THE FAMILY MEETING AS AN INSTRUMENT FOR THE SPIRITUAL CARE OF PALLIATIVE PATIENTS AND THEIR FAMILIES

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APPENDICES

Appendix I - Glossary of Terms

Appropriation

Appropriation, as described by Ricouer, occurs at the point during the interpretation process, at which the interpreter understands themselves either more completely or differently, as a result of their interpretation of the text.

Coding Report

A coding report is a report produced by NVivo software which contains the detail of all passages coded to a particular tree node address

Constructionism

Constructionism is an epistemological perspective which claims that meanings are constructed by human beings as they interact with a world which they are interpreting, and that in order for this to occur there must be beings who are capable of interpretation.

Dasein

Dasein is the term used by Heidegger to denote the essential nature of the human being.

Distanciation

Distanciation is a term used by Ricoeur to describe the process of standing separate from or being objective in relation to the text. He described several ways in which distanciation of text occurs in the interpretive process.

Epistemology

Epistemology is concerned with providing possible philosophical grounds for deciding what kinds of knowledge are possible and how this knowledge is acquired by human beings.

Free Nodes

NVivo software term which refers to unclassified nodes – a node which is not part of a tree or case structure.

Hermeneutic Phenomenology

Hermeneutic phenomenology is the process of interpreting the description (text) of human experience, in order to understand the central nature of that experience.

Hermeneutics

Hermeneutics art interpretation especially as it applies to text.

Interpretivism

Interpretivism is one of the philosophical perspectives informed by the epistemology of constructionism. Interpretivism places emphasis is on interpreting experienced or observed phenomena, rather than on explaining in the sense applied in natural science

Ontological

An ontological stance is one that has a focus on the nature of being.

Phenomenological reduction

Phenomenology

Phenomenology is the study of the essence of a phenomenon as it presents itself in lived experience in the world.

Semantics

Semantics refers to the literal meaning of a word or phrase.

Speaker

In this study the term speaker refers to the person being interviewed whether they were a patient, a family member or a staff member.

Spirituality

For the purposes of this study, the concept of spirituality is understood to be consistent with the 'transcendent' approach to spirituality, as described by Coyle (2002). This transcendent approach incorporates both a transpersonal connectedness to a higher power or consciousness and an intrapersonal connectedness that focuses on the potentialities of self. Both these aspects give rise to a knowing that emerges from different sources i.e. a higher power and contemplation of inner resource respectively. Both offer a way of finding meaning and purpose in living and dying. The discovery of this meaning and purpose includes the experience of hope, motivation, empowerment, guidance, meaningful relationships and a sense of self-identity.

Tree Node Address

The tree node address in NVivo software refers to a series of numbers from the root node to the selected node. Each node has a unique address.

Appendix II – Consent Forms

Government of South Australia
Central Northern Adelaide Health Service

CENTRAL NORTHERN ADELAIDE HEALTH SERVICE
The Queen Elizabeth Hospital & Lyell McEwin Hospital

CONSENT FORM

Title: Investigating the use of the family meeting in the spiritual care of palliative patients and their families.

Protocol Number: 2006065

I,.....

hereby consent to my involvement in the research project explained to me.

- I have read the information sheet, and I understand the reasons for this study. The research worker has explained the ways in which it will affect me. My questions have been answered to my satisfaction. My consent is given voluntarily.
- I understand that the purpose of this research project is to improve the quality of care, but my involvement may not be of benefit to me.
- The details of the research project have been explained to me, including:
  - The expected time it will take
  - The nature of the one family meeting
  - The nature of the one interview which I consent to have audio recorded
  - Any discomfort which I may experience
- I have been given the opportunity to have a member of family or a friend present while the project was explained to me.
- My identity will be kept confidential, and nothing will be published which could possibly reveal my identity.
- My involvement in the study will not affect my relationship with my medical advisers. I understand that I am able to withdraw from the study at any stage without having to give a reason, and that by withdrawing it will not affect my treatment through the palliative care service in the future.

SIGNATURE ..... **DATE** ……/……./…….

INVESTIGATOR ..... **DATE** ……/……./…….

Government of South Australia
Central Northern Adelaide Health Service

CENTRAL NORTHERN ADELAIDE HEALTH SERVICE
The Queen Elizabeth Hospital & Lyell McEwin Hospital

STAFF CONSENT FORM

Title: Investigating the use of the family meeting in the spiritual care of palliative patients and their families.

Protocol Number: 2006065

I, the undersigned .....

hereby consent to my involvement in the research project explained above.

- I have read the information sheet, and I understand the reasons for this study. The research worker has explained the ways in which it will affect me. My questions have been answered to my satisfaction. My consent is given voluntarily.
- I understand that the purpose of this research project is to improve the quality of care, but my involvement may not be of benefit to me.
- The details of the research project have been explained to me, including:
  - The expected time it will take
  - The nature of the one interview which I consent to have audio recorded
- I have been given the opportunity to discuss my participation with a member of family or a friend.
- My identity will be kept confidential, and nothing will be published which could possibly reveal my identity.
- My involvement in the study will not affect my relationship with my employers. I understand that I am able to withdraw from the study at any stage without having to give a reason, and that by withdrawing it will not affect my employment status now or in the future.

STAFF MEMBER SIGNATURE ..... **DATE** ……/……./…….

INVESTIGATOR ..... **DATE** ……/……./…….

Calvary Health Care Adelaide

A Service of the Sisters of the Little Company of Mary

CONSENT FORM - PATIENT

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Dr Christopher Barton – Research Fellow Uni. Adelaide
Heather Tan - PhD student University of Adelaide

1. The nature and purpose of the project have been explained to me. I understand them and agree to:
   - provide information for a short questionnaire
   - take part in a family meeting
   - take part in an audio-taped conversation with the investigator

2. I understand that I may not benefit directly from taking part in the study.

3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.

5. I understand that I will not be paid for taking part in this study.

6. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: ____
(Investigator)

Calvary Health Care Adelaide

A Service of the Sisters of the Little Company of Mary

CONSENT FORM – FAMILY MEMBER (FAMILY MEETING)

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Dr Chris Barton – Research Fellow Uni. Adelaide
Heather Tan - PhD student University of Adelaide

1. The nature and purpose of the project have been explained to me. I understand them and agree to
   - provide information for a short questionnaire
   - take part in the family meeting.

2. I understand that I may not benefit directly from taking part in this study.

3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

4. I understand that I can withdraw from the study at any stage and that this will not affect any medical care I may require now or in the future.

5. I understand that I will not be paid for taking part in this study.

6. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: _____
(Investigator)

Calvary Health Care Adelaide

A Service of the Sisters of the Little Company of Mary

CONSENT FORM – FAMILY MEMBER (CONVERSATION)

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Dr Chris Barton – Research Fellow Uni. Adelaide
Heather Tan - PhD student University of Adelaide

1 The nature and purpose of the project has been explained to me. I understand them and agree to having an audio-taped conversation with the investigator about the family meeting.

2 I understand that I may not benefit directly from taking part in this study.

3 I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

4 I understand that I can withdraw from the study at any stage and that this will not affect any medical care I may require now or in the future.

5 I understand that I will not be paid for taking part in this study.

6 I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: _____
(Investigator)

Calvary Health Care Adelaide

A Service of the Sisters of the Little Company of Mary

CONSENT FORM – STAFF/VOLUNTEER

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Dr Chris Barton – Research Fellow Uni. Adelaide
Heather Tan - PhD student University of Adelaide

1. The nature and purpose of the project have been explained to me. I understand them and agree to
   - answer a short questionnaire
   - take part in an audio-taped conversation with the investigator

2. I understand that I may not benefit directly from taking part in the study.

3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

4. I understand that I can withdraw from the study at any stage and that this will not affect my status within Calvary Health Care in any way, now or in the future.

5. I understand that I will not be paid for taking part in this study.

6. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: _____
(Investigator)

ROYAL ADELAIDE HOSPITAL

CONSENT FORM - PATIENT

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Heather Tan - PhD student University of Adelaide

1. The nature and purpose of the project has been explained to me. I understand it, and agree to take part.

2. I understand that I may not benefit directly from taking part in the study.

3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.

5. I understand that I will not be paid for taking part in this study.

6. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

7. I consent to the audio recording of my conversation with the investigator.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: ____
(Investigator)

ROYAL ADELAIDE HOSPITAL

CONSENT FORM – FAMILY MEMBER

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Heather Tan - PhD student University of Adelaide

1. The nature and purpose of the project has been explained to me. I understand it, and agree to take part in the Family Meeting.
2. I understand that I may not benefit directly from taking part in this study.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage and that this will not affect any medical care I may require now or in the future.
5. I understand that I will not be paid for taking part in this study.
6. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
7. I agree to take part in a one on one conversation with the researcher at another time and I agree to this conversation being audio recorded

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: _____
(Investigator)

ROYAL ADELAIDE HOSPITAL

CONSENT FORM – FAMILY MEMBER (CONVERSATION)

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Heather Tan - PhD student University of Adelaide

1 The nature and purpose of the project has been explained to me. I understand it, and agree to having a conversation with the investigator about the family meeting.

2 I agree to this conversation being audio recorded.

3 I understand that I may not benefit directly from taking part in this study.

4 I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

5 I understand that I can withdraw from the study at any stage and that this will not affect any medical care I may require now or in the future.

6 I understand that I will not be paid for taking part in this study.

8. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: _____
(Investigator)

ROYAL ADELAIDE HOSPITAL

CONSENT FORM – STAFF/VOLUNTEER

PROTOCOL NAME: The 'Family Meeting' as an instrument for the spiritual care of palliative patients and their families – Does if help?

INVESTIGATORS: Dr Anne Wilson – Lecturer University of Adelaide
Professor Ian Olver – Director Cancer Centre RAH
Heather Tan - PhD student University of Adelaide

1. The nature and purpose of the project has been explained to me. I understand it, and agree to take part.
2. I agree to my conversation with the investigator being audio recorded.
3. I understand that I may not benefit directly from taking part in the study.
4. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
5. I understand that I can withdraw from the study at any stage and that this will not affect my status within the Central Adelaide Palliative Service in any way, now or in the future.
6. I understand that I will not be paid for taking part in this study.
7. I have had the opportunity to discuss taking part in this investigation with a family member or friend.

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: _____ Dated: _____
(Investigator)

Appendix III– Information Sheets

CENTRAL NORTHERN ADELAIDE HEALTH SERVICE
The Queen Elizabeth Hospital & Lyell McEwin Hospital

PATIENT/FAMILY MEMBER INFORMATION SHEET

Title: Investigating the use of the family meeting in the spiritual & psychosocial care of palliative patients and their families

Protocol Number: 2006065

INVITATION TO PARTICIPATE

We invite you to participate in a research project which we believe is of potential importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand **why we are doing it**, and **what it would involve if you agreed.** We are therefore providing you with the following information. Please read it carefully and be sure to ask any questions you have. The researcher will be happy to discuss it with you and answer any questions that you may have. You are also free to discuss it with outsiders if you wish. (family, friends and / or your local doctor)

You do not have to make an immediate decision.

PARTICIPATION IS VOLUNTARY

Participation in any research project is voluntary. If you do not wish to take part, you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage without providing a reason.

Your decision to take part, not to take part or to withdraw will not affect your routine treatment, your relationship with those treating you, or your relationship with The Queen Elizabeth Hospital.

BACKGROUND TO THE STUDY

The purpose of this study is to assess the role and effectiveness of the family meeting in the spiritual care of palliative patients and their families. This study looks at spirituality and spiritual care in a very broad way. This includes things such as your attitude to life, reviewing your life, bringing closure to things that have happened, forgiveness of self and others, having hope, finding meaning and purpose in the things that have happened in your life and connecting to those who are most significant in your life. For some people, although not every one, it will also include religious practices and beliefs.

The family meeting, as it will be presented in this study, offers one way in which some of these things can be talked about and experienced. There will also be the opportunity to have a short closing ritual or blessing if that is something you and your family would like. Throughout the family meeting the researcher will be a facilitator.

A small grant to cover the costs of this research such as transport and transcribing costs has been made available by the Royal Adelaide Hospital and Institute of

Medical and Veterinary Science Research Committee. The Researcher is not being paid to do this research.

You have been referred to this study by staff of the Central Western Palliative Service because you may be able to assist us in evaluating this model of care for palliative patients and their families, in an area that is known to be important, but which at this stage has not been highly researched. It is hoped that about twenty families from around the Adelaide metropolitan area will be involved in the study.

PROCEDURES

If you decide to take part in this study the following things will happen:

- Family members whom you would like to invite will be contacted and asked if they would be willing to participate.
- An appointment will be made to have the family meeting at a time and place that is suitable for you and your family members whom you choose to invite.
- You and the family members who choose to be involved will be asked to complete a short questionnaire about some personal details (this does not include names).
- After the meeting another time will be made for the investigator to come and have a one on one conversation with each of those involved about the family meeting.
- With each person's consent this conversation will be audio recorded and later analysed.

Your participation in this study will involve one family meeting and one individual conversation with the investigator.

MEDICINES AND DRUGS

No drugs or medicines are involved in this study

YOUR WELL BEING

It is possible that the family meeting and the conversation with the investigator afterwards, may touch on issues that you find difficult or distressing. Below is a list of professionals who are willing and able to assist you, should you want further help with these issues.

- Your doctor
- Your nurse
- Your minister/pastor/priest
- Hospital chaplain 8222 6129
- Hospital social worker 8222 7250
- Grief link website: www.grieflink.asn.au

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED?

Your rights and privacy will always be respected in the following ways:

- You are free to withdraw at any time with no impact on you future medical care or that of your sick relative.
- All records of the conversation and your personal details will remain confidential and no identifying information will be released to anyone.
- You can request that the tape recorder be turned off at any time during your conversation with the investigator.
- All data will be stored in a locked filing cabinet in the Discipline of General Practice, in the University of Adelaide, for the legally required period of fifteen years. Only the specified investigators will have access to this.
- If you want to request copies of data that relates specifically to you this will be provided.

WHAT ARE MY RIGHTS?
Your participation in this study shall not affect any right to compensation you may have under common law.

IS THERE ANY PAYMENT FOR PARTICIPATION?
No payments will be made to participants of this study.

BENEFITS OF THE RESEARCH
Although it cannot be guaranteed, it is possible that you will benefit from your participation in this study. It is also hoped that the results of this study will be of benefit to future patients, their families and palliative care staff, by providing more information about effective ways to provide for their spiritual care.

WHAT IF I HAVE A QUESTION ABOUT THE STUDY?
If you or your family would like further information about this study you may contact the following investigators at anytime:

Heather Tan	0411 484 894
Dr Anne Wilson	8303 3593

The Central Northern Adelaide Health Service Ethics of Human Research Committee (TQEH & LMH) has approved this study.
Should you wish to speak to a person not directly involved in the study in relation to

- matters concerning policies,
- information about the conduct of the study
- your rights as a participant, or

should you wish to make a confidential complaint, you may contact The Executive Officer of this Committee, on (08) 8222 6841

Thank you for taking the time to read this information sheet

Calvary Health Care Adelaide

A Service of the Sisters of the Little Company of Mary

Information Sheet – patients

"The Role of the Family Meeting in the spiritual care of patients and their families"

You are invited to participate in a study whose purpose is to assess the role and effectiveness of the family meeting in the spiritual care of palliative patients and their families. This is not an investigation of religion but of spirituality, which is common to all people. This includes things such as your attitude to life, reviewing your life, bringing closure to things that have happened, forgiveness of self and others, having hope, finding meaning and purpose in the things that have happened in your life and connecting to those who are most significant to you.

The family meeting, as it will be presented in this study, offers one way in which some of these things can be talked about and experienced. Throughout the meeting the investigator will be a guide. You and the family members you invite, will each have the opportunity to speak about your life and the things that are important for you now. There will also be the opportunity to close the meeting with a short ritual or blessing if that is something you and your family would like.

It is hoped that the results of this study will be of benefit to you and your family, as well as to future patients, their families and palliative care staff, by providing more information about effective ways to provide for your and their needs in the important domain of spiritual care. However, this cannot of course be guaranteed.

Your participation would be appreciated, but this is a research study and so you do not have to be involved. If you do not wish to participate your medical care will not be affected in any way.

<u>Participation</u>

If you decide to take part in this study the following things will happen:

- Members of your family, or close friends, whom you choose to invite will be approached and invited to be involved in the family meeting
- You and the family members who choose to be involved will be asked to complete a short questionnaire about some personal details (this does not include names).
- An appointment will be made to have the family meeting at a time and place that is suitable for you.
- After the meeting another time will be made for the investigator to come and have a one on one conversation with you about the family meeting.
- With your consent this conversation will be audio recorded and later analysed. The audio tapes will be stored for 7 years as required and then destroyed.

Your Privacy

Your rights and privacy will always be respected in the following ways:

- You are free to withdraw at any time with no impact on you future medical care.
- All records of the conversation and your personal details will remain confidential and no identifying information will be released to anyone.
- You can request that the tape recorder be turned off at any time during your conversation with the Investigator.
- All data will be stored in a locked filing cabinet in the Department of General Practice. Only the investigators named below, will have access to this.
- If you want to request copies of data that relates specifically to you this will be provided.

The Main Investigator

Heather Tan in a PhD student at the University of Adelaide. She has both qualifications and experience in the fields of education, grief and palliative care counselling and pastoral care. She has previously carried out research in the field of spiritual care of palliative patients in a hospice setting. This work has been published.

Contact Information

- If you or your family would like further information about this study you may contact the following investigators at anytime:

Heather Tan	0411 484 894
Dr Anne Wilson	8303 6281
Prof. Ian Olver	8222 5577
Dr Chris Barton	8303 6228

- If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may wish to contact the Chairman, Research Ethics Committee, Calvary Health Care Adelaide on (08)
  8239 9135

Your Well-being

It is possible that the family meeting and the conversation with the investigator afterwards, may touch on issues that you find difficult or distressing. Below is a list of professionals who are willing and able to assist you, should you want further help with these issues.

- Your doctor
- Your nurse
- Your minister/pastor/priest
- Hospice chaplain 8239 9285
- Hospice social worker 8239 9147
- Grief link website: www.grieflink.asn.au

This study has been approved by the Human Research Ethics Committee of Calvary Health Care Adelaide

Thank you for taking the time to consider this information.

Calvary Health Care Adelaide

A Service of the Sisters of the Little Company of Mary

Information Sheet – family members

"The Role of the Family Meeting in the spiritual care of patients and their families"

You are invited to participate in a study whose purpose is to assess the role and effectiveness of the family meeting in the spiritual care of palliative patients and their families. This is not an investigation of religion but of spirituality, which is common to all people. This includes things such as your attitude to life, reviewing your life, bringing closure to things that have happened, forgiveness of self and others, having hope, finding meaning and purpose in the things that have happened in your life and connecting to those who are most significant to you.

The family meeting, as it will be presented in this study, offers one way in which some of these things can be talked about and experienced. Throughout the meeting the investigator will be a guide. You and other family members present, will each have the opportunity to speak about your life and the things that are important for you now. There will also be the opportunity to close the meeting with a short ritual or blessing if that is something you and your family would like.

It is hoped that the results of this study will be of benefit to you and your family, as well as to future patients, their families and palliative care staff, by providing more information about effective ways to provide for your and their needs in the important domain of spiritual care. However, this cannot of course be guaranteed.

Your participation would be appreciated, but this is a research study and so you do not have to be involved. If you do not wish to participate the medical care of your family member will not be affected in any way.

<u>Participation</u>

If you decide to take part in this study the following things will happen:

- You will be asked to complete a short questionnaire about some personal details (this does not include names).
- A suitable time will be set for the family meeting.
- After the family meeting you will be invited to make a time to have a one on one conversation with the investigator about the family meeting. You may choose to attend the family meeting but not have a later conversation with the investigator
- If you agree to the conversation it will, with your consent, be audio recorded and later analysed. The audio tapes will be stored for 7 years as required and then destroyed.

Your Privacy

Your rights and privacy will always be respected in the following ways:

- You are free to withdraw at any time with no impact on you future medical care or that of your sick relative.
- All records of the conversation and your personal details will remain confidential and no identifying information will be released to anyone.
- You can request that the tape recorder be turned off at any time during your conversation with the investigator.
- All data will be stored in a locked filing cabinet in the Department of General Practice. Only the investigators listed below will have access to this.
- If you want to request copies of data that relates specifically to you this will be provided.

The Main Investigator

Heather Tan in a PhD student at the University of Adelaide. She has both qualifications and experience in the fields of education, grief and palliative care counselling and pastoral care. She has previously carried out research in the field of spiritual care of palliative patients in a hospice setting. This work has been published.

Contact Information

- If you or your family would like further information about this study you may contact the following investigators at anytime:

Heather Tan	0411 484 894
Dr Anne Wilson	8303 6281
Prof. Ian Olver	8222 5577
Dr Chris Barton	8303 6228

- If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may wish to contact the Chairman, Research Ethics Committee, Calvary Health Care Adelaide on (08)
  8239 9135

Your Well-being

It is possible that the family meeting and the conversation with the investigator afterwards, may touch on issues that you find difficult or distressing. Below is a list of professionals who are willing and able to assist you, should you want further help with these issues.

- Your doctor
- Your nurse
- Your minister/pastor/priest
- Hospice chaplain 8239 9285
- Hospice social worker 8239 9147
- Grief link website: www.grieflink.asn.au

This study has been approved by the Human Research Ethics Committee of Calvary Health Care Adelaide

Thank you for taking the time to consider this information.

Calvary Health Care Adelaide

A Service of the Sisters of the Little Company of Mary

Information Sheet – Staff/Volunteer Workers

"The Role of the Family Meeting in the spiritual care of patients and their families"

You are invited to participate in a study whose purpose is to assess the role and effectiveness of the family meeting in the spiritual care of palliative patients and their families. This is not an investigation of religion but of spirituality, which is common to all people. This includes things such as your attitude to life, reviewing your life, bringing closure to things that have happened, forgiveness of self and others, having hope, finding meaning and purpose in the things that have happened in your life and connecting to those who are most significant to you.

The family meeting, as it will be presented in this study, offers one way in which some of these things can be talked about and experienced. Throughout the meeting the investigator will be a guide. Patients and other family members present, will each have the opportunity to speak about their life and the things that are important for them now. There will also be the opportunity to close the meeting with a short ritual or blessing if that is something the family would like.

It is hoped that the results of this study will be of benefit the patients and families involved, as well as to future patients, their families and palliative care staff, by providing more information about effective ways to provide for their needs in the important domain of spiritual care. However, this cannot of course be guaranteed.

As a professional or volunteer who has an important role in the care of palliative patients and their families, your participation would be appreciated, but this is a research study and so you do not have to be involved. If you do not wish to participate your status in the Central Adelaide Palliative Service will not be affected in any way.

<u>Participation</u>

If you decide to take part in this study the following things will happen:

- You will be asked to complete a short questionnaire about some personal details (this does not include names).
- An appointment will be with the investigator, at a time suitable for you, for a one on one conversation about your impressions of the impact of the family meeting on patients and their families as well as any implications for yourself and other staff.
- With your consent this conversation will be audio recorded and later analysed. The audio tapes will be stored for 7 years as required and then destroyed.

Your Privacy

Your rights and privacy will always be respected in the following ways:

- You are free to withdraw at any time with no impact on you future status in the Central Adelaide Palliative Service.
- All records of the conversation and your personal details will remain confidential and no identifying information will be released to anyone.
- You can request that the tape recorder be turned off at any time during your conversation with the investigator.
- All data will be stored in a locked filing cabinet in the Department of General Practice. Only the investigators listed below will have access to this.
- If you want to request copies of data that relate specifically to you this will be provided.

Contact Information

- If you would like further information about this study you may contact the following investigators at anytime:

  Heather Tan 0411 484 894
  Dr Anne Wilson 8303 6281
  Prof. Ian Olver 8222 5577
  Dr Chris Barton 8303 6228

- If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may wish to contact the Chairman, Research Ethics Committee, Calvary Health Care Adelaide on (08)
  8239 9135

Your Well-being

It is possible that the conversation with the investigator about the family meetings, may touch on issues that you find difficult or distressing. Below is a list of professionals who are willing and able to assist you, should you want further help with these issues.

- Your doctor
- Your nurse
- Your minister/pastor/priest
- Hospice chaplain 8239 9285
- Hospice social worker 8239 9147
- Grief link website: www.grieflink.asn.au

This study has been approved by the Human Research Ethics Committee of Calvary Health Care Adelaide on

Thank you for taking the time to consider this information.

Information Sheet – patients

CENTRAL ADELAIDE PALLIATIVE SERVICE

"The Role of the Family Meeting in the spiritual care of patients and their families"

The purpose of this study is to assess the role and effectiveness of the family meeting in the spiritual care of palliative patients and their families. This study looks at spirituality and spiritual care in a very broad way. This includes things such as your attitude to life, reviewing your life, bringing closure to things that have happened, forgiveness of self and others, having hope, finding meaning and purpose in the things that have happened in your life and connecting to those who are most significant in your life. For some people, although not every one, it will also include religious practices and beliefs.

The family meeting, as it will be presented in this study, offers one way in which some of these things can be talked about and experienced. There will also be the opportunity to have a short closing ritual or blessing if that is something you and your family would like. Throughout the meeting the investigator will be a guide.

It is hoped that the results of this study will be of benefit to future patients, their families and palliative care staff, by providing more information about effective ways to provide for the their needs in the important domain of spiritual care. This cannot of course be guaranteed.

Your participation would be appreciated, but this is a research study and so you do not have to be involved. If you do not wish to participate your medical care will not be affected in any way.

<u>Participation</u>

If you decide to take part in this study the following things will happen:

- Members of your family, or close friends, whom you choose to invite will be approached and invited to be involved in the family meeting
- You and the family members who choose to be involved will be asked to complete a short questionnaire about some personal details (this does not include names).
- An appointment will be made to have the family meeting at a time and place that is suitable for you.
- After the meeting another time will be made for the investigator to come and have a one on one conversation with you about the family meeting.
- With your consent this conversation will be audio recorded and later analysed.

<u>Your Privacy</u>

Your rights and privacy will always be respected in the following ways:

- You are free to withdraw at any time with no impact on you future medical care or that of your sick relative.
- All records of the conversation and your personal details will remain confidential and no identifying information will be released to anyone.
- You can request that the tape recorder be turned off at any time during your conversation with the investigator.

Contact Information

- If you or your family would like further information about this study you may contact the following investigators at anytime:

  Heather Tan 0411 484 894
  Dr Anne Wilson 8303 6281

- If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may wish to contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139

Your Well-being It is possible that the family meeting and the conversation with the investigator afterwards, may touch on issues that you find difficult or distressing. Below is a list of professionals who are willing and able to assist you, should you want further help with these issues.

- Your doctor
- Your nurse
- Your minister/pastor/priest
- Hospital chaplain 8222 4443
- Hospital social worker 8222 4025
- Grief link website: www.grieflink.asn.au

This study has been approved by the Human Research Ethics Committee of the Royal Adelaide Hospital.

Thank you for taking the time to consider this information.

Information Sheet – family members

"The Role of the Family Meeting in the psycho-spiritual care of patients and their families"

The purpose of this study is to assess the role and effectiveness of the family meeting in the psycho-spiritual care of palliative patients and their families. This study looks at spirituality and spiritual care in a very broad way. This includes things such as your attitude to life, reviewing your life, bringing closure to things that have happened, forgiveness of self and others, having hope, finding meaning and purpose in the things that have happened in your life and connecting to those who are most significant in your life. For some people, although not every one, it will also include religious practices and beliefs.

The family meeting, as it will be presented in this study, offers one way in which some of these things can be talked about and experienced. There will also be the opportunity to have a short closing ritual or blessing if that is something you and your family would like. Throughout the meeting the investigator will be a guide.

It is hoped that the results of this study will be of benefit to future patients, their families and palliative care staff, by providing more information about effective ways to provide for the their needs in the important domain of spiritual care. This cannot of course be guaranteed.

You are being invited to participate. Your participation would be appreciated, but this is a research study and so you do not have to be involved. If you do not wish to participate your medical care will not be affected in any way.

Participation

If you decide to take part in this study the following things will happen:

- You will be asked to complete a short questionnaire about some personal details (this does not include names).
- A suitable time will be set for the family meeting.
- After the family meeting you will be invited to make a time to have a one on one conversation with the investigator about the family meeting. You may choose to attend the family meeting but not have a later conversation with the investigator
- If you agree to the conversation it will, with your consent, be audio recorded and later analysed.

Your Privacy

Your rights and privacy will always be respected in the following ways:

- You are free to withdraw at any time with no impact on you future medical care or that of your sick relative.
- All records of the conversation and your personal details will remain confidential and no identifying information will be released to anyone.
- You can request that the tape recorder be turned off at any time during your conversation with the investigator.

All data will be stored in a locked filing cabinet in the Department of General Practice. Only the specified investigators will have access to this.
If you want to request copies of data that relates specifically to you this will be provided.

Contact Information

- If you or your family would like further information about this study you may contact the following investigators at anytime:

  Heather Tan 0411 484 894
  Dr Anne Wilson 8303 6281

- If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may wish to contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139

Your Well-being

It is possible that the family meeting and the conversation with the investigator afterwards, may touch on issues that you find difficult or distressing. Below is a list of professionals who are willing and able to assist you, should you want further help with these issues.

- Your doctor
- Your nurse
- Your minister/pastor/priest
- Hospital chaplain 8222 4443
- Hospital social worker 8222 4025
- Grief link website: www.grieflink.asn.au

This study has been approved by the Human Research Ethics Committee of the Royal Adelaide Hospital.

Thank you for taking the time to consider this information.

Information Sheet – Staff/Volunteer Workers

"The Role of the Family Meeting in the spiritual care of patients and their families"

The purpose of this study is to assess the role and effectiveness of the family meeting in the spiritual care of palliative patients and their families. This study looks at spirituality and spiritual care in a very broad way. This includes things such as your attitude to life, reviewing your life, bringing closure to things that have happened, forgiveness of self and others, having hope, finding meaning and purpose in the things that have happened in your life and connecting to those who are most significant in your life. For some people, although not every one, it will also include religious practices and beliefs.

The family meeting, as it will be presented in this study, offers one way in which some of these things can be talked about and experienced. There will also be the opportunity to have a short closing ritual or blessing if that is something the participating patients and family members would like. Throughout the meeting the investigator will be a guide.

It is hoped that the results of this study will be of benefit to future patients, their families and palliative care staff, by providing more information about effective ways to provide for the their needs in the important domain of spiritual care. This cannot of course be guaranteed.

As a professional or volunteer who has an important role in the care of palliative patients and their families, your participation would be appreciated, but this is a research study and so you do not have to be involved. If you do not wish to participate your status in the Central Adelaide Palliative Service will not be affected in any way.

Participation

If you decide to take part in this study the following things will happen:

- You will be asked to complete a short questionnaire about some personal details (this does not include names).
- An appointment will be with the investigator, at a time suitable for you, for a one on one conversation about your impressions of the impact of the family meeting for patients and their families as well as any implications for yourself and other staff.
- With your consent this conversation will be audio recorded and later analysed.

Your Privacy

Your rights and privacy will always be respected in the following ways:

- You are free to withdraw at any time with no impact on you future status in the Central Adelaide Palliative Service.
- All records of the conversation and your personal details will remain confidential and no identifying information will be released to anyone.
- You can request that the tape recorder be turned off at any time during your conversation with the investigator.
- All data will be stored in a locked filing cabinet in the Department of General Practice. Only the specified investigators will have access to this.
- If you want to request copies of data that relate specifically to you this will be provided.

Contact Information

- If you or your family would like further information about this study you may contact the following investigators at anytime:

Heather Tan	0411 484 894
Dr Anne Wilson	8303 6281
Prof. Ian Olver	8222 5577

- If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may wish to contact the Chairman, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139

Your Well-being

It is possible that the conversation with the investigator about the family meetings, may touch on issues that you find difficult or distressing. Below is a list of professionals who are willing and able to assist you, should you want further help with these issues.

- Your doctor
- Your nurse
- Your minister/pastor/priest
- Hospital chaplain 8222 4443
- Hospital social worker 8222 4025
- Grief link website: www.grieflink.asn.au

This study has been approved by the Human Research Ethics Committee of the Royal Adelaide Hospital.

Thank you for taking the time to consider this information.

Appendix IV– Human Research Ethics Committee Approvals

Government of South Australia
Central Northern Adelaide
Health Service

ROYAL ADELAIDE
HOSPITAL
North Terrace,
Adelaide, SA 5000
Tel: +61 8 8222 4000
Fax: +61 8 8222 5939
ABN 80 230 154 545
www.rah.sa.gov.au
Research Ethics Committee
Level 3, Hanson Institute
Tel: (08) 8222 4139
Fax: (08) 8222 3035

29 August 2005

Ms Heather Tan
Dept of General Practice
ROYAL ADELAIDE HOSPITAL

Dear Ms Tan,

Re: "The family meeting as an instrument for the spiritual care of palliative patients and their families - does it help?" Information Sheet & Consent Form for patients. Information Sheet & Consent Form for family members. Information Sheet & Consent Form for Staff/Volunteer workers.
RAH PROTOCOL No: 050811

I am writing to advise that Research Ethics Committee approval has been given to the above project.

Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct in Research Involving Humans.

The general conditions of approval follow:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
  (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
  (b) changes to the protocol,
  (c) premature termination of the study.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is ongoing, subject to satisfactory annual review. An annual review form will be forwarded to you at the appropriate time.

Yours sincerely,

Dr M James
CHAIRMAN
RESEARCH ETHICS COMMITTEE

COPY

THE UNIVERSITY OF ADELAIDE
AUSTRALIA

THE UNIVERSITY OF ADELAIDE
HUMAN RESEARCH APPROVAL NOTIFICATION

As Chief Investigator on a research project involving human participants, would you please complete this notification form if:

i. you have University of Adelaide personnel on your investigating team[1], and
ii. you **have not** applied to the University of Adelaide Human Research Ethics Committee for approval, but
iii. you **have** obtained ethical approval from another institutional Human Research Ethics Committee (HREC).

The information collected on this form is needed for the University of Adelaide to meet its reporting obligations, both institutional and statutory, and to ensure that all University investigators are appropriately indemnified whilst undertaking their research activities.[2] The completed form should be submitted within fourteen days of receiving ethical clearance (refer to submission details below).

1	Human Research Ethics approval obtained – please provide the name of the institutional HREC that granted approval for the project and the approval number:				
	Institution	Royal Adelaide Hospital			
	Approval Number	050811			
2	Chief Investigator – please complete the following details:				
	Name	Anne Wilson			
	Title	Dr			
	Position	Lecturer			
	University Affiliation	Academic Staff ☒	General Staff ☐	Student ☐	
		Clinical/Affiliate/Honorary Title Holder ☐			
	University Department or Institution (if no University affiliation)	Department of General Practice			
	Telephone Number	83036281	Email	anne.wilson@adelaide.edu.au	
3	How many University of Adelaide personnel[1] are investigators on this project?	3			
4	Please complete the following details for each of the above investigators: (for additional investigator details please use the extra page at the end of this notification form)				
	Name	Heather Tan			
	Title	Ms			
	Position	PhD student			

[1] University personnel include academic and general staff, clinical/affiliate/honorary title holders, and students.
[2] For advice please contact the Manager, Risk Management & Insurance, Tel 8303 5804.

THE UNIVERSITY OF ADELAIDE AUSTRALIA

	University Affiliation	Academic Staff ☐	General Staff ☐	Student ☒	
		Clinical/Affiliate/Honorary Title Holder ☐			
	University School or Department		Department of General Practice		
	Telephone Number	83034340	Email	heather.tan@adelaide.edu.au	
5	Project Title:	The family meeting as an instrument for the spiritual care of palliative patients and their families - does it help?			
6	Aim of Project: (please provide a concise description in lay terms)	A literature review has revealed that there are very large gaps in the areas of implementing and evaluating spiritual care programs for palliative patients and their families. This study will implement the "Family Meeting" intervention as described by Murphy (1999). An evaluation of the "Family Meeting" will be undertaken from the perspective of three categories of stakeholders. Category A – palliative patients How do palliative patients experience the 'Family Meeting'? Does it assist with their spiritual care? Is it more likely to assist in some settings of care (hospice, home care, hospital) than in others? Category B – patient family members How do family members experience the 'Family Meeting'? Does it assist with their spiritual care? Category C – palliative care staff and volunteers. It is anticipated that this category will include medical staff, nursing staff, volunteers, chaplains and pastoral care workers and allied health staff such as social workers, occupational workers and physiotherapists How do staff and volunteers, who care for these patients and their families, experience the impact of the 'Family Meeting' on patients and families? Do they consider it is a good intervention for regular implementation in care? What would they need for the implementation of the 'Family Meeting' into palliative care practice?			
7	Date project to begin or proposed commencement date:			1/10/05	
8	Estimated duration of project or expected completion date:			Data collection to be completed by March 2007	
9	Location of research: (if this is a multi-centre project, list all locations for project activity)	Palliative care wards of the Royal Adelalide Hospital Home of home care pallitive patients who are referred by RAH outreach service Mary Potter Hospice - subject ot Calvary ethics committee approval which is pending			

THE UNIVERSITY OF ADELAIDE AUSTRALIA

10	What is the scope of the project:					
	Clinical ☐	Qualitative ☒	Epidemiological ☐	Other ☐		
	Is it:	Invasive ☐	Non-invasive ☒			
11	Sponsor/Source of Funding:		Nil			
12	Is the Sponsor providing indemnification for the project?			Yes ☐	No ☐	
	If no, is a hospital providing indemnity?			Yes ☐	No ☐	
	If no, is the University of Adelaide providing indemnity?[2]			Yes ☐	No ☐	
13	Total number of participants to be recruited?			~~8080~~ 60 - 80		
14	Average number of participants to be involved per year?			50		
15	Please provide a brief description in lay terms of what will be done to, or asked of, participants: Medical staff will be asked to seek the permission of patients who meet the criteria, tosubmit their names as potential participants. Those referred will be approached, given full information and then if they agree to participate and give written consent those family members who they suggest will be approached to participate and will also be provided with the appropriate information. Written consent will also be sought. All patient and family member participants will be asked to complete a brief demographic questionnaire. They will then take part in a family meeting. Following the family meeting a time will be made with the patient and some family members to conduct individual in depth interviews about their experience of the family meeting . Staff member participants will be asked to fill out a brief demographic questionnaire and to take part in an individual in-depth interview to discuss their impressions of the impact of the family meeting on patients and family members and to discuss their view of its suitability as a regular part of the pallitive care program					

Signature (Chief Investigator):

Date:

Please submit this form to:
The Secretary, Human Research Ethics Committee, Research Ethics & Compliance Unit, University of Adelaide SA 5005, or email to: sabine.schreiber@adelaide.edu.au

THE UNIVERSITY OF ADELAIDE
AUSTRALIA

Question 4 – details of additional University of Adelaide personnel:

1	Name	Ian Olver			
	Title	Professor			
	Position	Professor of Cancer Care Univeristy of Adelaide. Please note he is also the Medical Director of RAH Caner Centre.			
	University Affiliation	Academic Staff ☒	General Staff ☐	Student ☐	
		Clinical/Affiliate/Honorary Title Holder ☐			
	University School or Department	Medical School			
	Telephone Number	82225577	Email	ian.olver@adelaide.edu.au	
2	Name				
	Title				
	Position				
	University Affiliation	Academic Staff ☐	General Staff ☐	Student ☐	
		Clinical/Affiliate/Honorary Title Holder ☐			
	University School or Department				
	Telephone Number		Email		
3	Name				
	Title				
	Position				
	University Affiliation	Academic Staff ☐	General Staff ☐	Student ☐	
		Clinical/Affiliate/Honorary Title Holder ☐			
	University School or Department				
	Telephone Number		Email		
4	Name				
	Title				
	Position				
	University Affiliation	Academic Staff ☐	General Staff ☐	Student ☐	
		Clinical/Affiliate/Honorary Title Holder ☐			
	University School or Department				
	Telephone Number		Email		

Calvary
Health Care
Adelaide

19 December 2005

Ms Heather Tan
University of Adelaide
Department of General Practice
Level 3 Eleanor Harrald Bld
ADELAIDE SA 5005

Dear Heather

Application for Ethics Clearance – Ref: 48/0905
The Family Meeting as an instrument for the spiritual care of Palliative Patients and their families – Does It Help?"

Further to our meeting on 5 December 2005 and your submission of the required amendments, I confirm approval of the above application.

Please provide a copy of any publication that results from your study to the Chair of the HREC and keep the Committee informed of progress in this matter.

Should you have any queries, please do not hesitate to contact me on (08) 8239 9100 or Larissa Miles, Executive Assistant, on (08) 8239 9135.

Yours sincerely

Ms Helen Walker, Project Advocate
Clinical Manager

"Being for others"
Calvary Health Care
Adelaide Ltd
ABN 85 106 314 229
89 Strangways Terrace
North Adelaide SA 5006
Ph: 08 8239 9100
Fax: 08 8239 9168
www.calvarysa.com.au

Government of South Australia
Central Northern Adelaide
Health Service

24 July 2006

Ms Heather Tan
Program Administrator
Graduate Program Grief & Palliative Care
Counselling Department of General Practice
University of Adelaide
ADELAIDE SA 5005

The Queen Elizabeth Hospital
28 Woodville Road
WOODVILLE SOUTH SA 5011

Lyell McEwin Hospital
Haydown Road
ELIZABETH VALE SA 5112

Dear Ms Tan

Application Number 2006065

The Ethics of Human Research Committee at the last meeting considered your protocol entitled:

"An evaluation of the family meeting as a model for the psycho-spiritual care of palliative patients and their families"

The following documents have been reviewed and approved:

- CNAHS Ethics of Human Research Committee (TQEH & LMH) Application Form
- Response Letter to queries dated 14 July 2006
- Patient / Family Member Invitation to Participate (undated)
- Staff Participants Information Sheet (undated)
- Demographic Questionnaires (Staff Member, Family Member, Patient)
- Possible Probe Questions

Approval Status: **FINAL**

Period of Approval: **24 July 2006 – 24 July 2007**

***Please note the terms under which Ethical approval is granted:**

1. Researchers are required to immediately report to the Ethics of Human Research Committee anything which might warrant review of ethical approval of the protocol, including:

a) serious or unexpected adverse effects on participants;
b) proposed changes in the protocol; and
c) unforseen events that might affect continued ethical acceptability of the project

2. Protocols are approved for up to twelve months only and a report is required at the end of the study or 12 month period. Extensions will not be granted without a report to the Committee.
3. Confidentiality of the research subjects shall be maintained at all times as required by law
4. All research subjects shall be provided with a Patient Information Sheet and Consent Form, unless otherwise approved by the Committee
5. The Patient Information Sheet and Consent Form shall be printed on the relevant site letterhead stating the contact details for the researchers
6. The Patient Information Sheet must state that the Executive Officer can be contacted for information regarding conduct of the study, policies and procedures, or if the participant wishes to make a confidential complaint
7. A report and a copy of any published material should be forwarded to the Committee at the completion of the project.

Yours sincerely

A/Prof Timothy Mathew
Chairman
Ethics of Human Research Committee (TQEH & LMH)

Appendix V – Information for Referring Staff

THE FAMILY MEETING AS AN INSTRUMENT FOR THE SPIRITUAL CARE OF PALLIATIVE PATIENTS AND THEIR FAMILIES

Heather Tan – PhD Candidate
Dr Anne Wilson – Principal Supervisor

CONTACT PERSONS FOR QUESTIONS:

Heather Tan - 0411 484 894 or heather.tan@adelaide.edu.au

Dr Anne Wilson – 8303 3593 or anne.wilson@adelaide.edu.au

INFORMATION FOR REFERRING STAFF

The Family Meeting:

- This type of family meeting focuses on spiritual and psychosocial issues.
- It is a time for making peace, discharging old resentments, giving thanks and saying goodbye and potentially a time for great emotional healing.
- It is an opportunity for all to speak.
- Murphy (1999) has developed a five-part paradigm to guide families through this process:
    - The patient's story
    - Worries and Fears
    - The family background
    - The family speaks
    - Closing the meeting

Selection Criteria for Patients:

- Patients who are considered able, by the attending medical staff, to be present at the family meeting.
- Patients who are aware of the terminal nature of their illness
- Patients who are able to read, write and converse in English
- Patients who are over 18 years of age.
- Patients who understand that they may withdraw from the study at any time without any impact on their treatment now or in the future.

Thank you for your assistance in facilitating this research project

Heather Tan

Appendix VI – Demographic Questionnaires

Demographic Questionnaire - Patient

Please complete the following personal details. If you would like the investigator to assist you with this please let them know. These details will not be used in a way that personally identifies you.

1. Age: _____ (last birthday)

2. Gender: M / F (circle)

3. Nature of Illness:
   Type of illness: _____
   Time since diagnosis: _____

4. Religious Affiliation: (tick the relevant one)

None:	____	Christian:	_____
Buddhist:	____	Moslem:	_____
Hindhu:	____	Other:	_____

5. Who is the closest to you?

Spouse/partner:	____	Son/Daughter:	____
Sibling:	____	Parent:	____
Friend:	____	Other Relative:	____
No one:	____		

6. How many people in your family do you have a close relationship with?

7. Place of care: home / hospice / hospital (circle)

Thank you

Demographic Questionnaire - Family Member

Please complete the following personal details. These details will not be used in a way that personally identifies you.

1. Age: _____ (last birthday)

2. Gender: M / F (circle)

3. Religious Affiliation: (tick the relevant one)

None:	____	Christian:	_____
Buddhist:	____	Moslem:	_____
Hindhu:	____	Other:	_____

4. What is your relationship to the person who is ill?

Spouse/partner:	____	Son/Daughter:	____
Sibling:	____	Parent:	____
Friend:	____	Other Relative:	____

5. Do you have a close relationship with this person Yes / No (circle)

7. How many people in your family do you have a close relationship with?

Thank you

Demographic Questionnaire - Staff Member/Volunteer

Please complete the following personal details. These details will not be used in a way that personally identifies you.

1. Age: _____ (last birthday)

2. Gender: M / F (circle)

3. Religious Affiliation: (tick the relevant one)

   None: ____ Christian: _____

   Buddhist: ____ Moslem: _____

   Hindhu: ____ Other: _____

4. What is your role in the care of palliative patients and their families?

   Medical staff: ____ Nursing Staff: ____

   GP: ____ Chaplain/Pastor ____

   Allied Health Prof. ____ (specify _____)

   Volunteer: ____ (specify _____)

5. Do you consider that spiritual care is an important part of patient care?
   Please circle the answer closest to your view.

   very important / important / marginally important / not important

6. Are you normally involved in the spiritual care of patients and their families?

   Yes / No

7. Have you had any specific training in spiritual care?

   Yes / No

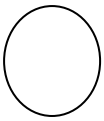
Thank you

Appendix VII – Family Geno Grams

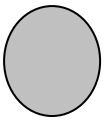
Key to Family Geno Grams

Male

Female

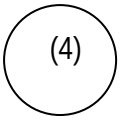


Not present at meeting

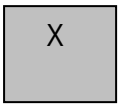


Age of family member e.g.

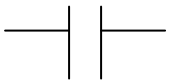
female aged 4



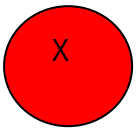
Deceased person X in circle or square



Broken relationship

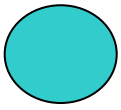


Died of same illness as patient has

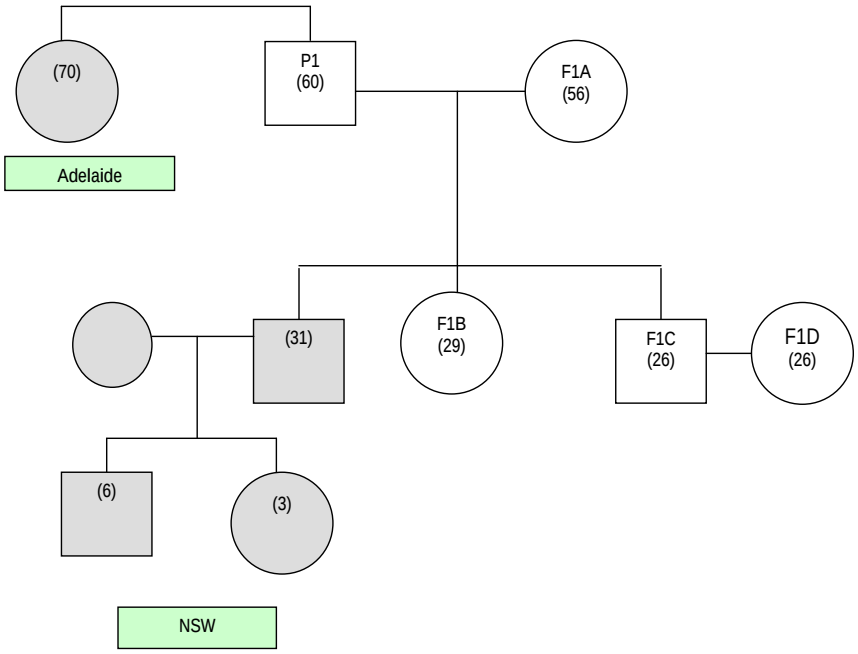


Significant information

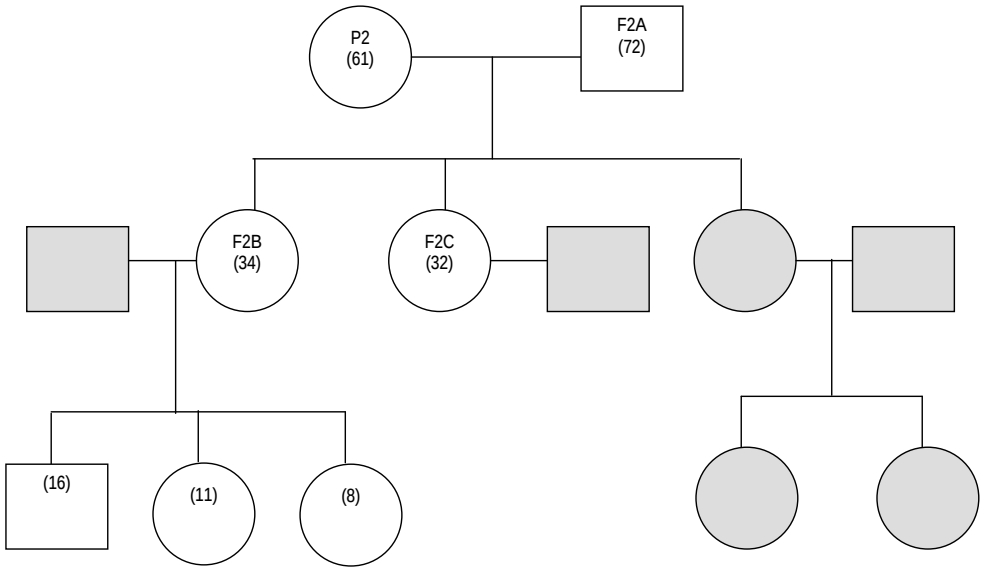
Diagnosed mental disability
(did not attend meeting)



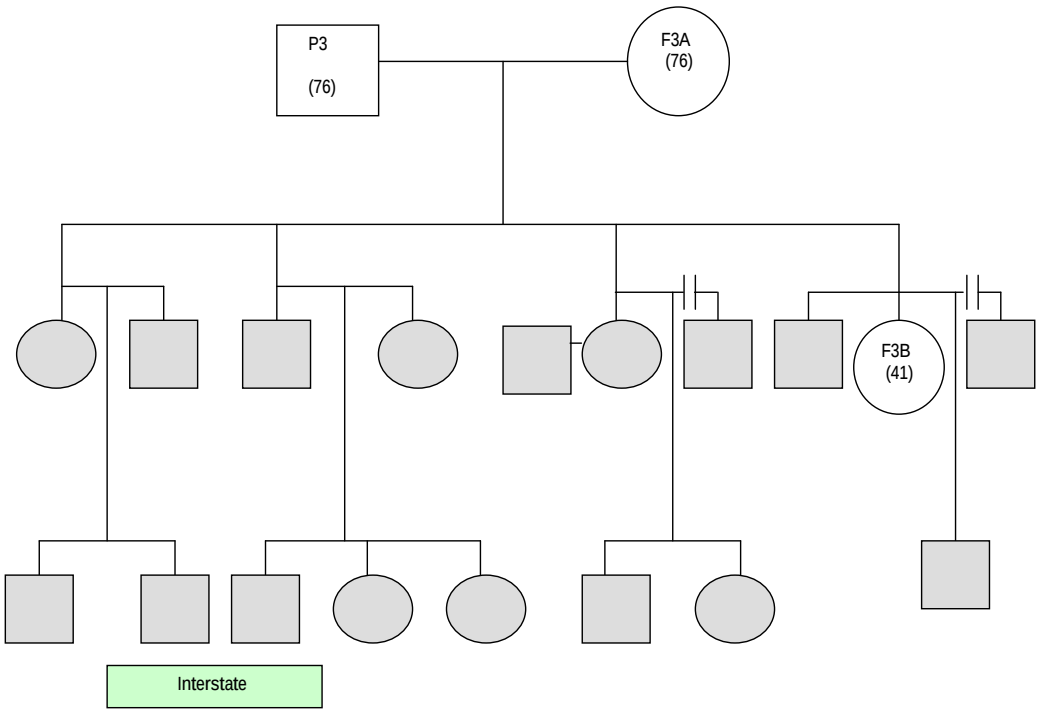
Appendix VII(1) - Geno Gram Family 1



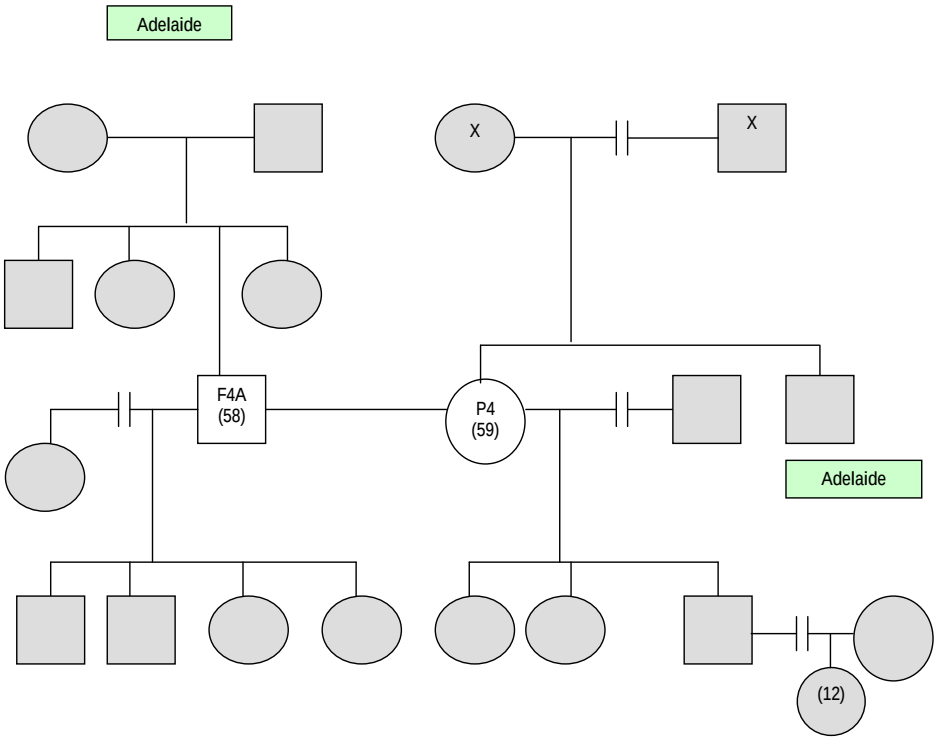
Appendix VII(2) - Geno Gram Family 2



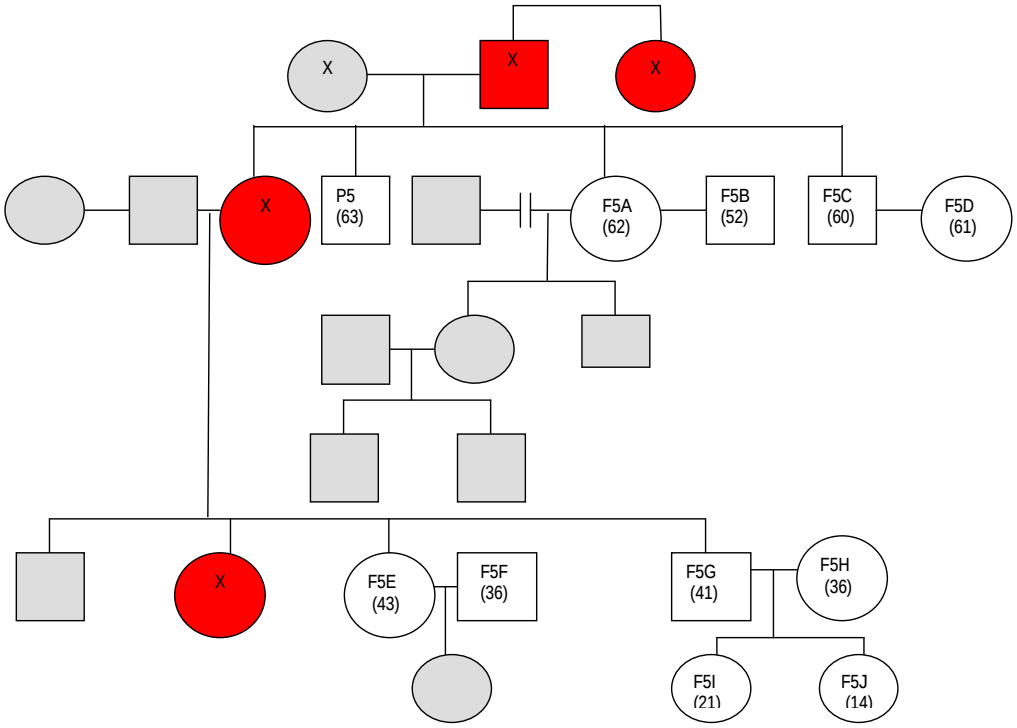
Appendix VII(3) – Geno Gram Family 3



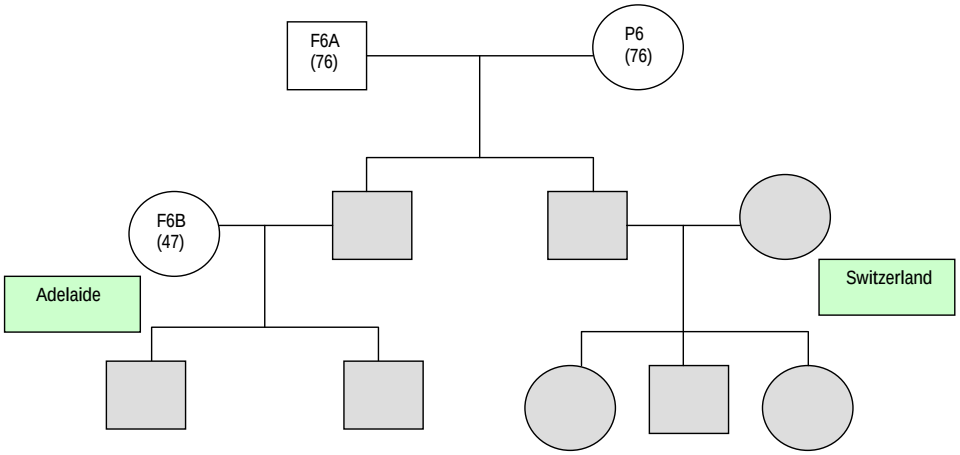
Appendix VII(4) - Geno Gram Family 4



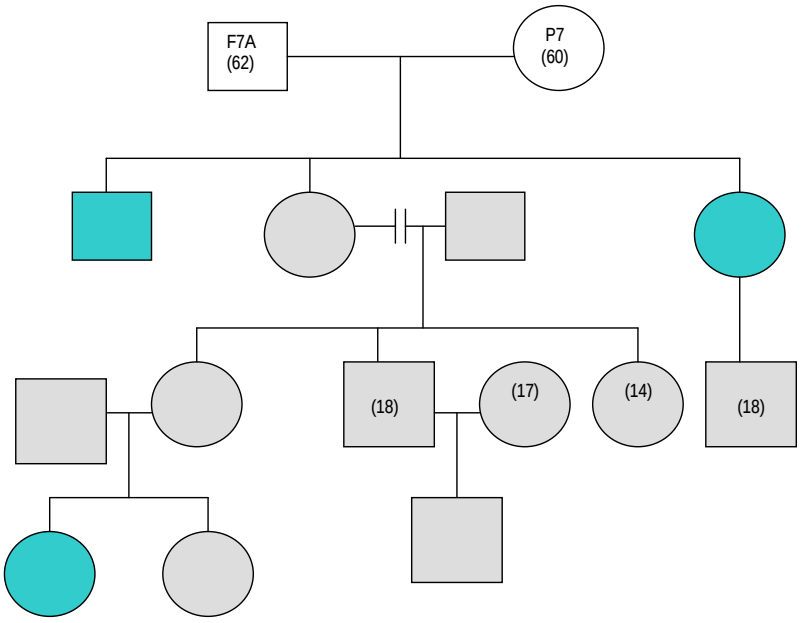
Appendix VII(5) - Geno Gram Family 5



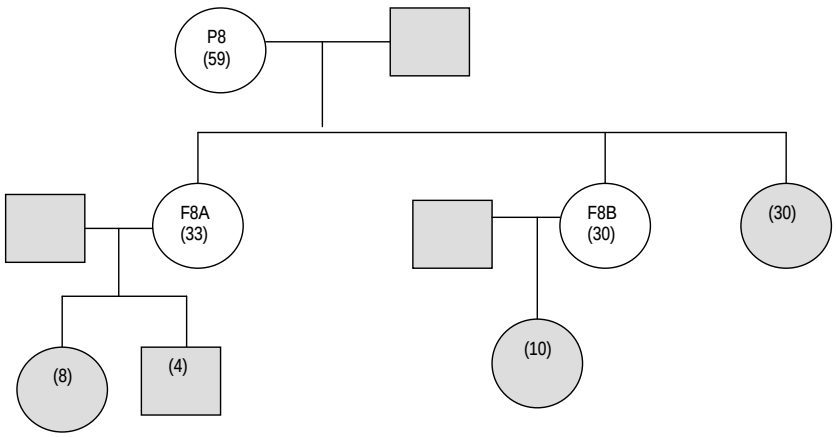
Appendix VII(6) - Geno Gram Family 6



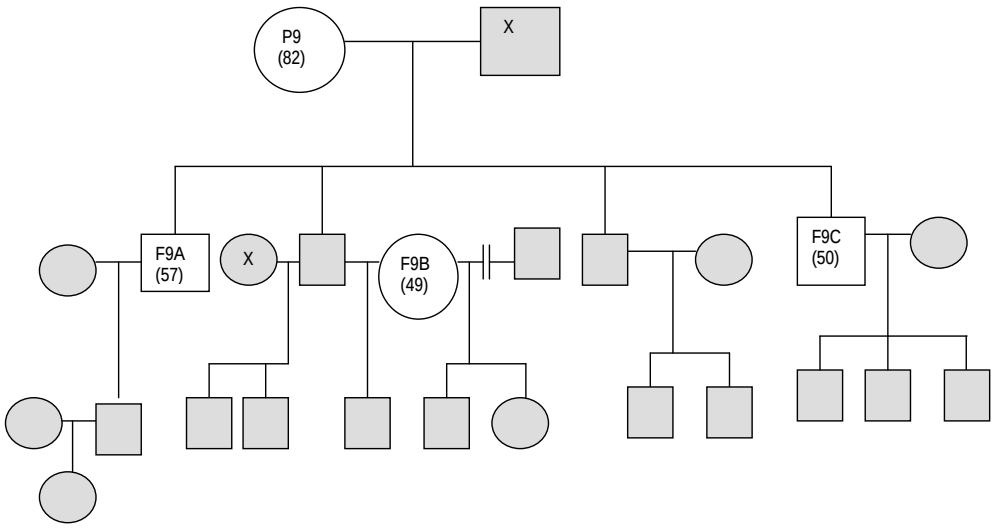
Appendix VII(7) - Geno Gram Family 7



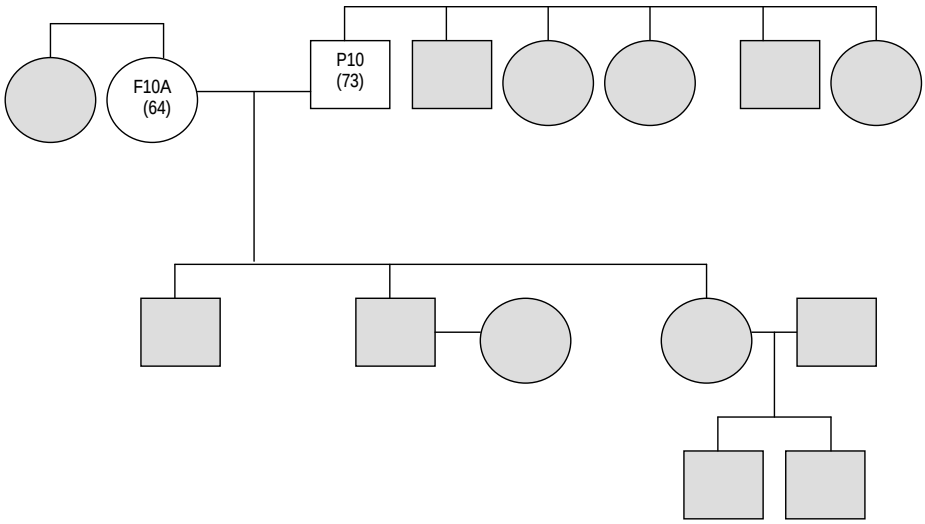
Appendix VII(8) - Geno Gram Family 8



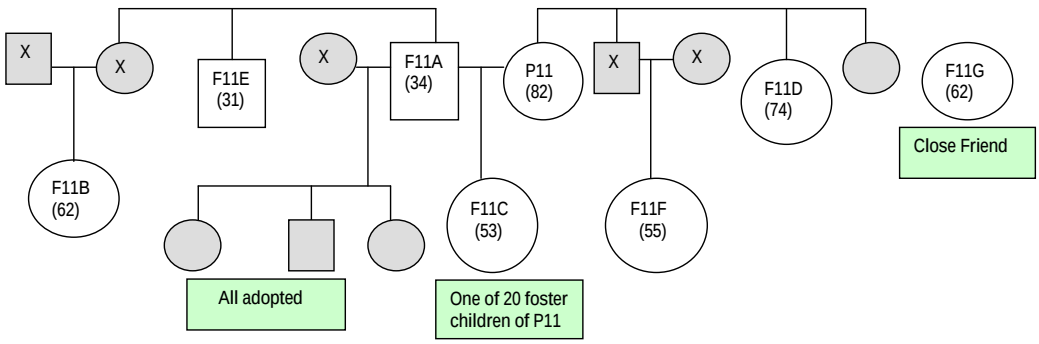
Appendix VII(9) - Geno Gram Family 9



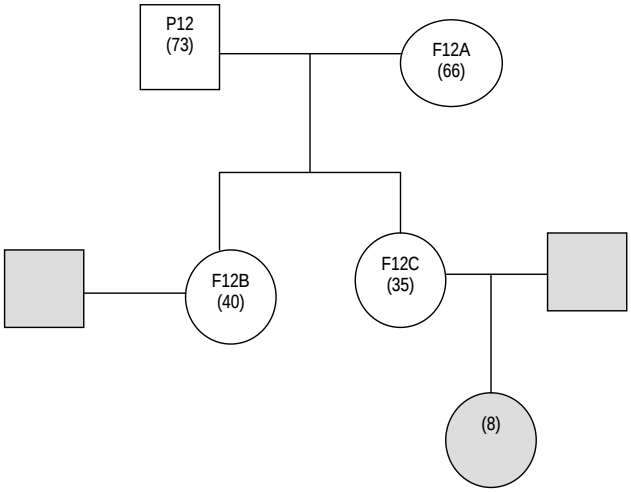
Appendix VII(10) - Geno Gram Family 10



Appendix VII(11) - Geno Gram Family 11



Appendix VII(12) - Geno Gram Family 12



Appendix VIII – Family Profiles

Profile Family 1

How the family relates to each other

They consider themselves very close but in practice this excludes to some degree children's partners Father (the patient) is dominant and likes to be in control.

Communication

They claim that openness and honesty are vital. The evidence does not support this to the degree claimed. Communication occurs much more on a one to one basis than as a family group.

Emotional Expression

Father does not express feelings much because 'everyone knows what I feel' although evidence does not support this. His son would like to express feelings more but does not have a role model. Females are expected to be more emotional although this makes father uncomfortable.

Values

"Christian values" are strongly held and supported by active church involvement. Although they display a general attitude of gratitude there is some evidence of thinking "good people do not deserve this". They are quite goal orientated.

Impacting History

No events in the history of the family came to light as having significant impact on the family's experience of the family meeting.

Socio-Economic Situation

This is a comfortable middle class family with predominantly tertiary education.

Profile Family 2

How the family relates to each other

The wife (patient) is the dominant partner with a culture of bickering between the two of them. It is not a close family although there are a couple of 'close' relationships with mother.

Communication

There is limited communication between some family members and no in-depth discussions or expression of true feelings about illness and death. The special things said about the patient would not normally have been expressed. Husband values talking to someone outside the family.

Emotional Expression

It seems that negative emotions such as anger have been expressed but fears, love and tears are not expressed.

Values

Hanging on to what you believe, whatever that is, and trusting is important to father patient's spouse) as is his desire to have a closer, more supportive family. They believe that children should be included in such matters as death and family meetings. Punctuality is a low family priority.

Impacting History

There is evidence of past history impacting on the relationship between the three sisters. They acknowledge that this had an impact on attendance and participation in the meeting.

Socio-economic Situation

Real Aussie battlers living in a dilapidated housing trust home with a history of unemployment and low levels of education.

Profile Family 3

How the family relates to each other

Father (patient) dominates the family and considers it close knit (others disagree) although he does acknowledge the presence of schisms. His image and role in the family seem very important to him.

Communication

Although the parents believe that communication is open, it is quite evident that there are boundaries that will not be crossed as evidenced by a strong wariness of entering into some areas of conversation. Things were said at this meeting that would never have normally been raised.

Emotional Expression

Emotions are not generally expressed in front of others and doubt was expressed about whether it was alright to be upset in the family meeting setting.

Values

A tradition of Christian faith is viewed as important by parents who regret that the younger generation have not taken it up. The parents feel no embarrassment about discussing spiritual matters.

Impacting History

The daughter considers that a Christian missionary history has a negative impact on family culture in that it prevents them from openly dealing with 'past schism and dark issues'. Fears are very evident both about what may be said and about the hereditary nature of muscular dystrophy.

Socio-economic Situation

They are professionals with high levels of education and a strong desire to assist with research work. They live in an upper class suburb.

Profile Family 4

How the family relates to each other

The wife (patient) seems dominant in the relationship and at times aggressive. There is however a seemingly loving connection between them. They have almost no contact with other family including her children of a previous marriage.

Communication

It was evident that there were communications difficulties between them.

Emotional Expression

The husband is reluctant to show his pain in front of her for fear of upsetting her.

Values

Both value their independence and share a strong love of the outback.

Impacting History

The wife had very difficult and disturbed childhood and has great fear of relationships, refusing any extended family contact. The husband misses his family. Their experience of the medical system before and after diagnosis was very difficult although they are very happy with the palliative care system now they have finally been referred to it.

Socio-economic Situation

At the time of the meeting they were living in a caravan. They have a limited educational background and have been employed as itinerate workers in the outback, earning high income in patches.

Profile Family 5

How the family relates to each other

There is a lot of tension and discord within this family but also a number of supportive relationships. They do not consider themselves close but have a lot of respect for the patient.

Communication

There is generally very poor communication within the family, the patient feeling the need of an outside confident.

Emotional Expression

There is strong fear of expressing emotions and it is considered weak and inconsiderate, and a display of self pity by some family members, to cry in front of the patient.

Values

There is a wide spread fear of death and a view that it is not good to talk about it. There is a culture of fighting pain rather than taking medication and a strong culture of macho males.

Impacting History

There is a very strong history of pancreatic cancer in the family including the family matriarch (patient's older sister) whose death has left much unresolved grief amongst family members. Past bad experience of hospice and problems communicating with doctors added to fears and uncertainty about the patient's future.

Socio-economic Situation

The patient is a single man who owns his unit. He had been a tradesman. The family members were generally blue-collar workers

Profile Family 6

How the family relates to each other

Father was somewhat patronising in his relationship to his wife (the patient) while she was quite domineering in her relationship to her sons and their wives. The participating daughter in law considers she has a close relationship with the patient.

Communication

In depth discussion about sensitive matters such as death do not usually happen in this family so doing this in the family meeting was to a large extent a new experience.

Emotional Expression

Open expression of emotions is not the norm in this family. The son resident in Adelaide offered many excuses as to why he couldn't attend a potentially emotional meeting.

Values

The patient and her husband have fairly close church connections including asking a minister to come to the hospice to meet with the family. Roles are very important, especially to the patient, who considering herself unable to actively pursue her role as matriarch in the way she had, wanted to die as soon as possible.

Impacting History

There was no obvious past history impacting on this family's experience of the family meeting.

Socio-economic Situation

This family lived in an expensive suburb and made it clear that money was not an issue. The husband and sons are all professionals.

Profile Family 7

How the family relates to each other

The patient and her husband seem very caring of each other. There is little evidence of support from their children or grandchildren, with the exception of one daughter who has her own relationship problems. The others are either too disabled or too young.

Communication

They talked a lot about the good times. Otherwise communication seems pretty superficial, avoiding the big issues in an attempt to maintain their habit of trying to protect each other.

Emotional Expression

There is strong concern that tears are upsetting and anything likely to stimulate them should be avoided.

Values

There is no evidence of bitterness about their very difficult situation but rather a strong attitude of acceptance and battling on.

Impacting History

No specific impacting situation arose but the nature of widespread disability in the family clearly has impacted on their life and their tendency to focus on the positive to the extreme, as a way of coping.

Socio-economic Situation

There is a strong family history of disability and unemployment. They live in a low socio-economic area in a housing trust house.

Profile Family 8

How the family relates to each other

The patient is seen as the glue in the family and all expressed concern about their future. They consider themselves close but also indicated that they rarely spoke of deep matters.

Communication

There is a lot they don't say and feelings in general are not discussed. One daughter is very aware of the need to speak more but has not been able to bring change in the family in this regard. It is felt that an outside stimulus assisted.

Emotional Expression

They all find it hard to express emotions and have a fear of doing so. To cry in front of others is considered to be letting them down.

Values

The grandparent role is seen as crucial in the family structure, especially in relation to a disabled grandchild. The norm is to hide tough issues rather than deal with them.

Impacting History

There have been many cases of cancer in the family and the younger ones have a sense of inevitability about eventually getting the disease in some form.

Socio-economic Situation

The parents live in a middle class family and own their house. The daughters have followed this path. They are mainly employed as trades people.

Profile Family 9

How the family relates to each other

The patient is a strong female in a male dominated family. There is evidence of discord between the daughters in law and between them and the patient. They consider themselves quite close but only get together as a group once a year.

Communication

There is minimal communication between the brothers at any time. In her presence they maintained the pretence that she will be going home although individually the sons do not believe it. The patient believes that the family does not have any secrets.

Emotional Expression

As a group they are 'not high on emotions' and are unused to talking about feelings. It is not considered good to cry in front of others.

Values

Christian faith is very strong in family of F9B but not elsewhere in the family. Mum (the patient) seemed to be one of the few common factors and they were all expected to go to her.

Impacting History

The main historical impact revolved around family of F9B. They have power of attorney which is obviously a point of conjecture. The first wife of the husband of F9B (second son of patient) died of cancer a few years ago and F9B has recently also undergone treatment for cancer.

Socio-economic Situation

Family members are employed in trades and professions and living in middle class suburbs.

Profile Family 10

How the family relates to each other

The patient and his wife feel they have a very close relationship. They also feel close to their siblings but the relationship with their children and grandchildren does not feature as strongly.

Communication

Communication within the family is considered to be open. It is clear that F10A values communication and support from her work colleagues some of whom are close friends.

Emotional Expression

There is a lot of denial of feelings such as anger and emotional pain that are clearly obvious in body language. The patient talks of himself as a victim at times.

Values

Their church community is important and faith influences their ability to talk openly about the illness. The wife's approach is 'don't give up at any cost' while the patient sees definite limits to treatment. This is the cause of tension between them.

Impacting History

The very positive attitude of a daughter in law (chronic leukaemia since childhood though currently in remission) and the experience of a father and brother with prostate cancer, also aid them in talking openly they think.

Socio-economic Situation

The patient is comfortably retired. His wife who is ten years younger, works because she likes the contacts and stimulation.

Profile Family 11

How the family relates to each other

This is a very unusual family with a large number of ex foster children considered part of the family as well as a few very close friends. The patient and her husband are very close and have no children having been married only 13 years. There are discords in the family though – the patient with two of her sisters and her husband with at least one of his adopted children from his first marriage. The patient tends to hold it all together and is a highly favoured aunt.

Communication

Communication is considered to be very open. There is evidence however of communication breakdown in parts of the family and also a tendency to down play the seriousness of her illness.

Emotional Expression

It is all a bit over positive with very little emotion expressed at all really during the meeting. The husband when alone with me shared some of his grief.

Values

Christian faith and values are very strong, especially for the patient. This seems to support an apparently very matter of fact view of death.

Impacting History

The patient's history as a welfare worker for many years has led to this unusual family. There is a general feeling of being honoured to be a part of it.

Socio-economic Situation

They are retired trade and professional people living in a comfortable middle class suburb.

Profile Family 12

How the family relates to each other

This family consider themselves close but also acknowledged that personality differences often result in tensions. The patient seems to be somewhat up on a pedestal in the eyes of the others.

Communication

Quite a few things seem to be presumed rather than verbalised, such as how the patient feels, the love between the patient and his wife and the issues related to his approaching death. The patient tends to skim over personal things rather than speak of them in any depth. Philosophical issues such as euthanasia were discussed readily until they became personal.

Emotional Expression

There is a strong culture between the patient and his wife that emotions should not be expressed in front of other people. The daughters seem more open in expressing their feelings although one in particular sees it as a weakness.

Values

A belief in euthanasia, in theory at least, dominates their thinking around many issues. It is thought for instance that death is somehow easier when there are no expectations of a life after death.

Impacting History

There are no obvious family history issues that impact on their experience of the meeting.

Socio-economic Situation

Family members have professional backgrounds and live in comfortable middle class suburbs.

Appendix IX – Theme Tables

Appendix IX(1): Data Analysis Table – Theme 1

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
1. Speakers experience of the meeting	a) The experience of speaking	1. The speaker's view of topics covered	The topics they thought were important and wanted to bring up were covered. 1.1.1 doc 1(1) F2B, doc 4(4) F3A, doc 6(1) P3, doc 7(4) F11A, doc 10(3)P6, doc 12(1) F8B, doc 13(1) F11C, doc 17(3) F11G, doc 22(2&6) F1B, doc 31(2) F6B, doc 36(1&3) P5; feeling able to avoid topics they did not want to talk about. 1.1.1 doc 16(2) F11F, doc 37(2) P4; Had hoped for more information 1.1.1 doc 32(1) F9A; Didn't cover anything new 1.1.3 doc5(1) F10A, 1.1.4 doc 18(1) P10, nothing inappropriate 1.1.1 doc 16(2) F11F, 1.1.2 doc 27(1) P12. pleasant things said 1.1.1doc 5(1) F3B; didn't cover everything 1.1.1doc5(2-3)F3B
		2. Perceived inhibitors to openness	Personal reticence to being open 1.1.1 doc 2(2-3) F2B, doc 14(1) F11D, doc 16(1) F11F; Openness not normal family culture. 1.1.1doc 9(1) F5F; Degree of openness of family determined by patient 1.1.1 doc 12(2) F8B; Didn't go far enough for some. 1.1.1doc 15(1) F11E; Reluctance to talk about death. 1.1.1doc 17(2) F11G, doc 29(2) F5I; doc 32(2-3) F9A; Lack of clear understanding of where it was going kept some back at first.1.1.1 doc 35(1) P8, doc 32(2-3) F9A.
		3. The experience of being open	No problem 1.1.1doc 6(2) P3, doc 17(1) F11G; Different and not as easy as one might think. 1.1.1 doc 6(3) P3; Being open & having that valued was a very good experience.1.1.1 doc 8(1) F1C, doc 24(1) F5A, doc 33(1) P11; Feeling relaxed enabled openness.1.1.1 doc 10(1-2) P6; Never been in this situation, found it a comfort. 1.1.1doc 11(1) F11B; Desire to help patient fostered an openness that wouldn't have been there. 1.1.1 doc 17(1) F11G; The meeting gave permission for more openness than usual.1.1.1 doc 4(1) F3A, doc 19(3) 12B; doc 20(1) 12C topic focus aided openness 1.1.3doc15(1) F6A Facilitation aided openness to topics that might have been taboo that needed to be raised.1.1.1 doc 19(3) F12B, doc 23(1&3) F1D; Not pressured to more openness. 1.1.1 doc 37(3) Int. Notes P4.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
1. cont		4. The value of speaking in the group	Great value in every one having access to everyone else's thoughts and experiences as normally only hear one here and one there. 1.1.1 doc 21(1-4) F1A, 1.2.2 doc 5(1) F11D; Definitely beneficial to sit and talk as a group.1.1.1 doc 7(5) F11A, doc 22(1&5) F1B, doc 27(1-2,4) F5G; One on one too afraid of offending to ask questions but in the group it was much easier.1.1.1 doc 24(2) F5A, doc 26(1-2)F5E; People were more open than they are one on one.1.1.1 doc 29(1) F5I; Opportunity to discover what others are interested in.1.1.1 doc 36(3) P5; if this could be available for everyone I'd die feeling better. 1.2.4doc 13(2) P5.
		5. The experience of review	Good 1.1.1 doc 37(1) P4; 1.12.2 doc 20(1)P12, 1.1.3 doc 15(2-3) F6A; Gave opportunity for releasing it and moving forward to what is to come.1.1.1 doc 22(4) F1B; Gave cause for reflection about changes to make & different perspective on things.1.1.1 doc 3(1) FM2 Notes doc 30(1) F6A; A lot of joy and comfort in remembering the good times too. 1.1.1doc 18(1) F12A, 1.3.1 doc 8(1) P6, 1.1.5 doc 31(3) P7 1.1.3 doc 18(1-5) FM7 Notes.
	b) How the speaker felt during/about the meeting	1. Perceived positive feelings	Happy and positive, 1.1.2 doc 1(1-2) F3A, doc 3(1) F1C, doc 8(1) F11D,doc 15(1-3) F5A, doc 26(1)P11, 1.2.4 doc 2(1) F4A, doc 3(2) F3A, doc 8(1) F1B, doc 11(1) F6A; honoured, 1.1.2 doc 5(7) F11B; warm, caring and comforting, 1.1.2 doc 5(3-5) F11B, 1.2.4 doc 1(1) F2A; comfortable & relaxed,1.1.1 doc4(5) F3A, 1.1.2 doc 4(2) P6, doc 10(2) F11G, doc 25(2) P1, doc 19(2) F5G, doc 26(1) P11, 1.1.3 doc 11(1) F1D; grateful, 1.2.4 doc 3(1) F3A, doc 4(1-3) F3B; enjoyment in being together 1.1.2 doc 16(1-3) F5A; drained at first but more positive each day, 1.1.2 doc 18(4) F5E; balanced – no one out of control emotionally 1.1.2 doc 25(1) P1; very pleased, 1.1.2 doc 30(1) P9, 1.2.4 doc 4(1-2) F3B; I felt easier – it eased the pain a little, 1.1.2 doc 19(2) F5G, doc 17(1-2)F5B, doc 19(1)F5G, 1.2.4 doc 1(1-2)F2A; felt free from past bondage to expectations of patient in particular, 1.2.4 doc 4(6-7) F3B; surprise, 1.2.4 doc 4(4) F3B, 1.1.3 doc 21(1)P9; thoughtful, reflective 1.1.3 doc 1(1) FM2;, Full on 1.1.2 doc 14(1-3) F1B; supported 1.2.4 doc 1(3) F12A; meaningful & powerful 1.1.2 doc14(5)F1B; nothing negative whatsoever 1.1.4 doc 4(1)F1C; Less threatening/emotional than I expected, 1.1.2 doc 7(1) F10A, doc 10(1) F11G,doc 28(2) P8; not intrusive 1.1.4 doc2(1)F3A; not angry, 1.2.4 doc 4(5) F3B

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
1. cont		2. Perceived negative feelings	Mixed feelings – a bit nervous/ no specific benefits 1.1.4 doc 18(2) P10, 1.1.2 doc 2(1-3) F3B, doc 15(1) F1D, doc 20(1-2) F5I, doc 24(1) Int. Notes P7, 1.1.4 doc 7(1)F1A, doc 16(1) Int. Notes F7A, 1.2.3 doc (2) Int. Notes F7A, 1.2.4 doc 12(1-2) FM5 Notes find it hard to talk in front of groups, 1.1.2 doc 9(1) F11F; found it quite traumatic, 1.1.2 doc 11(1) F12B; angry, 1.1.2 doc 12(1) F12C; a bit heavy hearted – it was painful – not that I consider that a negative it is part of the process. 1.1.2 doc 14(6) F1B, 1.1.4 doc 8(2-3)F1B; Concentrated painful memories was exhausting, 1.1.2 doc 18(1-3) F5E; a bit overwhelmed, 1.1.2 doc 22(1-2) F8A; momentarily awkward, 1.1.2 doc 20(1) F5I; 1.1.4 doc 1(2) F2B; uncomfortable (with talk about coffins), 1.1.4 doc 6(1) F11B; nothing bad really, 1.1.4 doc 1(1&3) F2B, doc 7(1) F1A, doc 4(1) F1C, doc 8(1) F1B, doc 9(1-2) F1D, ; more gruelling than I expected, 1.1.4 doc 10(1) F5E; a bit stressful, 1.1.4 doc 11(2) F5H; can't see the positive side of talking about death 1.1.4 doc 12(1) F5I; sadness – sorrow that patient had admitted that they were dying, 1.2.4doc 5(1) F5f. a bit unreal at times 1.1.4 doc 3(1-2) F3B
		3. Felt emotional	less emotional than expected, 1.1.2 doc 7(1) F10A; very emotional, 1.1.2 doc 5(1-2) F11B, doc 11(1) F12B, doc 13(1) F1A, doc 14(1-2) F1B; more emotional than expected, 1.1.4 doc 10(2) F5E; comfortable levels of emotional expression, 1.1.2 doc 15(2) F1D; don't normally express this emotion in the family group, 1.1.2 doc 21(1) F6A; didn't mind the crying but it is actually self pity, 1.1.2 doc 29(2) P5;
		4 Getting realistic	Now it is in the open I feel uncomfortable around him – I could pretend before 1.2.4 doc 10(1-3) F5I, 1.1.2 doc 20(3) F5I; started coming to terms with it now, 1.2.4 doc 1(4&5) F2A, doc 14(1) P4; it brings reality to the fore but we have to deal with it anyway 1.1.4 doc 13(1) F8A, 1.1.3 doc 6(3)F11F, doc 16(1) F8A, doc 22(1) P4, 1.2.2 doc 4(1) F2C, doc 7(1)F12C, 1.3.4.3 doc 12(4)F2C; hard to adjust to reality but this helped, 1.1.2 doc 11(2) F12B, 1.2.6 doc 3(1) F6B; impact for grandchildren became real, 1.2.2 doc 4(2) F2C. realistic, 1.1.2 doc 27(1) P12, doc 28(2) P8;

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
1. cont	c) New understanding	1. New understanding of self	Earlier losses could have been easier if there had been a culture of talking about it, 1.2.6 doc 4(1) FM5; new understanding of being appreciated and valued, 1.1.1 doc 36(3&5) P5, 1.1.3 doc 20(6-7) P5, 1.3.1 doc 10(2)F2C, 1.1.2 doc 28(1)P8; it makes you think about things,1.1.3 doc 1(1) FM2, 1.2.2 doc 2(1) F3B; it prompts self examination, 1.2.2 doc 9(1) F6A; made me realise I had done something good with my life, 1.2.2 doc 10(1) P5; I know where I stand in the family, 1.2.2 doc 8(1-2) F1D; would like that kind of thing if it was me 1.2.4doc 9(1)F5E.
		2. New understanding of other family members	clearer understanding of grand-son 1.1.3 doc 1(1) Notes FM2; learnt things about patients' thinking, 1.1.3 doc 2(1-2) F3A, doc 9(1) F12C; what dad said was a major revelation compared to his normal in-accessibility, 1.1.3 doc 3(1-3) F3B; a fuller picture of those she loves and trusts 1.1.3 doc 6(1) F11F; insight into parents relationship, 1.1.1 doc 31(1) F6B, 1.2.2 doc 2(1)F3B; understanding prospective sister-in-law/brother in law, 1.1.3 doc 10(3-5) F1B, doc 13(1) F5H; saw different side of sister, 1.1.3 doc 16(3) F8A; some of daughters comments surprised, 1.1.3 doc 2(3-4)F3A, doc 19(1) P8; didn't know that worried them, 1.1.3 doc 20(1) P5; surprised he took time off to come, 1.1.3 doc 21(1) P9; more interested than thought, 1.2.1 doc 8(5) P5; admiration 1.3.1 doc 16(2)F8A;
1. cont		3. New understanding of the family unit	people listened to each other better than usual, 1.1.1 doc 19(2) F12B; confirmed things I sort of knew but which had not been verbalised 1.1.1 doc 20(2) F12C, 1.2.2 doc 1(1) F2B, doc 5(1) F11D; I was so intrigued/surprised – I really wanted to listen 1.1.1 doc 23(2) F1D, ; 1.1.3 doc 20(5) P5; caught between not wanting to hear and wanting to know what others thought 1.1.1 doc 29(3) F5I; I thought the rest of the family is the same as me and they aren't 1.1.1 doc 36(5) P5, 1.1.2 doc 28(1) P8; heard things that had happened that I didn't know about 1.1.3 doc 6(2)F11F, doc 16(2) F8A, doc 17(1) F9B, doc 20(3) P5, 1.1.2 doc 9(2) F11F, doc 22(3) F8A, , doc 17(1) F9B, 1.2.2 doc 3(1)F11B; we understand each other better, 1.1.3 doc 4(1) P3, doc 10(1) F1B, 1.2.1doc 8(5)P5; you talk about it in a more holistic way and get a better picture 1.1.3 doc 8(1-4) F12B; good to understand how others feel 1.1.1 doc 2(1) F2B.1.1.3 doc 10(1) F1B, doc 12(1) F5G, doc 14(1) F5I, doc 20(3) P5, 1.1.3doc 12(1)F5G, 1.2.4 doc 13(1)P5; good for all of us to think about these sorts of things, 1.1.1 doc 14(2) F11D, 1.1.3 doc 15(1), 6A, 1.2.2 doc 3(1) F11B; found place in the family, 1.2.2 doc 8(1-2) F1D; cared more 1.1.3 doc 20(2) P5.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
2. Personal outcomes for the speaker	a) Freedom to speak	1. I said things I would never have otherwise said	Provided an arena to speak that would not have been available otherwise 1.2.1 doc 2(2) F3B; 1.1.1 doc 18(1) F12A, 1.3.1 doc 2(4) 2B, 1.3.4.3 doc 13(1) F8B, doc 17(1) F12A; I would not have said those things any other way as it would have seemed too manufactured, 1.2.1 doc 2(1) F3B; brings out lots of things people don't think to say normally 1.1.1 doc 22(3) F1B, doc 26(1-2) F5E, doc 27(5-6) F5G, doc 34(1) P12, 1.1.2 21(1) F6A; . Said things I've wanted to say but hadn't– now if she dies I know I said them.1.2.1 doc 1(2) F4A, Asked some awkward things I wanted to ask but couldn't before.1.1.1 doc 26(1-2) F5E;
		2.. Free in future to speak about important things	Would definitely broach these subjects with some family members now but not others, 1.2.1 doc 3(2-4) F5F, doc 5(1), doc 6(1-2) 5E, 1.1.2 doc 19(2) F5G;; feel free now to raise sensitive stuff with brother and with patient 1.2.1 doc 6(4-6) F5E; know that I can discuss these things without hurting people's feelings 1.2.1 doc 7(1) F5G; it will be easier to talk to them about it now, 1.2.1 doc 6(7-8) F5E, doc 8(1-2) P5, doc 8(4-5) P5, 1.1.1 doc 27(3) F5G, 1.3.4.3 doc 13(1) F8B; reassured – no longer have to be in the dark, 1.1.1 doc 25(1) F5B;
	b) Personal changes	1. Specific individual changes	Useful for getting me re-orientated to Father in heaven 1.2.6 doc 1(1) P3; focus on a greater power goes out of our lives in busy times but especially helpful at these times 1.2.6 doc 2(1) P6. Had had no contact with family for many years but meeting prompted re –connection with a grandchild. 1.2.6 doc 6(1) P4. Changes in dealing with child about death and funerals 1.2.1 doc 9(1) F5E.
		2. None/hard to know	Didn't effect me a great deal one way or the other, 1.2.5 doc 3(1) F12C; I don't think it will make any changes for me. 1.2.5doc 5(1-2) P1.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
2. cont	c) Making a contribution	1. Help research/ researcher	Grateful for the opportunity to be involved in research, 1.1.6 doc 2(1) F4A, doc 7(2) F11G, doc 9(2) F12B; insisted on going through with the interview although he had become very tired & weak 1.1.6 doc 15(1) FM12 Notes; useful research exercise, 1.1.3 doc 7(1-2) F11G; liked the researcher so willing to help 1.1.6 doc 6(3) P6, doc 7(2), doc 8(1) F12A.
		2. Help other families	Having the thought that your traumatic time can some how make things easier or better for some other family 1.1.6 doc 1(1-2) F2B, doc 8(1), doc 14(1-2) FM11 Notes , doc 16(1-2) FM5 Notes, doc 17(1) FM9 Notes, doc 18(1) P11, doc 19(1,3) P5, doc 20(1) P4, doc 6(1-2) P6; very keen to do something for others and to understand how this research might result in that 1.1.6 doc 3(1) FM5 Notes, doc 4(1) F3B,; if you can help one person you have done something worthwhile, 1.1.6 doc 11(1-2) F5A; willing to help even though unsure of purpose 1.1.6 doc 17(1) FM9 Notes.
		3. Help self or own family	To make this experience of death better for the family than the others by getting them to talk about it, 1.1.6 doc 5(1) F5F, doc 19(2) P5, 1.1.2 doc 29(1)P5; . Parents really wanted to do it so did it for them, 1.1.6 doc 9(1) F12B, doc 10(1) F12C, want to do what we can for patient1.1.6 doc 7(1) F11G, doc 12(1) F5G,; makes me feel useful, 1.1.6 doc 11(1-2) F5A,doc 13(1-2) F5I, doc 19(3) P5; just wanted him to get his story across, 1.1.2 doc 16(4) F5A.;

Key to Referencing:
1.1.6 - this refers to the coding report number from level 2 analysis

doc 7 - this refers to the number of the document within the coding report (note the coding report also shows original transcript from which the coding was made
(1) - indicates the passage from the relevant document which is being referred to i.e sometimes more than one passage from the same document is contained in the coding report.
F5A etc. – code identifying transcript
FM12 Notes – Researchers notes of family meeting 12
Int. Notes F7A – Interviewers notes for interview F7A

Appendix IX(2): Data Analysis Table – Theme 2

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
3. The speakers observations of other individual's experience	a) The speakers' observations of the patient's experience of the family meeting	1) Openness	More open than expected, 1.1.1 doc 4(3) F3A, 1.3.1 doc 6(1) F3B, doc 7(2)F1C; chance for patient to raise issue that speaker could not broach with him, 1.3.1 doc 5(1)F3A; relaxed atmosphere allowed verbalisation of feelings 1.3.1 doc 7(1) F1C; usual super positive view & did not tell all, 1.3.1 doc 12(1) F11E; good for him to talk, 1.3.1 doc 19(2) F5G; openness was for our benefit, 1.3.4.3 doc 9(2) F5F;. Not as open as would have liked, 1.1.1doc 5(4) F3
		2) Feelings	Made it less painful for her, 1.3.1 doc 1(2) F2A; grandkids there brightened her up 1.3.1 doc 1(3) F2A, doc 2(6) F2B, doc 10(2-3) F2C, doc 4(1)FM2 Notes sad 1.3.2 doc 10 F5A; appreciated it, 1.3.1doc 11(1) F8B; feeling supported, reassured & together, 1.1.1doc 25(1-2)F5B, 1.3.4.3 doc 15(1)F11E, 1.3.1 doc 12(2) F11E, doc 13(1) F11F, doc 20(2) F5H; made him feel more at ease, 1.3.1 doc 19(1) F5G; very happy, 1.3.1 doc 6(2)F3B, doc 25(2-3) F7 Int. notes,1.3.2 doc 1(1)F2A; teary 1.3.1 doc 6(3) F3B, 1.3.2 doc 2(1-2) F4A; touched 1.3.1 doc 3(1)FM5 notes
		3) New understandings	Nice for her to know how valued she is, 1.3.1doc 2(3) F2B; doc 24(1) F9C; 1.3.1doc 4(1) FM2. notes, doc10(2) F2C would have learnt new things about the rest of the family, 1.3.1doc 14(1) F1B; now knows we are behind him, 1.3.1doc 20(2) F5H; patient has been struggling with reality now understands more 1.3.1doc 23(1-2) F9B, 1.12.1doc 1(1) F2A; reminisce gave new perspective 1.3.1doc 25(1-3) FM7 notes; she can trust us more, 1.12.2doc 9(1) F11C.
		4) Other general comments	Some positives especially for patient, 1.3.1 doc 2(1) F2B; he thought it was good; real benefit to him 1.3.1 doc 16(1,3)F5A, doc 18(1) F5E, doc 20(1) F5H; got what he wanted out of it 1.3.1 doc 21(1) F5I; patient coped well, 1.3.1 doc 9(1) F11B, doc 16(2) F5A, doc 22(1) F6A; suggestion that tears means it made it harder for patient, 1.3.2 doc 2(1-2) F4A, doc 6(1) F5B, doc 8(1) Int. NotesF7A; uncertain if good for patient (makes it clear that is a reflection of how he might feel in the circumstances rather than any evidence that it was so for the patient), 1.3.2 doc 3(1-2) F5F, doc 5(1) F11F, doc 7(1)F9B; wanted to help us 1.3.4 doc 4(2)F5F,

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
3. cont	b) The speakers' observation of the experience of family members other than the patient, of the family meeting	1) Openness	People generally said what they thought 1.1.1 doc 4(2) F3A, doc 28(1) F5H; raw spot hard to be open, 1.3.4 doc 7(2-3) F1B; she has a few regrets about her degree of openness, 1.3.4 doc 13(1) P11; not as talkative as usual/ as hoped, 1.3.4 doc 14(2) P5, doc 14(2) P5, 1.1.3 doc 20(4) P5; conservative but loosened up as we went, 1.3.4 doc 14(3) P5, 1.3.4.3 doc 23 F5B; good for someone not very open, 1.3.4.3 doc 26(2) F5H; so much courage to be open, 1.3.4.3 doc 32(2) P1; very valuable for her, 1.3.4.3 doc 5(3) F3B; as open as they could be, 1.3.4.3 doc 35(1) P8;
		2) Feelings	They cried – unresolved grief of past losses, 1.3.1 doc 16(4) F5A; a bit upset but ok, 1.3.4. doc 2(1) F3A; uncomfortable, 1.3.4 doc 7(4) F1B, doc 11(1-2) F5I; comfortable 1.3.4.3 doc 7(1) F11A, doc 21(1) F1D, doc 25(2) F5G, doc 32(2) P1, 1.1.3 doc19(2) P8; embarrassed, 1.3.4 doc 3(1) F11A; coffins –surprise1.3.4 doc 3(2) F11A; emotional, 1.3.4 doc 6(1) F11F, doc 7(1) F1B, doc 14(1,4) P5, 1.3.4.3 doc 20(1) F1B; painful, 1.3.4 doc 7(5) F1B; slow to warm up 1.3.4 doc 8(1) F11A, 1.3.4.3 doc 23(2) F5B; looked stressed 1.3.4 doc 10(2) F5H; scary for her, 1.3.4 doc 11(1) F5I; very sensitive & senses others feelings 1.3.4 doc 14(4) P5; touched 1.3.4.3 doc 5(3) F3B; glad to have opportunity 1.3.4.3 doc6(3) P3; supported- knows I feel the same 1.3.4.3 doc 13(2) F8B, doc 15(2,5) F11E; confirmed closeness 1.3.4.3 doc 15(2) F11E; their relationship to patient was honoured by confidence 1.3.4.3 doc 15(4) F11E; they calmed down; good they brought their feelings out. 1.3.4.3 doc 36(1) P5; focused on what made them happy 1.3.4.3 doc 2(1)FM7 Notes.
		3) New understanding	facing reality, 1.3.4.3 doc 7(2) F11A, doc26(3) F5H, 1.12.1 doc 1(1) F3A; about patients views on next life 1.3.4.3 doc 5(3) F3B; they understand me better 1.3.4.3 doc 6(1-3) P3, doc 8(1) F1C, doc 13(2) F8B; knows now she is not alone,1.3.4.3 doc 13(2)F8B; now the time to patch up differences 1.3.4.3 doc 14(2) F11C; saw a new way of coping with disease compared to her past experience, 1.3.4.3 doc 16(1) F11F; learnt a lot 1.3.4.3 doc 33(2) P11; of parents relationship 1.1.1 doc 31(1)F6B; of state of patient 1.3.4 doc 5(1) F2C, doc6(1-2) F11F

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
3. cont		4) Other general comments	They thought went very well 1.3.1 doc 6(2) F3A; definite benefit 1.3.1 doc 17(1)n F5B, 1.3.4.3 doc 19(1) F12C, doc 26(1-2)F5H, doc 33(1)P11, doc 34(1)P12; hard/looked as though he didn't like it 1.3.4 doc 7(4) F1B, doc 9(1) F5A, doc 10(1) F5H; don't think he saw much point 1.3.4 doc 12(1-2) Int.NotesF9C; positive experience 1.3.4.3 doc 4(1) F3A, doc 15(2-5) F11E, doc 19(1) F12C, doc 23(1) F5B, doc 28(2) F6A; got more out of it than expected 1.3.4.3 doc 14(1) F11C; initially sceptical but found it good, 1.3.4.3 doc 34(1) P12.
12. Speakers observations of family unit experience & outcomes	a) Impact speaking together in future	1)Reminded of/taught the value of speaking about these things as a family	Painful but also showed it's better to talk about it than not to 1.3.4 doc 1(1) FM5 Notes, 1.3.4.3 doc 24(1) F5E; would have helped if we could have done this for previous deaths 1.1.5 doc 23(1) F5H; it is surprising what is revealed in these discussions 1.12.2 doc 3(4) P3; being informed takes the guess work out 1.12.3 doc (6) F5G; more said than ever before – even one on one 1.1.1 doc 31(1) F6B; must consider having a meeting with the rest of the family 1.12.1 doc 3(2)P3; reinforced value of talking together,1.12.1 doc 5(1) P6, doc 10(1) F1A, doc 11(1) F1B, doc 15(1) P8, 1.2.6 doc 5(1) P8; so grateful we can talk 1.12.3 doc 2(1)P6.
		2) Broke the ice on speaking about these things together	The ease with which this topic was drawn out in the meeting broke the ice for further family discussion, 1.3.4.3 doc 17(1) F12A, 1.12.1 doc 7(1-2) F8B, doc 8(1) F11C; makes it easier for everyone 1.3.4.3 doc 25(1) F5G; opened up a lot of little things 1.3.4.3 doc 36(4) P5; hoping he will be more willing to talk now 1.12.1 doc 2(1) F3A; may be more to come 1.12.1 doc 3(1) P3; planned excursion an opportunity for more talk 1.12.1 doc 4(1-2) F5F; stimulated more things to say 1.12.1 doc 9(1) F12B, doc 12(1) F5I; allowed overcoming of fear of upsetting someone if we talk about it 1.12.2 doc 13(1) F12A; brought us closer to talking about this stuff in the future, 1.12.2 doc 8(2) F8B,doc 10(1) F11D,doc 21(1)P8, 1.2.1 doc 6(3) F5E; will still be able to talk about it after he dies 1.12.4 Doc 1(3) F5F; talking about it is not taboo now, 1.12.4 doc 3(2) F12B, 1.12.1 doc 12(2)F5I
		3) Sense of achievement	Those things would not have been said – we now have a great memory 1.3.1 doc 2(4) F2B, doc 24(1) F9C, 1.12.1 doc 13(2) F8A; good to have talked – we don't know how long she will last 1.1.1 doc 7(5) F11A; we needed to say those things before it is too late 1.12.1 doc 7(3) F8B, doc 12(2) F5I; cleared the air, 1.12.1 doc 13(1-2) F8A.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
12 cont		4) Things won't change	Things wont' change – we are informed on a need to know basis 1.12.5 doc 3(2) F11F; certain things were unsaid which was disappointing 1.1.1 doc 5(2-3) F3B.
	b) Impact on relationships in the family	1) Strengthened family bonding	Brought everyone together- a bonding situation 1.12.2 doc 1(1-3) F2A, doc 3(3) P3, doc 10(2) F11D, doc 11(2) F11E, 1.2.1 doc 4(1) F11E; sense of togetherness through connection to patient 1.12.2 doc 12(1) F11F, 1.2.1 doc 6(3)F5E; We are starting a tradition where we make sure we pull together 1.12.2 doc 1(4-5) F2A;at least a short term togetherness – longer term? 1.12.2 doc 18(1) F9C,; an important step for the group 1.12.2 doc 21(1) P8, 1.1.2 doc 4(1) P6; opportunities to be together down the line 1.12.2 doc 8(1) F8B. supporting each other, 1.3.4.3 doc 27(1) F5I; good family networking 1.3.2 doc 3(2) F5F;
		2) Initiated new ways of being together	sisters meeting in ways they hadn't before1.12.1 doc 6(1) F2C, 1.12.2 doc 7(1) F2C, doc 14(2-3) F12B; raises question who will hold it together in future 1.12.2 doc 10(3) F11D; hopefully lead to full repair of relationship with sister 1.12.2 doc 10(4) F11D; cemented one member's position in the family 1.12.2 doc 4(1-2) F1C, doc 15(1) F1A, doc 19(2-3) P1; wonderful change now she is part of it, 1.12.2 doc 19(3) P1; girls now have a common theme to get together about 1.12.2 doc 8(1) F8B, doc 21(2) P8; sons got together with mother to discuss jewellery 1.12.5 doc 5(1) F9B; a family excursion 1.12.1 doc 4(2) F5F; We'll have a meeting once a month 1.2.6 Doc5(1)P8
		3) Created new awareness and understanding	We have more understanding & awareness of each other 1.12.2 doc 3(2) P3, doc 14(1) F12B; less likely to tread on toes in ignorance 1.12.2 doc 14(3) F12B; clarified the nature of a relationship 1.12.2 doc 17(1) F6B; more focus on supporting others while getting through it yourself 1.3.4.3 doc 27(1) F5I;
	c) Impact on feelings	1) more comfortable with each other	All found it comforting 1.3.4.3 doc 12(3) F2C; comfortable with each other 1.3.4.3 doc 21(1)F1D, doc 36(5) P5. 1.12.3 doc 4(2) F12B, feel supported/family behind me 1.12.2 doc 1(2) F2A; knowing there is someone there who is going through it too 1.12.2 doc 11(1) F11E;
		2) overall better	Focusing on the things that make them happy, 1.3.4.3 doc 2(1) FM7 ; made us all feel better – don't know how but it did 1.12.3 doc 3(1) F12A. done it while we still can 1.1.1 doc 7(1,5)F11A

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
	d) Impact on grieving process	1) May make it Easier	Those not present may find it more difficult to face up to what is going to happen 1.12.3 doc 1(1) P3; mental part post death will be easier 1.12.4 doc 1(1) F5F; grieving process generally easier 1.12.4 doc1(2) F5F, doc 3(1-2) F12B, 1.12.3 doc 2(1) P6; always sad but I think it will be easier 1.12.4 doc 4(1) F5G; might shorten the process a bit 1.12.4 doc 5(1) F5I;
		2) May have a different focus	Part of the grieving has happened – we'll be able to get on sooner with celebrating his life instead of having regrets 1.12.4 doc 1(3) F5F; being able to talk and touch now makes it so much better afterwards than not doing that 1.12.4 doc 2(1) P6.
	Family summarising comments	1.Family 1	Was as expected, 1.1.5 doc 17(1) F1A, very beneficial, 1.1.5 doc 18(1) F1B; excellent, never experienced anything like it. 1.1.5 doc 19(1-2) F1D
		2.Family 2	Quite nice, went pretty well positives for everyone 1.3.4.3 doc 1(1)F2B comforting 1.3.4.3 doc 12(3)F2C all benefited 1.12.5 doc 1(1) F2B, 1.3.4.3 doc 1(1) F2B 1.1.5 doc 1(2) F2A, doc 9(1) F2C. great being together 1.2.4 doc 1(6) F2A
		3. Family 3	Good, beneficial, given the people it went very well. More for us than we for you, 1.1.5 doc 28(1) F3A worthwhile 1.1.1doc 5(5)F3B, 1.1.5 doc 39(1) F3A positive 1.3.4.3doc 4(1)F3A 1.1.5 doc 3(1-2) F3A, doc 4(1-2) F3B, doc 5(1-2) P3, ,
		4. Family 4	Good experience 1.1.5 doc 37(1-2) P4.
		5.Family 5	Went very well, always good for families to get together, really good 1.1.5 doc 25(1-2) F5G, 1.1.4 doc 5(1) F5F idea, makes it easier for everyone, wishes we had had it before, 1.1.5 doc 23(1) F5H will tell the doctors how good it was, 1.1.5 doc 31(1) P5great that they actually came, recommend to anyone,1.1.5 doc 36(5)P5 all opened up more 1.3.4.3 doc 36(4)P5 all more relaxed 1.3.4.3 doc 36(5)P5; benefit but unclear what 1.1.5 doc 24 (1) F5I, doc 7(1-5) F5F, doc 20(1-6) F5A, doc 21 (1-3) F5B, doc 24(1) F5I, great doc 36(1-4) P5. Definite benefit 1.3.1.17(1) F5B, doc 22(1) F5A, 1.1.5 doc 23(2) F5H; helped everyone 1.3.4.3 doc 22(1) F5A good idea 1.1.5 doc 21(1-3) F5B
		6.Family 6	Very beneficial, 1.1.5 doc 25(1) F6B to all 1.3.1 doc 22(1)F6A, 1.3.4.3 doc 10(1) P6, doc 28(1) F6A, 1.2.4 doc 11(1) F6A

		7. Family 7	Quite good, in retrospect good chance to talk about the family 1.1.5 doc 32(1-2) F7A; doc 32(3-4) P7
		8. Family 8	Good, , all out there; very good , 1.1.5 doc 35(1) P8. 1.1.5 doc 10(1) F8B, 1.1.5 all right doc 26(1) F8A,
		9.Family 9	informality suited them well 1.1.5 doc 37(1-2) P9 minimal information 1.1.5 doc 27(1)
		10.Family 10	Definitely helpful, 1.1.5 doc 11(1) F10A, doc 33(1) P10.
		11. Family 11	Good 1.1.5 doc 34(2) P11, doc 6(1) F11A, doc 8(1-3) F11B; 1.12.5 doc 2(1) F11E; went very well, 1.1.5 doc 34(1) P11very positive concept, we need more of this, 1.1.5 doc 29(1-2) F11E all benefited 1.1.2 doc 5(6) F11B; very good 1.1.5 doc 12(1)F11D,. 1.1.1doc 7(1)F11A,
		12. Family12	Excellent, 1.1.5 doc 14(1) F12A really good, doc 15(1-2) F12B not a huge impact but good, certainly worthwhile, gained a lot 1.1.5 doc 16(1-2) F12C, absolutely beneficial 1.12.3 doc 4(1) F12B, I have to say thank you – we are so fortunate you chose us 1.12.5 doc 4(1) F12A. enjoyed it 1.1.5 doc 15(3) F12B

Key to Referencing:

1.1.6 - this refers to the coding report number from level 2 analysis

doc 7 - this refers to the number of the document within the coding report (note the coding report also shows original transcript from which the coding was made

(1) - indicates the passage from the relevant document which is being referred to i.e sometimes more than one passage from the same document is contained in the coding report.

F5A etc. – code identifying transcript

Int.NotesF3 – quote from interviewers notes for interviews family three

Appendix IX(3): Data Analysis Table – Theme 3

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
4. Meeting Facilitation	a) Speaker's experience of the meeting facilitation	1) How the speaker felt about their experience of the meeting facilitation	Very good/ very well facilitated/great/fine/quite good 1.4.1 doc 2(1)F3B, doc 3(1-2)F1C, doc 4(2)P6, doc 6(1)F10A, doc 7(1)F12A, doc 8(1)F1B, doc 10(1-2)F5A, doc 11(2)F5E, doc 13(1)P8, 1.4.3 Doc 5(1)F1C, doc 9(2)F12A, doc 11(1)F1D, doc 12(1)F5A; Very easy to talk/informal/comfortable/relaxed/gentle/not pressured/calmer- 1.4.1 doc 7(1)F12A, 1.4.2 doc 4(1)F12A, doc 5(1)F8B; 1.4.3 doc 5(1)F1C, doc 6(1-4)P6, doc 9(2-3)F12A, doc 11(1)F1D, 1.3.4.3 doc 22(2)F5A; frustrated person 'X' needed gagging- 1.4.3 doc 14(1)F5G; found some silences long- 1.4.3 doc 16(1)P8;
		2) Comment on specific techniques or parts of the meeting	Open prompts encouraged discussion on wide range of issues, 1.4.1 doc 5(1)F8B, 1.4.3 doc 12(1)F5A.; very easy approach to us, doc 1.4.1 doc 7(1)F12A; problem areas very tactfully handled 1.4.1 doc 11(1-2)F5E; excellent/nice ending to meeting, 1.4.3. doc1 (1-2)F2A, doc 2(1)F2B; gave reassurance by being willing to listen to individual's concerns before the meeting, 1.4.3 doc 4(1)F3B; allowed patient to set the scene first – rest of the family felt this gave them direction for the meeting, 1.4.3 doc 7(2)F8B; giving everyone a chance to speak with minimal interruptions, 1.4.3 doc 11(2)F1D;
	b) Identified qualities needed for facilitation	1) General qualities	Ability to draw people out & get them talking, 1.4.4 doc 2(1)FM7 Notes, 1.4.2 doc 5(2)F1B, 1.4.3 doc 5(1)F1C, doc 11(1)F1D; manner/demeanour/approach that attracts 1.3.4.3 doc 22(2)F5A, 1.4.1 doc 7(1)F12A, 1.4.3 doc 6(2)P6, doc 9(2&4)F12A; ability to make people feel comfortable/relaxed, 1.4.2 doc 4(1)F12A, doc 6(1)F1D, 1.4.1 doc 6(1)F10A, 1.4.3 doc 6(1)P6, doc 11(1)F1D; perceptive, 1.4.2 doc 5(2)F1B, 1.4.3 doc 10(1)F1B; ability to gain trust quickly, 1.4.2 doc 8(1)Int. Notes F2, tact, 1.4.1 doc 11(1)F5E.
		2) Qualities for handling problems	Being sensitive to touchy issues, 1.4.3 doc 9(1)F12A, 1.4.1 doc 11(2)F5E, 1.4.2 doc 7(1)F6B; Being adaptable to 'different' families 1.4.4 doc 7(1)FM7 Notes; dealing with people who interrupt/dominate others, 1.4.3 doc 11(2)F1D,doc 13(2)F5E, 1.4.4 doc 3(1)FM5 Notes, 1.4.3 doc 14(1) F5G.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
5/6. How could it have been different		3) The value of the 'outsider"	Easier with 'outsider' facilitator, 1.4.2 doc 2(1) F1C, doc 3(1)F5F; is more objective 1.4.2 doc 5(1)F1B, doc6(2)F1D, doc 7(1)F6B; Easier but must feel comfortable 1.4.2 doc 6(1)F1D.
	a) Who was present	1) numbers of people present	right number for patient & carer, 1.6.1 doc 1(1)F3A, doc 2(1-2)F3B; not sure about opening it to whole family, 1.6.1 doc 5(1)F10A; Preferred just her & the patient 1.6.2 doc 1(1-2)F2B; less – no more than 5 or 6, 1.6.2 doc 2(1-2)F5B.
		2 other family members they would have wanted	Good to have rest of family (? They fit in) 1.6.1 doc 3(1)P3; whole family 1.6.1 doc 4(1)F5F; the missing estranged group 1.6.1 doc 4(2-3)F5F, doc 8(1)F5A; rest of patient's children & their families, 1.61. doc 6(1)F11E, doc 7(1)F1A; my sister would have been interested 1.11.3doc 6(1)P1; could be of benefit to extended family, 1.11.3 doc 6(2)P1;
		3) children present?	Not for children, 1.6.3 doc 1(1)F2B, doc 4(1-2)P4; ? at meeting but they should certainly be included in conversations about what is happening. They have to come to terms with it too 1.6.3 doc 2(1-2)F12A; teenagers but not younger ones 1.6.3 doc 3(1)P8; useful to include children at meeting 1.5.4 doc 1(1)P3, 1.1.5 doc 1(1)F2A.
	b) More family meetings	1) yes	Value in another, 1.5.4 doc 1(2)P3, 1.5.2 doc 4(2)F1C, doc 7(2)F1B, 1.5.1 doc 2(1)F3A, doc 3(1)P3, doc 6(1)F1A, doc 7(1-2)F1D, doc 10(1)F5G, doc15(3)P5; would be more relaxed/more open 1.5.4 doc 2(1)F11G, doc 3(1)F12B, 1.5.1 doc 8(1)F5A, doc 9(2-3)F5E, doc 11(1)F5I, doc 15(2)P5; better- would know what to expect, 1.5.4 doc 4(1)F5I, doc 6(1)P8; spaced out meetings, 1.5.4 doc 6(1)P8, 1.5.1 doc 1(1)Int. NotesF1,doc 6(3)F1A, doc 12(1)Int. Notes F3, doc 15(4)P5; useful if don't communicate well, 1.5.4 doc 5(1)F8A; provide a cushion for the family as they go through it, 1.5.4 doc 4(2)F5I; follow up would be helpful, important 1.2.5 doc 1(1)Int. NotesF4A, 1.5.1 doc 4(1)F5F, doc 5(1)F12C, doc 13(1)P10, doc 14(1)P8; still much unfinished business 1.4.1 doc 6(1)F10A; follow up is lacking, 1.1.4 doc 15(1)Int. NotesF12, 1.2.1 doc 8(2)P5; probably 1.5.2 doc 1(1) F2B; as long it covered new areas/current stuff & not a repeat 1.5.2 doc 2(1)F4A, doc 4(1)F1C.
		2) doubtful/no	No a one off/ family wouldn't be prepared to go into more things 1.5.3 doc 1(1-2) F3B; wouldn't want to but would do it for him 1.3.1 doc 18(1)F5E; maybe, 1.5.2 doc 6(1)F11D, doc 10(1)F8A,might be too stressful for patient, 1.5.2 doc 9(1)F5B.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
5/6 cont	c) Meeting timing	1) earlier/Later/Just Right	Would be good very soon after diagnosis, 1.1.5 doc 2(1) Int. Notes F4A; a little bit earlier 1.6.6 doc 1(1)F9C; for some earlier would be better, 1.6.6 doc 1(2-4)F9C. Perhaps later closer to death 1.6.6 doc 3(1)P5;
	d) Needs the meeting did not meet	1) general need to talk one on one	Speaking of things of concern other than the meeting 1.3.4.3 doc 30(1)Int. Notes FM1, doc 31(1)Int. Notes FM9; issues still unresolved, 1.3.4.3 doc 37(1)FM4 Notes, 1.2.1 doc 1(1)Int. Notes F4A; need for one on one talk with someone outside family, 1.4.5 doc 1(2)Int. Notes F2A, 1.3.4.3 doc 18(1)F12B.
		2) things couldn't/wouldn't say at meeting	Difficulties coping with changes in patient, 1.1.2 doc 7(2-3)F10A; own fears, 1.4.6 doc1(2)FM10 Notes, 1.4.5 doc 2(1)Int. Notes F3A; concerns about patient, 1.4.6 doc 1(3)FM10 Notes; concern for family member, 1.4.6 doc 2(1) Int. Notes P7, doc 3(1-2)FM8 Notes, 1.4.4 doc 6(1)FM5 Notes; expressing own grief 1.4.5 doc 1(1)Int. Notes F2A,
	e) Other aspects of the meeting	1) Hear more from others	(X) open more 1.6.4 doc 4(1)F9B, 1.6.5 doc 1(1-3)3B, doc 8(1-2)9B; (X) show more emotion/less military, 1.6.4 doc 2(1)F1C, doc 3(1)F1D; patient talk more about their illness, 1.6.5 doc 5(1)F5B.
		2) Include other topics	more talk about the future & how to deal with that 1.6.5 doc 3(1)F11E; info about wills & documents 1.6.5 doc 3(2)F11E; more religious discussion 1.6.5 doc 7(1)F6A.
		3) Place/style of the meeting	Was expecting a question & answer sheet 1.6.5doc 2(1)F1C; meeting in kitchen would have been more relaxed 1.6.5 doc 4(1)F12B; Some sub-meetings with smaller groups would have been good, 1.6.5 doc 5(2)F5B; would have preferred it to be more directed/controlled / seemed to lack specifics 1.1.4 doc 14(1-3)F9C, doc 18(1)P10, 1.6.5 doc 9(1)F9C; communication difficulties within the family created lack of clarity about who was invited 1.6.5 doc 9(2)F9C; follow up brochure advising people how to talk to their families 1.6.5 doc 10(1)P5.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
11. General Applicability of meeting	a) Who would benefit?	1) Everyone	Generally beneficial 1.11.3 doc 3(1)F11E, doc 1(1)Int. NotesF4A, 1.11.2 doc 14(1)F1D, 1.11.1 doc 15(1-2)F12B, doc 18(1-3)F5A, doc 19(1-4)F5B, doc 21(1-3)F5G, doc 22(1-2)F5I, doc 23(2)F6B, doc 26(1)P10, doc 29(1)P5; if they choose 1.11.2 doc 5(1)F5F, 1.11.1 doc 13(1)F11G;offer to everyone, 1.11.2 doc 10(2)F11G, 1.11.1 doc 13(3)F11G, doc 14(1)F12A; beneficial even if it is tense, 1.11.1 doc 5(1)F1C, doc 9(2-5)F10A, doc 12(2-3)F11F.
		2) special circumstances	Those who haven't experienced a family death 1.1.4 doc 11(1)F5H; those recently diagnosed 1.11.3 doc 1(1-3) Int. NotesF4A, 1.11.1 doc 30(1)Int. Notes P4; those who don't know much about what is going on, 1.11.3 doc 4(1)F5H; those who don't talk openly to each other 1.11.3 doc 6(3)P1, 1.11.1 doc 11(1-2) F11D, doc 16(2)F12C; would be particularly healing in families with major difficulties, 1.11.2 doc 2(1)F3B, doc 4(1)F1C.
		3) Not for all	not valuable for all, 1.11.2 doc 1(1)F3A, 1.11.1 doc 8(1)F2C, doc 25(1)P1; Some might find it comforting 1.11.3 doc 2(1)F2C; would need to draw up guidelines for application 1.11.3 doc 5(1)F9C; timing important, 1.11.2doc 3(1)P3, doc 17(1)Int. Notes F9C; some retreat inside themselves 1.11.2 doc 6(4)F11B, 1.11.1 doc 13(1)F11G; some scared, 1.11.2 doc 8(1-2)F10A, doc 11(1)F12A, 1.11.1 doc 9(1,6)F10A; some can't face it 1.11.2 doc 10(1)F11G, doc 13(1)F1A, doc 16(1)F6A, 1.11.1 doc 4(1)F11A, doc 27(1)P11, Could be hard for patient – respect wishes 1.11.2 doc 5(1)F5F, 1.11.1 doc 12(1)F11F, 1.11.2 doc 6(1-2)F11B; some too volatile 1.11.2 doc 15(1)F5B, doc 16(2)F6A; different cultural issues, 1.11.2 doc 18(1)P8.
	b) Promoting the meeting	1) General comments	Purpose of meeting needs to be clear, 1.11.2 doc 7(1) F8B; make it clear it is not religious 1.11.2 doc 9(1)F11C; "family meeting' not such a good name, 1.11.2 doc 12(1)F12B; simple clear information 1.11.2 doc 17(1)Int. Notes F9C, doc 18(1)P8; putting emphasis on coping, 1.11.2 doc 18(3)P8; promote as getting insight into family, 1.11.1doc 16(1)F12C.
		2) Specific means of promotion	Add offer to palliative care brochures, 1.11.1 doc 10(1) F11C; special brochures for this, 1.11.1 doc 28(1) P8. Care agencies, 1.11.1 doc 10(2)F11C; hospices & cancer centres 1.11.1 doc 14(2)F12A; the health system – benefit can't be measured, 1.11.1 doc 15(3)F12B; religious groups, 1.11.1 doc 23(1)F6B; telling patients & families personally as well as through brochures, 1.11.1 doc 28(1)P8.

Key to Referencing:

1.11.1 - this refers to the coding report number from level 2 analysis

doc 7 - this refers to the number of the document within the coding report (note the coding report also shows original transcript from which the coding was made

(1) - indicates the passage from the relevant document which is being referred to i.e sometimes more than one passage from the same document is contained in the coding report.

Int. NotesF4A – Interviewers notes for interview F4A

FM4 Notes – Researcher's notes for family meeting four

Appendix IX(4): Data Analysis Table – Theme 4

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
14. Recruiting	a) Family Type	1) Those they would not recruit	those in crisis 1.14.1 doc 2(1)S10 dysfunctional families 1.14.1 doc6(2)S14, doc7(3,5-6) S2 very sensitive families 1.14.1 doc4(2) S12, doc11(2) S6 don't know the family 1.14.1 doc4(3) S12 those I think are anti religious 1.14.1 doc10(2-3) S5 cognitively impaired 1.14.1 doc2(2) S10 where information is being withheld 1.14.1 doc10(5) S5 excessive emotions 1.14.1 doc 11(2) S6 some cultural groups 1.14.1 doc12(3) S8 those I think would be distressed 1.14.1 doc13(1) S9 those resistant to people's involvement 1.14.4 doc2(2) S13, doc7(2)S7
		2) Signs of suitability they looked for	Talkative 1.14.1 doc1(1-2) S1, doc3(1-2) S11, doc11(2) S6, doc12(1) S8; like stories 1.14.1 doc3(5) S11, doc 6(1) S14, doc11(2) S6, doc12(1) S8; perceived as willing 1.14.1 doc5(1-3,5) S13, doc12(2) S8, doc13(1) S9; some degree of cohesiveness 1.14.1 doc7(3-4) S2, doc12(1) S8; some dysfunction 1.14.1 doc2(2) S10, doc6(1) S14, doc12(1) S8, not dealing with illness 1.14.1 doc1(3) S1 adequate language 1.14.1 doc6(3) S14, abnormal situations 1.14.1 doc3(4,6) S11, doc7(1-2) S2 unresolved anger 1.14.1 doc10(4) S5 have significant others 1.14.1 doc4(1) S12 exploring 1.14.1 doc5(4) S13, doc9(2) S4 social/existential distress 1.14.1 doc8(3) S3, doc9(1) S4, doc10(1) S5 timing 1.14.1 doc11(3) S6, 1.14.4 doc6(1)S9
		3) How they decided who was suitable	Their experience of family communication levels 1.14.1 doc1(2) S1 gut feeling about interest 1.14.1 doc3(2-3) S11, doc11(2) S6, doc12(1) S8, 1.14.4 doc2(1)S13, after general checking 1.14.1 doc5(2) S13, doc8(1) S3 really need to ask 1.14.1 doc 3(3)S11, doc6(4-5) S14, doc13(2) S9 down the list once a week 1.14.4 doc 5(2) S4
	b) Impact of being a study	1) Easier if routine	General easier 1.14.2 doc5(2-3) S4, doc 8(1) S7 Patients more willing 1.14.2 doc2(1-3) S14, doc6(1-2) S6, didn't tell them it was a study 1.14.2 doc2(1) S14 study seems like an extra 1.14.2 doc7(1) S8, 1.14.4 doc5(1) S4, doc7(3) S7.
		2) Drawbacks of being a study	Possible infringement on patients 1.14.2 doc1(1) S1 lack of certainty of efficacy of intervention 1.14.2 doc3(1) S2, doc4(3) S3 limited time frame 1.14.2 doc3(2) S2, doc4(3) S3 no regular involvement in studies 1.14.2 doc4(1-3) S3, doc7(1) S8, 1.14.4 doc4(1)S3.
		3) Advantages study	Patients freer to say no 1.14.2 doc5(1) S4, patients sometimes more willing 1.14.2 doc4(3-4) S3.

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
	c) Level of Illness	none	Cognitive/concentration/memory 1.14.3 doc5(1) S4, 1.14.1 doc8(2) S3; very ill/unstable/close terminal 1.14.3 doc1(1-2) S1, doc3(1) S12, doc4(2) S13,doc6(1) S6, doc7(1) S9 need to be fairly well 1.14.3 doc4(1) S13.
	d) Other issues	none	Should have referred all meeting minimum requirements 1.14.4 doc1(1)S1 term spiritual is a problem 1.14.4 doc3(1)S14, doc 7(1)S7; protectiveness of patients in a fragmented system 1.14.4 doc7(2)S7 not part of medical model of care so don't think of it 1.14.4 doc4(2)S3
15. Staff Observations of Outcomes for Meeting Participants	a) Positive	none	General positive 1.15.1 doc1(1)S10, doc2(1) S11,doc3(1) S12, doc 4(1) S13, doc7(1-2) S3, doc8(1) S4, doc10(1) S8, doc11(1) S7 1.14.1 doc12(1) S8, should be for everyone 1.14.2 doc4(1) S3 less pain issues afterwards 1.15.1 doc5(1) S14, dealing with whole family good 1.15.1 doc6(1) S2, long term benefits interesting 1.15.1 doc8(2) S4, less anxiety and distress 1.15.1 doc8(3) S4 beneficial to family 1.15.1 doc9(1-2) S5 not as emotional as expected 1.15.1 doc9(3) S5
	b) Neutral/mixed outcomes	none	No negative feedback 1.15.2 doc1(1) S12, doc2(1) S2, doc3(1) S4, doc5(1)S6, doc6(1) S7; mixed messages 1.15.2 doc4(1)S5, doc5(2) S6
17. Inclusion in Regular Services	a) A Good Thing	1) General Positives	Powerful/essential/brilliant 1.17.3 doc2(1,3)S10, 1.17.7 doc 1(1)S1, doc 10(2) S5, doc 11(2) S6,doc 12(3) S8; good 1.17.7 doc 8(1) S3, doc 9(3) S4, doc 14(1)S7 valuable/useful/beneficial 1.17.7 doc2(1)S10, doc5(1,2)S13,doc6(1,2)S14, doc10(1,5)S5, doc12(1,4,6,7) S8, doc13(1-3)S9, 1.17.9 doc5(1)S4, 1.14.1 doc13(1)S9; will get attention 1.17.7 doc2(3)S10 I'd want it 1.17.7 doc5(3)S13
		2) There is a Need	Need to talk 1.17.4 doc3(1-2)S11, doc6(1-3)S6 1.17.7 doc3(1)S11,doc10(3-4)S5, doc11(1)S6 lack of counselling/spiritual support for families 1.17.7 doc1(1)S1, doc7(1-4)S2, doc11(3)S6 to know most effective ways with families 1.17.7 doc4(1)S12
	b) Practical Barriers	1) Funding	Availability and priorities 1.17.2 doc7(1)S4, 1.17.3 doc2(3)S10, 1.17.6 doc1(4)S1, doc5(1)S5, doc6(1-2)S9, doc7(1,2)S7, 1.17.9 doc1(1)S10, doc2(1-2)S13, doc3(1-2)S14, doc4(1)S3, Doc5(1)S4, doc6(1)S5, doc7(1-3)S6, doc8(1)S8
		2) Staff time/numbers	Time 1.17.1 doc2(1)S12, doc3(2)S13 Numbers 1.17.1 doc1(1-3)S1, doc7(1) S8, Doc8(2)S9, 1.17.2 doc3(4) S12
		3) Other barriers	Language 1.17.6 doc1(2)S1, doc2(1)S10 cultural issues 1.17.6 doc1(3)S1

Sub-theme	Category	Sub-Category	Ideas and Related Node Coding Report References
	c) Staff qualities	1) Those needed	Adaptability 1.17.2 doc1(1)S1, doc4(5)S13; aware of own spirituality 1.17.2 doc3(1-2) S12; build repour 1.17.2 doc4(3-4)S13, doc5(1)S14; specialist 1.17.2 doc1(2)S1, doc 2(1)S10, doc6(1)S3, doc7(1)S4; 1.17.3 doc2(3)S10; many currently ill equipped for this 1.17.1 doc2(1)S12, doc3(3)S13, doc5(1)S3, doc9(1)S7
		2) Generalist versus specialist	Task priority 1.17.1 doc3(1)S13, doc8(1,3-4)S9, immediacy 1.17.2 doc3(3)S12, too many faces 1.17.2 doc4(1)S13; ? protecting patch 1.17.2 doc4(1)S13, 1.17.6 doc3(1)S12; ?aware of needed skills 1.17.2 doc4(1)S13.
	d) Ideas for Incorporating into system	1) Promoting the meeting	Telling patients about it 1.17.4 doc1(3)S1, doc4(1)S14, doc5(1)S3 1.17.6 doc4(1)S14 make it the normal thing 1.17.3 doc5(1)S13, doc7(1)S3, doc8(1)S4, doc9(1,3)S9 voluntary 1.17.3 doc5(1)S13
		2) Participation	Who to offer it to 1.17.5 doc1(1)S1, doc2(1)S10, doc3(1)S13, doc4(1)S2, doc5(1)S9, 1.17.3 doc 2(4)S10, doc5(2)S13, 1.17.7 doc2(2)S10, doc5(3)S13 number and timing of meetings 1.17.4 doc1(1-2)S1, doc7(1)S8, doc8(1)S9, 1.17.1 doc4(1)S14, doc6(1)S6.
		3) Other	Impact different cultures 1.17.4 doc2(1)S10, doc3(2)S11, interpreters 1.17.3 doc2(1)S10; Coordinate with other services 1.17.3 doc1(1)S1, start with the hospice 1.17.3 doc3(1)S11, trial period 1.17.3 doc9(2)S9, staff training 1.17.3 doc4(1)S12.

Key to Referencing:

1.11.1 - this refers to the coding report number from level 2 analysis

doc 7 - this refers to the number of the document within the coding report (note the coding report also shows original transcript from which the coding was made

(1) - indicates the passage from the relevant document which is being referred to i.e sometimes more than one passage from the same document is contained in the coding report.

Int. NotesF4A – Interviewers notes for interview F4A

FM4 Notes – Researcher's notes for family meeting four

Appendix X – Frequency and Distribution of Comment

Appendix X(1) – Theme 1: Frequency and Distribution of Comment

Sub-theme/Category/ Sub-category	Number of coded sections	Families Represented (Of total 12)	Families with more than 1 speaker	No. Individuals Making more than one Comment
1(a)1.The speaker's view of topics covered	32	11	F3 – 3/3 F6 – 2/3 F10 – 2/2 F11 – 4/9	2
1(a)2. Perceived inhibitors to openness	13	6	F5 – 2/8 F11 – 4/9	1
1(a)3. The experience of being open	18	7	F1 - 2/5 F11 – 4/9 F12 – 2/4	2
1(a)4.The value of speaking in the group	17	3	F1 - 2/5 F5 – 5/8 F11 – 2/9	1
1(a)5. The experience of review	15	8	0	1
1(b)1. Perceived positive feelings	55	12	F1 – 4/5 F3 - 2/3 F5 - 4/8 F6 - 2/3 F11 - 3/9	11
1(b)2. Perceived negative feelings	40	9	F1 – 4/5 F5 - 5/8 F11 – 2/9 F12 - 2/4	8
1(b)3. Felt emotional	11	7	F1 - 3/5	0
1(b)4. Getting realistic	19	7	F2 - 2/4 F8 – 2/3 F12 - 3/4	4
1(c)1.New under-standing of self	14	6	F2 – 2/4 F5 – 3/8	1
1(c)2. New under-standing of other family member	23	9	F3 - 2/3 F5 – 2/9 F8 – 2/3	4

Sub-category	Number of coded sections	Families Represented (Of total 12)	Families with more than 1 speaker	No. Individuals Making more than one Comment
1(c)3. New under-standing of the family unit	37	9	F1 – 2/5 F5 – 3/8 F8 – 2/3 F11 – 3/9 F12 – 2/4	11
2(a)1. I said things I would never otherwise have said	16	8	F5 – 2/8 F12 – 2/4	3
2(a)2 Free in the future to speak about important things	20	2	F5 – 5/8	2
2(b)1. Specific individual changes	4	4	0	0
2(b)2. None/hard to know	3	2	0	1
2(c)1.Help research/ researcher	9	4	F12 – 2/4	1
2(c)2. Help other families	19	7	F5 – 2/8	0
2(c)3. Help self or their own family	13	3	F5 – 5/8 F12 – 2/4	1

Key

F3 – indicates family number 3

4/8 – indicates 4 of a possible 8 family members spoke

Appendix X(2) – Theme 2: Frequency and Distribution of Comment

Sub-theme/Category/ Sub-category	Number of coded sections	Families Represented (Of total 12)	Families with more than 1 speaker	Number Individuals Making more than one Comment
3(a)1. Openness	9	4	F3 – 2/3 F5 – 2/8	3
3(a)2. Feelings	23	7	F2 – 3/4 F5 - 4/8 F11 – 2/9	2
3(a)3. New understandings	17	7	F2 – 3/4 F9 – 2/4	0
3(a)4. Other general comments	15	7	F5 – 6/8 F11 -2/9	2
3(b)1. Openness	17	6	F1 – 2/5 F3 – 2/3 F5 – 3/8	2
3(b)2. Feelings	32	6	F1 – 3/5 F3 – 3/3 F5 – 7/8 F8 – 2/3 F11 – 3/9	4
3(b)3. New understandings	18	7	F3 – 3/3 F11 – 4/9	1
3(b)4. Other general comments	21	8	F5 – 3/8 F11 – 3/9 F12 – 2/3	5
12(a)1. Reminded of or taught the value of speaking as a group	12	6	F5 – 3/8	3
12(a)2. Broke the ice on speaking about these things	20	5	F3 – 2/3 F5 – 5/8 F8 – 2/3 F11 – 2/9 F12 – 2/4	5
12(a)3.Sense of achievement	8	5	F8 – 2/3	1
12(a)4.Things won't change	2	2	0	0
12(b)1. Strengthened family bonding	16	7	F5 – 3/8 F8 – 2/3 F11 – 3/9	2

Sub-theme/Category/ Sub-category	Number of coded sections	Families Represented (Of total 12)	Families with more than 1 speaker	Number Individuals Making more than one Comment
12(b)2. Initiated new ways of being together	18	7	F1 – 3/5 F8 – 2/3	4
12(b)3. Created new awareness and understanding	5	4	0	1
12(c)1.More comfortable with each other	6	6	0	0
12(c)2. Overall better	4	3	0	1
12(d)1. May make it easier	8	4	F5 – 3/8	1
12(d)2. May have a different focus	2	2	0	0
Family summarizing comments	Number of coded sections	Not Applicable	Number of Family Members Speaking	Number Individuals Making more than one Comment
Family 1	4	N/A	3/5	1
Family 2	7	N/A	3/3 interviewed	3
Family 3	10	N/A	3/3	2
Family 4	1	N/A	1/2	0
Family 5	27	N/A	7/8	7
Family 6	5	N/A	3/3	1
Family 7	4	N/A	2/2	2
Family 8	3	N/A	3/3	0
Family 9	1	N/A	1/4	0
Family 10	2	N/A	2/2	0
Family 11	12	N/A	5/9	4
Family 12	8	N/A	3/4	2

Appendix X(3) – Theme 3: Frequency and Distribution of Comment

Sub-theme/category/ Sub-category	Number of coded sections	Families Represented (Of total 12)	Families with more than 1 speaker	Number Individuals Making more than one Comment
4(a)1. How the speaker felt about their experience of the meeting facilitation	29	7	F1 – 3/5 F5 – 3/8 F8 – 3/3	5
4(a)2. Comment on specific techniques or parts of the meeting	11	6	F2 – 2/3 F5 – 2/8	3
4(b)1. General qualities	18	7	F1 – 3/5 F5 – 2/8	4
4(b)2. Qualities for handling problems	8	5	F5 – 3/8	1
4(b)3. The value of the 'outsider'	6	3	F1 – 3/5	1
5/6(a)1. Numbers of people present	8	4	F3 – 2/3	2
5/6(a)2. Other family members they would have wanted	9	4	F1 – 2/5 F5 – 2/8	2
5/6(a)3. Children present?	8	4	F2 – 2/3	2
5/6(b)1. Yes	37	9	F1 – 4/5 F3 – 2/3 F5 – 6/8 F8 – 2/3 F10 – 2/2 F12 – 2/4	6
5/6(b)2. Doubtful/no	4	4	0	0
5/6(c)1. Earlier/Later/just right	6	3	0	2
5/6(d)1. Need to talk 1 on 1 talking	7	3	0	1

Sub-theme/category/ Sub-category	Number of coded sections	Families Represented (Of total 12)	Families with more than 1 speaker	Number Individuals Making more than one Comment
5/6(d)2. thing couldn't/wouldn't say at the meeting	6	5	F4 – 2/2	1
5/6(e)1. Hear more from others	9	3	F1 – 2/5	2
5/6/(e)2. Include other topics	3	2	0	1
5/6(e)3. Place/style of the meeting	10	5	F5 – 2/8	1
11(a/b)1. Everyone	31	7	F1 – 2/5 F5 – 6/8 F10 – 2/2 F11 – 3/9 F12 – 2/4	7
11(a/b)2. Special circumstances	12	6	F1 – 2/5 F4 - 2/2	1
11(a/b)3. Not for all	27	10	F1 – 2/5 F3 – 2/3 F5 – 2/8 F11 – 5/9	6
11(c)1. General comments	7	4	F8 – 2/3 F12 – 2/4	1
11(c)2. Specific means of promotion	7	4	F12 – 2/4	2

Key

F3 – indicates family number 3

4/8 – indicates 4 of a possible 8 family members spoke

Appendix X(4) – Theme 4: Frequency and Distribution of Comment

Sub-theme/ Category/Sub-category	Number of coded sections	Staff Represented (Of total 14)	Number Staff Members making more than one Comment
14(a)1. Those they would not recruit	17	10	4
14(a)2. Signs of suitability they look for	36	13	10
14(a)3. How they come to conclusions about suitability	13	9	4
14(b)1. Easier if routine	12	5	4
14(b)2. Drawbacks of being in a study	10	4	2
14(b)3. Advantages of being a study	3	2	1
14(c)none	9	7	2
14(d)none	5	4	1
15(a)none	18	11	4
15(b)none	7	6	1
17(a)1 General Positives	27	11	6
17(a)2. There is a need	16	6	4
17(b)1. Funding	17	10	6
17(b)2. Staff time/numbers	8	5	2
17(b)3. Other barriers	3	2	1
17(c)1. Those needed	16	8	5
17(c) 2. Generalist versus specialist	9	4	3
17(d)1. Promoting it	10	6	3
17(d) 2. Participation	15	8	4
17(d)3. Other	7	5	2

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