



## 2022 Concept of Self Survey – Information Sheet

The Australian MS Longitudinal Study *2022 Concept of Self Survey* is quite different to our regular surveys. We hope the following information on self-concept and the survey may assist in answering any questions that arise when completing the survey.

### What is self-concept?

The way you answer the question ‘who am I’ is an example of your self-concept; “I’m smart. I’m funny. I’m a hard worker”. Self-concept refers to how you see yourself and feel about yourself, and therefore how you relate to others and what you believe you are capable of.

### Does my self-concept have to be the same as how other people see me?

No, our self-concept is subjective. It is about who you believe/feel you are.

### Why is self-concept important?

Self-concept is one of the most important things about being human and directly affects our quality of life. It is related to almost everything we do, the decisions we make, and how we feel about ourselves.

### Why do we need a survey on self-concept?

It is important for clinicians and researchers to understand not just the physical and cognitive changes that may result from MS, but also the internal and personal changes that you may experience. Understanding how MS may have impacted your self-concept gives us an idea of how much MS has impacted your life, so we can improve our understanding of your lived experience. This understanding is central in facilitating the development of (and improvement to existing) programs or support services to improve the lives of those living with MS.

### Why do we need to know about changes in self-concept from diagnosis to now?

How much you think your self-concept has changed since diagnosis may be an important indicator of how much MS has impacted your life. While we acknowledge everyone’s individual journey from diagnosis to ‘now’ will be different, your answers will help us with the overall picture of how self-concept may change over the years after diagnosis. The AMSLS family includes people diagnosed very recently, people who were diagnosed over 60 years ago and everyone in between. We have previously collected when you were diagnosed, and this information will be an important factor in our analysis.

### What if I think my self-concept changes from day-to-day?

This is common, as we know that self-concept is influenced by other factors that may or may not be within our control. When answering these questions, try and indicate what is most common for you or how you feel most of the time.

### Won’t my self-concept have changed because of things other than my MS?

Yes, this is highly likely. We know that self-concept can also change due to aging and other key life events. However, getting information from you about how your self-concept may have changed since diagnosis is important, even if there are other things contributing to that change.