

Young people living with MS – making decisions for the future.

Panel outcomes

Panelists

- **Usman Khan**, Co-Chair, PROMS Initiative Working Group on Healthcare Systems and Policies (moderator)
- **Dimitri Georgiopoulos**, Global Business Franchise Head, N&I, Merck
- **Elisabeth Kasilingam**, Chief Executive Officer, European MS Platform
- **Giancarlo Comi**, President, European Charcot Foundation
- **Orla Galvin**, Executive Director, European Federation of Neurological Association

Introduction: Young people and Multiple Sclerosis

The average age of diagnosis for Multiple Sclerosis (MS) is 32, a time when people are often making major life decisions, from starting family life to accelerating their careers. The panel “*Young people living with MS – making decisions for the future*” attempts to understand the challenge young people face upon receiving an MS diagnosis and the early years of living with MS and explore potential solutions.

1. MS and family life

MS disproportionately affects women, representing two thirds of all diagnoses. The age of diagnosis is often when women are considering whether to have children. The disease greatly impacts family planning and the decision to have children, notably due to concerns about starting treatment and stabilizing the disease before starting a family, treatment disruption, and caring for children with a disability. To ensure that **parenthood is a choice for everyone**, a “whole system response”, including **multidisciplinary and integrated care teams**, is necessary. **MS awareness should be** extended to other clinicians (**primary care physicians, gynecologists**). Pregnancy and fertility care should also focus on limiting the time a birthing person will need to be off their disease modifying treatment (DMT), notably by ensuring timely access to fertility treatments if required.

2. MS and work life

Retaining employment is critical for people living with MS, as financial support is often inadequate, and employment has a positive impact on mental health. **Workplace adaptations** are needed for people living with MS to balance their work life with the disease. While many adaptations do not require systemic changes from employers, young people living with MS may be afraid to ask for these modifications for fear of discrimination. The lack of adapted working conditions will often make young people reconsider their career paths or leave employment altogether. **Training for employers must be improved and employability and workability should be measures through social indicators and also be included in Patient Reported Outcomes (PROs).**

3. MS and mental and physical health

MS impacts people’s mobility and ability to perform tasks that might seem straightforward to people without MS. People living with MS also suffer disproportionately from anxiety and depression. Poor mental health in people living with MS is linked to a deterioration in physical health, therefore, ensuring **access to psychological care for people with MS is critical.**

Key policy asks to improve the quality of life and opportunities for people living with MS

An **EU strategy or action plan on neurological diseases, including MS**, should be developed with:

- **Guidelines on care for women of childbearing age with neurological diseases**, especially those such as MS, where pregnancy can impact treatment.
- **A holistic approach to neurological and MS care**. Clinicians, including pediatricians, primary health providers, psychiatrists, psychologists, obstetricians and gynecologists should be trained to care for people with neurological diseases, including MS.
- **Tools for patients to better monitor their health and share their experience via Patient Reported outcomes (PROs)**, including mental health, social and employability indicators.
- **Guidelines on training for employers and workplace flexibilities** to provide equal opportunities for people living with neurological diseases, including MS.

This European Strategy should pave the way to the adoption, at national level, of **national plans for neurological disease management**.

In the context of the [Rethinking Multiple Sclerosis \(MS\) project](#), coordinated by the European Brain Council, several policy recommendations have been identified to improve the lives of people living with MS. The project challenges the status quo and refreshes the European policy debate on people living with MS and encourages multi-stakeholder-driven policy.