

ACT MS Cohort & Fatigue sub-study

ACT MS Symposium 2021
22 October 2021



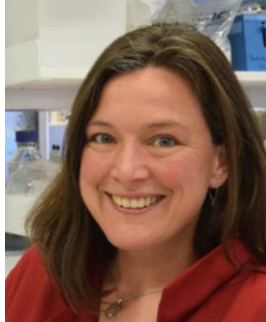
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MS Research Team



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ACT MS Cohort Study

- Longitudinal study involving adults living with and without MS
- Annual assessments to monitor changes in health and wellbeing over time
- Better understand how personal, environmental, and psychological factors affect the health and wellbeing of people living with MS



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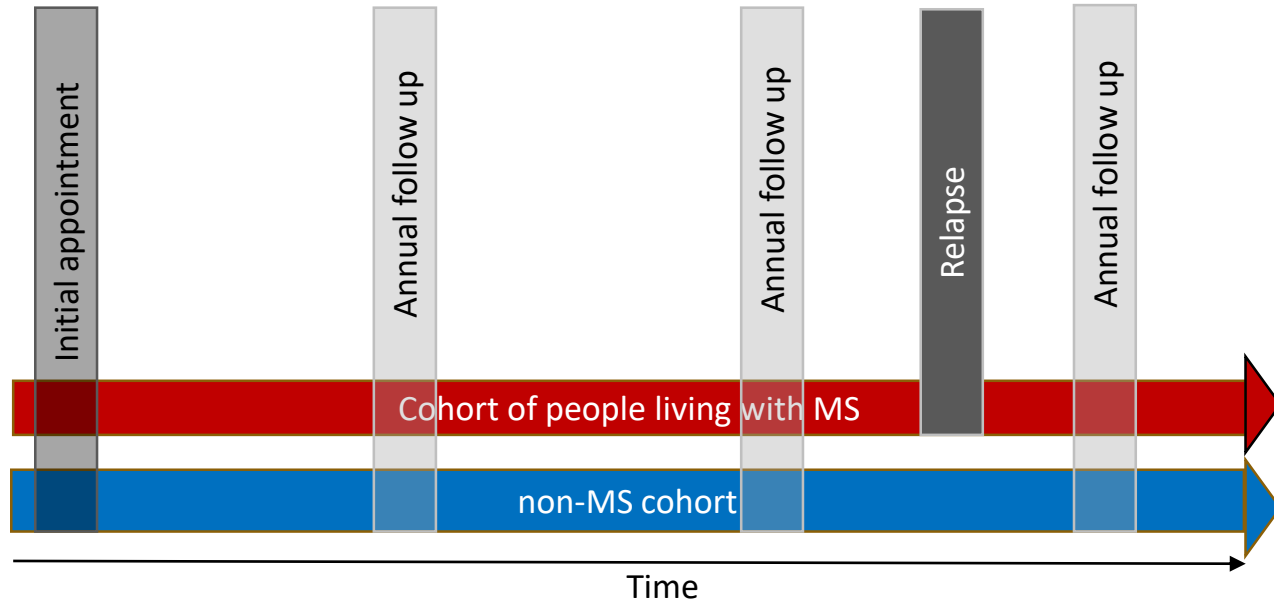
ACT MS Cohort Study: What's involved?

- Online questionnaires
 - Demographics, health and medical information
- Blood samples
- Measures
 - Expanded Disability Status Scale (EDSS)
 - Height and weight



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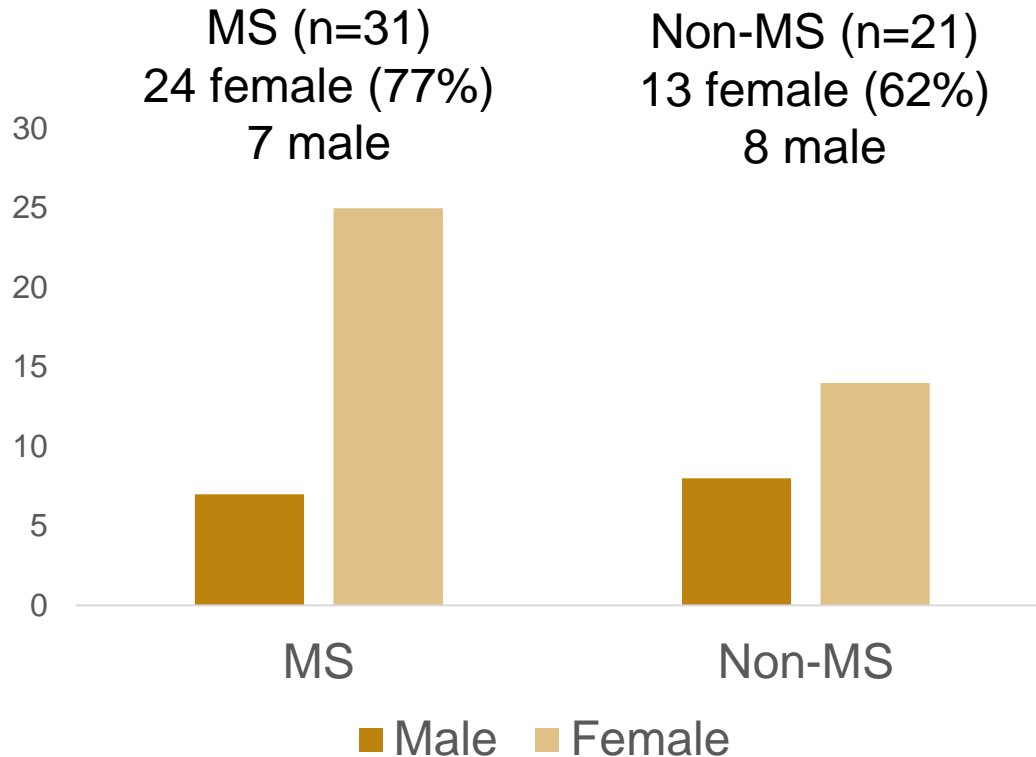
ACT MS Cohort Study



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ACT MS Cohort Study Participants

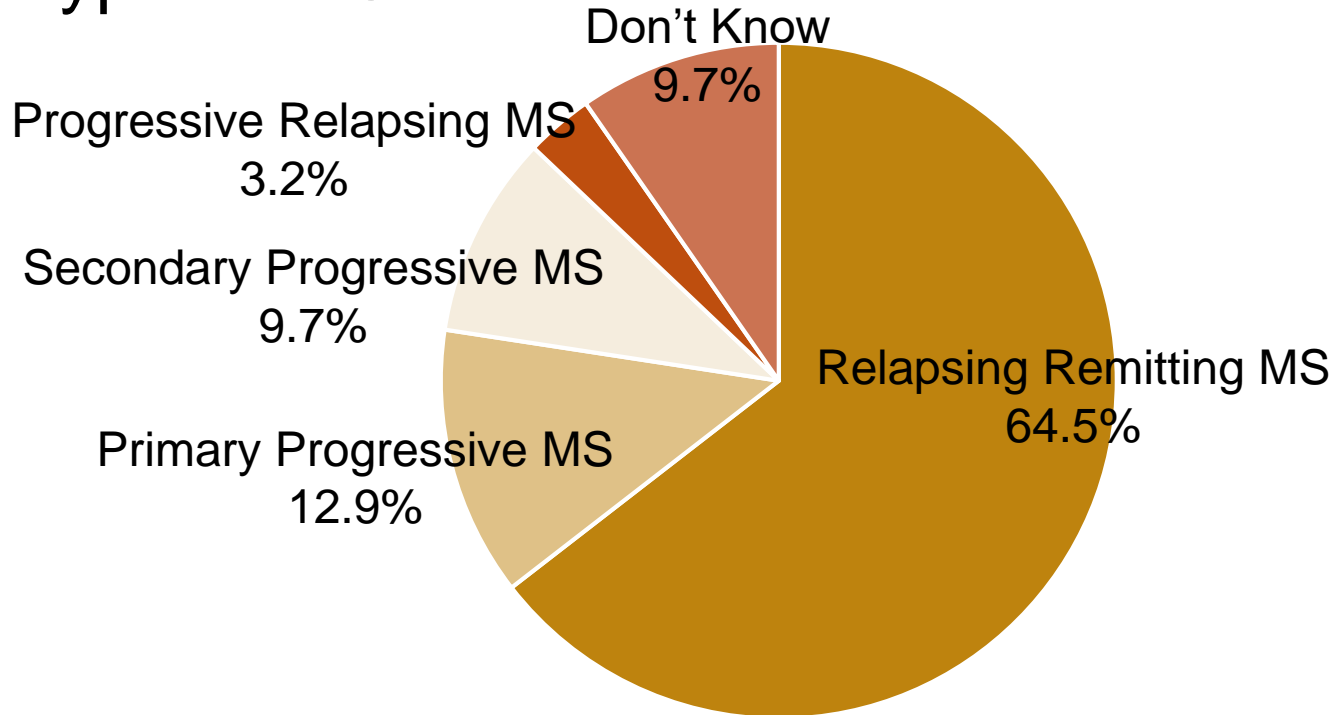
Sex



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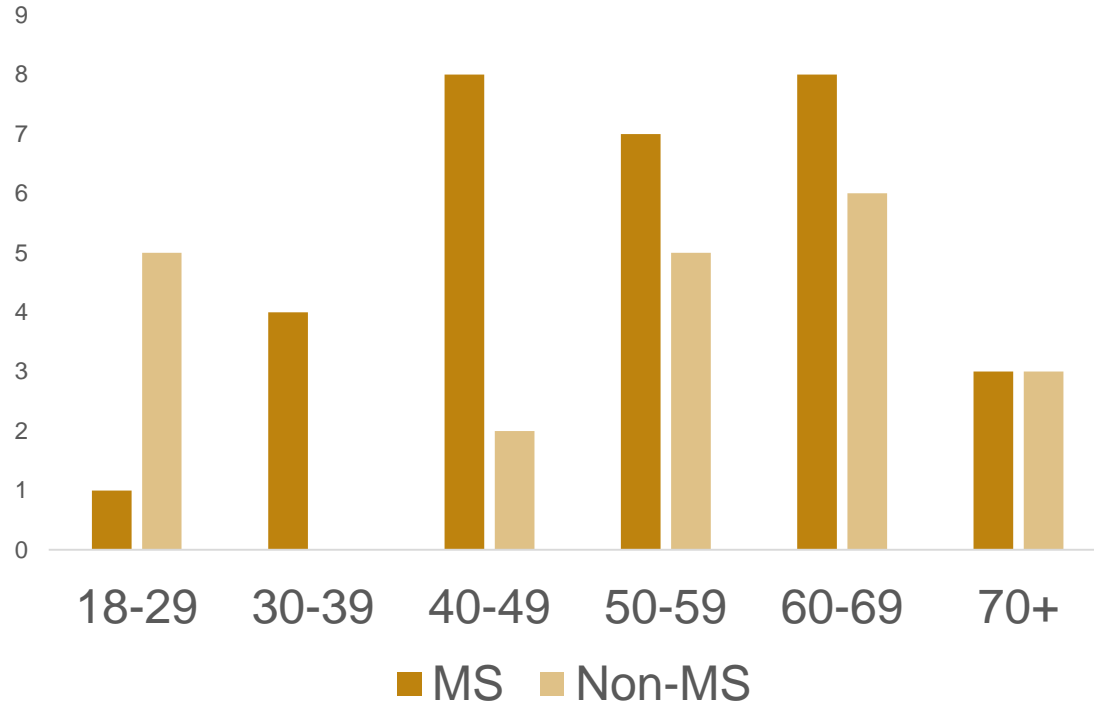
Type of MS



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ACT MS Cohort Study Participants

Age



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Moving forward

- Commencing our first annual reviews
- Recruiting more participants
- Collaborations



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Fatigue in MS

- Overwhelming sense of tiredness
- Most common and disabling symptom of MS
- Reported in all stages and types of MS
- Can be a feature of MS prodrome
- Has cognitive, emotional and physical components
- Impairs quality of life



“Persistent mental and physical fatigue has robbed me of the ability to do many of the things I used to enjoy, including work. Simple activities such as reading a book can be difficult, as I forget what I’ve just read and need to re-read it.”

“The fatigue from MS has really slowed me down. I can’t plan what I will do for the day, and don’t have the mental energy to follow things through.”



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“On the rare days I do have energy and clarity of thought, I realise what I have lost.”

Fatigue in MS

Primary MS fatigue

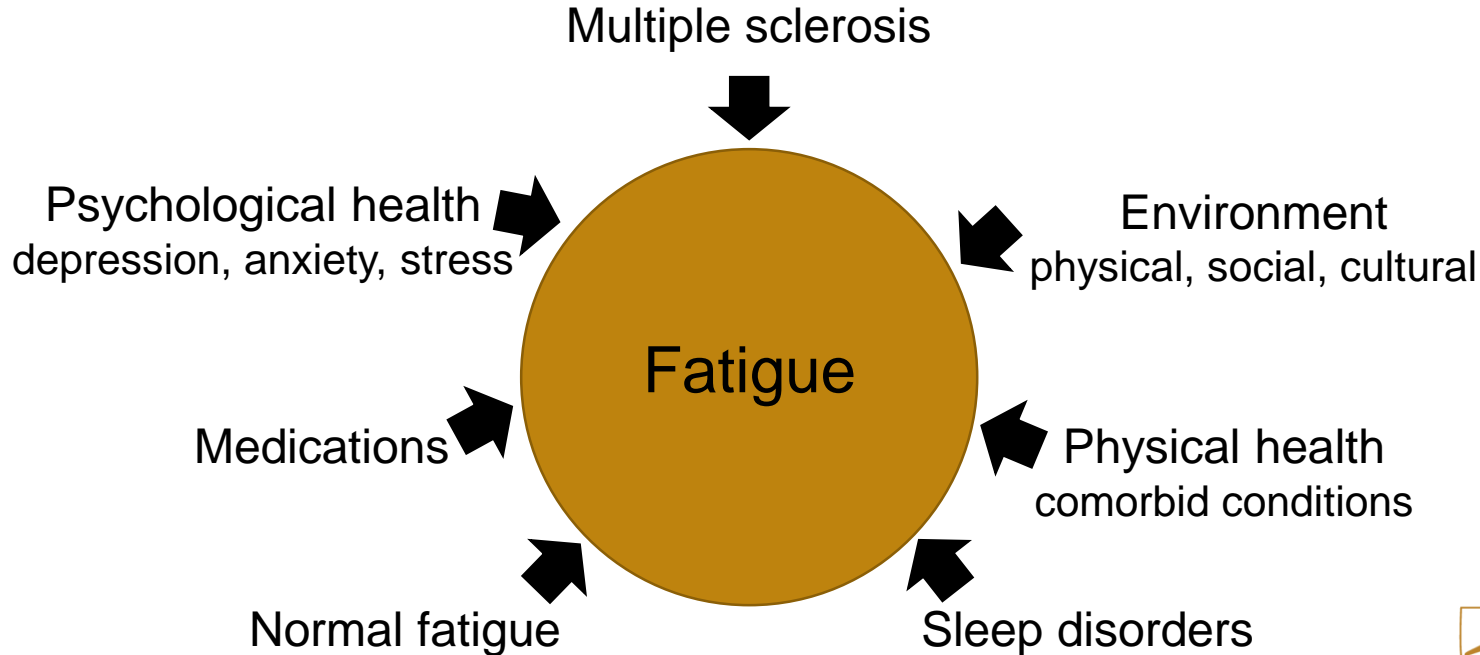
- Inflammatory/Neurodegenerative processes/impaired nerve condition

Secondary sources

- Sleep disturbance, medication side effects, other medical conditions, depression, pain, MS symptoms (muscle spasticity, bladder issues etc.)



Causes of fatigue



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Fatigue sub-study: Aims

- Understand more about the mechanisms of MS-related fatigue.
- Identify and examine possible biomarkers and track changes in MS-related fatigue.
- Investigate how MS-related fatigue and its biomarkers affect the health and wellbeing of people with MS (both with and without self-reported fatigue), and compare those factors for people who do not have MS.



Fatigue sub-study: Participants

- Participating in ACT MS Cohort Study
- 18 years or older
- With any type of MS (with or without self-reported fatigue)
- Without MS who are similar sex and age as participants living with MS in this study

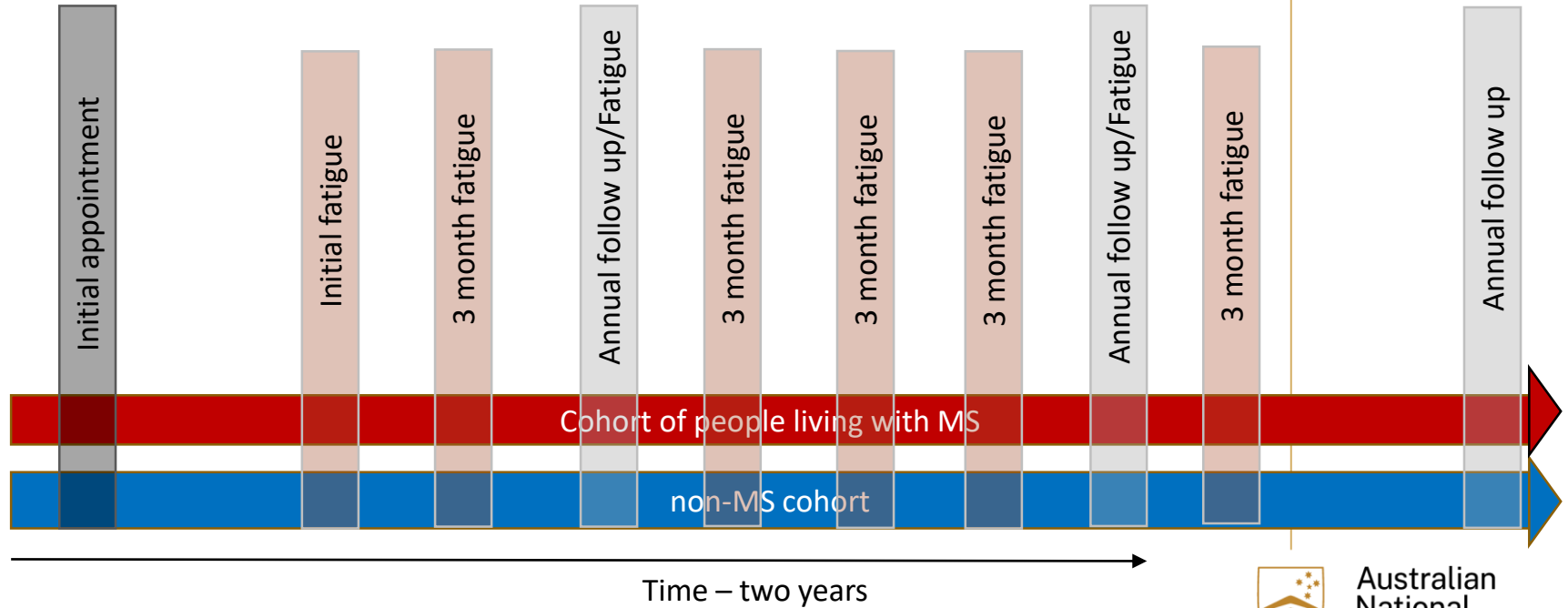


Fatigue sub-study: Study design

- Commence in 2022
- Visit the JCSMR every three months (8 visits over 2 years; people with MS may be asked to attend ANU if a relapse occurs between sessions)
- 90 minutes per session
- Transport to/from ANU provided



ACT MS Cohort Study: Fatigue sub-study



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Fatigue sub-study: What's involved

- Online questionnaires
 - Digital technologies, fatigue, mood, sleep
- Blood samples
- Measures
 - Cognitive tests
 - Vision assessment
 - Physical tests (hand and finger function, walking ability, balance)



Why is this research important?

We want to:

- Transform healthcare by developing new personalised health technologies and solutions in collaboration with people living with MS, clinicians and health care providers
- Improve the quality of life for people living with MS



<https://www.anu.edu.au/research/research-initiatives/our-health-in-our-hands>



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Find out more

About this MS study or others:

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Thank you

- Our participants
- Researchers across OHIOH and collaborators



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Thank you

- For your participation
- To all the facilitators
- To all the speakers
- To the organising committee
- Tobias James and Calo Huang



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