

## APPENDIX I: SAMPLE INTERVIEW SCHEDULES

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### Interview schedule: patients - first interview

1. Description of events leading to the time of the interview, from onset of spinal cord compression symptoms.
2. What do you understand about what has happened to you? What have you been told about your illness?
3. What do you expect will be happening to you in the next few weeks ... months?
4. Tell me about how much you are able to do (for yourself / work / leisure / important activities) at the moment. Are there things that you cannot do as a result of the SCC?
5. I'm interested in the rehabilitation you have had – the contact you have had, for example, with OTs and physios – interventions that have helped you to manage your everyday activities... could you tell me a bit about that? How it was introduced to you? What did you feel you needed? What was your understanding of what rehabilitation was aiming to achieve? Were you ever asked what your goals / hopes were?
6. *Will by now have got a sense of perceptions of being disabled. Phrasing of question will depend on what's come up so far.* You talk about what it's like living with a disability. Can you tell me how that has changed things for you? (How do you feel about yourself / about life?).
7. In your experience of spinal cord compression, what are the things that have been important to you / that have helped you / have not helped?
8. Is there anything that I haven't asked about that you think is important, that you would like to tell me about?
9. SEIQoL-DW and issues arising.

### Interview schedule: patients - subsequent interviews

1. Follow-up on events.
2. Understanding of diagnosis and prognosis and information given. Expectations of treatment.
3. Symptoms – initially experienced and ongoing.
4. Impact of disability on daily life. What's been helpful; what hasn't helped. (Why? / Can you give me an example)
5. Rehabilitation received and understanding of it.
6. Picking up issues from previous interview – e.g. last time x and y were important, how has that been going?
7. SEIQoL-DW and issues arising.

## APPENDIX I: SAMPLE INTERVIEW SCHEDULES

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### Interview schedule: carers

1. Description of events leading to the time of the interview, from onset of spinal cord compression symptoms.
2. What do you understand about what has happened to [patient]? What have you been told about the illness?
3. What do you expect will be happening in the next few weeks ... months?
4. Limitations in significant activities. Are there things that [patient] cannot do as a result of the SCC?
5. I'm interested in the rehabilitation [patient] have had – the contact with OTs and physios ... could you tell me a bit about that? I'm interested in the rehabilitation [patient] has had – any contact, for example, with OTs and physios – interventions that have helped to manage everyday activities... could you tell me a bit about that? How it was introduced to you? What did you feel [patient] needed? What did you feel you needed? What was your understanding of what rehabilitation was aiming to achieve?
6. In your experience of [patient's] spinal cord compression, what are the things that have been important? that have helped? have not helped?
7. Is there anything that I haven't asked about that you think is important, that you would like to tell me about?

### Interview schedule: health care professionals - rehabilitation staff

1. Start with an account of what happened. How much information did you have about [patient's] diagnosis and prognosis?
2. Organisational issues – how is the service provided? How was [patient] referred? What for?
3. Do you feel there is a place for rehabilitation with somebody like [patient] – (life-limiting illness). If not – why not? If so – what would you perceive as being [patient's] rehabilitation needs? To what extent did you feel you were able to meet these?
4. What did you feel was important to [patient]? How did you gauge that? The literature also talks about goal-setting as important for patients. Were you able to get a sense of [patient's] goals?
5. Any issues that are specific to the particular patient. (For example: Celia expressed neither dissatisfaction or satisfaction. I wonder how you would account for her apparent neutrality?)
6. Partnerships: literature describes importance. Is the idea of a 'professional-patient partnership' one which you think is important? How do you think that worked in [patient's] case?
7. Are there things about the case that you are particularly satisfied with? Are there things that you think might have happened and didn't? What would the effect have been? Is there anything you might have done differently?
8. Was [patient's] case typical of other patients with spinal cord compression that you have worked with?

## APPENDIX I: SAMPLE INTERVIEW SCHEDULES

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### Interview schedule: health care professionals - FEU nurses

1. Can you tell me how long you've been working on Frank Ellis / prior experience of working with cancer / SCC patients.
2. I'd like to ask about your experiences of looking after patients with SCC. How would you describe these patients as a group? (looking for – no different to others / difficult / diverse...).
3. In your opinion, what are the main problems that these patients experience? (Is continence mentioned? – if not, then raise later). What are the main issues for the nursing staff in caring for this group of patients?
4. If I was to ask you about the rehabilitation available to these patients on the ward, what would you understand by the term 'rehabilitation'?
5. What rehabilitation is available to SCC patients on the ward? (referrals and communication in the MDT. Where do the nurses get their information on future medical plans / prognosis from?)
6. What kinds of arrangements could / would be made for someone who was discharged home, who was going to have to cope with some level of disability (like having to use a walking frame or a wheelchair)?
7. Some of the patients I have interviewed have commented that they would like clearer information, for example, about their medical condition, about what they can expect when they are discharged, and about services available in the community. What are your thoughts about the information that's given to patients while they're on the ward?
8. Could you give me an example of a patient or an incident where things have gone well on the ward caring for someone with SCC? And contrast that with an example of a time when things could have been a little better?
9. Is there anything I have not asked that you would like to comment on?

### Interview schedule: health care professionals - consultants

1. Brief synopsis of what the results are showing. Checking this out.
2. The study that I'm doing is concerned with rehabilitation. Can I ask you what you would understand by the concept of rehabilitation?
3. Would you see this group of patients as having rehabilitation needs? What would these be?
4. Do you have an opinion on whether patients' rehab needs are being met? Or how we could do it better?
5. Issues specific to patient in question (e.g. Gill and stairlift: comments; the emphasis on 'getting out' – why? Is it justified?)
6. The way that communication works: no communication between doctors and rehab staff. Could you comment? Rehab staff joining ward rounds?
7. Continence – could it be managed better?
8. What kinds of arrangements could / would be made for someone who was discharged and might need future rehabilitation?

## APPENDIX I: SAMPLE INTERVIEW SCHEDULES

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### **Interview schedule: health care professionals - managers and specialists**

1. Brief synopsis of what the results are showing. Checking this out.
2. The study that I'm doing is concerned with rehabilitation. Can I ask you what you would understand by the concept of rehabilitation?
3. Would you see this group of patients as having rehabilitation needs? What would these be?
4. Do you have an opinion on whether patients' rehab needs are being met? Or how we could do it better?
5. Organisational constraints in providing rehabilitation. Checking out staff understandings of what's possible / not possible (e.g. occupational therapists' belief that they may only see patients destined for home).
6. Issues specific to a particular patient, if relevant.

## APPENDIX II: AUDIT DATA SHEET

### FRANK ELLIS UNIT MALIGNANT SPINAL CORD COMPRESSION REHABILITATION AUDIT DATA SHEET

Hospital No		Level of lesion	
Age		Treatment	
Sex		Died as i-p?	
Consultant		Alive 1/12	
Admitted from		Alive 3/12	
Admitted on		Alive 6/12	
Discharged on		Mobility - adm	
Discharged to		Mobility - disch	
Length of stay		Mobility 6/12	
Diagnosis			

Functional problems identified during admission

Referrals made for rehabilitation during admission

Rehabilitation intervention during admission

Rehabilitation follow-up

Care package


## APPENDIX III: RESEARCH ADVISORY GROUP

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The research study was supported by an advisory group that included patients, a carer, rehabilitation staff, Frank Ellis Unit nursing staff, medical staff, experienced researchers and academic staff. The group met twice yearly between January 2003 and December 2005 at approximately six-monthly intervals. Each meeting had a specific agenda and formal minutes were taken.

Jo Atkinson	<i>Lecturer in Occupational Therapy York St John College</i>
Professor David Foxcroft	<i>Director Of Research, School of Health Care Oxford Brookes University</i>
Ros Frost	<i>Carer</i>
Wendy Harris-Bailey	<i>Staff Nurse, Frank Ellis Unit Churchill Hospital, Oxford</i>
Val Howard	<i>Patient</i>
Dr Mary Miller	<i>Consultant in Palliative Medicine Sir Michael Sobell House, Oxford</i>
John Paley	<i>Senior Lecturer, Department of Nursing and Midwifery, University of Stirling</i>
Dr Marilyn Relf	<i>Head of Education, Sir Michael Sobell House, Oxford</i>
Dr Clare Taylor	<i>Principal Lecturer in Occupational Therapy, Coventry University</i>
Andy Ward	<i>Writer and former patient</i>
Dr Bee Wee	<i>Academic Director and Consultant in Palliative Medicine, Sir Michael Sobell House; and Senior Lecturer in Palliative Medicine, Oxford University</i>

## THE REHABILITATION NEEDS OF PATIENTS WITH MALIGNANT SPINAL CORD COMPRESSION

Researcher: Gail Eva

### RECRUITMENT PROTOCOL

Information for health care professionals

The following patients are eligible for inclusion in the study:

- ✓ Patients who have a diagnosis of malignant spinal cord compression (due to primary or secondary cancer).
- ✓ Patients who have any difficulty in managing their everyday activities as a result of the spinal cord compression.

The process of recruitment will have three stages:

1. The initial approach will be made by a health care professional who is involved in the patient's care. This could be, for example, a doctor, nurse, occupational therapist, physiotherapist or social worker.
2. If the patient is willing to consider being involved, the researcher will meet with the patient to explain the study in more detail.
3. The researcher will leave the patient with written information regarding the study, and a reply slip. If the patient wishes to be involved, he or she would return the reply slip to the researcher within two weeks.

Initial approach by health care professional:

If you identify a patient as being a potential participant in the study, a description along the following lines can be given to the patient:

*"I would like to tell you about a research study that is being carried out here at the Churchill Hospital, which looks at some of the problems experienced by patients who have been diagnosed with spinal cord compression. We know that some people who have spinal cord compression have difficulty managing their everyday activities, and this is a research study which aims to improve the kinds of services we are able to offer to these patients and their families. I am not asking you now whether you would like to take part, but do you think that it is something that you would be prepared to consider being involved in?"*

## APPENDIX IV: RECRUITMENT PROTOCOL

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If the patient's reply is 'no', you would not pursue the matter further, but reassure the patient that it is quite all right to choose not to be involved.

If the patient's reply is 'yes', then you would continue:

*"Would you be agreeable to the researcher coming to explain the study to you in more detail, so that you would understand what was involved? Talking to the researcher would not in any way commit you to taking part in the study. You would have a couple of weeks after the researcher has talked to you to decide whether or not you would like to take part."*

If a patient agrees to the researcher making contact:

If a patient is interested in further information about the study, please contact the researcher, Gail Eva, with the following details:

- ✓ The patient's name.
- ✓ The patient's contact details (hospital ward, or contact telephone number).

Contact details for Gail Eva:

Telephone:

*(internal)* ext 21741

*(external)* 01865 221741

*There is an answer phone on this line. If there is nobody in the office to take the call, please do leave a message.*

Palliative Care Support Team Office  
Level 6, C/D Corridor  
John Radcliffe Hospital.

E-mail: [gail.eva@orh.nhs.uk](mailto:gail.eva@orh.nhs.uk)



Oxford Radcliffe Hospitals



NHS Trust

Gail Eva, Lead Researcher  
Level 6 C/D Corridor  
The John Radcliffe Hospital  
Headley Way  
Headington  
Oxford  
OX3 9DU

Tel: 01865 221741  
Fax: 01865 221947

E-mail: [gail.eva@orh.nhs.uk](mailto:gail.eva@orh.nhs.uk)

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

THE NEEDS AND EXPERIENCES OF PATIENTS  
WITH SPINAL CORD COMPRESSION

(AQREC No.:A03.003)

You are being invited to take part in a research study which is being carried out at the Churchill Hospital. Before you decide, it is important for you to understand the purpose of the research, and what it will involve. Please take the time to read the following information carefully and discuss it with relatives, friends and your hospital doctor if you wish. Please ask either myself or a member of the ward staff if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

## WHAT IS THE PURPOSE OF THE STUDY?

Patients with spinal cord compression following a diagnosis of cancer may have difficulty managing their usual daily activities. For example, it may become difficult to move around at home or elsewhere, and there may be the need to use a wheelchair for a period of time.

These difficulties are sometimes similar to those experienced by a person who has a spinal cord injury and becomes a paraplegic as a result of – for example – a car accident. They are the sorts of problems that rehabilitation specialists, like physiotherapists and occupational therapists, would be able to help with. While we know a great deal about the needs and experiences of patients who damage their spinal cord as a result of an accident, we know very little about what it is like to live with spinal cord compression as a result of cancer. This makes it difficult to plan rehabilitation services effectively.

To work out what kinds of services would help patients with spinal cord compression resulting from cancer to be more independent, and better able to continue with their usual daily activities, we need to understand the needs and experiences of patients who are living with the condition.

This research study will take place over the next three years at the Churchill Hospital. It will aim to identify patients' needs so that we can learn how we might improve the range and quality of rehabilitation services that we are able to offer.

## WHY HAVE I BEEN CHOSEN?

You have been chosen because you have been diagnosed with spinal cord compression.

This is a 'qualitative' study, which means that the total number of patients taking part will be relatively small (between eight and twelve people), but that we will try to understand each person's experiences and needs as fully and as comprehensively as possible.

## DO I HAVE TO TAKE PART?

It is up to you to decide whether or not to take part. If you do decide to take part, you would be given this information sheet to keep, and you would be asked to sign a consent form. If you decide to take part, you are free to change your mind and withdraw at any time without giving a reason. This would not affect the standard of care you receive.

## WHAT WOULD HAPPEN TO ME IF I TAKE PART?

The following is an outline of the time and commitment that would be requested of you if you decided to take part:

- ✦ You would participate in a series of one-to-one interviews. It is difficult to specify the exact number of interviews, as this would depend on your individual circumstances, but there would be likely to be **two or three interviews**, each lasting between **half an hour and an hour**.
- ✦ It would be likely that the interviews would take place **over a two to three month period**, so that there would not be more than one interview a month.
- ✦ I would meet you at a time and place that was convenient for you, which could be at the hospital, or in your home. The interviews would ask about your experience of living with spinal cord compression, particularly in relation to the things that you want and need to be able to do on a daily basis.
- ✦ If appropriate, and with your agreement, a family member or carer would be invited to participate in a similar interview. Their participation would be entirely their own choice, and your agreement to participate in the study would not commit anyone else to being involved.
- ✦ With your agreement, I would talk to one or two of the members of staff who were involved with offering rehabilitation services to you (for example, your occupational therapist, or physiotherapist, or social worker). If appropriate, and with your permission, and the permission of the members of staff concerned, I may observe a rehabilitation session (for example, a physiotherapy treatment session).
- ✦ I would seek your agreement to look at your medical notes. The reason for looking at your notes would be to gain further information about the rehabilitation that was being provided to you.

All interviews would be tape-recorded. A transcription of each interview would be typed out in full. You would be welcome to read the transcriptions, to make sure that they accurately represented your views.

## WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

The results of this research will be used to develop and to evaluate the rehabilitation services that are offered to cancer patients. As a user of these services, your views are extremely valuable in helping us to understand what is important to you. We anticipate that the information we get from this study will help us to improve the services for future patients with spinal cord compression.

## WHAT ARE THE POSSIBLE RISKS OF TAKING PART?

Living with cancer can be stressful. It is possible that during the interview, you may talk about, or be reminded of, events that have been difficult for you. If you were to feel distressed during the conversation, we would terminate the interview immediately if that was your wish. I would be able to identify with you the best way of resolving your distress. This may be by talking about it together at the time, or otherwise making provision for you to talk it through with someone else with whom you feel comfortable.

## WOULD MY TAKING PART BE CONFIDENTIAL?

All material (tapes, written material) would be confidential, and would be kept securely locked when not in use. Any information about you which leaves the hospital would have your name and address removed so that you cannot be recognised from it. With your agreement, quotations from the interview may be used in the final report of this study, but all material would be quoted anonymously, and care will be taken that you could not be identified in any way. Your GP and your hospital Consultant will be informed of your participation in this study.

## WHAT WILL HAPPEN TO THE RESULTS OF THIS STUDY?

The results of this study will be published after the research is completed at the end of 2005. You would be welcome to copies of any publications relating to the study.

## WHO IS ORGANISING AND FUNDING THE RESEARCH?

This research is funded by a grant from the Oxfordshire Health Services Research Committee.

## WHO HAS REVIEWED THE STUDY?

This study has been reviewed and approved by the Oxfordshire Applied and Qualitative Research Ethics Committee (AQREC) The AQREC number for this study is A03.003.

Thank you for reading this. If you have any queries, or would like clarification on any of the above information, please do not hesitate to contact me. (My contact details are given on the first page of this information sheet.)

Oxford Radcliffe Hospitals



NHS Trust

Gail Eva, Lead Researcher  
Level 6 C/D Corridor  
The John Radcliffe Hospital  
Headley Way  
Headington  
Oxford  
OX3 9DU

Tel: 01865 221741  
Fax: 01865 221947

E-mail: [gail.eva@orh.nhs.uk](mailto:gail.eva@orh.nhs.uk)

INVITATION TO PARTICIPATE IN A RESEARCH STUDY (CARERS)

# THE NEEDS AND EXPERIENCES OF PATIENTS WITH SPINAL CORD COMPRESSION

(AQREC No.:A03.003)

You are being invited to take part in a research study which is being carried out at the Churchill Hospital. Before you decide, it is important for you to understand the purpose of the research, and what it will involve. Please take the time to read the following information carefully and discuss it with relatives and friends if you wish. Please ask either myself or a member of the ward staff if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

## WHAT IS THE PURPOSE OF THE STUDY?

Patients with spinal cord compression following a diagnosis of cancer may have difficulty managing their usual daily activities. For example, it may become difficult to move around at home or elsewhere, and there may be the need to use a wheelchair for a period of time.

These difficulties are sometimes similar to those experienced by a person who has a spinal cord injury and becomes a paraplegic as a result of – for example – a car accident. They are the sorts of problems that rehabilitation specialists, like physiotherapists and occupational therapists, would be able to help with. While we know a great deal about the needs and experiences of patients who damage their spinal cord as a result of an accident, we know very little about what it is like to live with spinal cord compression as a result of cancer. This makes it difficult to plan rehabilitation services effectively.

To work out what kinds of services would help patients with spinal cord compression resulting from cancer to be more independent, and better able to continue with their usual daily activities, we need to understand the needs and experiences of patients who are living with the condition.

This research study will take place over the next three years at the Churchill Hospital. It will aim to identify patients' needs so that we can learn how we might improve the range and quality of rehabilitation services that we are able to offer.

## WHY HAVE I BEEN ASKED TO PARTICIPATE?

You have been asked to participate because you are a family member or carer of a person who has been diagnosed with spinal cord compression. Your relative / friend has agreed to take part in this research. We be will carrying out a number of interviews with your relative / friend, to find out about his or her experiences of living with spinal cord compression. We would like to talk to you as well to find out about your experiences.

This is a 'qualitative' study, which means that the total number of patients taking part will be relatively small (between eight and twelve people), but that we will try to understand each person's experiences and needs as fully and as comprehensively as possible.

## DO I HAVE TO TAKE PART?

It is up to you to decide whether or not to take part. If you do decide to take part, you would be given this information sheet to keep, and you would be asked to sign a consent form. If you decide to take part, you are free to change your mind and withdraw at any

time without giving a reason. This would not affect the standard of care your relative / friend receives.

Your taking part does not affect your relative's / friend's involvement in the study. You are entirely free to make up your own mind about whether or not you would like to take part.

## WHAT WOULD HAPPEN TO ME IF I TAKE PART?

The following is an outline of the time and commitment that would be requested of you if you decided to take part:

- ✦ You would participate in a series of one-to-one interviews. It is difficult to specify the exact number of interviews, as this would depend on your individual circumstances, but there would be likely to be **two or three interviews**, each lasting around **half an hour**.
- ✦ It would be likely that the interviews would take place **over a two to three month period**, so that there would not be more than one interview a month.
- ✦ I would meet you at a time and place that was convenient for you, which could be at the hospital, or in your home. The interviews would ask about your experiences as a carer, and about your perceptions of your family member's experience of living with spinal cord compression, particularly in relation to the things that he or she wants and needs to be able to do on a daily basis.

All interviews would be tape-recorded. A transcription of each interview would be typed out in full. You would be welcome to read the transcriptions, to make sure that they accurately represented your views.

## WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

The results of this research will be used to develop and to evaluate the rehabilitation services that are offered to cancer patients. As the family member of a user of these services, your views are extremely valuable in helping us to understand what is important to you. We anticipate that the information we get from this study will help us to improve the services for future patients with spinal cord compression.

## WHAT ARE THE POSSIBLE RISKS OF TAKING PART?

Having a family member who has cancer can be stressful. It is possible that during the interview, you may talk about, or be reminded of, events or feelings that have been difficult for you. If you were to feel distressed during the conversation, we would terminate the interview immediately if that was your wish. I would be able to identify with you the best way of resolving your distress. This may be by talking about it together at the time, or otherwise making provision for you to talk it through with someone else with whom you feel comfortable.

## WOULD MY TAKING PART BE CONFIDENTIAL?

All material (tapes, written material) would be confidential, and would be kept securely locked when not in use. Any information about you which leaves the hospital would have your name and address removed so that you cannot be recognised from it. With your agreement, quotations from the interview may be used in the final report of this study, but all material would be quoted anonymously, and care will be taken that you could not be identified in any way.

## WHAT WILL HAPPEN TO THE RESULTS OF THIS STUDY?

The results of this study will be published after the research is completed at the end of 2005. You would be welcome to copies of any publications relating to the study.

## WHO IS ORGANISING AND FUNDING THE RESEARCH?

This research is funded by a grant from the Oxfordshire Health Services Research Committee.

## WHO HAS REVIEWED THE STUDY?

This study has been reviewed and approved by the Oxfordshire Applied and Qualitative Research Ethics Committee (AQREC) The AQREC number for this study is A03.003.

Thank you for reading this. If you have any queries, or would like clarification on any of the above information, please do not hesitate to contact me. (My contact details are given on the first page of this information sheet.)



Oxford Radcliffe Hospitals



NHS Trust

Gail Eva, Lead Researcher  
Level 6 C/D Corridor  
The John Radcliffe Hospital  
Headley Way  
Headington  
Oxford  
OX3 9DU

Tel: 01865 221741  
Fax: 01865 221947

E-mail: [gail.eva@orh.nhs.uk](mailto:gail.eva@orh.nhs.uk)

INVITATION TO PARTICIPATE IN A RESEARCH STUDY  
(PROFESSIONALS)

# THE REHABILITATION NEEDS OF PATIENTS WITH MALIGNANT SPINAL CORD COMPRESSION

(AQREC No.:A03.003)

This is an invitation to participate in a research study being carried out at the Churchill Hospital. Information about the study is set out in this leaflet, but please contact me if you would like any further details.

Thank you for reading this.

## WHAT IS THE PURPOSE OF THE STUDY?

Malignant spinal cord compression is recognised as an oncological emergency, occurring in up to 5% of all patients with systemic cancer. The need for swift diagnosis and treatment (for example, with steroids and radiotherapy) is well documented. What is less well described is the management, and specifically the rehabilitation, of those patients where the compression has resulted in neurological damage to the spinal cord. These individuals have many problems – loss of mobility, incontinence, sexual dysfunction, and the social and psychological sequelae of a sudden loss of independence. These are problems which in other conditions, for example, traumatic spinal cord injury, would merit an individual's participation in a structured programme of rehabilitation. However, while there are some similarities between people with traumatic spinal cord injury and those with malignant spinal cord compression, there are also stark contrasts. With a one-year survival rate of less than 20%, patients with a diagnosis of malignant spinal cord compression are likely to be facing a poor prognosis and having to cope with the implications of a life-limiting disease.

While rehabilitation is recognised as an important component of the management of malignant spinal cord compression, there is little indication of how this could be structured or delivered, particularly in the context of the patients' own perceptions of their difficulties. Without knowledge of what is important to patients and their carers, it is difficult to know how to target rehabilitation effectively.

The purpose of this study is therefore to determine the rehabilitation needs of patients with malignant spinal cord compression. Specifically, it will identify: what patients with malignant spinal cord compression, and their carers, perceive to be important aspects of their quality of life; how patients with malignant spinal cord compression, and their carers, understand their disability and their rehabilitation needs; the attitudes of health care professionals towards rehabilitation in people with malignant spinal cord compression; and the implications of the above for rehabilitation with people with malignant spinal cord compression.

## WHY HAVE I BEEN INVITED TO PARTICIPATE?

You have been invited to participate because you have recently had contact with one of the patients recruited into the study. Either (i) you are the doctor who diagnosed MSCC in this case, or (ii) you are a health care professional involved in the rehabilitation of this patient.

Interviews are being conducted with the patient, and with one of her/his carers; and I would also like to interview you. I am interested in the view health care professionals take of rehabilitation in cases of MSCC – both specifically, with respect to the patient concerned, and in general.

## DO I HAVE TO PARTICIPATE?

It is, of course, for you to decide whether or not to participate. If you agree to do so, you will be asked to sign a consent form; but you are naturally free to change your mind and withdraw at any time without giving a reason.

## WHAT ARE THE IMPLICATIONS OF PARTICIPATION?

This research study commences in January 2003, and will be completed by December 2005.

(i) If you are the doctor who diagnosed MSCC in this case, I would be requesting *one* interview, lasting between 30 and 45 minutes.

(ii) If you are a health care professional involved in the rehabilitation of this patient, I would be requesting one, and possibly two, interviews – depending on how long the rehabilitation programme lasts. Each interview would take between 30 and 60 minutes. I would also ask whether I could observe a single rehabilitation session (if I do make this request, the patient will already have agreed to this).

In all cases, interviews would take place at a time and place that are convenient for you.

All interviews would be tape-recorded. A transcription of each interview would be typed out in full. You would be welcome to read the transcriptions, to make sure that they accurately represent your views.

## WHAT ARE THE POSSIBLE BENEFITS?

It is anticipated that this study will lead to an improvement in the provision of rehabilitation for patients with malignant spinal cord compression. It is likely that this improvement could be implemented at relatively little additional cost: the structures for providing rehabilitation exist at present (for example, hospital and community rehabilitation staff). It is the knowledge of what is important to patients, and how rehabilitation for this patient population should be targeted, structured and delivered that is lacking. Once this is known, strategies can be developed for training and educating the health care professionals – across hospital / community / social services boundaries – who come into contact with this patient group.

A further potential benefit will be the improvement in the range of information about 'living with spinal cord compression' that could be made available to patients and their carers. This is in line with the priorities for improving the treatment of cancer patients set out in the NHS Cancer Plan.

## WHAT ARE THE POSSIBLE RISKS OF PARTICIPATION?

None.

## WOULD MY PARTICIPATION BE CONFIDENTIAL?

All material (tapes, written material) would be confidential, and would be kept securely locked when not in use. Any information about you which leaves the hospital would have your name and title removed so that you could not be identified. With your agreement, quotations from the interview may be used in the final report of this study; but all material would be quoted anonymously, and care will be taken that you could not be identified in any way.

As a researcher, my aim is to understand the rehabilitation needs of this group of patients; it is *not* to scrutinise or evaluate professional practice. However, in the event of harmful, illegal or blatantly unprofessional practice coming to light, I would of course be obliged to take appropriate action, which might include notifying the relevant authority.

## WHAT WILL HAPPEN TO THE RESULTS OF THIS STUDY?

The results of this study will be published after the research is completed at the end of 2005. You would be welcome to copies of any publications relating to the study.

## WHO IS ORGANISING AND FUNDING THE RESEARCH?

This research is funded by a grant from the Oxfordshire Health Services Research Committee.

## WHO HAS REVIEWED THE STUDY?

This study has been reviewed and approved by the Oxfordshire Applied and Qualitative Research Ethics Committee (AQREC) The AQREC number for this study is A03.003.

Thank you for reading this. If you have any queries, or would like clarification on any of the above information, please do not hesitate to contact me. (My contact details are given on the front of this information sheet.)

Gail Eva  
Lead Researcher.

Oxford Radcliffe Hospitals **NHS**  
NHS Trust

Gail Eva, Lead Researcher  
Level 6 C/D Corridor  
The John Radcliffe Hospital  
Headley Way  
Headington  
Oxford  
OX3 9DU  
Tel: 01865 221741  
Fax: 01865 221947

E-mail: gail.eva@orh.nhs.uk

CONSENT FORM (PATIENTS)

THE NEEDS AND EXPERIENCES OF PATIENTS  
WITH MALIGNANT SPINAL CORD COMPRESSION

AQREC No.: A03.003

Please initial box:

I confirm that I have read, and that I understand, the information sheet dated May 2003 for the above study, and have had the opportunity to ask questions.

I confirm that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my future care or legal rights being affected.

I agree that any words I may say during interviews can be used, anonymously, in the presentation of the research.

I agree to the researcher looking at my medical notes.

I agree that my GP can be informed of my participation in this study.

I agree to interviews being tape recorded.

I agree to take part in the above study.


\_\_\_\_\_  
Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

APPENDIX IX: CONFIRMATION OF ETHICAL AND ORH TRUST APPROVAL

Oxford Radcliffe Hospitals



NHS Trust

Our Ref: JB/VW/A03.003

**Gail Eva**  
**Palliative Care Support Team**  
**Level 6 C/D Corridor**  
**John Radcliffe**  
Oxford  
OX3 9DU

Applied & Qualitative Research Ethics Committee  
Research & Development Department  
Room 13, Manor House  
The John Radcliffe  
Headley Way  
Headington  
Oxford  
OX3 9DZ

Tel: 01865 222759  
Fax: 01865 222699  
Email: valerie.white@orh.nhs.uk

08 May 2003

Dear Gail

**RE: A03.003 The rehabilitation needs of patients with malignant spinal cord compression**

Thank you for your letter dated 7 May 2003 addressing the points raised by the Committee at their meeting on 25 April 2003. In accordance with the authority set out in the Terms of Reference, I am happy to confirm ethical approval and wish you every success with the study.

**Please note:**

- Ethical approval is valid for three years from the date of this letter. Annual updates of the progress of the research and a report of the outcome are required. (A reminder letter will be sent when these reports are due).
- No significant changes to the research protocol should be made without appropriate research ethics committee/chairman's approval. Any deviations from or changes to the protocol which increase the risk to subjects, affect the conduct of the research or are made to eliminate hazards to the research subjects, should be made known to AQREC.
- AQREC should be made aware of any serious adverse events.
- Whilst the study has received approval on ethical grounds, it is necessary for you to obtain management approval from the relevant Clinical Directors and/or Chief Executive of the Trusts (or Health Boards/StHAs) in which the work will be done.

I should be very grateful if you could send me a copy of any publication that may arise from this study.

Yours sincerely

**Dr Jenny Butler**  
Chair

Applied and Qualitative Research Ethics Committee

pp

APPENDIX IX: CONFIRMATION OF ETHICAL AND ORH TRUST APPROVAL



UNIVERSITY OF  
STIRLING

DEPARTMENT OF  
NURSING AND MIDWIFERY

Professor Andrew Watterson  
Chair, Dept Research Ethics Committee

University of Stirling  
Stirling FK9 4LA  
Scotland

Telephone: +44 (0) 1786 466340  
Facsimile +44 (0) 1786 466333  
E-mail: aew1@stir.ac.uk

AEW/TI

17 July 2003

Gail Eva  
Cherrymead  
Bledlow Road  
Saunderton  
Princes Risborough  
Buckinghamshire  
HP27 9NG

Dear Gail

**The Rehabilitation Needs Of Patients With Malignant Spinal Cord Compression**

Thank you for submitting your clarification letter for the proposal, entitled as above, to the Departmental Research Ethics Committee on 7 July 2003. I am pleased to advise you that the committee approved your proposal.

Yours sincerely

A handwritten signature in cursive script that reads "Andrew Watterson".

Andrew Watterson  
Chair

Oxford Radcliffe Hospitals



NHS Trust

JM/VW/A03.003

**Gail Eva**  
**Palliative Care Support Team**  
**Level 6 C/D Corridor**  
**John Radcliffe**  
Oxford  
OX3 9DU

From the Director of R&D  
Dr James Morris, FRCPath  
c/o R&D Office, Manor House  
The John Radcliffe Hospital  
Headley Way, Headington  
Oxford OX3 9DZ

Tel: Oxford (01865) 222642  
Fax: Oxford (01865) 222699

Dear Ms Eva

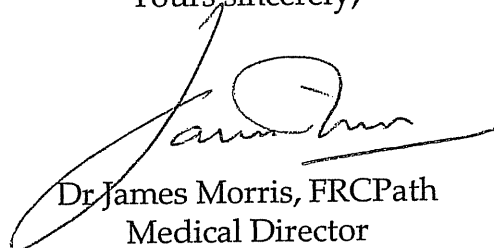
08 May 2003

**Re: A03.003 The rehabilitation needs of patients with malignant spinal cord compression**

Thank you for letting us have details of your proposed study. I can confirm that the Trust will provide indemnity.

I wish you every success with the study.

Yours sincerely,

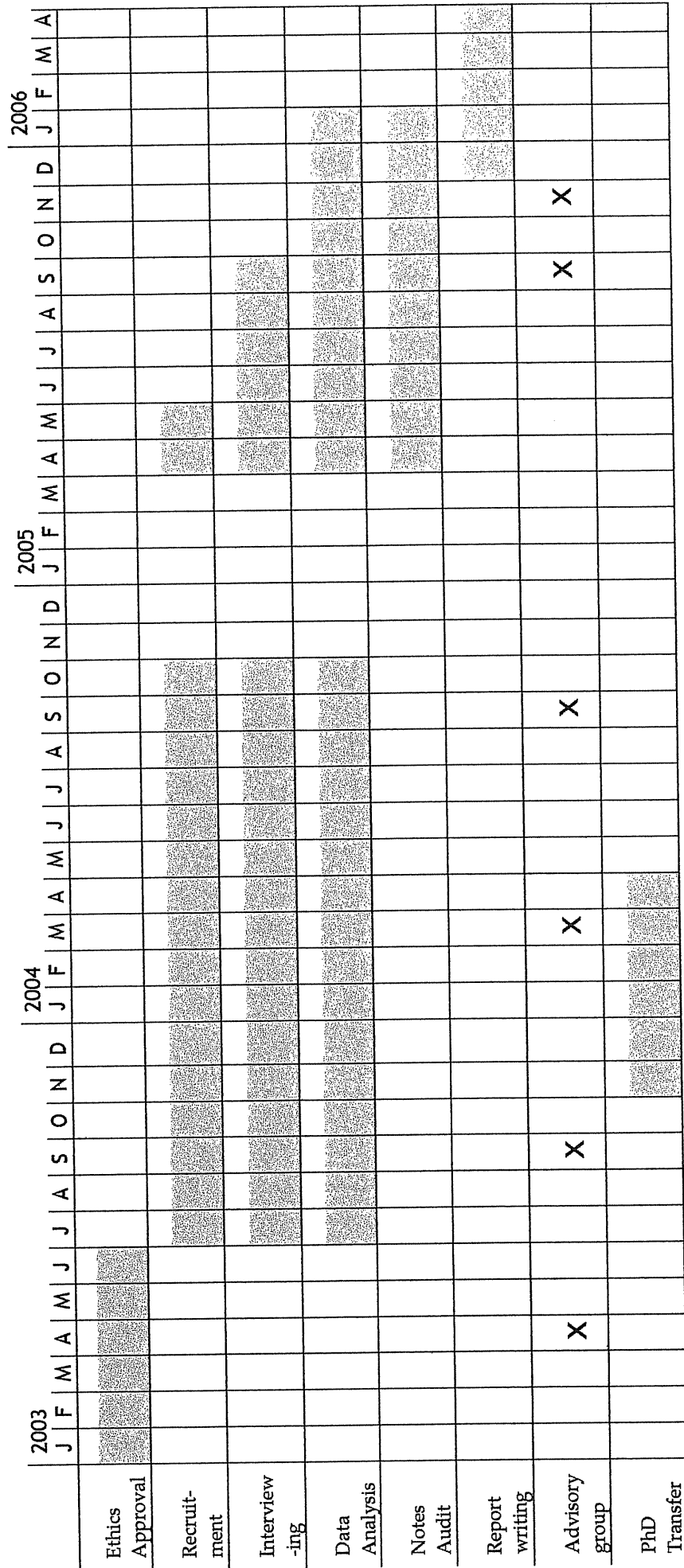


Dr James Morris, FRCPath  
Medical Director



APPENDIX X: GANTT CHART OF RESEARCH ACTIVITY

THE PROVISION OF REHABILITATION FOR PATIENTS WITH MALIGNANT SPINAL CORD COMPRESSION  
 Research Timetable January 03 - April 06 (Period of funding)



# The rehabilitation needs of patients with malignant spinal cord compression

Rehabilitation is an important component of the management of MSCC.

There is little indication of how rehabilitation could or should be structured or delivered, particularly in the context of the patients' own perceptions of their difficulties.

Without knowledge of what is important to patients and their carers, it is difficult to know how to target rehabilitation effectively.

This study will determine the rehabilitation needs of patients with MSCC:

What is important in terms of quality of life?

How are rehabilitation needs understood?

What are professionals' attitudes to disability and rehabilitation?

## Who is eligible?

Patients with a diagnosis of MSCC (through primary or secondary cancer), who have difficulty managing everyday activities as a result of the MSCC.

## Contact

If you know of patients who meet the above criteria, please contact:

GAIL EVA  
ext: 21741

e-mail: [gail.eva@orh.nhs.uk](mailto:gail.eva@orh.nhs.uk)