

APPENDICES

Developing a Capability Approach to Measure and Value Quality of Life: An application to chronic pain

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APPENDIX A

Invitation Letter – Focus Groups (Study Phase I)

Information Sheet – Focus Groups (Study Phase I)

Consent Form – Focus Groups (Study Phase I)

Preliminary Information Sheet (Study Phase I)

Topic Guide for Focus Groups (Study Phase I)

10 October 2006

Dear Sir/Madam,

Chronic Pain and Its Impact on Quality of Life

I am writing to inform you of a new study about to start which is being run by the University of East Anglia and the James Paget Hospital. The focus of the study will be on chronic pain and its impact on quality of life.

Please read carefully the Patient Information Sheet enclosed with this letter. If you **are interested in taking part** in this study please ask a member of staff at the James Paget Hospital for more information when you attend your next appointment at the Pain Management Clinic. Staff at the clinic will direct you to a member of the research team who will be able to answer any questions that you may have. If, when you are happy with the information that you have been given, you wish to take part in the study then you will be asked to sign a consent form.

It is entirely up to you to decide whether or not to take part; you do not need to give a reason for your decision. If you choose **not to take part** your medical treatment will not be affected in any way and you should attend your appointment at the Pain Management Clinic as normal.

I hope that you will be able to find time to take part in the above study.

Thank you for taking the time to read the information with this letter and to consider your decision.

Yours sincerely

Dr William Notcutt
Consultant Anaesthetist



An educational partner in UEA's School of Medicine, Health Policy and Practice

Patient Information Sheet – Group Discussion

Chronic Pain and its Impact on Quality of Life

You are being invited to take part in a new study being run by the University of East Anglia and the James Paget Hospital, which will focus on chronic pain. Please take time to read the following information carefully before you decide if you want to participate. You will have an opportunity to talk to a member of the research team when you attend your next appointment at the Pain Management Clinic, if you wish.

- Part 1 tells you the purpose of the study and what will happen if you take part.
- Part 2 gives more detailed information about confidentiality.

Part 1

What is the purpose of the study?

The main aim of the study is to assess the impact of chronic pain on quality of life. The study is being conducted as part of a wider project, by a research team at the University of East Anglia. The study will also contribute to the educational qualification of PhD in Health Economics for Mr Philip Kinghorn.

Why have I been chosen?

We are recruiting patients who attend the Pain Management Clinic at the James Paget Hospital due to chronic pain. Chronic pain is defined as pain which lasts for over six months and which has no useful purpose, unlike acute pain which acts as a warning that damage is being done to the body.

We are hoping to recruit between 24 and 36 patients, who are over the age of 18, to participate in this part of the study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be asked to sign a consent form when you attend your next appointment at the Pain Management Clinic. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.



What will the study involve?

Participation in this study will involve you being asked to share your views and experiences as part of a group. There will be six groups and each group will be made up of between 4 and 6 people.

You will be asked to consider how pain limits your freedom to achieve valuable tasks or roles. The groups will meet once for between 1 and 1 ½ hours.

What do I have to do?

You will be asked to attend one of the groups and take part in the discussion, which will last for no longer than 1 ½ hours. The group discussions will be held at the James Paget Hospital.

What will be the benefits of taking part? Are there any disadvantages?

Taking part in this study will not affect your treatment in any way. We will aim to make the discussion in the groups comfortable and participants often find it enjoyable to share their ideas and views.

It is possible that some participants will find it uncomfortable to discuss their views and experiences as a member of a group. If participants are uncomfortable with any issue raised then they can discuss this in confidence with Dr William Notcutt (James Paget Hospital).

Travel & Expenses:

Funds will be available to reimburse those who travel to take part in a group discussion. The research team will be happy to reimburse the full costs of public transport, or mileage (at £0.40 per mile).

Contact Details:

For further information speak to: **Philip Kinghorn** (University of East Anglia):
Contact via James Paget Hospital: **Telephone: 01493 452737**.

If you feel uncomfortable about any issues raised during this study then you can discuss this in confidence with **Dr William Notcutt** (Consultant Anaesthetist, James Paget Hospital).

If the information in part 1 of this information sheet has interested you and you are considering taking part in this study then please continue to read the additional information in part 2 before making a decision.

Part 2

Will the information and opinions that I give be kept confidential?

If you agree to take part in the study, some parts of your medical records will be looked at by authorised persons from the James Paget Hospital. The information which will be used from your medical notes will be: personal contact details, confirmation of age, and the period of time for which you have had experience of pain.

An audio recording will be made during the group discussions; tapes will be held in a locked cabinet and accessed only by authorised staff from the University of East Anglia and the James Paget Hospital. Written records will also be made of what is said in the groups, although, once again, these will only be looked at by authorised persons from the University of East Anglia and the James Paget Hospital. The audio tapes and any notes from the group discussions will be destroyed when the study has ended.

If parts of the discussion from the groups is quoted in the write-up of the study then it will be quoted anonymously. Furthermore, if any information relating to participants is held on a computer database then it will be identified by a code and not by the participant's name. The research team will ask all those who take part in the discussions to treat all information revealed in the groups as being strictly confidential; it should be noted, however, that due to the nature of the group discussions the research team cannot guarantee this.

What will happen to the research results?

The issues raised in the groups will be published as part of a wider academic report, although nothing will be published which can be used to identify individual participants.

The issues raised in the groups will also be used in the design of a new questionnaire, which will be used to assess quality of life in other patients with chronic pain.

Who is organising and funding the research?

The James Paget Hospital and the School of Medicine, Health Policy and Practice at the University of East Anglia are funding, organising and conducting the study.

Complaints:

If you have a concern about any aspect of this study then you should first discuss this with Philip Kinghorn (contact details above). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Who has reviewed the study?

This study has been approved by the Norfolk Research Ethics Committee and by the East Norfolk & Waveney Research Governance Committee.

Thank you for taking the time to consider your participation in the above study.

If you are interested in taking part in the study, please ask a member of staff at the Pain Clinic for more information when you attend your next appointment. Staff at the clinic will direct you to a member of the research team, who will be happy to answer any questions that you may have. If you are happy with the information you receive and wish to take part you will be asked to sign a consent form while at the clinic.

If you do not wish to take part please attend your next appointment at the pain clinic as normal.

Consent Form – Group Discussions

Chronic Pain and it's Impact on Quality of Life

Name of Researcher:

Before deciding whether to join this study by signing this form, please ensure that you have read and understand the PATIENT INFORMATION SHEET.

Please Initial box

1. I confirm that I have read and understand the information sheet dated August 2006 (version 1.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the James Paget Hospital, and from regulatory authorities, where it is relevant to my taking part in this study. I give permission for these individuals to have access to my records.
4. I understand that an audio recording will be made of the discussion in the groups.
5. I understand that I will take part in a group discussion which will last for between 60 and 90 minutes.
6. I agree to take part in the above study.

Please sign and date overleaf



Signatures:

Name of Patient Date Signature

Name of person taking consent
(if different from researcher) Date Signature

Researcher Date Signature

When Completed, 1 for patient; 1 for researcher; 1 (original) to be kept in medical notes

Preliminary Patient Information

Chronic Pain and Its Impact on Quality of Life

This form should be completed by Philip Kinghorn and information should be collected immediately after a signed and valid consent form is received for participation in the focus groups.

Centre: Pain Clinic, James Paget Hospital

Study Phase I

Patient Identification Number: _____

Patient's Name: _____

Gender: Male / Female

Age: _____

Employment:

- Paid Employment:
- Retired:
- Seeking work but currently unemployed:
- Not active in the labour market & not seeking employment:

Availability: (Please state any dates on which you will definitely NOT be able to attend a focus group)

October

1	2	3	4	5	6	7	8	9	10	11	12
13	14	15	16	17	18	19	20	21	22	23	24
25	26	27	28	29	30	31					

November

1	2	3	4	5	6	7	8	9	10	11	12
13	14	15	16	17	18	19	20	21	22	23	24
25	26	27	28	29	30						

Please state a preference over the following times:

Morning / Afternoon / Evening

Telephone Number: _____

- Welcome and thank you.
 - Introduce those members of the research team present.
 - The group discussion will last for about 1 ½ hours.
 - Please note that we will make an audio recording of the group discussion. Only the research team will listen back to this recording. We will also make careful notes during the discussion; once again only the research team will have access to these notes. If parts of this discussion are quoted in the write-up of this study they will be quoted anonymously.
 - We must request confidentiality from the group, however, by the nature of focus groups we, as the research team, are not able to guarantee this.
 - I have a list of pre-prepared, open questions, which I will use to initiate the discussion and keep the discussion moving.
 - This study is concerned with chronic pain, and the impact of pain on quality of life.
 - Does anyone have any questions that they would like to ask before we begin?
-

Prepared Questions:

1. To start with, I would like us to try and list any activities, freedoms or roles which you regard as being valuable and which you consider as contributing to a good quality of life.
 - If clarification is needed: These could include, for example, paid employment, having independence, informal childcare, or leisure activities.
 - Why do you feel that this particular activity/ role/ freedom is valuable?

2. Due to pain, or any treatment which you receive due to your pain, are you unable or restricted in your ability to do any of the activities or roles that you have just described as being valuable to you?
 - What impact do these restrictions have on your quality of life? For example, they may lead to a sense of frustration, isolation, loss of earnings.
3. Are there any valuable activities/ roles/ freedoms that you didn't include on the original list, because your pain means that you are unable to achieve these things?
4. Do you find that pain limits your freedom?
 - In what way?
5. Do you find that pain limits your independence?
 - In what way?
6. Do you find that pain has an impact on your relationship with others?
 - In what way?

APPENDIX B

Invitation Letter – Piloting of Questionnaire (Study Phase II)

Information Sheet – Piloting of Questionnaire (Study Phase II)

Consent Form – Piloting of Questionnaire (Study Phase II)

Feedback Form (Study Phase II)

21 June 2007

Dear Sir/Madam,

Assessing Quality of Life in Patients with Chronic Pain

I am writing to inform you of a new study about to start, which is being run by the University of East Anglia and the James Paget Hospital. The aim of the study is to gain feedback from patients on a new questionnaire that has been designed to assess quality of life in patients with chronic pain.

Please read carefully the Patient Information Sheet enclosed with this letter. When you attend your appointment at the Pain Clinic, a member of the research team will provide you with an opportunity to ask any questions that you may have regarding the study. If you are happy with the answers you are given and you **wish to take part** then you will be asked to sign a consent form.

It is entirely up to you to decide whether or not to take part; you do not need to give a reason for your decision. If, having read the Information Sheet, you **do not wish to take part** and you do not wish to discuss the study with a member of the research team, please inform staff when you present for your appointment. If this is the case then staff will ensure that your wishes are respected. If you choose not to take part your medical treatment will not be affected in any way and you should attend your appointment at the Pain Management Clinic as normal.

I hope that you will be able to find time to take part in the above study.

Thank you for taking the time to read the information with this letter and to consider your decision.

Yours sincerely

Dr William Notcutt
Consultant Anaesthetist



An educational partner in UEA's School of Medicine, Health Policy and Practice

Patient Information Sheet – Interviews

Assessing Quality of life in Patients with Chronic Pain

You are being invited to take part in a study being run by the University of East Anglia and the James Paget Hospital, which will focus on chronic pain. Please take time to read the following information carefully before you decide if you want to participate. Talk to a member of the research team if you wish.

- Part 1 tells you the purpose of the study and what will happen if you take part.
- Part 2 gives more detailed information about confidentiality.

Part 1

What is the purpose of the study?

This study is being conducted as part of a wider project, by a research team at the University of East Anglia. A questionnaire has been designed by this research team to assess the quality of life of patients with chronic pain. Before the questionnaire can be used to collect information we would like to check that there are no problems with the design and that the questions are clear and easy to understand; in order to do this we are asking patients to fill in the questionnaire while a member of the research team is there to offer help with any difficulties they may have. The research team will make a note of any problems and will be keen to collect feedback from patients so that the questionnaire can be improved.

The study will also contribute to the educational qualification of PhD in Health Economics for Philip Kinghorn.

Why have I been chosen?

We are recruiting patients who attend the Pain Management Clinic at the James Paget Hospital due to chronic pain. Chronic pain is defined as pain lasting for over six months and which serves no useful purpose, unlike acute pain which acts as a warning that damage is being done to the body. We are hoping to recruit between 12 and 16 patients, who are over the age of 18, to participate in this study.



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Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will the study involve?

Participation in this study will involve you being asked to fill-in a new questionnaire that has been designed to assess the quality of life of patients with chronic pain. A member of the research team from the University of East Anglia will explain how to complete the questionnaire and will help you if you have any difficulties. Because the questionnaire is new and has never before been shown to members of the public, there may be some questions that are not as clear as they could be. The research team will make a note of any difficulties that people have when filling-in the questionnaire and we can then make changes to the questionnaire so that it is easier for other patients to fill-in in the future.

We expect that it will take between 20 and 30 minutes to complete the questionnaire and then an extra 5 minutes to discuss your answers with a member of the research team. You will be asked to fill-in the questionnaire at the Pain Management Clinic at the James Paget Hospital, when you attend your next routine appointment.

What do I have to do?

Complete the questionnaire while at the Pain Management Clinic and discuss with a member of the research team how easily you were able to do this. You will be asked: if you had any difficulty understanding the questions; if the answers that were available for you to select were relevant to you; and if the instructions on how to fill-in the questionnaire were easy to understand. A member of the research team will also make a note of how long it took you to answer all of the questions and you will be able to offer any additional feedback that you may have.

Please be aware that the questionnaire is NOT a test of your knowledge and that there will be no right or wrong answers; the questionnaire will ask you to choose an answer that best matches your situation.

What will be the benefits of taking part? Are there any disadvantages?

Taking part in this study will not affect your treatment in any way. If you choose to take part then the consultation time that you have with the Doctor at the Pain Management Clinic will not be any different than it would normally have been. It is likely, however, that you will be asked to spend a few more minutes at the Clinic than you normally would in order to fill-in the questionnaire.

There is a small chance that patients will feel uncomfortable answering some parts of the questionnaire. If participants are uncomfortable with any parts of the questionnaire then they can discuss this in confidence with Dr William Notcutt (James Paget Hospital).

Travel & Expenses:

The cost of parking at the Hospital will be reimbursed on the day.

Contact Details:

For further information speak to: **Philip Kinghorn** (University of East Anglia):
Contact via James Paget Hospital: **Telephone: 01493 452737; e-mail: P.Kinghorn@uea.ac.uk**

If you feel uncomfortable about any issues raised during this study then you can discuss this in confidence with **Dr William Notcutt** (Consultant Anaesthetist, James Paget Hospital).

If the information in part 1 of this information sheet has interested you and you are considering taking part in this study then please continue to read the additional information in part 2 before making a decision.

Part 2

Will the information and opinions that I give be kept confidential?

If you agree to take part in the study, some parts of your medical records will be looked at by authorised persons from the James Paget Hospital. The information which will be used from your medical notes will be: personal contact details, confirmation of age, the period of time for which you have had experience of pain and the medication that you are taking to control your pain.

A note will be made of any problems that you had when filling-in the questionnaire and how long it takes you to answer all of the questions, these notes will only be looked at by authorised persons from the University of East Anglia and the James Paget Hospital. All notes that are made will be kept in locked storage.

All completed questionnaires will be kept in locked storage at the University of East Anglia and accessed by authorised members at the research team at the University.

If any information relating to participants is held on a computer database then it will be identified by a code and not by the participant's name.

What will happen to the research results?

The views and opinions given by patients in the interviews will be published as part of a wider academic report, although nothing will be published which can be used to identify individual participants.

The information and experience gained from this study may be used to improve the questionnaire, which will then be used to assess quality of life in other patients with chronic pain. Information from completed questionnaires may also be used anonymously in the write up of this study and will be

compared to future responses from the questionnaire after it has been changed.

Who is organising and funding the research?

The James Paget Hospital and the School of Medicine, Health Policy and Practice at the University of East Anglia are funding, organising and conducting the study.

Complaints:

If you have a concern about any aspect of this study then you should first discuss this with Philip Kinghorn (contact details above). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Who has reviewed the study?

This study has been approved by the Norfolk Research Ethics Committee and also by the East Norfolk & Waveney Research Governance Committee.

Thank you for taking the time to consider your participation in the above study.

If you wish to take part in the study, please ask to speak to a member of the research team when you attend your next appointment at the Pain Management Clinic. You will be given the opportunity to ask any questions you may have about the study and if you are happy with the answers that you receive then you will be asked to complete a consent form.

If you do not wish to take part in this study then you should still attend your next appointment at the Pain Management Clinic. You will NOT be placed under any pressure to take part.

Centre: Pain Clinic, James Paget Hospital
Study Phase 2
Patient Identification Number: _____

Lowestoft Road
Gorleston
Great Yarmouth
Norfolk
NR31 6LA

Tel: 01493 453320

Consent Form – Interviews

Assessing Quality of Life in Patients with Chronic Pain

Name of Researcher: Philip Kinghorn

Before deciding whether to join this study by signing this form, please ensure that you have read and understand the PATIENT INFORMATION SHEET.

Please Initial box

6. I confirm that I have read and understand the information sheet dated April 2007 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
7. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
8. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the James Paget Hospital, and the University of East Anglia, where it is relevant to my taking part in this study. I give permission for these individuals to have access to my records.
9. I understand that my completed questionnaire will be held by the research team at the University of East Anglia and that information from it may be used anonymously in the write up of this study.
10. I understand that I will be asked to fill-in a questionnaire and to discuss the questionnaire with a member of the research team, which is expected to take approximately 35 minutes in total.
6. I agree to take part in the above study.

Please sign and date overleaf



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Signatures:

Name of Patient Date Signature

Name of person taking consent
(if different from researcher) Date Signature

Researcher Date Signature

When Completed, 1 for patient; 1 for researcher; 1 (original) to be kept in medical notes

Feedback Form for Pilot Interviews



Assessing Quality of Life in Patients with Chronic Pain

1. Did you find that the instructions on how to complete the questionnaire were clear and easy to understand?

2. Did you find the instructions useful?

3. Did you find that the questions were easy to understand?

4. Did you find that any of the questions were difficult to answer?

Why?

5. Was it clear how you should indicate your response to each of the questions?

6. Did you find that any of the possible answers/options were very similar? Were there any questions for which you did or could have marked more than one answer/option?

7. Where there any questions for which none of the possible answers/options seemed appropriate?

8. Have you any other comments or suggestions that you would like to add?

THANK YOU

9. Time taken to complete: _____ Minutes & _____ Seconds

10. Any comments from the researcher:

APPENDIX C

Initial Capability Questionnaire

Follow-up Capability Questionnaire

Reminder Postcard

Assessing Quality of Life in Patients with Chronic Pain



Initial Questionnaire

Instructions:

The questions that follow are divided in to 3 sections. Most of the questions can be answered simply by ticking the option that best matches your situation. If, in the first two sections, you cannot give a precise answer to a specific question, please try to give your best estimate. Please try to answer ALL of the questions as accurately as possible.

All information you provide will be strictly confidential.

If you have any questions then please do not hesitate to contact me:

Philip Kinghorn, School of Medicine, Health Policy & Practice, University of East Anglia, Norwich, NR4 7TJ

Tel. 01603 593665 Email: P.Kinghorn@uea.ac.uk

Initial Questionnaire

Patient identification: Q ___ / ___

Date: ___ / ___ / 07

SECTION ONE: About You

1. **Date of Birth:** _____ Day _____ Month _____ Year

2. **Gender** (Please Tick): 1] Male..... 2] Female.....

3. **Which of the options below best describes where you live** (Please Tick)?

1] City.....

3] Village.....

2] Town.....

4] Farm.....

4. **Who do you live with** (Please tick all that apply)?

1] Spouse/Partner.....

4] Friend(s).....

2] Other People.....

5] Children.....

3] Relatives.....

6] Alone.....

7] Other (Please Specify) _____

5. **What is your total household income per month, after tax?**

£

6. **Which of the options below best describes your current work status** (Please Tick)?

1] Work Part-Time.....

2] Work Full-Time.....

3] Off-sick.....

4] Unemployed.....

5] Retired.....

6] Student.....

7] Housewife/husband.....

8] Full-time Carer.....

9] Other (Please Specify) _____

SECTION TWO: Visits to GP Surgery, Hospital and for Alternative Medicines:

Travel to Your GP Surgery

1. How long does it normally take you to travel to your GP's surgery (Please state)?

Length of time: ____ Hours ____ Minutes

2. How do you usually travel to your GP's surgery (Please Tick)?

- 1] Walk..... 4] Bus.....
2] Taxi..... 5] Community Car...
3] Car..... 6] Other (Please Specify) _____

3. If you usually have to pay any fares (e.g. taxi, bus, etc), what is the total cost of these fares ONE-WAY? (Please state '0' if you do not pay any fare)

£

4. If you usually travel to your GP's surgery by car, how much do you usually pay in parking fees? (Please state '0' if there are no parking fees incurred)

£

5. Do you usually attend your GP's surgery on your own or are you accompanied by another adult or adults?

- 1] By myself..... 2] Accompanied by ____ other adult(s)

If you are accompanied, does this person(s) usually lose earnings to attend the appointment with you (Please Tick)?

- 1] Yes 2] No..... 3] Not Applicable.....

6. How many times in the past 3 months have you visited your GP's surgery due to your pain (Please State)?

_____ Number of times.

Travel to the Hospital

7. Which hospitals do you usually visit for your chronic pain (Please State)?

Hospital 1: _____

Hospital 2: _____

8. How long does it usually take you to travel to the hospital (Please State)?

Hospital 1: Length of Time ____ Hours ____ Minutes

Hospital 2: Length of Time ____ Hours ____ Minutes

9. How do you usually travel to each of these hospitals (Please Tick)?

	Hospital 1	Hospital 2
1] Walk.....	<input type="checkbox"/>	<input type="checkbox"/>
2] Taxi.....	<input type="checkbox"/>	<input type="checkbox"/>
3] Car.....	<input type="checkbox"/>	<input type="checkbox"/>
4] Bus.....	<input type="checkbox"/>	<input type="checkbox"/>
5] Community Car.....	<input type="checkbox"/>	<input type="checkbox"/>
6] Other (Please Specify) _____		

10. If you usually have to pay any fares (e.g. taxi, bus, etc), what is the total cost of these fares ONE-WAY? (Please state '0' if there are no fares incurred)

Hospital 1: £ Hospital 2: £

11. If you usually take the car, how much do you usually pay in parking fees? (Please state '0' if there are no parking fees incurred)

Hospital 1: £ Hospital 2: £

12. Do you usually attend hospital appointments on your own or are you accompanied by another adult or adults?

- 1] By myself..... 2] Accompanied by: _____ other adult(s)

If accompanied, does this person(s) usually lose earnings to attend the hospital appointment with you (Please Tick)?

- 1] Yes..... 2] No..... 3] Not Applicable.....

Alternative Medicine

13. Have you used any type of complementary medicine because of your chronic pain?

- 1] Yes..... 2] No.....

If YES, please give details below. If NO, please go to question 14.

- 1] Osteopath..... 2] Herbalist.....
3] Accupuncturist..... 4] Chiropractic.....
5] Other (Please Specify) _____

How far do you usually travel for your alternative medicine?

Distance in Miles: _____

Length of time to get there: _____

How do you usually travel to your appointment?

- 1] Walk..... 2] Taxi....
3] Car..... 4] Bus....
5] Ambulance.... 6] Other (Please Specify) _____

Prescription Costs

14. Please tick the response that best describes how you pay for your prescriptions:

- 1] I have to pay the standard charge.....
2] I purchase pre-payment certificates.....
3] I do not have to pay for any of my prescriptions.....

Assistance from Other People

15. Since the onset of your chronic pain, have you arranged for anybody to come to your home to help with housework or gardening that you would usually have done yourself?

1] YES... 2] NO.....

If YES, please give details below. If NO, Please move on to SECTION THREE.

15b. How much do you pay for this help? (Please State)

Cost per hour:

£

15c. How many hours of help do you usually receive in a week?

Number of Hours:

15d. Who provides this help?

[1] A private business....

[2] A neighbour.....

[3] A family member.....

[4] A friend.....

Thank You, please turn over to complete Section Three

SECTION THREE:

Instructions:

The questions in this section ask you if your pain prevents you from being able to do a range of everyday activities. Not all of the questions in this section will be relevant to you (for example, you may not have children; you may choose not to work or be retired). Please do not miss any questions. If a question asks you about something that is not relevant to you then you should provide an answer based on whether you feel you could do what the question asks if you were in position where you had to try.

Please try to answer the questions as honestly as possible and please note that many of the questions ask you to consider what you have been able to do over a specific time period.

For all of the questions you should choose only one option from the four listed. Select your answer by placing a tick next to one of the options. If you want to change your answer, cross through the option that you have chosen and place a tick clearly next to your new answer.

Please read all of the options for each question before making your choice.

1. Self-Respect:

- A. I feel that I am treated with respect by others:
- All of the time
 - Most of the time
 - Rarely
 - Never
- B. I am able to be honest about the full severity of my pain:
- All of the time
 - Most of the time
 - Rarely
 - Never
- C. I find that I am believed when I talk about my pain (for example: by employers, colleagues, when seeking financial support from the State and by doctors):
- All of the time
 - Most of the time
 - Rarely
 - Never
- D. I feel that my core family have accepted (come to terms with the fact) that I have chronic pain:
- Totally accepting and supportive
 - Try to accept that I have chronic pain and do offer support
 - Find it hard to accept that I have chronic pain and are not good at offering support
 - Refuse to accept that I have chronic pain and don't offer support
- E. Over the past month, I have found that I have had to ask for help with basic, everyday tasks:
- Never
 - Rarely
 - Often
 - Always

F. Over the past month, I have been able to do things that I consider to be worthwhile and productive (for example: paid work, managing the home, voluntary work)

- As often as I could before my pain and as much as I have wanted to
- With some restriction and difficulty
- Rarely, and with great difficulty
- Not at all

G. Over the past month, I have been able to (or would have been able to) earn a wage:

- As high as I was able to earn before my pain
- That is less than before
- Due to pain, I have been (would have been) unable to earn a wage at all through employment
- I am aged over 60 and retired

2. Social Interaction

A. Over the past month, I have had the opportunity to meet new people or maintain existing friendships through employment (while at my place of work):

- I have been able to meet new people or maintain existing friendships while at work
- I have had to take some time off work over this period due to my pain
- Due to my pain, I am unable to work
- I do not work because I am retired or because I choose not to work

B. Over the past month, I have been able to go out and socialise (for example to the pub; to the cinema/theatre; to meetings held by a club/society):

- I have been able to do whatever I have wanted to do, and as often as I could have before my pain.
- Most of what I have wanted to do, and as often as I could before.
- Little of what I have wanted to do and less frequently than I have wanted or could before.
- I have tended to stay at home due to my pain

C. Over the past month, I have been able to visit friends and family:

- As often as I could before my pain and with no difficulty
- As often as before, but with some difficulty
- Less than I did before and with significant difficulty
- My pain stops me from ever visiting friends and family.

D. Over the past month have you felt included as part of a social group:

- I feel as included, socially, as I was before my pain
- I get included by my friends but I have to drop out of plans at short notice or leave events early due to my pain
- I feel that I am included less by my friends than I was before. Some friendships have faded out.
- I am no longer included in any social group and have few remaining friends.

E. Over the past month I have had enough money to:

- Go out and socialise as much as I did before
- Go out and do most of the things I once could
- Go out and do a few of the things I once could
- Buy only essential items

3. The Role of Parent or Grandparent

A. Over the past month I have been able to (**or would have been able to**) pick up, physically protect and hug young children:

- With no difficulty or pain
- With pain
- I have tended to (would) avoid this due to my pain
- I do not (would not) do this because my pain is too severe

B. Over the past month, I have been able to (**or would have been able to**) take part in games/activities/sports with children:

- With no difficulty or pain
- With pain
- I have tended to (or would) avoid this due to my pain
- I cannot (or would not be able to) do this due to my pain

C. Over the past **3 months**, I have been (**or would have been**) able to support my family financially and provide the financial security that I was able to provide before my pain:

- To the full extent that I was able to before
- Largely to the same extent as before
- Significantly less than I was before
- I have struggled a great deal more

4. Remaining Physically and Mentally Active

A. Over the past month, I have been able to pursue the same hobbies and interests as before my pain (for example: fishing, bowls, charity work, watching football):

- All of the same hobbies/interests, to the same extent that I could before my pain
- All of the same hobbies/interests, but with some restriction
- Most of the same hobbies/interests, with some restriction
- Few (or none) of the same hobbies/interests, and with some restriction

B. Over the past month, I have been able do the more physically demanding leisure activities that I could do before my pain (for example: walking, cycling, swimming, football, gardening):

- All of the same leisure activities, to the same extent as I could before my pain
- All of the same leisure activities, but with some restriction
- Most of the same leisure activities, with some restriction
- Few (or none) of the same leisure activities, and with some restriction

C. Over the past month, I have been able to (would have been able to) do paid work:

- Of the same type and the same hours as before my pain
- Of the same type, but less hours than before my pain
- A different type of work, and less hours than before
- I am not able to work at all / I am aged over 60 and retired*

* circle the description that is appropriate to you

5. Identity

A. Over the past month, I have had to ask others for special treatment:

- Never
- Rarely
- Often
- Always

B. Over the past month, I have noticed that people who *don't* know me well have treated me:

- The same way as before my pain
- A little differently than before my pain, but generally in a way that is positive
- People treat me differently simply because of my pain and this causes me to feel some embarrassment and frustration
- I tend to find that I am ignored or that people treat me in a way that causes me to feel shame and anger

C. Over the past month, I have found that I am able to engage in conversation that is not related to my pain (for example: work, hobbies, other interests):

- With ease
- With some additional effort
- With real difficulty (either due to the perception of others or due to the lack of "normal" things that I am able to do)
- It is virtually impossible

D. Over the past month, I have found that I am able to disguise or hide my pain:

- This is not a problem for me
- I have been able to hide my pain in order to be treated equally by others
- I have found it hard to hide my pain
- I have been unable to hide the fact that I am in constant pain

6. Independence and Control

A. Over the past month, I have been able to care for myself (dress, shower, and use the toilet):

- With no help at all from others and no difficulty
- With no help at all, but with some difficulty
- I have needed some help and/or have great difficulty dressing, showering or using the toilet
- I am completely dependent on others to dress, shower, or use the toilet

B. Over the last month, I have been able to drive and/or use public transport:

- As much as before and with *no* difficulty, discomfort or embarrassment
- As much as before, but with *some* difficulty, discomfort or embarrassment
- I tend to restrict travel to short distances if I can and it is difficult, uncomfortable and/or embarrassing due to the pain
- I am *unable* to drive due to my pain or medication and/or I avoid travelling as much possible because of the pain

C Over the past month, I have been able to walk to the local shop or bus stop:

- With ease
- With some difficulty and discomfort
- Not at all some days and with great difficulty on other days
- Not at all

D. Over the past month, I have had to base my daily routine around my medication:

- Not at all
- To a limited extent
- To a large extent
- My medication has a major impact on what I am able to do and when

- E. Over the past month, I have mostly been able to manage stairs:
- With ease
 - With some difficulty and discomfort
 - Not at all some days and with great difficulty on other days
 - Not at all
- F. Over the past month, I have been able to plan things in advance:
- With no uncertainty about how my health will impact on these plans
 - My pain has meant that I have to plan things in greater detail and there is some uncertainty about how my pain will impact on my plans
 - Planning things in advance is a real problem, I often don't know if I will have to cancel my plans due to my pain
 - Planning things in advance is virtually impossible
- G. Over the past month, I have been (or would have been) able to cook and look after the house:
- With ease
 - With some difficulty and discomfort
 - Not at all some days and with great difficulty on other days
 - Not at all

P. T. O.

7. Relationships:

Please answer **one** of the two questions from the box below; you should answer the **one** that is most appropriate to **you**. Consider how things have been over the past month:

EITHER

A. I have had the opportunity to meet **potential** partners/ develop **new** relationships:

- As frequently as before the pain
- Almost as frequently as before
- A lot less frequently than before
- Virtually never

OR

A. I have felt bad about my partner "missing out" due to my pain:

- Never
- Rarely
- Often
- Always

Once again, please answer **one** of the two questions from the box below; you should answer the **one** question that is most appropriate to **you**. Consider how things have been over the past month:

EITHER

B. I have (would have) had as much money to go out and enjoy time with a potential partner/date, as I had before the pain:

- As much as before
- A little less
- Significantly less
- This is (would be) a real struggle

OR

B. My pain has meant that I have shown *less* patience and emotional support towards my partner than I feel is necessary for a good relationship:

- Never
- On a few occasions
- On many occasions
- All of the time

C. Over the past month, I have been able to (would be able to) enjoy physical affection:

- With no pain
- With some pain
- I tend to avoid physical affection due to the pain
- I don't (wouldn't) have any physical affection due to the pain

P. T. O.

8. Physical and mental well-being:

A. Over the past month, I have been *free* of pain:

- All of the time (when sitting, standing, walking)
- Most of the time
- Rarely
- Never

B. I worry about the effects of my *current* medication on my future health:

- Not at all
- A little
- Frequently
- This is something that causes me a great deal of distress

C. Over the past month, I have experienced side-effects from my medication:

- None at all
- Some mild side-effects
- Some severe, but infrequent side-effects
- Severe and frequent side-effects

D. Over the past month, I have been able to sleep well:

- Every night
- Most nights
- Some nights
- Never

D. Over the past month, I have been able to get as much physical exercise as I could before my pain:

- As much as before
- Almost as much as before
- Much less than before
- None at all

E. Over the past month, I would regard myself as having been *free* of depression;

- I have not been depressed at all
- There have been occasions when I have felt depressed
- I have had days when I have felt very depressed
- Most of the time I have felt very depressed

P.T.O.

9. Enjoyment

- A. Over the past month, my pain has made me feel tired and frustrated
- Never
 - Rarely
 - Often
 - Always
- B. Over the past month, I have felt:
- No embarrassment due to my pain or envy of other people who are without chronic pain
 - Some embarrassment and/or envy
 - Ashamed that I am unable to cope better with my pain and envious of others who are in good health
 - Like I want to "hide away" due to my shame and envious of other people
- C. Over the past month, I have been able to take enjoyment from:
- All of the things I enjoyed doing before the pain
 - Most of the things I did before
 - Small things that I am able to do, given my pain
 - Very few of the things that I now do day to day
- D. When I think about the future:
- I have few concerns
 - I know that my pain will continue and I have concerns about my health and well-being
 - I know that my pain will get worse and I have concerns about my health and well-being
 - I know that my pain will continue and I question how I will be able to cope with my pain and I feel depressed

THANK YOU

Initial Questionnaire ~ Version 1.3 (Jul '07)

Assessing Quality of Life in Patients with Chronic Pain



Follow-up Questionnaire

Instructions:

The questions in the first section ask you about visits to a GP surgery or Hospital and also ask if your circumstances have changed at all since you completed the Initial Questionnaire at the Pain Management Clinic.

The questions in the second section ask you if your pain prevents you from being able to do a range of everyday activities. Not all of the questions will be relevant to you (for example, you may not have children; you may choose not to work or be retired). Please do not miss any questions. If a question asks you about something that is not relevant to you then you should provide an answer based on whether you feel you *could* do what the question asks if you were in position where you had to try.

Please try to answer the questions as honestly as possible and please note that many of the questions ask you to consider what you have been able to do over a specific time period.

For the questions in the second section you should choose only one option from the four listed. Select your answer by placing a tick next to one of the options. If you want to change your answer, cross through the option that you have chosen and place a tick clearly next to your new answer.

Please read all of the options for each question before making your choice.

Please return this questionnaire within the next two weeks using the pre-paid envelope provided.

All information you provide will be strictly confidential.

If you have any questions then please do not hesitate to contact me:

Philip Kinghorn, School of Medicine, Health Policy & Practice, University of East Anglia, Norwich, NR4 7TJ

Tel. 01603 593665 Email: P.Kinghorn@uea.ac.uk

12 Month Follow-Up Questionnaire

Patient identification: Q ___ ___ ___ / ___

12

SECTION ONE:

1. Date of Completion: ___ / ___ / 2008

2. Has your employment situation changed in the last 3 months as a result of your pain? (Please Tick)

1] YES.... 2] NO.....

If YES, please tick an option below. If NO, please go to Question 3.

1] STOPPED WORK:

- 1.1] Off-Sick.....
- 1.2] Unemployed.....
- 1.3] Retired Early.....
- 1.4] Other (Please Specify) _____

2] HOURS WORKED:

- 2.1] Reduced.....
- 2.2] Increased.....

3] RETURNED TO WORK:

- 3.1] Part-time.....
- 3.2] Full-time.....

4] OTHER:

Please Specify _____

3. During the last 3 months, how many days or part days have you and/or your partner taken off work as a result of your pain: (If none, please state '0')

YOU: _____ Days

YOUR PARTNER: _____ Days

Did you lose earnings for this time off work? (Please Tick)

YOU: Yes..... No..... Not Applicable.....

YOUR PARTNER: Yes..... No..... Not Applicable.....

4. During the last 3 months, how many days or part days has your pain prevented you and/or your partner from carrying out Household tasks? (Please Specify)

YOU: ____ Days

YOUR PARTNER: ____ Days

5. During the last 3 months, how many times have you visited one of the following health professionals at your GP's surgery, for your pain? (Please state '0' if you have not visited your GP's surgery)

1] GP: ____ (Number of visits)

2] NURSE: ____ (Number of visits)

3] OTHER: (Please Specify) _____

6. How long did you usually spend at the GP's surgery?

Time spent waiting in the surgery: ____ Hours ____ Minutes

Time spent with the doctor/nurse: ____ Hours ____ Minutes

Did you usually lose earnings to attend the appointment?

1] YES.....

2] NO.....

3] NOT APPLICABLE.....

7. During the last 3 months, how many times have you visited, or been visited by, one of the following health professionals, due to your pain?

	Number of Visits	Treatment Site (e.g. Home, or name of Hospital)
1] HOSPITAL DOCTOR/ CONSULTANT	_____	_____
2] OCCUPATIONAL THERAPIST	_____	_____
3] PHYSIOTHERAPIST	_____	_____
4] HOSPITAL NURSE	_____	_____
5] OTHER: _____	_____	_____

8. How long did you usually spend with the above health professional?

Time spent waiting: _____ Hours _____ Minutes

Time spent with health Professional: _____ Hours _____ Minutes

9. Did you usually lose earnings to attend the appointment?

1] YES..... 2] NO..... 3] NOT APPLICABLE.....

10. During the last 3 months, have you received any type of complementary medicine for your pain?

1] YES.... 2] NO.....

If YES, Please give details below. If NO, Please go to Question 11.

1] Who? (E.g. Herbalist, Osteopath) _____

Number of Visits: _____ Cost per Visit: £ _____ . _____

2] Who? (E.g. Herbalist, Osteopath) _____

Number of Visits: _____ Cost per Visit: £ _____ . _____

11. During the last 3 months, have you been admitted to hospital or day unit because of your pain?

1] YES.... 2] NO.....

If YES, please complete the table below. If NO, please go to Question 12.

	Date Admitted	Date Discharged	Name of Hospital
Stay 1			
Stay 2			
Stay 3			

12. During the last 3 months, has your doctor changed the type or dosage of your medication?

- 1] YES... 2] NO.....

If YES, please give details below. If NO, please go to Question 13.

- 1] Changed type of medication

From (name of medication) _____ to _____

- 2] Changed dosage of medication

From (dose) _____ to _____

13. During the past 3 months, have you bought any over-the-counter medication to ease your pain? (i.e. medication that is not prescribed)

	Name of Medication	Number of packs bought	Cost per Pack
	<i>(e.g. Paracetamol)</i>	<i>(e.g. 2)</i>	<i>(e.g. £0.90)</i>
1.			
2.			
3.			

14. During the past 3 months, have you had to buy any aids or have you made any adaptations to your home, car or garden because of your pain?

- 1] YES... 2] NO.....

If YES, please give details below. If NO, please go to Question 15.

Description of aid/modification: _____

Approximate Cost (if known): _____

Who Paid? (Please Tick)

- 1.1] Self or Family.....
 1.2] NHS.....
 1.3] Social Services.....
 1.4] A Charity/Voluntary Organisation.
 1.5] Other (Please Specify) _____

15. At present, do you claim any of the following benefits as a result of your pain?

- 1] YES... 2] NO.....

If YES, please tick:

- 1] SICKNESS BENEFIT.....
2] INVALIDITY/INCAPACITY BENEFIT.....
3] DISABLED WORKING ALLOWANCE.....
4] DISABLED LIVING ALLOWANCE.....
 4.1] MOBILITY.....
 4.2] ATTENDANCE.....
5] ATTENDANCE ALLOWANCE (AGE >65)...
6] DISABLED STICKER FOR CAR.....
7] OTHER (Please Specify) _____

16. During the past 3 months, have you arranged for anybody to come to your home to help with housework or gardening that you would usually have done yourself?

- 1] YES... 2] NO.....

If YES, please give details below. If NO, Please move on to SECTION TWO.

16b. How much did you pay for this help? (Please State)

Cost per hour: £ _____ . _____

16c. How many hours of help did you receive each week?

Number of Hours: _____

16d. Who supplied this help?

- [1] A private business.....
[2] A friend/neighbour.....
[3] A family member.....

Please turn over to SECTION TWO

SECTION TWO

1. Self-Respect:

A. I feel that I am treated with respect by others:

- All of the time
- Most of the time
- Rarely
- Never

B. I am able to be honest about the full severity of my pain:

- All of the time
- Most of the time
- Rarely
- Never

C. I find that I am believed when I talk about my pain (for example: by employers, colleagues, when seeking financial support from the State and by doctors):

- All of the time
- Most of the time
- Rarely
- Never

D. I feel that my core family have accepted (come to terms with the fact) that I have chronic pain:

- Totally accepting and supportive
- Try to accept that I have chronic pain and do offer support
- Find it hard to accept that I have chronic pain and are not good at offering support
- Refuse to accept that I have chronic pain and don't offer support

E. Over the past month, I have found that I have had to ask for help with basic, everyday tasks:

- Never
- Rarely
- Often
- Always

F. Over the past month, I have been able to do things that I consider to be worthwhile and productive (for example: paid work, managing the home, voluntary work)

- As often as I could before my pain and as much as I have wanted to
- With some restriction and difficulty
- Rarely, and with great difficulty
- Not at all

G. Over the past month, I have been able to (or would have been able to) earn a wage:

- As high as I was able to earn before my pain
- That is less than before
- Due to pain, I have been (would have been) unable to earn a wage at all through employment
- I am aged over 60 and retired

2. Social Interaction

A. Over the past month, I have had the opportunity to meet new people or maintain existing friendships through employment (while at my place of work):

- I have been able to meet new people or maintain existing friendships while at work
- I have had to take some time off work over this period due to my pain
- Due to my pain, I am unable to work
- I do not work because I am retired or because I choose not to work

B. Over the past month, I have been able to go out and socialise (for example to the pub; to the cinema/theatre; to meetings held by a club/society):

- I have been able to do whatever I have wanted to do, and as often as I could have before my pain.
- Most of what I have wanted to do, and as often as I could before.
- Little of what I have wanted to do and less frequently than I have wanted or could before.
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C. Over the past month, I have been able to visit friends and family:

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- I feel as included, socially, as I was before my pain
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C. Over the past **3 months**, I have been (**or would have been**) able to support my family financially and provide the financial security that I was able to provide before my pain:

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- I am aged over 60 and retired
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- It is virtually impossible

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- I am *unable* to drive due to my pain or medication and/or I avoid travelling as much possible because of the pain

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- To a limited extent
- To a large extent
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 - Not at all
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- G. Over the past month, I have been (or would have been) able to cook and look after the house:
- With ease
 - With some difficulty and discomfort
 - Not at all some days and with great difficulty on other days
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Please answer **one** of the two questions from the box below; you should answer the **one** that is most appropriate to **you**. Consider how things have been over the past month:

EITHER

A. I have had the opportunity to meet potential partners/ develop new relationships:

- As frequently as before the pain
- Almost as frequently as before
- A lot less frequently than before
- Virtually never

OR

A. I have felt bad about my partner "missing out" due to my pain:

- Never
- Rarely
- Often
- Always

Once again, please answer **one** of the two questions from the box below; you should answer the **one** question that is most appropriate to **you**. Consider how things have been over the past month:

EITHER

B. I have (would have) had as much money to go out and enjoy time with a potential partner/date, as I had before the pain:

- As much as before
- A little less
- Significantly less
- This is (would be) a real struggle

OR

B. My pain has meant that I have shown *less* patience and emotional support towards my partner than I feel is necessary for a good relationship:

- Never
- On few occasions
- On a many occasions
- All of the time

C. Over the past month, I have been able to (would have been able to) enjoy physical affection:

- With no pain
- With some pain
- I tend to avoid physical affection due to the pain
- I don't (wouldn't) have any physical affection due to the pain

8. Physical and mental well-being:

A. Over the past month, I have been *free* of pain:

- All of the time (when sitting, standing, walking)
- Most of the time
- Rarely
- Never

B. I worry about the effects of my *current* medication on my future health:

- Not at all
- A little
- Frequently
- This is something that causes me a great deal of distress

C. Over the past month, I have experienced side-effects from my medication:

- None at all
- Some mild side-effects
- Some severe, but infrequent side-effects
- Severe and frequent side-effects

D. Over the past month, I have been able to sleep well:

- Every night
- Most nights
- Some nights
- Never

D. Over the past month, I have been able to get as much physical exercise as I could before my pain:

- As much as before
- Almost as much as before
- Much less than before
- None at all

E. Over the past month, I would regard myself as having been *free* of depression;

- I have not been depressed at all
- There have been occasions when I have felt depressed
- I have had days when I have felt very depressed
- Most of the time I have felt very depressed

P. T. O.

9. Enjoyment

- A. Over the past month, my pain has made me feel tired and frustrated
- Never
 - Rarely
 - Often
 - Always
- B. Over the past month, I have felt:
- No embarrassment due to my pain or envy of other people who are without chronic pain
 - Some embarrassment and/or envy
 - Ashamed that I am unable to cope better with my pain and envious of others who are in good health
 - Like I want to "hide away" due to my shame and envious of other people
- C. Over the past month, I have been able to take enjoyment from:
- All of the things I enjoyed doing before the pain
 - Most of the things I did before
 - Small things that I am able to do, given my pain
 - Very few of the things that I now do day to day
- D. When I think about the future:
- I have few concerns
 - I know that my pain will continue and I have concerns about my health and well-being
 - I know that my pain will get worse and I have concerns about my health and well-being
 - I know that my pain will continue, I question how I will be able to cope with my pain and I feel depressed

THANK YOU

Version 1.3 (Jul '07)

Reminder Postcard

Dear *Participant*,

Re: Assessing Quality of Life in Patients with Chronic Pain

Thank you for agreeing to take part in the aforementioned study.

About 2 weeks ago I sent you a follow-up questionnaire for you to complete and return. Many people have already responded, but we have not yet received your response. Please take a few moments to complete the follow-up questionnaire and return it to me in the prepaid envelope provided.

If your response is already in the post then please ignore this reminder. If you require a new copy of the follow-up questionnaire then please do not hesitate to contact me (01603 593665).

Completed questionnaires should be sent to: Philip Kinghorn (Research Student), School of Medicine, Health Policy & Practice, University of East Anglia, Norwich, NR4 7TJ

Thank you for all your help,

Yours sincerely,
Philip Kinghorn (University of East Anglia)

APPENDIX D

Invitation Letter (Study Phase III)

Information Sheet (Study Phase III)

Consent Form (Study Phase III)

Example of Participant Pack (Study Phase III)

14 April 2008

Dear Sir/Madam,

RE: Developing a scoring system for a questionnaire designed to assess quality of life.

I would like to invite you to take part in a study which is being run by the University of East Anglia. I have written to you to inform you of this study because you have previously indicated that you would be willing to take part in studies conducted by the University of East Anglia.

Please take some time to read the *Participant Information Sheet* enclosed with this letter. If you wish to take part, please return the Consent Form in the pre-paid envelope provided. It is entirely up to you to decide whether or not you wish to take part; you do not have to give a reason for your decision.

Yours sincerely,

Philip Kinghorn

Health Economics Group
School of Medicine, Health Policy and Practice
University of East Anglia

Participant Information Sheet

University of East Anglia
Norwich NR4 7TJ England

Telephone
01603 593665

Fax
01603 593604

Developing a scoring system for a questionnaire designed to assess quality of life.

I would like to invite you to take part in a new study which is being run by the University of East Anglia. Please take time to read the following information. If you would like more information, please contact Philip Kinghorn: tel. 01603 593665, or p.kinghorn@uea.ac.uk.

What is the purpose of the study?

The purpose of this study is to develop a scoring system for responses to a questionnaire, which is currently being used to assess quality of life in patients with long-term pain.

The study will also contribute to the educational qualification of PhD in Health Economics for Philip Kinghorn.

Background to the Study:

In *previous* work we have developed a questionnaire to assess quality of life in patients with long-term pain. Each question relates to one aspect of everyday life (for example paid work or child care). Patients are asked to state the degree to which their pain has an impact on the specific aspect of everyday life covered by each of the questions.

In *this study* participants will be asked to consider how good or bad a hypothetical patient's quality of life would be, given the extent to which their pain impacts on their everyday life. Should you choose to take part you would be asked to position various hypothetical scenarios on a simple scale of best to worst. This, in turn, will allow us to give patients a single score in terms of quality of life according to their responses on the questionnaire.

Why have I been chosen?

We are *not* looking for people with long-term pain to take part in this stage of the study; we are recruiting members of the public who have previously indicated that they are willing to participate in studies conducted by the University of East Anglia. We are hoping to recruit a total of 38 people to take part.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you agree to take part you are still free to withdraw at any time and without giving a reason.

What will the study involve?

In this current stage of the research we will be asking people *without chronic pain* to consider how good or bad different hypothetical situations would be, in which the ability to perform some task or role is withdrawn. As an example, you may be asked to attach a value of between 0 (worst possible quality of life) and 100 (best possible quality of life) to life in which an individual is reliant on the help and support of others in order to care for them self and dress.

What do I have to do?

You will first be asked to work through a simple, paper-based exercise. Once the exercise has been completed you will be offered an opportunity to discuss it with the wider group. An audio recording will be made of the short group discussion. Each group will consist of three or four people. We anticipate that the tasks will take no longer than one hour. You will then be asked to complete a short health questionnaire, containing just six questions.

Travel & Expenses:

By means of a thank you and to cover any expenses incurred, participants will receive £15 for taking part in the study.

What will happen to the results?

Responses to the health questionnaire will be used solely to compare the general health of everyone participating with that of the general population; this is useful because it is sometimes the case that a person's own health might influence how they view the health of others.

The values given during the simple paper-based exercises will be published as part of a wider academic report; nothing will be published which can be used to identify individual participants.

The values given will also be used to score answers from the questionnaire, which will be used to assess quality of life in patients with long-term pain.

How will data be stored?

The health questionnaires will be anonymous (contain only a reference number). Information on the questionnaire will only be reported anonymously and the questionnaires themselves will be kept in locked storage at the UEA.

Audio tapes will be kept in locked storage at the UEA and any quotations used in the write-up of the study will be anonymous.

Who is organising and funding the research?

The James Paget Hospital and the School of Medicine, Health Policy and Practice at the University of East Anglia are funding the study. The Study is being conducted by Philip Kinghorn, who is a postgraduate research student in the School of Medicine, Health Policy & Practice at UEA.

Contact Details:

For further information speak to: **Philip Kinghorn** (University of East Anglia):

Telephone: 01603 593665; email: P.Kinghorn@uea.ac.uk.

Consent Form

Developing a scoring system for a questionnaire designed to assess quality of life.

Before signing this form, please ensure that you have read and understand the PARTICIPANT INFORMATION SHEET. **Please return completed forms in the pre-paid envelope provided.** If you have any questions then you may speak to a member of the research team before returning the Form.

Please Initial Box

1. I confirm that I have read and understand the information sheet for the above study.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that I will be asked to complete a short health questionnaire
4. I understand I will be asked to complete a paper-based exercise and then discuss the exercise as a member of a group, and that an audio recording will be made of the group discussion.
6. I agree to take part in the above study.

Signatures:

Name of Participant

Date

Signature

Researcher

Date

Signature

Participant Pack

Developing a scoring system for a questionnaire designed to assess quality of life.

BU1

Participant's name: _____

Date: ___ / ___ / 08

ID Number: _____

Scaling Exercise for Levels

Introduction:

In previous work we have developed a questionnaire to assess quality of life in NHS patients who have long-term pain. Each question describes one aspect of everyday life (for example paid work, or child care) and asks patients to state the degree to which their pain has an impact on that specific aspect of life. For each question there are four levels of impact and patients are asked to select the one level that best fits with their circumstances. The top level will always be the best situation, where their pain has no negative impact. The bottom level will always be the worst situation, where the patient's pain has the most extreme negative impact.

The middle two levels will fit somewhere in between the best level (situation) and the worst level (situation). This exercise is designed to find out exactly where the middle two levels should sit on this scale of best to worst. So, for example, on some questions the middle two levels might be very similar; for some questions they might be closer to the top of the scale than to the bottom, and so on.

The Task:

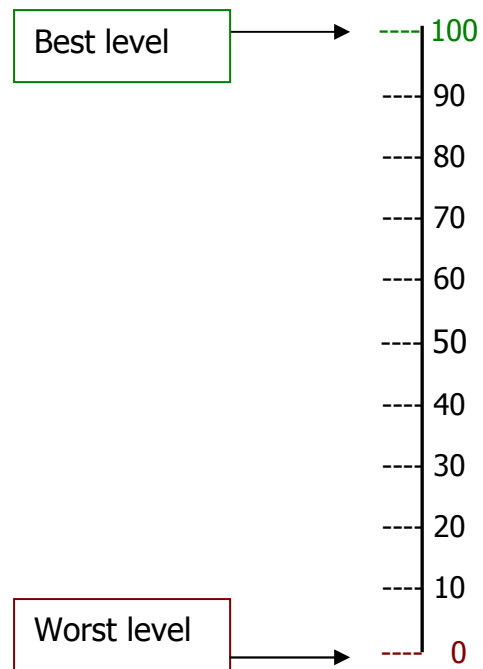
The diagrams below each illustrate a scale, above which various aspects of daily life are described. We are interested in the degree to which each aspect of daily life can be good or bad. The bottom of each scale represents the worst level at which the particular aspect of life can be experienced. The top of each scale represents the best level at which each aspect of life can be experienced.

In each case there are a further two levels at which the aspect of daily life could be experienced. You will be asked to place these additional two levels at appropriate positions along the scale. You should only consider the one aspect of everyday life to which the question refers. There are no wrong answers, simply place the remaining two levels at a point on the scale according to how good or bad you believe their impact would be on the specific aspect of daily life being considered.

The two additional (or missing) levels will be labelled A and B. Please mark a point on the scale for A and a point on the scale for B.

Finally, remember that you are NOT being asked to mark on the scale how good or bad your own personal circumstances are, instead you are being asked to place the two additional, or 'missing', levels (A and B) onto the scale.

Example:

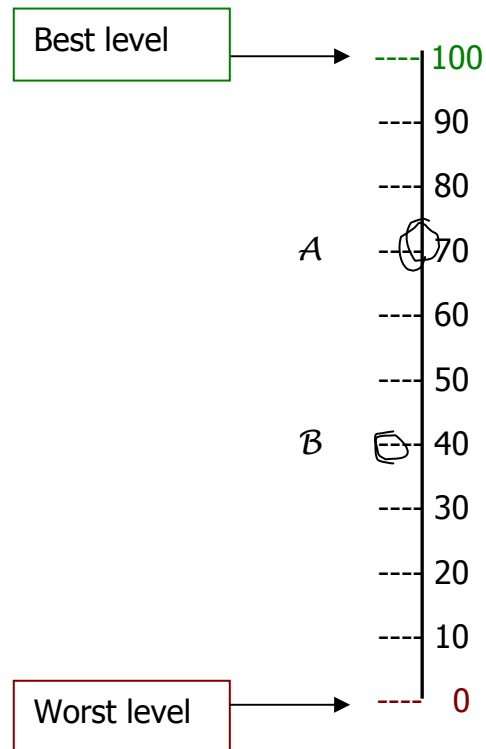


The missing levels are:

- A.** 'description of A'
- B.** 'description of B'

Please place a letter 'A' and a letter 'B' at appropriate positions along the scale.

... An example:



The missing levels are:

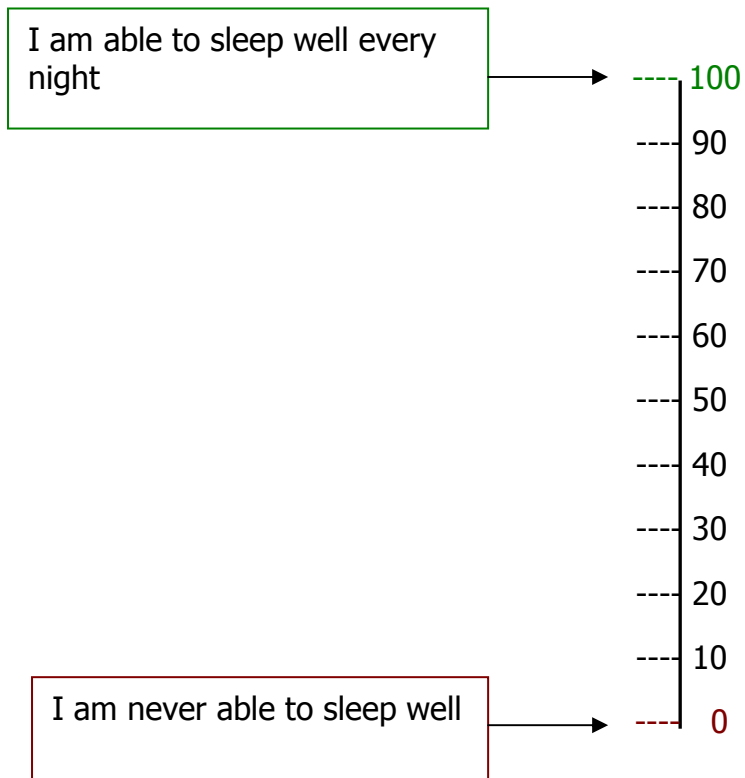
A. 'description of A'

B. 'description of B'

Please place a letter 'A' and a letter 'B' at appropriate positions along the scale.

Now, please work through the following three questions...

1. Here, you should consider your ability to get a good night's sleep

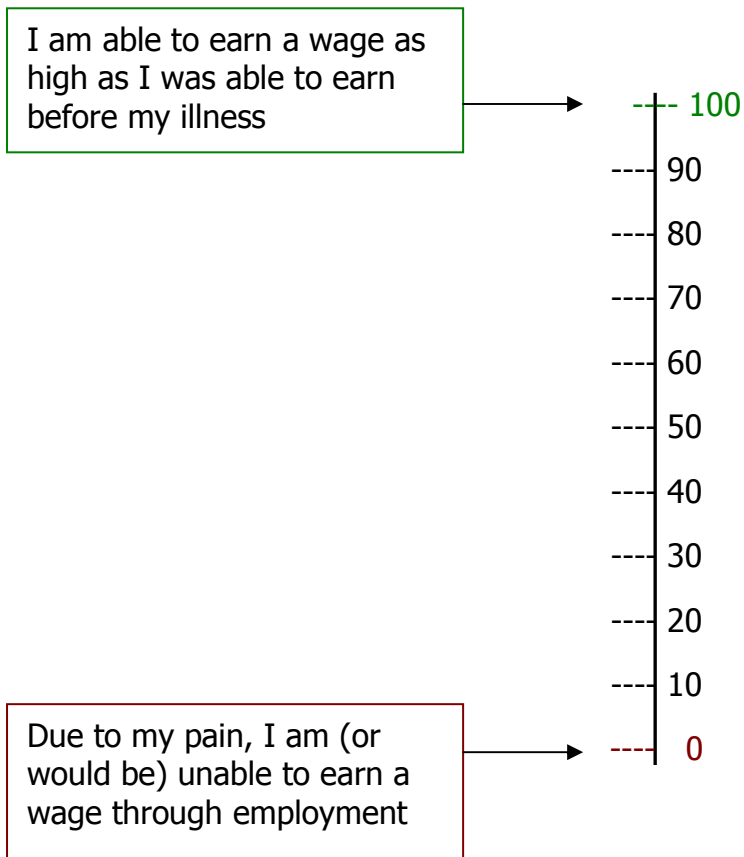


The missing levels are:

- A.** I am able to sleep well **most** nights.
- B.** I am able to sleep well **some** nights

Please place a letter 'A' and a letter 'B' at appropriate positions along the scale.

2. Here, you should consider your ability to earn a wage.



The missing levels are:

- A.** I am (or would be) able to earn a wage that is **less** than before.
- B.** I am aged over 60 and retired.

... Continued up to Question Seven

Scaling Exercise for Categories

Introduction:

The questions that you considered in the first exercise can be split up into nine categories. Each category is labelled with a short heading, for example: "Social Interaction", or "Independence and Control".

When a patient is at the highest level on all of the questions in a particular category then that category can be said to be "at best".

When a patient is at the lowest level for all of the questions in a particular category then that category can be said to be "at worst".

If all nine categories are "at best", then the patient could be said to have the best possible quality of life. If all categories are "at worst" then the patient can be thought of as having the worst possible quality of life. When some categories are "at best" and some "at worst" it is less obvious where we should position the patient's quality of life on the scale of overall best to worst. It is these middle combinations that we will consider in the following exercise.

The Task:

The diagrams below each illustrate a scale of best possible quality of life (at 100) to worst possible quality of life (at zero). You will be asked to consider scenarios in which some of the nine categories are "at best" and some are "at worst" and to decide where a patient in this scenario would be on the scale.

You will be asked to consider a total of four scenarios, labelled with the letters A to D. The first scenario has already been fixed at a position on the scale. Please place the remaining three scenarios (B, C & D) at positions along the scale relative to the position of A. For example, if you consider scenario D to be twice as good as scenario C then you should ensure that you mark the letter 'D' at a position on the scale that is twice as high as the position of letter 'C'.

Once again, there are no wrong answers.

An Example:

Start by considering scenario A, in which all nine categories are "at worst". A description of scenario A is given below:

Scenario A

All categories are at worst, the categories are:

1. Self-respect

You are unable to do things that you feel are worthwhile and productive. You have to rely on others for help with everyday tasks.

Your family have refused to accept your illness and don't offer support. You don't feel as if you are treated with respect by others.

2. Enjoyment

You feel tired and frustrated due to your illness and rarely take enjoyment from the things you do day to day. Your illness causes you to experience embarrassment.

When you think about the future you know that your pain will continue and you question how you will cope.

3. Physical & Mental Well-being

You are never free of pain, and experience frequent and severe side-effects from medication. You are unable to sleep well and are unable to do any physical exercise.

Most of the time you feel very depressed.

4. Relationships

You feel as if a partner is missing out due to your illness and feel as if your illness is placing strain on your relationship. You avoid physical affection due to the pain or discomfort it would cause you.

5. Identity

You find that other people ignore you or treat you differently due to your illness in a way that causes you to feel shame or anger.

You are unable to hide from others the fact that you are in constant pain.

6. The Role of a parent or grandparent

You do not (or would not) hug, protect or take part in games/activities with young children in your family because of the pain or discomfort it would cause you.

You struggle (or would struggle) a great deal to support your family financially.

7. Social Interaction

You very rarely have the opportunity to meet new people and struggle to maintain existing friendships. You do not feel included as part of a social group.

8. Independence and Control

You are completely dependent on others to dress, shower, etc and you are unable to cook or look after the home.

You are extremely limited in your ability to get around (on foot, in the car or using public transport).

You have to base your daily routine around your medication and variation in how you feel day-to-day makes it very difficult to plan anything in advance.

9. Remaining Physically and Mentally Active

You are able to pursue very few of the same hobbies or interests and none of the more physically demanding leisure activities (such as sport, swimming, or gardening) that you were able to do before your illness.

You are unable to do any paid work.

Now, consider scenario B, where your condition has improved. Here, one or more of the 9 categories may have improved to 'at best'.

Scenario B

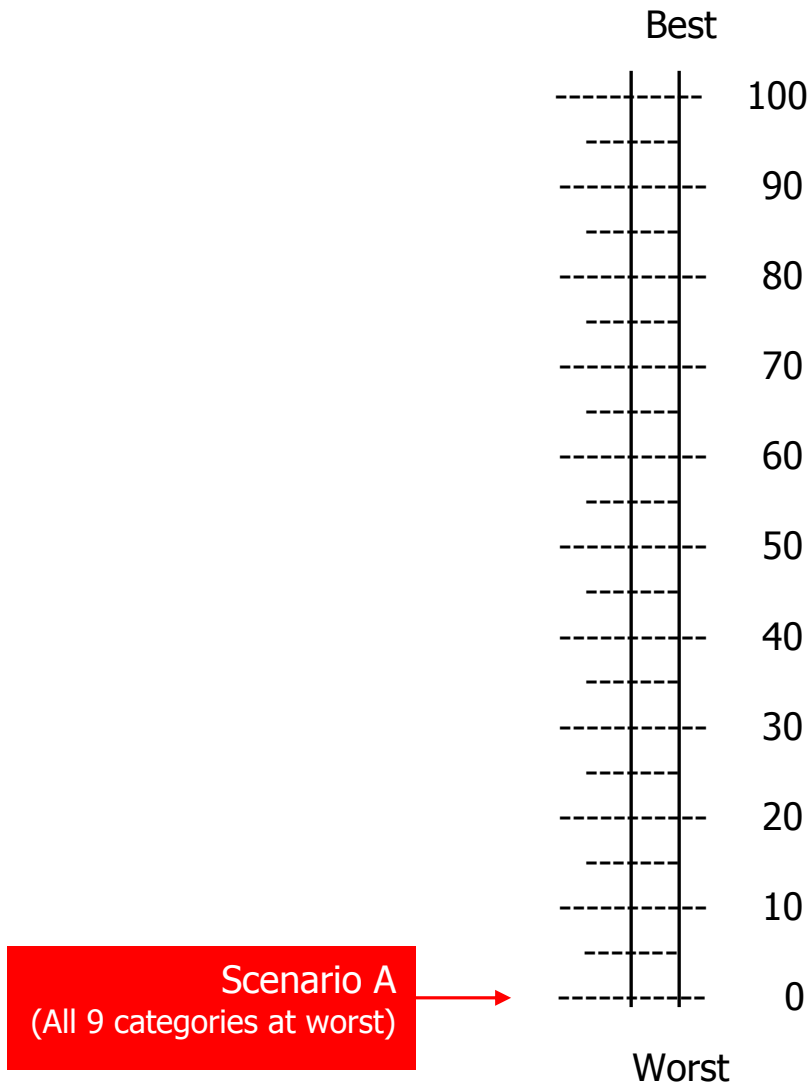
Here, category 4 (Relationships) has improved to 'at best'. All of the other categories remain at worst, i.e. how they were in Scenario A. A new summary of Category 4 is given below.

4. Relationships

You never feel as if your partner is missing out due to your illness and do not feel as if your illness is placing any strain on your relationship. You can enjoy physical affection without experiencing any pain or discomfort.

.... An Example:

Place a letter 'B' at a position along the scale according to how good or bad your own quality of life would be, given this improvement in health.



The Scenarios

Scenario A

All categories are at worst, the categories are:

1. Self-respect

You are unable to do things that you feel are worthwhile and productive. You have to rely on others for help with everyday tasks.

Your family have refused to accept your illness and don't offer support. You don't feel as if you are treated with respect by others.

2. Enjoyment

You feel tired and frustrated due to your illness and rarely take enjoyment from the things you do day to day. Your illness causes you to experience embarrassment.

When you think about the future you know that your pain will continue and you question how you will cope.

3. Physical & Mental Well-being

You are never free of pain, and experience frequent and severe side-effects from medication. You are unable to sleep well and are unable to do any physical exercise.

Most of the time you feel very depressed.

4. Relationships

You feel as if a partner is missing out due to your illness and feel as if your illness is placing strain on your relationship. You avoid physical affection due to the pain or discomfort it would cause you.

5. Identity

You find that other people ignore you or treat you differently due to your illness in a way that causes you to feel shame or anger.

You are unable to hide from others the fact that you are in constant pain.

6. The Role of a parent or grandparent

You do not (or would not) hug, protect or take part in games/activities with young children in your family because of the pain or discomfort it would cause you.

You struggle (or would struggle) a great deal to support your family financially.

Continued...

7. Social Interaction

You very rarely have the opportunity to meet new people and struggle to maintain existing friendships. You do not feel included as part of a social group.

8. Independence and Control

You are completely dependent on others to dress, shower, etc and you are unable to cook or look after the home.

You are extremely limited in your ability to get around (on foot, in the car or using public transport).

You have to base your daily routine around your medication and variation in how you feel day-to-day makes it very difficult to plan anything in advance.

9. Remaining Physically and Mentally Active

You are able to pursue very few of the same hobbies or interests and none of the more physically demanding leisure activities (such as sport, swimming, or gardening) that you were able to do before your illness.

You are unable to do any paid work.

Now, consider scenarios B, C and D in which your health has improved relative to scenario A. In scenarios B, C and D, although categories 1 to 6 will remain the same (i.e. are still at worst) one or more of categories 7 to 9 may have improved.

Scenarios B, C and D are summarised overleaf.

Scenario B

Here, only category 3 has improved to 'at best'. All other categories remain at worst, i.e. how they were in Scenario A. A new summary of category 3 is given below:

3. Physical & Mental Well-being

You are free of pain all of the time and are able to sleep well.

You are able to get as much physical exercise as you wish.

You are free of depression.

Scenario C

Here, categories 7, 8 and 9 have improved to 'at best'. All of the other categories remain at worst, i.e. how they were in Scenario A. New summaries of categories 7, 8 and 9 are given below:

3. Physical & Mental Well-being

You are free of pain all of the time and are able to sleep well.

You are able to get as much physical exercise as you wish.

You are free of depression.

7. Social Interaction

You have plenty of opportunity to meet new people and maintain existing friendships and you feel included as part of a social group.

9. Remaining Physically and Mentally Active

You are able to pursue hobbies and interests and are able to do more physically demanding leisure activities (such as sport, swimming, dancing or gardening).

You are able (should you choose) to do paid work.

Scenario D overleaf...

Scenario D

Here, categories 8 and 9 have improved to 'at best'. All other categories remain at worst, i.e. how they were in Scenario A.

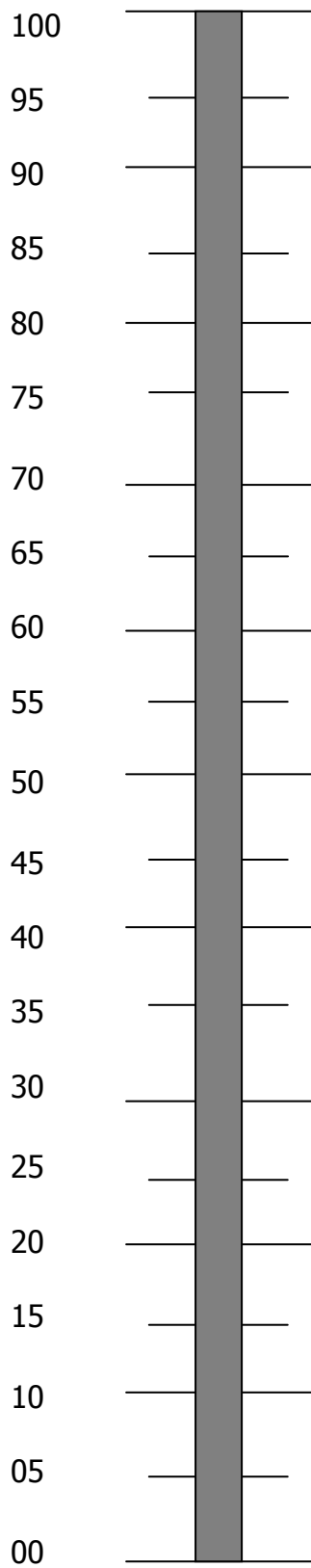
9. Remaining Physically and Mentally Active

You are able to pursue hobbies and interests and are able to do more physically demanding leisure activities (such as sport, swimming, dancing or gardening).

You are able (should you choose) to do paid work.

Please place the letters 'B', 'C' and 'D' at a position along the scale according to how good or bad your own quality of life would be, given the improvement in your health that is described in scenarios B, C and D.

Best possible quality of life



Please mark on the letters B, C and D at appropriate positions along the scale.

Scenario A (all categories at worst)

Worst possible quality of life

APPENDIX E

Links between Capability Questionnaires Developed within the Context of Health

Links between Capability Questionnaires Developed within the Context of Health

Kinghorn		Dolan & Lorgelly	Grewal & Coast
Capability	Dimension		
Self-Respect	1A I feel that I am treated with respect by others		
	1B I am able to be honest about the full severity of my pain		
	1C I find that I am believed when I talk about my pain		
	1D I feel that my core family have accepted and come to terms with my chronic pain	At present how easy or difficult do you find it to enjoy the love, care and support of your family and friends?	
	1E I have had to ask for help with everyday tasks		I am able to be completely independent
	1F I have been able to do things that I consider to be worthwhile and productive		I am able to do all of the things that make me feel valued
	1G I have been able to earn a wage		
Social Interaction	2A I have had the opportunity to meet people through work and maintain existing friendships through employment	Are you able to meet socially with friends, relatives or work colleagues?	I can have all of the love and friendship that I want & I can have all of the enjoyment and pleasure that I want
	2B I have been able to go out and socialise	How often have you been able to enjoy recreational activities?	
	2C I have been able to visit friends & family	At present how easy or difficult do you find it to enjoy the love, care and support of your family and friends?	
	2D I have felt included as part of a social group		
	2E I have had enough money to go out & socialise		
Role of Parent or Grandparent	3A I have been able to hug/protect young children		I can have all of the love and friendship that I want & I am able to do all of the things that make me feel
	3B I have been able to take part in games/ activities/ sports with children		

			valued
	3C I have been able to support family financially		
Remaining Physically & Mentally Active	4A I am able to pursue the same hobbies & interests as before my pain	Does your health in any way limit your daily activities compared to most people of your age?	I can have all of the enjoyment and pleasure that I want
	4B I am able to do the more physically demanding leisure activities that I could do before my pain		
	4C I have been able to do paid work		I am able to do all of the things that make me feel valued
Identity	5A I have had to ask for special treatment		I am able to be completely independent
	5B I have noticed that people who don't know me have treated me differently		
	5C I have been able to engage in conversation unrelated to my pain		
	5D I am able to disguise/hide my pain		
Independence & Control	6A I have been able to care for myself		I am able to be completely independent
	6B I have been able to drive/ use public transport	Does your health in any way limit your daily activities compared to most people of your age?	
	6C I have been able to walk to the local shop or bus stop		
	6D I have had to Base my daily routine around my medication		
	6E I have been able to manage stairs		
	6F I have had the ability to plan things in advance with no uncertainty about my health	I am free to decide for myself how I live my life	
	6G I have been able to cook and look after the home	Does your health in any way limit your daily activities compared to most people of your age?	

Relationships	7A (i) I have had the opportunity to meet new partners/ develop new relationships		I can have all of the love and friendship that I want
	7A(ii) I have felt bad about my partner missing out due to my pain		
	7B (i) I have had the money to go out and enjoy time with a date		
	7B (ii) Showing patience & emotional support towards a partner		
	7C I am able to enjoy physical affection without experiencing pain		
Physical & Mental Wellbeing	8A I have been free of pain		
	8B I worry about the effects of medication on my future health		I can think about the future without any concern
	8C I experience side-effects from medication		
	8D I have been able to sleep well		
	8E I have been able to get as much physical exercise as I could before my pain		
	8F I have been free of depression		I can have all of the enjoyment and pleasure that I want
Enjoyment	9A My pain has made me feel tired and frustrated		
	9B I have experienced embarrassment due to my pain		
	9C I have been able to take enjoyment from life		I can have all of the enjoyment and pleasure that I want
	9D I have concerns about the future	How often have you lost much sleep over worry?	I can think about the future without any concern