Palliative Care in Thailand: Hospice & Homecare

A Framework for the Assessment of Costs and Benefits

A comprehensive packet produced by students of the Worcester Polytechnic Institute in Worcester, MA, USA in conjunction with the Mahavachiralongkorn Thanyaburi Cancer Center, in Pathum Thani, Thailand.

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Forward

In 2000, the World Health Organization reported about 12% of deaths worldwide were caused by cancer and that about 80% of cancer cases in developing countries have already become terminal before diagnosis (WHO, 2005). In Thailand specifically, cancer is one of the leading causes of death, claiming lives at a rate of 68 per every 100,000 people a year. In addition, hospital admission rates for cancer patients are approximately 78 people per 100,000, suggesting that almost 90% of diagnosed cancer patients die from the disease (WHO, 2000). For many patients and their loved ones, hospice and homecare offer an alternative approach to facing a terminal illness. Palliative care is used when patients decide to discontinue curative care. Palliative care programs are geared towards ensuring that the final days of the patient are peaceful and dignified. However, in some developing countries, such as Thailand, hospice and homecare are not fully utilized.

This is a comprehensive packet detailing an approach for assessing costs and benefits hospice and homecare systems. Specifically discussed is how to evaluate the effectiveness of a program and how to prepare services for costbenefit analysis. The intention of such an assessment is the promotion of these alternatives to terminal care programs. Included are explanations of hospice and homecare, a quality of life survey and instructions for administration and analysis, a patient demographics sheet and instructions for compilation, and a breakdown of services and associated costs.

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Additional information, documents and programs can be found on the attached CD.

What are Hospice and Homecare?

Hospice and homecare are both alternative terminal care programs that give strictly non-curative care. As such, they are considered palliative care programs. The goal of a palliative care program is to ensure that the final days of a patient are pain free and comfortable. They also provide support for families whose loved ones are facing an incurable illness. Improving the quality of life (QOL) of a patient is the desired result of all palliative care programs. A professional team works with the patient and family to make sure that the patient dies a dignified and comfortable death. Through palliative care programs, patients are not only treated for the physical ailments but also their psychological needs.

Palliative programs aim to provide holistic care to their patients. In order to accomplish that task, the programs must offer services that cover all the areas of patient needs. These areas and a list of commonly found hospice and homecare services are listed below. To meet these needs, palliative care programs utilize a combination of medicines, therapies, counseling sessions, and clinics. The goal of each service is to provide support for the patient. This support ranges anywhere from management of pain, to management of financial documents, to bereavement sessions for grieving family members. By offering many services, a palliative care program has the opportunity to improve the quality of all aspects of a patient's life.

Examples of Palliative Care Services

Physical

- Pain management • through medication
- Symptom management
- through external support •
- Physical therapy •
- Nutrition planning Exercise programs
- Beauty therapy
- Massage therapy

Social

- Care clinics for relatives/caregivers
- Support groups
- Illness education semi-
- Bereavement counseling •

Social work

Spiritual

- Meditation classes •
- Positive thinking
- Readings of Buddhist teachings

Psychological

- Relaxation techniques
- Emotional support groups
- Music therapy

Hospice and Homecare in Thailand

Palliative care programs typically consist of inpatient hospice services and/or outpatient homecare services. In Western medical communities, palliative care, hospice, and homecare are practically synonymous because the majority of the care (about 90%) given to terminally ill patients happens in the home (HospiceNet, 2005). Contrary to the Western model, Thai hospice operates in a slightly modified manner. In Thailand, hospice and homecare services are completely separate entities. At the only Thai cancer hospice, in the Mahavachiralongkorn Cancer Center, all of the services are inpatient.

"To cure sometimes, to relieve often, to comfort always"

- I. Jon Russell

nars

- Financial

Quality of Life

What is Quality of Life?

QOL has been defined as a "global evaluation of satisfaction with one's life" (Cooley 1998). It is also seen as one of the most important outcomes of effective end-of-life care. A good QOL means that the patient is comfortable with the management of his/her illness.

Measuring Quality of Life

QOL assessments are necessary to help a hospital ensure that their patient's needs are being met. In addition, measuring QOL can generate the necessary data to prove or disprove the benefits of a care program. Those same data can also be a powerful tool to prove both the effectiveness and success of a care program. Valid assessments can only be conducted by utilizing an instrument that is sensitive to all aspects of the patient's life. To obtain a holistic view of the life of a patient, one must examine the myriad of factors that influence their life. This examination is no small task considering the wide range of influences experienced by a patient. However, it is made easier by grouping these influences into major categories. The categories are physical, mental, spiritual, social, and finance. To understand how to measure QOL it is necessary to explore all these categories in the context of how they will affect a patient's perception of their life.

QOL Categories

Physical

- Physical Body
 - Symptom management Pain management Fatigue/energy Nourishment Climate
- Body Response to Environment Noise Level Privacy

Social

- Emotional Support
- Informational Support
- Caring relationships
- Affection and Love
- Trust

Financial

Economic Pressure Familial burden Monetary restrictions

Spiritual

- Self Acceptance Self Esteem Dignity Appearance Meaningfulness of their life Personal growth
- Existential Wellbeing Standing in the world Influence on coming to terms with life Coming to terms with how they lived
 - Religion Preparedness to pass on

Mental

- Psychological Hope Positive Thinking Concentration
- Independence

The following pages contain a survey that has been adapted and tested with Thai terminally ill cancer patients. Instructions and survey question explanations are provided, as well as a system for scoring results.



QOL Surveys

Instructions for QOL Survey Administration

The administration of this survey should be overseen by a knowledgeable, informed and involved staff member. This is key to eliminating the discrepancies caused by the survey variables. An administrator needs to be fully aware of the purpose of the survey and the meaning of each question. They must pay careful attention to how they clarify



any questions in order to prevent patient bias or discontinuity in the results. They need to be sensitive to the level of education of each patient so that they can give appropriate explanations. Also, an administrator needs to be aware of language nuances and connotations in the medical world to make sure he/she is not unknowingly influencing a patient.

Before surveying patients, it is crucial that an administrator be completely aware of the intricacies of our survey. For this reason, the pages 6-8 describe in more detail the intent of each question. By taking the appropriate amount of time to familiarize themselves with this material, the administrator should be well prepared to accurately administer this survey. The English version of our survey can be found on pages 9&10; the Thai version can be found on the CD provided.

Instructions for QOL Survey Analysis



Once the QOL patient survey has been administered, compilation and analysis are needed to make use of the data obtained. A hardcopy of the scoring sheet can be found on pages 11-13; this can also be found on the CD, as well as an excel program for computing these scores. This scoring method weights the QOL scores according to each individual patient's priorities and has been

cross analyzed with two other processes to check validity.

Patient QOL Survey Question Explanations

Physical

1. Are you satisfied are you with the management of your pain and discomfort?

This refers to pain and physical discomfort of the patients caused by either their disease or symptoms of their disease and how well it is controlled through drugs, meditation, etc.

2. Are you satisfied with your level of energy?

This question is about the amount of energy a patient has. This could be affected by fatigue, poor nourishment, etc. For patients that still desire to be active, are they able to do the things they want? Or do they feel too drained and tired to do the things they want?

Does the patient experience any negative feelings?

3. Are you satisfied are you with your ability to do daily activities?

Some examples of daily activities might be patients dressing themselves, bathing themselves, eating by themselves, etc. This was also described as level of Independence. Can the patient still do these things or do they rely on someone else? Are they satisfied with how reliant they are on other people?

4. Are you comfortable with your living conditions?

This is about the physical environment surrounding the patient, whether at home or in the hospital. Factors could include noise, temperature, privacy, etc. Are they satisfied with these conditions or do they detract from the patient's comfort?

Mental health

5. Do you feel positive about your future?

Even though the patient is sick now, do they still believe there is a chance of things getting better in the future? This can be future in this life or the next. Or does the future seem bleak, without hope of good things happening? Some patients become overwhelmed by their sickness and cannot see past the bad things in their life. Can they see good things in their future? Are they still thinking positively?

6. Do you experience feelings of sadness, dejection or anxiety?

Does the patient become sad, dejected or anxious because of their current state of health? Does the patient experience any negative feelings?

7. When you look in the mirror, do you feel comfortable with your body?

This is about patient self esteem. Can they be happy with themselves even if they have lost hair, limbs, etc.? Can they accept their current physical state?

8. When you are with others, are you self-conscious because of the effects of your illness?

This is about the dignity of the patient. For example, some patients have urine bags. Are the effects of their illness embarrassing or are they comfortable around others?

Spiritual health

9. Do your beliefs give you enough support to face your disease?

This is about the patient's ability to accept their disease and pain and move on from it. Can they recognize that their illness affects their body, not their soul? Does their religion give them the strength and knowledge to be able to do this?

10. Do your attachments to loved ones, possessions, and memories make you sad?

Are they able to let go of the physical world around them or are they so attached still that it interferes with their happiness? When they think back on memories or visit with loved ones, do they long to return to their everyday life or are they satisfied with what they have experienced in their life?

11. Do you feel at peace with yourself?

Is the patient uneasy everyday? Is there something that hangs over their head? Or do they experience harmony with the world? Have they accepted themselves and the things they have done in their life?

12. Are you satisfied with the spiritual merit (punya) you've earned in this life?

Is they patient happy with the amount of spiritual merit/punya that they have built up in this life? Are they worried about karma and their rebirth into the next life? Do they feel they have done enough in this life to earn good merit?

Social

13. Are you satisfied with the state of your relationships with your loved ones?

Do they have healthy relationships with family, friends and other important people in their life? Are they in contact with their loved ones as much as they would like to be?

14. Can you rely on your loved ones to help you during your illness?

Do the patient's family and friends have enough time to help them? Do they have someone that is reliable as a caregiver? Are they supported through their illness?

15. Do you receive enough love and affection from those around you?

Does the patient receive enough attention and feel cared for? Or do they feel like they are treated indifferently, like just another person/patient.?

"Is the patient happy with the amount of spiritual merit that they have built up in this life? 16. Do you feel safe and secure with the caregivers in your life?

This can be family, other caregivers, or hospital staff. Does that patient trust the people around them? Does the patient feel that their caregivers are looking out for the patient's best interest and that they will make the best decisions?

Finances

17. Do you worry about paying for your medical services?

Does the patient feel that their financial status affects the services they receive? Does the patient spend a lot of time worrying about how they are going to pay for the services they need? Does the patient decline certain treatments because they cannot afford them?

18. Do you worry about how your disease affects your family's financial status?

Does the patient worry about being a financial burden on their family? Do they worry about how their family will make enough income without the patient's help? Or can the patient's family support them patient and still have enough money to support themselves?

Overall

19. How important are physical factors to your quality of life?

20. How important are mental health factors to your quality of life?

21. How important are spiritual factors to your quality of life?

22. How important are social factors to your quality of life?

23. How important are financial factors to your quality of life?

These five questions ask how important various general categories are to the patient. For example, is the patient highly concerned with their financial situation or can they still be happy even if their financial situation is not very good? How much do these factors affect the patient's quality of life?

"Does the patient decline certain treatments because they cannot afford them?

Patient QOL Survey

Patient Quality of Life

We are students from Massachusetts, USA doing research on patient quality of life. This survey includes questions on different factors that we have found to influence a patient's quality of life. Please take a few minutes to respond to the best of your ability.

Instructions: Please mark a check () in the column that best indicates your feelings on the topic. There are 5 sections. Please answer all questions.

1. Physical

		Never	Hardly Ever	Occasionally	Often	Always
1	Are you satisfied are you with the management of your pain and discomfort?					
2	Are you satisfied are you with your level of energy?					
3	Are you satisfied are you with your ability to do daily activities?					
4	Are you comfortable with your living conditions?					

2. Mental Health

		Never	Hardly Ever	Occasionally	Often	Always
5	Do you feel positive about your future?					
6	Do you experience feelings of sadness, dejection or anxiety?					
7	When you look in the mirror, do you feel comfortable with your body?					
8	When you are with others, are you self-conscious because of the effects of yo <mark>j</mark> ur illness?					

3. Spiritual

-		Never	Hardly Ever	Occasionally	Often	Always
9	Do yourbeliefs give you enough support to face your disease?					
10	Do your attachments to loved ones, possessions, and memories make you sad?					
11	Do you feel at peace with yourself?					
12	Are you satisfied with the spiritual merit (punya) you've earned in this life?					

4. Social

		Never	Hardly Ever	Occasionally	Often	Always
13	Are you satisfied with the state of your relationships with your loved ones?					
14	Can you rely on your loved ones to help you during your illness?					
15	Do you receive enough love and affection from those around you?					
16	Do you feel safe and secure with the caregivers in your life?					

5. Financial

17 Do you worry about paying for your medical services?		Never	Hardly Ever	Occasionally	Often	Always
18 Do you worry about how your disease affects your family's financial situation?	18 Do you worry about how your disease affects your family's financial situation?					

	6. Overall	Very				Very
		Unimportant	Unimportant	Neutral	Important	Important
19	How important are physical factors to your quality of life?					
	How important are mental health factors to your quality of					
20	life?					
21	How important are spiritual factors to your quality of life?					
22	How important are social factors to your quality of life?					
23	How important are financial factors to your quality of life?					

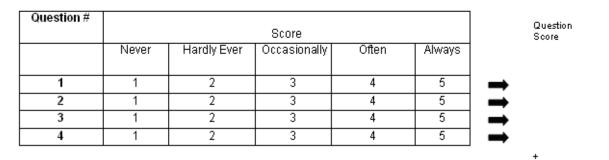
QOL Survey Analysis Scoring Sheet

This sheet assesses patient QOL according to predetermined weights. You will need the patient's response form filled out and you may need a calculator. There are 5 parts to this analysis sheet and each part needs to be completed in order to determine the patient's quality of life score.

Part 1

This part has 5 subsections, each corresponding to the first 5 sections on the patient QOL survey. You will need the patient response survey to complete this section. For each response given to questions in the survey, there is an associated value. Please note that response values may differ from question to question.

In the grids provided, indicate the response given and the corresponding value. Write the score on the right <u>under</u> "Question Score". At the end of each subsection, you will need to add up the scores for later use.



1. Physical Factors



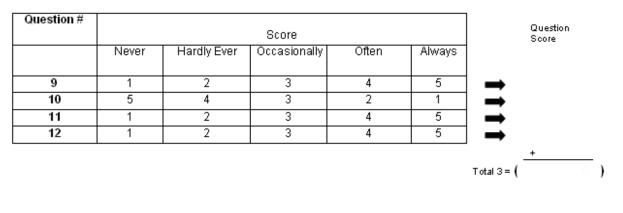
)

2. Mental Factors

Question #			Score				Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
5	1	2	3	4	5	\rightarrow	
6	5	4	3	2	1	\rightarrow	
7	1	2	3	4	5	\rightarrow	
8	5	4	3	2	1	\rightarrow	



3. Spiritual Factors



)

Total 5 = (

4. Social Factors Question # Question Score Score Never Hardly Ever Occasionally Often Always **QOL Survey Analysis** 13 1 2 3 4 5 14 1 2 3 4 5 15 2 3 5 1 4 2 3 16 1 4 5 Total 4= () 5. **Financial Factors** Question # Score Question Score Never Hardly Ever Occasionally Often Always 17 10 8 6 4 2 18 10 8 6 4 2

Part 2

To complete this section, you will need the patient survey completed. Please indicate which response the patient chose, and note the score in the provided space.

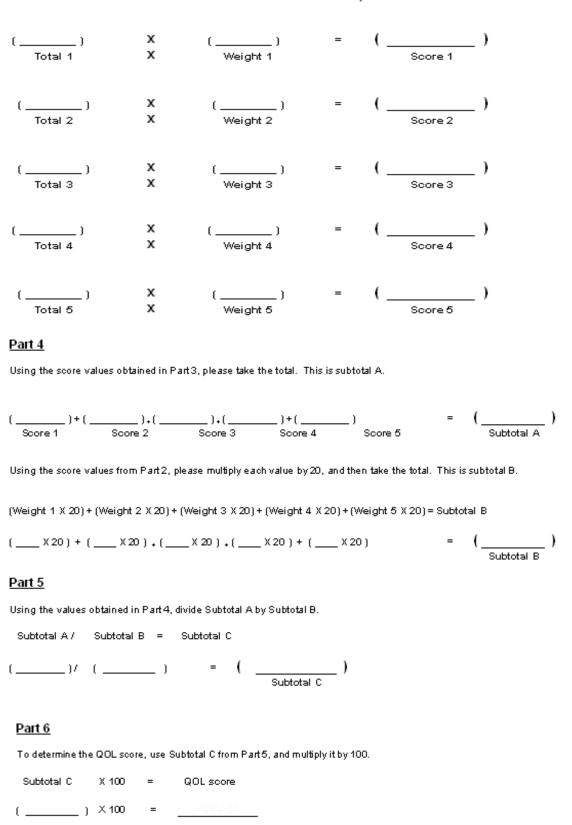
6. Overall

Question #			Score					
	Very Unimportant	Unimportant	Neutral	Important	Very Important			
19	1	2	3	4	5	\rightarrow	= \/\	Vei
20	1	2	3	4	5	\rightarrow	 = \A	
21	1	2	3	4	5	\rightarrow	= \%	
22	1	2	3	4	5	\rightarrow	= W	
23	1	2	3	4	5	\rightarrow	 = \%	

Part 3

Please use the values obtained from Parts 1 and 2 above. You may need a calculator.

QOL Survey Analysis



Patient demographics are vital to interpreting the results of cost-benefit analysis. Identifying a patient base can place a numerical QOL score in context. These demographics are also a valuable management tool in decision making. If a program is cost effective for one type of cancer patient but a hospital never treats that specific illness, the benefits are irrelevant. Patient demographics serve as a source of basic but essential information. If compiled correctly, the statistics may be useful for providing insight for administrative decisions. Moreover, these demographics could be useful in the future for cost benefit analyses of services; in order to find average treatment costs, the demographics of an "average" patient must first be determined.

Instructions for Recording Demographics

For an accurate representation of the patient population, demographic information needs to be documented for each admitted patient. Pages 15-16 contain demographic sheets that contain the categories necessary to record for preparation of cost-benefit analysis. They are intended to be utilized at the moment of patient check-in. They are best utilized by the patient reception or an equivalent department.



The patient copy of the information sheet is to be filled out by the patient upon admittance and the nurse copy is to be filled out by a member of the nursing team or reception staff. Filling out this form as each patient comes in will eliminate the possibility of overlooking patients. An excel program for compiling this information can be found on the attached CD along with a sample data set.

Identifying a patient base can place a numerical QOL score into context.

Patient Demographics

Patient Information Survey – Patient Copy

These demographics are also a valuable	1. Level of Education None Elementary School College Prep Bachelors Degree Graduate Degree 2. Salary Below 10,000 BHT 10,000-19,999 BHT 20,000-29,000 BHT 30,000-49,000 BHT 50,000 BHT or above
management tool in decision making.	 3. Who do you live with? □ Mom/ Dad □ Spouse □ daughter/son □ other relatives □ friends
	 4. Where are you originally from? Bangkok
	5. Approximately how far is your house from a health clinic? 1 km or less 1-5 km 5-10 km 11-15km 16-20 km 20km or over
	6. Approximately how long does it take you to get to a health clinic? Not more than 10 minutes 10-30 min 30min-1 hour 1-2 hours more than 2 hours

Patient Demographics

Patient Information Survey- Nurse Copy

Section 1: General Background Information

- 1. Patient Hospital No._____Date Survey was completed_____
- Sex
 Male
 Age
 20-30 years old
- Female
 31-45 years old
 - □Single □Married
- □ 46-60 y.o. □ Over 61 □ Divorced/Separated

- Marital Status
 Healthcare Provider
 - □ 30 BHT program
 - Private Insurance
- Employer
- Government Drivate Pay

Section 2: Patient Medical Information

- 1. Diagnosis__
- 2. Stage of Cancer

	Stage 0	Stage 1	Stage 2	Stage 3	Stage 4
Stage when patient first found out					
Stage when the patient first sought					

3. Treatment action

Radiation _____Fraction

Chemotherapy____Cause

- Surgery
- □Palliative Treatment

4. How long has the patient stayed here? What is the estimated amount of time that the patient will remain in the hospice?



Services and Associated Costs

Analysis of costs of hospice and homecare services can be used as a method of supporting the utilization of such programs in Thailand. By noting what services are provided, how much they cost to run and the associated benefits, the information supplied will serve as a tool to illustrate how improving QOL via these services is financially feasible. Before one can place a value on a service, it is important to understand what types of costs are generally studied in economic analysis. These types of costs can be useful when trying to evaluate things such as the efficiency of a program, whether or not to add services or the average costs of patients. By understanding these costs, an executive can make the most appropriate decisions based on cost analysis results.



The first step to cost analysis is identification of services and expenses. Programs at different hospitals will have a wide range of services to offer. Hospice and homecare services mainly focus on nursing and counseling (Sykes, 1998). As such, the services that need to be recorded for analysis are mostly performed by the nurses. There are also many other expenses, such as capital and overhead costs, that contribute to the overall cost of a program and need to be considered for accurate cost-analysis of a program. The following is a list of possible expenses that are associated with palliative care.

Examples of Palliative Care Costs

Facility Maintenance

- Cleaning
- Electricity
- Updating medical equipment
- Air-conditioning
- Equipment maintenance

Medical Services

- Homecare travel costs
- Chemotherapy
- Bereavement programs
- Counseling and therapy
- Surgery

Startup Capital Costs

- Real-estate
 - Construction
- Loans
- Medical equipment
- Furniture

Staff Expenses

- Training programs
- Fixed staff salaries
- Variable staff salaries
- Employee benefits
- Workmen's compensation

- Patient Consumables

 Food
 - Medications
- Wound dressings
- Oxygen
- Urine bags

Cost Analysis

Cost analysis is used to compare costs to units of outcome. The three types of cost analysis (summarized below) are cost-effectiveness, cost-benefit analysis and cost-of-illness. After services have been clearly identified and valuated, the most appropriate type of cost analysis for the purpose of the study can be chosen and completed.



When using any of these methods of cost analysis, there are some key attributes that need to be considered. Because these attributes can vary between different studies, it is important for someone using cost analysis results to understand which attributes were used. Some of the important attributes are point of view, time horizon, discounting, nature of payer, sensitivity analysis, and cultural influences. Incorrect assumptions made about these attributes can greatly alter the interpretation of analysis results.

Cost-benefit Analysis

Cost-benefit analysis is particularly useful for administrators because it puts all expenses and outcomes in terms of monetary units. When used in conjunction with patient demographic statistics and a tool such as our Patient QOL Survey, costbenefit analysis can show the advantages and disadvantages of a program.

			Cost-effe	ectiveness		
	Cost-	Cost-	Cost-		Cost-	
	of-Illness	effectiveness:	minimalization	Cost-utility	consequence	Cost-benefit
Description:	Measure the	Determines the	Determines the	Compares costs	Compares costs	Compares costs
	economic	cost per unit	least expensive	per time unit	with un-weighted	to benefits; both
	effects of an	of standardized	service possible	adjusted by	categorized	measured in
	illness	health effect	to achieve a	utility weights	outcomes	monetary units
			pre-set outcome			
Cost unit of						
measurement:	\$	\$	\$	\$	\$	\$
Operator for comparison:	VS.	÷	VS.	÷	vs.	÷ or –
Outcome		Natural units		Utility (e.g. QALY:		
unit of	None	(e.g. Year of	Set as equal	Quality adjusted	Natural units	Monetary (\$)
measurement:		life gained)		life year)		
Best for:	Measuring	Showing the	Finding the most	Relating costs	Comparisons of	
	the burden	usefulness of	effective program	to one or more	situations with	Comparisons of potential benefits
	of a disease on society.	under funded	alternatives.	health effects	multiple outcomes	to costs
	011 0001017.	programs.			Galconico	
Other:		Measures the	By setting the	Biased against		Benefits studied
		cost per natural	outcome as good	elderly who have		may not be
		unit gained, not	care one can	shorter life spans.		common to all
		the quality of	compare continual	Benefits studied]	alternatives.
		unit gained.	çare programs.	may not be		Hard to assign
				common to all		Costs to value of
				alternatives.		human life.

Types of Cost Analysis

This table is adapted from: Brown & Smith (2000) and NICHSR (August 2004).

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Acknowledgements

We would like to acknowledge the following people for their contributions to the success of our project work. Without their assistance, guidance, and support we could not have completed our project as successfully. Thank you!

- Khun Ahn
- Joy Bhosai
- Professor Chrys Demetry
- Professor Rob Krueger
- Thitwan Lertpiya
- Lopburi Hospital Staff
- Mahavachiralongkorn Thanyaburi Cancer Center Staff

Janet Mullen

- Khun Natchaa
- Dr. Patchai
- Professor Supawan
- Dr. Thanadej
- **Professor Seth Tuler**

Professor Rick Vaz

Further Reading

For more information on the content of this packet, please see our full research report included on the CD. This report include background research information, methodology, findings and recommendations. The research detailed in the full report provided the means to create this packet.

