MS-PAVED -
Plattform for connection, trust, experience, and documentation

msregister

dmsg Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V.

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Disclosures

AR had no personal financial interests to disclose other than being an employee of the GMSR. 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.
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MS-PAVED is a participatory research project developing an innovative patient documentation portal that enables People with MS (PwMS) to independently report data about their MS.

Rationale

- Healthcare Professionals (HCP) often lack time to address psychosocial, lifestyle, and daily management issues relevant to PwMS, which are keys to disease progression and quality of life (QoL).
- These patient-centered aspects are underrepresented in routine clinical documentation, claims data and MS research.
- The German MS Register (GMSR), established in 2001 by the German MS Society (DMSG), aims to improve MS care and to close knowledge gaps through a nationwide data collection.
- Over 180 MS centers (outpatient clinics, hospitals, rehabilitation centers, etc.) contribute clinical data to the GMSR, but data are primarily HCP-driven and primarly reflect the clinical perspective.
- Patient-reported outcomes (PROs) are not systematically captured; surveys require HCP-mediated recruitment through designated centers.
- PwMS cannot currently register for the GMSR independently of clinical sites, limiting patient-centered data collection.

Objectives

- MS-PAVED empowers PwMS to directly report their own experiences, enabling a deeper understanding of their daily lives and healthcare needs.
- The project integrates PROs — including QoL and lifestyle factors — alongside traditional clinical data in MS research.
- The goal is to improve long-term MS care and increase awareness of non-clinical factors that significantly impact QoL.
- The project evaluates the acceptance and feasibility of PRO surveys among PwMS, HCPs, and researchers.
- A key objective is to assess the potential integration of the MS-PAVED documentation portal into the foundation of the GMSR, supporting a more patient-centered approach to data collection.

Methods

- Co-creation process to ensure multiperspective experiences into the design of the portal.

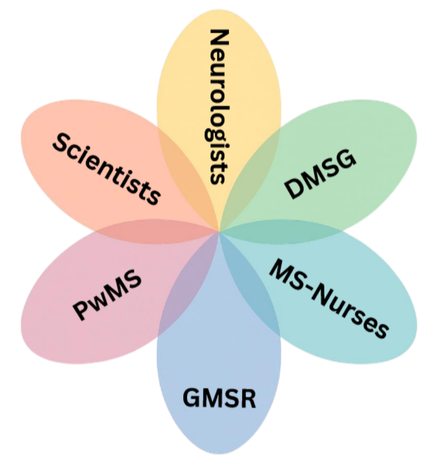

Figure 1: Participatory process - Team members and perspectives

Pilot study

- The pilot study is conducted online and web-based, offering PwMS the option to join either digitally or via paper.

Online participation

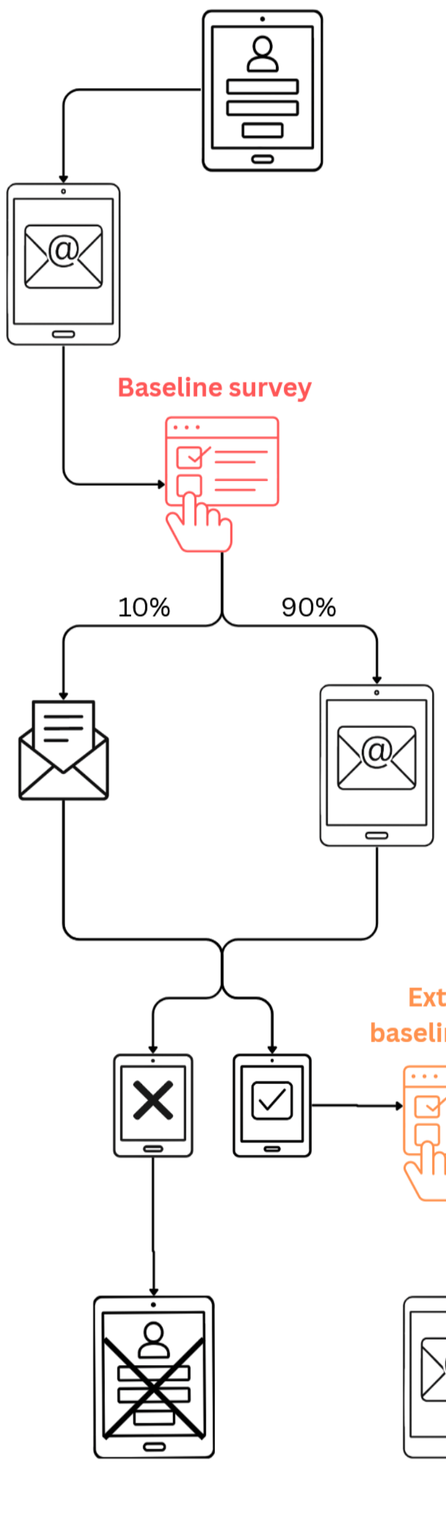

Figure 2: Procedure for Online Participation

- The online participation involves a baseline survey, an extended baseline survey, and a follow-up survey approximately 3 to 6 months later.

Process:

- PwMS **register on the MS-PAVED website** and receive a link to the **baseline survey** via e-mail. This survey collects basic information about MS history and QoL. After completion, participants are invited to a more **detailed baseline survey** focusing on MS care, treatment, and lifestyle - also delivered via email.
- **Follow-up survey:** Approximately 3–6 months after the baseline survey, all participants receive a follow-up questionnaire via e-mail to assess any changes in their situation since the first survey.
- After completing the questionnaires, participants may also fill out additional **standardised questionnaires** regarding the individual MS symptoms.
- Data Verification: To ensure data authenticity, verification is conducted primarily by e-mail. In 10% of cases, verification is done by postal mail. This allows us to evaluate the effectiveness of each method. All other participants will be verified via email.
- Information about the online participation will be posted on all DMSG and GMSR social media channels and promoted in person at MS centers.

Paper participation

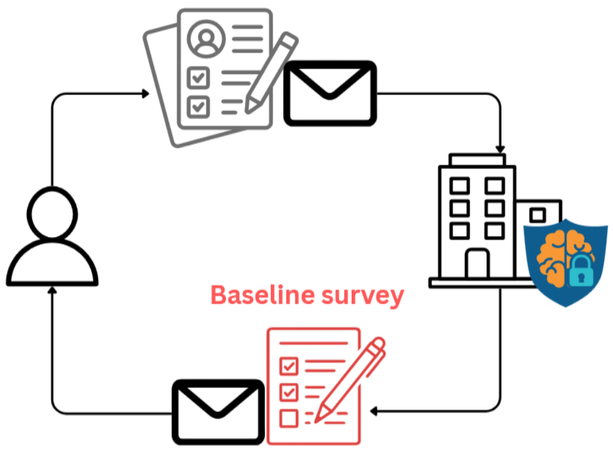

Figure 3: Procedure for Paper-Pencil Participation

- The paper-based participation involves a single data collection at baseline.

Process:

- Participants who prefer the traditional method send their **registration form** to the MS-PAVED Trust Center and receive the baseline survey by mail.
- Registration forms are available at the DMSG and at the MS centers.