

**Uncertainty in Systemic Lupus
Erythematosus (SLE) and Rheumatoid
Arthritis (RA): Development and Validation of
a New Patient Reported Instrument**

Volume 2 of 2

Thesis submitted to University College London for the degree
of Doctor of Philosophy (PhD)

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Appendices

Appendix 1 Supporting Documents for Chapter 1

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APPENDIX 1: Chapter 1 Supporting Documents

Appendix 1.1: Data Extraction Forms

Quantitative Studies	
ID	
Discipline	
Authors	
Condition/Sample	
Study Objectives	
Study design	
Methodology	
Measurement of patient uncertainty	
Other outcome measures	
Statistical analysis	
Sample characteristics	
Results	
Findings/Conclusions	
Conceptualisation of uncertainty	
Study limitations	
Qualitative Studies	
ID	
Discipline	
Authors	
Condition/Sample	
Study Objectives	
Study design	
Methodology	
Outcome measures	
Statistical analysis	
Sample characteristics	
Results	
Uncertainty themes	
Findings/Conclusions	
Conceptualisation of uncertainty	
Study limitations	

Appendix 1.2 Literature Review Search Strategies

MEDLINE (R) (searched using the Ovid Interface from 1967 to 2008)

No.	Term & sub-headings	Results
1	Uncertain*	22149
2	Chronic Disease or Illness	397704
3	Patient*	1308654
4	Lupus, Erythematus Systemic	42507
5	Arthritis, Rheumatoid	18403
6	Rating scale or Questionnaire or Patient Assessment	27226
7	2 or 3 or 4 or 5 or 6	1716704
8	1 AND 7	5135

AMED (searched using the Ovid Interface from 1967 to 2008)

No.	Term & sub-headings	Results
1	Uncertain*	394
2	Chronic Disease or Illness	8940
3	Patient*	29202
4	Lupus, Erythematus Systemic	114
5	Arthritis, Rheumatoid	1281
6	Rating scale or Questionnaire or Patient Assessment	5985
7	2 or 3 or 4 or 5 or 6	37248
8	1 AND 7	158

EMBASE (searched using the Ovid Interface from 1967 to 2008)

No.	Term & sub-headings	Results
1	Uncertain*	28251
2	Chronic Disease or Illness	277692
3	Patient*	1738663
4	Lupus, Erythematus Systemic	55536
5	Arthritis, Rheumatoid	82845
6	Rating scale or Questionnaire or Patient Assessment	82754
7	2 or 3 or 4 or 5 or 6	2108193
8	1 AND 7	6197

PsychINFO (searched using the Ovid Interface from 1967 to 2008)

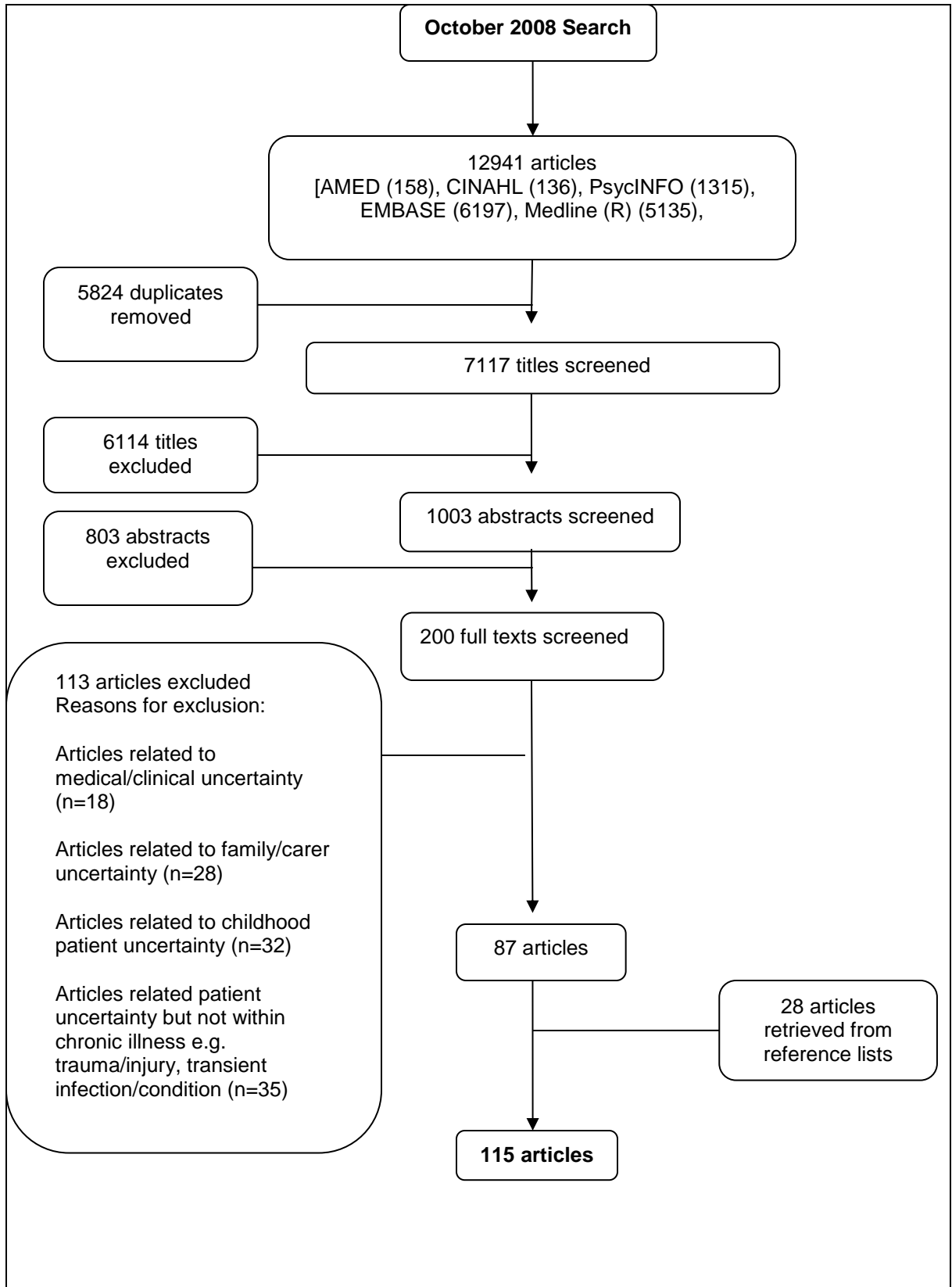
No.	Term & sub-headings	Results
1	Uncertain*	11677
2	Chronic Disease or Illness	7635
3	Patient*	120337
4	Lupus, Erythematus Systemic	505
5	Arthritis, Rheumatoid	3
6	Rating scale or Questionnaire or Patient Assessment	32806
7	2 or 3 or 4 or 5 or 6	211186
8	1 AND 7	1315

Appendix 1.2 (cont`d)

CINAHL (searched using the EBSCO interface from 1967 to 2008)

No.	Term & sub-headings	Results
1	Uncertainty or uncertain	476
2	Chronic Disease or Illness	4641
3	Patient*	15942
4	Lupus, Erythematsus Systemic	77
5	Arthritis, Rheumatoid	430
6	Rating scale or Questionnaire	3976
7	2 or 3 or 4 or 5 or 6	23000
8	1 AND 7	136

Appendix 1.3: Literature Review Search



Appendix 1.4 Derivation of the Rating Scale Rasch Model

Simple Logistic Model

$$\text{Probability "yes"} = \frac{e^{(B_n - D_i)}}{1 + e^{(B_n - D_i)}} \quad \text{Probability "no"} = \frac{1}{1 + e^{(B_n - D_i)}}$$

Rating Scale Model

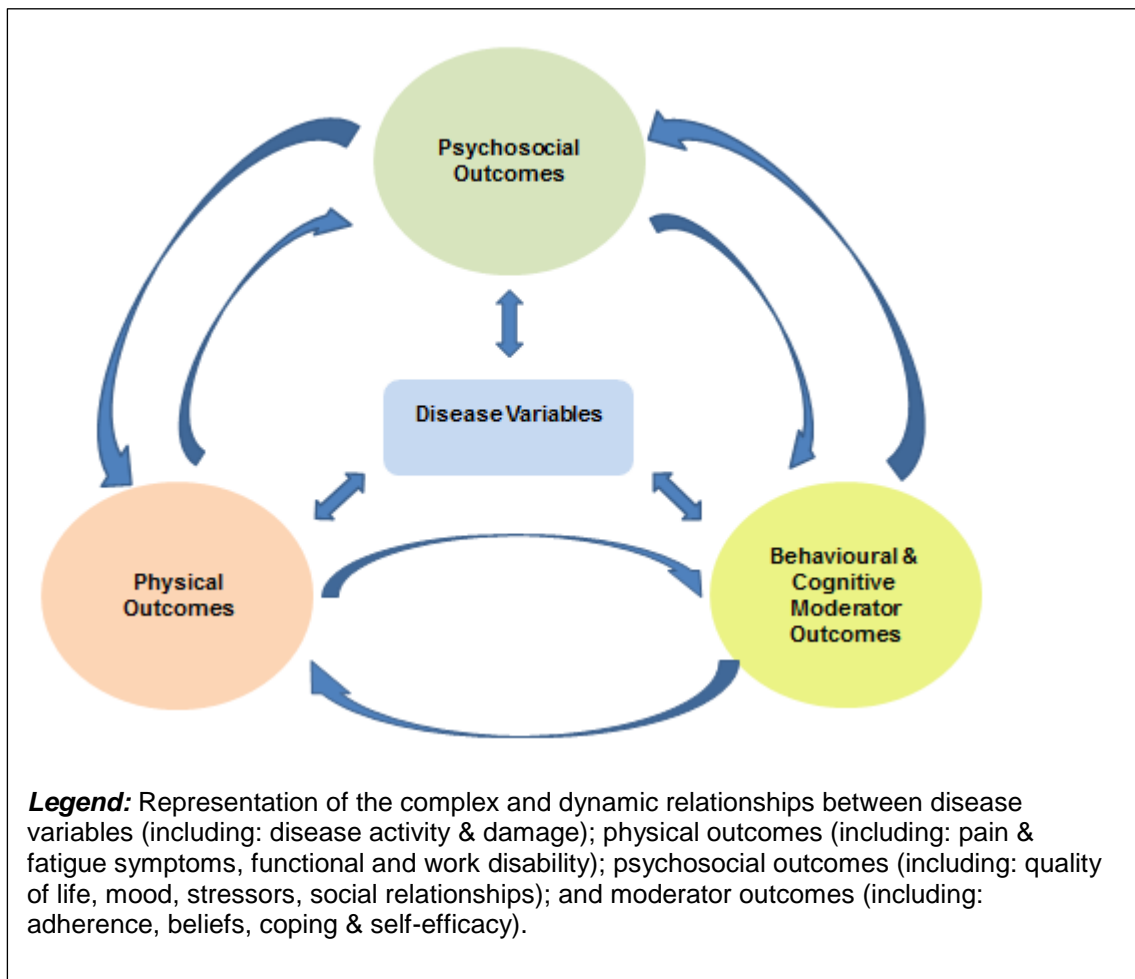
$$\text{Odds ratio of "yes"} = \frac{\frac{e^{(B_n - D_i)}}{1 + e^{(B_n - D_i)}}}{\frac{1}{1 + e^{(B_n - D_i)}}} = e^{(B_n - D_i)}$$

$$\text{Log of the odds of success} = \text{Log}_n \left\{ \frac{\text{Probability "yes"}}{1 - \text{probability "yes"}} \right\} = (B_n - D_i)$$

Legend: The derivation of the David Andrich Rasch Rating Scale Model as outlined in the Hobart & Cano 2009 Monograph. The probability (P) of a person (n) to respond (x) to item (i), where B = the location/ability of a person; D= location/difficulty.

Appendix 2: Supporting Documents for Chapter 2

Appendix 2.1 Representation of the Complex Relationships between Disease and Patient Variables



Appendix 3: Supporting Documents for Chapter 3

Appendix 3.1: Qualitative Interviews Invitation Letter

University College London Hospitals 
NHS Foundation Trust

Invitation letter, version 1, 16/12/08

Unit of Behavioural Medicine
University College London
1st Floor Charles Bell House
67-73 Riding House Street
London
W1W 7EJ

Email: 

Dear...

I am writing to invite you to take part in a study which the Unit of Behavioural Medicine at UCL is conducting together with us at the Department of Rheumatology of University College Hospital. We are always striving to understand as best as we can what our patients are going through. To assist in this, we would like to explore in this study, any uncertainty you may experience due to your illness.

The study will involve an interview with one of the researchers, at a time that suits your schedule. The purpose of the interview is to understand your views on how your condition affects your everyday life. I have attached an information sheet with more information about the study for you to read through. If you do wish to take part, a researcher will be at the clinic on the day of your next outpatient appointment so that you can book a time for the interview.

Thank you for taking the time to read this letter.

Yours sincerely,

Prof. David Isenberg / Dr. Michael Shipley



UCL Hospitals is an NHS Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, The Middlesex Hospital, National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.

University College London Hospitals 
NHS Foundation Trust

Participant Information Sheet
(Version 4: 20/01/10)

Uncertainty in Rheumatological Conditions Study

Investigators: Professor Stanton Newman, Professor David Isenberg, Dr. Michael Shipley, Dr Stefan Cano, Sophie Cleanthous.

Contact details: Unit of Behavioural Medicine, 1st Floor Charles Bell House, 67-73 Riding House Street, London W1W 7EJ
Email: [REDACTED], Tel: 02076799044

You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and ask us 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.

What is the purpose of the study?

Although various studies have examined the course of rheumatological conditions, very little has been undertaken which investigates this experience from the perspective of the patients. It is important for us to have a clear view of your understanding and expectations about the future course of your condition and how this affects your everyday life. Enhancing our understanding on the patients` perspective will help us plan long term care better.

Why have I been chosen?

You are being asked to take part in this study because you have a diagnosis of one of the following rheumatological conditions, Rheumatoid Arthritis or Systemic Lupus Erythematosus.

Do I have to take part?

It is completely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form agreeing to take part in the study. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision not to take part or to withdraw at any time, will not affect the standard of care you receive.

continued....

Appendix 3.2 (cont`d)

What does the study involve?

If you agree to take part in this study we shall make an appointment for you to meet with the researcher on a day and at a time that suit your schedule. The meeting will take place at the Centre for Rheumatology & Bloomsbury Rheumatology Unit (The Windeyer Building) UCL, on 46 Cleveland street very close to the University College Hospital. The meeting will involve an interview with the researcher which will be audio taped. We shall be happy to reimburse you for any public transport costs (please keep the receipts). You will be asked a few questions about your illness condition, and issues related to living with it. The conversation will largely be guided by what and how much information you want to share with us. Please note that you will be free to share only as much information as you wish. It is anticipated that the process will take 60-90 minutes. The information we obtain from you will be kept confidential.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in this study, it is hoped that this work will contribute to improving the long-term care of patients with rheumatological conditions.

Confidentiality of records

We also need permission to access your medical records, which relate directly to this study. All the information we obtain will be strictly confidential. UCL will overview the collection, storage and handling of the data and Professor Newman, in his capacity as chief investigator, will be responsible for security and access to the data. Only study investigators (named above) will have access to the data. All of the information collected during the study, excluding your name, will be stored and analysed confidentially in a computer. No identifiers on the data held by computer will enable a third party to link the data to you. A study ID number will be assigned to you and this will appear on all data including medical information and questionnaires. All data will be kept strictly confidential and secured under lock and key in UCL. The data will be stored for 7 years after the study has been completed. The results of this study may be published within the medical literature, however; but no personal details will be revealed. Copies of the publications will be available to you from the researchers on request. A report of the findings of the research will be sent to all interested participants in approximately 2 years from the start of the study.

Comments or concerns during the study

If you have a concern about any aspect of this study you should speak to the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Complaints Manager, UCLH, 2nd Floor West, 250, Euston Road, London NW1 2PQ. Please quote the UCLH project number at the top of this information sheet.

Ethics Committee Review

All proposals for research on human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Ethics Committee in Ethics of Human Research. Thank you for taking the time to read this. If you decide to take part you will be given a copy of this information sheet and a signed consent form to keep.

Appendix 3.3: Qualitative Interviews Participant Consent Form

University College London Hospitals



NHS Foundation Trust

**CONSENT FORM
(Version 2, 08/01/09)**

Uncertainty in Rheumatological Conditions Study

Investigators: Miss Sophie Cleanthous, Dr. Stefan Cano, Professor Stanton Newman, Dr. Mike Shipley, Professor David Isenberg.

Please read the following statements and initial box

1. I confirm that I have read and understood the information sheet for the above study.	
2. I confirm that I have had the opportunity to consider the information, ask questions and have had these answered satisfactory.	
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected.	
4. I understand that all data will be kept strictly confidential to this research and give permission for the above investigators to have access to my <u>medical</u> records.	
5. I consent to my quotations being used anonymously in relevant publications	
6. I agree to take part in the above study.	

Name of Patient

Date

Signature

Name of Investigator

Date

Signature

Appendix 3.4: Pre-Testing Invitation Letter

University College London Hospitals



NHS Foundation Trust

Patient Feedback - Invitation letter

Unit of Behavioural Medicine
University College London
1st Floor Charles Bell House
67-73 Riding House Street
London
W1W 7EJ
Email: [REDACTED]

Dear...

Thank you very much for taking the time to participate in the study entitled “Uncertainty in Rheumatological Conditions” that was conducted last year. Based on the findings of this study, we are currently developing a new questionnaire to assess patient uncertainty in rheumatology. Involving patients in the development of a new questionnaire is considered very important in assuring the suitability of the questionnaire.

I am writing to invite you to take part in the next phase of this study involving the development and validation of this new uncertainty questionnaire. If you agree to participate in this study, you will be asked to complete the newly developed questionnaire and interviewed on one occasion. The purpose of the interview will be to get your feedback on the questionnaire. The interview will be carried out at a time that suits your schedule.

In the next week or so you will be contacted by our researcher, Sophie Cleanthous, who will explain more about the study.

Thank you for taking the time to read this letter.

Yours sincerely,

Prof. David Isenberg / Dr. Michael Shipley

University College London Hospitals



NHS Foundation Trust

Participant Information Sheet

(23/11/2010Version 1)

Uncertainty in Rheumatological Conditions: Patient Feedback

Investigators: Professor Stanton Newman, Professor David Isenberg, Dr. Michael Shipley, Dr Stefan Cano, Sophie Cleanthous.

Contact details: Sophie Cleanthous, Centre for Rheumatology Research, The Windeyer Building, 46 Cleveland Street London W1T 4JF
Email: [REDACTED], Tel:0207 040 0873

You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and ask us 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.

What is the purpose of the study?

We are always striving to understand as best as we can what our patients are going through and incorporating their view in improving patient care and management. This is often achieved by the use of standardised questionnaires completed by patients themselves to inform and guide patient management and care.

Based on the findings of the “Uncertainty in Rheumatological Conditions” study that you have taken part in, we are currently developing a new questionnaire to assess patient uncertainty in rheumatology. Involving patients in the development of a new questionnaire is considered very important in assuring the suitability and appropriateness of each questionnaire.

In the second phase of this study, we wish to assess the newly developed uncertainty questionnaire. Making sure that this questionnaire correctly represents uncertainty experienced by rheumatology patients is crucial for its effective use in patient management. Furthermore it is also very important for us to make sure that questionnaire items are appropriate and acceptable to rheumatology patients.

Why have I been chosen?

You have been chosen to take part in this study because you have a diagnosis of Rheumatoid Arthritis or Systemic Lupus Erythematosus and have previously been interviewed for the purposes of this study.

continued....

Appendix 3.5 (cont`d)

Do I have to take part?

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

What does the study involve?

In the next week, you will be contacted by our researcher, Sophie Cleanthous, who will explain more about the study. If you agree take part in this study this will involve making an appointment to meet with the researcher on a time that suits your schedule. The meeting will take place at the Centre for Rheumatology Research, The Windeyer Building, 46 Cleveland Street London W1T 4JF.

At the appointment you will be presented with the newly developed questionnaire relating to the uncertainty of your condition and asked to comment on the questionnaire items whilst completing them. This process will be audio taped and is anticipated to last about 30 to 60 minutes. Please note that you will be free to share only as much as you want with us. The information we obtain from you will be kept confidential.

Will I have to pay for travel?

We shall be happy to reimburse you for any public transport costs (please keep the receipts).

What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in this study, it is hoped that this work will contribute to improving the long-term care of patients with rheumatic conditions.

Confidentiality of records

All of the information collected during the study, excluding your name, will be stored and analysed confidentially in a computer. No identifiers on the data held by computer will enable a third party to link the data to you. A study ID number will be assigned to you and this will appear on all data including medical information and questionnaires. All data will be kept strictly confidential and secured under lock and key in UCL. The data will be stored for 7 years after the study has been completed. The results of this study may be published within the medical literature, however; but no personal details will be revealed. Copies of the publications will be available to you from the researchers on request. A report of the findings of the research will be sent to all interested participants in approximately 2 years from the start of the study.

Comments or concerns during the study

If you have a concern about any aspect of this study you should speak to the researcher (Sophie Cleanthous, email: [REDACTED], tel: 0207 040 0873) who will do her best to answer your questions. If you remain unhappy and wish to complain formally you can do this through the Complaints Manager, UCLH, 2nd Floor West, 250, Euston Road, London NW1 2PQ. Please quote the UCLH project number at the top of this information sheet.

Ethics Committee Review

All proposals for research on human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Ethics Committee in Ethics of Human Research. Thank you for taking the time to read this. If you decide to take part you will be given a copy of this information sheet and a signed consent form to keep.

Appendix 3.6: Pre-Testing Consent Form

University College London Hospitals 
 NHS Foundation Trust

CONSENT FORM
(23/11/2010, version 1)

Uncertainty in Rheumatological Conditions Study – Patient Feedback

Investigators: Miss Sophie Cleanthous, Dr. Stefan Cano, Professor Stanton Newman, Dr. Mike Shipley, Professor David Isenberg.
 Contact details: Unit of Behavioural Medicine, 1st Floor Charles Bell House, 67-73 Riding House Street, London W1W 7EJ
 Email: [REDACTED], Tel: 02076799044

Please read the following statements and initial box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.	
2. I confirm that I have had sufficient time to consider whether or not I wish to participate in the study.	
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason and without my medical care or legal rights being affected.	
4. I understand that the information collected during this research will remain confidential	
5. I agree to take part in the above study.	

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Investigator	Date	Signature

Appendix 3.7: Initial Patient Certainty Questionnaire

Thank you for agreeing to fill out this questionnaire which includes questions about current and future issues related to your lupus/RA. Please answer each question according to **HOW CERTAIN** you are about each of these issues. Please answer all of the questions. If you are not sure, make your best guess. All of the information you provide is **COMPLETELY CONFIDENTIAL**.

Section A: Current Issues

Questions 1- 3 relate to the state and symptoms of your lupus/RA at the moment.

1. The following questions relate to your lupus/RA symptoms. Thinking about your lupus/RA, how certain are you that you understand lupus/RA symptoms? Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) I can tell which symptoms are specific to lupus/RA.	1	2	3	4
b) I can tell apart lupus/RA symptoms from natural symptoms of growing older.	1	2	3	4
c) I can tell lupus/RA symptoms apart from side-effects caused by the medication I am taking.	1	2	3	4
d) I can tell apart everyday lupus/RA symptoms from flares.	1	2	3	4
e) I know how serious my lupus/RA symptoms are.	1	2	3	4
f) I know that my lupus/RA symptoms are not imaginary.	1	2	3	4
g) I can tell straight away when I am experiencing a lupus/RA symptom.	1	2	3	4
h) I know when to expect a lupus/RA symptom.	1	2	3	4
i) I know how long my lupus/RA symptoms last.	1	2	3	4
j) I know what triggers my lupus/RA symptoms.	1	2	3	4
k) I know all the symptoms related to my lupus/RA.	1	2	3	4

2. Think about the medication you are taking and the side effects you are experiencing (if any). Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I am experiencing side effects because of the medication I am taking	1	2	3	4

3. Think about the state of your lupus/RA and how well you are at the moment. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
My lupus/RA is under control at the moment.	1	2	3	4

Questions 4 – 9 relate to the rheumatology doctor who looks after your lupus/RA and your lupus/RA treatment and care.

4. Think about how your lupus/RA is being treated. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) I understand how my lupus/RA is treated.	1	2	3	4
b) I understand why I am being treated.	1	2	3	4

5. Think about the medications you are taking for your lupus/RA at the moment. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) The medication I am taking is helping my lupus/RA symptoms.	1	2	3	4
b) The medication I am taking is controlling my lupus/RA.	1	2	3	4
c) I need the medication I am currently taking for my lupus/RA.	1	2	3	4
d) I need stronger or more medication for my lupus/RA.	1	2	3	4
e) I need additional medication for my lupus/RA.	1	2	3	4
f) I need alternative medication for my lupus/RA.	1	2	3	4

6. Think about the support you get from the hospital team that looks after your lupus/RA. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I have the continuous support of the hospital team (e.g. I can get an emergency appointment if I need to).	1	2	3	4

7. Think about the medical tests you usually have for your lupus/RA (e.g. blood tests or scans). Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I understand what my medical test results mean.	1	2	3	4

8. Think about the things you discuss with your rheumatology doctor. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I understand my doctor's questions and recommendations.	1	2	3	4

9. How well do you think your rheumatology doctor knows your lupus/RA? Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) My doctor knows exactly what caused my lupus/RA.	1	2	3	4
b) My doctor knows exactly how active I should be.	1	2	3	4
c) My doctor knows which medication dose is the best for me.	1	2	3	4
d) My doctor knows which medication will work best for me.	1	2	3	4
e) My doctor knows exactly how my lupus/RA will progress.	1	2	3	4
f) My doctor knows exactly what's wrong with me.	1	2	3	4
g) My doctor knows how to help me control the physical aspects of my lupus/RA.	1	2	3	4
h) My doctor knows how to help me with the non-physical aspects of my lupus/RA (e.g. feeling low).	1	2	3	4

Questions 10 – 13 relate to the things you do to control and manage your lupus/RA.

10. Thinking about your lupus/RA, how certain are you that you can help control your lupus/RA? Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
There are things I can do to help control my lupus/RA (e.g. avoid or recover from flares).	1	2	3	4

11. Think of the things you do to take care of yourself and your lupus/RA. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I know exactly how to manage my lupus/RA.	1	2	3	4

12. Think about the things you report to your rheumatology doctor. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I know which symptoms I need to report to my doctor.	1	2	3	4

13. Think about the effect of your physical activities on your lupus/RA. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I know which types of physical activity I should be doing and which I should avoid.	1	2	3	4

Question 14 refers to the impact lupus/RA has on the planning of your activities.

14. Think about the ways in which lupus/RA affects the planning of your life. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) I can plan everyday things e.g. grocery shopping & housework	1	2	3	4
b) I can plan social events in advance e.g. attending a wedding	1	2	3	4

c) I can plan holidays in advance	1	2	3	4
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Questions 15 – 16 relate to your social relationships in association with your lupus/RA.

15. Think about your family and loved ones in relation with your lupus/RA. Please **circle** the option that best describes **how certain** you are about the following statements.

My family and loved ones...	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) ...are supportive of my lupus/RA.	1	2	3	4
b) ...understand the variety and severity of lupus/RA symptoms I am experiencing.	1	2	3	4

16. Thinking about how people react to your lupus/RA, how certain are you about revealing your diagnosis? Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I can confidently reveal my lupus/RA diagnosis to others.	1	2	3	4

Section B: Future Issues

Questions 17 – 20 relate to your future lupus/RA symptoms and how your lupus/RA will develop in the future.

17. Think about your symptoms and how they could develop in the future. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I know what could cause my symptoms to get worse.	1	2	3	4

18. Think about the future development of your lupus/RA and how easy it is for you to predict it. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) I can predict that my lupus/RA will flare-up in the future.	1	2	3	4
b) I can predict what type of flare-ups I will experience.	1	2	3	4
c) I can predict when I will experience a flare-up.	1	2	3	4
d) I can predict how often I will experience a flare-up.	1	2	3	4
e) I can predict how lupus/RA will affect me in the future.	1	2	3	4
f) I can predict how severe my flare-ups will be.	1	2	3	4

19. Think about the changes in your symptoms and your health status (i.e. how well you are). Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) I can predict how well I will be in six months.	1	2	3	4

b) I can predict how well I will be next month.	1	2	3	4
c) I can predict how well I will be next week.	1	2	3	4
d) I can predict how well I will be tomorrow.	1	2	3	4

20. Think about how your lupus/RA will develop in the future. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) The state of my lupus/RA will stay the same in the future.	1	2	3	4
b) Lupus/RA will not affect my life expectancy	1	2	3	4

Questions 21-24 relate to the future treatment of your lupus/RA and the continuity of your care.

21. Think about the effectiveness of your medication in the future. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
The medication I am taking will continue to control my symptoms in the future.	1	2	3	4

22. Think about what additional treatments for your lupus/RA you might need to have in the future. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I will NOT need to have surgery in the future.	1	2	3	4

23. Think about what effect (if any) the medication you are taking for lupus/RA could have on your body. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
The medication I am taking will NOT have any side effects.	1	2	3	4
The medication I am taking will NOT have any severe side effects.	1	2	3	4

24. Think about how safe and reassured you feel when seeing your personal rheumatology doctor. Please **circle** the option that best describes **how certain** you would feel about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) I would feel confident if a doctor other than my personal consultant saw me in the clinic.	1	2	3	4
b) I would feel confident moving my lupus/RA care to a different hospital.	1	2	3	4
c) I would feel confident receiving healthcare whilst abroad (outside the UK).	1	2	3	4

Question 25 relates to how you will manage your lupus/RA in the future

25. Think about how your lupus/RA might develop. How certain are you that you will be able to manage your lupus/RA in the future? Please **circle** the option that best describes **how certain** you are about the following statement.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I will be able to manage my lupus/RA in the future.	1	2	3	4

Question 26 relates to the possible effect lupus/RA could have on your personal life.

26. Think of how lupus/RA could affect aspects of your personal life. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain	Not applicable
a) Lupus/RA will affect my ability to keep a job.	1	2	3	4	na
b) Lupus/RA will affect my ability to find a job.	1	2	3	4	na
c) Lupus/RA will affect my finances.	1	2	3	4	na
d) Lupus/RA will affect my ability to complete my education.	1	2	3	4	na
e) Lupus/RA will affect my ability to exercise.	1	2	3	4	na
f) Lupus/RA will affect my ability to cook.	1	2	3	4	na
g) Lupus/RA will affect my ability to dress myself.	1	2	3	4	na
h) Lupus/RA will affect my ability to travel abroad.	1	2	3	4	na
i) Lupus/RA will affect my mobility (e.g. my ability to walk).	1	2	3	4	na
j) Lupus/RA will burden my relationship with my partner.	1	2	3	4	na
k) Lupus/RA will affect my ability to maintain a relationship with my partner.	1	2	3	4	na
l) Lupus/RA will affect my ability to find a partner.	1	2	3	4	na
m) Lupus/RA will affect my ability to care for my children.	1	2	3	4	na

n) Lupus/RA will cause problems to my pregnancy.	1	2	3	4	na
o) Lupus/RA will affect my ability to get pregnant.	1	2	3	4	na

Question 27 relates to the practical and emotional support you will from your family and loved ones in the future.

27. Thinking about the future, how certain are you that your family and loved ones will support you? Please **circle** the option that best describes **how certain** you are about the following statements.

My family and loved ones...	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
a) ... will be supportive of my lupus/RA.	1	2	3	4
b) ... will help me manage the day-to-day issues of my lupus/RA.	1	2	3	4
c) ... will care for me if necessary.	1	2	3	4

Appendix 3.8: Pre-Testing Item Modifications

Item Index			Modified Version
5d	I need stronger or more medication for my lupus/RA.	→	I do NOT need stronger or more medication for my lupus/RA.
5e	I need additional medication for my lupus/RA.	→	I do NOT need additional medication for my lupus/RA.
5f	I need alternative medication for my lupus/RA.	→	I do NOT need alternative medication for my lupus/RA.
26a	Lupus/RA will affect my ability to keep a job.	→	Lupus/RA will NOT affect my ability to keep a job.
26b	Lupus/RA will affect my ability to find a job.	→	Lupus/RA will NOT affect my ability to find a job.
26c	Lupus/RA will affect my finances.	→	Lupus/RA will NOT affect my finances.
26d	Lupus/RA will affect my ability to complete my education.	→	Lupus/RA will NOT affect my ability to complete my education.
26e	Lupus/RA will affect my ability to exercise.	→	Lupus/RA will NOT affect my ability to exercise.
26f	Lupus/RA will affect my ability to cook.	→	Lupus/RA will NOT affect my ability to cook.
26g	Lupus/RA will affect my ability to dress myself.	→	Lupus/RA will NOT affect my ability to dress myself.
26h	Lupus/RA will affect my ability to travel abroad.	→	Lupus/RA will NOT affect my ability to travel abroad.
26i	Lupus/RA will affect my mobility (e.g. my ability to walk).	→	Lupus/RA will NOT affect my mobility (e.g. my ability to walk).
26j	Lupus/RA will burden my relationship with my partner.	→	Lupus/RA will NOT burden my relationship with my partner.
26k	Lupus/RA will affect my ability to maintain a relationship with my partner.	→	Lupus/RA will NOT affect my ability to maintain a relationship with my partner.
26l	Lupus/RA will affect my ability to find a partner.	→	Lupus/RA will NOT affect my ability to find a partner.
26m	Lupus/RA will affect my ability to care for my children.	→	Lupus/RA will NOT affect my ability to care for my children.
26n	Lupus/RA will cause problems to my pregnancy.	→	Lupus/RA will NOT cause problems to my pregnancy.
26o	Lupus/RA will affect my ability to get pregnant.	→	Lupus/RA will NOT affect my ability to get pregnant.
1b	I can tell apart lupus/RA symptoms from natural symptoms of growing older.	→	I can tell apart lupus/RA symptoms from the natural symptoms of getting older
16	I can confidently reveal my lupus/RA diagnosis to others	→	I can confidently reveal my lupus/arthritis diagnosis to a potential employer or at my workplace.
		→	I can confidently reveal my lupus/arthritis diagnosis to others (e.g. social circle, friends).
17	I know what could cause my symptoms to get worse.	→	I know what may cause my symptoms to get worse.
23a	The medication I am taking will NOT have any long-term side effects.	→	The medication I am taking will NOT cause any side effects in the future.
23b	The medication I am taking will NOT have any severe long-term side effects.	→	The medication I am taking will NOT cause any severe side effects in the future.

