



Belgian rheumatologists' preferences regarding measures of disease activity in patients with rheumatoid arthritis: results from a mixed-methods study

D. De Cock¹ · E. Buckinx¹ · S. Pazmino¹ · D. Bertrand¹ · V. Stouten¹ · R. Westhovens^{1,2} · P. Verschueren^{1,2}

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Abstract

The reliability and clinical usefulness of the different composite disease activity scores and their individual components in Rheumatoid Arthritis (RA) are still debated. This study investigated which measures of disease activity were preferred by rheumatologists. A mixed-method study was performed. First, ten Belgian rheumatologists were invited for individual interviews on their current practice and preferences for measurement of RA disease activity. Results of this qualitative study and evidence from literature served as input for developing a survey. This survey asked rheumatologists to rate preferred standard disease activity score(s), their individual components, ultrasound and related patient-reported outcomes (PROs), by maximum difference scaling. The relative importance score (RIS) for each indicator was calculated using hierarchical Bayes modeling. The qualitative study included 6/10 invited rheumatologists. Composite scores and components were perceived as useful, while PROs were found subjective. Interestingly, ultrasound was used to mediate discrepancies between physician and patient. The survey based on this was sent to 244 Belgian rheumatologists, 83/244 (34%) responded, including 66/83 (80%) complete and 17/83 (20%) incomplete surveys (two missing essential information). Most rheumatologists (75/81, 93%) used a disease activity score and 68/81 (84%) preferred the DAS28-CRP. Swollen joint count obtained the highest mean \pm SD RIS (22.54 ± 2.64), followed by DAS28 ESR/CRP (20.61 ± 4.06), ultrasound (16.47 ± 7.97), CRP (13.34 ± 6.11) and physician's global assessment (12.59 ± 7.83). PROs including fatigue, pain, and patient's global assessment, and Health Assessment Questionnaire, obtained the lowest mean RIS (0.34–2.54). Rheumatologists place more faith in self-assessed disease activity components or in laboratory tests. Trust in PROs to evaluate disease activity is low in clinical practice.

Keywords Disease activity · Disease activity components · Rheumatoid arthritis · Daily practice · Mixed methods · Survey · Maximum difference scaling

Introduction

Rheumatoid arthritis (RA) should be treated early, intensive and to-target [1]. This target is set to remission or low disease activity. The quantification of these thresholds depends on disease activity scores [2]. These composite measures

generally include a combination of laboratory, clinical and patient-reported measures. The introduction in daily practice of DAS scores for evaluation of the treatment response and as a treatment target led to more csDMARD adaptations and more patients in low disease activity [3, 4]. It is to be noted that no disease activity score is shown to be better than another to reach remission or low disease activity. Recent studies showed however that adhering too strictly to a treat-to-target strategy, could lead to over- or undertreatment [4–7].

The reliability of the composite disease activity scores is related to each component. Firstly, the laboratory markers C-Reactive protein (CRP) and erythrocyte sedimentation rate (ESR) are proxies of inflammation but are not disease-specific and dependent on patient's factors such as age, weight and gender [8], and limited by low specificity and sensitivity

D. De Cock and E. Buckinx share a first co-authorship.

✉ D. De Cock
diederik.decock@kuleuven.be

¹ Skeletal Biology and Engineering Research Centre, KU Leuven, ON IV Herestraat 49, P. O. Box 813, 3000 Leuven, Belgium

² Department of Rheumatology, University Hospitals of Leuven, 3000 Leuven, Belgium

[9]. Moreover, RA therapies, mainly IL-6 antagonists and Janus Kinase (JAK) inhibitors, directly decrease CRP levels independent from real clinical changes [10]. Secondly, clinical markers such as tender and swollen joint counts (TJC/SJC) are limited by intra-observer and inter-observer variability [11]. Finally, many evaluations also incorporate patient-reported outcomes (PROs) such as Patient Global Assessment (PGA), fatigue and pain on a numeric rating scale (NRS) or visual analog scale (VAS), and the Health Assessment Questionnaire (HAQ) score. Variations in scale formulation, the time interval inquired and other barriers in understanding questions asked by means of VAS or NRS cause intra-observer and inter-observer variability [12–16]. Each individual disease activity measure is thus associated with factors potentially contributing to a decreased accuracy, supporting that no indicator on itself can serve as “gold standard” for RA disease activity management.

Over 40 different disease activity scores for RA have been developed [2]. Rheumatologists have the liberty to choose how they evaluate disease activity in clinical practice, possibly leading to variations in treatment decisions. For example, disease activity scores based on 28-joint counts (DAS28) do not include counts of joints in the feet. Both CRP and ESR can be used to calculate a DAS28 score, and often similar cut-offs for different disease states are used. However, multiple studies confirmed that using a DAS28-CRP results in lower scores than using a DAS28-ESR [17, 18]. Additionally, there can be a discordance between patients’ and physicians’ rating of disease activity as patient and physician assess health status from a different point of view. This discrepancy can again lead to over- or underestimation of disease activity [19, 20], and could be a barrier for an optimal holistic management of patients with RA.

It is unclear on which indicators rheumatologist rely the most to evaluate a patient’s disease activity and make medical decisions in clinical practice. Therefore, this mixed-method study aims to investigate (I) which (type of) disease activity scores are used, (II) what the most valued disease activity measures are according to Belgian rheumatologists in clinical practice, and (III) if the order of most valued disease activity measures changes if there is a discrepant opinion between rheumatologist and patient.

Participants and methods

Part I: qualitative study

To construct a survey concerning preferences of rheumatologists regarding measures of disease activity, an extensive literature search and a qualitative study with semi-structured interviews of a purposive sample of Belgian rheumatologists was performed. Appendix 1 includes the full interview

guide. The three main objectives were to know (I) how a routine rheumatology consultation was performed in practice, (II) what barriers and facilitators exist regarding disease activity evaluations and (III) what happens in case of discrepancy between the opinion of patient and physician.

The rheumatologists were interviewed online, via telephone or face to face in their own practice. The whole interview was recorded and transcribed ad verbatim afterwards. In total, 10 Belgian rheumatologists were invited to participate in this first part of the study. The geographical location and variation in type of practice of the rheumatologists (private, regional hospital, university hospital) were considered. Analysis was based on the Qualitative Analysis Guide of Leuven (QUAGOL) [21].

Part II: survey

The survey was developed based on the results of the qualitative study and literature review. It consisted of three main sections. To start, the rheumatologists had to indicate their gender (male, female or other), type of rheumatology practice (private practice, university or general hospital) and the number of years of experience as a rheumatologist (0–10, 11–20 or > 20 years). Appendix 2 includes the full survey (English).

The first section consisted of three questions. First, the rheumatologists were presented a list of disease activity scores and were asked to indicate the score(s) they routinely use in their daily clinical practice. Secondly, for every indicated response option, based on a list of pre-set options, an explanation was asked. Finally, rheumatologists were asked to rank how frequently they used different types of tender and swollen joint counts in their daily practice. See supplement 2 for details.

In the next survey section, rheumatologists were asked to rank DAS28, standard components of composite scores and relevant PROs from most to least informative with respect to a patient’s disease activity state via the Maximum Difference Scaling (MDS) method provided by Sawtooth Software. This MDS method produces a relative importance score (RIS), for every factor in the survey. The higher the score, the more likely the factor was chosen as most important (and not as least important). The method uses Hierarchical Bayesian methods to estimate individual level scores by combining information from individuals’ specific choices with the distribution of scores across participants. Average RIS were calculated via iteration. To facilitate interpretation, the scores were subsequently rescaled on a scale from 0 to 100; the higher the score, the more important the factor. So, a disease activity measure with a RIS of 10 is twice more often chosen than an RIS of 5. The RIS of rheumatologists was compared by region, gender, practice type and rheumatologist’s years of experience.

In our survey, 11 different sets, each consisting of four measures selected from a list including the DAS28 score, disease activity components (TJC, SJC, ESR, CRP, PGA, PhGA), ultrasound and PROs (Pain, Fatigue, HAQ), were presented to the participants (MDS1). In the final section of the survey, the same items were presented to the respondents for ranking from most to least informative about a patient's disease activity, but this time imagining there was a discrepancy in disease activity evaluation between themselves and the patient with RA (MDS2). So, MDS 1 refers to the evaluation of disease activity components in general. MDS 2 refers to the evaluation in case of discrepancy between the patient's and physician's perception of the disease activity.

The survey was drafted in Dutch, French and English and the language could be chosen by the rheumatologists. The survey was sent by mail to all Belgian rheumatologists who were members of the Royal Belgian Society of Rheumatology. A first and a second reminder followed 2 and 4 weeks later. The survey was constructed and partly analyzed using the Sawtooth Software's SSI Web platform (version 9.8.1), for which an academic grant was acquired. Additional analyses were performed in Microsoft Excel, Statdisk and VassarStats.

When appropriate, paired and unpaired t-tests and ANOVA or Wilcoxon signed rank tests, Mann–Whitney U tests, Kruskal–Wallis and χ^2 tests were used to compare

continuous variables. Normality was assessed by the Ryan-Joiner test. All statistical tests were two-sided and evaluated at the 0.01 significance level, to correct for multiple comparisons.

Results

Qualitative study

In total, 6/10 (60%) of invited rheumatologists agreed to be interviewed. After analysis by QUAGOL, a conceptual framework (Fig. 1) emerged.

Perceptions of composite scores

The DAS28 was calculated by everyone. Other mentioned scores were the full-DAS, SDAI and CDAI. The interviewed rheumatologists really valued using scores because they thought it is a way of more objectively defining the disease activity of a patient.

“I find that easy. I find that something objective. It's in your file. ...so why don't you figure it out? That's no extra effort, is it?”

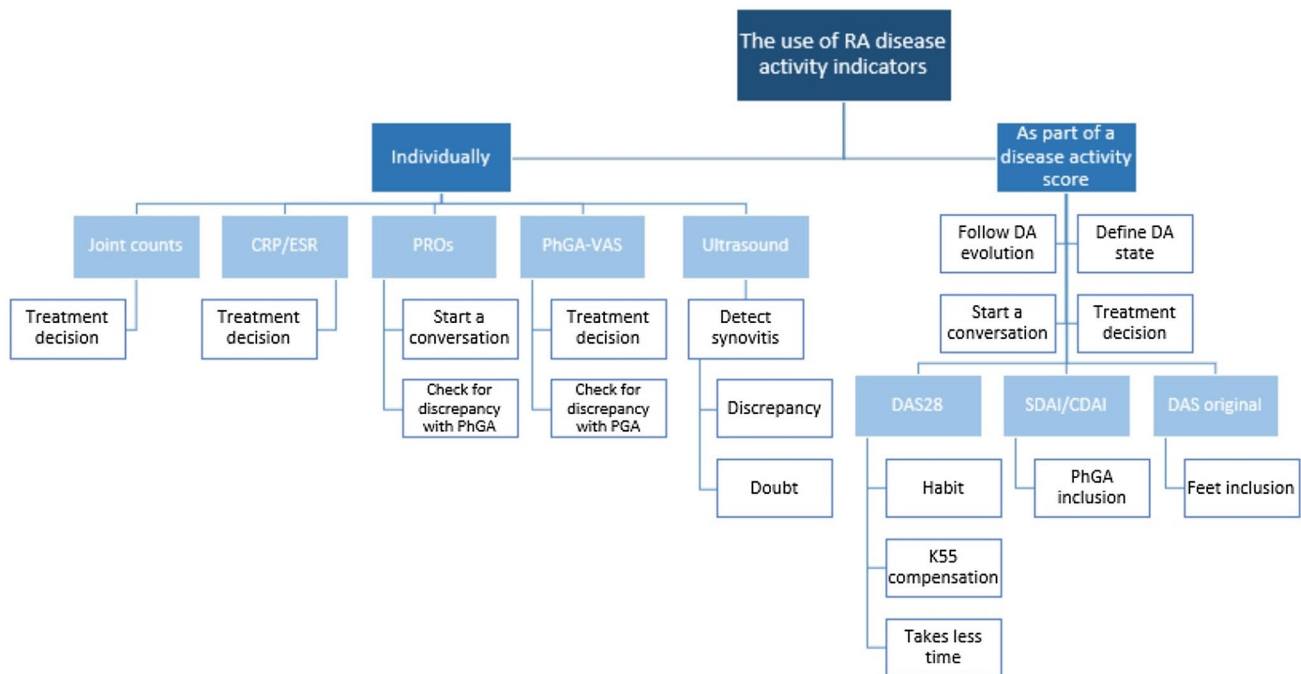


Fig. 1 Conceptual framework of the interview data. *CRP* C-Reactive Protein, *ESR* Erythrocyte Sedimentation Rate, *PROs* Patient Reported Outcomes, *PhGA-VAS* Physician's Global Assessment on a Visual Analog Scale, *PGA* Patient Global Assessment, *DA* Disease Activ-

ity, *DAS* Disease Activity Score, *DAS28* DAS using 28-joint counts, *SDAI* Simplified Disease Activity Index, *CDAI* Clinical Disease Activity Index

However, most rheumatologists emphasized several times how important it was to give the right interpretation to this disease activity score in daily practice.

“I don't think rheumatology is a discipline you can say we're going to treat a patient here purely on the basis of scores.”

Other rheumatologists preferred not using the absolute value of disease activity scores, but rather the current evaluation relative to previous evaluations.

“What I just wanted to say about that DAS, no matter how I use it, is that if you start a treatment, that often your evolution of your DAS is sometimes more important than really your starting values.”

Rheumatologists were asked to explain why they routinely calculated a specific disease activity score. The DAS28 was calculated as it was less time consuming. One rheumatologist admitted that the score was calculated out of habit. Furthermore, another rheumatologist emphasized that the financial compensation provided in Belgium was an important stimulus to calculate the DAS28, even if the reliability and validity could be debated. The SDAI and CDAI were calculated because PhGA is part of it. The original full-DAS was mentioned as preferred outcome because feet are included in the score. However, some rheumatologists reported time limitations in performing a full joint count or waiting for laboratory results before making treatment decisions.

“I used to use the original DAS, with the Ritchie articular index, but the problem was I had a lot of work on it.”

Perceptions of individual components of disease activity scores

The rheumatologists reported to evaluate disease activity in a standardized way by assessing multiple disease activity components including TJC, SJC, CRP and/or ESR, PhGA and certain PROs (mainly PGA and HAQ). In addition, some rheumatologists also evaluated pain and fatigue.

The individual components mentioned as the most reliable for evaluation of actual inflammation were joint counts, mainly the SJC, CRP and/or ESR, and PhGA.

“I give advice and at the level of treatment, treatment of the disease, it's mostly based on swollen joint count. Sometimes the CRP, but the swollen joint count is more important.”

Perceptions on additional patient-reported outcomes

Although many individual disease activity measures were assessed, the participating rheumatologists did not assign them the same weight. PROs were perceived as less precise, too subjective and dependent on underlying personal factors to evaluate disease activity accurately.

“... both VAS and HAQ, they have been validated in different RA cohorts, but they obviously cannot, I would say, avoid certain [interfering] factors. I'll take one example: if you're depressed. But you can't obviously remove depression out of the questionnaire.”

PROs were thus perceived as challenging in terms of subjectivity, language problems, misinterpretations and misconceptions. In contrast, other rheumatologists said that there are indeed some challenges to interpret PROs in terms of disease activity in clinical practice but believed that a rheumatologist should be able to see the whole picture of their patient with RA, regardless of the barrier.

“We're used to that as clinicians, I think, to interpret that a little and deal with it practically.”

Rheumatologists still underlined that assessing PROs is important. PROs promoted an open conversation between patient and rheumatologist to search for underlying problems.

“I think it's important because by asking your VAS to your patient, you let your patient think for himself. That's the same with your HAQ too. You let the patients think about their disease, about their disease activity, about what's going on and what's not.”

Perceptions on ultrasound

An interesting disease activity indicator in case of patient-rheumatologist discordance was ultrasound. This tool was used in specific situations where there was uncertainty if synovitis was present. Besides treating RA, rheumatologists indicated that it is also their task to find out what the underlying problem is and to try to solve this by providing extra support.

“I don't think you can get away with saying: your RA is good, I don't care about the rest.”

Survey

In total, 244 rheumatologists received the link to the survey. Of this total number of invited rheumatologists, 96 (39%)

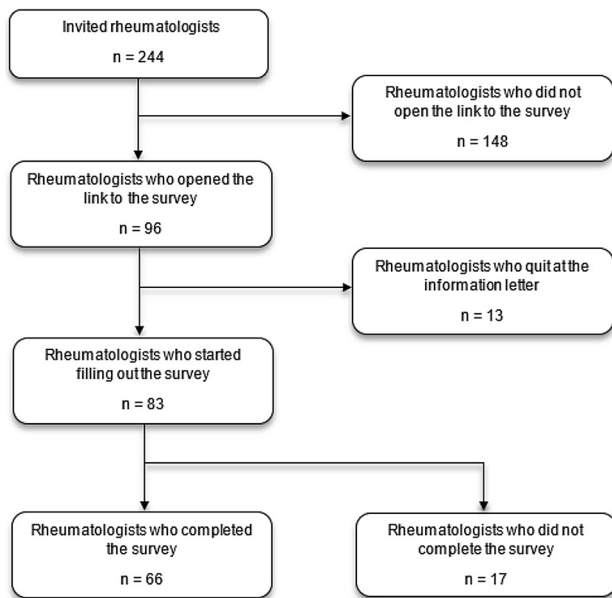


Fig. 2 Flowchart of the rheumatologists who were invited to complete the survey. Thirteen rheumatologists quit after reading the information letter, whereas 83 rheumatologists started filling out the survey. In the end, 66 complete surveys and 17 incomplete surveys were collected. Among the 17 rheumatologists who did not fully complete the survey, 2 rheumatologists quit the survey before completing the question about the disease activity scores (question 1), 8 before the joint counts part (question 2) and 7 at the Maximum Difference Scaling (MDS) method part (question 3). *N* number

Table 1 Demographic table of participating rheumatologists

Total, <i>n</i> (%)	83
Survey language, <i>n</i> (%)	
Dutch	50 (60%)
French	33 (40%)
Gender, <i>n</i> ^a (%)	
Female	44 (54%)
Type of practice, <i>n</i> ^a (%)	
Private practice	16 (20%)
University hospital	25 (30%)
General hospital	41 (50%)
Years of experience, <i>n</i> ^a (%)	
0–10 years	20 (24%)
11–20 years	11 (13%)
> 20 years	51 (62%)

n number

^aOne rheumatologist chose to not fill out the question where gender, type of practice and years of experience had to be indicated

opened the link, whereas 148 (61%) did not open the link (Fig. 2). Table 1 describes participants' demographics.

Rheumatologists' preferences

Of 81 rheumatologists, 75 (93%) reported they routinely calculated a disease activity score. The DAS28-CRP was calculated by 68/81 (84%) and the DAS28-ESR by 49/81 (60%).

Six/81 (7%) rheumatologists indicated to never calculate a disease activity score.

In general, the most indicated reason for calculating a certain disease activity score (80%) was to follow the disease activity evolution of the patient. The specific Belgian financial compensation (called K55) when assessing twice yearly DAS28 and HAQ of a patient, was indicated by over 50% of rheumatologists.

Most rheumatologists ranked the 28 TJC/SJC first, the 44 TJC/SJC second and the 68/66 TJC/SJC third for use in daily clinical practice. Detailed information on rheumatologists' preferences on the use of disease activity scores and indicators can be found in appendix 3.

Maximum difference scores

In the final survey section, 2 maximum difference scaling (MDS) exercises were performed, the 1st MDS evaluates disease activity components in general, and the 2nd MDS refers to the evaluation in case of discrepancy between the patient's and physician's perception of the disease activity. Both MDS exercises were completed by 66 rheumatologists. Figure 3 shows the scores of both MDS scenarios. Table 2 compares the RIS between both MDS exercises for each indicator. The RIS of the PGA ($p=0.0003$) and DAS28 ($p=0.0061$) were lower in case of discrepancy between the patient's and physician's perception on disease activity. In contrast, ultrasound ($p=0.0039$) and the HAQ ($p=0.0039$) obtained a higher mean RIS in case of discrepancy.

The RIS of the DAS28 was higher for female rheumatologists (21.61 versus 18.77, $p=0.0006$). The RIS for the fatigue-VAS was higher for rheumatologists working in a private practice (1.16 versus 0.01 and 0.25, $p < 0.0001$) compared to the other two types. Moreover, the RIS of the ultrasound was the lowest for rheumatologists working at a private practice (10.69 versus 17.11 and 18.19, $p=0.0093$). More experienced rheumatologists preferred more the SJC (22.54 versus 20.12 and 21.29, $p=0.0033$), CRP (16.36 versus 8.42 and 11.15, $p=0.0005$) and fatigue-VAS (0.67 versus 0.00 and 0.07, $p < 0.0001$), while they preferred less the TJC (4.53 versus 7.68 and 6.30, $p=0.0094$) compared to less experienced rheumatologists. The rheumatologists with 11–20 years of experience assigned a lower RIS to the HAQ compared to the other two groups (0.21 versus 3.97 and 1.24, $p=0.0005$).

This table compares the relative importance attributed to several disease activity components by the participating rheumatologists, either in general, or imagining there would

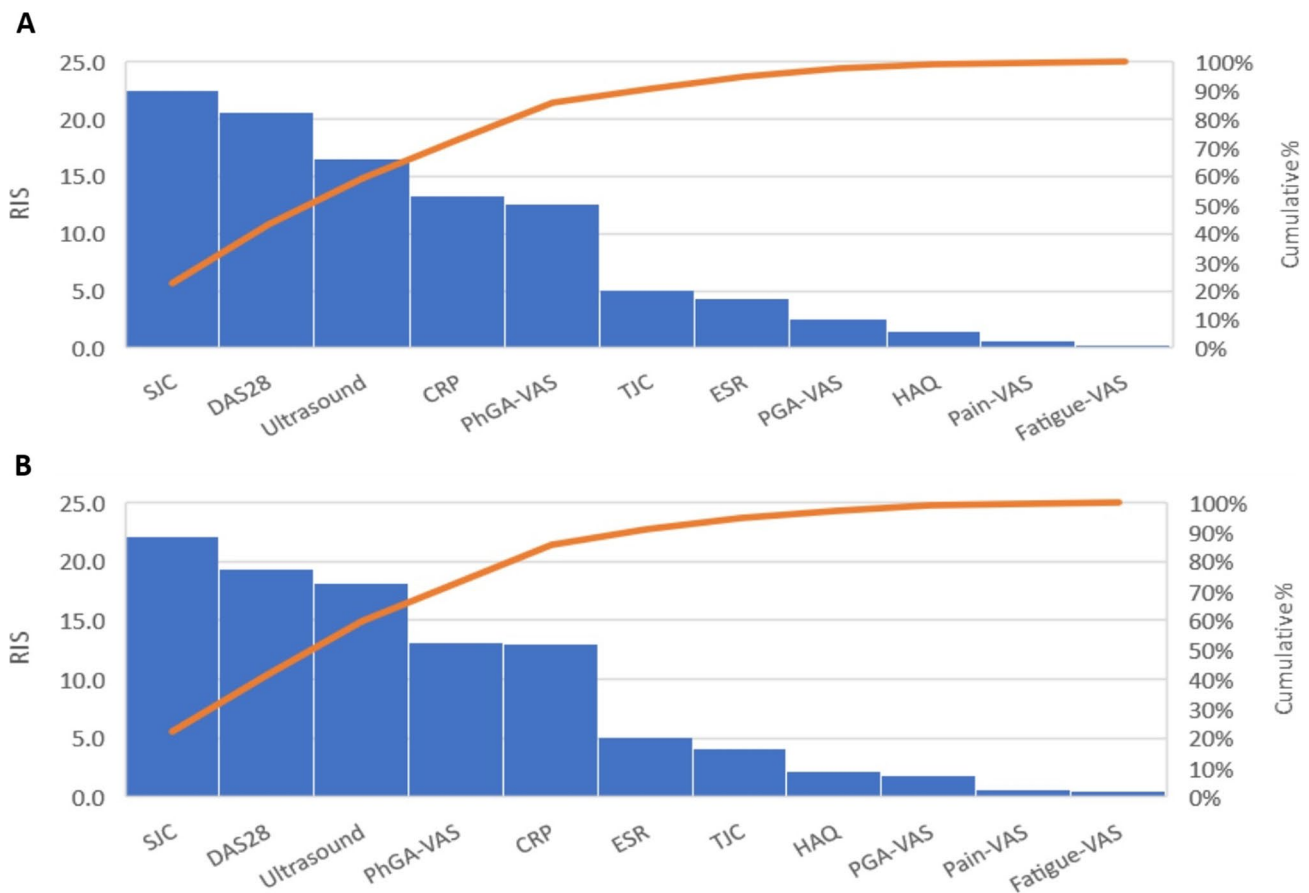


Fig. 3 The mean relative importance scores of individual disease activity components for RA using the Hierarchical Bayesian method. The preference score refers to how much information a disease activity indicator gives about a patient's disease activity in comparison to the others according to the rheumatologists (**A**) in general, and **B** in case of discrepancy between the patient's and physician's perception on the disease activity. The orange line represents the cumulative per-

centage of the preference scores. *SJC* Swollen Joint Count, *DAS28* Disease Activity Score using 28-joint counts, *CRP* C-reactive protein, *PhGA-VAS* Physician Global Assessment on a Visual Analog Scale, *ESR* Erythrocyte Sedimentation Rate, *TJC* Tender Joint Count, *HAQ* Health Assessment Questionnaire, *PGA-VAS* Patient Global Assessment on a VAS, *RIS* Relative Importance Score

be a discrepancy between rheumatologist and patients with regard to the evaluation of disease activity. Although differences were relatively small, the DAS28 and Patient Global Assessment became less important in case of discrepancy, while Ultrasound and the Health Assessment Questionnaire became more important.

Discussion

This study investigated the perceptions of rheumatologists on the use of different disease activity score systems and their components as well as certain PROs and ultrasound to evaluate RA disease activity in clinical practice. A majority indicated to routinely calculate a disease activity score, in most cases the DAS28-CRP. In general, objective measures of disease activity and the rheumatologist's own perception

were valued more important in rating disease activity compared to PROs.

The routine use of disease activity scores by Belgian rheumatologists is in line with a recently performed study in which 80% of Dutch rheumatologists participating in a small survey indicated to use any kind of score [22]. In contrast, data from the US, Australia and Israel showed lower use of scores ranging between 16–43% [23–26]. Some caution is warranted about the precise motivation of participating rheumatologists to measure disease activity. It should not necessarily be assumed that scores are used in a treat-to-target strategy, since a financial compensation twice a year per patient exists in Belgium for measuring the HAQ and DAS28 (K55 compensation). Logically, this may stimulate the use of the DAS28 score, also relative to other scores, as indicated by over 50% of the Belgian rheumatologists in our study.

Table 2 Comparison of the RIS of the disease activity components between MDS question 1 and 2

Disease activity indicator	MDS 1 RIS mean \pm SD	MDS 2 RIS mean \pm SD	<i>p</i> value
Swollen joint count	22.54 \pm 2.64	22.14 \pm 2.50	0.1096
DAS28	20.61 \pm 4.06	19.35 \pm 5.07	0.0061
Ultrasound	16.47 \pm 7.97	18.15 \pm 7.71	0.0039
C-reactive protein level	13.34 \pm 6.11	12.98 \pm 6.14	0.7344
Physician's global assessment	12.59 \pm 7.83	13.06 \pm 7.32	0.4095
Tender joint count	5.05 \pm 4.82	4.11 \pm 4.04	0.0536
Erythrocyte sedimentation rate	4.36 \pm 4.16	5.11 \pm 4.91	0.0873
Patient global assessment	2.54 \pm 2.98	1.79 \pm 3.13	0.0003
Health assessment questionnaire	1.51 \pm 2.38	2.14 \pm 2.67	0.0039
Pain-VAS	0.65 \pm 0.88	0.61 \pm 1.01	0.2041
Fatigue-VAS	0.34 \pm 1.47	0.56 \pm 2.32	0.1236

Bold: $p < 0.01$ was considered statistically significant

MDS 1 refers to the evaluation of disease activity components in general. MDS 2 refers to the evaluation in case of discrepancy between the patient's and physician's perception of the disease activity. Significance level $p < 0.01$

VAS Visual Analog Scale, DAS28 Disease Activity Score using 28-joint counts using either Erythrocyte Sedimentation Rate or C-Reactive Protein, MDS Maximum Difference Scaling, RIS Relative Importance Score, SD Standard Deviation

Another remarkable finding in our study was the preference of Belgian rheumatologists for CRP in comparison to ESR, as individual components and as part of the composite DAS28. It is largely unknown why rheumatologists prefer the one above the other, but a possible reason might be that CRP differs from ESR in that it more rapidly rises in case of inflammation, has a larger sensitivity to change and a shorter half-life, which may more accurately measure the presence of inflammation [8]. Another explanation might be that some laboratories do not routinely perform ESR as it is not fully automated which could explain regional differences.

Our study shows clearly that rheumatologists prefer their own evaluation and objective serological measures to estimate disease activity. van Hulst et al. also found SJC and PhGA, apart from DAS as top reasons for treatment escalation by Dutch rheumatologists [27]. Studenic et al. revealed the strong association between SJC and PhGA, reinforcing these outcomes [28]. However, these preferences could be regionally bound as US and Australian studies showed higher importance for RAPID3, HAQ, ESR and hemoglobin as perceived by rheumatologists [23, 24].

According to the EULAR recommendations, treatment decisions must be based on a shared decision between the patient and the rheumatologist [1]. However, in case of discrepancy between the patient's and rheumatologist's perception on disease activity, the Belgian rheumatologists seemed to value the same disease activity components, with an even

decreased preference for PGA. The question arises if the patient's remaining disease burden not directly related to disease activity, could partially explain this discrepancy. These findings support the notion that there might be an unmet need for patients with RA when it comes to the evaluation of the disease activity and further treatment decisions taken by their rheumatologist [29]. This result underlines the dual approach theory in evaluating RA, that distinguishes between remaining disease activity which can often be solved with pharmacological treatment and not directly disease-activity-related aspects that need non-pharmacological interventions [30]. The higher preference for ultrasound in case of discrepancy could likewise indicate the focus on biologic remission by rheumatologists. Ultrasound as a tool for steering treatment might however also result in overtreatment [31]. On the other hand, in the qualitative part of this study, rheumatologists clearly indicated to take care of the whole person and mostly used ultrasound to discuss synovitis with the patient.

A few limitations should be noted. The small qualitative study to develop the survey cannot be used to draw any definite conclusions about the use of RA disease activity components in clinical practice as we did not aim for data saturation. Although external validity cannot be assumed, the extensive literature search and the mixed-method approach add to the trustworthiness of results. Another limitation arose with regards to the two MDS questions of the survey, assuming a situation with or without a discrepancy between the opinion of rheumatologist and patient about disease activity. Since questions and results were comparable, some participants may have filled out the questions without properly understanding or reading what the difference between the two different questions was. Likewise, some issues of circularity and interpretation could occur when comparing the DAS28 with its components in these scenarios. Additionally, it might have been unclear to the participants if we aimed to assess only disease activity or disease severity and impact measures as well. However, although rheumatologists may perceive these measures as different entities, patients may discriminate less between disease activity and severity and score total disease burden. Additional limitations may be the absence of an interviewer which could have provided more clarification on open-ended questions, reporting bias due to the anonymity of the survey and the sample selection, as perhaps only rheumatologists using the DAS28CRP may wanted to fill out the survey.

This study also has its strengths. First, 34% of all the Belgian rheumatologists participated in the survey, and 27% fully completed it, representing a significant sample of Belgian rheumatologists. To further increase the generalisability to Belgian rheumatology, characteristics of participating rheumatologists in this study were also comparable to those of a previous rheumatologist's survey in

Belgium [32]. An additional strength is the survey design as qualitative work supported the content and the survey was pilot-tested [33]. Another strength of the survey was the MDS method. This method is preferred above the normal ranking exercise as it is more rapid to perform for participants, comparisons between different subsets of participants can be easily made and there is no scale-related bias. Extrapolation of some results might be difficult, as for instance the financial incentive to use DAS28 is specific for Belgium. However, this study demonstrates that this incentive seems to work in terms of DAS28 uptake.

We can conclude that Belgian rheumatologists indicate to routinely calculate a composite disease activity score, mostly the DAS28 score, in daily clinical practice. Laboratory and physician-derived measures were given more importance by rheumatologists compared to patient-reported measures to estimate disease activity. More emphasis on the added value of patient-reported outcomes is probably needed, especially from the standpoint of a clinician trying to apply a more holistic approach to his patients. Traditional disease activity components might be too limited and the addition of PROs might facilitate discussions between patients and health professionals to harmonize their perceptions on diseases activity in view of making a shared decision on pharmacological and/or non-pharmacological interventions [34]. Only targeting less inflammation or swollen joints may result in missing residual pain, fatigue and functional quality of life [6, 35]. Moreover, the importance of PROs in disease management is increasing as telemedicine and mhealth are more and more introduced in clinical practice. Healthcare professionals should take PROs into account to correctly assess the impact of disease on their patient.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00296-021-05020-0>.

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Author contributions DDC, EB, RW and PV designed the study. DDC and EB drafted the manuscript. All authors supported the analysis of the results, revised the paper critically for important intellectual content; approved the final version of the draft and agreed to be accountable for all aspects of the work.

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Availability of data and material The data source is available upon reasonable request by authors.

Code availability The survey was constructed and partly analyzed using the Sawtooth Software's SSI Web platform (version 9.8.1), for which

an academic grant was acquired. Additional analyses were performed in Microsoft Excel, Statdisk and VassarStats.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval The Ethical Committee of the KU Leuven approved this study (MP011755) on 23/12/2019. Participants had to indicate to have read and accept an information letter before starting this anonymous survey.

Informed consent Authors reporting on experimental work on humans should, where relevant, submit evidence that the work has been approved by an institutional clinical research panel or its equivalent.

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