The content validity and acceptability of the Evaluation of Daily Activity Questionnaire in musculoskeletal conditions

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Abstract

Introduction: The Evaluation of Daily Activity Questionnaire is a detailed self-report measure of activity limitations. It has two parts: 10 scales of symptom severity; and 14 daily activity domains, including 138 activities. It has good psychometric properties in rheumatoid arthritis. The aim was next to establish its' content validity and acceptability in seven musculoskeletal conditions: ankylosing spondylitis; osteoarthritis; systemic lupus erythematosus; systemic sclerosis; chronic pain; chronic hand/ upper limb musculoskeletal disorders; and Primary Sjőgren's Syndrome.

Method: Participants completed the Evaluation of Daily Activity Questionnaire in their own time, followed by a cognitive debriefing interview to identify their views of importance of including each item and EDAQ acceptability.

Results: Six to 12 people with each condition were interviewed (n=70): 17 men and 53 women, 57.38 (SD 12.83) years of age and with 13.15 (SD 11.02) years condition duration. Overall, all 10 scales and 138 activities were considered important to include. Most found it: had clear instructions (93%); was easy to complete (87%); included about the right amount of activities (77%); and would help an occupational therapist gain insight into their conditions' effects (87%).

Conclusion: The Evaluation of Daily Activity Questionnaire has good content validity and acceptability in these seven conditions.

[Abstract 199 words]

Keywords: outcome measures; arthritis; activities of daily living; occupational therapy

[Main text 4499 words]

Key findings

The Evaluation of Daily Activity:

- has good content validity and acceptability in seven musculoskeletal conditions
- and participants' considered it gives appropriate insight into their conditions' impact on daily life.

What the study has added (max 30 words)

For the first time, content validity and acceptability of the Evaluation of Daily Activity Questionnaire in seven musculoskeletal conditions have been demonstrated.

Introduction

The NHS Quality Agenda emphasises valid and reliable outcome measures lead to better quality care (National Quality Board 2011). The College of Occupational Therapists (2013) states that evidencebased outcome measures should be used to justify intervention choices and demonstrate occupational therapy effectiveness. A British Society for Rheumatology Position Statement (2010) also highlights clinicians should demonstrate their care is effective by using measures of clinical improvement and patient reported outcome measures (PROMs). In practice, occupational therapists working in rheumatology often still use semi-structured interviews based on non-validated checklists to identify clients' activity limitations (Hammond et al, 2014a; Hammond 1996). Valid, reliable PROMs are used with some patients, as necessary. The most common are the Health Assessment Questionnaire (HAQ: including 20 daily activities; Pincus et al 1983), the Arthritis Impact Measurement Scales 2 (AIMS2: 28 daily activities; Meenan et al 1992) and Disability Arm Shoulder Hand scale (21 daily activities, Hudek et al 1995). Reasons why standardised assessments are not used regularly by occupational therapists include: unsuitability of available measures; a lack of sensitivity of available measures to capture the effectiveness of occupational therapy; insufficiently detailed to facilitate treatment planning; the time-consuming nature of administering standardised measures make them less feasible in a busy setting; and not being sufficiently "client centred" (Stapleton and McBrearty, 2009; Blenkiron, 2005; Hammond, 1996). PROM development should be informed by people with the target condition, ensuring issues most relevant to them are included and they are acceptable (Kirwan et al 2005; US Department of Health and Human Services, Food and Drug Administration (USFDA 2009); Fitzpatrick et al, 1998).

The Evaluation of Daily Activity Questionnaire

The Evaluation of Daily Activity Questionnaire (EDAQ) was developed in Sweden to meet occupational therapists' needs of for a reliable, valid and detailed PROM (Nordenskiold et al 1996, 1998). The occupational therapist introduces the EDAQ to the client, who then completes it at home, allowing time to reflect on any difficulties. In Sweden, it is used in clinical practice in rheumatoid arthritis (RA) and in other musculoskeletal conditions (MSCs). However, it was developed initially with women with RA and psychometric testing was limited to RA only. It has been used in research to evaluate occupational therapy in RA (Nordenskiold et al 1998) and in epidemiological studies of the impact on activity ability of: early RA (Thyberg et al 2004, 2005); systemic sclerosis (Sandqvist et al 2004); and hand-arm vibration syndrome (Cederlund et al 2001, 2007).

We linguistically validated (i.e. forward and backward translated from Swedish to English) and culturally adapted an English EDAQ, identifying new activities which men and women with RA in the United Kingdom (UK) commonly report as problematic. We conducted cognitive debriefing interviews and focus groups with people with RA and Rheumatology occupational therapists to identify which activities should be included and to finalise the EDAQ's wording and content. We then systematically

linked the EDAQ with the International Classification of Function, Disability and Health (ICF: WHO 2001) and the ICF Core Set for RA (Stucki et al, 2004) (Hammond et al, 2014a). The English EDAQ consists of:

- Part 1: 10 scales evaluating common symptoms (e.g. pain, fatigue) and impacts of arthritis (e.g. sleep, mood). This addresses health domains from the ICF of Body Functions
- Part 2: 14 domains (including 138 activities) which can be combined into two components: Self- Care (Eating, Dressing, Personal Care, Cooking, Cleaning the House, Laundry and Communication) and Mobility (Bathing, Moving Indoors, Transfers, Moving Outdoors, House & Garden Maintenance); plus two additional domains of Caring and Leisure/Social Activities. Part 2 addresses the domains of Activities and Participation in the ICF. Each EDAQ domain is divided into two sections. Section A asks ability without using assistive devices, alternate methods or help. Section B asks ability with assistive devices or alternate methods (if used). Each section is scored on a 0 (no difficulty) to 3 (unable to do) scale.
- Part 3: (optional): a checklist of assistive devices.

PROMs must be valid, reliable, responsive and acceptable to respondents We subsequently psychometrically tested the English EDAQ in RA (n= 502), identifying that each Part 1 scale and Part 2 domain is reliable and valid in RA, and we calculated the minimal detectable change (MDC_{95}) score for each domain. The acceptability of the EDAQ was good: 83% considered it would help occupational therapists to understand their problems; and 87% that it included about the right amount of activities. We recommend Part 3 is optional to reduce completion time, which is 35 minutes on average. Although this might imply a high responder burden, it reflects what people with RA considered applicable (Hammond et al 2015).

Having demonstrated the EDAQ has the psychometric properties to be used for research, audit and is applicable for clinical use in RA, we next investigated whether it would be suitable for use with other MSCs commonly referred to occupational therapists. The content validity and acceptability of the EDAQ in these MSCs needs investigating prior to psychometric testing, as these properties have only been established in RA (Hammond et al, 2014a). Content validity assesses whether items adequately address the domain of interest, and to be acceptable the PROM must be in a language understandable to respondents and have an appropriate length and completion time (Fitzpatrick et al. 1998). PROMs should be developed with and tested in the target populations for which they will be used (Fitzpatrick et al, 1998). It is therefore important to establish whether the EDAQ's content reflects the symptoms, condition impact and activity limitations experienced by people with other MSCs, as these could differ to those of people with RA. Some MSCs can impact on cognitive function and thus it is also important to further investigate acceptability of the EDAQ. The aims of this study were therefore to establish content validity and acceptability in: ankylosing spondylitis (AS); osteoarthritis (OA); systemic lupus erythematosus (SLE); systemic sclerosis [scleroderma] (SS); chronic pain (CP) (including fibromyalgia (FM), widespread, back or neck pain); and chronic (ie >3

months) hand/ upper limb musculoskeletal disorders (CULMD). The MSCs included were selected as these are most frequently referred to Rheumatology occupational therapists. Whilst other types of arthritis are prevalent (e.g. polymyositis) these are either relatively less often referred to occupational therapy or patients can experience very similar daily activity limitations to people with RA (e.g. psoriatic arthritis). During the study, the opportunity arose to also include people with Primary Sjőgren's Syndrome (PSS). To further investigate validity, we systematically linked the EDAQ with the "Activities and Participation" component of the relevant ICF Core Sets.

Method

Ethical approval

Approval was obtained from: the North West 9 (Greater Manchester West) Research Ethics Committee [11/H1014/5] and University of Salford Research Ethics Panel.

Participants

Participants were adults diagnosed by a Consultant or General Practitioner with one of the seven MSCs listed above; able to speak, read and write English (as we were validating an English version of the EDAQ); and no other confounding medical conditions affecting activity ability (eg stroke or respiratory condition. (Secondary OA or FM were not exclusions, as these are common sequelae of many MSCs). Exclusion criteria were about to, or recently started, a disease modifying or biologic drug, low dose oral steroids or received an intra-muscular or intra-articular steroid injection (as medication change could affect test-retest reliability). People diagnosed with mental health conditions (particularly depression) were also excluded as completing a detailed activity assessment, potentially identifying multiple problems, could risk increasing symptoms.

Recruitment

Participants were recruited by research nurses and occupational therapists from eight Rheumatology departments in England. All participants received a study information sheet, had the opportunity to ask questions and provided informed written consent.

Sample size

We purposively sampled at least 10 participants in each MSC to ensure a broad range of demographic and disease duration characteristics.

Content validity and acceptability

Cognitive debriefing interviews are commonly used during PROM development to investigate the appropriateness of and gain insight into participants' understanding of the content of measures (Acquadro et al, 2004; Willis and Miller, 2011). As the EDAQ wording had already been tested for understandability with people with RA (Hammond et al, 2014a), the interviews focused on people with

these seven MSCs' views of the appropriateness of content. Participants were given the EDAQ to complete in their own time. The EDAQ includes written instructions as to its purpose, how to complete it and an example page to illustrate completing Part 2. In the next two weeks, participants took part in structured cognitive debriefing interviews either at home or by telephone. In advance, we explained we would ask them to rate how important they considered each item in the EDAQ, for people with their condition and not just themselves. During the interview, they rated each on a 5 point scale: 1=not at all; 2 =a little; 3 = moderately; 4 = very and 5 = extremely important to include. They were then asked if any other important items had been missed. Finally, they were asked their opinions, using closed questions, of the acceptability of the EDAQ in terms of; clarity of instructions; ease of completion; length; and whether the EDAQ would provide an occupational therapist with an adequate insight into any difficulties they may have. Any additional comments made were recorded verbatim. The readability of the EDAQ was also investigated.

ICF Linking

To further evaluate content validity of the EDAQ, items were systematically linked by two researchers to the International Classification of Functioning, Disability and Health (ICF) Core Sets for AS, chronic widespread pain, low back pain, osteoarthritis and MSCs for post-acute care (ICF Research Branch, 2013) using the ICF linking rules (Cieza et al, 2002; 2004). ICF Core Sets for the other conditions have not yet been developed.

Sample size

We purposively sampled at least 10 participants in each MSC. Typically, cognitive debriefing requires a small sample (i.e. five to 10) of people from the target populations, unconnected to health professions, representing a mix in terms of age, gender, level of education, socio-economic background and condition characteristics appropriate to the instrument's target population(s) (Acquadro et al, 2004).

Analysis

Median (IQR) scores of importance for including each item in Part 1 and 2 were calculated. Items with a median score <3 (no or little importance) were considered for exclusion. The frequencies of responses to acceptability of items were calculated. The qualitative data provided by participants, i.e. additional items suggested, were content analysed, grouped into themes and frequency counts produced (Burnard, 1991). Items suggested by \geq 10% participants were considered for inclusion. Readability statistics were calculated using the Flesch Reading Ease and Flesch-Kincaid Index (Kincaid et al, 1975) in Word (Microsoft 2013) and the National Institute of Adult Continuing Education's online Simplified Measure of Gobbledygook (SMOG) Calculator (2014) (McLaughlin, 1969). As readability is enhanced by having few passive sentences, the percentage of passive sentences was also reviewed using the readability statistics function in Word 2013 and passive sentences changed to active where possible.

Results

Ninety eight people consented to participate of whom 70 completed the EDAQ and interview (see Table 1 for demographic and disease characteristics). Of the 28 non-participants, eight withdrew: one was excluded as having another condition (RA) and the remaining 19 were contacted on multiple occasions but interview dates could not be arranged. We collected minimal data at consent to facilitate recruiting a broad range of participants. From this, we identified there were no differences in disease duration, modified HAQ scores or gender between participants and non-participants. However, non-participants were significantly younger (mean 51.07 years (SD 13.04) than participants (mean 57.38 years (SD 12.83; p = 0.03).

The EDAQ Part 1:

Overall, participants considered 5 of the 10 numeric rating scales "extremely important" to include: pain on moving; stiffness; limitations in joint movement; fatigue; and sleep. The remaining five were "very important" to include: level of condition activity; pain on resting; mood; worry; and satisfaction with life. No scale had a median score <3 in any condition (see Table 2). No additional scales were suggested by $\geq 10\%$ (i.e. 7 or more) of participants. The most common other suggestions were: cognitive function (memory/concentration: n=5 (2 with CP, 2 with SLE and one with PSS); family and personal relationships (n=4: one each with SS, CP, SLE and CULMD); and work (n=3; two with AS and one with OA).

The EDAQ Part 2:

Although some activities were rated <3 in some MSCs (see Table 3), no activities were excluded as none were rated <3 overall. Twenty five participants suggested 48 additional activities for domains 1 to 13 and 8 additional leisure activities for domain 14. Of these, none were suggested by $\geq 10\%$ (n ≥ 7) participants. The most common suggested were:

- Three which were integrated into the EDAQ by modifying existing items: use a mobile phone (n=4) was included into to "use a phone" and specified to include calling and texting; manage wood burners/fires (n=4) (to "manage heating"); and handle debit/credit cards/use ATM (n=4) (to "handle money"); and
- Two suggested by three people only: moving wheeliebins and going on holidays/weekends away. These were not included.

Other activities were suggested by one or two people only and not included. However, bicycling (suggested by two people) was added to "doing physical activities" (domain 14: Leisure) as we were simultaneously developing and testing a Dutch version of the EDAQ, and this is a common activity in

the Netherlands. During the interviews, a number of participants commented it was important to include leisure and social activities, for example:

"It affects people's mood as well if you can't do leisure and hobbies; it reduces well-being and restricts life. So it's very important to include all these." [63 year old woman, CULMD for 2 years].

"It's important ... because you need to be able to keep your interests going; to give your mind a rest from the pain and distract yourself. So it's a big part of coping with pain. " [54 year old woman, back pain for 30 years].

Opinions of the EDAQ:

i. Clarity of instructions and ease of completion:

Sixty-five (93%) replied the instructions were clear and the example page for completing Part 2 was helpful. Comments made were, for example:

"No it wasn't difficult, it can't get any easier. You've not got to write reams with it. A lot of thought has gone into it and you need to compare the two sides: with and without solutions. I followed it OK." [65 year old woman, SS for 30 years].

"It's easy once you get used to it. It might look a bit daunting to some people and feel too much overall at first. But it's OK once you get used to it." [45 year old man, AS for 10 years].

Most (61/70; 87%) considered the EDAQ easy to complete. Of the remaining nine, one had difficulty with completion because of difficulty with reading; and eight considered it partially easy to complete. Reasons given were that they: had to re-read the instructions a few times (n=3); perceived the Part 1 scales as being about general body not regional symptoms (n=2: both with CULMD); it was too long (n=1); they wanted someone to verbally explain how to complete it first (n=1); and it was depressing to consider their abilities performing so many activities (n=1). There were no significant demographic or disease characteristic differences between people considering it easy or not/partially easy to complete. Of the 12 older participants (aged 70-85), only one had any difficulty, that "sections A and B were a bit confusing" but she completed it nonetheless. No one with FM (n=7), which can cause cognitive problems, reported difficulty, for example:

"No, it's set out quite nice. It's not difficult, it's easy to do. I didn't have to write much, just tick, as I have difficulty writing. It was easy to follow." (60 year old woman, FM for 20 years].

For those finding it easy, some still reported they had to re-read instructions or refer back to the example page to complete the first few Part 2 domains, until familiar with it. Some said they had help

from family or friends to complete the EDAQ but they had found this beneficial, as it helped others understand their difficulties.

ii. Length of the EDAQ

Most (54/70:77%) considered it had "about the right amount of questions"; 14 (20%) "too many"; and 2 (3%) "too few." There were no significant differences in demographic or disease characteristics between people considering it too long or about right. Those considering it too long were spread across the seven conditions (the commonest being SLE (n=5) and AS (n=3)). All 14 reported the EDAQ was easy to complete. Their main reason for considering it had too many activities was they did not have difficulty with many themselves. Some participants considering it "about right" commented the EDAQ was long but were positive this was necessary to find out the specific problems a person has, for example:

"At first I thought "Crikey, there are a lot of questions." But when I read it through, I thought all of it was relevant. It's easy to go through; I don't have problems with it being longer." (54 year old woman; AS for 24 years).

"Fibromyalgia affects you in many ways. it gives a good overall picture and you couldn't do it in less. You look at it and think, "Oh, its long" but if you keep going back to it, it's OK, it will help" (62 year old woman; FM for 5 years).

"... you might get some who say it's too long. But it's a good basis for assessment. It didn't take me too long, I did it in two sessions for about 30 minutes altogether and I re-read it" (63 year old woman, SS for 7 years).

iii. Application in Occupational Therapy

The majority considered the EDAQ would help an occupational therapist gain appropriate insight into how their condition affects their daily activities (n=61; 87%). Eight thought it would not completely do so as, although it would inform about their activities, an occupational therapist would still need to ask questions about their specific condition symptoms (eg swallowing, breathlessness, Raynaud's). One did not respond, as she was the only participant unaware of what occupational therapy is.

iv. The process of completing the EDAQ

Although not an aim of the study, some insightful comments were made at the end of interviews by some participants about how completing the EDAQ had helped them, and relatives, to understand their condition better and the possibility of solutions to problems. For example:

"I preferred filling it in at home. I did it over a weekend so I could take my time to think about it. My partner helped me. I think it helped him understand my problems better too" (60 year old woman; FM for 20 years).

"For me it was informative, as it made me think that there can be solutions then. There could be lots of things to help. It helps to kind of advertise that there are solutions, so it's all very relevant.The EDAQ helps concentrate your thoughts and understand your illness more. This has helped me to come to focus on things, and try to live life differently to cope with life. The EDAQ focuses the mind and makes me think to do differently. As I am on my own I have to manage it.At first, I thought a lot doesn't apply to me. But it does when you think about the activities. You live with your illness and accept it...... It helped me a lot to see there could be solutions. But all the activities are relevant, the questionnaire makes you think about your arthritis" (65 year old woman; SS for 30 years).

Readability of the EDAQ

From the readability statistics calculated in Word (Microsoft 2013), the Flesch Reading ease score was 79 and Flesch-Kincaid Grade level was 5.2, indicating the EDAQ requires a reading age of 11-12 year olds. The SMOG Index is 13.9, i.e matching the readability level of the Sun newspaper, which has a SMOG Index <14). Only one percent of sentences were identified as passive following analysis and modifying sentences to be phrased actively.

Linking to ICF Core Sets

The EDAQ has good content validity compared to the Activities and Participation components of the five relevant ICF Core Sets available, as between 63-95% of items are included. However, there were no items included in the EDAQ, and none were additionally suggested by participants, related to ICF Chapters: 1 Learning and Applying Knowledge; 2 General Tasks and Demands; and 7 Interpersonal Interactions and Relationships (see Table 4).

Discussion

The EDAQ is a self-report PROM normally completed in the person's own time. It is not intended to wholly replace an occupational therapists' initial interview but rather it allows more in-depth data collection about the person's activity abilities (part 2), in the context of understanding their current health status (part 1). Part 1 scales were all considered important by participants, although some wanted additional scales related to their MSC's specific symptoms, such as Raynaud's in SS and dry eyes in PSS. We did not include additional MSC specific scales, as an occupational therapist assesses a person within the context of understanding their medical diagnosis and asks additional

questions about specific symptoms. Researchers would use additional measures specific to that MSC, if relevant. In Part 2, no activities were considered "not at all" or only "a little" important overall and thus none were excluded. Thus the EDAQ has good content validity in these seven MSCs, as well as in RA (Hammond et al, 2014a). This further emphasised the importance of culturally adapting PROMs, as a larger number of activities than those included in the Swedish EDAQ were considered relevant (Nordenskiold et al, 1996; 1998). As in the earlier RA study, although the Caring domain was either partially or wholly inapplicable to many, those with long-standing conditions highlighted childcare had been difficult when they had young children, and so it should be retained (Hammond et al 2014a). The Leisure domain was also considered very relevant as having a varied leisure and social life was seen as an important part of managing an MSC and having a balanced lifestyle.

It is essential outcome measures are acceptable to patients (Fitzpatrick et al, 1998). Commonly, this is evaluated by examining response and item completion rates and/or the time taken to complete measures, both of which were already evaluated in the EDAQ in RA study (Hammond et al, 2014a; 2015). Directly assessing people's views about acceptability is preferable but less often done and considered difficult to evaluate directly (Fitzpatrick et al. 1998; Haywood, 2007). However, we were able to do this successfully in the cognitive debriefing interviews. Anecdotally, occupational therapists' main concern about using the EDAQ is whether people will complete it due to its length. However, In general, the EDAQ instructions, appearance and length were well accepted by most people with MSCs, consistent with the findings of the EDAQ in RA study, in which 87% considered the EDAQ includes the right amount of questions (Hammond et al, 2014a). We had particular concerns that, for people with FM, the EDAQ would be too long because concentration problems are common. In contrast, this group preferred its length, as it more fully identified their problems. The length was not a problem as they could complete the EDAQ over several days and take time to reflect on their difficulties and current solutions. Some participants did consider the EDAQ too long. Most of them were either men with AS or people with SLE who did not have hand problems. As a result, they considered many activities requiring finer hand function were unimportant for people with their condition. The EDAQ includes many hand function items, reflecting the prevalence of hand problems in many MSCs. Whilst AS presents as chronic inflammatory low back pain, causing mobility problems, it can affect upper limb joints. Women with AS have more peripheral involvement and worse functioning than men, despite having fewer radiological abnormalities (Tournadre et al, 2013). Most of the women participants with AS considered such hand activities were applicable. SLE leads to systemic symptoms, such as malaise and fatigue However, peripheral arthritis in the hands and wrists are also common (Wright et al, 2006), indicating such activities are still relevant for many with SLE.

Most participants could complete the EDAQ without assistance just by using the instructions contained within. The implications for practice are that it can be mailed in advance to patients referred to Occupational Therapy, as well for use in research. In practice, for new client referrals, a covering letter would be needed, explaining the aims of occupational therapy, the purpose of the EDAQ and

how the occupational therapist will collaborate with the client to resolve any problems identified. If appropriate, this could be supported by a telephone explanation and opportunity to ask questions in advance of the therapy appointment. Respondents in this study indicated that completing the EDAQ in their own time at home allowed time to reflect on difficulties and the EDAQ increased their awareness that there were likely to be solutions. This increased awareness could assist occupational therapists in increasing the breadth of solutions recommended. Occupational therapists have previously indicated that they consider the EDAQ could make appointments more efficient, reducing assessment time and focusing on clients' needs more quickly (Hammond et al, 2014a).

Clearly, it is essential to be able to read and write to complete the EDAQ. The National Literacy Trust (2014) estimates 16% of the English population are functionally illiterate. The literacy level of the EDAQ is similar to that of the Sun newspaper, making it accessible to most literate people. Almost half our group had either no or lower secondary stage educational qualifications and were no more likely to indicate the EDAQ was too long or they had difficult completing it, than those with higher qualifications. The EDAQ is not suitable for everyone and not all literate people wish to complete long questionnaires. However, it is likely the majority could complete it.

The main limitations were that fewer people than planned with PSS were recruited, as we needed to progress to the next stage of the study: psychometric testing. It was also difficult to recruit people with MSCs with young children, to obtain feedback about the Caring domain, as demographically many of these MSCs have a peak onset in middle- to older age, although many had grandchildren they cared for. We conducted a structured interview, but impromptu comments by participants led to insights into why they considered domains or completing the EDAQ beneficial. In future research we could explore: such perceptions in more depth; how the EDAQ might contribute to clients' satisfaction with occupational therapy services; and for whom it is less applicable. Subsequently, the psychometric properties of the EDAQ in these seven MSCs have been established (Hammond et al, 2014b) and the EDAQ is now available for use.

In conclusion, most participants found the EDAQ acceptable and it had good content validity as all content was considered important to include. Only minimal changes to the EDAQ were required.

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The EDAQ and EDAQ User manual are now available for free download and use under Creative Commons Licenses from: EDAQ Parts 1 and 2: <u>http://usir.salford.ac.uk/30755/</u> EDAQ Parts 1 to 3: <u>http://usir.salford.ac.uk/30754/</u> EDAQ User Manual: <u>http://usir.salford.ac.uk/30752/</u>

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	AS	0A	SLE	SS	CP	CUL	PSS	Total
	(n=12)	(n=11)	(n=10)	(n=10)	(n=10)	(n=11)	(n=6)	(n=70)
Age:(Mean (SD)	53.08 (11.30)	66.45 (15.71)	45.20	60.10 (8.57)	59.0 (5.68)	55.45 (10.94)	66.0 (6.57)	57.38
			(14.64)					(12.83)
Gender (M:F)	5:7	3:8	1:9	1:9	3:7	4:7	0:6	17:53
Condition duration (years)	18.08 (15.77)	9.27 (7.55)	11.82 (7.24)	15.33 (7.87)	16.1 (13.94)	7.54 (5.48)	13.0 (13.77)	13.15
(Mean (SD):								(11.02)
Marital status: n:								
Single/divorced/widowed	2	4	3	4	3	1	4	21 (30%)
Married/living with partner	10	7	7	6	7	10	2	49 (70%)
Living status: n								
Alone	2	4	0	4	3	1	4	18 (26%)
Family/significant other	10	7	10	6	7	10	2	52 (54%)
Children living at home (n)	3	2	5	3	1	3	0	17 (24%)
Employment status:								
Paid employment	6	3	6	2	4	4	1	26 (37%)
Unemployed	1	0	1	0	0	1	0	3 (4%)
Early retired ill-health	2	3	1	2	3	1	1	13 (19%)
Retired	3	5	2	6	3	5	4	28 (40%)
Education level (ISCED):								
1: Compulsory school	2	6	1	2	4	1	1	17 (24%)
2: Secondary first stage	4	2	2	1	2	3	2	16 (23%)
3: Secondary second	1	0	2	1	0	1	0	5 (7%)
4: Post-secondary	1	2	3	4	1	3	1	15 (22%)
5: Tertiary	4	1	2	2	3	3	2	17 (24%)
Pain (0-1). (Mean (SD)	3.00 (2.05)	8.11 (1.83)	5.22 (2.86)	3.33 (3.78)	6.44 (1.67)	5.30 (3.27)	2.67 (2.66)	5.03 (3.09)
Fatigue (0-1). (Mean (SD)	4.99 (1.66)	6.67 (2.74)	6.22 (2.17)	4.83 (3.06)	5.75 (2.66)	4.60 (2.80)	5.0 (2.0)	5.45 (2.45)
mHAQ (0-3). (Mean (SD)	0.47 (0.62)	1.0 (0.45)	0.46 (0.46)	0.56 (0.78)	1.0 (0.60)	0.31 (0.49)	0.15 (0.20)	0.59 (0.61)

Table 1: Demographic characteristics of participants in Phase 1 (n= 70)

Key: mHAQ = modified Health Assessment Questionnaire; ISCED Levels include, for example: 1 = no formal qualifications/ School Leaving Certificate; Level 2 = CSE/O Level/ GCSE; Level 3 = A Level, BTEC; Level 4 = City & Guilds, NVQ; Level 5 = Diplomas, Higher Diplomas, Higher Certificates, Bachelors, Masters, Doctoral degree

Table 2:	Median (IQR) importance	ratings for	EDAQ Part 1: numeric rating scales of condition effects (r	n=70)
			J J	- /

Part One: numeric rating scales	AS	OA	SLE	SS	СР	CULMD	PSS	Total
	(n=12)	(n=11)	(n=10)	(n=10)	(n=10)	(n=11)	(n=6)	(n=70)
Condition/ disease activity	5 (4-5)	4 (3-5)	5 (4-5)	5 (3.75-5)	4 (3.75-5)	4 (4-5)	3.5 (2.75-5)	4 (4-5)
Mood	5 (4-5)	4 (2-4)	4.5 (3-5)	4 (4-5)	4 (3.25-5)	4 (3-5)	5 (4.5-5)	4 (4-5)
Pain when resting	5 (4-5)	4 (4-5)	4 (3-5)	4.5 (3-5)	4 (3.75-5)	4 (4-5)	4 (2.5-5)	4 (3.75-5)
Pain when moving	5 (4-5)	5 (4-5)	5 (4-5)	5 (4-5)	5 (4-5)	5 (4-5)	5 (3.25-5)	5 (4-5)
Stiffness	5 (5-5)	4 (4-5)	5 (4-5)	5 (4-5)	5 (4-5)	4 (4-5)	5 (2.5-5)	5 (4-5)
Limitations in joint movement	5 (4.25-5)	4 (4-5)	5 (4-5)	4.5 (3.75-5)	4 (3.75-5)	4 (4-5)	5 (3.25-5)	5 (4-5)
Fatigue	5 (4-5)	5 (4-5)	5 (4-5)	4.5 (4-5)	5 (3.75-5)	4 (3-5)	5 (4.75-5)	5 (4-5)
Worry	5 (3-5)	4 (3-5)	4 (3-5)	4 (3.75-5)	4 (2.5-5)	4 (4-5)	4.5 (3-5)	4 (3-5)
Sleep problems	5 (4-5)	5 (4-5)	4.5 (3-5)	4.5 (3-5)	4.5 (3.25-5)	5 (4-5)	5 (4-5)	5 (4-5)
Satisfaction with life	4 (4-5)	4 (4-4)	4.5 (2.75-5)	4 (4-5)	4.5 (3.25-5)	4 (4-4)	5 (4.75-5)	4 (4-5)

	EDAQ Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>1.</u>	Eating	()		(=.)	(=)	((=)	(0)	(
1.	Lift a glass	3.5 (2.25-4)	4 (3-5)	3 (1.75-4)	4.5 (2.5-5)	3 (1-4.25)	4 (4-5)	4.5 (3.5-5)	4 (2.75-5)
2.	Lift a cup/mug	3.5 (2.25-4)	4 (3-5)	3 (1.75-4)	4.5 (2.5-5)	4 (2.5-5)	4 (4-5)	5 (3.5-5)	4 (3-5)
3.	Use a knife and fork	3.5 (3-4.75)	4 (3-5)	3.5 (1.75-5)	4.5 (2.5-5)	4 (2.5-5)	4 (4-5)	5 (3.5-5)	4 (3-5)
4.	Slice food (e.g. bread, cheese)	3.5 (3-4.75)	4 (3-5)	3.5 (1.75-4.25)	4.5 (3-5)	4 (3.75-5)	4 (3-5)	4.5 (2.75-5)	4 (3-5)
5.	Get the milk out of the fridge	3.5 (1.25-4)	4 (2-5)	2.5 (1.75-4)	4.5 (2.5-5)	4 (2.5-5)	4 (4-5)	4.5 (2.75-5)	4 (2.75-5)
6.	Open a milk carton/plastic bottle and pour out	4 (3-5)	4 (3-5)	4 (1.75-4.25)	5 (4-5)	4 (3-5)	4 (4-5)	5 (3.75-5)	4 (3-5)
7.	Open a bottle top (e.g. lager)	4 (3-5)	4 (3-5)	4 (1-4)	5 (3.75-5)	3.5 (1.75-5)	4 (3-5)	5 (3-5)	4 (3-5)
8.	Open a screw top jar or bottle	4 (3-5)	4 (3-5)	4 (2-5)	5 (4-5)	4.5 (3-5)	4 (4-5)	5 (3.75-5)	4 (4-5)
9.	Open a tin or a ring-pull can	4.5 (3-5)	4 (3-5)	4 (2-4.25)	5 (4-5)	4.5 (3.75-5)	4 (3-5)	5 (2.75-5)	4 (3-5)
10.	Open a packet/pouch	4 (3-5)	4 (3-5)	3.5 (1.75-4)	4.5 (3-5)	4 (2.5-5)	4 (3-5)	5 (3-5)	4 (3-5)

Table 3: Median (IQR) importance ratings for EDAQ Part 2: daily activities (n=70)

	Domain and Items	AS (n=12)	OA N-11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD	PSS	Total
<u>2</u>	. In the Bathroom/ Personal Care	(11-12)	N- 11	(11-10)	(1=10)	(11-10)	(1-11)	(11=0)	(11=70)
1.	Get on and off the toilet	4 (3-5)	4 (4-5)	4 (1.75-4.25)	4 (2-5.5)	5 (4-5)	4 (3-5)	4.5 (3.5-5)	3.75 (4-5)
2.	Wipe yourself with toilet paper /clean self below	4 (4-4.75)	3 (4-5)	3 (1.75-5)	3.5 (1.75-5)	4 (4-5)	4 (4-5)	4.5 (3.5-5)	4 (3-5)
3.	Use suppositories/tampons	3.5 (1.25-4)	4 (3-4.5)	2 (1-4.5)	4 (2-4.5)	4 (2.5-5)	4 (4-5)	4.5 (3.5-5)	4 (2-5)
4.	Flush the toilet	4 (2-4.75)	4 (3-5)	3 (1.75-4)	3.5 (2.5-5)	3.5 (1.75- 4 25)	4 (4-4)	4 (2.75-5)	4 (2.75-5)
5.	Arrange your clothes after going to toilet	4 (3-5)	4 (3-4)	3 (1.75-4.25)	3.5 (1-4.25)	4 (3-4.25)	4 (3-5)	4 (2.75- 4.25)	4 (3-4)
6.	Wash your hands	4 (2.25-4.75)	4 (3-5)	3 (1.75-4.25)	4 (1-5)	4 (2.5-5)	4 (2-5)	4.5 (3.5-5)	4 (2.75-5)
7.	Brush and comb your hair	3.5 (2-4)	4 (3-4)	4 (1.75-4.25)	3.5 (1.75-	4 (3.75-5)	4 (4-5)	4 (2.75-5)	4 (2.75-4)
8.	Brush your teeth	3 (2-4)	4 (3-5)	3 (1.75-4.25)	3.5 (1-4.25)	4 (3-5)	4 (4-5)	4 (4-5)	4 (3-4.25)
9.	Use a tube of toothpaste	3.5 (2.25-4.75)	4 (3-5)	3 (1.75-3.5)	3.5 (1-4.25)	4 (3.75-4)	4 (3-5)	4.5 (4-5)	4 (3-4)
10.	Open a medicine bottle/ blister pack	4 (3.25-4)	4 (3-5)	4 (2.75-5)	4 (1-5)	4 (4-4)	4 (4-5)	5 (4.75-5)	4 (4-5)
11.	Do your make up or shave	3.5 (2.25-4)	4 (3-5)	2.5 (1.75-4)	3 (1-4.25)	4 (2-5)	4 (4-5)	4 (3.5-5)	4 (2-4)
12.	Put on jewellery/watch	3 (2-4)	3 (3-5)	2 (1-3.25)	3 (2.5-4)	4 (1.75- 4.25)	4 (4-4)	3.5 (2.75-5)	3 (2-4)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>3</u>	. Getting Dressed/ Undressed	()		((((,	((
1.	Put on / take off a coat	4 (3-4.75)	4 (3-4)	4 (2-4.25)	4.5 (3.25-5)	4 (3-4.25)	4 (4-5)	4 (3.75- 4.25)	4 (3-5)
2.	Pull clothes over your head	4 (4-5)	4 (3-4)	4 (2.75-4.25)	4 (2.5-5)	3.5 (3-5)	4 (4-5)	4.5 (3-5)	4 (3-5)
3.	Put on front-opening clothes	4 (2.25-4)	4 (3-4)	3.5 (1.75-4)	4 (2.75-5)	4 (3-5)	4 (4-5)	4 (3-5)	4 (3-4)
4.	Do up/undo buttons	4 (2.25-4.75)	4 (3-4)	4 (2.5-4)	4.5 (3.75-5)	4 (3.75-5)	4 (4-5)	4.5 (3.75-5)	4 (3-5)
5.	Pull clothes over your feet	4 (2.25-5)	4 (4-5)	4 (2.5-5)	4 (2.75-5)	4.5 (3.75-5)	4 (3-5)	4 (3-5)	4 (3-5)
6.	Do up /undo zips	4 (3-4)	4 (3-5)	3.5 (1.75- 4 25)	4 (1.75-5)	4 (3-5)	4 (4-5)	4.5 (3.75-5)	4 (3-5)
7.	Put on tights/socks	4 (3.25-5)	4 (3-5)	4 (2.5-5)	4 (2.75-5)	5 (3.75-5)	4 (4-5)	4.5 (3.75-5)	4 (3-5)
8.	Take shoes/ boots on and off	4 (4-5)	4 (3-5)	3 (1.75-4.25)	3.5 (2.75-5)	4.5 (3.75-5)	4 (4-5)	4.5 (3.75-5)	4 (3-5)
9.	Tie shoelaces	4.5 (4-5)	4 (4-5)	3 (1.75-4.25)	3.5 (2.75-5)	4 (3-5)	4 (4-4)	4.5 (2.75-5)	4 (3-5)
10). Put on/take off gloves	3 (2-4)	3 (2.75-5)	3 (1-4)	4 (1-5)	2.5 (2-3)	4 (3-4)	4 (3-4.25)	3 (2-4)
11	. Fasten clothes at the back	4 (4-5)	4 (3-5)	4 (1.75-4.25)	4 (4-5)	4.5 (3-5)	4 (4-5)	4.5 (3-5)	4 (4-5)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>4</u>	. Bathing/Showering	()		(((()	((
1.	Get in and out of the bath	4 (3-4.75)	5 (4-5)	5 (2.5-5)	5 (4-5)	4 (4-5)	4 (4-5)	4.5 (3.5-5)	4 (4-5)
2.	Shower whilst standing	4 (4-5)	3 (2-5)	3 (2.5-4.5)	4.5 (2.5-5)	4.5 (4-5)	4 (3-5)	5 (3.5-5)	4 (3-5)
3.	Use shower controls /bath temperature mixers	4 (3-4.75)	3 (3-5)	3 (2.5-3.5)	4 (2.5-5)	4 (2.5-5)	4 (4-5)	5 (4.25-5)	4 (3-5)
4.	Turn taps	4 (3-4.75)	4 (3-5)	3 (1.75-5)	4 (2.75-5)	4 (3-5)	4 (4-5)	5 (4.25-5)	4 (3-5)
5.	Wash your back and neck	4 (3.25-5)	4 (3-5)	4 (2.5-5)	4 (2.75-5)	4 (3.75-5)	4 (4-5)	5 (3.5-5)	4 (3-5)
6.	Dry your back and neck	4 (3.25-5)	4 (3-5)	3 (2.5-5)	4 (2.75-5)	4 (3.75-5)	4 (4-5)	4.5 (2.75-5)	4 (3-5)
7.	Wash and dry your feet	4 (3.25-5)	3 (3-5)	4.5 (2.5-5)	4 (3-5)	4 (3.75-5)	4 (4-5)	5 (3.5-5)	4 (3-5)
8.	Wash your hair	4 (1.5-4.75)	4 (3-5)	3 (2.5-5)	4 (2.5-5)	4 (3.75-5)	4 (4-5)	5 (3.5-5)	4 (3-5)
9.	Style/ blow-dry your hair	3 (1.25-4)	3 (3-5)	3 (1-4)	4 (2.5-4.25)	4 (3.75-5)	4 (4-5)	4.5 (3.5-5)	4 (3-5)
10	. Cut/file your finger nails	4 (3.5-4.75)	3 (3-5)	3 (1.75-4)	4 (2.5-4.25)	4 (1.75-5)	4 (3-5)	4.5 (2-5)	4 (2.75-4.25)
11	. Take care of your feet	4 (4-5)	4 (3-5)	3 (1.5-5)	4.5 (3.25-5)	4.5 (4-5)	4 (4-5)	5 (2-5)	4 (3-5)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>5.</u>	Cooking	()		(((()	((
1.	Stand while working in the kitchen	4 (3-5)	4 (3-5)	3 (1-5)	4 (3.75-5)	5 (4-5)	4 (3-4)	4.5 (2.75-5)	4 (3-5)
2.	Set the table/ carry plates, cups etc	3 (2.25-4.75)	3 (2-5)	3 (1-4.25)	4.5 (2.5-5)	4 (3.5-5)	4 (3-5)	4 (2.75-5)	4 (3-5)
3.	Peel and chop vegetables	4 (3-5)	4 (3-5)	2.5 (1.75- 4.25)	5 (4-5)	4 (4-5)	4 (4-5)	4.5 (2.75-5)	4 (3-5)
4.	Carry a full pan to/ from the cooker	4 (3.25-5)	5 (4-5)	4 (1-5)	5 (4-5)	4 (4-5)	4 (4-5)	5 (4.75-5)	4 (4-5)
5.	Drain water from a saucepan (e.g. vegetables, pasta)	4 (3-5)	4 (3-5)	4 (2-5)	5 (4-5)	4 (3.75-5)	4 (4-5)	5 (3.5-5)	4 (3.75-5)
6.	Remove heavy items (e.g. bag of	4.5 (3.25-5)	4 (3-5)	5 (2-5)	5 (3.75-5)	4 (4-5)	4 (3-5)	5 (2.75-5)	4 (3-5)
7.	Baking (eg. cakes, bread, pastry)	2.5 (1-4.75)	3 (2-5)	3 (1-4)	3.5 (1-5)	4 (2-4.25)	4 (3-4)	4 (2-5)	3 (2-4)
8.	Take things in/out of oven	3.5 (2.25- 4.75)	4 (3-5)	4 (1.75-4.25)	5 (3.75-5)	4 (4-5)	4 (4-5)	5 (3.5-5)	4 (3.75-5)
9.	Wash up	3 (1.25-4.75)	3 (3-5)	3.5 (1.75-4)	4 (2.5-5)	4 (3.75-4)	4 (3-5)	4.5 (2.75-5)	4 (3-5)
10	. Put crockery/pans etc into kitchen cupboards	3.5 (3-5)	3 (3-5)	4 (1.75-4)	4 (3.25-5)	4 (3.75- 4.25)	4 (4-5)	5 (2.75-5)	4 (3-5)
11	. Use a kettle (e.g. fill, pour)	3.5 (2.25-5)	4 (3-5)	4 (1.75-5)	4.5 (1-5)	4.5 (3.75-5)	4 (4-5)	4.5 (3.5-5)	4 (3-5)
12	. Turn cooker knobs	2.5 (1.75- 4.75)	3 (2-5)	3.5 (1.75-4)	4.5 (1-5)	4 (2.75- 4.25)	4 (4-5)	4.5 (3.5-5)	4 (2-5)
13	. Open fridge door	2.5 (1.75- 4 75)	3 (2-5)	3 (1-3.25)	4.5 (1-5)	3 (1-4)	4 (4-4)	4.5 (3.5-5)	4 (2-5)
14	. Prepare and cook a snack and/or a	4 (2-5)	4 (3-5)	3.5 (1.75-4)	5 (3.75-5)	4 (3.75-	4 (3-4)	5 (4.25-5)	4 (3-5)

_	meal					4.25)			
<u>6.</u>	Domain and Items Moving Around Indoors	AS (n=12)	OA n=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
1.	Walk indoors (e.g. get to toilet/ bathroom; round kitchen)	4 (3.25-5)	4 (4-4)	3 (2-5)	4 (1.75-5)	4 (4-4.25)	4 (2-4)	5 (4.25-5)	4 (3-5)
2.	Open the front or back door	3 (1.25-4.75)	3 (3-5)	3 (2-4.5)	4 (1-5)	4 (3.5-4)	4 (3-5)	5 (4.25-5)	4 (2.75-5)
3.	Lock and unlock doors	3 (1.25-4.75)	4 (3-5)	3.5 (2-4.25)	4.5 (3.25-5)	4 (4-4.25)	4 (4-5)	5 (3.5-5)	4 (3-5)
4.	Get to the front door in time to answer	4 (3-4)	4 (3-5)	4 (2-4.25)	4 (2.5-5)	4 (3.75- 4.25)	4 (2-4)	4 (2.75-5)	4 (3-4)
5.	Get to the phone in time to answer	3.5 (3-4)	4 (3-5)	4 (2-4.25)	4 (1-5)	4 (3.75-	4 (2-4)	4 (2.75-5)	4 (3-4)
6.	Stand for longer periods	4.5 (4-5)	4 (4-5)	4 (2.75-5)	5 (4-5)	4 (4-5)	3 (2-4)	4.5 (3-5)	4 (4-5)
7.	Get up and down steps/ stairs	4.5 (4-5)	4 (4-5)	5 (4-5)	5 (4-5)	5 (4-5)	4 (2-5)	5 (3.75-5)	5 (4-5)
8.	Bend to floor/pick up items	4.5 (4-5)	4.5 (3.75-5)	4 (3.75-5)	4.5 (3.75-5)	4.5 (4-5)	4 (3-5)	4.5 (3.75-5)	4 (4-5)
9.	Reach up	4 (3.25-5)	3 (3-5)	4 (2-5)	4.5 (3.75-5)	4 (4-5)	4 (2-5)	4 (3-5)	4 (3-5)
10	. Kneel	5 (3.25-5)	4 (4-5)	5 (3.75-5)	5 (4-5)	5 (4-5)	4 (3-4)	4.5 (3-5)	4 (4-5)
11	. Carry heavy items around the house	4.5 (3.25-5)	4 (3-5)	4 (3.75-5)	5 (3.75-5)	4.5 (4-5)	4 (4-5)	4 (3-5)	4 (4-5)
12	. Manage heating (e.g. controls)	3.5 (2.25-4)	3 (3-5)	3.5 (1.75-4)	4.5 (1-5)	4 (2-4.25)	4 (4-5)	5 (3.5-5)	4 (3-5)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>7.</u>	Cleaning the House	\ /		(((()	((, 0)
1.	Make the bed	4 (2.25-5)	4 (3-4)	4 (2-4)	4 (3-5)	4.5 (4-5)	4 (3-5)	4 (3-5)	4 (3-5)
2.	Dust and wipe surfaces	2.5 (2-4)	4 (3-4)	3 (2-4)	4 (1-5)	4 (1.75-5)	4 (3-5)	3.5 (2.75-5)	4 (2-5)
3.	Sweep up/ mop floor	4 (2.25-5)	3 (3-4)	4 (2-4)	4 (3-5)	4 (3-5)	4 (3-5)	4.5 (3-5)	4 (3-5)
4.	Wring out a cloth	3.5 (2-5)	4 (3-4)	4 (2-4.5)	4 (3.75-5)	4.5 (3.5-5)	4 (4-5)	3.5 (3-5)	4 (3-5)
5.	Vacuum clean	4 (2.25-5)	4 (3-4)	4 (2.5-4)	4 (3.75-5)	4.5 (4-5)	4 (3-5)	4.5 (3-5)	4 (3-5)
6.	Open a window	3 (2.25-5)	3 (3-5)	3 (2-4.5)	4 (2.5-5)	4 (3.75-5)	4 (3-4)	4.5 (3.75-5)	4 (3-5)
7.	Clean windows	3.5 (2-5)	3 (2-4)	4 (3-4.5)	4 (4-5)	4 (3.75-5)	4 (3-5)	3.5 (2.75-5)	4 (3-5)
8.	Clean the bath	4 (2-5)	4 (3-4)	4 (2.5-4.5)	4 (3.75-5)	4 (4-5)	4 (3-5)	4.5 (3-5)	4 (3-5)
9.	Heavy housework (e.g. move furniture, take down curtains)	4.5 (3.25-5)	4 (4-5)	5 (3-5)	4.5 (4-5)	5 (4-5)	4 (3-5)	4.5 (2.75-5)	4 (4-5)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>8.</u>	Laundry & Clothes Care	()		(()	(()	((
1.	Do the hand washing	3 (1.25-4)	3 (2-4)	4 (3-5)	4 (3-5)	3.5 (2-5)	4 (3-5)	3 (2-4)	3.5 (2-4)
2.	Use a washing machine (e.g. load and unload)	4 (2.25-4)	3 (3-5)	3 (1.5-4)	4 (2-5)	3.5 (3-5)	4 (3-5)	4 (3-5)	4 (3-5)
3.	Hang out washing	4 (3.25-5)	3 (3-4)	4 (2-4)	4 (3.5-5)	4 (3-5)	4 (3-5)	4 (2.75-5)	4 (3-5)
4.	Plug in and pull out a plug	4 (2.25-4.75)	3.5 (3-5)	3 (1-4.5)	4 (3-5)	4 (2.5-5)	4 (4-5)	4 (3.5-4.25)	4 (3-5)
5.	Put up an ironing board	4 (2.25-4)	3 (3-5)	4 (1-4)	4 (3-5)	3.5 (3-4.25)	4 (3-5)	4 (3-5)	4 (4-5)
6.	Iron	4 (4-5)	3 (2-4)	4 (2.5-5)	4 (4-5)	4 (3-5)	4 (4-5)	4 (3-5)	4 (3-5)
7.	Do small repairs e.g. hemming, buttons	2.5 (1.75- 4.75)	3 (2-5)	4 (2.25-4)	5 (4-5)	3.5 (1-4.25)	4 (2-4)	3.5 (2.75- 4.25)	4 (2-5)
8.	Cut cloth and/ or use scissors	3.5 (2-4)	3 (3-5)	3 (1.5-4)	5 (4.5-5)	3 (2.5-4.25)	4 (3-4)	4 (2-5)	4 (3-5)
9.	Pick up pins/needles	4 (2.75-4.75)	3 (1-5)	3 (2.5-4)	5 (4-5)	4 (1-4.25)	3 (2-4)	4 (2-5)	4 (2-5)

Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
9. Moving & Transfers	()		(11-10)	(11-10)	(11-10)	(=)	(11-0)	(11-7-0)
1. Get into and out of bed	4 (4-5)	4 (4-5)	4.5 (3-5)	3.5 (1.75-5)	5 (4-5)	4 (3-5)	4.5 (3.75- 5)	4 (4-5)
2. Turn over and sit up in bed	4 (4-5)	4 (3-4)	4.5 (3.75-5)	4 (2.75-5)	5 (4-5)	4 (3-5)	4 (2.75-5)	4 (4-5)
3. Stand up from a chair without armrests	4 (4-5)	4 (4-5)	4.5 (3.25-5)	4 (2.75-5)	5 (4-5)	4 (3-5)	4 (3-5)	4 (4-5)
4. Pull up bedclothes/duvet	3.5 (2.25-5)	4 (2-5)	4 (1.75-5)	4.5 (1.75-5)	4.5 (3-5)	4 (4-5)	4 (3.5- 4.25)	4 (3-5)
5. Getting a comfortable sleeping position	4 (4-5)	4 (4-5)	4.5 (3.75-5)	4.5 (2.75-5)	5 (5-5)	4 (3-5)	4.5 (4-5)	4.5 (4-5)
6. Sit for longer periods (e.g. in a car, train)	4 (3-4.75)	4 (3-5)	4.5 (2-5)	4 (3-5)	5 (4.75-5)	4 (3-5)	4 (3.75-5)	4 (3-5)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>10</u>	.Communication	()		()	(()	()	()	(
1.	Use a phone	3 (1-4.75)	4 (3-5)	4 (2.5-5)	4.5 (2-5)	4 (3.5-5)	4 (4-5)	5 (3.5-5)	4 (3-5)
2.	Hold a book	3 (1-3.75)	3 (3-5)	3 (2-4.5)	3.5 (2.75-5)	4 (1.75-5)	4 (4-5)	3 (2.75- 4.25)	4 (3-5)
3.	Write	3.5 (3-5)	4 (3-5)	4 (4-5)	4 (2.75-5)	4 (3.5-5)	4 (4-5)	4 (3.5-4.25)	4 (3-5)
4.	Handle money/ credit cards	3 (1-4.5)	4 (3-5)	3.5 (3-5)	5 (2.75-5)	4 (4-4)	4 (3.75- 4.25)	5 (3.5-5)	4 (3-5)
5.	Use a computer and a mouse	2 (1-4)	3 (3-4.25)	3 (2-4.5)	3.5 (2.75-5)	4 (2.5-4.25)	4 (4-5)	4 (4-4.25)	4 (3-5)
6.	Use remote controls (e.g. TV)	2 (1-3.75)	3 (2-5)	3 (1-5)	3.5 (1.75-5)	3.5 (1.75-4)	4 (3.75-5)	4 (2.75-5)	3 (2-4)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>11</u> SI	I.Moving Around Outdoors/ hopping	()	••-••	(•)	()	(()	(•)	(•)
1.	Walk on level ground	4 (3-4.75)	4 (3-5)	4 (2-5)	4.5 (4-5)	5 (3.5-5)	4 (3-5)	5 (3.75-5)	4 (3-5)
2.	Go for a long walk (e.g. a mile)	4 (3.25-5)	4 (3-5)	5 (3.75-5)	5 (4-5)	5 (4-5)	4 (2-4)	4 (3-5)	4 (3-5)
3.	Go up stairs without a handrail	4.5 (4-5)	4 (4-5)	5 (3-5)	5 (4-5)	5 (4-5)	4 (4-5)	5 (3.5-5)	5 (4-5)
4.	Travel by public transport	4 (3-5)	4 (3-5)	3.5 (1-5)	4 (3.75-5)	5 (4-5)	4 (3-4)	4.5 (3.75-5)	4 (3-5)
5.	Get in and out of a car	4.5 (4-5)	4 (4-5)	4.5 (2.5-5)	4 (3.75-5)	5 (4-5)	4 (3-4)	4.5 (3.75-5)	4 (4-5)
6.	Drive a car (e.g. hold steering wheel, turn car key, change gear)	4 (2-5)	5 (3-5)	4 (1.75-5)	4.5 (3.75-5)	4.5 (4-5)	4 (4-5)	3.5 (3-5)	4 (4-5)
7.	Fill the car with petrol	4 (2-5)	4 (4-5)	3.5 (1.75-5)	4.5 (3.75-5)	4 (3.25-5)	4 (4-5)	4 (3.5-5)	4 (3-5)
8.	Open a heavy (e.g. shop/lift) door	4 (4-4)	4 (3-5)	4.5 (2.75-5)	4.5 (3-5)	5 (4-5)	4 (4-5)	4 (3-5)	4 (4-5)
9.	Walk around the shops	4 (4-5)	4 (3-4)	4 (3.5-4.5)	4.5 (2.75-5)	5 (4-5)	4 (2-5)	4 (3-5)	4 (4-5)
10.	. Carry shopping	4 (4-5)	4 (4-4)	4.5 (2.5-5)	5 (4-5)	5 (4-5)	4 (4-5)	4 (3.75-5)	4 (4-5)
11.	. Do the weekly shopping	4 (4-5)	4 (3-4)	4.5 (1-5)	4.5 (3.75-5)	5 (4-5)	4 (4-5)	4.5 (4-5)	4 (4-5)
12.	. Hold a walking stick	4 (1.25-4.75)	4 (3-5)	3 (1-5)	3.5 (2.5-5)	4 (4-5)	4 (4-4)	5 (3.75-5)	4 (3-5)
13.	Use a mobility scooter	4 (2.5-4.25)	3 (1.5-4.5)	4 (1-5)	3 (2-5)	4.5-3-5)	4 (2-5)	4.5 (2-5)	4 (3-5)

Domain and Items		AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>12. Gardening& Household</u> Maintenance		()		((= : ;)	()	(=)	(0)	(
1.	Change a light bulb	4 (3.25-5)	4 (4-5)	3.5 (1.75- 4.25)	3.5 (3-5)	4 (3-4.5)	4 (3-5)	4 (2.75-5)	4 (3-5)
2.	Light gardening (e.g. weed, prune, plant)	4 (3-4.75)	3 (1-4)	3 (1-4)	4 (3-5)	4 (3.5-4)	4 (3-5)	4.5 (2.75-5)	4 (3-5)
3.	Heavy gardening (e.g. dig, mow)	4 (2.25-4.75)	3 (1-5)	5 (3-5)	4 (3-5)	4 (3.5-4.5)	4 (4-5)	3.5 (2.75-5)	4 (3-5)
4.	Climb ladders	4 (3.25-5)	4 (2-5)	5 (3.5-5)	3 (3-5)	4 (3.5-4.5)	4 (3-5)	4.5 (3.5-5)	4 (3-5)
5.	Clean the car (inside and out)	4 (1-4)	3 (1-4.5)	3.5 (1.75-5)	3 (3-4.25)	4 (3-4)	4 (3-5)	3.5 (2.75-5)	4 (3-4)
6.	Do household repairs	4 (2.25-4.75)	3 (3-5)	3.5 (1.75-5)	3 (3-5)	4 (3-4)	4 (3-4)	3.5 (2.75-4.25)	4 (3-5)
7.	Car maintenance (eg oil, water)	4 (2-4)	3 (1.25-5)	3 (1.75-5)	3 (3-3.5)	3 (3-5)	4 (3-4)	3.5 (2.75-4.25)	3 (2.5-4)

Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
13 Caring					(- <i>y</i>	、	(- <i>)</i>	(-)
1. Feed a child, prepare bottles	4 (2-4)	3.5 (3-4.25)	3.5 (2.75-5)	4.5 (3-5)	4 (4-5)	4 (4-5)	3.5 (2.75-5)	4 (3-5)
2. Bathe a child/ change nappies	4 (4-4)	3.5 (3-4.25)	4 (2.5-5)	4.5 (3.75-5)	4 (4-5)	4 (4-5)	4 (2-5)	4 (3-5)
3. Dress a child	4 (3-4)	3.5 (3-4.25)	4 (2.5-5)	4.5 (3.75-5)	4 (4-5)	4 (4-5)	4 (2.75-5)	4 (3-5)
4. Do a child's hair	4 (1-4)	3 (3-4.25)	3.5 (2.5-5)	4 (2.5-5)	4 (3-5)	4 (4-5)	3.5 (2.7525)	4 (3-4)
5. Use children's equipment (e.g. high chair, push chair, car seat)	4 (4-4)	3 (3-4.25)	4 (2.5-5)	4 (3.75-5)	4 (4-5)	4 (4-5)	4.5 (2.75-5)	4 (3-5)
 Put a child in/ out of high chair, pus chair, high seat 	h 4 (2-4)	3 (3-4.25)	4.5 (2.5-5)	4.5 (3.75-5)	4 (4-5)	4 (4-5)	4.5 (2.75-5)	4 (3-5)
7. Lift and carry a child	4 (3-4)	3 (2.75- 4.25)	5 (2.5-5)	5 (3.75-5)	4 (4-5)	4 (4-5)	4.5 (3-5)	4 (3-5)
8. Play with children	4 (3-4)	3 (3-4.25)	4 (2.5-5)	4 (3-5)	4 (3.5-4.5)	4 (4-4)	4.5 (2.75-5)	4 (3-4)
9. Care for others (e.g. elderly relatives)	4 (3.25-4.75)	3 (3-4)	5 (1.75-5)	5 (4-5)	4 (4-5)	4 (4-5)	4 (3.5-5)	4 (3-5)

	Domain and Items	AS (n=12)	OA N=11	SLE (n=10)	SS (n=10)	CP (n=10)	CULMD (n=11)	PSS (n=6)	Total (n=70)
<u>14.Hobbies, Leisure & Social</u> <u>Activities</u>		(=.)		((((=)	(0)	(
1.	Crafts (e.g. knitting, crochet, sewing, embroidery, model making)	4 (3-5)	3 (2-5)	4 (1-5)	4.5 (2.5-5)	4 (2.5-4)	4 (4-5)	4 (3-5)	4 (3-5)
2.	Do-It-Yourself (e.g. using tools, painting and decorating)	3.5 (3-4)	3.5 (2-4.25)	3.5 (1.75- 4.25)	4.5 (3-5)	4 (3-4.5)	4 (4-5)	3.5 (2.75-5)	4 (3-5)
3.	Visit friends/ socialising	4 (3.25-5)	4 (3-5)	3.5 (1-5)	4 (2.5-5)	4 (3-4.5)	4 (3-4)	4.5 (4-5)	4 (3-5)
4.	Attend community / religious groups or classes	4 (1.5-4)	3 (1.75- 4.25)	3.5 (1-5)	4 (2.5-5)	4 (2.5-5)	4 (3-4)	4.5 (3-5)	4 (3-4)
5.	Physical activities (e.g. dance, active sports, swimming)	4 (3-5)	3 (3-5)	4 (1-5)	4.5 (2.5-5)	4 (3.5-5)	4 (3-5)	4 (3.75-5)	4 (3-5)
6.	Quiet recreation (e.g. painting, cards)	4 (3-5)	3 (2-4)	2.5 (1-4.25)	4 (2.5-5)	4 (2.5-4)	4 (4-5)	4 (3-4.25)	4 (3-4.5)
7.	Performing arts (e.g. music, choir, dramatics)	4 (2-4)	2.5 (1-4)	3 (1-4.25)	4 (2.5-5)	3 (3-4)	4 (4-4)	4 (3-4.25)	4 (3-4)
8.	Pet care (e.g. feed, groom)	3.5 (2-4)	3 (1-4)	3.5 (1-4.25)	4 (2.5-5)	4 (2.5-4.5)	4 (4-5)	4 (2.75-5)	4 (2.5-4)
9.	Take dog for a walk (e.g. hold leash)	4 (1-4)	3 (14.25)	4 (2.5-5)	4 (3-5)	4 (3.5-5)	4 (4-5)	4 (2.75-5)	4 (3-5)

Key: items in **bold** = scored <3; potentially considered for deletion

Table 4: EDAQ part 2 content linked to Activities and Participation components of ICF Core Sets for ankylosing spondylitis, osteoarthritis, chronic widespread pain, low back pain and musculoskeletal conditions for post-acute care.

ICF Code	ICF Category title	AS	OA	CWP	LBP	MSC
d155	Acquiring skills				_	Х
d160	Focusing attention			Х		
d175	Solving problems			Х		
d177	Making decisions					Х
d220	Undertaking multiple tasks		_	Х		
d230	Carrying out daily routine	Х		Х		Х
d240	Handling stress and other psychological	Х		Х	Х	Х
	demands					
d310	Communicating with – receiving – spoken					Х
	messages					
d410	Changing basic body position	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
d415	Maintaining a basic body position	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
d420	Transferring oneself				\checkmark	\checkmark
d430	Lifting and carrying objects	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
d440	Fine hand use		√			√
d445	Hand and arm use		√		✓	√
d450	Walking	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
d455	Moving around	\checkmark	\checkmark	\checkmark	✓	
d460	Moving around in different locations				√	√
d465	Moving around using equipment	<i>.</i>	,	,	√	✓
d470	Using transportation	√	√	√	√	
d475	Driving	√	√	√	√	,
d510	Washing oneself	√	\checkmark	\checkmark	\checkmark	√
d520	Caring for body parts	√				√
d530	Toileting	√	√		√	√
d540	Dressing	✓	✓	✓	✓	√
d550	Eating					√
d560	Drinking					✓
d570	Looking after one's health	X		X	X	Х
d620	Acquisition of goods and services	✓	✓	✓	√	
d630	Preparing meals		1	1	v	
d640	Doing housework	V	V	√	v	
d650	Caring for household objects		1	V	v	
d660	Assisting others	V	V	V	✓	
d/10	Basic interpersonal interactions				Х	
d/20	Complex Interpersonal Interactions			X		
d/60	Family relationships	X		X	X	Х
	Intimate relationships	X	Х	X	X	
0845 d850	Acquiring, keeping and terminating a job	X		X	X	
0000	Nen remunerative employment		v	V V	v	
0000	Non-remunerative employment			v		
0009	unspecified				X	
d870	Economic self-sufficiency	Х				
d910	Community Life	\checkmark	\checkmark	\checkmark	\checkmark	
d920	Recreation and Leisure	\checkmark	\checkmark	\checkmark	\checkmark	
	Total no. EDAQ items in Core Set	16	18	17	22	15
	Total no. items in Core Set	23	19	27	29	22
	Percentage EDAQ items included	69%	95%	63%	76%	68%

Key: AS = ankylosing spondylitis; OA= osteoarthritis; CWP= chronic widespread pain; LBP= low back pain; MSC = musculoskeletal conditions for post-acute care; shaded boxes = ICF category is part of conditions' Core Set; * = item included in Part 1; \checkmark /x = activity in/not in EDAQ Part 2.