Validation of the educational needs assessment tool as a generic instrument for rheumatic diseases in 7 European countries

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ABSTRACT

Objectives To validate the educational needs assessment tool (The ENAT) as a generic tool for assessing the educational needs of patients with rheumatic diseases in European Countries.

Methods A convenience sample of patients from seven European countries was included, comprising the following diagnostic groups: ankylosing spondylitis (AS), psoriatic arthritis (PsA), systemic sclerosis (SSc), systemic lupus erythematosus (SLE), osteoarthritis (OA) and fibromyalgia syndrome (FMS). Translated versions of the ENAT were completed through surveys in each country. Rasch analysis was used to assess the construct validity of the adapted ENATs including differential item functioning by culture (cross-cultural DIF). Initially, the data from each country and diagnostic group were fitted to the Rasch model separately, and then the pooled data from each diagnostic group.

Results The sample comprised 3015 patients, the majority, 1996 (66.2%) were women. Patient characteristics (stratified by diagnostic group) were comparable across countries except the educational background, which was variable. In most occasions, the 39-item ENAT deviated significantly from the Rasch model expectations (item-trait interaction χ^2 $p<0.05$). After correction for local dependency (grouping the items into seven domains and analysing them as "testlets"), fit to the model was satisfied (item-trait interaction χ^2 $p>0.18$) in all pooled disease group datasets except OA ($\chi^2=99.91$; $p=0.002$). The internal consistency in each group was high (Person Separation Index above 0.90). There was no significant DIF by person characteristics. Cross-cultural DIF was found in some items, which required adjustments. Subsequently, interval-level scales were calibrated, to enable transformation of ENAT scores when required.

Conclusions The adapted ENAT is a valid tool with high internal consistency, providing accurate estimation of the educational needs of people with rheumatic diseases. Cross-cultural comparison of educational needs is now possible.

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Introduction

Patient education should be an integral part of the management of rheumatic diseases.[1-4] It is an interactive process between patients and health care professionals aimed at enabling patients to participate actively in their health care, strengthen their ability to manage symptoms and treatment, improve coping strategies and increase self-care abilities.[5-7] It is important for health professionals to assess patient's experiential knowledge about arthritis, their own expectations, educational needs and priorities before providing education. This will help to tailor education to individual needs, and promote shared decision-making, which are important in helping patients to manage their illness and maintain quality of life.[8-10]

The educational needs assessment tool (ENAT) is a self-completed questionnaire, which allows patients with arthritis to prioritise their educational needs. If completed immediately before the consultation, the health professional is able to provide education based on the patient's immediate priorities.[11] It was developed by people with arthritis and their practitioners in the UK, and comprises 39 items grouped into seven domains: managing pain (six items), movement (five items), feelings (four items), disease process (seven items), treatments (seven items), self-help measures (six items) and support systems (four items). Items are completed by the use of Likert scales ranging from 1 - 'not important at all' to 5 - 'extremely important'. Early research found the ENAT to be acceptable to patients, easy to complete and having good test-retest reliability.[11] The ENAT was further validated using Rasch analysis where it demonstrated a good fit to the Rasch model indicating a good construct validity and invariance to gender, age, disease duration and educational background.[12] In order to extend its use to European countries and allow multinational comparison of educational needs of people with rheumatoid arthritis (RA), the ENAT was adapted for use in six other European countries; (Finland, The Netherlands, Norway, Portugal, Spain and Sweden) and was found to have cross-cultural validity and invariance with some adjustments required for The Netherlands.[13] Since the ENAT was intended to be a generic measure across rheumatic diseases, further work was undertaken in the UK to validate it in other major rheumatic diseases, that is ankylosing spondylitis (AS), psoriatic

arthritis (PsA), systemic sclerosis (SSc), systemic lupus erythematosus (SLE), osteoarthritis (OA) and fibromyalgia syndrome (FMS).[14] The aim of this study was to validate the ENAT as a generic tool with which to assess the educational needs of patients with rheumatic diseases in seven European countries.

Methods

Study design and patients

This was a multicentre European collaborative study, funded by a research grant from European League Against Rheumatism (EULAR grant reference HPR011). It followed a cross-sectional survey design, requiring patient completion of the translated versions of the ENAT on one occasion and testing its cross-cultural validity using Rasch analysis. The study was led from the University of Leeds (UK) and involved seven European countries; Austria, Finland, The Netherlands, Norway, Portugal, Spain and Sweden. The methods were set out a priori in the study protocol (unpublished), and all collaborating centres obtained ethical approvals from their respective countries before undertaking the study.

Convenience sampling was used to recruit patients from rheumatology outpatient clinics, day units, in-patient wards, databases, rehabilitation centres and/or from the community in the collaborating countries. The inclusion criteria were: (i) positive diagnosis of the target diseases (AS, PsA, SSc, SLE, OA or FMS) (ii) aged 18 years or above and (iii) willingness and ability to complete and return a questionnaire. The exclusion criteria were (i) inability to complete the ENAT unaided, (ii) having more than one form of rheumatic disease and (iii) having mental impairment.

Measures

The cross-cultural adaptation of the original (English) ENAT into the respective European languages was previously undertaken in RA,[13] using an established process for cross-cultural adaptation of self-report measures.[15] The process involved five steps: (1) forward translation - from English into the target language, (2) synthesis of the translations; (3) back (blind) translation into the original (English)

language; (4) expert committee review which decided on equivalence between the source and target versions; and (5) test of the pre-final version - testing the "adapted" version with 30 patients. Due to inclusion of different diagnostic groups in the present study, it was agreed in the set-up meeting, to use the term 'rheumatic disease' for inflammatory arthritis and connective tissue disease groups, and keep 'arthritis' for people with OA. However, in other countries such as Portugal and Spain, the term "rheumatic disease" was used for all diseases, including OA. This is because in those countries the term "arthritis" implies the presence on synovitis/effusion; and OA is also a rheumatic disease and recognised by patients and health care professionals as such (albeit degenerative rather than inflammatory).

The translated versions of the ENAT were given to patients in their respective countries to complete as postal surveys or before their clinic consultations or at the beginning of their rehabilitation programme. The ENATs were anonymous but contained patients' demographical data such as gender, age, educational background and self-reported disease duration. Once completed, the ENATs were sent by post to the University of Leeds for analysis. The ENAT data were then entered into a database (IBM SPSS, version 19)[16] and were subjected into Rasch analysis using RUMM2020[17] software.

Data analysis

Rasch analysis is a mathematical modelling technique used to assess properties of outcome measures against a measurement model developed by the Danish mathematician Georg Rasch.[18] The Rasch model provides a formal representation of fundamental measurement, and in Rasch analysis the observed data from questionnaires are measured against the Rasch model to assess how well they 'fit' the model. Fit to the model implies a criterion-related construct validity, reliability and statistical sufficiency.[19-21] Further details of Rasch Analysis tests of fit are published elsewhere.[22]

All ENAT items were assessed individually and collectively for fit to the model, testing for the assumption of local independence of items and the overall fit. Local independence means that items that fit the Rasch model are expected to be independent of each other, that is, there should not be

any correlation between two items after the effect of the underlying construct is conditioned out.[23] In the analysis, the items that were found to be locally dependent (a correlation of ±0.3 being the threshold for local dependency)[24] were combined into a subtest and treated as a 'testlet', which is defined as a subset of items that is treated as a measurement unit in test construction, administration and/or scoring.[25]

The data from each diagnostic group from each country were tested for the overall fit to the Rasch model and differential item functioning (DIF) by gender, age, disease duration and educational background. DIF occurs when two groups of equal ability levels are not equally able to correctly answer an item. If the factor leading to DIF is not part of the construct being tested, then the item is biased, that is, observed scores should depend only on latent construct scores, and not on group membership or occasion.[26-29] It is important to identify the biased items, so that adjustments can be made, which may sometimes involve discarding the item.[29] To allow for group comparisons, age and disease duration, which are continuous data, were converted into categorical data by splitting at the medians. Educational background was simply categorised as: those with only compulsory (basic) education and those with further education. Group comparisons tested the assumption of invariance (absence of DIF) of the ENAT across all patient subgroups, that is age groups, gender, disease duration and educational background. Following country-specific analyses, the data was pooled in each disease group and fit to the Rasch model was assessed. The pooled data were additionally tested for DIF by culture (cross-cultural bias). Where cross-cultural DIF was found, a post-hoc (Tukey test) was performed to assess where the significant difference lies, and the biased items were adjusted for the using the method described by Tennant et al[29] and Brodersen et al.[28]

The overall fit statistics are reported as χ^2 probability, where p-value is expected to be non-significant for adequate fit to the model. In most analyses, the *p*-values were Bonferroni-adjusted to the αlevel (ie, p = 0.05/number of tests carried out), to avoid type I errors due to multiple testing.[30] Reliability is reported as Person Separation Index (PSI), which estimates the internal consistency of

the scale equivalent to Cronbach's α, only using the logit value as opposed to the raw score in the same formulae. A minimum value of 0.7 is required for group use and 0.85 for individual use.[22]

Following fit to the Rasch model, the test of strict unidimensionality of the ENAT was conducted using the t-test method suggested by Smith,[31] where unidimensionality is confirmed if less than 5% of independent t-tests on the latent estimates derived from two independent sets of items lie outside the ±1.96 range. The ENATs were then calibrated into an interval-level scale to allow for Rasch-transformation of the ordinal data into interval level data when required.[32]

Results

A total of 3219 patients were recruited in this study. In all, 74 patients with undifferentiated spondyloarthropathy from Sweden and 130 with RA from Austria were excluded from the analysis, as these diagnostic groups were not included in the protocol. This meant that data from 3015 patients were analysed. Patient characteristics (stratified by diagnostic group) were comparable across countries except for educational background, which was variable. **Table 1** summarises the country-specific gender distribution, mean age, disease duration, educational background and the availability of data in each diagnostic group.

Table 1 Sample characteristics by country

Country	*Gender*	*Age*	*Disease duration*	*Educational background*	*Diagnostic groups*						
	Female (%)	**Mean (SD)**	**Mean (SD)**	**Only basic education (%)**	**AS**	**PsA**	**SSc**	**SLE**	**OA**	**FMS**	**Sample size (N)**
Austria	96 (55.8)	55.3 (11.1)	12.5 (10.6)	86 (51.5)	-	125	-	-	47	-	172
Finland	368 (82.1)	53.2 (12.1)	12.2 (10.3)	115 (24.6)	84	86	171	-	-	108	449
The Netherlands	368 (69.0)	53.3 (15.1)	13.8 (11.9)	37 (6.7)	85	112	103	126	126	-	552
Norway	398 (68.9)	51.9 (12.0)	10.6 (9.9)	143 (24.4)	146	147	-	-	149	144	586
Portugal	362 (64.0)	50.8 (15.3)	13.0 (10.1)	228 (42.1)	121	132	28	146	88	53	568
Spain	321 (63.8)	48.2 (13.8)	12.6 (9.8)	180 (37.0)	141	124	59	99	23	57	503
Sweden	83 (44.9)	55.8 (12.5)	21.0 (12.1)	55 (29.7)	102	83	-	-	-	-	185
Pooled	1996 (66.2)	52.6 (13.1)	13.7 (10.7)	844.0 (28.0%)	679	809	361	371	433	362	3015

AS,Ankylosing spondylitis; FMS, fibromyalgia syndrome; OA, Osteoarthritis; PsA, Psoriatic arthritis; SLE, Systemic lupus erythematosus; SSc, Systemic sclerosis.

The data from each diagnostic group and country were fitted to the Rasch model separately **(Table 2)** and then they were pooled into diagnostic group datasets **(Table 3).** In most diagnostic groups (AS, PsA, SSc and SLE), the five response categories (Likert scales) were found to work as expected. The

preliminary analysis of the individual 39 items resulted in significant deviation from the Rasch model, that is, the p values of the χ^2 interaction were significant in all disease groups (**Table 2: Analysis 1**). Lack of fit to the model was caused by significant correlations of items within each domains (a residual correlation of ±0.3 being the threshold for local dependency).[24] Correction for local dependency involved grouping the 39 items into their respective seven domains (ie, pain, movement, feelings, disease process, treatments, self-help and support) and scoring the ENAT as a 'seven-testlet' scale. Fit to the Rasch model was achieved in all country–specific data following correction for local dependency with the exception of the OA disease group from Portugal. In all country-specific datasets, the internal consistency was high (PSI>0.88 - PSI of 0.7 is required for group use) (**Table 2: Analysis 2**). These results mean that the domain (subscale) scores of the ENAT can be summed up to give a total score.

Table 2 Country-specific results of Rasch analysis

			Item Fit Residual		**Person Fit Residual**		**Chi Square Interaction**				**Proportion of significant (95% CI)**
		Analysis	**Mean**	**SD**	**Mean**	**SD**	**Value (df)**	**p**	PSI	N	
Norway	AS	Analysis 1	0.315	1.643	-0.238	1.186	163.045 (78)	0.001	0.97	142	
		Analysis 2	0.189	0.87	-0.322	1.131	12.005 (14)	0.606	0.947	142	0.085 (0.049, 0.120)
Finland	AS	Analysis 1	0.418	1.197	-0.214	2.136	38.262 (39)	0.503	0.969	85	
		Analysis 2	0.421	0.612	-0.237	1.102	8.780 (7)	0.269	0.927	85	0.094 (0.048, 0.140)
Sweden	AS	Analysis 1	0.379	0.991	-0.25	2.136	121.031 (78)	0.001	0.901	102	
		Analysis 2	0.38	0.624	-0.277	1.19	6.818 (7)	0.448	0.623	102	0.040 (-0.003, 0.082)
The Netherlands	AS	Analysis 1	0.355	1.362	-0.261	2.208	50.328 (39)	0.106	0.978	82	
		Analysis 2	0.481	0.998	-0.25	1.167	4.281 (7)	0.747	0.947	82	0.123 (0.076, 0.171)
Portugal	AS	Analysis 1	0.421	1.353	-0.662	2.946	54.546 (39)	0.502	0.966	121	
		Analysis 2	0.372	0.291	-0.364	1.205	6.021 (7)	0.537	0.902	121	0.057 (0.019, 0.097)
Spain	AS	Analysis 1	0.277	1.947	-0.289	2.199	184.606 (78)	0.001	0.976	129	
		Analysis 2	0.301	1.116	-0.345	1.175	12.970 (14)	0.529	0.953	128	0.070 (0.033, 0.108)
Austria	PsA	Analysis 1	0.286	1.147	-0.382	2.041	97.313 (78)	0.068	0.967	123	
		Analysis 2	0.611	1.021	-0.363	1.284	11.541 (14)	0.643	0.931	119	0.076 (0.036, 0.115)
Norway	PsA	Analysis 1	0.379	1.258	-0.08	1.671	156.851 (78)	<0.001	0.969	142	
		Analysis 2	0.442	0.654	-0.237	1.023	10.012 (14)	0.761	0.933	142	0.056 (0.021, 0.093)
Finland	PsA	Analysis 1	0.297	1.121	-0.159	2.032	55.614 (39)	0.041	0.977	82	
		Analysis 2	0.138	0.88	-0.256	1.041	6.044 (7)	0.535	0.954	82	0.061 (0.014, 0.108)
Sweden	PsA	Analysis 1	0.432	1.003	-0.269	2.169	51.271 (39)	0.09	0.96	82	
		Analysis 2	0.519	0.617	-0.39	1.281	10.698 (7)	0.152	0.91	82	0.074 (0.027, 0.122)
The	PsA	Analysis 1	0.609	1.708	-0.233	2.301	77.078 (39)	<0.001	0.974	110	

Netherlands		Analysis 2	0.805	1.316	-0.255	1.181	6.117 (7)	0.526	0.936	108	0.093 (0.051, 0.134)
Portugal	PsA	Analysis 1	0.379	1.862	-0.679	2.986	162.025 (78)	<0.001	0.983	126	
		Analysis 2	0.438	1.119	-0.499	1.357	12.743 (14)	0.547	0.959	126	0.065 (0.026, 0.103)
Spain	PsA	Analysis 1	0.544	1.761	-0.169	2.166	90.500 (39)	<0.001	0.974	115	
		Analysis 2	0.44	1.154	-0.301	1.125	5.473 (7)	0.602	0.954	114	0.070 (0.030, 0110)
Finland	SSc	Analysis 1	0.532	1.596	-0.476	2.613	126.607 (78)	<0.001	0.969	167	
		Analysis 2	0.297	0.897	-0.427	1.32	17.624 (14)	0.224	0.929	167	0.083 (0.051, 0.117)
The Netherlands	SSc	Analysis 1	0.453	1.59	-0.188	2.154	89.627 (39)	<0.001	0.978	99	
		Analysis 2	0.836	0.745	-0.248	1.248	6.862 (7)	0.443	0.951	99	0.040 (-0.003, 0.083)
Portugal	SSc	Analysis 1	0.38	0.798	0.055	1.999	22.310 (39)	0.985	0.977	28	
		Analysis 2	0.645	0.529	-0.011	0.975	3.037 (7)	0.882	0.938	28	0.107 (0.026, 0.188)
Spain	SSc	Analysis 1	0.291	1.146	-0.052	1.748	52.626 (39)	0.071	0.98	39	
		Analysis 2	0.475	0.859	-0.057	0.881	4.891 (7)	0.673	0.969	39	0.051 (-0.017, 0.120)
The Netherlands	SLE	Analysis 1	0.511	1.818	-0.329	2.626	112.920 (39)	<0.001	0.970	123	
		Analysis 2	0.397	1.176	-0.346	1.244	5.862 (7)	0.556	0.939	123	0.059 (0.020, 0.098)
Portugal	SLE	Analysis 1	0.182	1.264	-0.426	2.405	164.349 (78)	<0.001	0.973	142	
		Analysis 2	0.416	0.957	-0.423	1.317	11.591 (14)	0.639	0.936	142	0.049 (0.013, 0.085)
Spain	SLE	Analysis 1	0.508	1.542	-0.020	1.700	104.037 (39)	<0.001	0.964	95	
		Analysis 2	0.494	0.651	-0.233	1.053	19.581	0.144	0.933	95	0.055 (0.010, 0.100)
Finland	FMS	Analysis 1	0.262	1.401	-0.192	1.824	57.954 (39)	0.026	0.969	105	
		Analysis 2	0.324	0.879	-0.171	0.953	3.438 (7)	0.842	0.936	105	0.059 (0.017, 0.101)
Norway	FMS	Analysis 1	0.267	1.612	-0.107	1.529	126.819 (78)	<0.001	0.96	133	
		Analysis 2	0.222	0.736	-0.257	1.009	12.144 (14)	0.595	0.928	133	0.045 (0.008, 0.082)
Portugal	FMS	Analysis 1	0.527	0.725	-0.227	2.635	73.211 (39)	<0.001	0.99	41	
		Analysis 2	0.687	0.589	-0.128	1.201	7.339 (7)	0.394	0.984	41	0.073 (0.006, 0.140)
Spain	FMS	Analysis 1	0.388	1.518	0.166	1.548	120.972 (39)	<0.001	0.971	50	
		Analysis 2	0.195	0.640	-0.105	0.706	8.157 (7)	0.319	0.946	50	0.040 (-0.020, 0.100)
Austria OA	OA	Analysis 1	0.147	0.827	-0.122	1.794	61.360 (39)	0.013	0.951	47	
		Analysis 2	0.55	1.136	-0.224	1.141	12.759 (7)	0.078	0.886	47	0.085 (0.023, 0147)
The Netherlands	OA	Analysis 1	0.431	1.497	-0.257	2.42	333.770 (273)	0.007	0.976	121	
		Analysis 2	0.294	0.784	-0.284	1.154	5.692 (7)	0.576	0.947	121	0.041 (0.003, 0.081)
Norway	OA	Analysis 1	0.227	1.489	-0.255	1.72	113.076 (78)	0.006	0.97	138	
		Analysis 2	0.395	0.811	-0.296	1.103	16.310 (14)	0.295	0.947	138	0.044 (0.007, 0.081)
Portugal	OA	Analysis 1	-0.427	1.832	-1.885	3.593	78.487 (39)	<0.001	0.992	77	
		Analysis 2	0.493	1.710	-0.452	1.350	14.765 (7)	0.039	0.987	77	0.064 (0.016, 0.114)
Spain	OA	Analysis 1	0.284	0.8	0.143	2.329	70.762	0.001	0.95	23	
		Analysis 2	0.272	0.543	-0.121	0.967	7.426 (7)	0.386	0.89	23	0.130 (0.041, 0.220)
Expected values for a perfect model fit			**0**	**1**	**0**	**1**		**> 0.05**	**> 0.70**		**Lower-bound CI <0.05**

Analysis 1=Rasch analysis of the ENAT as a 39-item scale; Analysis 2=Rasch analysis of the ENAT as a 7-domain scale. AS,Ankylosing spondylitis; DF, degrees of freedom, ENAT, educational needs assessment tool; FMS, fibromyalgia syndrome; OA, Osteoarthritis; P, χ^2 probability, (significant p, item misfit); PsA, Psoriatic arthritis; PSI, Person Separation Index; SLE, Systemic lupus erythematosus; SSc, Systemic sclerosis.

In each pooled (diagnostic-specific) data, fit to Rasch model was also satisfied, with the exception of the OA dataset **(Table 3)**. In all pooled analyses, person separation index (PSI) was greater than 0.93 indicating an excellent reliability (internal consistency) for both group and individual uses. Strict unidimensionality of the overall scale was confirmed in all disease groups except in the AS and PsA diagnostic groups in which the proportions of significant t-tests (95%CI) were 0.074 (0.058, 0.092) and 0.071 (0.056, 0.086) respectively, indicating a small degree of multidimensionality. Post-hoc analyses that followed later (**Table 4**), suggested this to be caused by cross-cultural DIF.

Table 3 Diagnostic group (pooled datasets) results of Rasch analysis

Diagnostic group		Item Fit Residual		Person Fit Residual		Chi Square Interaction		PSI	N	Proportion of significant T-Tests (95% CI)
	Analysis	Mean	SD	Mean	SD	Value (df)	p			
Pooled AS	Analysis 1	0.563	2.959	-0.557	2.584	683.931 (351)	<0.001	0.972	661	
	Analysis 2	0.314	0.905	-0.493	1.347	72.674 (63)	0.189	0.938	660	0.074 (0.058, 0.092)
Pooled PsA	Analysis 1	0.957	3.096	-0.499	2.517	787.691 (351)	<0.001	0.975	780	
	Analysis 2	0.575	1.218	-0.445	1.279	70.460 (63)	0.242	0.944	777	0.071 (0.056, 0.086)
Pooled SSc	Analysis 1	0.699	2.232	-0.532	2.634	527.415 (351)	<0.001	0.976	333	
	Analysis 2	0.664	1.270	-0.384	1.262	43.006 (35)	0.166	0.949	333	0.051 (0.026, 0.074)
Pooled SLE	Analysis 1	0.560	2.559	-0.497	2.551	476.407 (234)	<0.001	0.969	360	
	Analysis 2	0.514	1.166	-0.421	1.298	39.817 (42)	0.567	0.932	358	0.051 (0.028, 0.074)
Pooled FMS	Analysis 1	0.607	2.482	-0.251	1.972	450.441 (273)	<0.001	0.972	329	
	Analysis 2	0.378	0.986	-0.257	1.016	47.060 (42)	0.273	0.950	329	0.025 (0.001, 0.048)
Pooled OA	Analysis 1	0.775	2.689	-0.701	3.022	709.905 (351)	<0.001	0.976	430	
	Analysis 2	0.406	1.845	-0.434	1.273	99.906 (63)	0.002	0.950	429	Misfit
Expected values for a perfect model fit		**0**	**1**	**0**	**1**		**> 0.05**	**> 0.70**		**Lower-bound CI <0.05**

Analysis 1=Rasch analysis of the ENAT as a 39-item scale; Analysis 2=Rasch analysis of the ENAT as a 7-domain scale.
AS,Ankylosing spondylitis; DF, degrees of freedom, ENAT, educational needs assessment tool; FMS, fibromyalgia syndrome; OA, Osteoarthritis; P, $\chi 2$ probability, (significant p, item misfit); PsA, Psoriatic arthritis; PSI, Person Separation Index; SLE, Systemic lupus erythematosus; SSc, Systemic sclerosis

A formal assessment of invariance (DIF analysis) was performed in the diagnostic groups that satisfied the Rasch model requirements (AS, PsA, SSc, SLE and FMS). There was no significant DIF by gender, age, disease duration or educational background in the country specific datasets. This suggests that the ENAT is not biased by person characteristics. However, in the pooled datasets, DIF by culture was detected across the diagnostic groups indicating a cross-cultural bias especially in the PsA disease group (**Table 4**).

Table 4 Domains adjusted for cross-cultural DIF

	AS	*PsA*	*SSc*	*SLE*	*FMS*
Pain	X	X	S	S	S
Movements	S	S	S	X	S
Feelings	S	S	S	S	S
Disease process	S	X	S	S	S
Treatments	S	X	X	X	S
Self-help	S	X	S	S	S
Support	X	X	X	S	S

AS, Ankylosing spondylitis; DIF, differential item functioning; FMS, fibromyalgia syndrome; PsA, Psoriatic arthritis; S, cross-cultural invariance satisfied; SLE, Systemic lupus erythematosus; SSc, Systemic sclerosis; X, lack of cross-cultural invariance.

Adjustments were made in the biased items to account for the cross-cultural DIF. This involved 'splitting' the biased item into two; where one is rendered unique for the affected country and the other for the rest of the countries. For example in the AS disease group (**Table 5)**, there are two pain testlets, one unique for Norway and the other for the rest of the countries. The unsplit (pure) items act as links in the calibration of the scale thus discounting the cross-cultural bias.[28,29] Following this adjustment, the resulting testlets were found to adequately fit the model (**Table 5**). This means that the ENAT can be used in its present form within each country without any need for adjustments. However, when data across countries are being pooled or compared, then adjustment for cross-cultural DIF will be required. We have calibrated DIF-adjusted interval-level scales for this purpose (see online supplementary tables 1-14).

Table 5 Fit statistics after adjustment for cross-cultural DIF in the affected testlets

Domain	*Testlet*	*Location*	*SE*	*Fit Residuals*	X^2	*P*
AS						
Pain	Pain-Norway	-0.15	0.03	-1.13	7.76	0.56
	Pain- Others	-0.01	0.01	0.47	14.70	0.10
Movement	Movement	0.07	0.01	-0.80	10.73	0.29
Feelings	Feelings	0.04	0.01	-0.18	16.08	0.07
Disease process	Disease process	-0.14	0.01	0.21	8.11	0.52
Treatments	Treatments	0.04	0.01	0.83	7.97	0.54
Self-Help	Self-Help	-0.10	0.01	2.04	5.59	0.78
Support	Support –The Netherlands	0.15	0.04	-0.96	7.18	0.62
	Support - Others	0.09	0.01	0.70	10.02	0.35
PsA						
Pain	Pain - Austria	-0.06	0.03	-1.07	6.73	0.46
	Pain - Norway	-0.70	0.04	0.23	6.54	0.48
	Pain – The Netherlands	0.13	0.03	-0.09	5.69	0.58
	Pain - Others	0.08	0.02	-0.57	5.65	0.58
Movement	Movement	0.20	0.01	2.51	8.28	0.31
Feelings	Feelings	0.16	0.01	2.45	4.09	0.77
Disease process	Disease process - Finland	-0.15	0.04	-1.93	4.71	0.70
	Disease process - Others	-0.13	0.01	-0.11	4.99	0.66
Treatments	Treatments - The Netherlands	-0.08	0.03	0.77	8.07	0.33
	Treatments- Sweden	-0.05	0.03	1.35	5.09	0.65
	Treatments - Others	0.14	0.01	-0.27	7.72	0.36
Self-Help	Self-Help - The Netherlands	-0.22	0.03	2.54	17.90	0.01
	Self-Help - Portugal	0.16	0.03	0.38	3.55	0.83
	Self-Help - Others	-0.05	0.01	0.37	9.73	0.20
Support	Support - Austria	0.49	0.03	1.37	4.74	0.69
	Support- Finland	-0.40	0.05	-0.93	6.53	0.48
	Support - Portugal	0.21	0.03	0.87	5.68	0.58
	Support - Others	0.25	0.02	0.44	8.69	0.28
SSc						
Pain	Pain	0.06	0.02	0.17	6.93	0.23
Movements	Movements	0.12	0.02	-0.99	8.34	0.14
Feelings	Feelings	0.09	0.02	1.79	3.37	0.64
Disease process	Disease process	-0.21	0.02	-0.02	10.97	0.05
Treatments	Treatments- The Netherlands	-0.06	0.03	1.96	3.50	0.62
	Treatments-Others	0.03	0.02	0.74	5.61	0.35
Self-Help	Self-Help	-0.16	0.02	0.77	4.13	0.53
Support	Support - The Netherlands	0.22	0.04	1.23	3.62	0.61
	Support - Others	-0.09	0.03	1.28	10.51	0.06
SLE						
Pain	Pain	0.01	0.02	-0.13	5.31	0.50
Movement	Movements-Spain	0.03	0.03	-0.43	4.41	0.62
	Movements - Others	0.06	0.02	0.05	2.28	0.89
Feelings	Feelings	-0.04	0.02	2.16	5.56	0.47
Disease process	Disease process	-0.18	0.01	-0.60	12.62	0.05
Treatments	Treatments - Spain	0.18	0.02	0.27	4.02	0.67
	Treatments - Others	-0.02	0.02	0.75	4.23	0.65
Self-Help	Self-Help	-0.12	0.02	0.18	6.20	0.40
Support	Support	0.08	0.02	2.05	9.22	0.16
FMS						
Pain	Pain	-0.04	0.02	0.40	5.38	0.37
Movements	Movements	-0.04	0.02	0.68	3.56	0.61
Feelings	Feelings	-0.05	0.02	0.79	3.20	0.67
Disease process	Disease process	-0.13	0.02	-1.24	6.88	0.23
Treatments	Treatments	0.28	0.02	1.96	5.52	0.36
Self-Help	Self-Help	-0.08	0.02	0.13	8.72	0.12
Support	Support - The Netherlands	0.06	0.02	-0.14	6.12	0.29

SE = Standard error, P = Bonferroni-adjusted X^2 probability, (non-significant P = Fit to the model),

Following adjustment to the cross-cultural DIF (in the AS, PsA, SSc and SLE diagnostic groups), the raw ENAT domain scores were mapped against the corresponding Rasch-transformed scores (based in logits) and were linearly transformed to calibrate interval-level, DIF-adjusted scales of the same range (see online supplementary tables 1-14). The details on the use and scoring of the ENAT are given in the online supplementary material.

Discussion

This study set out to test the cross-cultural validity of the ENAT as a generic measure of educational needs in people with AS, PsA, SSc, SLE, OA and FMS in different European countries. The results indicate that, following its adaptation; the ENAT maintained its validity in each disease group that was tested (with limitations in OA). The implications of the results in terms of clinical use and measurement aspects are set out below.

In the clinical practice, the ENAT is used as a template/checklist to assess what are the most important educational/informational needs from the patient's point of view. Patients using the ENAT have consistently found it easy to complete and effective in identifying their needs and raise questions which they would not have otherwise considered.[12,33] This information, along with the clinicians' insight of what the patient needs to know, allows the provision of timely and meaningful education tailored to the needs of each individual patient. When used in this way (for clinical purposes), the ENAT does not need scoring. However, when used as an outcome measure or for comparison of educational needs across groups, then the measurement properties of the ENAT need to be considered.

From the measurement point of view, the adapted ENAT has been shown to fit the Rasch model, a requirement for questionnaires with items that are intended to be summed together to provide a total score.[22] While the level of 'educational needs' represented by each domain may differ across disease groups, fit to the Rasch model confirms the validity of the 'educational needs' construct as measured by the ENAT in each disease group (with limitations in OA). Local dependency was the

main issue affecting measurement properties of the ENAT. Since the items within a domain are by definition related, it was not surprising to find significant item-item correlations within respective domains. This was also seen in a similar study in RA.[13] Correction for this may involve removing the redundant items or grouping all the locally-dependent items into a testlet (hence scoring them as a unit). We used the 'testlet' approach as it helps to retain the clinically relevant items, yet meeting the measurement requirements of the scale. This approach to scoring is similar to that used in other scales such as the HAQ[34] and the HADs.[35]

While the ENAT was invariant to person characteristics, some items worked differently in some countries especially in the OA and SpA disease groups. Therefore, when the data across different countries are combined/compared, adjustments will be required (cross-cultural comparisons are not possible in OA). We have calibrated interval-level scales (see online supplementary tables 1-14), which are adjusted to cross-cultural DIF, thus enabling accurate estimation of educational needs and comparison across the countries when required. Previous estimation of educational needs for people with arthritis used the ENAT ordinal measures and non-parametric methods,[33,36] which can be limiting if other outcome measures have to be taken into account in the analyses such as in linear regression models. Conversion of the ordinal measures into interval levels (Rasch-transformed values) enables the use of ENAT scores in parametric analyses,[32] alongside other measures, given adequate sample sizes and normal distribution. Recently, Rasch-transformed scores from the ENAT have been used to assess to its correlation with disease activity and disability in RA and PsA.[37]

While the ENAT remains a valid country-specific measure of education needs for people with OA, strong conclusions cannot be made about its cross-cultural validity, which warrants further research. One of the reasons for the lack of fit in this group may be the inherent heterogeneous nature of OA, where educational needs of patients with hand OA may be different from those of patients with hip or knee OA. This implies that when assessing the educational needs of people with OA, the data from different countries should not be pooled until their cross-cultural validity has been established.

This study has four main limitations. First, in most countries the data were collected from limited sources and therefore not representative of the countries involved. However, this does not affect the conclusions of this tool validation research, as this research did not set out to assess the educational needs but rather to determine the validity of the ENAT and its psychometric properties following its adaptation. Second, not all disease groups were represented in each country. Therefore the results apply only in the available disease groups. Third, being a cross-sectional study, the ENAT's stability to change has not been established. However, given the nature of needs assessment, it is difficult to establish 'stability' as the educational needs are dynamic. Lastly, due to developments in the understanding of rheumatic diseases and their management, coupled by developments in information technology, the ENAT items do not cover everything there is to know about rheumatic diseases. However the ENAT domains remain relevant in assessing patient priorities and the items are formulated in a way that is open to change. Future developments will address this limitation by creating item banking for computerised adaptive assessment. This means having more and 'dynamic' items but delivering few targeted items according to need.

The instructions of how the ENAT is used and scored, are provided in the online supplementary material, and the different versions of the ENAT can be obtained by writing to the Psychometric Laboratory at the University of Leeds (http://www.leeds.ac.uk/medicine/rehabmed/psychometric/index1.htm) or the corresponding author.

Conclusion

This study has established that the ENAT is a valid and a reliable tool, providing an accurate measure of educational needs for people with rheumatic diseases. While clinical use of the ENAT as a simple checklist does not require scoring, its interval-level scale provides estimates that can be used alongside other variables in parametric analyses. In addition, a facility is available for cross-cultural comparisons when required. Further research is required in its use in electronic formats and development as a computerised adaptive assessment.

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Contributors

JH, MN and AT designed the study. The following were local investigators: AB (Sweden), MLK (Finland), AM and PM (Portugal), JT (Spain), TPMV and JM (The Netherlands), TS (Austria), and HZ and BH (Norway). MN, AT and MH undertook the statistical analyses. MN, AT, MH and JH interpreted the results. All authors participated in the preparation of the manuscript, read and approved the final version.

Competing interests

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