Annual Conference EMSP

Prevention
in Multiple Sclerosis and Related Disorders:
Uncovering Risk and Protective Factors

PRAGUE | 16-17 MAY 2025

emsp
EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Czech multiple sclerosis society
MS UNIE ROSKA

Annual
Conference
EMSP

PRAGUE | 16-17 MAY 2025

Just Do It! Fostering Community, Diversity & Inclusion in Multiple Sclerosis

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“ They say we ***are hard to reach*** but we are not hard to reach! we are here!”

“I was diagnosed at age 55 so was always excluded from clinical trials. I had given up all hope because of my age and disability..”

“ They make assumptions about who is interested or not in taking part in research… just ask.. Don’t make assumptions.”

“No one in the research team looks like me”

“I’ve never been asked to take part in research”

“I am interested in taking part in research, but I only hear about them when they are finished.”

The voices of people with MS from diverse backgrounds, age and disability levels

Examples of diversity & inclusion in research & clinical care

Queen Mary
University of London

CHARIOT MS

Chief Investigator:
Professor Klaus Schmierer

London sites
Luton & Dunstable
Queen's Hospital Romford
St. Georges Hospital
Royal London Hospital
Royal Free Hospital

- First DMT trial for people with advanced MS (EDSS 6.5-8.5)
- No upper age limit
- Primary outcome measure is upper limb function
- We believe the information from this study will produce a unique dataset for people with MS at both an advanced age and disability

chariot@qmul.ac.uk
www.chariotms.com

PCTU
Pragmatic Clinical Trials Unit

Multiple Sclerosis and Related Disorders 85 (2024) 105529

Contents lists available at ScienceDirect

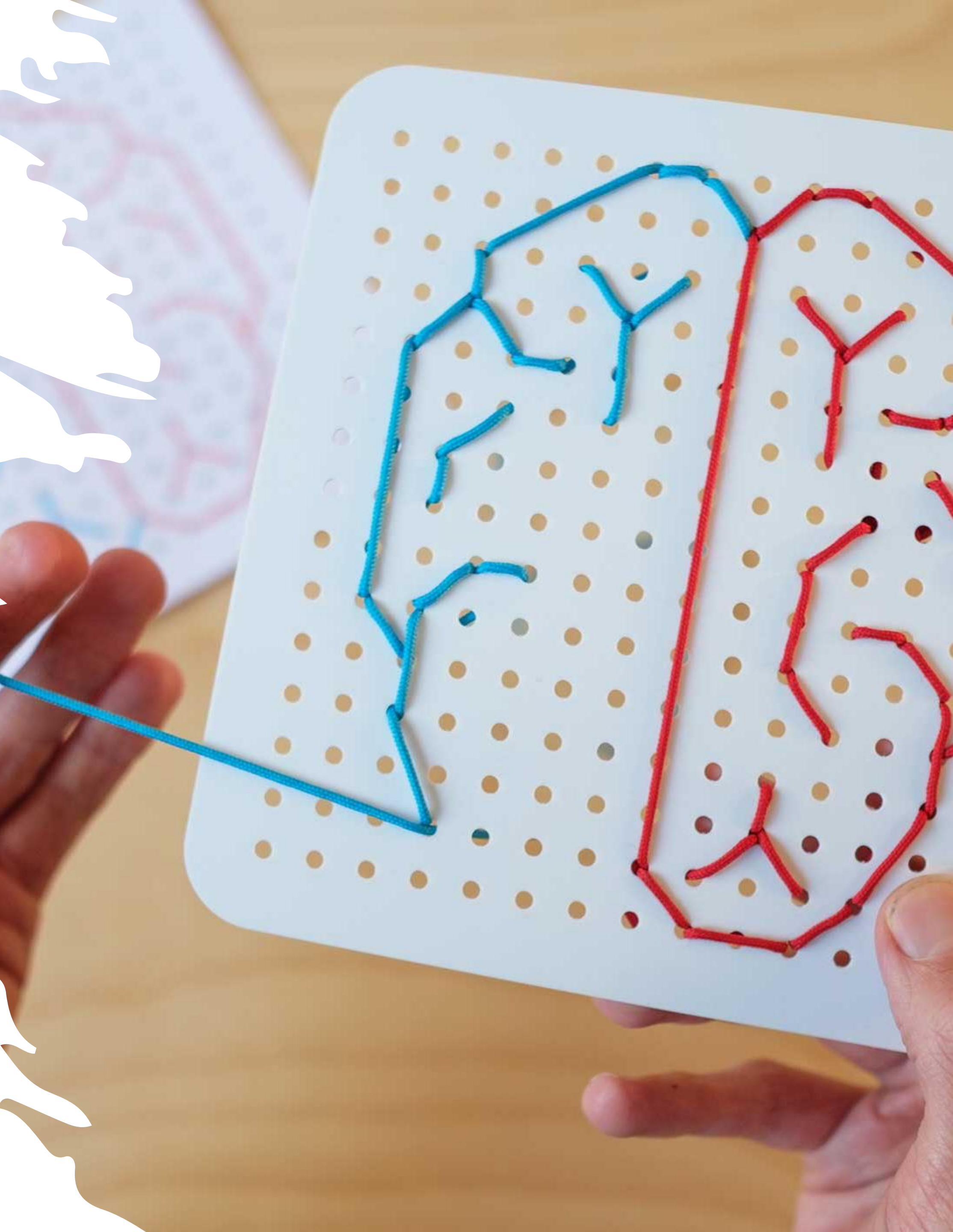
Multiple Sclerosis and Related Disorders

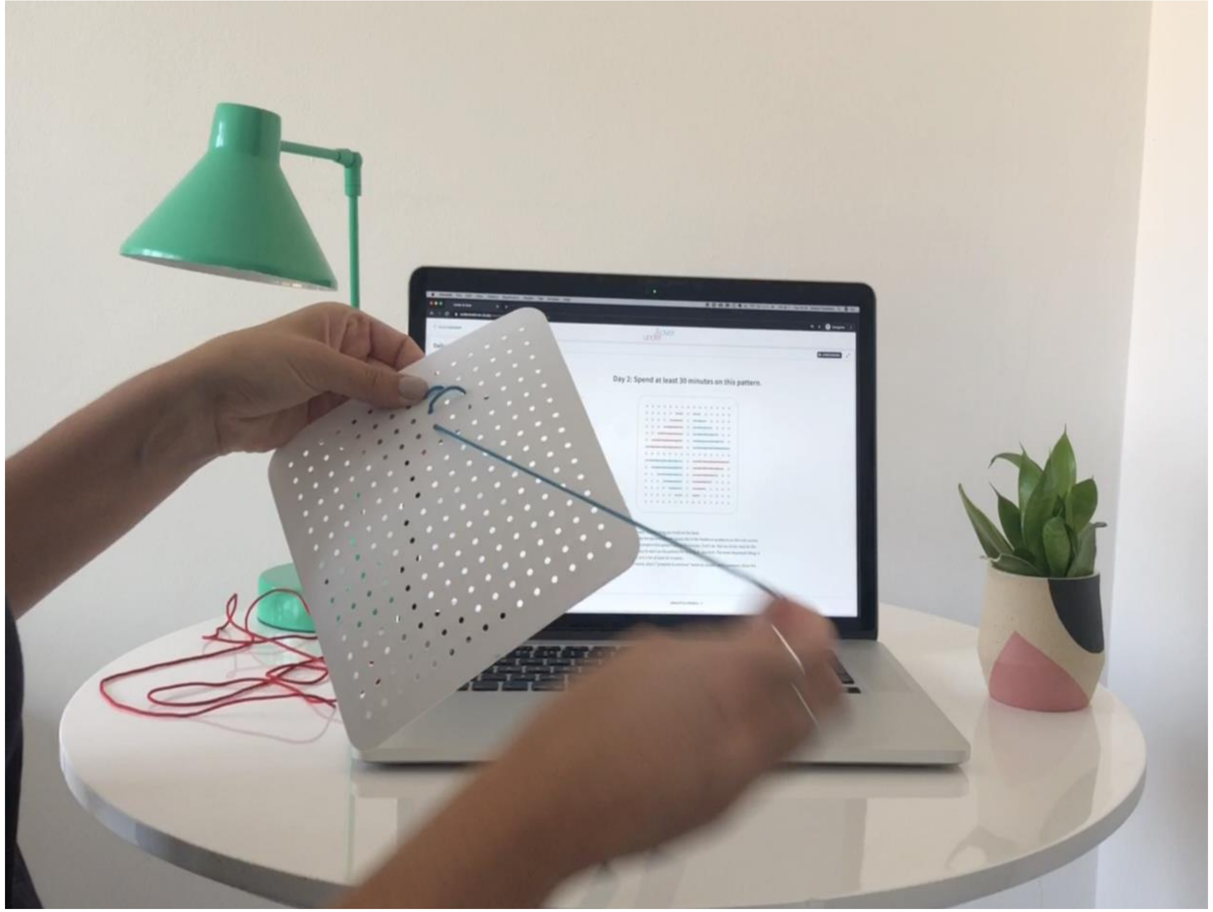
journal homepage: www.elsevier.com/locate/msard

Under & Over: A randomised controlled study to develop an upper limb rehabilitation tool for people with Multiple Sclerosis

Alison Thomson [a,*], Andrea Stennett [a], Canan Metin [a], Jonathan Bestwick [a], Gavin Giovannoni [b], Ruth Dobson [a]

[a] Wolfson Institute of Population Health, Queen Mary University of London, London, UK
[b] Blizard Institute, Queen Mary University of London, London, UK

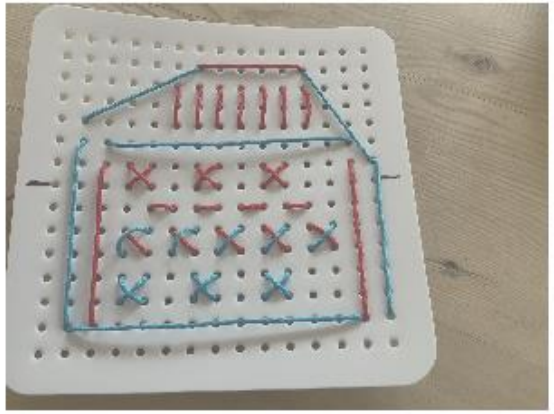




An online platform hosted the study and the 12-week rehab programme. Technical support videos were created by the study team to demonstrate how to use the tool and the platform.

Different stitch

Posted by Participant 11 on May 10, 2021



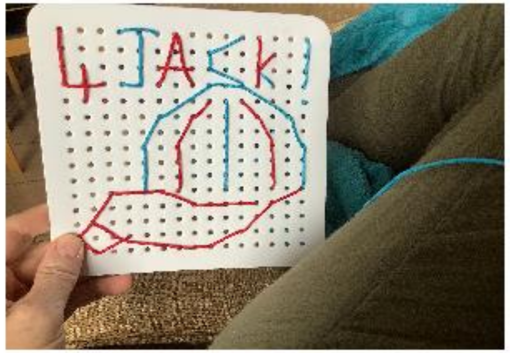
Links of Life

Posted by Participant 68 on May 30, 2021

Posted by Participant 68 on June 13, 2021

All of it plus a bit more

Posted by Participant 108 on August 17, 2021



Thomson *et al. Research Involvement and Engagement* (2024) 10:62
https://doi.org/10.1186/s40900-024-00586-y

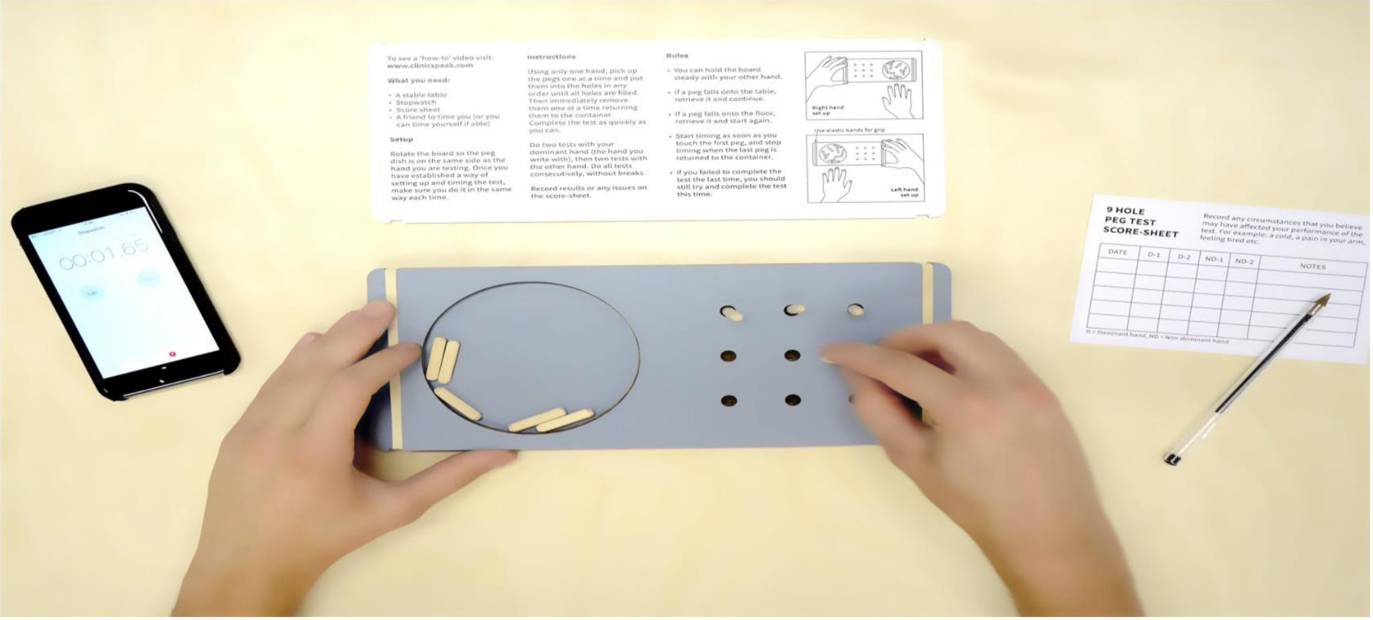
Research Involvement
and Engagement

COMMENT **Open Access**

Engaging a community to focus on upper limb function in people with multiple sclerosis: the ThinkHand campaign case study

Alison Thomson[1*], Rachel Horne[2], Christine Chapman[2], Trishna Bharadia[2], Patrick Burke[2], Elizabeth Colwell[2], Mark Harrington[2], Bonnie Boskovic[2], Andrea Stennett[1,4], David Baker[3], Gavin Giovannoni[1,3,4] and Klaus Schmierer[3,4]

Fig. 2 The cardboard poster presented at ECTRIMS conference 2017, being made by poster authors by hand



To see a 'how-to' video visit:
www.clinicspeak.com

What you need:

- A stable table
- Stopwatch
- Score sheet
- A friend to time you (or you can time yourself if able)

Setup

Rotate the board so the peg dish is on the same side as the hand you are testing. Once you have established a way of setting up and timing the test, make sure you do it in the same way each time.

Instructions

Using only one hand, pick up the pegs one at a time and put them into the holes in any order until all holes are filled. Then immediately remove them one at a time returning them to the container. Complete the test as quickly as you can.

Do two tests with your dominant hand (the hand you write with), then two tests with the other hand. Do all tests consecutively, without breaks.

Record results or any issues on the score-sheet.

Rules

- You can hold the board steady with your other hand.
- If a peg falls onto the table, retrieve it and continue.
- If a peg falls onto the floor, retrieve it and start again.
- Start timing as soon as you touch the first peg, and stop timing when the last peg is returned to the container.
- If you failed to complete the test the last time, you should still try and complete the test this time.

9 HOLE PEG TEST SCORE-SHEET

Record any circumstances that you believe may have affected your performance of the test. For example: a cold, a pain in your arm, feeling tired etc.

DATE	D-1	D-2	ND-1	ND-2	NOTES

D = Dominant hand, ND = Non dominant hand

Examples from routine clinical care

Clinical trials for MS

We carry out lots of clinical trials for people with MS – trials for those who are recently diagnosed and trials for those who have had for MS years. While we offer trials for people at all stages of their MS journey, in order to take part in a clinical trial, you must meet a set of defined characteristics known as the eligibility criteria.

To find out what MS clinical trials we offer at Barts Health and who can take part in them, check out **section 5 of our BartsMS Navigator**, **email our clinical trials team**, or speak to your medical team directly.

You can also learn out more about what taking part in research involves – and all the different ways you can do it – **on our Research at Barts Health webpages**.

The **BartsMS Navigator** resource document provides information about MS, your MS Team, treatment options, clinical trials and expectations of being under our care. Visit: [download.cfm (bartshealth.nhs.uk)](download.cfm) or please scan the QR code below:

Scan me !

The CoachMS workshop: coaching newly diagnosed people with multiple sclerosis

Andrea Stennett[1,2], Joela Mathews[2], Karen Magor[3], Alon Kotev[3], Roshan das Nair[4,5], Anat Achiron[3,6], Klaus Schmierer[1,2]

[1]The Blizard Institute, Centre for Neuroscience, Surgery & Trauma, Queen Mary University of London, UK [2]Clinical Board Medicine (Neuroscience), The Royal London Hospital, Barts Health NHS Trust, UK [3]Multiple Sclerosis Center, Sheba Medical Center, Israel, [4]Health Research, SINTEF Digital, Norway, [5]Faculty of Medicine and Health Sciences, University of Nottingham, UK, [6]Sackler School of Medicine, Tel-Aviv University, Israel

Introduction

Coaching newly diagnosed people with MS (pwMS) is a novel concept within MS care. It hinges on the principles that providing early emotional support and strategies for coping with MS are key for early treatment initiation and improving overall quality of care.

However, to facilitate this shift in the management of MS, the workforce requires ‘*upskilling*’.

Aims

To evaluate the views of participants who attended the first international CoachMS workshop (figure 1).

Figure 1: Participants of the 1st CoachMS workshop

Methods

A 2-day workshop led by a team experienced in coaching pwMS early after diagnosis was held in London, 19-20 Feb 2024.

Modules included:

- (i) early interactions between healthcare professionals (HCPs) and pwMS
- (ii) dealing with resistance
- (iii) emotional care pathway development,
- (iv) goal setting
- (v) measuring success.

Participants (N=25) included healthcare professionals (HCPs), academics and pwMS across the UK. Pre-and post-workshop questionnaires were completed. Data were analysed using descriptive statistics.

Coaching may enable newly diagnosed pwMS to rapidly adapt to their diagnosis thereby minimising detrimental effects of MS

Innovative practices

… these simple but innovative practices helps to build trust and communication with all people with MS.

Practical considerations

Low hanging fruit!

Fostering community, diversity & inclusion : Research

- Know your population: audits/service improvement projects.
- **A data driven approach: build stronger evidence base in Europe.**
- Need research using not only top-down approaches but also bottom up- include the lived experiences of people with MS.
- Allocate research funding/grants to address health disparities and improve outcomes in people with MS.

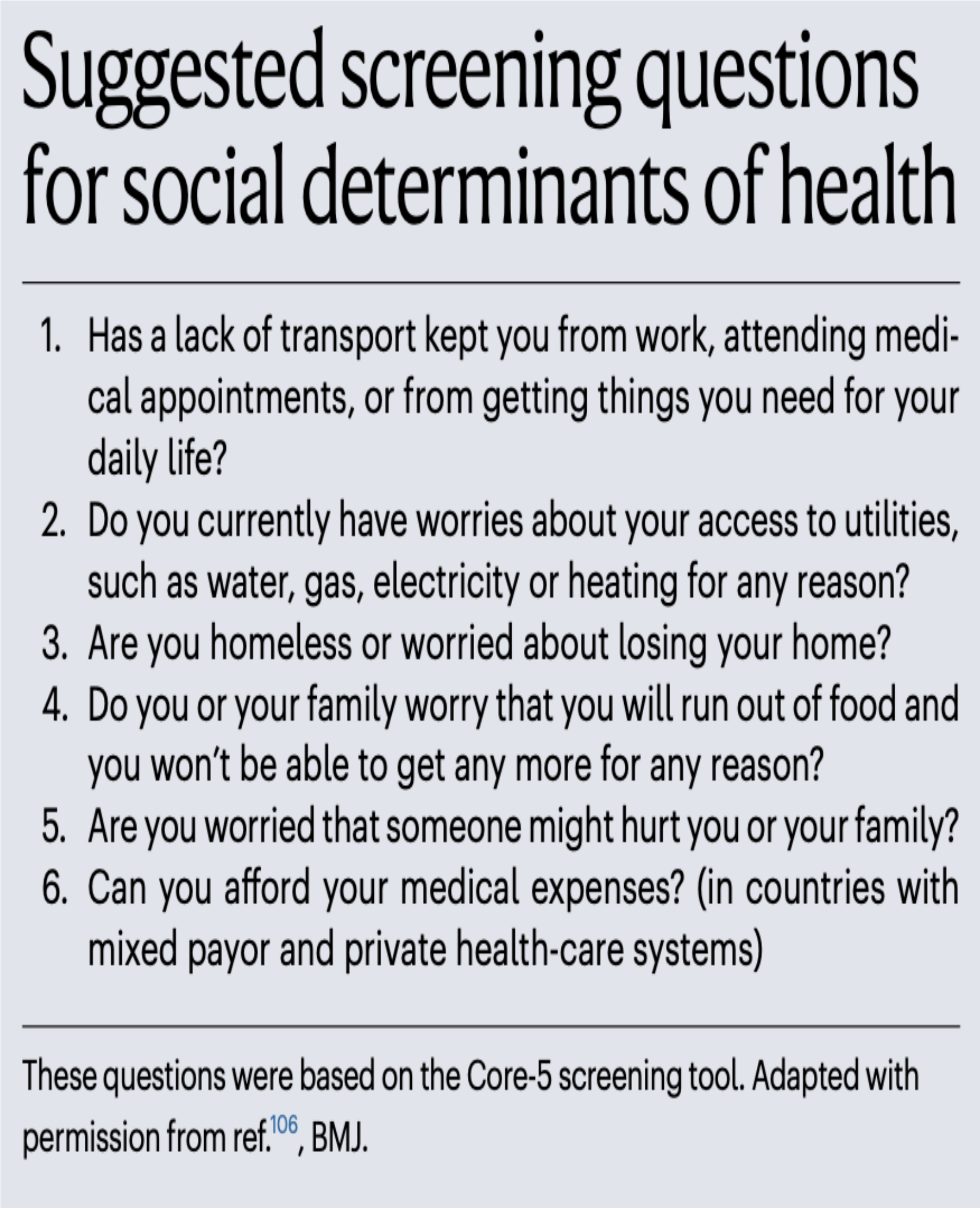
Fostering community, diversity & inclusion: Education

- A wide range of initiatives to raise awareness of MS, symptoms and impact in all communities- e.g media, videos, social media, MS charities, community engagement groups, religious groups etc.
- MS teams should have access to services that can provide information/educational resources in different languages.
- Cultural awareness education/training programs to understand and respect cultural differences- HCP training.

Workforce * diverse workforce to meet the needs of a diverse population.

Fostering community, diversity & inclusion: Access to healthcare

- Ensure better access to healthcare irrespective of gender, race, ethnicity and sexual orientation.
- **At risk register to identify/screen social determinants of health.**
- Access to rehabilitation services, social prescribing, vocational rehab, financial/ housing support.



Suggested screening questions for social determinants of health

1. Has a lack of transport kept you from work, attending medical appointments, or from getting things you need for your daily life?
2. Do you currently have worries about your access to utilities, such as water, gas, electricity or heating for any reason?
3. Are you homeless or worried about losing your home?
4. Do you or your family worry that you will run out of food and you won't be able to get any more for any reason?
5. Are you worried that someone might hurt you or your family?
6. Can you afford your medical expenses? (in countries with mixed payor and private health-care systems)

These questions were based on the Core-5 screening tool. Adapted with permission from ref.[106], BMJ.

Dobson et al 2022

Fostering community, diversity & inclusion : Assess/Monitor/Review

- Strategic and coordinated plans to assess, monitor and review health disparities across MS teams –locally, nationally, across Europe and globally.
- **Set up a MS taskforce to address health disparities. ***
- Access to health services can be measured in terms of service availability, utilisation and experience.
- Use of patient feedback/within trials design to assess effectiveness of inclusive interventions.
- Review polices and adjust as Social Determinants of Health (SDOH) changes.

Take home messages: all hands-on deck!

- We need a global collaborative approach! e.g people with MS, HCPs, key stakeholders, government/policy makers, charities, patient advocacy groups, philanthropists, industry partners.
- Respect each others belief/ culture and be aware of our own assumptions and biases.
- **Fostering community, diversity and inclusion starts with us! *Just do it!***

Thank you for listening!