## **S2A Appendix.** **Search terms and results.**

| “All Fields” Search Terms | Number of Results |
| --- | --- |
| ‘nusinersen' AND 'spinal muscular atrophy' | 398 |
| ‘risdiplam' AND 'spinal muscular atrophy' | 34 |
| ‘onasemnogene abeparvovec-xioi' AND 'spinal muscular atrophy' | 22 |
| ‘zolgensma' AND 'spinal muscular atrophy' | 49 |
| ‘AVXS-101' AND 'spinal muscular atrophy' | 25 |
| ‘spinraza' AND 'spinal muscular atrophy' | 309 |
| ‘branaplam' AND 'spinal muscular atrophy' | 6 |
| ‘reldesemtiv' AND 'spinal muscular atrophy' | 1 |
| ‘SRK-015' AND 'spinal muscular atrophy' | 2 |
| ‘Hammersmith' AND 'spinal muscular atrophy' | 130 |
| ‘motor function measure 20' AND 'spinal muscular atrophy' | 57 |
| ‘motor function measure 32' AND 'spinal muscular atrophy' | 16 |
| ‘fatigue severity scale' AND 'spinal muscular atrophy' | 13 |
| ‘SF-36' AND 'spinal muscular atrophy' | 6 |
| ‘revised upper limb module' AND 'spinal muscular atrophy' | 19 |
| ‘Bayley III scales of infant and toddler development' AND 'spinal muscular atrophy' | 0 |
| ‘6-minute walk test' AND 'spinal muscular atrophy' | 44 |
| ‘SMA independence scale' AND 'spinal muscular atrophy' | 7 |
| ‘CHOP-INTEND' AND 'spinal muscular atrophy' | 30 |
| ‘CHOP-ATEND' AND 'spinal muscular atrophy' | 1 |
| ‘Egan Klassifikation' AND 'spinal muscular atrophy' | 0 |
| ‘Peabody development motor scales' AND 'spinal muscular atrophy' | 0 |
| ‘world health organization motor milestones' AND 'spinal muscular atrophy' | 1 |
| ‘pediatric quality of life inventory' AND 'spinal muscular atrophy' | 13 |
| ‘assessment of caregiver experience in neuromuscular disease' and 'spinal muscular atrophy' | 5 |
| ‘time up and go' AND 'spinal muscular atrophy' | 3 |
| ‘time to rise' AND 'spinal muscular atrophy' | 11 |
| ‘time to climb' AND 'spinal muscular atrophy' | 4 |
| ‘9-hole peg test' AND 'spinal muscular atrophy' | 0 |
| ‘SMARFS' AND 'spinal muscular atrophy' | 4 |
| ‘SMAIs' AND 'spinal muscular atrophy' | 0 |
| ‘PROMIS' AND 'spinal muscular atrophy' | 3 |
| ‘PEDI-CAT' AND 'spinal muscular atrophy' | 1 |
| ‘SMA-HI' AND 'spinal muscular atrophy' | 1 |
| ‘FSHD-HI' AND 'spinal muscular atrophy' | 0 |
| ‘CMT-HI' AND 'spinal muscular atrophy' | 0 |
| MeSH Terms |  |
| ‘spinal muscular atrophy' OR 'survival of motor neuron 1 protein' | 4,527 |
| Total | **5,742** |

## **S2B Appendix.** **Search result details.**

The initial search on July 14–15, 2020 identified 5,395 publications. Subsequent searches on September 1, 2020 and June 1, 2021 identified an additional 69 and 278 publications, respectively (Figure 1A – B). Four articles were handpicked from a review and congress report for consideration. Overall, 5,480 publications were excluded due to duplication (875), article type (1,245), and lack of relevance (3,360). An additional 144 were excluded for the following reasons: lack of use of established motor function scales/PROs (68), high-risk of reporting bias due to selective reporting and/or incomplete data (RoB2.0) (24), missing relevant data (17), unspecified SMA diagnosis criteria (12), previously reported data (2), review article (2), patients with SMA not included (1), and papers that included a scale used in <5 total papers (18).