

# MANAGING THE TRANSITION TO SECONDARY PROGRESSIVE MULTIPLE SCLEROSIS: A SCOPING REVIEW



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## BACKGROUND

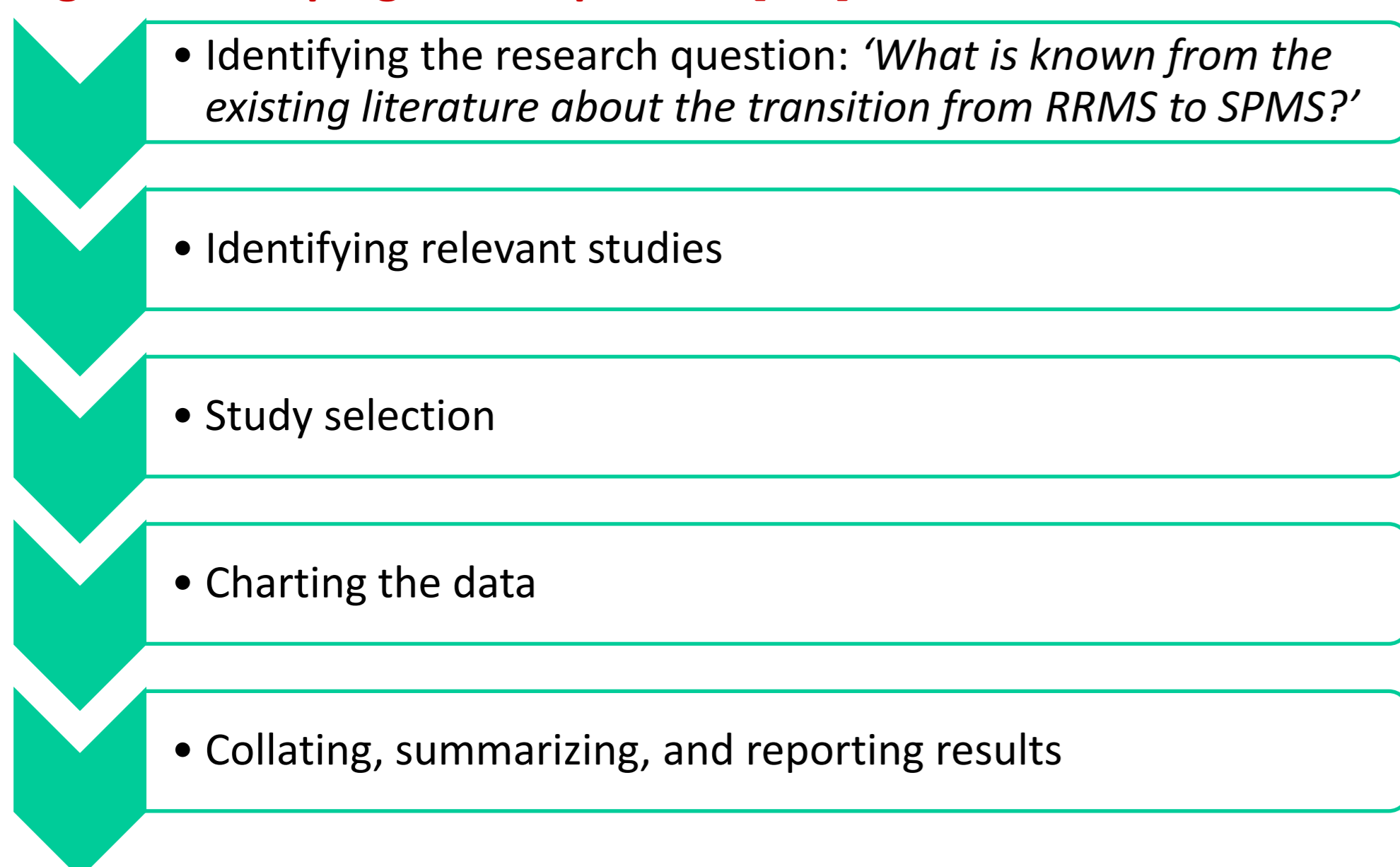
Approximately 50% of patients with relapsing remitting multiple sclerosis (RRMS) will develop secondary progressive MS (SPMS) within 15 years of disease onset[1]. The transition phase is characterized by a period of diagnostic uncertainty that may last several years. Evidence about transition to SPMS is scarce.

The “Managing the Transition (ManTra)” seeks to develop and test a user-led resource for newly diagnosed SPMS patients, using mixed methodology [2]. As a preparatory step, we aimed to perform a literature review.

## METHODS

A scoping review was performed to map the existing literature, using the Arksey & O'Malley framework (Figure 1) [3,4]. We searched MEDLINE, EMBASE, PsycINFO, CINAHL, Google scholar (selective search) from inception to 2017. Trial and dissertation registers were also searched for published and unpublished studies. We included primary research focused on the process of transition from RRMS to SPMS related to patients, carers or health professionals.

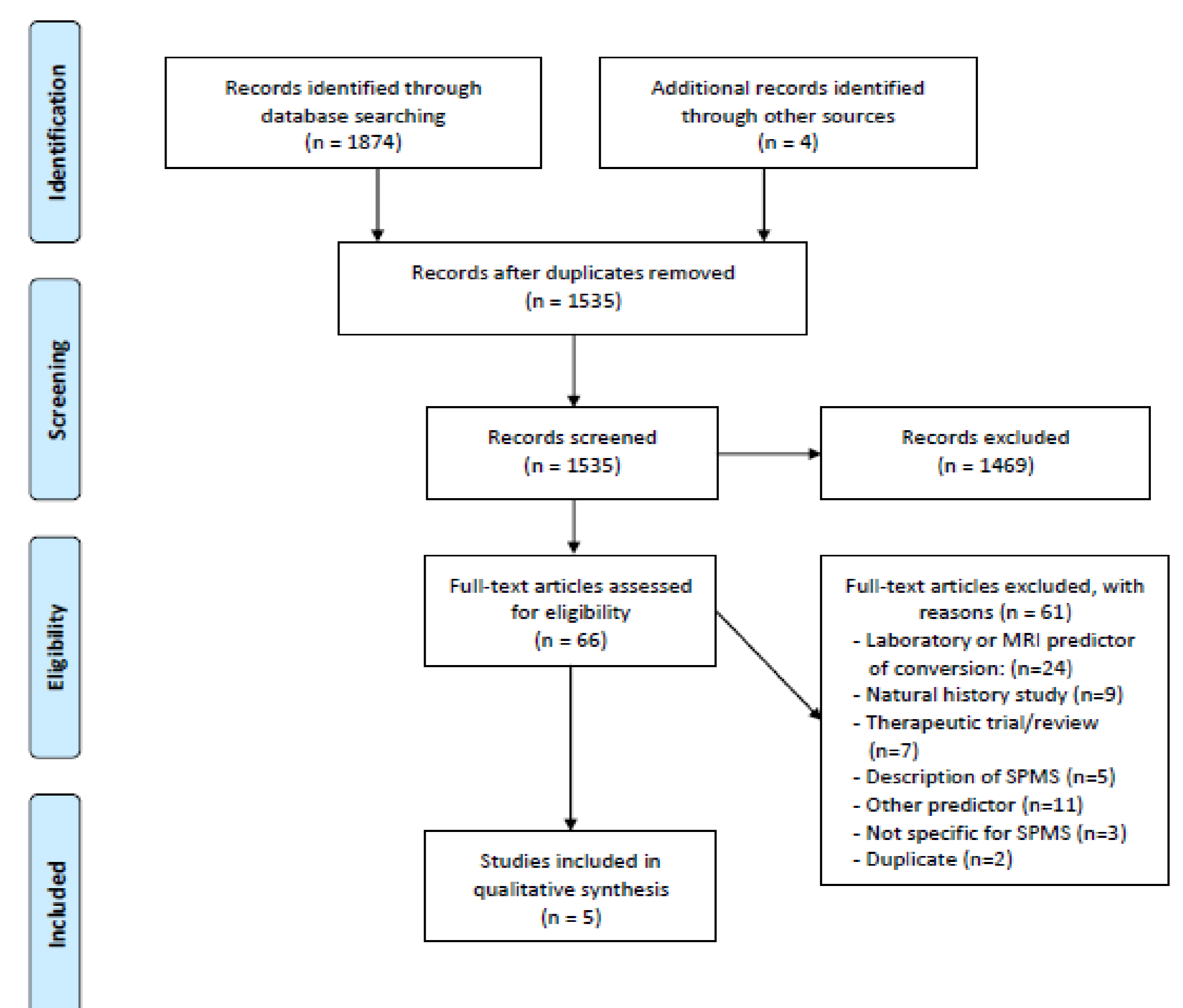
Figure 1 . Scoping review process [3,4]



## RESULTS (I)

A total of 1874 references from MEDLINE, Embase, CINAHL, PsycINFO, were identified in our screening. Among these, 37 duplicates were excluded, and 1469 citations were excluded after initial screening. Sixty-six full-text articles were retained for further screening. Of these, 61 were excluded because they were studies addressing laboratory or MRI predictor of conversion, natural history studies, therapeutic trial/review, descriptive of SPMS (n=5), other predictor (n=11), not specific for SPMS (n=3), duplicates.

Figure 2. PRISMA 2009 flow diagram of included studies



**RESULTS (II)** We included 5 studies. Of these, 4 were qualitative studies, and one was a retrospective cohort study (Figure 1). Five studies fulfilled the inclusion criteria and were analysed [5-9]. Of these, 4 were qualitative studies conducted in UK between 2013 and 2015[5-9], and one was a retrospective cohort study conducted in US in 2014, the latter aiming to characterize the transition to SPMS.

The qualitative studies investigated the lived experience of adults with SPMS and documented views of carers and HPs during transition. Main themes identified pertained to reclassification of SPMS, and its consequences on patients, carers and health professionals. Furthermore, possible strategies were identified to support these groups. The quality of reporting of the qualitative studies was good.

**CONCLUSION** Despite the importance of this topic, only few research results have been published targeting the process of transition to SPMS, mainly focussing on qualitative studies. No interventions to empower and support patients, carers, and HPs are available and more research is needed to address this important issue.

This scoping review will inform subsequent phases of the ManTra project.

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