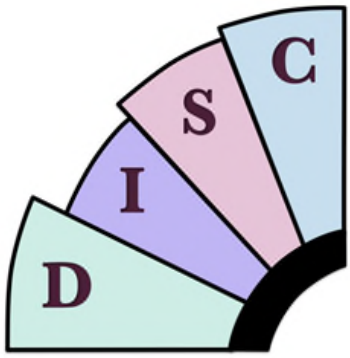


Dupuytren's Interventions Surgery vs Collagenase

One Year Questionnaire Booklet

FOR STUDY PARTICIPANT COMPLETION

Site ID: ☐☐

Participant Study Number: ☐☐☐☐

Participant Initials: ☐☐☐

Visit date: ☐☐ / ☐☐ / ☐☐☐☐
day *month* *year*

University of York

NHS University Hospitals of Leicester NHS Trust

This project was funded by the National Institute for Health Research Health Technology Assessment Programme (project number 15/102/04).

Instructions for this questionnaire booklet

The purpose of this questionnaire booklet is to find out about your Dupuytren's Contracture and the impact it has on your daily activities. Please answer the questions in relation to your reference hand (the hand which is being treated as part of this research study). The answers you give in this questionnaire booklet will be treated confidentially.

The questions should be answered by either
- putting a cross in a box
- putting a number in a box
- putting a circle around a number
- marking on a line

When you have finished, please check that you have answered all questions, and return the questionnaire booklet to a member of staff at the clinic.

If you have further questions or need help with filling in this questionnaire booklet, please ask the DISC trial nurse or doctor.

Alternatively, please contact a member of the trial team, whose details you will find on your DISC Trial Patient Information Leaflet.

You will note that certain questions have been repeated, this is deliberate, and we thank you in advance for your cooperation in filling out every section of this questionnaire booklet.

Please turn overleaf to continue filling in this questionnaire booklet.

Section A – Research Study Hand

To be completed by a member of the research team

Please tick to confirm which hand is being treated as part of this research study.

☐ **Left hand**

☐ **Right hand**

Please proceed to Section B

Section B – Patient Evaluation Measure (PEM)

The questions below ask about your hand and treatment.

Please answer the following questions in relation to your hand which is being treated as part of this research study (as detailed in Section A).

If you do not complete some of the activities in the questions, please provide an answer based on a similar activity you do (e.g. if you are retired and the question asks about work, please answer the question in relation to any hobbies you have).

Part One - **Treatment**

Please cross the box next to the number that is the closest to the way you feel about how things have been for you. There are no right or wrong answers.

1. Throughout my treatment at the hospital, I have seen the same doctor:

Every time 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Not at all

2. When the doctor saw me, he or she knew about my case:

Every time 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Not at all

3. When I was with the doctor, he or she gave me a chance to talk:

Every time 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Not at all

4. When I did talk to the doctor, he or she listened and understood me:

Every time 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Not at all

5. I was given information about my treatment and progress:

Every time 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Not at all

Part Two - **How your hand/wrist/finger is right now: *Hand Health Profile***

1. The FEELING/SENSATION in my hand is now:

Normal 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Absent

2. When my hand/wrist/finger is cold and/or damp the PAIN is now:

Non-existent 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Unbearable

3. MOST of the time, the PAIN in my hand is now:

Non-existent 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Unbearable

4. The duration that my PAIN is present is:

Never 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ All the time

5. When I try to USE my hand for fiddly things it is now:

Skilful 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Clumsy

6. Generally, when I MOVE my hand it is:

Flexible 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Stiff

7. The GRIP in my hand is now:

Strong 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Weak

8. For everyday ACTIVITIES, my hand is now:

No problem 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Useless

9. For my WORK, my hand is now:

No problem 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Useless

10. When I look at the APPEARANCE of my hand now, I feel:

Unconcerned 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Embarrassed and self-conscious

11. Generally, when I think about my hand I feel:

Unconcerned 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Very upset

Part Three - **Overall Assessment**

1. Generally my treatment at the hospital has been:

Very satisfactory 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Very unsatisfactory

2. Generally, my hand is now:

Very satisfactory 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Very unsatisfactory

3. Bearing in mind my original injuries or condition, I feel my hand is now:

Better than I expected 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Worse than I expected

Please proceed to Section C

Section C – Unité Patient Rated Outcome Measure (URAM)

The questions below ask about actions you may use your hands for.

Please answer the following questions in relation to your hand which is being treated as part of this research study (as detailed in Section A).

Please provide an answer for all questions.

Can you:

	Without difficulty (0)	With very little difficulty (1)	With some difficulty (2)	With much difficulty (3)	Almost impossible (4)	Impossible (5)
1. Wash yourself with a flannel, keeping your hand flat?	☐	☐	☐	☐	☐	☐
2. Wash your face?	☐	☐	☐	☐	☐	☐
3. Hold a bottle in one hand?	☐	☐	☐	☐	☐	☐
4. Shake someone's hand?	☐	☐	☐	☐	☐	☐
5. Stroke something or caress someone?	☐	☐	☐	☐	☐	☐
6. Clap your hands?	☐	☐	☐	☐	☐	☐
7. Spread out your fingers?	☐	☐	☐	☐	☐	☐
8. Lean on your hand?	☐	☐	☐	☐	☐	☐
9. Pick up small objects with your thumb and index finger?	☐	☐	☐	☐	☐	☐

Please proceed to Section D

Section D – Michigan Hand Questionnaire (MHQ)

The questions below ask about your hands and your health.

If you do not complete some of the activities in the questions, please provide an answer based on a similar activity you do (e.g. if you are retired and the question asks about work, please answer the question in relation to any hobbies you have).

I. The following questions refer to the function of your hand(s)/wrist(s) ***during the past week***. (Please circle one answer for each question). Please answer ***EVERY*** question, even if you do not experience any problems with the hand and/or wrist.

A. The following questions refer to your ***right*** hand/wrist.

		Very Good	Good	Fair	Poor	Very Poor
1.	Overall, how well did your ***right*** hand work?	1	2	3	4	5
2.	How well did your ***right*** fingers move?	1	2	3	4	5
3.	How well did your ***right*** wrist move?	1	2	3	4	5
4.	How was the strength in your ***right*** hand?	1	2	3	4	5
5.	How was the sensation (feeling) in your ***right*** hand?	1	2	3	4	5

B. The following questions refer to your ***left*** hand/wrist.

		Very Good	Good	Fair	Poor	Very Poor
1.	Overall, how well did your ***left*** hand work?	1	2	3	4	5
2.	How well did your ***left*** fingers move?	1	2	3	4	5
3.	How well did your ***left*** wrist move?	1	2	3	4	5
4.	How was the strength in your ***left*** hand?	1	2	3	4	5
5.	How was the sensation (feeling) in your ***left*** hand?	1	2	3	4	5

II. The following questions refer to the ability of your hand(s) to do certain tasks ***during the past week.*** (Please circle one answer for each question). If you do not do a certain task, please estimate the difficulty with which you would have in performing it.

A. How difficult was it for you to perform the following activities using your ***right hand?***

		Not at All Difficult	A Little Difficult	Somewhat Difficult	Moderately Difficult	Very Difficult
1.	Turn a door knob	1	2	3	4	5
2.	Pick up a coin	1	2	3	4	5
3.	Hold a glass of water	1	2	3	4	5
4.	Turn a key in a lock	1	2	3	4	5
5.	Hold a frying pan	1	2	3	4	5

B. How difficult was it for you to perform the following activities using your ***left hand?***

		Not at All Difficult	A Little Difficult	Somewhat Difficult	Moderately Difficult	Very Difficult
1.	Turn a door knob	1	2	3	4	5
2.	Pick up a coin	1	2	3	4	5
3.	Hold a glass of water	1	2	3	4	5
4.	Turn a key in a lock	1	2	3	4	5
5.	Hold a frying pan	1	2	3	4	5

C. How difficult was it for you to perform the following activities using ***both of your hands?***

		Not at All Difficult	A Little Difficult	Somewhat Difficult	Moderately Difficult	Very Difficult
1.	Open a jar	1	2	3	4	5
2.	Button a shirt/blouse	1	2	3	4	5
3.	Eat with a knife/fork	1	2	3	4	5
4.	Carry a grocery bag	1	2	3	4	5
5.	Wash dishes	1	2	3	4	5
6.	Wash your hair	1	2	3	4	5
7.	Tie shoe laces/knots	1	2	3	4	5

III. The following questions refer to how you did in your ***normal work*** (including both housework and school work) during the ***past four weeks***. (Please circle one answer for each question).

		Always	Often	Sometimes	Rarely	Never
1.	How often were you unable to do your work because of problems with your hand(s)/wrist(s)?	1	2	3	4	5
2.	How often did you have to shorten your work day because of problems with your hand(s)/ wrist(s)?	1	2	3	4	5
3.	How often did you have to take it easy at your work because of problems with your hand(s)/ wrist(s)?	1	2	3	4	5
4.	How often did you accomplish less in your work because of problems with your hand(s)/wrist(s)?	1	2	3	4	5
5.	How often did you take longer to do the tasks in your work because of problems with your hand(s)/ wrist(s)?	1	2	3	4	5

IV. The following questions refer to how much ***pain*** you had in your hand(s)/wrist(s) ***during the past week***. (Please circle one answer for each question).

A. The following questions refer to **pain** in your ***right*** hand/wrist.

1. How often did you have pain in your ***right*** hand(s)/wrist(s)?

    1. Always
    2. Often
    3. Sometimes
    4. Rarely
    5. Never

If you answered **never** to **question IV-A1** above, please skip the following questions and go to the next page.

2. Please describe the pain you had in your ***right*** hand(s)/wrist(s)?

    1. Very mild
    2. Mild
    3. Moderate
    4. Severe
    5. Very severe

		Always	Often	Sometimes	Rarely	Never
3.	How often did the pain in your ***right*** hand(s)/wrist(s) interfere with your sleep?	1	2	3	4	5
4.	How often did the pain in your ***right*** hand(s)/wrist(s) interfere with your daily activities (such as eating or bathing)?	1	2	3	4	5
5.	How often did the pain in your ***right*** hand(s)/wrist(s) make you unhappy?	1	2	3	4	5

B. The following questions refer to **pain** in your ***left*** hand/wrist.

1. How often did you have pain in your ***left*** hand(s)/wrist(s)?

    1. Always
    2. Often
    3. Sometimes
    4. Rarely
    5. Never

If you answered **never** to **question IV-B1** above, please skip the following questions and go to the next page.

2. Please describe the pain you had in your ***left*** hand(s)/wrist(s).

    1. Very mild
    2. Mild
    3. Moderate
    4. Severe
    5. Very severe

		Always	Often	Sometimes	Rarely	Never
3.	How often did the pain in your ***left*** hand(s)/wrist(s) interfere with your sleep?	1	2	3	4	5
4.	How often did the pain in your ***left*** hand(s)/wrist(s) interfere with your daily activities (such as eating or bathing)?	1	2	3	4	5
5.	How often did the pain in your ***left*** hand(s)/wrist(s) make you unhappy?	1	2	3	4	5

V. A. The following questions refer to the appearance (look) of your ***right*** hand **during the past week**. (Please circle one answer for each question).

		Strongly Agree	Agree	Neither Agree **nor** Disagree	Disagree	Strongly Disagree
1.	I am satisfied with the appearance (look) of my ***right*** hand.	1	2	3	4	5
2.	The appearance (look) of my ***right*** hand sometimes made me uncomfortable in public.	1	2	3	4	5
3.	The appearance (look) of my ***right*** hand made me depressed.	1	2	3	4	5
4.	The appearance (look) of my ***right*** hand interfered with my normal social activities.	1	2	3	4	5

B. The following questions refer to the appearance (look) of your ***left*** hand **during the past week.** (Please circle one answer for each question).

		Strongly Agree	Agree	Neither Agree **nor** Disagree	Disagree	Strongly Disagree
1.	I am satisfied with the appearance (look) of my ***left*** hand.	1	2	3	4	5
2.	The appearance (look) of my ***left*** hand sometimes made me uncomfortable in public.	1	2	3	4	5
3.	The appearance (look) of my ***left*** hand made me depressed.	1	2	3	4	5
4.	The appearance (look) of my ***left*** hand interfered with my normal social activities.	1	2	3	4	5

VI. A. The following questions refer to your satisfaction with your ***right*** hand/wrist **during the past week**. (Please circle one answer for each question).

		Very Satisfied	Somewhat Satisfied	Neither Satisfied **nor** Dissatisfied	Somewhat Dissatisfied	Very Dissatisfied
1.	Overall function of your ***right*** hand	1	2	3	4	5
2.	Motion of the fingers in your ***right*** hand	1	2	3	4	5
3.	Motion of your ***right*** wrist	1	2	3	4	5
4.	Strength of your ***right*** hand	1	2	3	4	5
5.	Pain level of your ***right*** hand	1	2	3	4	5
6.	Sensation (feeling) of your ***right*** hand	1	2	3	4	5

B. The following questions refer to your satisfaction with your ***left*** hand/wrist **during the past week.** (Please circle one answer for each question).

		Very Satisfied	Somewhat Satisfied	Neither Satisfied **nor** Dissatisfied	Somewhat Dissatisfied	Very Dissatisfied
1.	Overall function of your ***left*** hand	1	2	3	4	5
2.	Motion of the fingers in your ***left*** hand	1	2	3	4	5
3.	Motion of your ***left*** wrist	1	2	3	4	5
4.	Strength of your ***left*** hand	1	2	3	4	5
5.	Pain level of your ***left*** hand	1	2	3	4	5
6.	Sensation (feeling) of your ***left*** hand	1	2	3	4	5

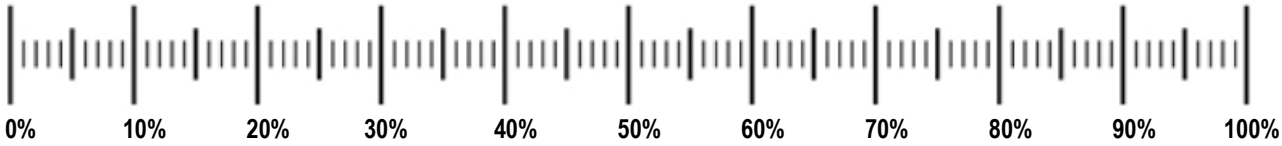
Please proceed to Section E

Section E – Single Assessment Numeric Evaluation and Overall Assessment

Please answer the following questions in relation to your hand which is being treated as part of this research study (as detailed in Section A).

How would you rate your hand function today (with normal being 100%)?

Mark on the line below:



(for office use only)

Overall, how are the problems now with the hand in which you had treatment compared to before?

- ☐ Cured
- ☐ Much better
- ☐ A little better
- ☐ The same
- ☐ A little worse
- ☐ Much worse
- ☐ Terrible

Please proceed to Section F

Section F – EQ-5D-5L

The questions below ask about your general health.
Under each heading, please tick the **ONE** box that best describes your health **TODAY**

MOBILITY

I have no problems in walking about ☐
I have slight problems in walking about ☐
I have moderate problems in walking about ☐
I have severe problems in walking about ☐
I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐
I have slight problems washing or dressing myself ☐
I have moderate problems washing or dressing myself ☐
I have severe problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

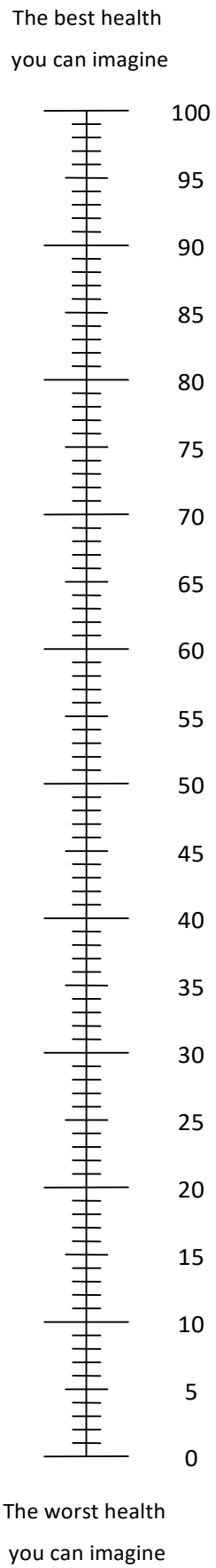
I have no problems doing my usual activities ☐
I have slight problems doing my usual activities ☐
I have moderate problems doing my usual activities ☐
I have severe problems doing my usual activities ☐
I am unable to do my usual activities ☐

PAIN/DISCOMFORT

I have no pain or discomfort ☐
I have slight pain or discomfort ☐
I have moderate pain or discomfort ☐
I have severe pain or discomfort ☐
I have extreme pain or discomfort ☐

ANXIETY/DEPRESSION

I am not anxious or depressed ☐
I am slightly anxious or depressed ☐
I am moderately anxious or depressed ☐
I am severely anxious or depressed ☐
I am extremely anxious or depressed ☐



- We would like to know how good or bad your health is TODAY.
- The scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.

  0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = | | | |

Please proceed to Section G

Section G – Resource Use

This <u>final</u> section asks about the health care you have received related to your fingers or hands over the <u>past 6 months</u>.

<u>Care from the NHS NOT in the hospital</u>:

Since you had your first treatment for your finger/hand, have you had any care over the **past 6 months** NOT in the hospital? ☐ Yes ☐ No

If 'Yes', over the **past 6 months**, how many times have you:

1. Seen your **GP** at your GP **practice about your fingers/hands?**
   (please record the number of times in the boxes) | | *If none enter '0'*

2. Seen a **nurse** at your GP **practice about your fingers/hands?**
   (please record the number of times in the boxes) | | *If none enter '0'*

3. Seen a community **physiotherapist about your fingers/hands?**
   (please record the number of times in the boxes) | | *If none enter '0'*

4. Seen an **occupational therapist about your fingers/hands?**
   (please record the number of times in the boxes) | | *If none enter '0'*

<u>Care from the NHS IN the hospital:</u>

Please do not include the visit related to your initial treatment on your finger/hand when you are answering the following questions.

Since you had your first treatment for your finger/hand, have you had any **<u>outpatient visit</u>** to the hospital over the **past 6 months**?

5 **Outpatient** visit with a **surgeon about your fingers/hands?** ☐ Yes ☐ No

If 'Yes', how many times have you seen them for the following procedures?

5.1 for a follow-up assessment?
(please record the number of times in the boxes) | | *If none enter '0'*

5.2 for a surgical hand procedure?
(please record the number of times in the boxes) | | *If none enter '0'*

5.3 for a collagenase injection?
(please record the number of times in the boxes) | | *If none enter '0'*

5.4 for manipulation (to bend your finger) including an anaesthetic injection?
(please record the number of times in the boxes) | | *If none enter '0'*

If you didn't see a surgeon, how many other outpatient visits have you had?

6. **Outpatient** visit with **a nurse about your fingers/hands?**
(please record the number of times in the boxes) | | | *If none enter '0'*

7. **Outpatient** visit with **a physiotherapist about your fingers/hands?**
(please record the number of times in the boxes) | | | *If none enter '0'*

8. **Outpatient** visit with **an occupational therapist about your fingers/hands?**
(please record the number of times in the boxes) | | | *If none enter '0'*

9. **Outpatient** visit to **a pain clinic about your fingers/hands?**
(please record the number of times in the boxes) | | | *If none enter '0'*

Finally, since you had your first treatment for your finger/hand, have you had **<u>any other of the following visits to the hospital</u>** over the **past 6 months?:**

10. **Visited <u>Accident and Emergency</u> about your fingers/hands?**
(please record the number of times in the boxes) | | | *If none enter '0'*

11. How many nights have you **stayed in hospital as an <u>inpatient</u> about your fingers/hands?**
(please record the number of nights in the boxes) | | | *If none enter '0'*

<u>Return to work</u>

<u>Please tick one box for the category that describes your current employment</u>

In full time employment (30 hours or more a week) ☐

In part time employment (less than 30 hours a week) ☐

Not in paid employment ☐
(e.g. housework, voluntary work, caring duties)

Retired ☐

12. **If you are in PAID** employment, how many working days over the **past 6 months** have you missed because of **your hand or finger problem?**

Please include any (paid or unpaid) sick days taken as the result of your condition (e.g. if you miss 2 and a half days then put 2.5) ☐☐.☐

13. During the **past 6 months**, have you lost time from your normal activities (e.g. housework, caring duties, voluntary work, shopping, leisure and hobbies) which you would normally do but could not do for reasons related to your hand or finger? ☐ Yes ☐ No

If Yes, approximately how many hours were lost per week? ☐☐.☐

<u>Private treatments</u>: Could you please tell us about **any additional medical treatments you have received, which you have paid for (e.g. personal cost or personal private insurance health care) relating to your hands or fingers. Please also include any private health care paid for by company insurance.**

Over the **past 6 months**, how many times have you:

14. Seen a private hand specialist or physiotherapist for a clinical assessment? ☐☐
(please record the number of times in the boxes) *If none enter '0'*

15. Seen a private hand specialist for a collagenase injection? ☐☐
(please record the number of times in the boxes) *If none enter '0'*

16. Seen a private hand specialist for a surgical treatment? ☐☐
(please record the number of times in the boxes) *If none enter '0'*

Thank you for taking the time to fill in this questionnaire.

Please check all the pages to make sure that you have answered every statement.