FOCAL-MS2 study: triangulation method to detect meaningful deterioration in patients' autonomy using a new Multiple Sclerosis Autonomy Scale (MSAS) questionnaire

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Ambition Autonomie

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Introduction

Multiple Sclerosis (MS) & Autonomy

Measuring a patient's autonomy is critical in Multiple Sclerosis (MS) care. Understanding these shifts is key to providing effective and responsive support.

To better track this, the Multiple Sclerosis Autonomy Scale (MSAS) was developed[1] as a new patient-reported outcome (PRO) specifically designed to assess autonomy in MS patients.

Establishing the MCId

Our study aims to define what constitutes a clinically meaningful deterioration to determine when a change in MS patient-reported autonomy warrants a care plan adjustment.

Our study aims to define this threshold by using a triangulation[2] method to combine clinical and patient-experience data. This will enable timely and appropriate adjustments to patient care.

Results:

A total of **158 patients** answered the questionnaires at baseline and at 1 year.

Anchor-based methods identified clinically important deterioration in 38 patients (24.1%) for the "Overall Perceived Autonomy" anchor, 22 patients (13.9%) for "Clinical EDSS Score", and 31 patients (19.6%) for "Recent Impactful Event Affecting MS" (Figure 2).
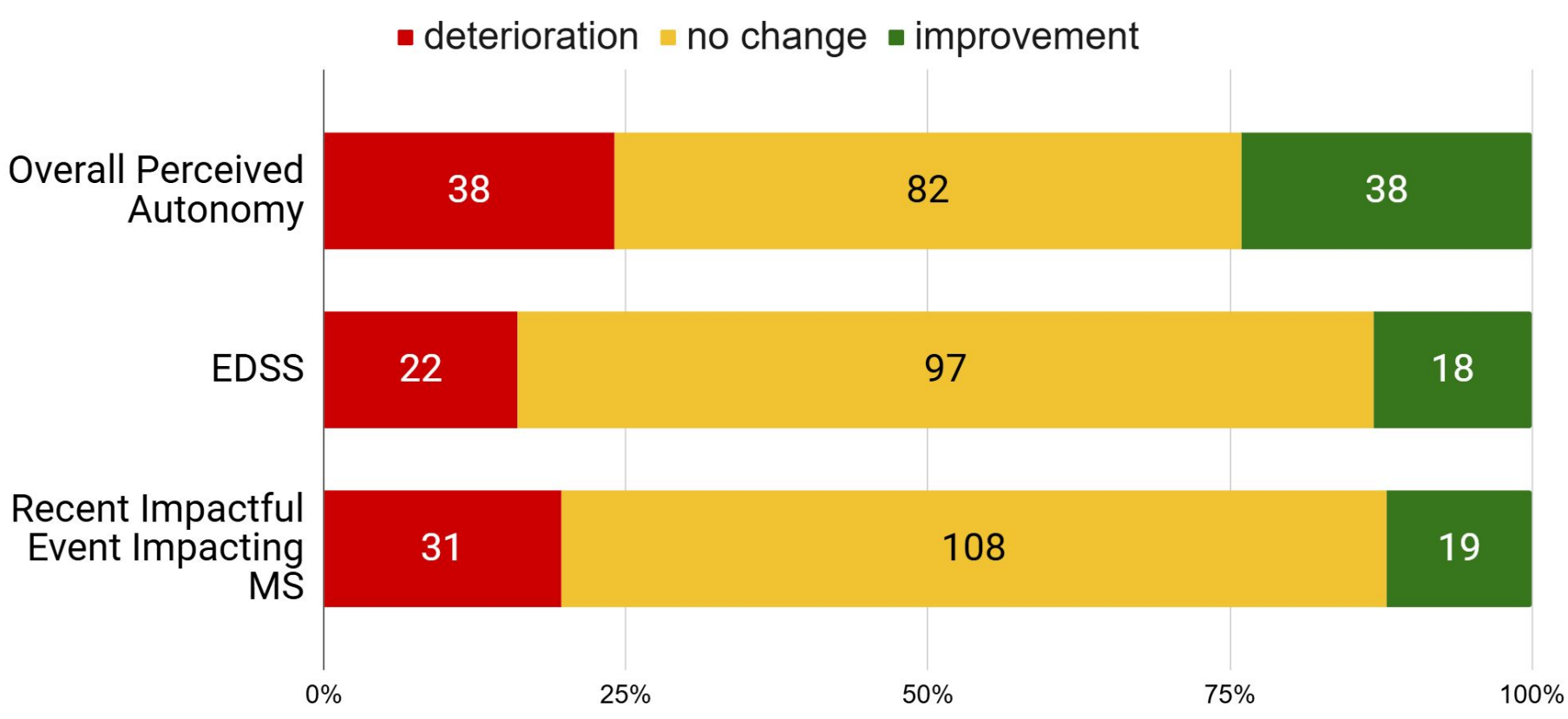
Weighted Minimal Change Thresholds (MCT) were calculated for each Minimal Clinically Important Difference (MCID) method[3] and for both Scores (Table 1):

The Standard Error of Measurement (SEM) was 5.1. The mean change from baseline MCT (5.7) for the Global Score was the only value to surpass this SEM. **Consequently, 5.7 was established as our MCId**.

We examined the **difference in score between D360 and D0** for each patient and analysed how many patients reached the MCId (5.7). It was observed that 49 patients (31%) achieved a Global Score difference greater than 5.7 (Figure 3)
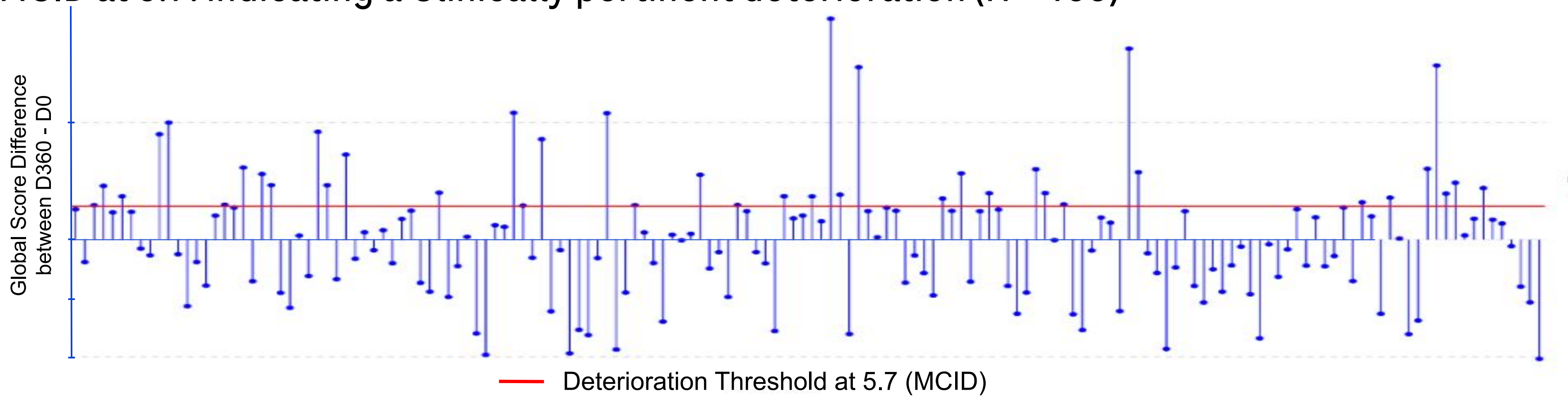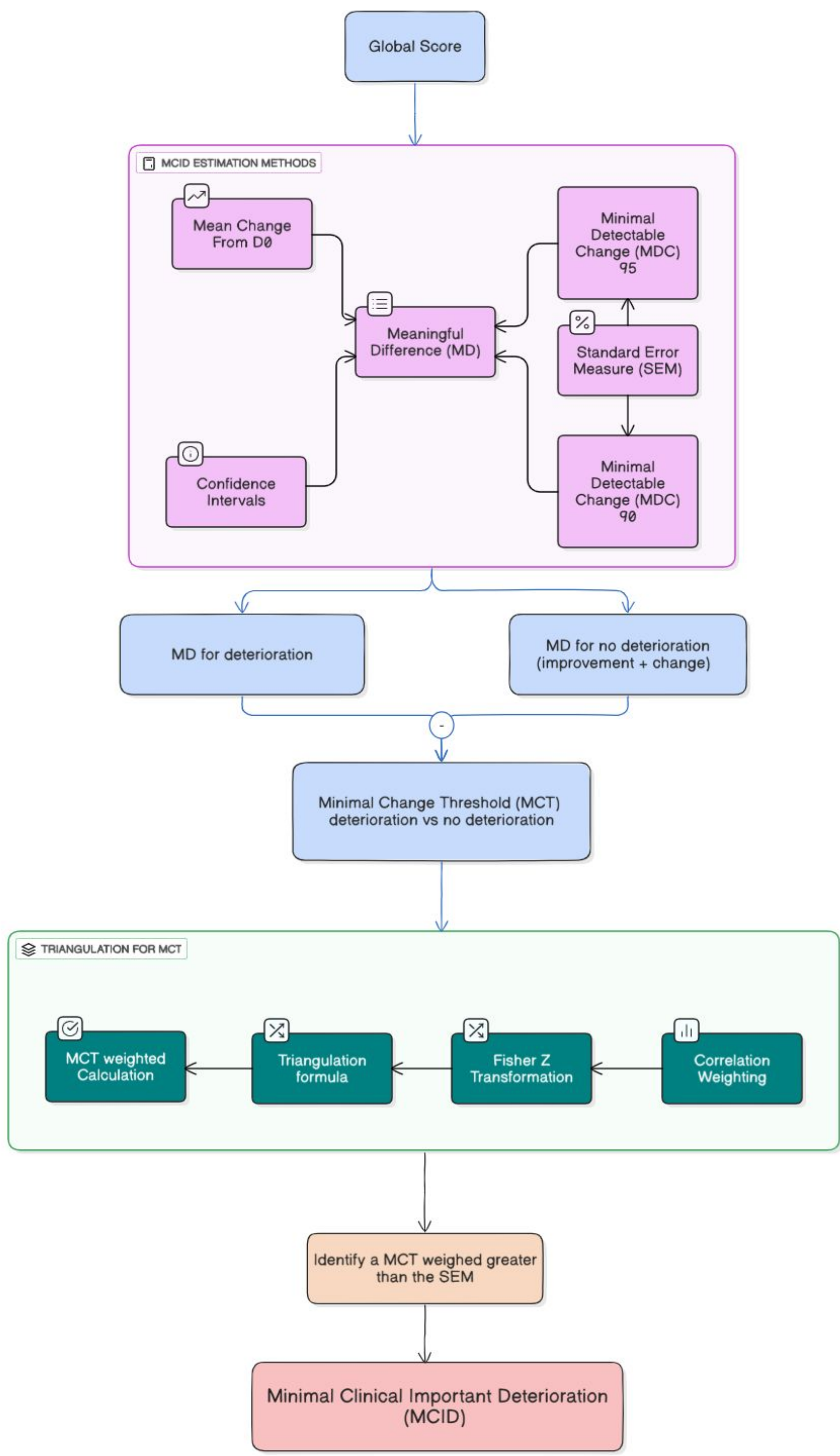
Methods

The MSAS Questionnaire comprises 10 questions of importance and **25 Impact Questions** (Likert Scale 0-5 scale) specific to each dimension and two anchor-based questions.

All resulting scores are standardized from 0 to 100. For measuring change from D0 to D360 we used the **Global Score** which is the average of all impact scores

To define patients' evolution categories (Figure 2) we used three-anchor grouping approach *considering any change*:

- **Overall Perceived Autonomy**: Likert scale (1-5) MSAS question
- **Recent Impactful Event Affecting MS**: A binary (Yes/No) MSAS question
- **EDSS Score**: A clinical measure (0-10), considering any score change.

Table 1: Minimal Change Threshold calculated using Triangulation (N = 158)

MCT weighted	Global Score
MDC 95	2.8
MDC 90	1.6
Mean Change From D0	5.7

Figure 2: Categories of evolution of patient's autonomy and their respective effectifs calculated between D0 and D360

Legend: deterioration / no change / improvement

Overall Perceived Autonomy: 38 | 82 | 38
EDSS: 22 | 97 | 18
Recent Impactful Event Impacting MS: 31 | 108 | 19

Figure 1 : Triangulation method and Identification of a Minimal Clinical Important deterioration (MCId)

Figure 3: Identification of 49 patients with a Global Score difference (D360 - D0) reaching the MCID at 5.7: indicating a Clinically pertinent deterioration (N = 158)

Global Score Difference between D360 - D0

— Deterioration Threshold at 5.7 (MCID)

Conclusion

MCID Utility

A change of **5.7** points represents a threshold for **detecting a clinically significant deterioration in autonomy**. This **patient-centered approach** using patient's perception allows the identification of dimensions and items responsible for this deterioration.

Future Perspectives:

- Evaluate the MCId on **other cohorts of patients** with MS (Multiple Sclerosis).
- **Clinicians** will have to determine **in routine practice** whether a score passing this threshold has truly changed patient's autonomy.
- Observe whether the threshold remains relevant for longitudinal follow-up over more than a year.

References:
(1) Donzé, Cécile et al. (2025). Development of a new patient-reported outcome measure for patients with multiple sclerosis: the Multiple Sclerosis Autonomy Scale (MSAS). *Multiple Sclerosis and Related Disorders*, 92, 105925.
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(3) Sedaghat, Ahmad R. (2019). Understanding the Minimal Clinically Important Difference (MCID) of Patient-Reported Outcome Measures. *Otolaryngology–Head and Neck Surgery*, 161(3), 565–567. https://doi.org/10.1177/0194599819852604