

Real-world data on the prevalence and therapy of symptomatic bladder and bowel dysfunction in people with multiple sclerosis

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msregister

Disclosure of conflict of interest

Niklas Frahm is an employee of the German MS Register (MS Forschungs- und Projektentwicklungs-gmbH – MSFP). Moreover, he is an employee of Rostock's University Medical Center and received travel funds for research meetings from Novartis. None resulted in a conflict of interest.

Melanie Peters, David Ellenberger, Maximilian Bardo and Mathia Kirstein had no personal financial interests to disclose other than being employees of the German MS Register.

Alexander Stahmann has no personal financial interests to disclose, other than being the leader of the German MS Register, which receives (project) funding from a range of public and corporate sponsors, recently including the German Innovation Fund for Health Services Research of the German Federal Joint Committee (G-BA, funding code: 01VSF23024), the German Retirement Insurance, the German MS Trust, the German MS Society, Biogen, Bristol Myers Squibb, Merck, Novartis and Roche. None resulted in a conflict of interest.

Christoph Kleinschnitz has received speaker's fees, honoraria for attending advisory boards, and financial support for conducting research projects from Merck Serono GmbH, Germany and Merck KgaA, Germany. None resulted in a conflict of interest.

Kerstin Hellwig has received speaking fees and/or institutional grant support from Bayer, Biogen, BMS, Merck Serono, Novartis, Roche, Sanofi-Genzyme, and Teva. None resulted in a conflict of interest.

Tim Friede has received personal fees for statistical consultancies (including data monitoring committees) from Actimed, Aslan, Bayer, BiosenseWebster, BMS, CSL Behring, Daiichi Sankyo, Enanta, Fresenius Kabi, Galapagos, IQVIA, Immunic, KyowaKirin, LivaNova, Minoryx, Novartis, PINK! gegen Brustkrebs, PPD, RECARDIO, Recordati, Relaxera, Roche, Servier, Viatrix, Vifor, and VICO Therapeutics. None resulted in a conflict of interest.

Friedemann Paul has received speaking fees, travel support, honoraria from advisory boards and/or financial support for research activities from Bayer, Novartis, Biogen, Bristol Myers Squibb, Teva, Sanofi-Aventis/Genzyme, Merck Serono, Alexion, Chugai, MedImmune, Shire, German Research Council, Werth Stiftung of the City of Cologne, German Ministry of Education and Research, EU FP7 Framework Program, Arthur Arnstein Foundation Berlin, Guthy Jackson Charitable Foundation and National Multiple Sclerosis of the USA. He serves as academic editor for PLoS ONE and associate editor for Neurology, Neuroimmunology and Neuroinflammation. None resulted in a conflict of interest.

Clemens Warnke has received institutional support from Novartis, Alexion, Sanofi Genzyme, Biogen, Merck and Roche. None resulted in a conflict of interest.

Peter Flachenecker has received speaker's fees and honoraria for advisory boards from Almirall, Bayer, Biogen Idec, BMS-Celgene, Coloplast, Genzyme, GW Pharma, Hexal, Janssen-Cilag, Novartis, Merck, Roche, Sanofi, Stadapharm and Teva. None resulted in a conflict of interest.

Michaela Mai is an employee of the German MS Society, federal association, which receives funding from a range of public and corporate sponsors, recently including BMG, G-BA, the German MS Trust, Biogen, BMS, Merck Serono, Novartis, Roche, Sanofi, and Viatrix. None resulted in a conflict of interest.

Uwe K. Zettl has received speaking fees, travel support and /or financial support for research activities from Alexion, Almirall, Bayer, Biogen, Bristol Myers Squibb, Janssen, Merck Serono, Novartis, Octapharma, Roche, Sanofi Genzyme, Teva as well as EU, BMBF, BMWi and DFG. None resulted in a conflict of interest.

Bladder and bowel dysfunction in MS

- Embarrassment
- Reduced quality of life
- Social stigma
- Social isolation
- ...

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ORIGINAL COMMUNICATION

“It’s just horrible”: a qualitative study of patients’ and carers’ experiences of bowel dysfunction in multiple sclerosis

Lesley Dibley^{1,2} · Maureen Coggrave³ · Doreen McClurg⁴ · Sue Woodward³ · Christine Norton³

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RESEARCH PAPER

Bladder dysfunction and quality of life for people with multiple sclerosis

Catherine Browne¹, Nancy Salmon¹, and Maria Kehoe²

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Neurourology and Urodynamics 35:8–14 (2016)

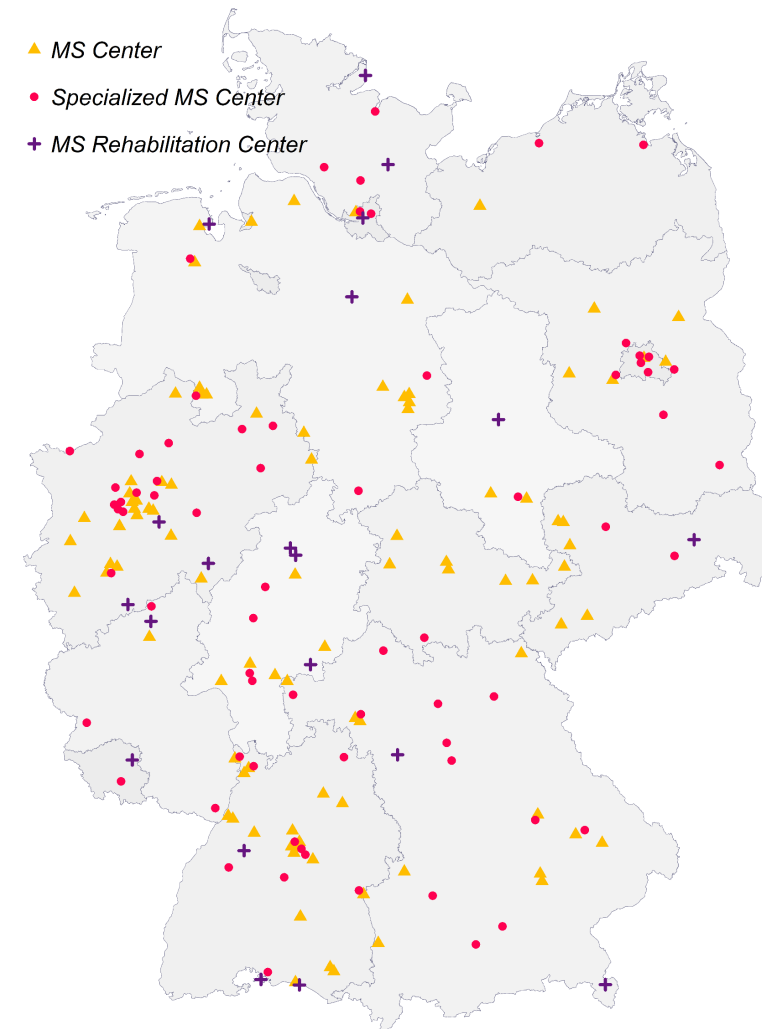
Patient Reported Outcomes Measures in Neurogenic Bladder and Bowel: A Systematic Review of the Current Literature

Darshan P. Patel,^{1*} Sean P. Elliott,² John T. Stoffel,³ William O. Brant,¹ James M. Hotaling,¹ and Jeremy B. Myers¹

German MS Register: Profile

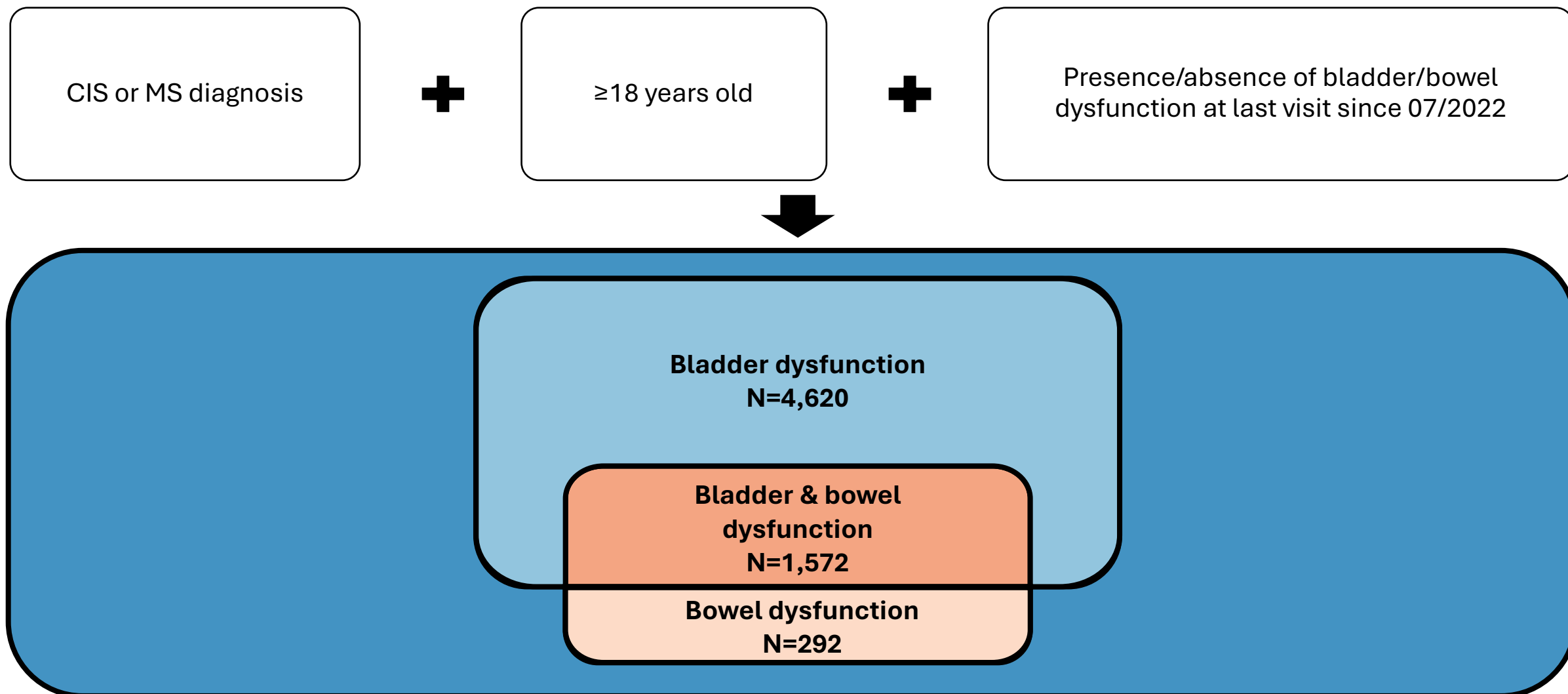
- **Since 2001:** Recruitment of 80,000+ patients since
- **2014-2016:** Major technical & dataset revision
- **Currently:** Data from 186 MS centers distinguished by the German MS Society

➔ Register platform allows to conduct **register analyses** as well as **registry-based RCTs** and **special cohorts** (PowerMS1&2, EmBioProMS, Lotus-MS)

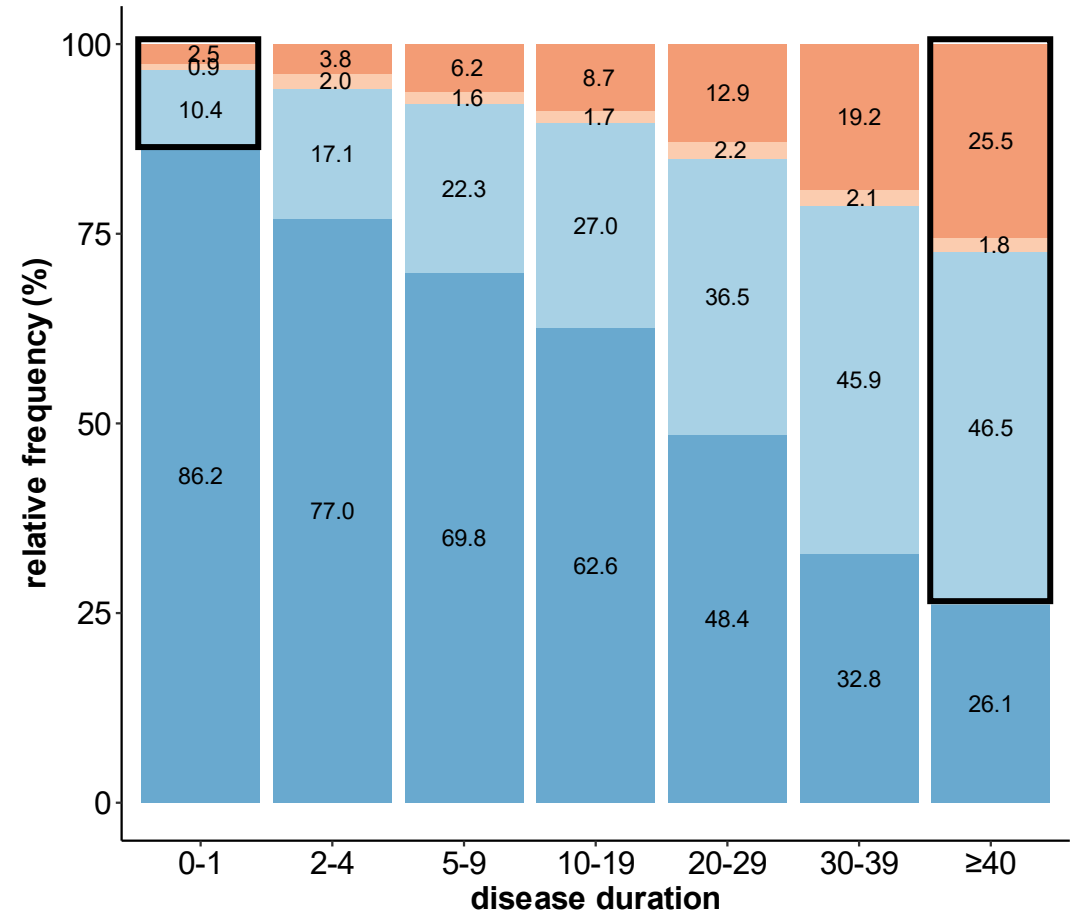
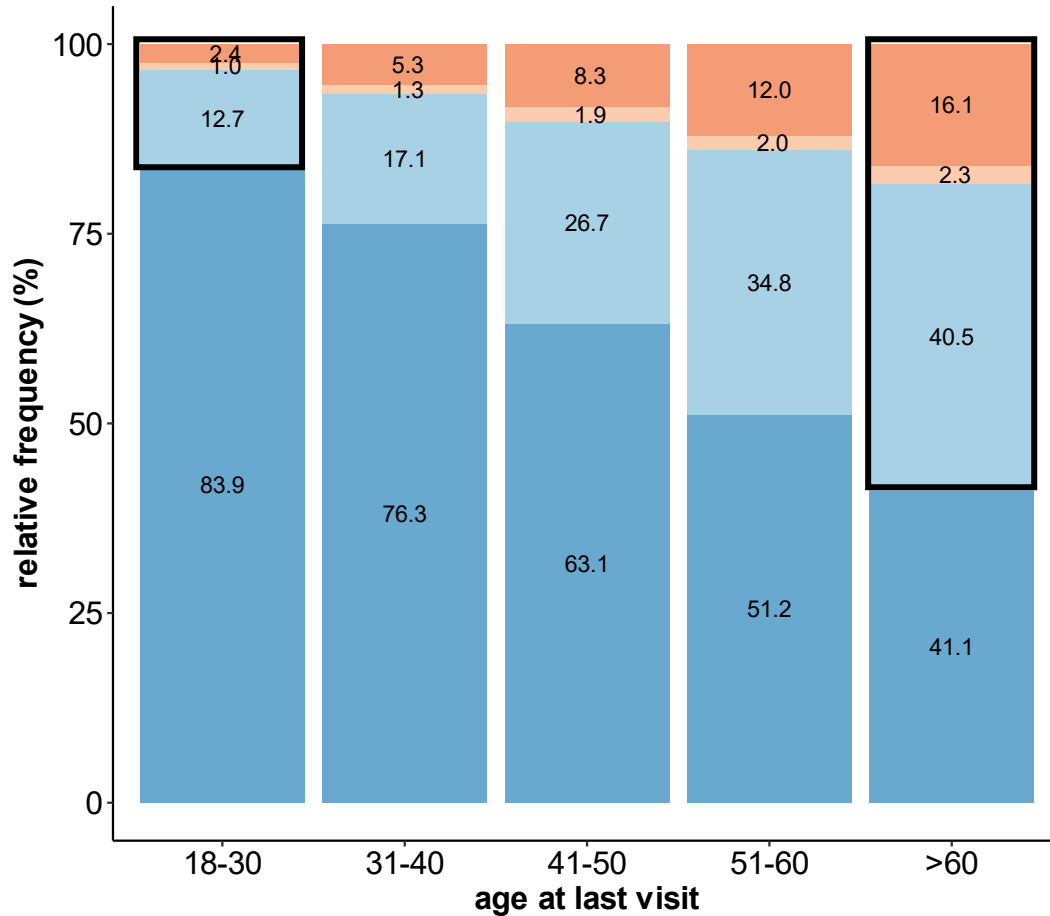


The map was created with R 4, based on data from gadm.org.

Data on bladder and bowel dysfunction in the German MS Register



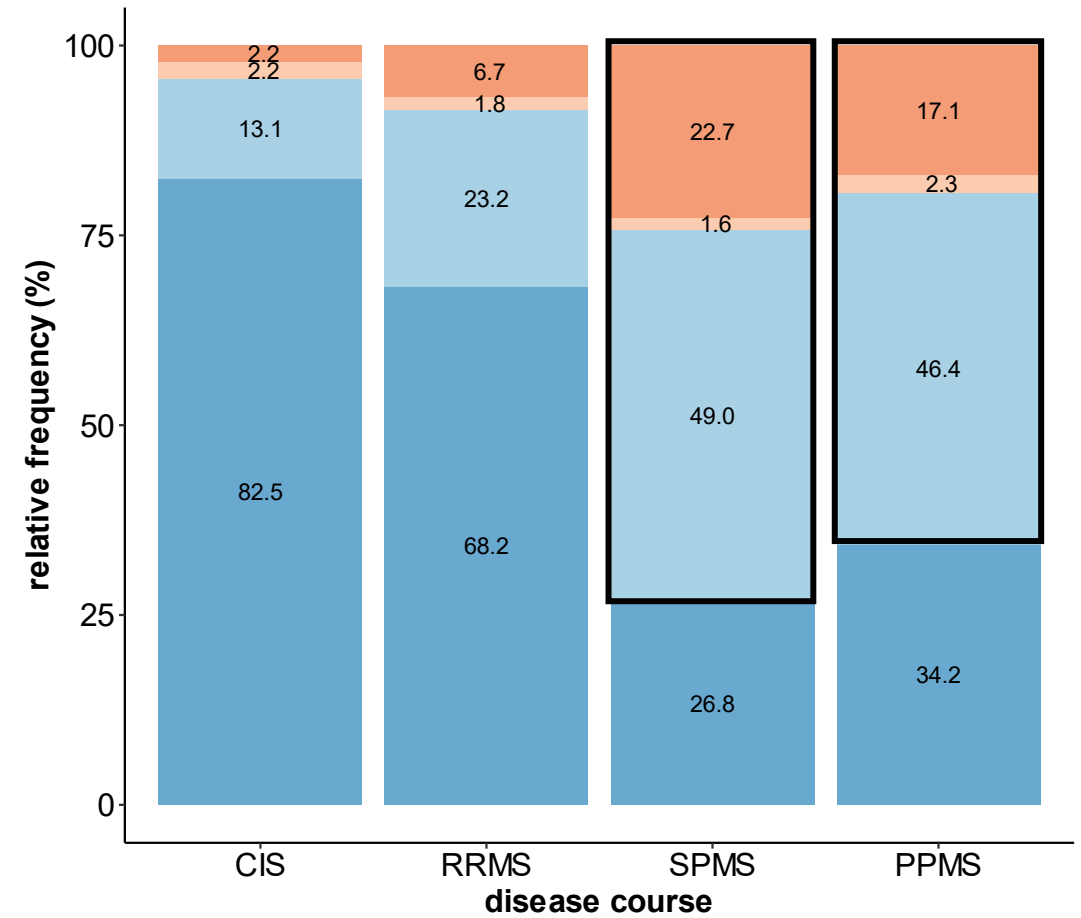
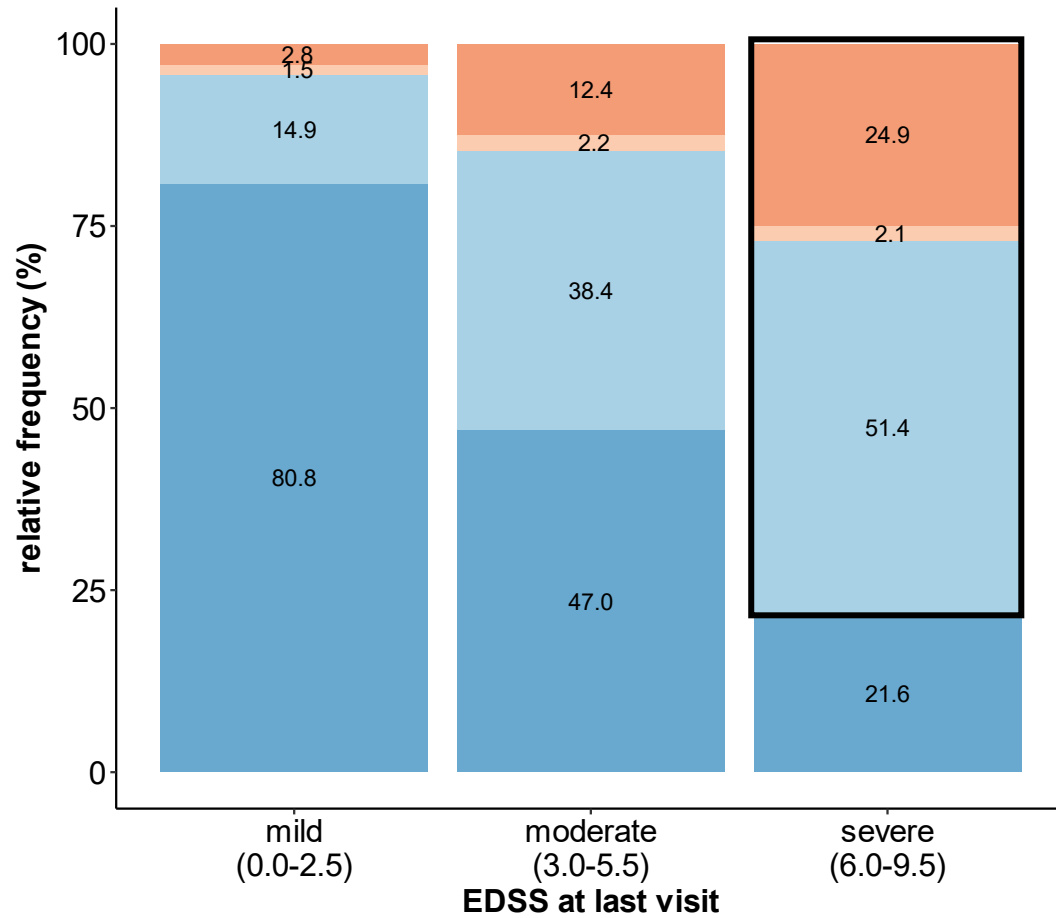
Prevalence of bladder and bowel dysfunction: Age and disease duration



■ bladder/bowel dysfunction ■ bladder dysfunction
■ bowel dysfunction ■ no bladder/bowel dysfunction

■ bladder/bowel dysfunction ■ bladder dysfunction
■ bowel dysfunction ■ no bladder/bowel dysfunction

Prevalence of bladder and bowel dysfunction: Disability and disease course

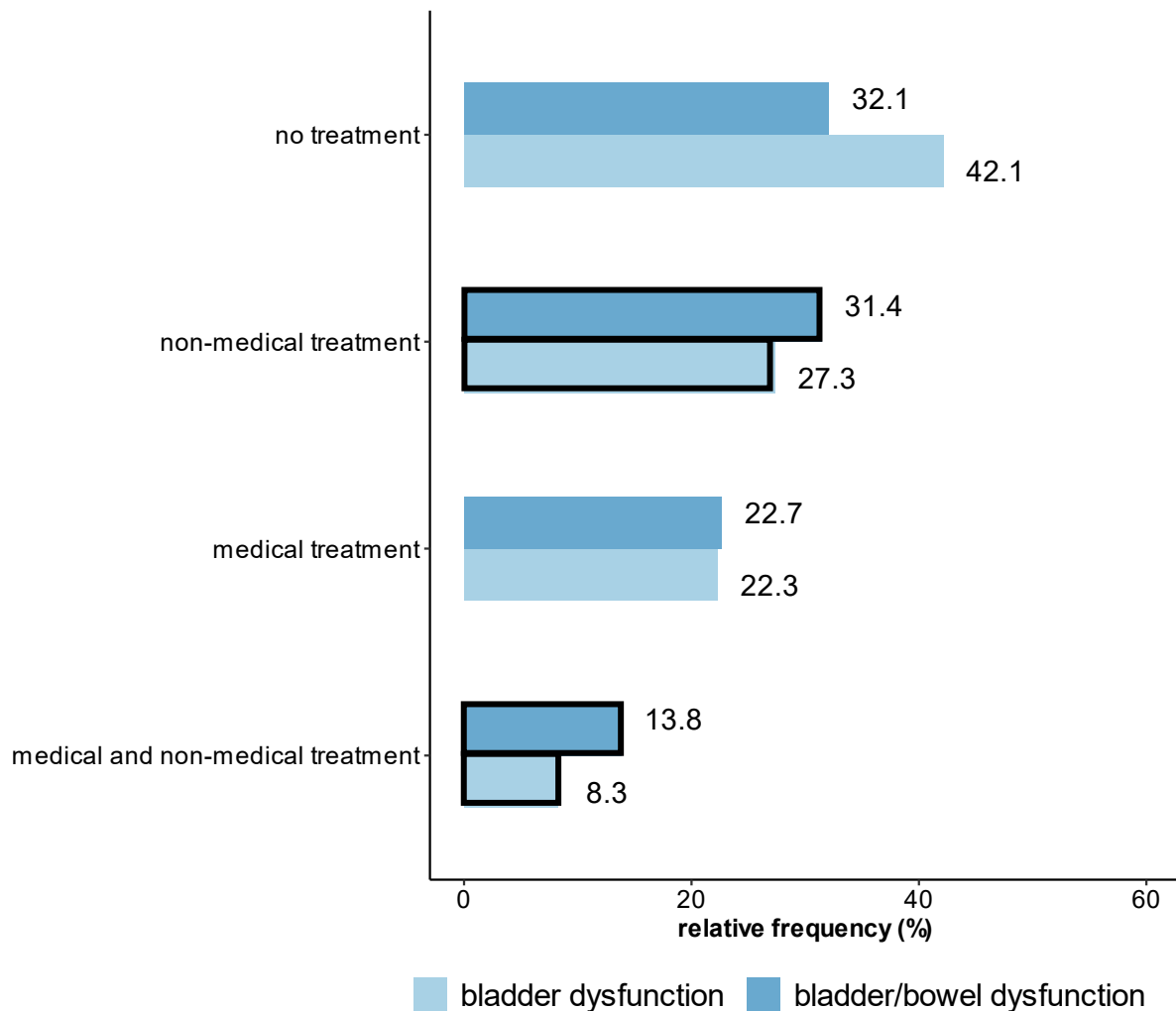


bladder/bowel dysfunction bladder dysfunction
 bowel dysfunction no bladder/bowel dysfunction

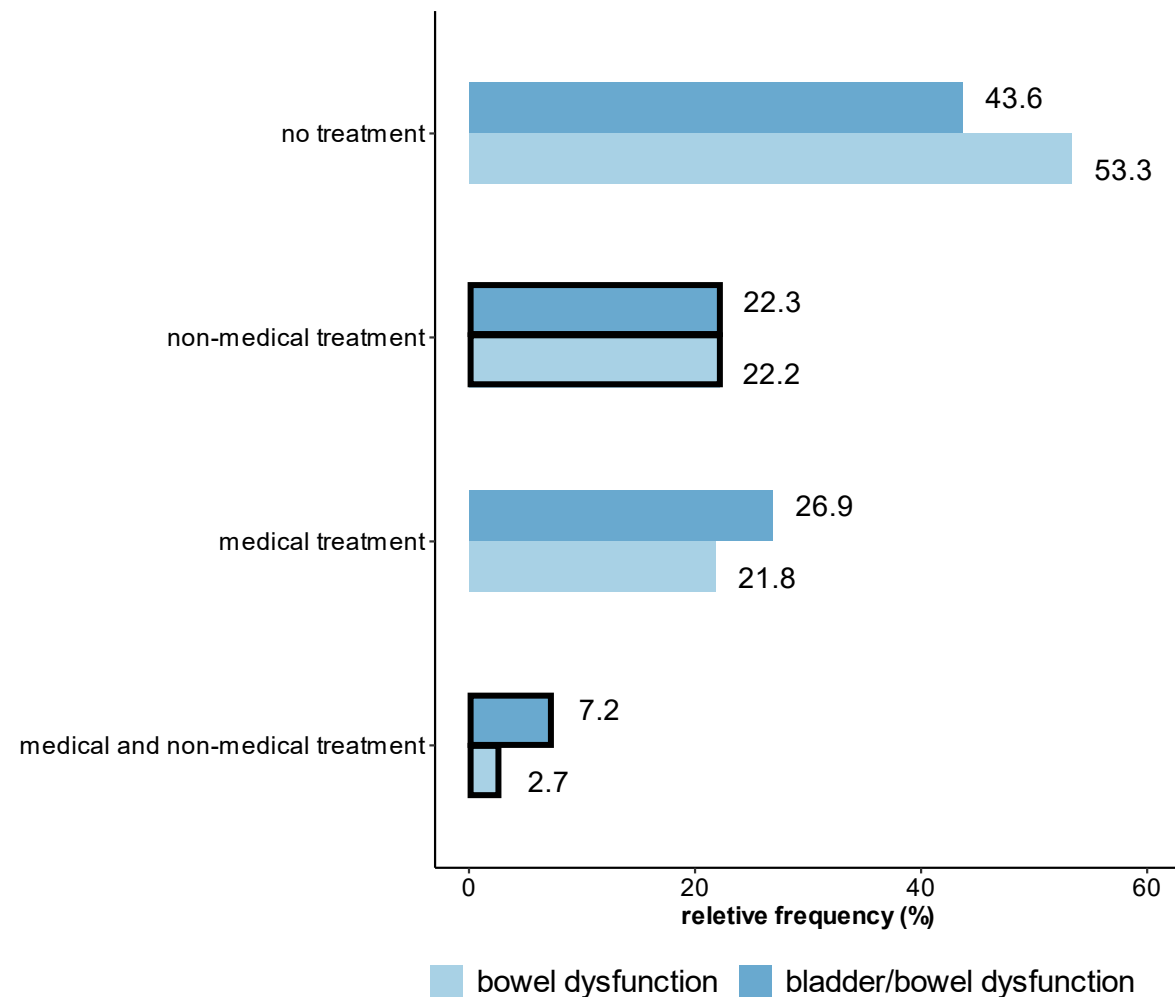
bladder/bowel dysfunction bladder dysfunction
 bowel dysfunction no bladder/bowel dysfunction

Symptom therapy

Bladder dysfunction

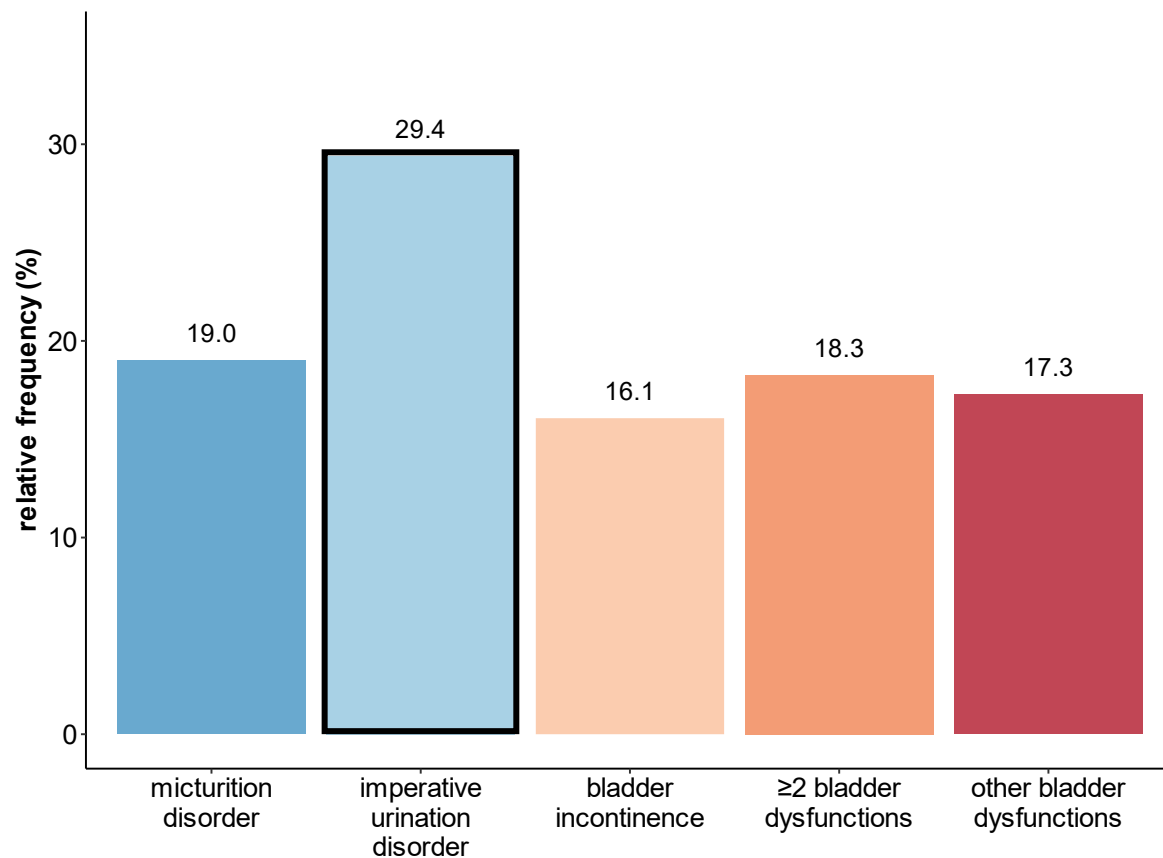


Bowel dysfunction

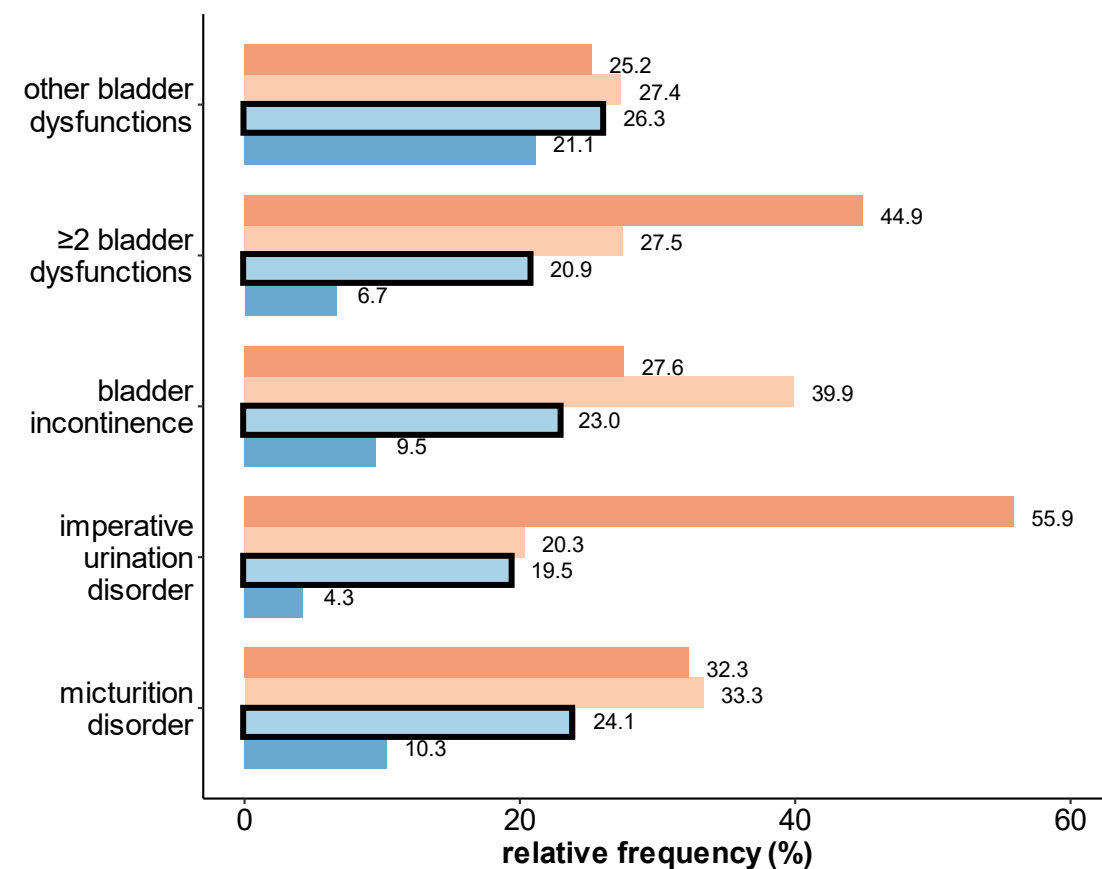


Specification of bladder dysfunction

Prevalence



Therapy



■ medical and non-medical treatment
 ■ non-medical treatment
■ medical treatment
 ■ no treatment

Conclusions

- Bladder and bowel dysfunction are frequently prevalent BUT often untreated
- Precise number of unreported cases remains uncertain
 - ➔ What is the extent of the issue?



The presented analysis is part of
the current joint research project:

Patient-orientated provision of aids for bladder and bowel dysfunction in people with multiple sclerosis (MS-Vita)

<https://www.msregister.de/forschung/ms-vita/>



<https://www.ostfalia.de/cms/de/forschung/forschungsfelder/teilhabe-versorgung/>



<https://www.mhh.de/institut-fuer-epidemiologie/forschung/forschungsschwerpunkt-gesundheitsoekonomie-und-gesundheitspolitik>



<https://dmsg-niedersachsen.de/>

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<https://uol.de/>

20 Sept 2024



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Die Gesundheitskasse.
AOK Niedersachsen

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Thank you for your attention!

Please visit us at

<https://www.msregister.de>

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