

An Evidence-Based Global MS Patient Charter Created by a Multi-stakeholder Alliance

Pauline Gieseler¹, Santosh Tiwari², Akshay Joshi², Martin Duddy³, Anita Williams⁴, Edmund Pezalla⁵, Jon Strum⁶, Bart Van Wijmeersch⁷, Noreen Barker⁸, Robert K. Shin⁹, Simona Bonavita¹⁰, Kathy Costello¹¹, Leonhard Schaeztl¹², Wolfgang Oertel¹³

¹Hasso-Plattner-Institute, Potsdam, Germany; ²Novartis Healthcare Pvt. Ltd, Hyderabad, India; ³Newcastle upon Tyne Hospitals Trust, Newcastle upon Tyne, UK; ⁴The Beta Pond, LLC, Colorado, USA; ⁵Enlightenment Bioconsult, Florida, USA; ⁶RealTalk MS podcast, USA; ⁷University MS Centre, Hasselt University, Hasselt, Belgium; ⁸National Hospital for Neurology & Neurosurgery, University College London Hospital Foundation Trust, London, UK; ⁹Georgetown University, Washington, D.C, USA; ¹⁰University of Campania "Luigi Vanvitelli", Naples, Italy; ¹¹Johns Hopkins MS Center, Baltimore, MD, USA; ¹²Novartis Pharma A.G., Basel, Switzerland; ¹³Philipps University, Marburg, Germany.



Scan to obtain:

Poster

<https://tinyurl.com/yqep9f7y>

Copies of the poster obtained through Quick Response (QR) code are for personal use only and may not be reproduced without permission of the authors.

KEY FINDINGS & CONCLUSIONS

- The Global MS Patient Charter highlights the clinical, lifestyle, professional workspace, and counselling services needed to deliver timely and appropriate care, offering guidance for optimal patient care throughout the MS journey
- To our knowledge, this is the first SLR to summarise and highlight the contemporary unmet needs (i.e., in the last five years) that exists among PwMS and their caregivers
- Of the studies included in the SLR, approximately 50% followed a qualitative approach wherein a deeper understanding of unmet needs can be extracted compared to quantitative studies
- This evidence-based Global MS Patient Charter aims to establish guidance towards improving patient-centered MS care

This study is sponsored by Novartis Pharma AG, Basel Switzerland

Poster presented at the 31st Annual Meeting of the European Charcot Foundation, held on 13:00 – 14:00 CET, 10 November 2023

INTRODUCTION

- Multiple sclerosis (MS) disease-modifying treatments have changed the treatment landscape, however, people living with MS (PwMS) often experience unmet needs in relation to their care provision that impact the quality of daily living

- For optimal, patient-centered MS care, it is key to utilise multi-stakeholder shared partnerships to develop evidence-based guidance that accurately reflects current patient unmet needs
- Here we describe the process used to develop a patient charter document, aimed to provide valuable guidance irrespective of geography, to inform and assist all stakeholders involved in the care provision of PwMS

METHODS

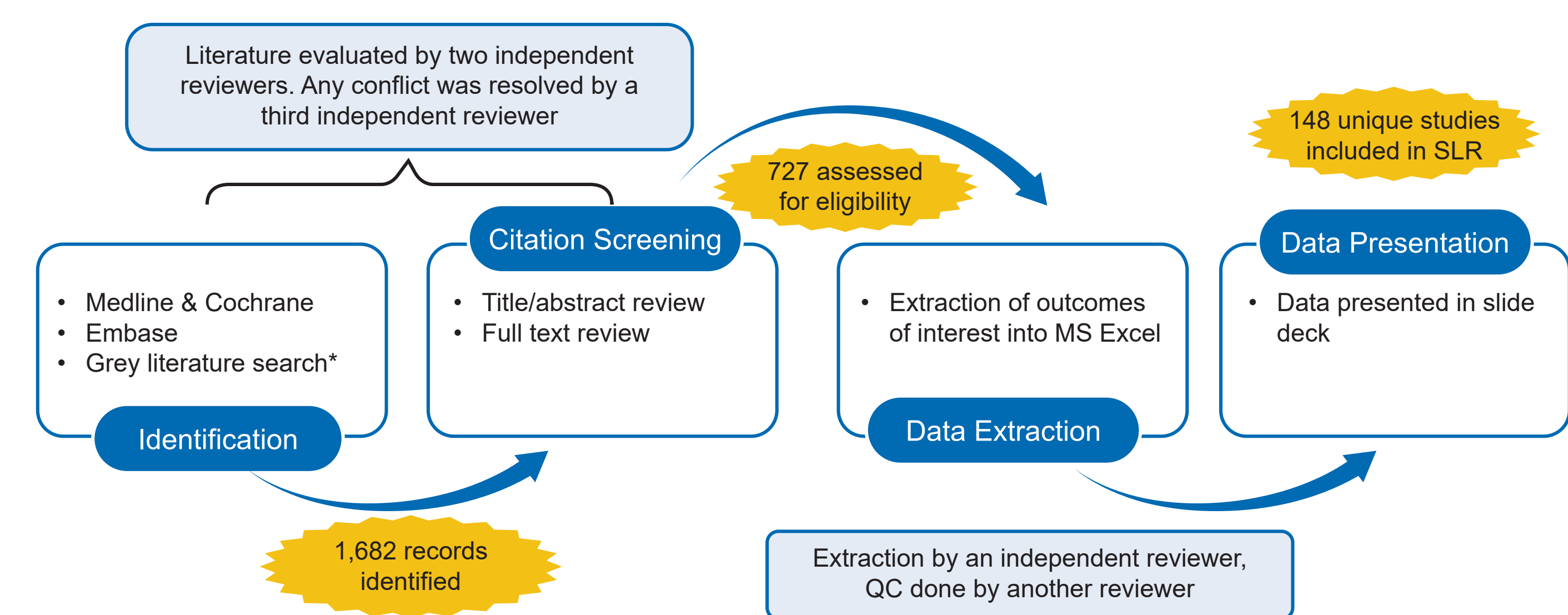
Systematic Literature Review

- The systematic literature review (SLR) search of key databases (EMBASE™, MEDLINE®, MEDLINE®-In-Process, and Cochrane library) using the Ovid™ platform and spanning dates from 01.01.2017 to 07.07.2022, was performed in accordance with The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement¹
- In addition, grey literature from relevant websites were screened
- Studies reporting unmet needs in PwMS were included
- The SLR process (Figure 1) and search terms aimed to encompass:
 - PwMS or people in a formal or informal caregiver capacity, irrespective of age, race or gender
 - All outcomes related to unmet needs, its impact, reasons for their occurrence, and practices to overcome the unmet needs in PwMS
 - Randomised controlled trials (RCTs), non-RCTs, and observational studies, both comparative and non-comparative
- The methodological quality of the included studies was assessed using the Mixed Methods Appraisal Tool (MMAT)²

Multi-stakeholder Alliance

- A multi-stakeholder alliance of experts (payers and policy, PwMS, medical experts, industry and patient advocacy groups) assessed and categorised the findings of the unmet needs SLR to develop a Global MS Patient Charter

Figure 1. Overview of the SLR process



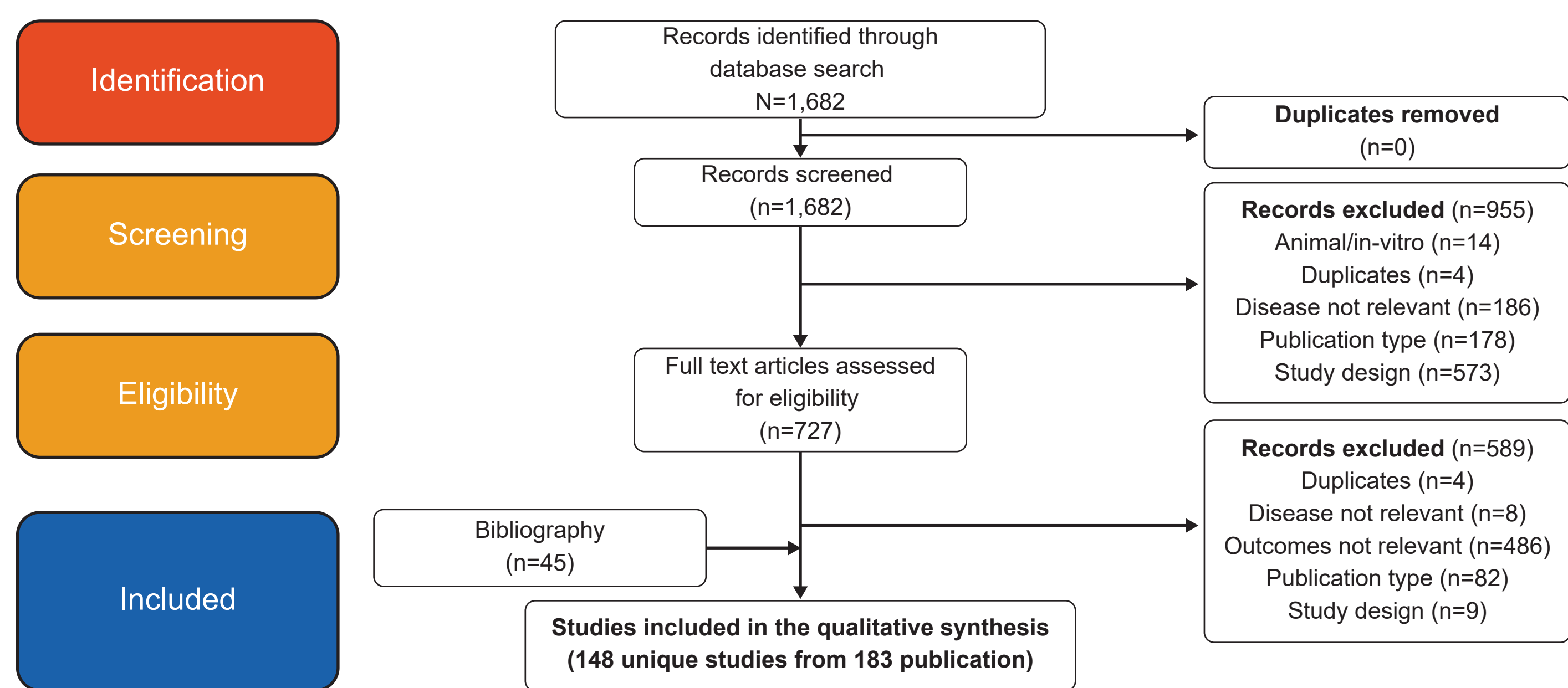
*Includes conferences, HTAs and MS societies
HTAs, health technology assessments; MS, multiple sclerosis; QC, quality control

RESULTS

SLR Summary

- In total, 1,682 records were identified, of which, 148 unique studies were included in the SLR (Figure 2)

Figure 2. PRISMA Flow Diagram

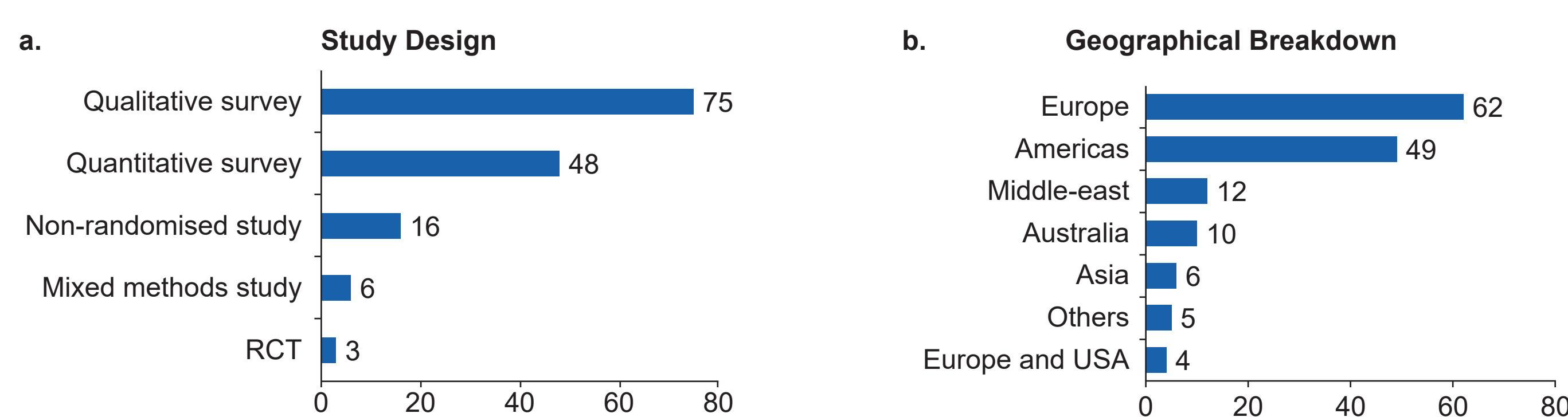


PROs, patient-reported outcomes; QoL, quality of life; MS, multiple sclerosis; SLR, systematic literature review.

Overview of Eligible Studies

- PwMS included in the eligible studies were aged 27 to 64 years, with a disease duration of 1.7 to 32 years
- Overall, 50% (n=72) were qualitative surveys, 32% (n=48) were quantitative surveys (Figure 3a)
- Geographically, 42% (n=62) of studies were from Europe and 33% (n=49) from North America (Figure 3b)

Figure 3. Overview of studies included

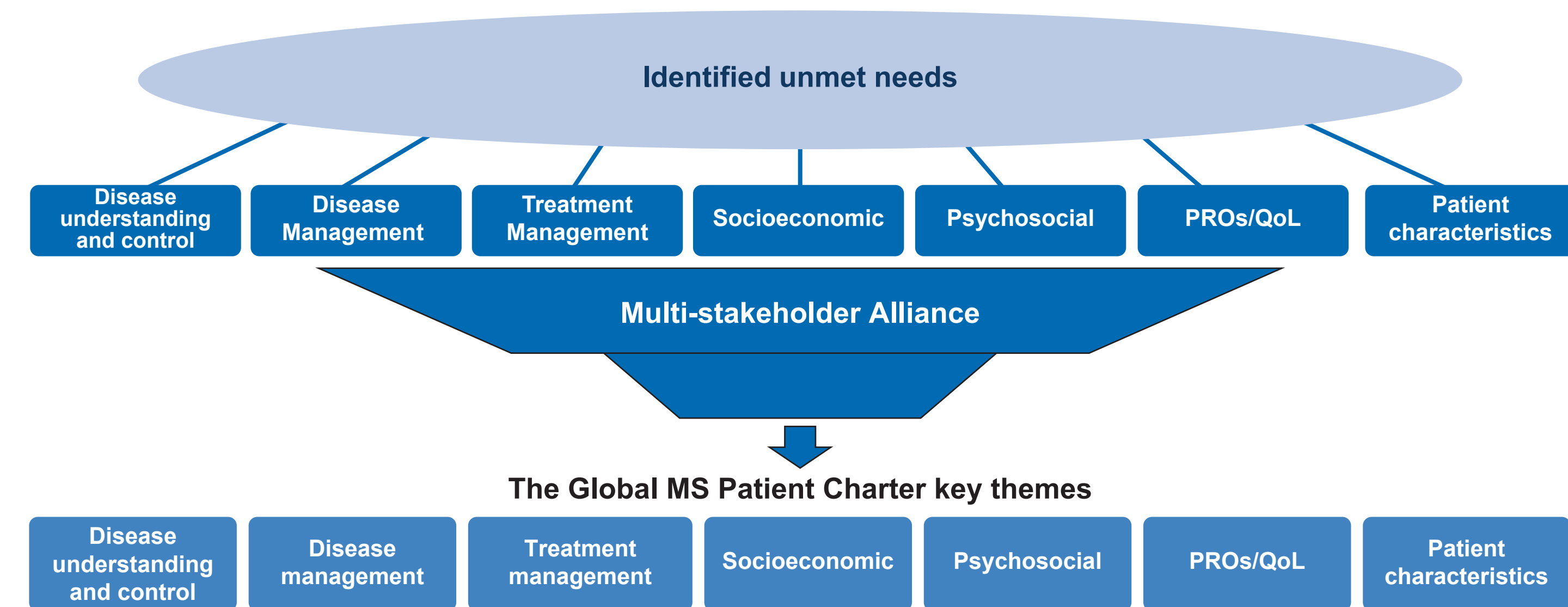


MMAT, Mixed Methods Appraisal Tool; MS, multiple sclerosis; PRISMA, preferred reporting items for systematic reviews and meta-analyses; PROs, patient reported outcomes; PwMS, people with MS; QoL, quality of life; RCT, randomised controlled trial; SLR, systematic literature review. The main categories were further subcategorised to facilitate in-depth discussion and interpretation by the multi-stakeholder group to formulate the key themes to support the development of a global MS patient charter

Summary of Identified Unmet Needs

- From the 148 unique studies included in the SLR, unmet needs were broadly categorised as: disease understanding and control, disease management, treatment management, socioeconomic, psychosocial, patient-reported outcomes (PROs)/ quality of life (QoL), and patient characteristics (Figure 4)
- The multi-stakeholder group consolidated the data from each main category into the six key themes that guided the development of a global patient charter

Figure 4. Main categories of unmet needs identified by the SLR



Note, the psychosocial theme broadly covers psychological/social support, social isolation and social stigma; patient characteristics refers to unmet needs of PwMS relating to psychological, urology, societal home and community care service, perception of reasons related to, the impact of, and the provisions to address the unmet needs.

PROs, patient-reported outcomes; QoL, quality of life; MS, multiple sclerosis; SLR, systematic literature review.



The Global MS Patient Charter

- These themes feature as the core topics of the Global MS Patient Charter which aim to provide guidance for all involved in the shared partnership of MS care

References

- Page MJ, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Syst Rev*. 2021;10(1):89. doi:10.1186/s13643-021-01626-4.
- Hong QN, et al. Improving the usefulness of a tool for appraising the quality of qualitative, quantitative and mixed methods studies, the Mixed Methods Appraisal Tool (MMAT). *J Eval Clin Pract*. 2018;24(3):459-467. doi:10.1111/jep.12884

Acknowledgments

Medical writing support was provided by Erik O'Hanlon and Paul Coyle, Novartis Ireland; and design support was supported by Saketh Vellanki, Novartis Healthcare Pvt. Ltd., Hyderabad, India. The final responsibility for the content lies with the authors.

Disclosures

Pauline Gieseler reports personal fees for activities as a patient consultant from Novartis, Martin Duddy, MD FRCP, Consultant Neurologist reports speaker or consulting honoraria and/or travel/congress grants in the last 3 years from: Biogen, Bristol Myers Squibb, Janssen, Merck, Novartis, Roche, Sanofi, Anita Williams reports acting as an independent MS patient consultant for Novartis and received fees for services, Edmund Pezalla, MD, MPH is an independent consultant. He has received honoraria and consulting fees related to market access consulting from several firms including Sanofi, Novartis and Bristol Myers Squibb, Robert K. Shin, MD, Consultant neurologist reports speaker or consulting honoraria for Alexion, Biogen, Bristol Myers Squibb (BMS), EMD Serono, Genentech, Horizon, Novartis, Sanofi, and Research support from Genentech, Jon Strum reports receiving sponsorship fees from the National Multiple Sclerosis Society, EMD Serono, Merck KGAA, and Sanofi, reimbursement for travel-related expenses from the National Multiple Sclerosis Society and the International Progressive MS Alliance, honoraria from Novartis and consulting fees from the Accelerated Cure Project for MS, Bart van Wijmeersch, MD, PhD, Consultant Neurologist reports speaker fees, research

support and travel grants from Almirall, Actelion/Janssen, Bayer, Biogen, Celgene/BMS, Imcys, Merck, Novartis, Roche, Sanofi-Cenzyme and Teva, Noreen Barker, Consultant Nurse, reports receiving support to attend conferences and meetings, and honoraria for advisory boards from Novartis, Biogen, Sanofi, Teva, Merck, Roche and Sandoz, Simona Bonavita, MD, Consultant Neurologist reports speaker honoraria and/or travel/congress grant da: Novartis, Merck-Serono, Alexion, BMS, Biogen, Roche, Janssen-Cilag, Research grant da Roche, Kathy Costello reports participating on Advisory Boards for Bristol Myers Squibb, Sandoz, Novartis, EMD Serono, Sanofi and Genentech. In addition, Can Do MS receives funding from Biogen, EMD Serono, Genentech, Sanofi, Sandoz, TG Therapeutics, Horizon, and Viatrix, Wolfgang Oertel, MD PhD, Professor of Neurology reports speaker honoraria including travel reimbursement for educational symposia with Stada Pharmaceuticals and consulting honoraria with Intrabio Inc, Lario-Therapeutics and Modag – all activities are unrelated to the disease field Multiple Sclerosis and unrelated to the particular topic of this abstract. Santosh Tiwari and Akshay Joshi are employees of Novartis Healthcare Pvt Ltd, Hyderabad, India, Leonhard Schaeztl is an employee of Novartis Pharma AG, Base, Switzerland.

Copyright © 2023 Novartis Pharma AG. All rights reserved.