

Does over-reliance on Manual Muscle Testing (MMT8) commonly negate patient voice? Does this cause treatment delays that lead to long-term disability in people living with Myositis Diseases?

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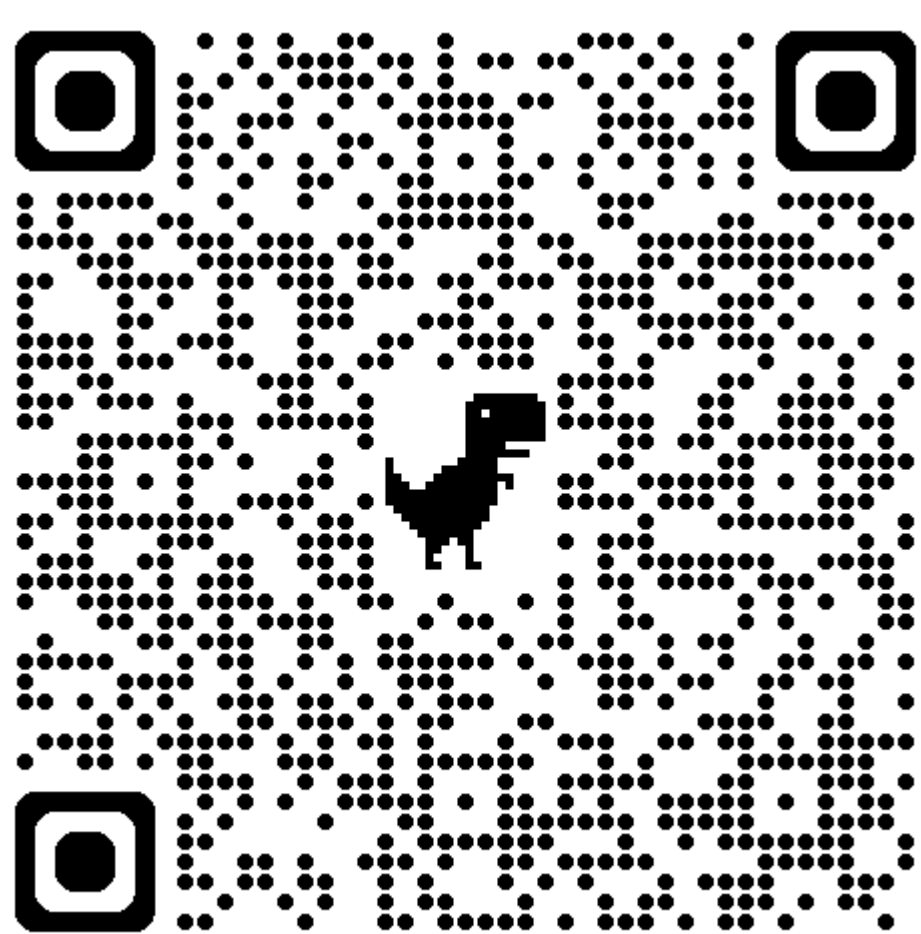
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Objectives

- Investigate the potential underpinnings for patient perceived misrepresentation of their disease experience by the MMT 8 and other traditional measures.
- Develop a patient research strategy to understand the extent of this concern in the patient community.
- Provide preliminary guidance for patient-clinicians decision-making that factors patients' experience into treatment considerations.

Background

- Idiopathic inflammatory myopathies (IIMs) are rare diseases whereby muscle injury can lead to permanent disability. IIMs can also affect other organ systems.
- Long-term disability due to treatment delay associated with clinician's over-reliance on MMT8 rather than on patient-reported progressive weakness, is a key concern of people living with myositis.
- MIHRA's Patient Advisory perceived that long-term disability result missed opportunities for timely treatment, due to lead to treatment delay despite:
 - Elite athletes providing detailed objective records of deteriorating performance and/ or
 - Concurrently active (symptoms of) skin disease.



QR 1. Leads to further information on MMT8, video of FI-3 and PDFs to help guide in clinical decision-making.

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Methods

Scoping Review

On the current state of detection and patient experience regarding muscle impairment.



Develop Patient Research Plan

How to examine & address patient concerns of progressive impairment.



Develop Preliminary Guidance for Joint Patient-Clinician:

- Consideration of active progressive disease
- Shared decision-making (SDM) based strategies



Support Development of Improved Disease Activity Assessment

- Through patient involvement in research
- Shared decision-making (SDM) based strategies

Results

1. Dynamic assessment of muscle function such as the Functional Index-3 (FI-3), is more sensitive to detect muscle impairment compared to the MMT8 (Fig. 1). **This corroborates the discordance of patient experiences of muscle impairment vs MMT8 results.**

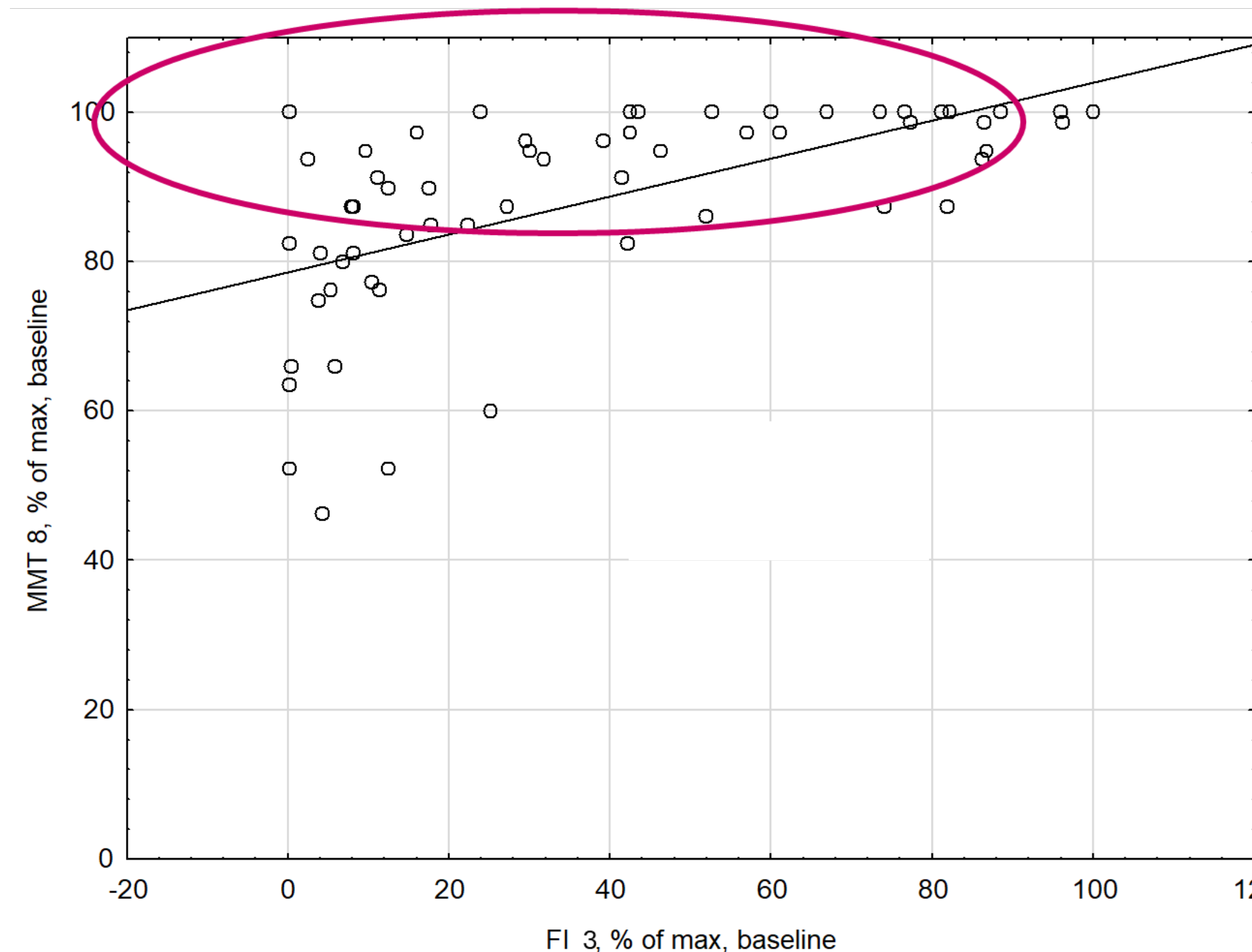


Figure 1. MMT8; Manual Muscle test, FI-2 / FI-3. The small circles indicate each of the 72 patients tested. The large red circle indicates those with a near perfect MMT 8 but significant impairment on FI-3

2. Items for clinical considerations from patients' view & scoping review to recognize the likelihood of active muscle disease despite 'normal' traditional measures (Fig 2).

Fig 2. Clinical Considerations to Recognize the Likelihood of Active Muscle Disease When Traditional Measures are Indeterminate

Are there any muscle symptoms suggestive of inflammation, like pain, burning, tightness, tenderness to touch, decreased muscle endurance, or aching not made better by rest.

Have the patient's symptoms been itemized? With each symptom, queried if better, same or worse?

Have the relevant patient-reported functional activities been itemized and queried if better, same or worse?

Though diagnostics suggest low or no activity, is there a chance the patient's symptoms are related to treatable active disease and reversible inflammation?

Is there another organ that seems to have active disease, e.g. skin, lungs, leading to reasonable conclusion muscle may also be active?

Is there progression? Slow or rapid in the patient's opinion are both valid rates of perceived loss.

Prolonged or high dose use of steroids? Is steroid myopathy a possibility? Have steroids been tapered too quickly without other sufficient immunosuppressive therapy?

Has there been DMARD medication switching rather than attempts to reasonably add-on medications?

Is myositis of recent onset? Or has a "flare" occurred recently?

Conclusion

Motivated by common experience, we present approaches for joint clinical decision-making that may improve quality care for people with myositis diseases.

This work contributes toward a proposed priority project within **MIHRA's Public Private Partnership** with US FDA Center for Drug Evaluation & Research.

3. Items for shared-decision-making when 'normal' traditional measures contradict patient report. (Fig 3).

