**S1 Table.** Reason for exclusion at stage 2 (assessment of full text reports): Categories are as reported in original review

|  |  |
| --- | --- |
| **Reason** | **n** |
| Review/overview/discussion only, no outcome recommendations | 94 |
| Core outcomes/ outcome recommendations not made | 24 |
| Health-related quality of life (HRQL)\* | 5 |
| Studies relating to how, rather than which, outcomes should be measured  | 56 |
| ICF core set development | 0 |
| Quality indicators – included an aspect of outcomes | 0 |
| Not relevant | 133 |
| ICF core set validation | 0 |
| Quality indicators – structure and/or process of care only | 2 |
| One outcome/ domain only | 7 |
| Recommendations for clinical management in practice not research  | 38 |
| Instrument development | 2 |
| Recommendations by single author only | 1 |
| Registry development | 0 |
| Describes features of registry | 0 |
| Preclinical/ Early phase only (0, I, II) | 2 |
| Ongoing studies | 9 |
| Duplicate | 11 |
| Quantitative description (e.g. frequency of symptoms) | 0 |
| Studies reporting the design/ rationale of single trial  | 1 |
| Oral presentation only | 0 |
| Value attributed to outcomes | 1 |
| Studies reporting the use of a COS\*\* | 1 |
| Systematic reviews of clinical trials\*\* | 2 |
| Studies that elicit stakeholder group opinion regarding which outcome domains or outcomes are important\*\* | 6 |
| Assessed in original review\*\* | 14 |
| Linked to studies published in original review\*\* | 2 |
| **TOTAL** | **400** |

*\* These studies included qualitative studies describing the impact of a treatment on a patient’s quality of life, studies to determine particular domains of quality of life, and single patient narratives of the impact of a condition or treatment on their quality of life. The focus of these studies was quality of life only.*

*\*\* These studies did not fit into any of the existing categories identified in the original review and so additional categories were created.*