DecodeME Questionnaire

This is a copy of the DecodeME questionnaire that is for information only.

Please DO NOT post it to us, your responses won't be processed. Please complete the online questionnaire if you want to participate.

If you require a paper version of the questionnaire, please contact us at info@DecodeME.org.uk or 0808 196 8664, and we will post you all the documents.

I am providing information on behalf of another person:

- ☐ Yes
- ☐ No *(Skip to the next page)*

If you answered "Yes", are you the other person's:

- ☐ Parent or legal guardian
- ☐ Child
- ☐ Sibling
- ☐ Partner
- ☐ Other family member
- ☐ Friend
- ☐ Other

Please give your name here: ______________________

Part 1: Consent Form

To take part in DecodeME, you need to give your consent, which you can do by crossing the box below. You must then sign the form at the bottom.

I confirm that I've read and understood the Participant Information Document for the DecodeME study and have had the opportunity to ask questions.

I agree to give a saliva sample for DNA analysis for DecodeME to look for genetic factors that play a role in ME/CFS. I understand that this analysis may in future include looking at the full sequence of my DNA.

I'm happy for the UK National Biosample Centre and the University of Edinburgh to store my DNA sample until it can be used by DecodeME.

I understand I won't benefit financially if this research leads to the development of a new treatment, medical test or other product.

I understand it's completely up to me whether to take part in DecodeME and that I'm free to withdraw at any time without giving any reason.

I agree to take part in DecodeME.	☐ Yes	☐ No

The following items are optional for DecodeME. Please cross 'Yes' or 'No' to show your choice.

I give permission for the research team to receive past, present and future data on my health that the NHS will provide from my medical records. I give permission for the NHS to link my NHS or hospital or Community Health Index (CHI) number to my study data, and for the NHS to pass the linked data to the University of Edinburgh.	☐ Yes	☐ No
I'd like to be kept up-to-date on DecodeME's progress and results. I'm happy for Action for ME to store my email address for this purpose.	☐ Yes	☐ No

The following items are optional and are about studies outside DecodeME by other researchers. Please cross 'Yes' or 'No' to show your choice.

I'm happy for my data to be shared with other researchers in future studies approved by DecodeME. The studies might be about diseases other than ME/CFS. I understand that it won't be possible to identify me from my data and that my NHS health data won't be shared.	☐ Yes	☐ No
I'm happy for you to contact me in future with opportunities to take part in other studies approved by DecodeME that need new data and/or samples.	☐ Yes	☐ No

Date: ____________________ Signature: ____________________

Part 2: Personal Information

For the purposes of research we need to use the **information shown on your birth certificate** to ensure consistency of the data throughout your life.

1. First name at birth: ______________________

2. Do you have a middle name or names?
   - ☐ Yes
   - ☐ No *(Skip to Question 4)*

3. Middle name(s) at birth: ______________________

4. Last name at birth: ______________________

5. Date of birth (DD/MM/YYYY): ______________________

6. Place of birth: ______________________

7. Country of birth: ______________________

8. What was your sex assigned at birth?
   ⓘ *Knowing this allows us to quality control the genetic data.*
   - ☐ Female
   - ☐ Male
   - ☐ Intersex
   - ☐ Prefer not to say

9. What is your ethnic group?
   - ☐ Asian or Asian British
   - ☐ Black, African, Caribbean or Black British
   - ☐ Mixed or multiple ethnic groups
   - ☐ White
   - ☐ Other ethnic group
   - ☐ Prefer not to say

10. What is your blood group?
    ⓘ *Knowing this allows us to quality control the genetic data.*
    - ☐ A
    - ☐ B
    - ☐ AB
    - ☐ O
    - ☐ Don’t know

Part 3: Illness Assessment

1. Have you been given a diagnosis of ME, CFS, ME/CFS or CFS/ME by a health professional?
   - ☐ Yes
   - ☐ No

2. How long have you had your illness?
   - ☐ Less than 6 months
   - ☐ Between 6 months and 1 year
   - ☐ Between 1 year and 3 years
   - ☐ Between 3 years and 5 years
   - ☐ Between 5 years and 10 years
   - ☐ Over 10 years
   - ☐ All my life; I was born with this illness

3. Thinking about your activities, how much can you do now compared to before you got ill? If you cannot remember being well, compare yourself to an average person your age.
   - ☐ I can do **half or less** of what I could before
   - ☐ I can do **more than half** of what I could before, or just **as much as** before

4. How would you describe your illness? Please only choose **ONE** answer.
   - ☐ Getting worse
   - ☐ Relapsing and remitting (good periods with no symptoms alternating with symptomatically bad periods)
   - ☐ Fluctuating (my symptoms vary day to day but don't go away)
   - ☐ Not much change from day to day
   - ☐ Getting better
   - ☐ I am recovered and have no symptoms

Fatigue

5. Do you have fatigue (lack of energy) often, repeatedly, or all the time?
   - ☐ Yes
   - ☐ No

6. Please tick one box that most closely matches your experience of fatigue (lack of energy):
   - ☐ I feel like a battery that can never fully recharge even when I rest
   - ☐ I feel like I fully recharge when I rest

7. We want to understand what's causing your fatigue (lack of energy). Please only choose **ONE** answer that most closely matches your experience:
   - ☐ I often feel fatigue, and this can get worse when I'm active
   - ☐ My lifestyle is so busy (e.g. with work, exercise and/or socialising) that it causes my fatigue

8. How often do you have this fatigue (lack of energy)?
   - ☐ Not very often but once in a while
   - ☐ Often, but less than half of the time
   - ☐ More than half of the time

9. Have your activities (personal, at home, social, educational, and/or occupational) been affected by this fatigue (lack of energy)?
   - ☐ No, I can still do all my normal daily activities
   - ☐ Yes, but only a little. I can still carry out most of them normally, without problems
   - ☐ Yes, I have had to significantly reduce my activities, or I no longer can do many of the activities that I used to do

10. Is your fatigue (lack of energy) disabling?
    - ☐ Yes
    - ☐ No

11. Does your fatigue affect you physically and/or mentally? Please only choose **ONE** answer.
    - ☐ Yes, I feel physically **and** mentally fatigued
    - ☐ I only feel mentally fatigued
    - ☐ I only feel physically fatigued
    - ☐ I do not feel physically or mentally fatigued

Symptoms after effort or activity

12. In the last 6 months, what happens to your symptoms after you do more physical or mental activity than usual (exceed your energy limit)?
    If you pace your energy, we want you to think about what would have happened if you didn't. Please only choose **ONE** answer.
    - ☐ My symptoms (such as pain, fatigue or feeling out-of-sorts) get worse, or I get new symptoms, and this reduces how much I can do
    - ☐ My symptoms either stay the same or improve *(Skip to Question 14)*

13. In the last 6 months, after you have done more physical or mental activity than usual (exceeded your energy limit), how long does the change in your symptoms usually last?
    If you pace your energy, we want you to think about what would have happened if you didn't. Please only choose **ONE** answer.
    - ☐ The change in my symptoms lasts a long time, which can be more than 24 hours
    - ☐ I bounce back straight away or my symptoms don't last very long given the effort I just made

Cold or flu-like symptoms

14. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Fever or chills
    - ☐ Flu-like feeling
    - ☐ Less viral infections than I used to get
    - ☐ Sore throat
    - ☐ Swollen or tender glands in the armpits or at the side of the neck
    - ☐ Viral infections with long recovery periods

Sensitivities

15. In the last 6 months, have you been over-sensitive or intolerant to any of the following things often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Alcohol
    - ☐ Chemicals
    - ☐ Food
    - ☐ Light
    - ☐ Medicine
    - ☐ Noise
    - ☐ Smells
    - ☐ Touch
    - ☐ Other things

Muscle/joint symptoms

16. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Chest pain
    - ☐ Joint pain that can move to other joints without swelling or redness
    - ☐ Joint pain without swelling or redness
    - ☐ Muscle pain
    - ☐ Muscle stiffness
    - ☐ Muscle twitching/spasms
    - ☐ Muscle weakness

Gut symptoms

17. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Feeling sick (nauseous)
    - ☐ Gut symptoms or irritable bowel-type symptoms such as diarrhoea, constipation, bloating or abdominal pain
    - ☐ Heartburn

Headaches

18. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Headache
    - ☐ Eye pain or pain behind the eyes
    - ☐ Feeling of pressure in the head or at the base of the skull
    - ☐ Migraine

Problems with thinking, sensation or movement

19. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Confusion or ‘brain fog’
    - ☐ Disorientation (confusion about time, identity, directions, or places)
    - ☐ Finding it hard to concentrate
    - ☐ Finding it hard to make decisions
    - ☐ Finding it hard to remember things
    - ☐ Finding it hard to understand things or think clearly
    - ☐ Numbness or tingling in arms or legs
    - ☐ Poor balance or unsteadiness when standing
    - ☐ Poor coordination or unsteadiness when walking
    - ☐ Problems finding or saying words
    - ☐ Ringing in ears (tinnitus)
    - ☐ Short-term memory problems
    - ☐ Slow thinking
    - ☐ Speech problems
    - ☐ Temporary eyesight problems or unable to focus vision

Sleep

20. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Feeling sleepy more than is normal
    - ☐ Night sweats
    - ☐ Problems with how well or how long you sleep, such as insomnia, sleeping during the day instead of the night, waking during the night, and so on. Do not count sleep apnoea, where your breathing stops and starts again during your sleep.
    - ☐ Unrefreshing sleep

Automatic body functions

21. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Bladder problems, such as feeling that you suddenly need to pee or pee more often than usual
    - ☐ Cold hands or feet
    - ☐ Difficulty remaining standing
    - ☐ Excessive sweating
    - ☐ Feeling as though you cannot get enough air, difficulty in breathing or shortness of breath during effort or activity
    - ☐ Feeling dizzy or faint when standing up
    - ☐ Feeling of being sick or unwell
    - ☐ Feeling of burning in the lungs
    - ☐ Having a very pale face
    - ☐ Lightheadedness
    - ☐ Palpitations while standing up or at other times
    - ☐ Tight feeling in the chest

Neuroendocrine

22. In the last 6 months, have you had any of the symptoms below often, repeatedly, or constantly? Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Finding it hard to cope with being in very hot or cold places
    - ☐ Less interest in sex and/or difficulties with sexual function
    - ☐ Symptoms getting worse with stress
    - ☐ Unusual change in your appetite, so that you want to eat a lot more or a lot less than usual; or putting on or losing weight without meaning to

Mood

23. In the last 6 months, have you experienced any of the following **due to your illness**? (We want to know the impact of your illness on your mood. We'll ask about specific diagnoses later.) Please mark any that apply. If none apply, leave all the boxes blank.
    - ☐ Feeling easily annoyed or irritable
    - ☐ Feeling easily nervous or anxious
    - ☐ Feeling low or down
    - ☐ Feeling worried
    - ☐ Mood swings
    - ☐ Racing thoughts

Further Questions

24. Do you take recreational drugs or drink alcohol so much that they affect you being able to work, study, eat, sleep, and enjoy life?
    - ☐ Yes
    - ☐ No

25. Did you have an infection when, or just before, your first ME/CFS symptoms started?
    - ☐ Yes, glandular fever
    - ☐ Yes, COVID-19
    - ☐ Yes, another infection
    - ☐ No *(Skip to Question 27)*
    - ☐ Don’t know *(Skip to Question 27)*

26. Was the infection that you had at the onset of your symptoms confirmed by a test?
    ⓘ *If you don’t remember or don’t know, please select “No”.*
    - ☐ Yes
    - ☐ No

27. How severe is your illness? Please choose the group you fit most often, or that best describes how severe your illness is overall, even if the detail doesn't exactly match your experience.
    - ☐ **Mild** – People with mild ME/CFS care for themselves and do light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off or use the weekend to cope with the rest of the week.
    - ☐ **Moderate** – People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.
    - ☐ **Severe** – People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.
    - ☐ **Very severe** – People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

Please answer the following questions ONLY if you answered “Yes, COVID-19” in to Question 25, which asked whether you had an infection when, or just before your symptoms started.

28. Were you admitted to hospital as an in-patient because of COVID-19?
    - ☐ Yes
    - ☐ No

29. Has a health professional told you that you have heart or lung damage due to COVID-19?
    - ☐ Yes
    - ☐ No

Part 4: Other Conditions

1. If a health professional has **ever** told you that you had any of the conditions below, please select all that apply. If the conditions don't apply to you, please do not select any box. Please mark:

   Active – If the condition has given you symptoms in the past 6 months.
   Not active – If the condition has not given you symptoms in the past 6 months, either because it has died down or treatment has controlled it.

Active	Not active	
☐	☐	Adrenal insufficiency (Addison's disease)
☐	☐	Anaemia needing treatment or blood transfusions
☐	☐	B12 deficiency not treatable with injections
☐	☐	Bipolar disorder
☐	☐	Cancer (including lymphoma, leukaemia, melanoma, carcinoma, neuroendocrine tumours)
☐	☐	Clinical depression
☐	☐	Coeliac disease
☐	☐	Diabetes
☐	☐	Fibromyalgia
☐	☐	Haemochromatosis (iron overload)
☐	☐	Hepatitis
☐	☐	HIV/AIDS
☐	☐	Irritable Bowel Syndrome (IBS)
☐	☐	Lupus
☐	☐	Lyme disease
☐	☐	Mast cell activation syndrome (MCAS)
☐	☐	Multiple sclerosis (MS)
☐	☐	Myasthenia gravis (MG)
☐	☐	Narcolepsy
☐	☐	Overactive adrenal glands (Cushing disease)
☐	☐	Overactive thyroid (hyperthyroidism)
☐	☐	Q fever
☐	☐	Parkinson's disease (PD)
☐	☐	Polymyalgia rheumatica
☐	☐	Polymyositis
☐	☐	Rheumatoid arthritis (RA)
☐	☐	Sarcoidosis
☐	☐	Schizophrenia
☐	☐	Shingles
☐	☐	Sjogren's syndrome
☐	☐	Sleep apnoea
☐	☐	Tuberculosis
☐	☐	Underactive thyroid (hypothyroidism)
☐	☐	Upper airway resistance syndrome (UARS)

If you have been diagnosed with a condition that was not listed above, please tell us below. You can also tell us if you made a mistake in any of the questions or share other comments.

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