find useful information such as lodging, spiritual care, child care, local support group meetings and schedules, counseling and other local relevant services.

Design of Cowlitz C.A.R.E. Web portal

The organization of Cowlitz C.A.R.E. Web portal consists of three sections. This portal will evolve over time and will include forums and FAQ.

- (1) Local Cancer Resources such as support groups, respite care service, interpreter service, relocation placement options, spiritual care, counseling, etc. will be included in the Web portal. Currently, referrals of many of these resources are found through care provider, word of mouth, phone book and not in a unified Web location resource.
- (2) Cancer Literature – this section will include links to trusted sites such as MedlinePlus, Cancer.gov, etc. The goal is to provide a link to high quality cancer information in easy to understand language.
- (3) Non-Local Special Cancer Resource – this section will include links to Websites of recommended vendors for prosthetics, nutritional services, equipment banks, medical supply, financial service, etc.

Figure 6 - Cowlitz C.A.R.E. Web Portal Design Structure

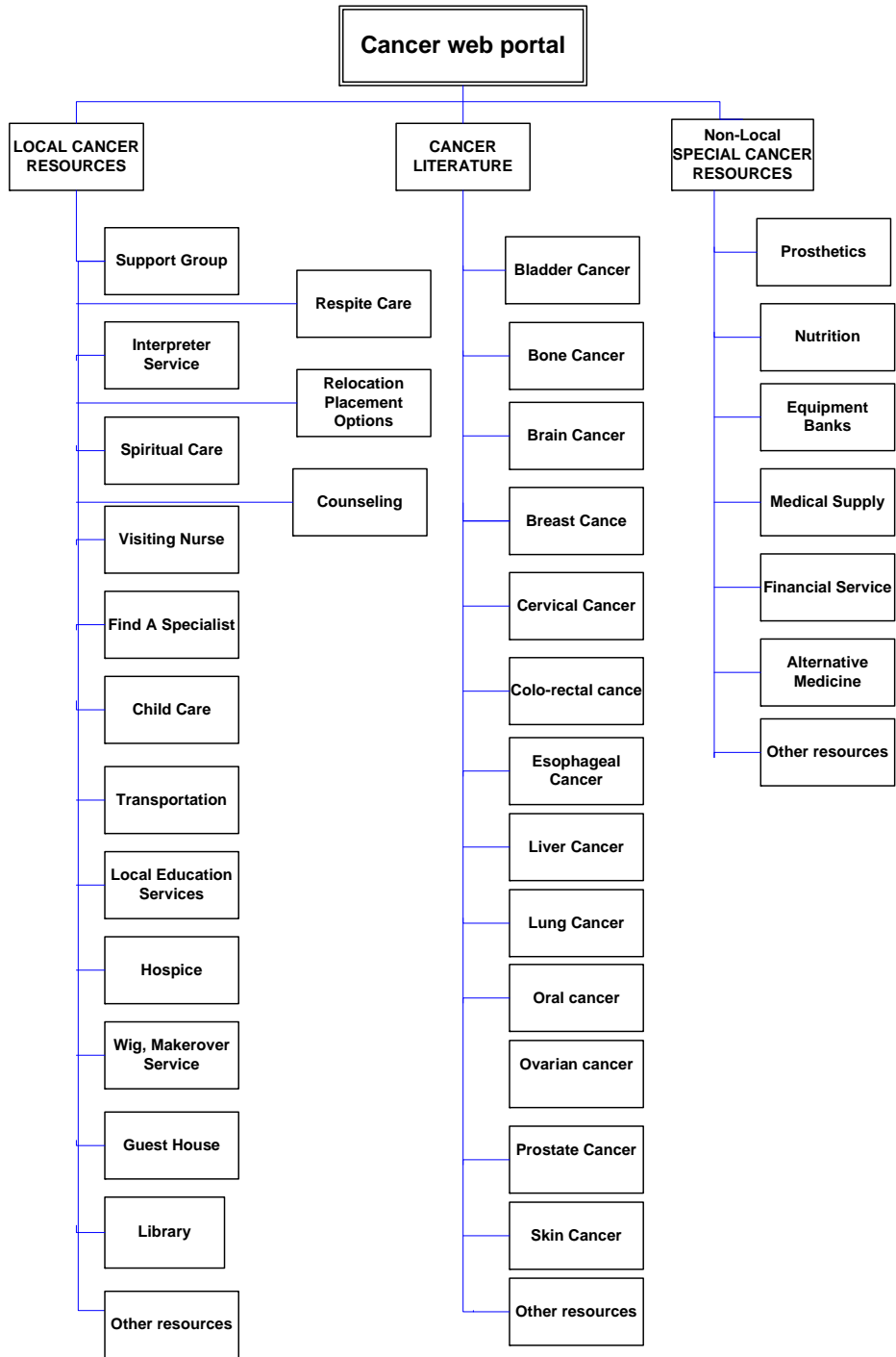


Table 2 - Cancer Literature URL

ID	description	LANGUAGE	URL	
1.1	Bladder cancer	ENGLISH	http://www.cancer.gov/pdf/WYNTK/WYNTK_bladder.pdf	
1.2	Bladder cancer	CHINESE		
1.3	Bladder cancer	SPANISH	http://www.nlm.nih.gov/medlineplus/spanish/bladdercancer.html	<i>Cáncer de vejiga</i>
2.1	Bone cancer	ENGLISH	http://www.cancer.gov/cancertopics/factsheet/Sites-Types/bone	
2.2	Bone cancer	CHINESE		
2.3	Bone cancer	SPANISH	http://www.cancer.gov/cancertopics/factsheet/Sites-Types/bone-spanish	<i>El cáncer de hueso</i>
3.1	Brain cancer	ENGLISH	http://www.cancer.gov/cancertopics/wyntk/brain.pdf	
3.2	Brain cancer	CHINESE		
3.3	Brain cancer	SPANISH	http://www.nlm.nih.gov/medlineplus/spanish/tutorials/braincancerspanish/htm/index.htm	<i>Tumores Cerebrales</i>
4.1	Breast cancer	ENGLISH		
4.2	Breast cancer	CHINESE	http://www.cancer.org/downloads/ASN/Breast_Cancer_Overview.pdf	<i>乳癌</i>
4.3	Breast cancer	SPANISH		
5.1	Cervical cancer	ENGLISH	http://www.cancer.gov/cancertopics/wyntk/cervix.pdf	
5.2	Cervical cancer	CHINESE		
5.3	Cervical cancer	SPANISH	http://www.cancer.gov/pdf/WYNTK/WYNTK_cervixsp.pdf	<i>uterino</i>
6.1	Colo-rectal cancer	ENGLISH	http://www.nlm.nih.gov/medlineplus/colorectalcaner.html	
6.2	Colo-rectal cancer	CHINESE	http://www.healthinfotranslations.org/pdfDocs/Cancer_Colon_Rectum-CHT.pdf	<i>結腸和直腸癌</i>
6.3	Colo-rectal cancer	SPANISH	http://www.nlm.nih.gov/medlineplus/spanish/colorectalcaner.html	<i>Cáncer del colon y del recto</i>
7.1	Esophageal cancer	ENGLISH	http://www.cancer.gov/cancertopics/wyntk/esophagus.pdf	
	Esophageal cancer	CHINESE		
7.2	Esophageal cancer	SPANISH	http://www.nlm.nih.gov/medlineplus/spanish/esophagealcancer.html	<i>Cáncer de esófago</i>
7.3	Liver cancer	ENGLISH	http://www.cancer.gov/cancertopics/wyntk/liver.pdf	
7.4	Liver cancer	CHINESE		
7.5	Liver cancer	SPANISH	http://www.nlm.nih.gov/medlineplus/spanish/livercancer.html	<i>Cáncer de hígado</i>
8.1	Lung cancer	ENGLISH		
8.2	Lung cancer	CHINESE	http://www.fda.gov/downloads/ForConsumers/ByAudience/ForWomen/FreePublications/UCM135089.pdf	<i>肺癌</i>
9.1	Oral cancer	CHINESE	http://www.cda.org/library/articles/oralcancerchinese.pdf	<i>口腔癌</i>
9.2	Oral cancer	SPANISH		
10.1	Prostate cancer	CHINESE	http://www.cancer.org/downloads/ASN/Prostate.pdf	<i>前列腺癌</i>
10.2	Prostate cancer	SPANISH		
11.1	Testicular cancer	ENGLISH		
11.2	Testicular cancer	CHINESE	http://www.healthinfotranslations.org/pdfDocs/TesticularSelfExam-TCH_TrChi_FINAL.pdf	<i>辜丸自檢</i>
11.3	Testicular cancer	SPANISH		

Database Design

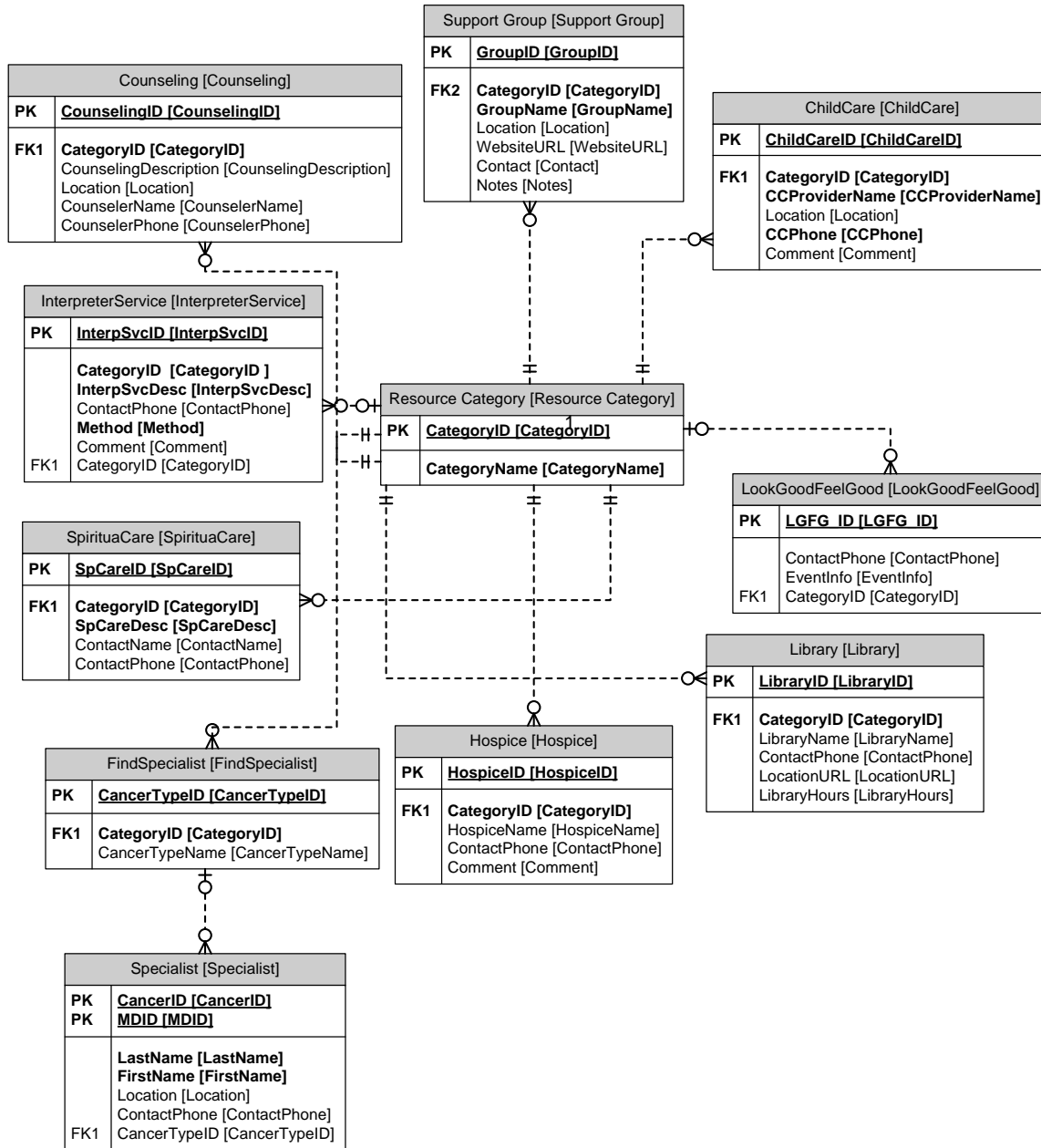
The topics described above require the storage of many variables and data types. Oftentimes the relationships among variables can become quite complicated. For example, a patient may need to know the local or the next closest resource. As an example, for sign language services, first

choice would be Longview, second choice is Olympia, then Seattle, New York, etc. However, for some services, the resource must be local. For meals, housing, counseling, and spiritual care, only local service would be useful. The goal of our database is to store and access information and to have it be easily maintained (insert new information, update existing information, and remove obsolete information). Oracle Express, a license-free software, will be used to store the data for our portal. Application Express, which is a component of Oracle Express, is being used to build the portal. The database is constructed with three schemas:

1. Local resource schema: Local resources database with ER diagram depicted in Figure 7. It contains 12 tables – Resource Category, Counseling, Support Group, Child Care, Spiritual Care, Hospice, Find Specialist, LookGoodFeelGood, Library, Interpreter Service, etc.
2. Cancer literature schema: Cancer literature with ER diagram depicted in Figure 8, which contains three tables – (a) cancer category; (b) language; (c) universal resource locator (url).
3. Non-local special cancer resource schema will have the same pattern as the local resource schema. Vendor information such as service product, contact information will be stored in the database.

ER diagram, entities, attributes and relationship for local resources database

Figure 7 - ER diagram of local resource database



Sample data stored in schema tables

Table 3 - Support Group Entity

Category ID	Group ID	SupportGroupName	Contact phone	Location	Website URL	Notes
01	01	Learning to live with cancer	3604147968	Cancer Center	na	A structured group educational program for adult cancer patients and their families and friends.
01	02	Cancer Support Group	3604147968	Cancer Center	na	Meets first and third Monday monthly.
01	03	Reach to Recovery	3604142701	TBD	na	One to one individual service, conducted by a volunteer.
01	04	Moving Thru Cancer – Cancer Wellness Program	3604147968	St. John Wellness Center	na	8-week exercise, nutritional counseling, education and peer support.
01	05	Breast Cancer Support Group	3604142701	SJMC Conf Rm	na	Meets monthly.
01	06	New Hope Cancer Recovery	3604257978	New Life Fellowship Church		Meets 1 st & 3 rd Mondays monthly

Table 4 - Counseling Entity

Category ID	Counseling ID	Counseling Description	Counselor Phone	Counselor Name	Location
02	01	Coping with a new diagnosis	3604147968	De-identified	Cancer Center
02	02	Adjusting to life changes	3604147968	De-identified	Cancer Center
02	03	Maintaining hope	3604147968	De-identified	Cancer Center
02	04	Managing stress and depression	3604147968	De-identified	Cancer Center
02	05	Caregiver and family support	3604147968	De-identified	Cancer Center
02	06	Advance directives	3604147968	De-identified	Cancer Center
02	07	Long and short term planning	3604147968	De-identified	Cancer Center
02	08	Crisis intervention	3604147968	De-identified	Cancer Center

Table 5 - Spiritual Care Entity

Category ID	SpCare ID	SpCareDesc	Contact Name	Contact Phone	Location
03	01	Sacramental & Ritual Support	na	3604147575	TBD
03	02	Advanced Directives	na	3604147575	TBD
03	03	Pastoral Counseling	na	3604147575	TBD
03	04	Medical Decision Making	na	3604147575	TBD
03	05	Guest Housing	na	3604147575	TBD
03	06	Parish Nursing	na	3604147575	TBD
03	07	Bereavement Support Group	NA	3604147575	TBD

Table 6 - Library Entity

Category ID	Library ID	Library Name	Library URL	Contact Phone	Library Hours
08	01	Minthorn Medical Library, SJMC		3604147462	8 – 5
08	02	Longview City Library			
08	03	Castle Rock Public Library			
08	04	Kelso Public Library			
08	05	Lower Columbia College Library			
08	06	Ranier Public Library			
08	07	Women’s Health Library			

ER diagram, entities, attributes and relationship for cancer literature database

Figure 8 - ER Diagram of Cancer Information Database

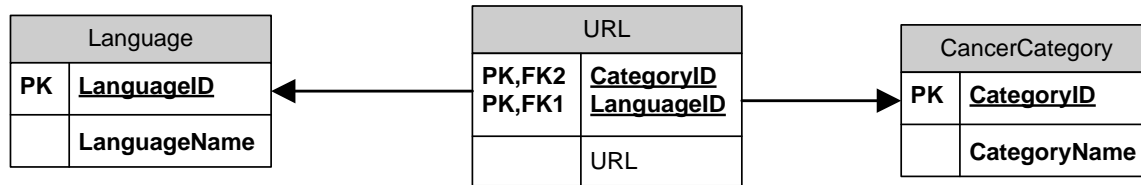


Table 7 - Language Entity

Language ID	Language Name
01	English
02	Spanish
03	Chinese
04	Russian
05	Vietnamese
06	French
07	Ukranian

Table 8 - Cancer Category Entity

Category ID	Category Name
01	Bladder
02	Bone
03	Brain
04	Breast
05	Cervical
06	Colorectal
07	Esophageal

Table 9 - URL Entity

Category ID	Language ID	URL
01	01	http://www.cancer.gov/pdf/WYNTK/WYNTK_bladder.pdf
01	02	http://www.nlm.nih.gov/medlineplus/spanish/bladdercancer.html
01	03	NULL
02	01	http://www.cancer.gov/cancertopics/factsheet/Sites-Types/bone
02	02	http://www.cancer.gov/cancertopics/factsheet/Sites-Types/bone-spanish
02	03	NULL
03	01	http://www.cancer.gov/cancertopics/wyntk/brain.pdf

DISCUSSION

Building a Web portal is not very difficult. However, maintaining the web portal requires a great deal of commitment, planning, organizational skill, and collaborative human resources. As a medical librarian keeps track of books and journals on the shelf, on line journals, catalogs, year of publication, vendors, patrons, and so on, a Web portal master must keep track of every piece of the content on a Web portal; have a version control mechanism and work closely with medical professionals to certify the content of every piece of information. Agility that allows a Web master to quickly tailor the Web pages based on an individual cancer patient's need is one of the most critical challenges of this portal. The questions like what information a patient wants, and what information a patient needs should be addressed on a regular basis. To accomplish this, we have several recommendations. Brainstorming sessions that include health professionals, patients, families, and IT professionals, should be scheduled on a regular basis. A survey about the usability of this C.A.R.E Web portal must be designed, and the qualitative and quantitative analysis should be completed. Additionally, the data base must be kept current. Hardware, software, database, networking resources must be in place and maintained by professionals. Protocol and policies must be in place for quality assurance purposes. This requires adequate funding and community commitment. Also a continuous promotion and community outreach is necessary to promote this C.A.R.E Web portal

CONCLUSION

This cancer information portal provides a starting access point for newly diagnosed cancer patients to access needed information. It has the potential to help patients make informed healthcare decisions and actively participate in their disease management. It is important the system evolve based on user needs over time. One unique feature of this information portal is that it includes local resources such as support groups, relevant local resources and other useful information for cancer patients.

This framework is a starting point of a multi-phase project that requires organizational commitment and funding. This project is about empowering cancer patients in their journey, where they need fast answers, information, hope, support, prayers, etc. By putting together all these pieces, we will create valuable synergy that the patients, their families and care givers can benefit from. As a consumer health information provider, I see a strong possibility that Cowlitz C.A.R.E. Web portal will improve cancer information consumers' access to information. I am motivated to advocate the building of such a cancer Web portal for Cowlitz County. Statistics from Washington State Cancer Registry shows clearly that cancer in Washington and in particular in Cowlitz County, is on the rise. The justification for building the Cowlitz C.A.R.E. Web portal is compelling.

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APPENDIX – some Websites consulted

SJMC intranet sites:



Spiritual Care & Ethics

- [Main Page](#)
- [Who's Who](#)
- [Prayer Requests](#)
- [Reflections](#)
- [Advance Directives](#)
- [Bereavement Program](#)
- [Cultural Diversity](#)
- [Ethics](#)
- [Palliative Care](#)
- [Guest House](#)
- [Interpreter Program](#)
- [Patient Rights](#)
- [Chapel](#)



Welcome to the St. John Medical Center Spiritual Care & Ethics Website


[Prayer of the Day](#)

[Reflections](#)

Advance Directives	Interpreter Program	Patient Rights
Bereavement Program	Ethics	Cultural Diversity
Palliative Care	Prayer Requests	Guest House
Busy Person's Retreat		

[back to top](#)

Palliative Care

Palliative Care Policy		<p>Palliative Care Carts For information call Elizabeth at extension 7931</p>
<p>Supportive Care of the Dying A Coalition for Compassionate Care</p>	<p>We are a coalition of like-minded Catholic health care providers and service organizations dedicated to promoting cultural change that embraces supportive care, compassionate relief of suffering and pain, and symptom management for helping people living with life-threatening illness. We recognize a better death is possible.</p>	
<p>CAPC Center to Advance Palliative Care</p>	<p>The Center to Advance Palliative Care (CAPC) is dedicated to increasing the availability of quality palliative care services in hospitals and other health care settings for people with life-threatening illnesses, their families, and caregivers.</p>	
<p>National Hospice & Palliative Care Organization</p>	<p>The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.</p>	

Quick Links

- [Director's Corner](#)
Updates from the Director
- [Dictionary of Cancer Terms](#)
Cancer-related terms
- [NCI Drug Dictionary](#)
Definitions, names, and links
- [Funding Opportunities](#)
Research and training
- [NCI Publications](#)
Order/download free booklets
- [Advisory Boards and Groups](#)
Information, meetings, reports
- [Science Serving People](#)
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Información en español

Questions about cancer?
• 1-800-4-CAICER



NCI Highlights

- [The Nation's Investment in Cancer Research FY 2010](#)
- [Latin American Cancer Program](#)
- [Report to the Nation Finds Continued Declines in Cancer Rates](#)
- [NCI Funded Research Portfolio](#)
- [caBIG: Connecting the Cancer Community](#)
- [Independent Task Force Update on Breast Cancer Screening](#)



Types of Cancer

Common Cancer Types

- [Bladder Cancer](#)
- [Breast Cancer](#)
- [Colon and Rectal Cancer](#)
- [Endometrial Cancer](#)
- [Kidney \(Renal Cell\) Cancer](#)
- [Leukemia](#)
- [Lung Cancer](#)
- [Melanoma](#)
- [Non-Hodgkin Lymphoma](#)
- [Pancreatic Cancer](#)

- [Prostate Cancer](#)
- [Skin Cancer \(Nonmelanoma\)](#)
- [Thyroid Cancer](#)

All Cancer Types

- [A to Z List of Cancers](#)
- [Cancers by Body Location/System](#)
- [Childhood Cancers](#)
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- [Cancer Health Disparities](#)
- [NCI Fact Sheets](#)
- [Physician Data Query \(PDQ®\)](#)

A to Z List of Cancers



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Questions about cancer?

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NCI Highlights

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- [The Nation's Investment in Cancer Research FY 2010](#)
- [Report to the Nation Finds Continued Declines in Cancer Rates](#)

- [A - D](#) | [E - K](#) | [L - M](#) | [N - R](#) | [S - Z](#) | [All](#)

A

- [Acute Lymphoblastic Leukemia, Adult](#)
- [Acute Lymphoblastic Leukemia, Childhood](#)
- [Acute Myeloid Leukemia, Adult](#)
- [Acute Myeloid Leukemia, Childhood](#)
- [Adrenocortical Carcinoma](#)
- [Adrenocortical Carcinoma, Childhood](#)
- [AIDS-Related Cancers](#)
- [AIDS-Related Lymphoma](#)
- [Anal Cancer](#)
- [Appendix Cancer](#)
- [Astrocytomas, Childhood](#)
(See [What Are Childhood Astrocytomas?](#))
- [Atypical Teratoid/Rhabdoid Tumor, Childhood, Central Nervous System](#)

B

- [Basal Cell Carcinoma, see Skin Cancer \(Nonmelanoma\)](#)
- [Bile Duct Cancer, Extrahepatic](#)
- [Bladder Cancer](#)
- [Bladder Cancer, Childhood](#)
- [Bone Cancer, Osteosarcoma and Malignant Fibrous Histiocytoma](#)
- [Brain Stem Glioma, Childhood](#)
- [Brain Tumor, Adult](#)
- [Brain Tumor, Brain Stem Glioma, Childhood](#)
- [Brain Tumor, Central Nervous System Atypical Teratoid/Rhabdoid Tumor, Childhood](#)
- [Brain Tumor, Central Nervous System Embryonal Tumors, Childhood](#)
(See [What Are Childhood Central Nervous System Embryonal Tumors?](#))
- [Brain Tumor, Astrocytomas, Childhood](#)
(See [What Are Childhood Astrocytomas?](#))
- [Brain Tumor, Craniopharyngioma, Childhood](#)
- [Brain Tumor, Ependymoblastoma, Childhood](#)
(See [What Are Childhood Central Nervous System Embryonal Tumors?](#))
- [Brain Tumor, Ependymoma, Childhood](#)
- [Brain Tumor, Medulloblastoma, Childhood](#)
- [Brain Tumor, Medulloepithelioma, Childhood](#)
(See [What Are Childhood Central Nervous System Embryonal Tumors?](#))
- [Brain Tumor, Pineal Parenchymal Tumors of Intermediate Differentiation, Childhood](#)
(See [What Are Childhood Central Nervous System Embryonal Tumors?](#))
- [Brain Tumor, Supratentorial Primitive Neuroectodermal Tumors and Pineoblastoma, Childhood](#)
- [Brain and Spinal Cord Tumors, Childhood \(Other\)](#)
- [Breast Cancer](#)
- [Breast Cancer and Pregnancy](#)
- [Breast Cancer, Childhood](#)
- [Breast Cancer, Male](#)
- [Bronchial Tumors, Childhood](#)
- [Burkitt Lymphoma](#)

Search for Clinical Trials

Clinical Trial Questions?
Get Help:
1-800-4-CANCER

Search NCI's list of 8,000+ clinical trials now accepting participants, or use more search options to search the set of 19,000+ clinical trials that are no longer recruiting.

Search Tip: Skip any items that are unknown or not applicable.

- Quick Links**
- [Help Using the NCI Clinical Trials Search Form](#)
 - [Educational Materials About Clinical Trials](#)
 - [About NCI's Cancer Clinical Trials Registry](#)
 - [Dictionary of Cancer Terms](#)
 - [NCI Drug Dictionary](#)

Cancer Type/Condition ?

Stage/Subtype

Location ?

Near ZIP Code
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 At NIH

Near ZIP Code

Show trials located within:

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Trial/Treatment Type Search by trial type, drug, or treatment/intervention ?

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Keywords/Phrases Search by word or phrase (use quote marks with phrases) ?

PDQ®



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NCI Highlights

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- [The Nation's Investment in Cancer Research FY 2010](#)
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PDQ (Physician Data Query) is NCI's [comprehensive cancer database](#). It contains summaries on a wide range of cancer topics; a registry of 8000+ open and 19,000+ closed cancer clinical trials from around the world; and a directory of professionals who provide genetics services. PDQ also contains the NCI Dictionary of Cancer Terms, with definitions for 6000+ cancer and medical terms, and the NCI Drug Dictionary, which has information on 1200+ agents used in the treatment of cancer or cancer-related conditions.

PDQ (Physician Data Query)

[PDQ® - NCI's Comprehensive Cancer Database](#)
Full description of the NCI PDQ database.

Cancer Information Summaries

[PDQ® Cancer Information Summaries: Adult Treatment](#)
Treatment options for adult cancers.

[PDQ® Cancer Information Summaries: Pediatric Treatment](#)
Treatment options for childhood cancers.

[PDQ® Cancer Information Summaries: Supportive and Palliative Care](#)
Side effects of cancer treatment, management of cancer-related complications and pain, and psychosocial concerns.

[PDQ® Cancer Information Summaries: Screening/Detection \(Testing for Cancer\)](#)
Tests or procedures that detect specific types of cancer.

[PDQ® Cancer Information Summaries: Prevention](#)
Risk factors and methods to increase chances of preventing specific types of cancer.

[PDQ® Cancer Information Summaries: Genetics](#)
Genetics of specific cancers and inherited cancer syndromes, and ethical, legal, and social concerns.

[PDQ® Cancer Information Summaries: Complementary and Alternative Medicine](#)
Information about complementary and alternative forms of treatment for cancer patients.



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1/5



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- Promising Therapies**
- + PSK
- + Bovine Cartilage
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- Shark Cartilage Protocol
- Oerson Therapy
- Essiac
- + Hulda Clark's "Cure for All Cancers"
- Other**
- Links
- + Recommended Books

Alternative and Complementary Therapies Section Home

Evaluating Alternative Therapies

- [Some Thoughts on Alternative Therapies](#)
Some of my ideas on evaluating therapies and avoiding traps.
- [Separating the Wheat from the Chaff \(will open in new window\)](#)
Thoughts on Filtering Worthwhile Alternative Therapies from Nonsense.

Information on Specific Therapies

These are in three groups. **First**, I list things that I consider promising - I put these first because I am first and foremost interested in what might actually help cancer patients. **Second**, I list therapies I happen to have come across which are little known where the information here might be relatively unique. **Third**, I list some popular therapies I happen to have looked into. I make no attempt to be comprehensive in this area.

Promising Therapies

Please understand that my opinion that something is "promising" only means I think it might have *some* efficacy. It absolutely doesn't mean I think it's a guaranteed miracle cure and, in fact, I know of no alternative therapy that has a *proven* high rate of success. I strongly believe that it is a potentially lethal error to substitute alternative therapy for other treatment in any case where