

# A review of international clinical guidelines for rehabilitation of people with neurological conditions: what recommendations are made for upper limb assessment?

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The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest

### *Author contribution statement*

Burridge led the project and was the main author of the manuscript. All authors contributed to conception, protocol and design of study and to acquisition of data and critical revision of the report for important intellectual content. Burridge and Hughes conducted the initial literature search and McNicholas conducted an updated search. Burridge, Hughes and McNicholas screened records with input from all other authors where needed.

### *Keywords*

Practice guidelines, Neurological conditions, Upper limb, outcome and process assessment, Systematic review, guidelines, impairment

### *Abstract*

Word count: 350

**Background:** Upper limb impairment is a common problem for people with neurological disabilities, affecting activity, performance, quality of life and independence. Accurate, timely assessments are required for effective rehabilitation, and development of novel interventions. International consensus on upper limb assessment is needed to make research findings be more meaningful, provide a benchmark for quality in clinical practice, more cost-effective neurorehabilitation and improved outcomes for neurological patients undergoing rehabilitation.

**Aim:** To conduct a systematic review, as part of the output of a European COST Action, to identify what recommendations are made for upper limb assessment.

**Methods:** We systematically reviewed published guidance on measures and protocols for assessing upper limb function in neurological rehabilitation via electronic databases from January 2007 - December 2017. Additional records were then identified through other sources. Records were selected for inclusion based on scanning of titles, abstracts and full text by two authors working independently, and a third author if there was disagreement. Records were included if they referred to 'rehabilitation' and 'assessment' or 'measurement'. Reasons for exclusion were documented.

**Results:** From the initial 552 records identified (after duplicates were removed), 34 satisfied our criteria for inclusion and only six recommended specific outcome measures and /or protocols. Records were divided into National Guidelines and other practice guidelines published in peer reviewed Journals. There was agreement that assessment is critical, should be conducted early and at regular intervals and that there is a need for standardised measures. Assessments should be conducted by a healthcare professional trained in using the measure and should encompass body function and structure, activity and participation.

**Conclusions:** We present a comprehensive, critical and original summary of current recommendations. Defining a core set of measures and agreed protocols requires international consensus between experts representing the diverse and multi-disciplinary field of neurorehabilitation including clinical researchers and practitioners, rehabilitation technology researchers and commercial developers. Current lack of guidance may hold-back progress in understanding function and recovery. Together with a Delphi consensus study and an overview of systematic reviews of outcome measures it will contribute to the development of international guidelines for upper limb assessment in neurological conditions.

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Generated Statement: All datasets generated for this study are included in the manuscript and the supplementary files.

1 **A systematic review of international clinical guidelines for rehabilitation of people with**  
2 **neurological conditions: what recommendations are made for upper limb assessment?**  
3

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26 **Contributions of authors**

27 Burridge led the project and was the main author of the manuscript. All authors contributed to  
28 conception, protocol and design of study and to acquisition of data. Critical revision of the  
29 report for important intellectual content. Burridge and Hughes conducted the initial literature  
30 search and McNicholas conducted an updated search. Burridge, Hughes and McNicholas  
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18 international guidelines for upper limb assessment in neurological conditions.

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21 **Key words**

22 Practice guidelines

23 Neurological conditions

24 Upper limb

25 Outcome and process assessment

26 Systematic review

27 Guidelines

28 Impairment

29 Activity

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## **1.0.Introduction**

Worldwide prevalence of stroke in 2010 was 33 million, with 16.9 million people having a first stroke, of which 795,000 were American and 1.1 million European (Mozaffarian et al., 2016). It has been estimated that approximately one third of people fail to regain upper limb capacity, despite receiving therapy (Houwink, 2013). This has important implications for both individuals and the wider society as reduced upper limb function is associated with dependence and poor quality of life for both patients and carers (Mayo et al., 2002, Morris, 2013, Sprigg et al., 2013) and impacts on national economies (Nichols et al., 2012 ).

While stroke has the highest prevalence, other neurological conditions such as Multiple Sclerosis (MS), Spinal Cord Injury (SCI) and Traumatic Brain Injury, have a significant incidence and there are often similarities in presentation, and treatment and therefore assessment. The worldwide incidence of SCI is 40 to 80 cases per million population and the estimated European mean annual rate of MS incidence is 4.3 cases per 100 000 (Pugliatti et al., 2006). Recently, Kister et al (Kister et al., 2013) reported that 60% of people with MS have impaired hand function. The impact of upper limb dysfunction on ADL is higher than in stroke, as both sides are often affected (Bertoni et al., 2015). Although dysfunction after SCI depends on level of injury, upper limb function is consistently cited as a health priority. The incidence rate of TBI in Europe is about 235 per 100,000 population (Tagliaferri et al., 2006). Outcome data among European countries are very heterogeneous. From the US however, it is known that about 1.1% of the population suffer a TBI resulting in long term disability (Zaloshnja et al., 2008).

### **1.1. Rationale**

Providing evidence-based and cost-effective upper limb rehabilitation is a priority for patients and healthcare services and is increasingly important because of the growth in new technology-based interventions designed to augment conventional occupational therapy and physical therapy. Outcome data are key to delivering best practice and identifying which interventions are effective. To design trials that will deliver unequivocal results, so that useful, and only useful interventions can be translated into clinical practice and delivered optimally, we need to understand the complexity and interaction between patient and intervention. To do that requires a large amount of comparable data – i.e. data generated from an agreed small set of valid outcome measures (OM) using agreed protocols. By standardising OM and protocols, aggregated data can be mined to generate a better understanding of what interventions are effective, at what dose, when, with whom and in what setting they should be used. This will enable clinicians to make better informed decisions and thus improve patient outcomes. Agreed, widely used, valid and practical OMs and assessment protocols are important in research into and treatment of all neurological conditions, but may be particularly important in conditions where incidence is lower and therefore data sets smaller.

Guidelines on best practice aim to improve treatment standards, including rehabilitation, and directing future research. And, as we argue above, OMs are key to achieving that goal. It would seem reasonable therefore that clinical guidelines would be a source of guidance on selection of OMs and protocols for their use. In this study, we have therefore systematically reviewed recent and current guidelines on stroke, MS, SCI and TBI. We have excluded all other neurological disabilities such as Parkinson's Disease and cerebellar ataxia as the assessment protocols and tools for these conditions are very different. We have extracted recommendations on assessment in terms of outcome measures (OM), frequency of assessment and who should conduct assessments, when and with what purpose.

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## 1.2. Objectives

This study is one of three components in the development of European Guidelines on assessment of the upper limb in neurological conditions. Two studies have already been published: A Delphi study which reported the views of experts (Hughes et al., 2016) and an overview of systematic reviews of OMs (Alt Murphy et al., 2015). The project was driven by a realisation that progress in upper limb neurological rehabilitation research and consequently improvement in quality of care was hampered by the absence of consensus on OMs and protocols for assessment. To conduct effective metanalysis requires multiple clinical studies to use the same measures using comparable protocols, and for the same OMs to be used in clinical practice. Practice guidelines are an obvious source of information on useful measures and protocols for assessment. The objective of this study was therefore to explore published and web-based guidance and to extract and synthesise recommendations on assessment measures and protocols for assessment of the upper limb function for people with neurological conditions.

## 1.3. Research Question

Our research question was: What recommendations are made by international clinical guidelines for the assessment of the upper limb in neurological conditions?

## 2.0. Methods

### 2.1. Study design and search strategy

Published studies were identified through Pubmed and Evidence Search databases (MEDLINE in Ovid, Embase, CINAHL, AMED, Web of Science, PEDro and Google Scholar) for the period from January 2007 to December 2017. The search strategy comprised the following medical subject heading (MeSH) terms: *stroke*, *multiple sclerosis*, *spinal cord injuries* and *neurological rehabilitation* with filters for *guidelines*, *recommendations*, *practice guidelines* and *consensus development conference*. The search was as follows (((("Stroke"[Mesh]) OR "Multiple Sclerosis"[Mesh]) OR "Spinal Cord Injuries"[Mesh]) OR "Traumatic Brain Injury"[Mesh]) OR "Neurological Rehabilitation"[Mesh])) AND (((Practice Guideline[pt] OR Recommendation OR Guideline[pt] OR Consensus Development Conference[pt])) AND ("2007/01/01"[PDat] : "2017/12/31"[PDat])). Using the search engine Google, applying the terms "[nation]", guideline, stroke", members of the COST action searched for their National Stroke Guidelines in their respective languages: UK, Netherlands, Italy, Spain, Germany, Switzerland, Sweden and Estonia. Using the same terms, we also searched, in English for any other National Guidelines from any country for stroke, SCI, MS, TBI or Neurological Conditions. Additional records were also identified through other sources, especially references from the retrieved records.

### 2.2. Systematic review protocol and data extraction

Two review authors (JB and AH) independently screened references for relevance based on their abstract, and methodological quality, where there were any disagreements the wider group were consulted. Records were only included in the review if they referred to upper limb 'assessment' or 'measurement' and 'physical rehabilitation' of 'neurological disorders' and were either a 'National Guideline' or either 'practice guideline' or 'recommendations' published in a peer-reviewed Journal. Additional studies were identified from references within the records and, where they satisfied these criteria were included in the review. Although our interest was primarily in upper limb assessment, the guideline literature usually encompassed the broad topic of assessment, i.e. both upper and lower limb, activities of daily

1 living and impact on quality of life. Such articles were screened, but only included for  
2 further review when guidelines on upper limb assessment were included. We did not use a  
3 standard tool to assess quality. Records that satisfied the criteria for inclusion were then  
4 categorised by two independent authors (AH and JB) into: National guideline; other practice  
5 guidelines or recommendations published in peer-reviewed journals or web-based resources  
6 and then by condition into: stroke; multiple sclerosis (MS); Spinal cord injury (SCI),  
7 traumatic brain injury (TBI) or ‘other neurological conditions.’ Each record was then  
8 reviewed (LM, JB and AH). Data were then extracted from each record and tabulated.

### 9 10 **2.3. Data analysis**

11 Based on the review a classification structure (see below) was designed to reflect the relevant  
12 areas in which recommendations were made.

#### 13 14 **Classification structure:**

- 15 1. Why assessment is important
- 16 2. When during the rehabilitation period assessment should be conducted
- 17 3. Clinical Utility - who should conduct the assessment
- 18 4. Single vs. multiple OMs within the ICF Framework
- 19 5. Assessment of body function and structures (impairment) and activity:
- 20 6. Assessment of Activities of Daily Living (ADL) and participation
- 21 7. Psychometric properties and appropriateness of OMs:
- 22 8. Self-Efficacy and goal orientated measures – assessment integrated into therapy.

### 23 24 **3.0 Results**

25 The records retrieved for the review and the results of the selection process are shown in the  
26 flow diagram (Figure 1.)

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28 *Figure 1. Flow diagram of the studies retrieved for the review*

#### 29 30 **3.1. Study selection characteristics**

31 Our primary aim was to review and synthesise recommendations for the selection and use of  
32 upper limb OMs (both conventional and technology-based) in neurorehabilitation. Our search  
33 identified no records that focussed exclusively on the UL and the majority made only brief  
34 reference to either assessment or measurement tools (Winstein et al., 2016, RCOT, 2015,  
35 Royal College of Physicians, 2016, J.M. Veerbeek, 2014, Teasell, 2016). Where reference  
36 was made to measurement there was explicit consensus that measures should follow the  
37 World Health Organisation (WHO) International Classification of Function (ICF) framework  
38 (World Health Organisation, 2001, World Health Organisation, 2013).

#### 39 40 **3.2. Synthesized findings**

41 Of the 34 publications included in the review only six (two National Guidelines)  
42 recommended specific measures of body function and structures, activity and participation  
43 (Winstein et al., 2016, RCOT, 2015, J.M. Veerbeek, 2014, Teasell, 2016, Finlay and Evans,  
44 2014, VA/DOD, 2010). Seven recommended global scales but gave no specific measures for  
45 the upper limb (Wechsler et al., 2017, Bates et al., 2016, Majersik et al., 2015a, SIGN, 2013b,  
46 NICE, 2013, Pürg K, 2011). Most National Guidelines focussed on service delivery. Some  
47 acknowledged that standardised OMs are required for effective neurorehabilitation, without  
48 reference to specific tools or how they should be chosen. The need for OMs that encompass  
49 all domains of the ICF was agreed.

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Nine publications referred to the importance of global or upper limb assessments being conducted by appropriately trained or qualified healthcare professionals (HCP) (RCP, 2016, Foundation, 2017, (NICE), 2013, NICE, 2014, Bryer et al., 2011, Miller et al., 2010a, Hachinski et al., 2010, VA/DOD, 2010, Bayley et al., 2007). Protocols for and timing of assessment was only included in four records (J.M. Veerbeek, 2014, Finlay and Evans, 2014, VA/DOD, 2010, Hebert et al., 2016). In total, reviews identified 47 different global and upper limb specific OMs, but only one referred to effectiveness, validity or reliability of the recommended measures (J.M. Veerbeek, 2014).

Fourteen National Guidelines were included from the following countries: The Netherlands, Sweden, UK (4), Scotland (2), Estonia, South Africa, Singapore, Australia, New Zealand and the USA. National guidelines were condition specific: 11 stroke, 1 brain injury, 1 SCI and 1 MS. National Guidelines provided the most comprehensive and broad recommendations. All National stroke guidelines except the South African (Bryer et al., 2011) and Swedish (Swedish\_National\_Board\_of\_Health\_and\_Welfare, 2011) make some reference to assessment, but in almost all cases it was brief, non-specific and not related either to rehabilitation or the UL. There were two exceptions to this.

The Dutch National guideline (J.M. Veerbeek, 2014), provided very comprehensive recommendations on the diagnostic process and included recommendations for specific tools, within each ICF domain, that should be used for diagnosis – to allow informed clinical decision-making; to predict recovery and to assess progress. Recommendations are summarized as follows: Any patient with a stroke should be systematically assessed in terms of body functions, activities, and participation prior to the start of the physical therapy process, preferably using reliable, valid, and responsive measurement instruments. These measurements should be administered at predefined moments during the physical therapy process, in order to objectively monitor the patient’s clinical course. Basic upper limb measurement should include: muscle strength, dexterity and ADL. Tools were selected by the guideline development team on the basis of their reliability, responsiveness, predictive and construct validity, and finally their practical feasibility. They make recommendation for future practice: *‘many publications fail to report follow-up data, and if they do, the timing of follow-up assessments varies widely. This means that the long-term added value of nearly all interventions is unknown.’* It is suggested that *‘frequent and systematic assessment of functional changes over time (monitoring)’* is an important factor contributing to higher quality of care. They recommend considering measures before each multidisciplinary meeting.

The US National Guideline (Winstein et al., 2016) also makes comprehensive recommendations on assessment for best clinical practice. It acknowledges the need for a single assessment used throughout the course of stroke recovery, referring to measures of body function/structure and citing the upper limb motor section of the Fugl-Meyer scale or the Box and Block Test for measuring arm motor deficits. The Australian Guideline (Boddice et al., 2010), focuses on interventions, but recommends assessment using valid measures, although without reference to physical assessment of the upper limb. The New Zealand (NZ, 2010) guideline makes recommendations on all aspects of stroke management and prevention based on level of evidence, expert opinion and clinical experience, however, the only reference to assessment is in relation to acute care and of people who want to return to work.



1 Six UK Guidelines (of which 2 were Scottish) were found: three for Stroke (Royal College of  
2 Physicians, 2016, NICE, 2013, SIGN, 2017), one for SCI (NSCISB, 2012), one for brain  
3 injury (SIGN, 2013a) and one for MS (NICE, 2014). The Royal College of Physicians (RCP)  
4 stroke Guideline is a comprehensive guideline for best clinical practice. The RCP Guideline  
5 considered the general principles of measurement in stroke rehabilitation, for example the  
6 importance of measuring function and understanding which domain of the WHO ICF  
7 framework an instrument is measuring. It states that instruments should be appropriate to the  
8 intervention in question and clinicians should be trained in the use of measurement scales to  
9 ensure consistent use within the team. The National Institute of Clinical Excellence (NICE)  
10 recommendations (NICE, 2013) guidelines were mainly concerned with the organisation of  
11 health and social care and specifically the delivery of best practice. Specific  
12 recommendations were: screening on admission and on transfer from hospital to community  
13 using the WHO ICF to provide information on functional abilities; use of standardised  
14 screening instruments; treatment and assessment should be provided by HCPs who have  
15 appropriate skills and training and patients should be assessed and fitted for wrist and hand  
16 splints by trained HCPs. The third UK guideline on MS makes no reference to upper limb  
17 problems, however does specify that assessments should be conducted by a 'healthcare  
18 professional with appropriate expertise in rehabilitation and MS'. The fourth UK Guideline,  
19 on SCI (Gall, 2008) also makes no reference to upper limb assessment, focusing only on  
20 medical assessment except for brief reference to the need for a musculoskeletal assessment  
21 including spasticity, joint range of movement and pain. Neither the Singapore  
22 (Venketasubramanian et al., 2011) nor the Swedish  
23 (Swedish\_National\_Board\_of\_Health\_and\_Welfare, 2011) Guidelines make  
24 recommendations on assessment. The Singapore Guidelines<sup>1</sup>(Venketasubramanian et al.,  
25 2011) state the importance of assessment in acute stroke, giving recommendations, but make  
26 no reference to assessment in rehabilitation. Although not an official National publication, we  
27 have included the Canadian Web-based Stroke Rehabilitation Evidence-Based Review  
28 SREBR guidelines<sup>1</sup> which provide comprehensive recommendations on assessment and  
29 present level of evidence for a wide range of clinical scales. The SREBR consolidates the  
30 best available scientific evidence for the effectiveness of stroke rehabilitation and is an  
31 excellent resource. The review is constantly updated and includes a substantial section on  
32 OMs. The SREBR used the ICF Framework and in addition to the usual measures of  
33 reliability and validity, also considered appropriateness and responsiveness (floor and ceiling  
34 effects), precision, interpretability, acceptability, feasibility and the thoroughness of testing.  
35 The scope is very wide, including tests for cognition, depression etc. It does not address  
36 upper limb assessments per se, but includes a number of UL focussed impairment and  
37 activity measures, which are scored in each category.

38  
39 Nineteen other articles were included in the review. Peer review articles were generally less  
40 comprehensive than the National Guidelines and often focused on a specific area of  
41 neurological rehabilitation, for example Occupational Therapy or tele-rehabilitation. They  
42 were however more focused on upper limb OMs and some gave recommendations for  
43 specific measures.

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45 *Insert Table 1*

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<sup>1</sup> (<http://www.ebrsr.com/>),

1 In total, 51 outcome measures were recommended, of which 39 addressed stroke (76%), 5  
2 TBI (10%), 3 SCI (6%), 1 MS (2%). Four outcome measures (8%) were recommended  
3 without specifying which pathology it should be used for. Regarding stroke guidelines, the  
4 most frequently recommended OMs were NIHSS (5), FIM (4), Barthel Index (3), and FMA  
5 (3). For the other pathologies, recommended OMs were scattered across different OMs.  
6

7 We have synthesized recommendations made by the National Guidelines and published  
8 articles under the following headings: Why, when and by whom assessments should be  
9 conducted and what should be measured.  
10

### 11 **3.2.1. Why assessment is important**

12 ‘Not Everything That Counts Can Be Counted’ (Einstein) but without valid, reliable and  
13 sensitive measures that are meaningful to patients, clinicians and researchers our field cannot  
14 advance. We will not know what works, when or with whom. Neurological rehabilitation is  
15 complex in terms of both patients and intervention (SIGN, 2013b, SIGN, 2011) There are few  
16 interventions or conditions for which there is a single measure as there is for example in  
17 testing a new drug for hypertension. Winstein (Winstein et al., 2016) acknowledges the  
18 challenge faced in assessing services, patient outcomes and effectiveness of neurological  
19 rehabilitation stating that: *“the array of rehabilitation services delivered to stroke patients in  
20 the United States is broad and highly heterogeneous, varying in the type of care settings  
21 used; in the duration, intensity, and type of interventions delivered.”* and that this *“brings  
22 with it challenges in terms of determining the quality of care delivered by the system”* and *“in  
23 terms of assessment of which research findings...are applicable to the system”*. Alexander  
24 (Alexander et al., 2009) identified the need for agreed measures in their multi-disciplinary  
25 study of current and evolving tools for evaluating people with spinal cord Injury (SCI),  
26 reporting that none of the findings of major clinical trials of new interventions had translated  
27 into standard care and argued that to achieve translation, *‘agreed, appropriate and valid  
28 primary end points and intervention protocols are needed’*.

### 29 **3.2.2. When during the rehabilitation period should assessments be conducted?**

30 Nine publications (seven stroke) referred to timing of assessments in relation to rehabilitation  
31 recommending soon after admission and on transfer of care. Beyond that there was wide  
32 variation, particularly in frequency of assessments. The Dutch Guidelines recommended that  
33 patients were assessed within one week of admission and discharge (or when transferring  
34 treatment to another colleague) and at the end of the 1<sup>st</sup> week, 3<sup>rd</sup> month and 6<sup>th</sup> month post-  
35 stroke. They also recommended considering measures before each multidisciplinary meeting.  
36 The NZ guidelines stated that patients should be assessed when treatment choices were being  
37 made, as assessments were fundamental to measuring deficits, planning goals, and planning  
38 management. It recommended that all assessments occurred as soon as possible after  
39 admission (aiming for within the first two days) with the stroke team working together so as  
40 not to overburden the patient by duplicating questions.

41 The COT and ACPIN Report (College of Occupational Therapists and Association of  
42 Chartered Physiotherapists in Neurology, 2015) was concerned with splinting and suggested  
43 that specified outcomes should be recorded at baseline and at defined intervals, but they did  
44 not suggest what these should be (Majersik et al., 2015b). Winstein (Winstein et al., 2016),  
45 recommends that *“all patients should undergo a formal assessment of their rehabilitation  
46 needs before discharge”* and Finlay (Finlay and Evans, 2014) recommend that physiotherapy  
47 assessments be carried out within 24-48 hours of admission and that the assessment should  
48 include pre-admission mobility and motor dysfunction. The Canadian best practice

1 guidelines state initial screening and assessment should be conducted within 48 hours by  
2 rehabilitation professionals.

3 There were only two publications which referenced timing of assessment in MS and SCI, The  
4 American Physical Therapy Association Neurology Section task force recommended using  
5 OM to track MS patient status over a long-term period or as patients transition across settings  
6 (Potter 2014). The Guidelines and Audit Implementation Network (GAIN) recommends PT  
7 and OT therapy assessments (pain, motor and sensory dysfunction) for SCI should be carried  
8 out within 24-48 hours of admission and prior to discharge.

### 9 **3.2.3. Clinical Utility - who should conduct the assessment**

10 A strong consensus was found in favor of assessments being conducted by appropriately  
11 trained HCPs. Patients with difficulties in performance of daily activities should be assessed  
12 by a clinician trained in the use of whichever scales are chosen to ensure consistency of their  
13 use within the team and an understanding of their purposes and limitations (NZ, 2010). This  
14 view is supported by (Miller et al., 2010a) recommending that clinicians obtain not only  
15 training to establish administration and scoring consistency, but also, routine retraining to  
16 ensure they maintain this consistency (Potter et al., 2014a). They highlight the fact that  
17 although OMs have benefits in physical therapist practice multiple barriers interfere with  
18 their use, most notably, a limited understanding of how to select and apply the best OM.

### 19 **3.2.4. Single vs. multiple and specific OMs, within the ICF Framework**

20 No records recommended a single OM with the exception of Winstein (Winstein et al., 2016)  
21 who suggested the use of a computerised questionnaire called the “*Activity Measure for Post-*  
22 *Acute Care*” as an outcome measure for all stroke patients to ‘*track stroke rehabilitation*  
23 *outcome*’. Billinger (Billinger et al., 2014) suggested that accelerometry was likely to be  
24 used as an OM for future clinical trials as it measured changes in free-living physical activity  
25 and compliance with exercise programmes.

26 There was consensus between the Dutch, UK and US guidelines that patients should be  
27 assessed in each domain of the ICF framework, but conflict between using a single measure  
28 to enable progress to be monitored throughout recovery and multiple measures to allow for  
29 changes in setting, goals and ability levels. The US guidelines recommend multiple OMs  
30 whereas the most recent stroke guidelines from the UK National Institute for Health and Care  
31 Excellence (NICE) (NICE, 2013) recommend primary and secondary OMs, with the primary  
32 assessing function and secondary including measures of impairment, activity limitation and  
33 quality of life. The Scottish Intercollegiate Guidelines Network (SIGN, 2013b) recommended  
34 using a range of assessment tools to assist goal-setting. Multiple OMs were often  
35 recommended (Winstein et al., 2016, RCOT, 2015, J.M. Veerbeek, 2014, Finlay and Evans,  
36 2014, Potter et al., 2014b) arguing, for example, that it would be challenging to select only 1  
37 or 2 OMs for use with all people with Motor Neurone Disease (MD) and Multiple Sclerosis  
38 (MS) (Lamers et al., 2014) (Lamers and Feys, 2014) due to variation in disability levels and  
39 treatment in a variety of settings. Ontaneda (Ontaneda et al., 2012) concurred, recommending  
40 different OMs for people at different stages of MS and the RCOT (Royal College of  
41 Occupational Therapists, 2010) agreed with (Potter et al., 2014a) that a ‘*one size fits all*’  
42 intervention with a single outcome measure was of limited, if any, value. The SIGN TBI  
43 guideline (SIGN, 2013b) stated that because rehabilitation interventions usually target  
44 multiple or complex outcomes, and because individual goals vary, a single measure may be  
45 impossible or inappropriate.

46

### 1 **3.2.5. Assessment of body function and structures (impairment)**

2 The US Guidelines were skeptical about the use of measures in the body structure and  
3 function (impairment) domain of the ICF framework, considering that the psychometric  
4 properties of tools had not been established. They referred specifically to measures of  
5 spasticity / hypertonicity citing the equivocal evidence for validity and inter-rater reliability  
6 for the Modified Ashworth Scale. The VA/DOD Guidelines (The Management of Stroke  
7 Rehabilitation, 2010) however, made very strong and clear recommendations for measuring  
8 motor function both at the impairment (ability to move in a coordinated manner in  
9 designated patterns) and at the activity level (performance in real life or simulated real life  
10 tasks) using assessments with established psychometric properties.

11 In terms of measuring spasticity, Miller et al (Miller et al., 2010a) acknowledged the problem  
12 of validity and interrater reliability of the most commonly used Modified Ashworth Scale, but  
13 that other spasticity measures reported in the literature have problems with respect to clinical  
14 feasibility and the range of joints that could be assessed. Alexander (Alexander et al., 2009)  
15 was one of the few to discuss the use of electrophysiological measurements such as  
16 Electromyography (EMG), Motor Evoked Potentials (MEPs) and Somatosensory Evoked  
17 Potentials (SEPs) to assess spinal conductivity and spasticity in SCI. Hachinski (Hachinski et  
18 al., 2010) was one of the few records to refer to the need for assessments to measure the  
19 mechanisms of recovery. It reported the consensus of a 'Synergium', commissioned to  
20 finding new ways of accelerating progress in reducing the risks, effects, and consequences of  
21 stroke.

### 22 **3.2.6. Assessment of Activities of Daily Living (ADL) and participation**

23 While upper limb function has a significant impact on ADL, QoL and participation, it is  
24 beyond the scope of this review to consider in detail the recommendations for OMs in these  
25 categories, especially as they do not specifically assess the upper limb. The Dutch guidelines,  
26 however, proposed a range of measures to assess factors that may impact on recovery of UL  
27 function and therefore ability to participate in everyday life (J.M. Veerbeek, 2014).

### 28 **3.2.7. Psychometric properties and appropriateness of OMs**

29 The Australian Guidelines recommended that Clinicians use tools that meet the needs of the  
30 patient and are valid and reliable in the stroke population. The NZ guidelines added that  
31 while, because of the enormous variety of assessment tools and measures, they did not make  
32 specific recommendations, it was important to choose a specific tool based on the validity (in  
33 a stroke population), reliability, and availability. Miller (Miller et al., 2010b) recommended  
34 standardised, valid and reliable test procedures to document the severity of upper and lower  
35 limb impairment and to document the levels of assistance needed for mobility. Alexander  
36 (Alexander et al., 2009) emphasized the importance of using measures that were valid,  
37 reliable and sensitive in the SCI population and concluded that further work was needed on  
38 existing measures to identify the most appropriate tools for specific targets. Finlay (Finlay  
39 and Evans, 2014) directed the reader to The Rehabilitation Measures Databases<sup>2</sup> both of  
40 which provide information on a wide range of useful assessments and OMs. These are  
41 excellent repositories of measures, providing information on conditions where they might be  
42 used, availability, time taken to complete the tests, training required to conduct them and  
43 links to references, some of which include data on psychometric properties. They do not,  
44 however, make recommendations per se.

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<sup>2</sup> <http://www.rehabmeasures.org/default.aspx> and <http://www.neuropt.org/professional-resources/neurology-section-outcome-measures-recommendations>

### 3.2.8. Self-Efficacy and goal orientated measures – assessment integrated into therapy

The RCP (Royal College of Physicians, 2016) recommended that people with stroke should be helped to identify goals with specific, time-bound and measurable outcomes, but does not recommend specific measurement tools to assess whether goals have been achieved. There is a clear distinction between measuring what a person ‘can do’ and what they ‘do do’. Many of the standardised, recommended and commonly used measures of impairment and activity do not address the latter, whereas Patient Reported Outcome Measures (PROMs) and measures of self-efficacy, focus on what the patient actually does (or reports doing) in their day-to-day life. In relation to this, Ataxia UK (Bates et al., 2016), stated that OMs should focus on engagement and satisfaction because a tool that measures impairment does not always demonstrate effectiveness. The Management of Stroke Rehabilitation Report (The Management of Stroke Rehabilitation, 2010) recommended both a self-report measure (e.g., the Motor Activity Log) and an objective measure (e.g., accelerometry) to assess daily use of the affected upper limb and also as a motivational or self-management tool for participants taking part in clinical trials (Billinger et al., 2014). Despite these recommendations, the review of OMs used in (neurorehabilitation) limb splinting evaluation studies, conducted by the Royal College of Occupational Therapy (RCOT) and Association of Physiotherapists in Neurology (ACPIN), found that patient satisfaction was the least common OM used (College of Occupational Therapists and Association of Chartered Physiotherapists in Neurology, 2015).

*Insert Table 2. Summary of the National Guideline records included in the review*

*Insert Table 3. Summary of the peer reviewed and practice guideline records included in the review*

### 3.3. Risk of Bias

Data sources were predominantly English language, which may have biased the main findings. However, in mitigation, as authors, who were members of the COST Action, covered several languages we were able to search for (and include) National Stroke Guidelines in a range of languages. Differences in health care systems worldwide may also have been a source of bias reflected in the recommendations made in the primary publications.

Finally, the quality of identified guidelines was not evaluated with a standard tool such as AGREE II (Appraisal of Guidelines for REsearch and Evaluation). AGREE generates summary scores, in which all items and domains have equal weight. This tool is useful in judging the quality of the Guidelines and was used in Jolliffe et al’s recent systematic review of Clinical Guidelines for Stroke and other Acquired Brain Injuries (Jolliffe et al., 2018). However, their aim was to identify high quality guidelines, whereas ours was more specific; to ‘identify what recommendations are made for upper limb assessment’. Instead we therefore used descriptive analysis to identify evidence-based consensus on upper limb assessment across multiple pathologies to generate an in-depth knowledge of the quality and content of each guideline.

## 4.0. Discussion

### 4.1. Summary of Main findings

1 Our review of National Guidelines and published articles on recommendations for OMs in  
2 UL rehabilitation following Stroke, MS, SCI and other neurological conditions has identified  
3 some areas in which there is a clear consensus. For example, that assessment is important in  
4 neurological rehabilitation, should encompass all domains of ICF Framework and that, with  
5 one exception, multiple OMs should be used. Where recommendations included protocols for  
6 use of OMs, there was no disagreement to the following: they should be applied by HCPs  
7 who are trained to use them and at regular intervals during the rehabilitation pathway.  
8 Although intervals vary, global measures are recommended within 24 hours of admission and  
9 UL specific measures within 1 week. All published articles and Guidelines recommend early  
10 assessment and assessment prior to discharge, while many recommend far more frequent  
11 assessments. The importance of linking assessment to goal-setting (Bates et al., 2016, SIGN,  
12 2017, SIGN, 2011), the use of measures to encourage and motivate patients (Bates et al.,  
13 2016) as well as the importance of patient reported outcome measures (PROMS) (VA/DOD,  
14 2010) was evident. These recommendations reflected recognition of the importance of self-  
15 efficacy and independence and PROMS to assess what a patient actually does rather than can  
16 do is important. What we found lacking was recommendation to use specific outcome  
17 measures for which validity and reliability have been demonstrated. There was also lack of  
18 consensus on which measures should be used; although there was more agreement about  
19 global measures of participation and ADL than UL specific measures of impairment and  
20 activity limitation. The FIM for example is recommended in six reviews.

21  
22 There was very little agreement across the Guidelines about what outcome measures should  
23 be used, even within pathologies and the categories of the ICF (Table 1). Even regarding the  
24 condition for which the majority of OM recommendations were made (76%), stroke,  
25 guidelines fail to agree on a specific set of OMs to be used. The most recommended OMs in  
26 stroke guidelines were 3 global stroke OMs (NIHSS, FIM, Barthel Index) and only 1 specific  
27 upper limb OM (FMA). Two of those regarded OMs on Activity level (global), NIHSS and  
28 FIM, between which no consensus was apparent either.

29 Without an internationally agreed core set of outcome measures that satisfy the requirements  
30 identified in this review, progress in neurorehabilitation will remain hampered and data will  
31 be wasted. From the research perspective, it is well known that clinical trials of conventional  
32 and novel interventions are expensive, often return equivocal results and frequently fail to  
33 recruit adequate samples of patients. An important way that we can advance the field of  
34 neurorehabilitation, gain a better understanding of the recovery processes and disease  
35 progression and understand what works, with whom, when and in what dose is through meta-  
36 analysis of multiple trials, audits and longitudinal studies. Meta-analysis can only be done  
37 effectively if common outcome measures have been applied. Lack of meta-analyses impacts  
38 not only research into effectiveness of existing and novel therapies but also in delivering best  
39 practice.

40 National strategies and frameworks continue to emphasise the need for informed decision  
41 making in healthcare that are research led and evidence-based, yet the UK, Australian and US  
42 National Clinical Guidelines for Stroke indicate that there is limited research to assess  
43 efficacy of rehabilitation technologies, either individually or in combination (Winstein and  
44 Cramer, 2016, Foundation, 2017, Royal College of Physicians, 2016)

45

#### 46 **4.2. Limitations**

47 This systematic review has explored ‘National Guidelines’, or ‘practice guidelines’ and  
48 ‘recommendations’ published in peer-reviewed journals, focusing on assessment of the UL.  
49 We did not generate quantitative data, conduct a statistical analysis or use a standardized tool

1 to assess the quality of the publications (see 3.3 above). We included all guidelines that  
2 satisfied our criteria and have not provided critical analysis of the quality of each publication.

### 3 4 **4.3. Conclusion**

5 Clinical practice guidelines provide very little specific guidance on assessment of the UL,  
6 even within ICF domains and/or pathology-specific recommendations. Agreement on a core  
7 set of OMs is not achieved by systematic reviews of guidelines such as this, predominantly  
8 due to a lack of explicit OM recommendations in most of the identified guides. Nevertheless,  
9 our extensive and rigorous review has provided a comprehensive summary of current  
10 recommendations, and therefore arguably current use of OMs. Defining a core set of  
11 measures and agreed protocols requires international consensus between experts representing  
12 the diverse and multi-disciplinary field of neurorehabilitation. The group should include  
13 representation from research and clinical practitioners as well as rehabilitation technology  
14 researchers and commercial developers, so that recommendations are made cognoscente of  
15 the future potential for technology in assessment and neurorehabilitation. If such a consensus  
16 was achieved, a standardized approach to assessment would make research findings be more  
17 meaningful and provide a benchmark for quality in clinical practice and potentially improved  
18 standards and more cost-effective neurorehabilitation. Our review has identified agreement  
19 that assessment is critical and should encompass body function and structure, activity and  
20 participation and that there is a need for standardised measures.

### 21 **6.0. Acknowledgements**

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24 the coordination of European research in the area of rehabilitation robotics.

### 25 **7.0 Conflict of Interest**

26 The submitted work was carried out by the authors without any personal, professional or  
27 financial relationships that could potentially be construed as a conflict of interest.

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In review

In review

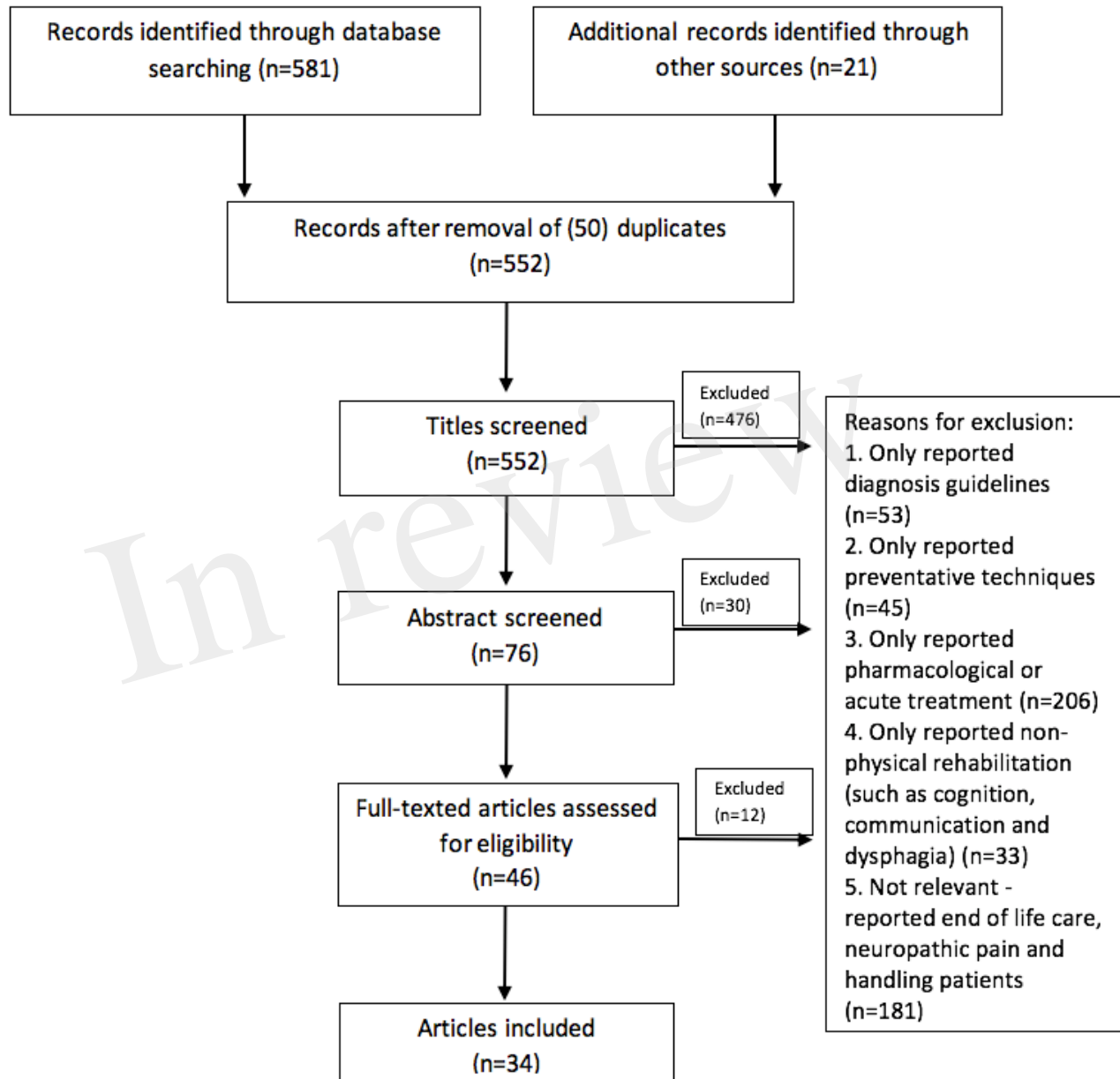


Figure 1: Study selection flow diagram

**Table 1. Frequency with which different outcome measures were recommended in total and for each pathology included in the review**

<i>Domain</i>	<i>Outcome measures</i>	<i>Total number of records / Refs</i>	<i>Number of records per pathology</i>				
			Stroke	MS	SCI	TBI	Other
<i>Impairment</i>	Fugl-Mayer Assessment (FMA)	3 (Winstein et al., 2016) (J.M. Veerbeek, 2014) (Teasell, 2016)	3	0	0	0	0
	Modified Ashworth Scale (MAS)	2 (J.M. Veerbeek, 2014, Finlay, 2014)	1	0	1	0	0
	Muscle power (Myotome chart and Oxford grading)	1 (Finlay, 2014)	0	0	1	0	0
	Passive Range of motion	2 (Finlay, 2014) (VA/DOD, 2010)	1	0	1	0	0
	Electro-goniometer (range of motion)	1 (Winstein et al., 2016)	1	0	0	0	0
	Grip strength (e.g. Jamar dynamometer)	1 (Winstein et al., 2016)	1	0	0	0	0
	Co-ordination and selective muscle activity	1 (VA/DOD, 2010)	1	0	0	0	0
	Grasp and release test	1 (Alexander et al., 2009)	0	0	1	0	0
	Box and Block test (BBT)	1 (Winstein et al., 2016)	1	0	0	0	0
	Nine-hole-peg-test (9HPT)	2 (Teasell, 2016) (J.M. Veerbeek, 2014)	2	0	0	0	0
	Motricity Index (MI)	1 (J.M. Veerbeek, 2014)	1	0	0	0	0
<i>Impairment (Sensation &amp; Pain)</i>	Visual Analogue Scale (VAS)	1 (RCOT, 2015)	1	0	0	0	0
	Light touch	1 (Finlay, 2014)	0	0	1	0	0
	von-Frey filaments	1 (Winstein et al., 2016)	1	0	0	0	0
	Proprioception	1 (Finlay, 2014)	0	0	1	0	0
<i>Activity (UL)</i>	Wolf Motor Function Test (WMFT)	1 (Teasell, 2016)	1	0	0	0	0
	Assessment of Motor Processes and Skills (AMPS)	1 (Bates et al., 2016)	0	0	0	0	1

	Arm Activity Measure	1 (RCOT, 2015)	0	0	0	0	1
	Action Research Arm Test (ARAT)	3 (Teasell, 2016) (RCOT, 2015) (J.M. Veerbeek, 2014)	2	0	0	0	1
	Chedoke McMaster	1 (Teasell, 2016)	1	0	0	0	0
	Computerised questionnaire	1 (Winstein et al., 2016)	1	0	0	0	0
	Frenchay Arm test (FAT)	1 (J.M. Veerbeek, 2014)	1	0	0	0	0
<i>Activity (Global)</i>	National Institute of Health Stroke Scale (NIHSS)	5 (VA/DOD, 2010) (Majersik et al., 2015) (NICE, 2013) (Pürg K, 2011) (J.M. Veerbeek, 2014)	5	0	0	0	0
	Canadian Occupational Performance Measure (COPM)	1 (Law et al., 1990)	1	0	0	1	0
	Goal Attainment Scale (GAS)	2 (Bates et al., 2016) (Majersik et al., 2015)	1	0	0	0	1
	Functional Independence Measure (FIM)	5 (Majersik et al., 2015) (Teasell, 2016) (VA/DOD, 2010) (SIGN, 2013) (Pürg K, 2011)	4	0	0	1	0
	Multiple Sclerosis Functional Composite (MSFC)	1 (Ontaneda et al., 2012)	0	1	0	0	0
	Motor Activity Log (MAL)	1 (VA/DOD, 2010)	1	0	0	0	0
	Berg Balance Scale (BBS)	1 (Pürg K, 2011)	1	0	0	0	0
<i>Participation &amp; QoL</i>	Barthel Index (BI)	4 (Pürg K, 2011) (J.M. Veerbeek, 2014, SIGN, 2013, NICE, 2013)	3	0	0	1	0
	Personal Activities of Daily Living (PADL)	1 (Finlay, 2014)	0	0	0	1	0
	Nottingham Extended ADL	1 (J.M. Veerbeek, 2014)	1	0	0	0	0
	Stroke Specific Quality of Life Scale (SSQoL)	1 (J.M. Veerbeek, 2014)	1	0	0	0	0
	<b>Total = 52</b>		<b>39</b>	<b>1</b>	<b>3</b>	<b>5</b>	<b>4</b>





**Table 2. Summary of the National Guideline records included in the review**

Record	Year	Summary of recommendations	Recommended measures
Australian Stroke Foundation (Boddice et al., 2010). (Stroke)	2017	Use of valid measures; assessment made by trained clinicians. No reference to physical assessment of the upper limb	None
Winstein, C. J., et al. (Winstein and Cramer, 2016) (Stroke)	2016	Recommends a single assessment used throughout the course of stroke recovery	Computerised questionnaire: “ <i>Activity Measure for Post-Acute Care</i> ”; dynamometer (grip strength) (Bohannon et al., 2006); electro-goniometer (range of motion) (Shiratsu and Coury, 2003) and Frey filaments (tactile sensory deficits) (Fruhstorfer et al., 2001). Fugl-Meyer (Fugl-Meyer et al., 1975) and Box and Block Test (Mathiowetz et al., 1985)
ROYAL COLLEGE OF PHYSICIANS (Royal College of Physicians, 2016) (Stroke)	2016	Use of the WHO ICF and instruments appropriate to the intervention. Clinicians should be trained in the use of measurement scales; set agreed goals (including patient and carers)	None
Veerbeek, J.M., et al. Dutch Guidelines (J.M. Veerbeek, 2014) (Stroke)	2014	Measures that are valid, reliable, responsive and feasible within each ICF domain. Use for diagnosis, clinical decision-making, to predict recovery and assess progress.  Measure at predefined times to monitor recovery e.g. within one week of admission and discharge (or when transferring care) end of the 1 <sup>st</sup> week, 3 <sup>rd</sup> month and 6 <sup>th</sup> month post-stroke. Consider measures before each multidisciplinary meeting.	Motricity Index (Demeurisse et al., 1980); Fugl-Meyer (FMA UE)(Fugl-Meyer et al., 1975) Frenchay Arm Test [FAT]) (Heller et al., 1987), Action Research Arm Test (ARAT) (Lyle, 1981) and Nine Hole Peg Test (NHPT) (Mathiowetz et al., 1985). MAS (Carr et al., 1985); Nottingham Extended ADL (Nouri and Lincoln, 1987); Global measures:  SSQoL (Williams et al., 1999); Barthel Index (Mahoney and Barthel, 1965), NIHSS (Brott et al., 1989)

NICE 2014 Multiple Sclerosis (NICE, 2014). (MS)	2014	No reference to upper limb problems.  Assessment should be conducted by a 'healthcare professional with appropriate expertise in rehabilitation and MS'.	None
SIGN 2013. Guideline 130 Brain injury rehabilitation in adults (SIGN, 2013) (TBI)	2013	Brief reference to assessment and OM: 'A range of tools can assist in the assessment and setting of goals'; no specific recommendations on measures or timing.	COPM (Law et al., 1990), FIM/FAM (Keith, 1987), Barthel Index (Mahoney and Barthel, 1965).
NICE 2013. Stroke rehabilitation in adults - NICE guideline (NICE, 2013) (Stroke)	2013	Screen for impairment, activity limitations, participation restrictions & environmental factors to direct treatment on admission and on transfer from hospital to community.  Standardised valid and reliable screening instruments should be used by HCPs who have appropriate skills and training. Wrist and hand splints should be assessed and fitted by trained HCPs. In research, the primary outcome measure should be improvement in function, with secondary outcomes assessing impairment, function and quality of life.	NIHSS (Brott et al., 1989); Barthel Index (Mahoney and Barthel, 1965)
NSCISB. The National Spinal Cord Injury Strategy Board (NSCISB, 2012). (SCI)	2012	Only reference to rehabilitation is passive movement to maintain joint range with no reference to assessment.	None
Bryer, A., et al. The South African guideline (Bryer et al., 2011) (Stroke)	2011	Early assessment and planning of discharge and comprehensive assessment of medical problems, impairments and disabilities by specialist staff is needed.	None
Swedish National Board of Health and Welfare. Quality and efficiency of stroke care in Sweden. (Swedish_National_Board_of_Health_and_Welfare, 2011). (Stroke)	2011	No recommendations for OM.	None recommended

Venketasubramanian N., et al Singapore Clinical Practice Guidelines Workgroup on Stroke (Venketasubramanian et al., 2011) (Stroke)	2011	Recommends multi-disciplinary medical assessment in acute stroke or transient ischemic attack (TIA). No reference to UE assessment	None
Guideline 118. SIGN. Management of patients with stroke (SIGN, 2011). (Stroke)	2011	Assessment of patient's needs to set goals and re-assess progress against goals. No reference to UE assessment	None
Estonian clinical guidelines for stroke rehabilitation (Pürg K, 2011) (Stroke)	2011	Use of valid and standardized measures including assessment of sensorimotor function, cognition, speech and ADL in predefined time points.	NIHSS (Brott et al., 1989), FIM (Keith, 1987), Barthel Index (Mahoney and Barthel, 1965), Modified Ashworth Scale (Pandyan et al., 1999); Berg Balance Test (Berg et al., 1989)
New Zealand Clinical guidelines for Stroke Management (NZ, 2010). (Stroke)	2010	Reference to assessment in acute care and of those who want to return to work.	None

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**Table 3. Summary of the peer reviewed and practice guideline records included in the review**

Record	Year	Summary of recommendations	Recommended measures
Wechesler, L. R., et al. (Wechsler et al., 2017) (Stroke)	2017	Improve quality monitoring and outcomes and consider sharing patient data. NIHSS score done remotely during transit to hospital. (Schwamm et al., 2009)	NIHSS score (Brott et al., 1989)
Intitut National d'excellence en sante et en sociaux - (TBI)	2017	Guidance on global assessment and rehabilitation interventions including motor control. No specific reference to, or recommendation for UE assessment	None
ATAXIA UK. <i>Ataxia UK</i> (Bates et al., 2016) (Non-specific pathology)	2016	No reference to UE specifically. Measure patient engagement and satisfaction with the performance of an activity,	Assessment of Motor and Process Skills (AMPS)(Park et al., 1994), Goal Attainment Scale (GAS)(Kiresuk and Sherman, 1968), Canadian Occupational Performance Measure (COPM) (Law et al., 1990), self-efficacy tools and quality of life measures.
Wolf et al. (Wolf et al., 2015) (Stroke)	2015	No recommendations for assessment	None
Hebert et al. Canadian stroke best practice recommendations.(Hebert et al., 2016) (Stroke)	2015	Assessment within 48 hours including: function, safety, physical readiness, and ability to learn and participate in rehabilitation. No specific reference to UE	None
Majersik, J. J. et al. (Majersik et al., 2015). (Stroke)	2015	Studies exploring genetic factors should also measure stroke outcomes. Medical and global outcomes, impairment and activity early post stroke, at 3 months and ideally at 6 and 12-months' post stroke. Document access to and amount of therapy	No specific upper limb measures. NIHSS (Brott et al., 1989), GAS (Kiresuk and Sherman, 1968), FIM (Keith, 1987)
Haselkorn, J. K. (Haselkorn et al., 2015). (Stroke)	2015	No specific recommendations	None
COLLEGE OF OCCUPATIONAL THERAPISTS AND ASSOCIATION OF	2015	Use valid and reliable measures across the ICF framework. Global measures are unlikely to be sensitive to changes, but should be included; choice and	Arm Activity Measure (Ashford et al.,

Record	Year	Summary of recommendations	Recommended measures
CHARTERED PHYSIOTHERAPISTS IN NEUROLOGY. (RCOT, 2015). (Splinting. Non-specific pathology)		timing of OM is important. Recommendations for future research include use, choice and timing of OM	2013) Visual Analogue Scale (Downie et al., 1978); ARAT (Lyle, 1981)
Potter, K., Cohen, E. T. et al. (Potter et al., 2014). (MS)	2014	Important to consider measures that can be used in different settings (hospital vs. home) to track patients over a long period	No specific recommendations
Billinger, S. A. et al. (Billinger et al., 2014). (Stroke)	2014	No specific OM for UL	None
Finlay, P. & Evans, N. (metastatic spinal cord compression). (Finlay and Evans, 2014) (SCI)	2014	Pain, motor and sensory dysfunction assessment should be carried out within 24-48 hours of admission and prior to discharge. Pain should be re-assessed at least daily. Only when the MSCC is deemed stable or more active rehab is permitted can the full assessment be completed. A wide range of measures can be obtained through: <a href="http://www.rehabmeasures.org/default.aspx">http://www.rehabmeasures.org/default.aspx</a>	Light touch sensation; Sharp/blunt or pin prick sensation; Joint proprioception; Muscle power (myotome chart and Oxford classification); Muscle tone: flaccidity or spasticity (MAS) (Pandyan et al., 1999); Joint ROM (active/passive) and muscle length; Personal activities of Daily Living (PADL): Activities of Daily Living (ADL):
Ontaneda, D., Larocca, N et al. (MS) (Ontaneda et al., 2012). (MS)	2012	A universally accepted measurement instrument that is precise, reliable, easy to administer, captures key neurological domains affected by MS, is sensitive at all levels of disability and accurately reflects neurological and neuropsychological disability is still lacking.  Agreeing on single clinical measure that is useful at all stages of the disease is challenging	Multiple Sclerosis Functional Composite (MSFC) approach.  Recommends the development of a database focused on MSFC and follow-up projects aimed at developing patient-reported outcomes, imaging markers and biological markers of the MS disease process.
Canadian EBRSR ( <a href="http://www.ebrsr.com/">http://www.ebrsr.com/</a> ) (Teasell, 2016) (Stroke)	2012	Use of the ICF Framework; reference to reliability, validity, appropriateness and responsiveness (floor and ceiling effects), precision, interpretability, acceptability, feasibility. Does not address UE assessments per se, but includes a number of UE focussed impairment and activity measures, which are scored in each category. Provides information for selection of most	Impairment: FMA (Fugl-Meyer et al., 1975), and MAS (Carr and Shepherd, 1987, Carr et al., 1985)  Activity: ARAT (Lyle, 1981), B&B



Record	Year	Summary of recommendations	Recommended measures
		appropriate measure.	(Mathiowetz et al., 1985a), Chedoke-McMaster (Gowland et al., 1993), FIM (Keith, 1987), 9HPT (Mathiowetz et al., 1985b) (Mathiowetz et al. 1985), WMFT (Wolf, 2001)  Participation: COPM (Law et al., 1990)
Miller, E. L. et al. (Miller et al., 2010). (Stroke)	2010	Hypertonicity should be assessed, but no recommended tools. The MAS has poor validity and inter-rater reliability. Other measures have not been shown to be feasible clinically. Acknowledges importance of trained assessors. Recommends ADL Assessment post-discharge from rehabilitation Tools should be agreed by the MDT and be valid and reliable. No reference to UE	15 Upper Limb Motor assessments are listed as 'commonly used'
Hachinski, V. et al. (Hachinski et al., 2010). (Stroke)	2010	Calls for consensus on, then implementation of, standardized clinical and surrogate assessments. No reference to UL  Tools for measuring the biology of stroke recovery are needed to inform optimal timing, intensity, duration, and content of therapy.  The best standardized measures of behaviour and outcomes after stroke need to be defined and used in clinical practice. Standardized rater training needs to be developed. Surrogate markers of treatment effect could also be used as predictive tools for outcome and thus be of value for entry criteria in clinical trials or in evaluating treatment outcomes and guide clinical decision-making. No specific reference to UL assessment.	None
VA/DOD The Management of Stroke Rehabilitation. (VA/DOD, 2010).	2010	NIHSS performed by trained, certified assessors within the first 24 hours, and consider re-assessing prior to discharge from acute care. Motor function assessed at impairment and activity levels using assessments	Functional Independence Measure (FIM) (Keith, 1987). NIHSS (Brott et al., 1989)

Record	Year	Summary of recommendations	Recommended measures
(Stroke)		<p>with established psychometric properties.</p> <p>A standardized assessment tool should be used to assess ADL/IADL</p> <p>A MDT assessment should be undertaken to establish the patient's rehabilitation needs and goals.</p>	<p>Motor function: muscle strength for all muscle groups, active and passive range of motion, muscle tone, ability to isolate the movements of one joint from another, gross and fine motor co-ordination.</p> <p>The daily use of the paretic extremity should be assessed using a self-report measure (e.g., the Motor Activity Log) (Carr et al., 1985) and accelerometry.</p>
Alexander, M. S et al. (Alexander et al., 2009) (SCI):	2009	Evaluation of UE impairment is important, but generic tests of hand function are ill-suited for use with persons with SCI, with the exception of the Grasp and Release test - developed to assess the effect of a neuroprosthesis.	Grasp and release test (Mulcahey et al., 2007)
Gall, A. et al. (Gall, 2008) (SCI).	2008	No reference to upper limb assessment, except for brief general mention of spasticity, joint range of movement and pain assessment	None
Steeves, J. D et al. (Steeves et al., 2007). (SCI)	2007	Recommends assessment of UE function, including sensation in clinical trials and acknowledges lack of agreement and absence of SCI specific tests for SCI and lack of sensitivity in current measures. Discusses a range of tools without giving specific recommendations	Accurate sensitive and functional measures
Bayley et al., ABIKUS. (Bayley et al., 2007) (TBI).	2007	Recommendations based on a systematic review. Recommends assessment of spasticity and motor function by trained professionals	None

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# PRISMA 2009 Checklist – manuscript Burridge et al 2019

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Page 1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Page 1
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Page 3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Page 3-4
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	No registration
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Page 4-5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Page 4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Page 4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Page 4-5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Page 5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Page 5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	No (mentioned page 4)
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Not applicable (review of



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			guidelines)
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	Descriptive analysis, Page 5-6

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NA
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Page 5 and figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1 and 2 (no presentation of study sizes though as they were guidelines <sup>o</sup> )
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Page 11
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	NA-guidelines, but overviews in table 1 and 2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Descriptive syntheses p5-11
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA-



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			guidelines
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Page 11-12
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Page 12
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Page 12
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Page 12

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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