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Abstract for the topic: “Data, Registries, and Data-Driven Evidence”

Title:

MS-PAVED "Platform for connection, trust, experience, and documentation”

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Description:

MS-PAVED is a research project developing an innovative patient documentation portal that enabe People with MS (PwMS) to independently report data about their MS.

Rationale:

Health Care Professionals (HCP) often lack the time address the full range of issues relevant to PwMS, and routine clinical documentation may not fully reflect the patient perspective. In particular, these issues include, psychosocial aspects, lifestyle factors, everyday disease management, and informal support in daily life which are relevant for the progression of MS and the quality of life (QoL) of PwMS. However, such factors remain insufficiently captured in MS research and routine clinical care.

The German MS Register (GMSR) was initiated in 2001 by the German MS Society in order to obtain reliable data and new insights into MS through a nationwide registry. The GMSR aims to close gaps in MS knowledge and improve MS care.

Under the current infrastructure, clinical data are documented for the GMSR by over 180 MS centers. These include outpatient clinics, medical offices, university hospitals, specialist clinics, and rehabilitation clinics. The documentation is performed by HCPs and therefore mainly reflects the clinical perspective rather

than patient-reported outcomes (PROs). Within the GMSR cohort, patient-centered surveys can only be conducted through designated MS centers, and require HCPs to actively contact PwMS and recruit them for such surveys. Currently, there is no way for PwMS to register for the GMSR independently of participating clinical sites.

Objective:

Through MS-PAVED, we aim to better understand the experiences and needs of PwMS in daily life and health care by enabling them to directly report their own data. To this end, we will include questionnaires on QoL and lifestyle in MS research in addition to the usual medical parameters/values. The goal is to improve long-term MS care and raise awareness of these important aspects that affect QoL.

In addition, the project is going to evaluate the acceptance of patient-reported surveys within the MS patient, HCPs and research community with aim of integrating the documentation portal into the foundation of the GMSR.

Development:

MS-PAVED is been developed through a co-creation process involving PwMS, scientists, MS nurses, HCPs, and employees of the German MS Register (GMSR) and the German MS Society. This co-creation process ensures inclusion of multiperspective experiences into the design of the portal.

Study plan:

The pilot study survey will be conducted both paper- and web-based, allowing participants to register either online or by letter. All data are collected and stored in pseudonymised form via the MS-PAVED trust center.

Paper-based participation:

Participants who prefer to participate using traditional paper-based surveys should submit their registration form to the MS-PAVED trust center. Upon receipt, they will receive the baseline questionnaire by mail. The baseline survey will collect fundamental information about the patient and their MS disease.

Web-based participation:

After registering on the MS-PAVED website, online participants will receive a link to the baseline survey. The baseline survey will collect fundamental information about the patient and their MS disease. Once completed, the participants will be invited to fill out a more detailed questionnaire focusing specifically on the medical history, health- related QoL, treatments and lifestyle factors. Invitations will be sent via the registration email.

After approximately 3-6 months, participants will be invited by email to fill in a follow-up questionnaire. This survey aims at assessing whether any changes have occurred in the patient’s situation since the first survey.

To ensure data authenticity, verification will be conducted primarily via email, and in 10% of cases by postal mail. This allows us to evaluate which verification method is most effective in maintaining data integrity.

Funding:

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Disclosures:

AR had no personal financial interests to disclose other than being an employee of the GMSR.

RB has nothing to diclose in the context of this abstract.

PF has nothing to diclose in the context of this abstract.

NF had no personal financial interests to disclose other than being an employee of the GMSR and of Rostock’s University Medical Center.

MM had no personal financial interests to disclose, other tha being employee of DMSG, which receives (project) funding from various public and private donors; available here: https://www.dmsg.de/fileadmin/public/DMSG/Dokumente/Selbstauskunft/SKM_C360i25100807041.pdf and here: https://www.dmsg.de/fileadmin/public/DMSG/Dokumente/Gesch%C3%A4ftsberichte/DMSG_GB24_FINAL_20251028__1_.pdf

SP has no conflicts of interest to disclose.

JS declares no conflict of interest. JS reports previous employment in the pharmaceutical industry (>3 years ago) unrelated to this work.

AS Alexander Stahmann has no personal pecuniary interests to disclose, other than being the lead of the German MS Register, which receives (project) funding from a range of public and corporate sponsors, recently including The German Innovation Fund (G-BA), The German Retirement Insurance, The German MS Trust, The German MS Society, The German Ministry of Health, Bristol Myers

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