



Mesothelioma Outcomes, Research and Experience survey (MORE Survey).

Mesothelioma UK would like to invite mesothelioma patients to have the opportunity to describe what their experience of investigations, treatment and care has really been like.

The survey will enable Mesothelioma UK to inform health care providers about what is being done well, what could be improved and hopefully where there are variations in treatment and care. It will also assist Mesothelioma UK to develop its services to complement those of the NHS. Mesothelioma UK will make recommendations representing the patient experience and circulate these to the wider mesothelioma community and health care providers

Thank you for taking the time to complete the survey. I confirm that any details that you give on the survey will be completely anonymised.

Yours sincerely

Liz Darlison Head of Services

Welcome to the Mesothelioma Outcomes Research and Experience (MORE) Survey. Please complete all 3 sections and ask your MESO UK nurse to check and validate section 3 before submitting

Section 1

Information about you - your experience of care and treatment

Please enter the unique patient identifier supplied by your Meso UK nurse

Are you resident in the UK?

- Yes (if yes, please continue)
 No (if no, please do not complete the study)

Q1.1. What is the first part of your home postcode?
e.g. BS35

Q1.2. How old are you now?

- Under 18 46-50
 19-25 51-55
 26-30 56-60
 31-35 61-65
 36-40 66-70
 41-45 70+

Q1.3. Are you

- Male Female

Asbestos exposure

Q1.4. From your memory were you ever exposed to asbestos?

- Yes, through my own work (please go to Q1.5)
 Yes, through another person's work
e.g. laundering clothing
 Yes, my house contained asbestos e.g. whilst undertaking DIY
 Yes, by living near to the asbestos industry
 Don't know

Q1.5. If exposed at work, what was your occupation at that time?

- I was not or don't think I was exposed at work
 Joiner or carpenter
 Electrician
 Plumber
 Builder
 Lagger
 Teacher
 Nurse
 Doctor
 Engineer
 Secretarial or Admin
 Other

Q1.6. Is there a history of mesothelioma in your family?

- Yes No Don't know

Q1.7. Since being diagnosed with Mesothelioma were you ever helped to identify where the asbestos exposure may have occurred?

- Yes No

Q1.8. Have you ever been a member of the armed forces?

- Yes (if yes, please go to Q1.9)
 No (if no, please go to Q1.11)

Q1.9. If you have been a member of the armed forces which service?

- Army
 Royal Navy
 Royal Airforce
 Other

Q1.10. If you have been a member of the armed forces what was your length of service?

- Less than 5 years
 5-10 years
 10-15 years
 15-20 years
 More than 20 years

Medical History

Q1.11. To the best of your ability, can you recall the approximate date when you first experienced symptoms relating to your mesothelioma?

- Yes (if yes, please go to Q1.12)
 No (if no, please go to Q1.13)

Q1.12. Date when first experienced symptoms

Please write 1st of month and year

Q1.13. To the best of your ability, can you recall the date you were diagnosed with mesothelioma?

Please write 1st of month and year

Q1.14. Can you remember approximately how many times you presented to your GP with symptoms related to mesothelioma before being referred to the hospital for further tests?

- None
 1-2
 3-4
 5+
 Don't know

Q1.15. In the last year, related to your mesothelioma, how many outpatient visits have you attended – ie in total for hospital visits, clinical appointments, scans, tests or treatment

- None 16-20
 1-5 20+
 6-10 Don't know
 11-15

Q1.16. In the last year how many hospital admissions have you had related to mesothelioma?

- None
 1-2
 3-4
 5+
 Don't know

Q1.17. In the last year how many nights have you had to spend in hospital related to their mesothelioma?

- None 16-20
 1-5 20+
 6-10 Don't know
 11-15

Your personal experience in the management of your mesothelioma

Q1.18. Who was it that first told you about your mesothelioma diagnosis?

- GP
 Hospital doctor
 Mesothelioma nurse specialist
 Other nurse specialist
 Relative or a friend
 Nobody, I / we worked it out for ourselves
 Someone else

Q1.19. Was the explanation of the mesothelioma diagnosis given in an understandable way?

- Yes, completely
 Yes, to some extent
 No
 Don't know

Q1.20. Was the explanation given in a sensitive way?

- Yes
 Somewhat, but it could have been given more sensitively
 No
 Cannot remember

Q1.21. Did someone explain that a multidisciplinary team had reviewed your case?

- Yes No Don't know

Q1.22. Have you received all of your care and treatment at the same hospital?

- Yes, I was diagnosed and treated at the same hospital
 No, I received my treatment at another hospital

If yes, please go to Q1.24

Q1.23. If you were referred to another hospital for treatment, has all your treatment continued there?

- Yes
 No, I have returned to the hospital where I was diagnosed
 No, I have shared care between the hospitals

Q1.24. Was written information provided about treatment and side effects of treatments given to or shared with you?

- Yes, at the hospital where I was diagnosed
 Yes, at the hospital where I received my treatment (if these are not the same)
 No
 Don't know
 Can't remember

Q1.25. Were the appointments with your hospital doctor/team frequent enough?

- Yes No

Q1.26. If you needed to arrange an outpatient appointment how easy was it?

- Very easy Very difficult
 Fairly easy Don't know
 Not very easy I can't remember

Q1.27. Do you think that the doctors diagnosing mesothelioma knew enough about the condition and treatment?

- Yes
 Yes, to some extent
 No

Q1.28. Do you think that the doctors treating mesothelioma knew enough about the condition and treatment?

- Yes
 Yes, to some extent
 No

Q1.29. When you have had CT scans, have you received the results in a timely manner?

- Yes No

Q1.30. Did hospital doctors and nurses do everything they could to help control any breathlessness?

- I haven't had this symptom
 Yes, they did
 Yes, to some extent
 No, they didn't

Q1.31. Did hospital doctors and nurses do everything they could to help control any fatigue?

- I haven't had this symptom
 Yes, they did
 Yes, to some extent
 No, they didn't

Q1.32. Did hospital doctors and nurses do everything they could to help control any coughing?

- I haven't had this symptom
 Yes, they did
 Yes, to some extent
 No, they didn't

Q1.33. Did hospital doctors and nurses do everything they could to help control any pain?

- I haven't had this symptom
 Yes, they did
 Yes, to some extent
 No, they didn't

Q1.34. Did the doctors and the nurses give the person with mesothelioma and the family all the information needed to help care at home?

- Yes, definitely
 Yes, to some extent
 Yes, to the person with mesothelioma only
 No, family and friends were not involved
 Family or friends did not need the information
 They did not want the family or friends to be given the information
 Don't know
 I can't remember
 Not applicable at present

Q1.35. Was good support received from your GP in relation to your mesothelioma diagnosis?

- Yes definitely
 Yes, to some extent
 No

Q1.36. Were you informed of the name of the Mesothelioma UK Nurse, Nurse Specialist or other keyworker?

- Yes, Mesothelioma UK Nurse
 Yes, other Nurse Specialist
 Yes, other keyworker
 No
 Don't know / I can't remember

Q1.37. Were you informed of a Mesothelioma UK specifically funded nurse?

- Yes, my nurse specialist is a Mesothelioma UK Nurse
 Yes, I was informed by my Nurse Specialist, other keyworker
 No, I was not informed
 Don't know / I can't remember

Q1.38. How easy was it to contact your Mesothelioma UK Nurse, other Nurse Specialist or keyworker?

- Very easy
 Fairly easy
 Not very easy
 Very difficult
 Don't know / I can't remember

Q1.39. Does the Mesothelioma UK Nurse, other Clinical Nurse Specialist or keyworker answer important questions in an understandable way?

- Yes, completely
 Yes, to some extent
 No
 Don't know / I can't remember

Q1.40. Were you given information about self-help groups or support groups for people with mesothelioma?

- Yes
 No
 Don't know / I can't remember

Q1.41. Have you attended a patient and carer support group?

- Yes (if yes, please go to Q1.43)
 No (if no, please go to Q1.42)

Q1.42. If no, would you like to have attended a patient and carer support group?

- Yes Maybe No

Q1.43. Was enough support provided at home (for example district nurses, carers, physiotherapists or occupational therapists)?

- Yes
 Yes, to some extent
 No
 No, support at home has not been needed

Q1.44. Was support received from a community palliative care nurse (for example a Macmillan Nurse or Marie Curie Nurse)?

- Yes
 Yes, to some extent
 No
 No, this support has not been needed

Q1.45. Was support received in relation to planning care towards the end of life?

- Yes
 No
 Didn't want to discuss it
 Don't know
 I can't remember
 Not applicable at present

Q1.46. Overall have all the professionals involved in your diagnosis worked well together to provide the best possible care?

- Yes
 Yes, to some extent
 No

Q1.47. Overall have all the professionals involved in your treatment worked well together to provide the best possible care?

- Yes
 Yes, to some extent
 No

Q1.48. Has the person with mesothelioma, relative or friend ever been in contact with Mesothelioma UK via telephone, the helpline or email?

- Yes
 No
 Don't know / I can't remember

Q1.49. Were you given information about how to get financial help or benefits?

- Yes
 No
 Don't know / I can't remember

Q1.50. Have you been in contact with an asbestos support group?

- Yes
 No
 Don't know / I can't remember

Q1.51. Were you advised about how to contact a lawyer who specialises in claims for mesothelioma?

- Yes, at the time of my diagnosis
 Yes, after the time of my diagnosis
 No
 Don't know / I can't remember

Q1.52. Have clinical trials ever been discussed with you?

- Yes, at the time of my diagnosis
 Yes, during or after my treatment
 No
 Don't know / I can't remember

Q1.53. Have you ever been enrolled into a clinical trial?

- Yes (if yes, please go to Q1.54)
 No (if no, please go to Q1.56)
 Don't know / I can't remember (If don't know, please go to Q1.56)

Q1.54. If you have been enrolled into a clinical trial were you given enough information?

- Yes
 No
 I can't remember

Q1.55. If you have been enrolled into a clinical trial, can you say approximately how long your journey to the hospital for the trial or to receive treatment takes?

- less than 30 minutes 151-180 minutes
 31-60 minutes 181-210 minutes
 61-90 minutes 210-240 minutes
 91-120 minutes more than 240 minutes
 121-150 minutes

Q1.56. Regarding treatment for your Mesothelioma were you ever given information about obtaining a second opinion?

- Yes (if yes, please go to Q1.57)
 No (if no, please go to Q1.58)
 Don't know (if don't know, please go to Q1.58)

Q1.57. If you attended another hospital for a second opinion, can you say approximately how long it takes on each journey for a second opinion?

- less than 30 minutes 151-180 minutes
 31-60 minutes 181-210 minutes
 61-90 minutes 210-240 minutes
 91-120 minutes more than 240 minutes
 121-150 minutes

Q1.58. Have you been able to claim cost of travel to the hospital where you obtained a second opinion or attended due to a clinical trial?

- Yes, from the trial itself
 Yes, from Mesothelioma UK
 Yes, from another source of funding
 No, I did not want to claim it
 Not applicable

Q1.59. Has the cost of travel insurance for holidays abroad ever been an issue for you?

- Yes No

Q1.60. Have you or are you expecting to have to pay for any private treatment?

- Yes
 Yes and provision has been made for this as part of my legal claim
 No
 Don't know

Did you know that deaths thought to be due to mesothelioma or other asbestos related diseases are regarded as 'unnatural' and must be referred to the local coroner (procurator fiscal in Scotland) who carries out an investigation?

Q1.61. Were you or a family member informed about the role of the coroner / procurator fiscal?

- Yes
 No
 Don't know / I can't remember

Section 2

Quality of Life Assessment Questionnaire

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

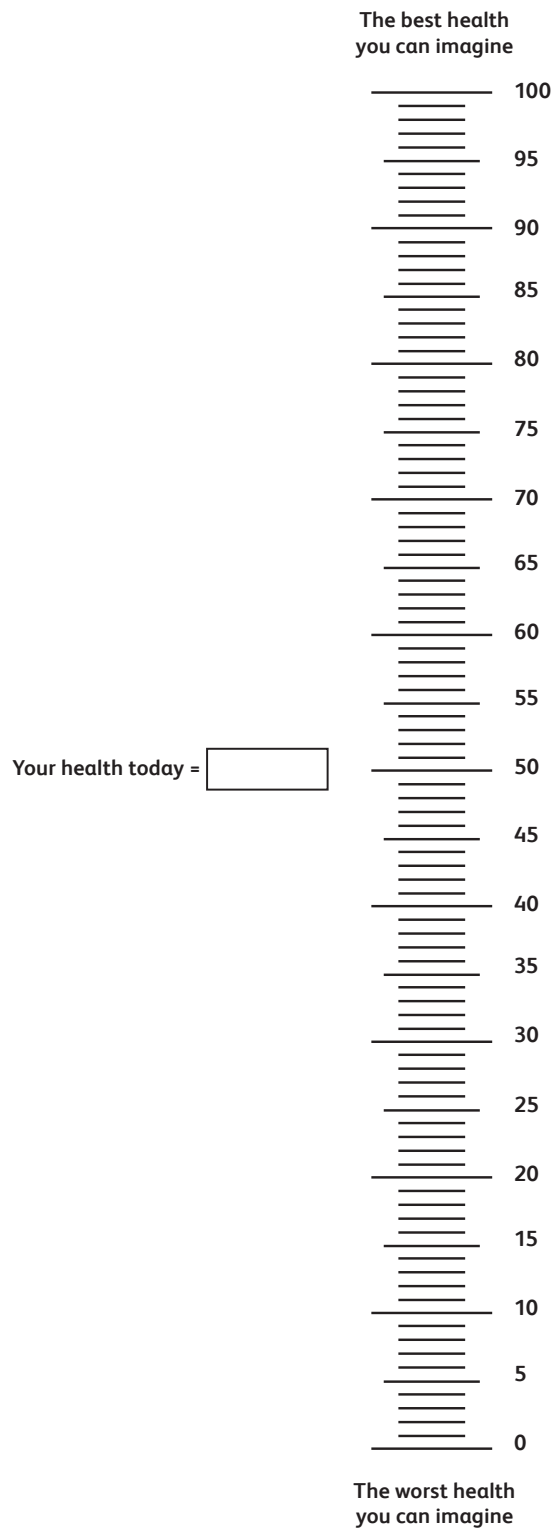
PAIN / DISCOMFORT

- 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
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst 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.



Section 3

Clinical Management of Mesothelioma.
(To be validated with a clinical nurse)

Q3.1. What was the location of your tumour at diagnosis?

Tick as many as apply

- Left Pleural
 Right Pleural
 Peritoneal
 More than one place
 Other

Q3.2. What type of Mesothelioma do you have?

- Epithelioid
 Sarcomatoid
 Mixed/Biphasic
 Unspecified
 Don't know (To be validated by the nurse and classified to one of the above)

Q3.3. What was the stage of tumour at diagnosis?

- Suitable for surgery
 Unsuitable for surgery
 Suitable for surgery but I declined
 Not staged
 Don't know (nurse to fill in one of above)

Q3.4 Which of the following procedures have you previously undergone?

Tick as many as apply

- CT scan ([please go to Q3.5](#))
 Ultrasound scan
 PET scan
 MRI scan
 CT guided biopsy
 Bronchoscopy Laparoscopy
 Fluid drained from the lung ([please go to Q3.6](#))
 Fluid drained from the abdomen
 Permanent or indwelling drain (Pleurx/Rocket)
 Thoracoscopy with local anaesthetic, ie awake
 Thoracoscopy with general anaesthetic/asleep
 Surgical biopsy

Q3.5. Within the last year how many CT scans have you received?

- 0
 1-2
 3-4
 5+

If you had fluid drained from the lung

Q3.6. How many times in total have you had fluid drained from the lung?

- 0 3
 1 4
 2 5+

Q3.7. Were you offered a permanent or indwelling drain?

- Yes No Don't know

Q3.8. Which of the following treatments (either in or out of a clinical trial) have you been offered but not taken?

Tick as many as apply

- Surgery
 Radiotherapy
 Chemotherapy
 Immunotherapy
 Targeted Therapy
 None

Q3.9. Which of the following treatments (either in or out of a clinical trial) have you received to date?

Tick as many as apply

- Surgery ([please go to Q3.10](#))
 Radiotherapy ([please go to Q3.18](#))
 Chemotherapy ([please go to Q3.26](#))
 Immunotherapy
 Targeted Therapy
 None

If you are currently or have previously received surgery for your mesothelioma can you provide the month and year when you received this treatment and what was it for? Q3.10 – Q3.17

Complete as many as apply

Q3.10. First surgical procedure

Please write 1st of month and year

Q3.11. What was it for?

Tick as many as apply

- Biopsy
 Biopsy and drain fluid combined
 Drain fluid
 Remove some of the tumour
 Remove all of the tumour
 Address complications of surgery
 Other

Q3.12. Have you had a second procedure? Yes No**Q3.13. Second surgical procedure***Please write 1st of month and year***Q3.14. What was it for?***Tick as many as apply*

- Biopsy
- Biopsy and drain fluid combined
- Drain fluid
- Remove some of the tumour
- Remove all of the tumour
- Address complications of surgery
- Other

Q3.15. Have you had a third procedure? Yes No**Q3.16. Third surgical procedure***Please write 1st of month and year***Q3.17. What was it for?***Tick as many as apply*

- Biopsy
- Biopsy and drain fluid combined
- Drain fluid
- Remove some of the tumour
- Remove all of the tumour
- Address complications of surgery
- Other

If you are currently or have previously received radiotherapy for your mesothelioma can you provide the month and year when you received this treatment and what was it for? Q3.18 – Q3.25

*Complete as many as apply***Q3.18. First course of radiotherapy***Please write 1st of month and year***Q3.19. What was it for?***Tick as many as apply*

- To prevent tumour from spreading
- To reduce a lump
- To treat area/s of disease growth
- To treat an area of disease causing pain

Q3.20. Have you had a second course of radiotherapy? Yes No**Q3.21. Second course of radiotherapy***Please write 1st of month and year***Q3.22. What was it for?***Tick as many as apply*

- To prevent tumour from spreading
- To reduce a lump
- To treat area/s of disease growth
- To treat an area of disease causing pain

Q3.23. Have you had a third course of radiotherapy? Yes No**Q3.24. Third course of radiotherapy***Please write 1st of month and year***Q3.25. What was it for?***Tick as many as apply*

- To prevent tumour from spreading
- To reduce a lump
- To treat area/s of disease growth
- To treat an area of disease causing pain

If you are currently receiving or have previously received chemotherapy for your mesothelioma can you provide the following information. Q3.26–Q3.41

Q3.26. First course of chemotherapy*Please write 1st of month and year***Q3.27. Was this as part of a Clinical Trial?** Yes No

Q3.28. What was the treatment?

- Pemetrexed and Cisplatin
- Pemetrexed and Carboplatin
- Pemetrexed as a single drug
- Pemetrexed, Cisplatin and Bevacizumab (Avastin)
- Pemetrexed, Carboplatin and Bevacizumab (Avastin)
- Bevacizumab (Avastin) as a single drug
- Gemcitabine and Cisplatin
- Gemcitabine and Carboplatin
- Vinorelbine
- Any other drugs in a clinical trial
- Any other drugs not in a clinical trial

Q3.29. How many cycles did you complete?

- 1 5
- 2 6
- 3 More than 6, still receiving it
- 4

Q3.30. Did you continue on maintenance treatment?

- Yes No

Q3.31. Did you have a second course of chemotherapy?

- Yes No

Q3.32. Second course of chemotherapy

Please write 1st of month and year

Q3.33. Was this as part of a Clinical Trial?

- Yes No

Q3.34. What was the treatment?

- Pemetrexed and Cisplatin
- Pemetrexed and Carboplatin
- Pemetrexed as a single drug
- Pemetrexed, Cisplatin and Bevacizumab (Avastin)
- Pemetrexed, Carboplatin and Bevacizumab (Avastin)
- Bevacizumab (Avastin) as a single drug
- Gemcitabine and Cisplatin
- Gemcitabine and Carboplatin
- Vinorelbine
- Any other drugs in a clinical trial
- Any other drugs not in a clinical trial

Q3.35. How many cycles did you complete?

- 1 5
- 2 6
- 3 More than 6, still receiving it
- 4

Q3.36. Did you continue on maintenance treatment?

- Yes No

Q3.37. Did you have a third course of chemotherapy?

- Yes No

Q3.38. Third course of chemotherapy

Please write 1st of month and year

Q3.39. Was this as part of a Clinical Trial?

- Yes No

Q3.40. What was the treatment?

- Pemetrexed and Cisplatin
- Pemetrexed and Carboplatin
- Pemetrexed as a single drug
- Pemetrexed, Cisplatin and Bevacizumab (Avastin)
- Pemetrexed, Carboplatin and Bevacizumab (Avastin)
- Bevacizumab (Avastin) as a single drug
- Gemcitabine and Cisplatin
- Gemcitabine and Carboplatin
- Vinorelbine
- Any other drugs in a clinical trial
- Any other drugs not in a clinical trial

Q3.41. How many cycles did you complete?

- 1 5
- 2 6
- 3 More than 6, still receiving it
- 4

Q3.42. Did you continue on maintenance treatment?

- Yes No

Q3.43. At this current moment in time what of the following best describes you?

- I have had surgery but no other treatment and my disease is stable
- I have never received any treatment and my disease is stable
- I have never received any treatment and my disease is active/progressing
- I am waiting to start my first course of chemotherapy
- I am currently receiving chemotherapy for the first time
- I have previously received chemotherapy once and my disease is stable
- I have previously received chemotherapy once, but my disease is active/progressing
- I am currently receiving treatment (chemotherapy/ immunotherapy/targeted therapy) for the second time as my disease is active/progressing

- I have previously received treatment (chemotherapy/immunotherapy/targeted therapy) twice and my disease is stable
- I have previously received treatment (chemotherapy/immunotherapy/targeted therapy) twice, the treatment is now ineffective, and my disease is active/progressing
- I have received 3 or more treatments (chemotherapy/immunotherapy/targeted therapy) and my disease is stable
- I have received 3 or more treatments (chemotherapy/immunotherapy/targeted therapy), the treatment is now ineffective and my disease is progressing

Q3.44. Do you know your current performance status, (known as ECOG), which is scored on a scale of 0 to 4?

- Yes (*if yes, please go to Q3.45*)
- No (*if no, please go to Q3.46*)

Q3.45. What is the status score that has been given to you?

- 0: Fully active, able to carry on all pre-disease performance without restriction
- 1: Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature e.g. light housework, office.
- 2: Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours.
- 3: Capable of only limited selfcare, confined to bed or chair for 50% of waking hours.
- 4: Completely disabled. Cannot carry out any selfcare. Totally confined to bed or chair.

Q3.46. Your Mesothelioma Nurse will tick the performance score on your behalf

- 0: Fully active, able to carry on all pre-disease performance without restriction
- 1: Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature e.g. light housework, office.
- 2: Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours.
- 3: Capable of only limited selfcare, confined to bed or chair for 50% of waking hours.
- 4: Completely disabled. Cannot carry out any selfcare. Totally confined to bed or chair.

If you have any further comments you would like to share please email Mesothelioma UK at info@mesothelioma.uk.com

Q3.47. Name of MESO Nurse

- to be supplied by MESO UK
- Unknown

Q3.48. Please enter your unique patient identifier

Q3.49. Name of hospital

You have now completed this questionnaire.

Please confirm if Section 3 has been validated by the Meso UK nurse

- Yes
- No, to be validated later

