

Considerations and priorities for incorporating the patient perspective on remission in Rheumatoid Arthritis: An OMERACT 2020 Special Interest Group report

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ABSTRACT

Objective: To determine how best to incorporate the patient perspective into rheumatoid arthritis remission criteria.

Methods: At OMERACT 2020, several studies, including a longitudinal multi-centre study testing the validity of adding patient-valued domains to the ACR/EULAR criteria, were presented and discussed by the virtual Special Interest Group.

Results: Overall consensus was that there is insufficient evidence to change the remission criteria at this point. Future work should focus on measurement of the new domain of independence, clarifying the value of the patient global assessment, and optimizing the input of domains that patient value in the criteria.

Conclusion: Incorporating the patient perspective into remission criteria should be further explored.

Keywords: OMERACT, rheumatoid arthritis, patient perspective, remission, patient-reported outcomes, independence, quality of life.

INTRODUCTION

Remission is the desired outcome in rheumatoid arthritis (RA) treatment. At Outcome Measures in Rheumatology (OMERACT) 10 (2010), concerns were raised as to whether the American College of Rheumatology/European Alliance of Associations for Rheumatology (ACR/EULAR) remission criteria (Felson *et al.*, 2011; Van Tuyl *et al.*, 2011), including tender and swollen joint count, C-reactive protein and patient global assessment of disease activity (PtGA) adequately incorporate the patient perspective. The OMERACT 'Remission in RA: Patient Perspective' Working Group (WG) was formed to explore what patients consider to be essential criteria for describing remission, and whether this differs from the remission criteria used by ACR/EULAR (Van Tuyl *et al.*, 2011). The timeline of work in RA remission from 2006 to 2021 can be seen in *Figure 1*.

First, qualitative focus groups were conducted to identify what remission ("disease activity as good as gone") meant to people with RA (Van Tuyl *et al.*, 2013).

Participants defined remission under three broad themes: reduction/absence of symptoms; reduction of impact of their disease; and a "return to normality" of life.

Within these, a list of 26 domains were identified. Second, a survey study asked RA patients from six countries (n=274) to rank these 26 domains in order of importance (Van Tuyl *et al.*, 2017). Domains most frequently included in the top three by participants were: pain, fatigue, and independence. The third phase was to identify candidate instruments for these domains, and explore their value in assessing RA remission in an international longitudinal cohort study (Rasch *et al.*, Submitted).

We aimed to explore how to best incorporate the patient perspective into RA remission criteria following the presentation of these data at OMERACT 2020.

PRESENTING EVIDENCE

This was an OMERACT special interest group (SIG) meeting, informed by primary and secondary research studies, presented below.

Scoping literature review: Two scoping literature reviews were conducted (led by Remission Fellow BJ) to:

1. identify any studies (qualitative and quantitative) that aimed to incorporate the patient perspective into an existing core outcome set for a long-term physical health condition.
2. identify any studies (qualitative and quantitative) that explored the patient perspective of the definition of remission in RA to ensure the work of the remission group was still necessary and relevant.

In July 2019 comprehensive literature searches were conducted for both reviews using online databases: MEDLINE, EMBASE and CINAHL Plus, and reviewing citations from key publications in the field. For both reviews, the search strategy covered from 2011 (publication year of ACR/EULAR remission criteria) until July 2019 (when the searches were conducted). Both reviews only included results with adult participants, and had no limit on study design.

The search strategy for the inclusion of the patient perspective into a core set was: core set AND (patient perspective OR opinion* OR preference OR PRO* OR patient reported outcome*).

The search strategy for the patient perspective on remission in RA review was: remission AND rheumatoid arthritis AND (patient perspective OR opinion* OR preference OR PROM OR Patient-reported OR "Patient reported" OR PRO OR patient-evaluated OR "patient evaluated").

CONSORT diagrams outlining the number of eligible papers at each stage for Searches One and Two are presented in *Figures 2 and 3* respectively. Search One identified three published papers from the OMERACT remission in RA working group (Van Tuyl *et al.*, 2015; Rasch *et al.*, 2017; Van Tuyl *et al.*, 2016). Search Two did not identify any studies that aimed to incorporate the patient perspective into a pre-existing core set. Therefore, this review identified no substantial new evidence beyond the work of this group.

Meta-analysis of PtGA and remission. An individual patient data meta-analysis from 11 randomised controlled trials (led by Remission Fellow RF: Ferreira *et al.*, 2020) concluded that the current remission definition that includes the PtGA, in addition to tender and swollen joint counts and C-reactive protein, performs better than a remission definition that excludes PtGA, for predicting a good functional outcome (change ≤ 0.0 units in the Health Assessment Questionnaire-Disability Index [HAQ-DI] from month 12 and 24). However, adding PtGA to the remaining three remission criteria reduced the predictive accuracy (sum of true positive and true negative rates) for good radiographic outcomes (from 51.1% to 40.5%), with a potential risk for overtreatment.

Longitudinal cohort study: A longitudinal cohort study of RA patients with low disease activity (Disease Activity Score 28 joint count [DAS28]<3.2) or patient-perceived remission (i.e., answering 'yes' to the question "Would you say that at this moment your disease activity is as good as gone, yes or no?") was led by Remission past-Fellow LR and Co-chair MB. Participants (n=246) were recruited from four countries, with two sites providing longitudinal data at three (n=152) and six months (n=142). Validated instruments to measure pain and fatigue were selected, and a numerical rating scale was created to measure independence. These were tested in addition to ACR/EULAR Boolean-based remission (with and without PtGA) for prediction of functional outcome (HAQ-DI). Radiographic damage progression was an intended outcome measure but due to significant missing data was not analysed. Different disease activity scenarios (i.e., stable vs unstable in patient-perceived remission and in DAS28<2.6, at 0-3 and 3-6 months) were used and different sensitivity analyses were tested. Further details on this study can be found in the affiliated paper (Rasch et al, submitted).

Special Interest Group: 46 participants attended the virtual SIG (27th Oct 2020). Of these, 16 were patient research partners (PRPs). The WG's previous research (described above) was summarized (CF), and MB presented a more detailed account of the longitudinal study findings and responded to questions. Delegates contributed to group discussion either verbally or in a text chat stream running simultaneously throughout the meeting. At the end, a series of questions were posed to the attendees with the teleconferencing polling function used for voting (yes/no) (Table 1).

GROUP DISCUSSIONS

Independence

The measure used for independence in the longitudinal study is not validated, and therefore identified by the WG as a potential area of future research for discussion in the SIG. It was suggested that measurement of independence could be subjective and influenced by contextual factors such as access to social support networks and mobility aids, weather, time of day/year, and other conditions or injuries. Patients with longer disease duration and greater joint damage may have permanent loss of independence, which would reduce ability to reach remission:

“Achieving independence is wonderful and indeed what we are striving for, but as a domain for remission it then means that a patient with established RA will never be in remission, despite when pain and fatigue are gone” (patient delegate)

“Independence is a challenging one as loss of independence may still remain”
(patient delegate)

A broader concept of independence that included quality of life and the ability to adjust to self-management was also discussed:

“I also wonder how much independence is helpful versus the term quality of life.”
(patient delegate)

“In a way I like to propose a new definition of health as “the ability to adjust and to self-manage” more than the more global term ‘independence’.” (patient delegate)

Patient Global Assessment (PtGA)

The influence of the PtGA on determining remission in RA has received much

attention in the literature (Boers, 2020; Nikiphorou *et al.*, 2016). Overall, two main suggestions were made: 1. To increase the PtGA cutoff from one to two out of 10 for remission criteria (Studenic *et al.*, 2020), supported by data from the validation study (Rasch *et al.*, Submitted), which found a substantial proportion of patients in self-declared remission score their PtGA as two; 2. To develop a patient's perspective of remission criteria separate from the physician's perspective (Ferreira *et al.*, 2019).

Some PRPs mentioned they were unsure how to consider impact of multiple conditions in the PtGA; and whether to take the domains of pain, fatigue, and independence into account when answering the PtGA. There was consideration of whether altering the anchor of the PtGA or to directly ask whether patients' RA was "as good as gone" might incorporate these domains identified as important from a patient perspective into remission criteria:

"As a patient with RA, I agree that my own criteria for the patient global score differs at times so I imagine each patient's criteria varies as well." (patient delegate)

"I never know what I should be thinking about when giving my patient global score."
(patient delegate)

"It's hard to attribute fatigue to one disease over the other so the scale is always hard to complete" (patient delegate)

Factors influencing measurement of remission

Delegates noted that patients may not experience off-drug remission, highlighting impact of on- versus off-drug remission as an area for future research. The concept

of modifiers for remission, including medication, was welcomed by many in the group.

“Why can't there be various modifiers/qualifiers for "Remission" depending on context and trial? Time period, on/off meds” (Health professional delegate)

The duration of reduced or no symptoms was also raised by PRPs as important in defining remission. The existing criteria do not have specific requirements on time, and it was clarified that there was no agreement among patients in the initial focus groups regarding how long the RA symptoms would need to be absent for it to be considered RA remission (Van Tuyl *et al.*, 2013), therefore duration was not taken forward into further studies by this WG. Further research may be needed to reach consensus on a minimum clinically relevant duration of no symptoms:

“It can also have a huge impact on someone being told they are in remission and understanding if they truly are in remission ...or just having a good day” (patient delegate)

Wider implications

It was noted that while RA remission criteria are intended for use in clinical trials, they may have wider implications if used in clinical practice. For example, RA patients deemed to be in remission may be denied social security support or disability pension payments; or changes to employment duties or education may occur. Delegates were reminded that the goal of OMERACT is to develop outcome measures for clinical trials and while the criteria may filter into clinical practice, they

are not intended for clinical practice:

“I don't like the term remission as people equate it with remission in cancer and think you can go back to work, stop benefits, etc.” (patient delegate)

Result of voting during session

The SIG voted on five questions. Thirty-nine participants (including 16 PRPs) voted on questions 1-4, and 38 participants voted on question 5. Table 1 reports delegate voting results for the entire group including patient stakeholders as well as for patient stakeholders separately.

Delegates reached consensus that there is insufficient evidence from existing data to propose a change to the remission criteria (92). However, consensus was also reached that independence is an important domain (92) and that efforts should be made to validate a numeric rating scale for independence (90) (Table 1).

Additionally, consensus was reached that work should continue on the PtGA for remission criteria (95).

Future of the working group and next steps

The Remission in RA: Patient Perspective WG has now met its initial aim to identify the domains that are important to patients regarding the concept of remission. The suggested future direction of the WG is to develop and test a measure of independence for RA, firstly through further qualitative work to explore how patients understand and define the domain of independence in more depth. Additional work on the PtGA in relation to remission is also needed, but this may be beyond the scope of this WG and researchers have already begun to address this in the

literature (Hirsh *et al.*, 2019; Ferreira *et al.*, 2020). Exploring the value of a separate patient-perspective measure of remission is also a potential area for future research, although this was not voted on in the SIG.

Conclusion

In conclusion, there is insufficient evidence from the current data to propose a change to the existing ACR/EULAR remission criteria. However, independence is an important domain in need of further research to clarify the meaning with patients and to identify the best way to measure this. Work should also continue on the patient global assessment in relation to remission.

Declaration of competing interests:

Dr. Hetland reports grants from AbbVie, grants and personal fees from Biogen, grants from BMS, personal fees from CellTrion, grants from Eli Lilly, personal fees from Janssen, personal fees from MSD, grants and personal fees from Pfizer, grants from Roche, personal fees from Samsung Biopis, grants from Sandoz, grants from Novartis, outside the submitted work; Prof. Singh reports personal fees from Crealta/Horizon, Medisys, Fidia, Two labs Inc, Adept Field Solutions, Clinical Care options, Clearview healthcare partners, Putnam associates, Focus forward, Navigant consulting, Spherix, MediQ, UBM LLC, Trio Health, Medscape, WebMD, and Practice Point communications; and the National Institutes of Health and the American College of Rheumatology, other from TPT Global Tech, Vaxart pharmaceuticals and Charlotte's Web Holdings, Inc., other from Amarin, Viking and Moderna pharmaceuticals, outside the submitted work; Prof Smolen received grants to his institution from Abbvie, AstraZeneca, Janssen, Lilly, Merck Sharpe & Dohme, Pfizer, and Roche and provided expert advice for, or had symposia speaking

engagements with, AbbVie, Amgen, AstraZeneca, Astro, Bristol-Myers Squibb, Celgene, Celltrion, Chugai, Gilead, ILTOO Pharma, Janssen, Lilly, Merck Sharp & Dohme, Novartis-Sandoz, Pfizer, Roche, Samsung, Sanofi, and UCB; Dr. Studenic reports grants from Abbvie, outside the submitted work;

The remaining authors declare no conflicts of interest.

Funding: None

CRedit author statement:

Bethan Jones: Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review and editing **Caroline Flurey:** Conceptualization, Methodology, Investigation, Resources, Writing – reviewing & editing; Visualization, Supervision; Project Administration **Susanna Proudman:** Methodology, Investigation, Resources, Writing – review & editing, Supervision, Project administration **Ricardo J. O.**

Ferreira: Conceptualization, Formal analysis, Writing – Reviewing & Editing **Marieke**

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Editing, **Josef S Smolen:** Conceptualization, Writing – Reviewing & Editing **Jose**

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Reviewing & Editing **Tanja Stamm:** Writing – Reviewing & Editing **Paul Studenic:**

Writing – Reviewing & Editing **Maarten de Wit:** Conceptualization, Writing –

Reviewing & Editing **Peter Tugwell**: Conceptualization, Methodology, Investigation, Writing – Reviewing & Editing **Maarten Boers**: Conceptualization, Methodology, Validation, Writing – Reviewing & Editing

Acknowledgements: The authors would like to thank the patients who have participated in all of the group’s work on remission to date. The members of the OMERACT Remission in RA: Patient Perspective Working Group who have contributed to the continual development of this work not listed as co-authors: Cecilie Heegaard Brahe, Catia Duarte, Laure Gossec, Martina Durechova, Victor Sloan, Dirkjan van Shaardenburg, and George Wells. Kiera Shaughnessy for administrative support to produce the manuscript.

We would also like to thank all who participated in our OMERACT 2020 virtual SIG session, and the OMERACT executive and secretariat for their ongoing support of this work, particularly Shawna Grosskleg for administrative support.

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Table 1: Delegate voting results from virtual Remission SIG at OMERACT 2020

Question	Weighted Total		Patients only		Professionals only		
	total Yes % (pPts + pHCP)/2)	n=39 (%)	n=17 (%)	n=22 (%)			
	%	Yes	%	Yes	%	Yes	%
Do you agree that...:							
a decision on the current criteria needs to be taken now?	24	10	26	2	12	8	36
there is insufficient evidence from the data to change the ACR/EULAR remission criteria at this time?	91	36	92	14	82	22	100
independence is an important domain?	91	36	92	14	82	22	100
the current numeric rating scale for independence should be further validated?	90	35	90	16	94	19	86
Should we continue to work on patient global assessment?*	95	36	95	17	100	19	90

***NB: only 21 professionals completed the final question.**

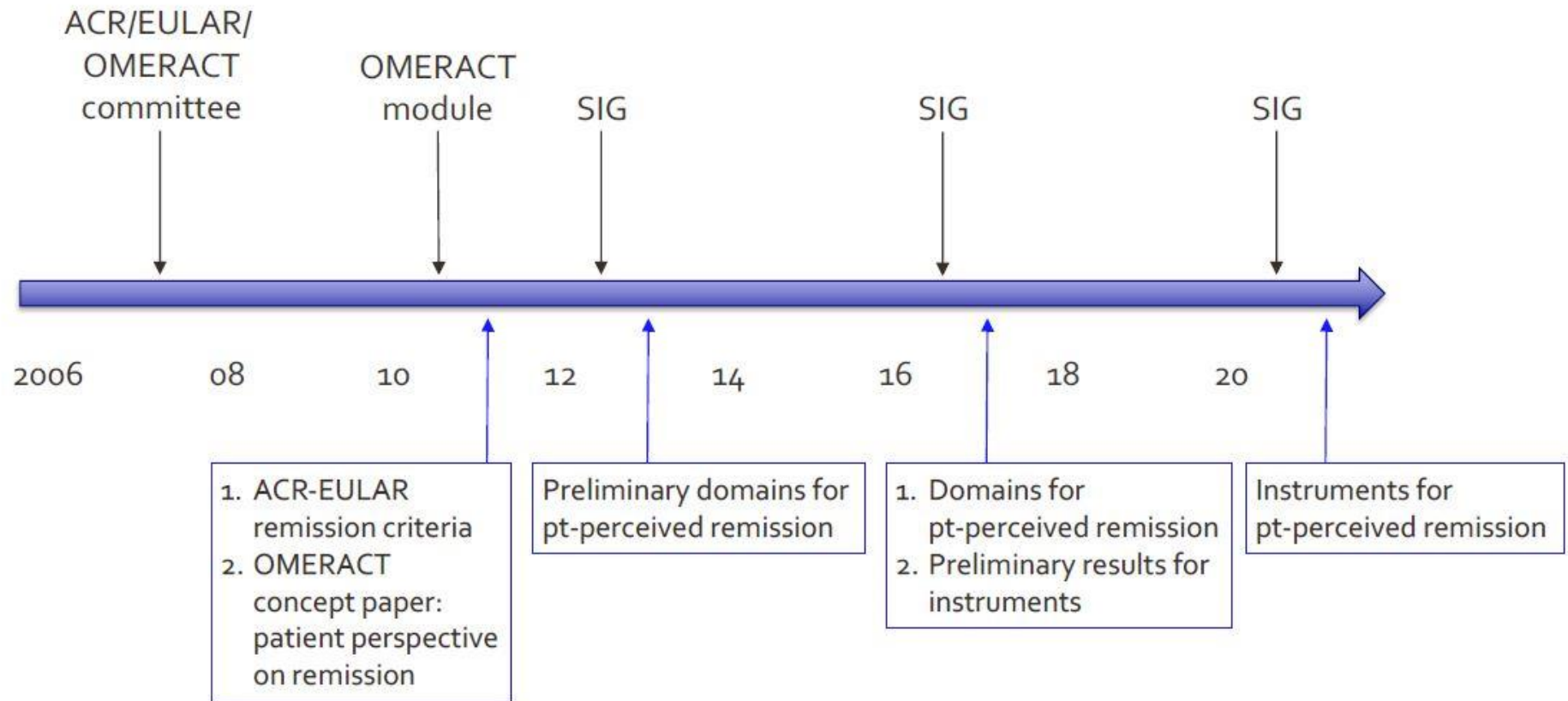


Figure 1: Timeline of rheumatoid arthritis remission from 2006 to 2021

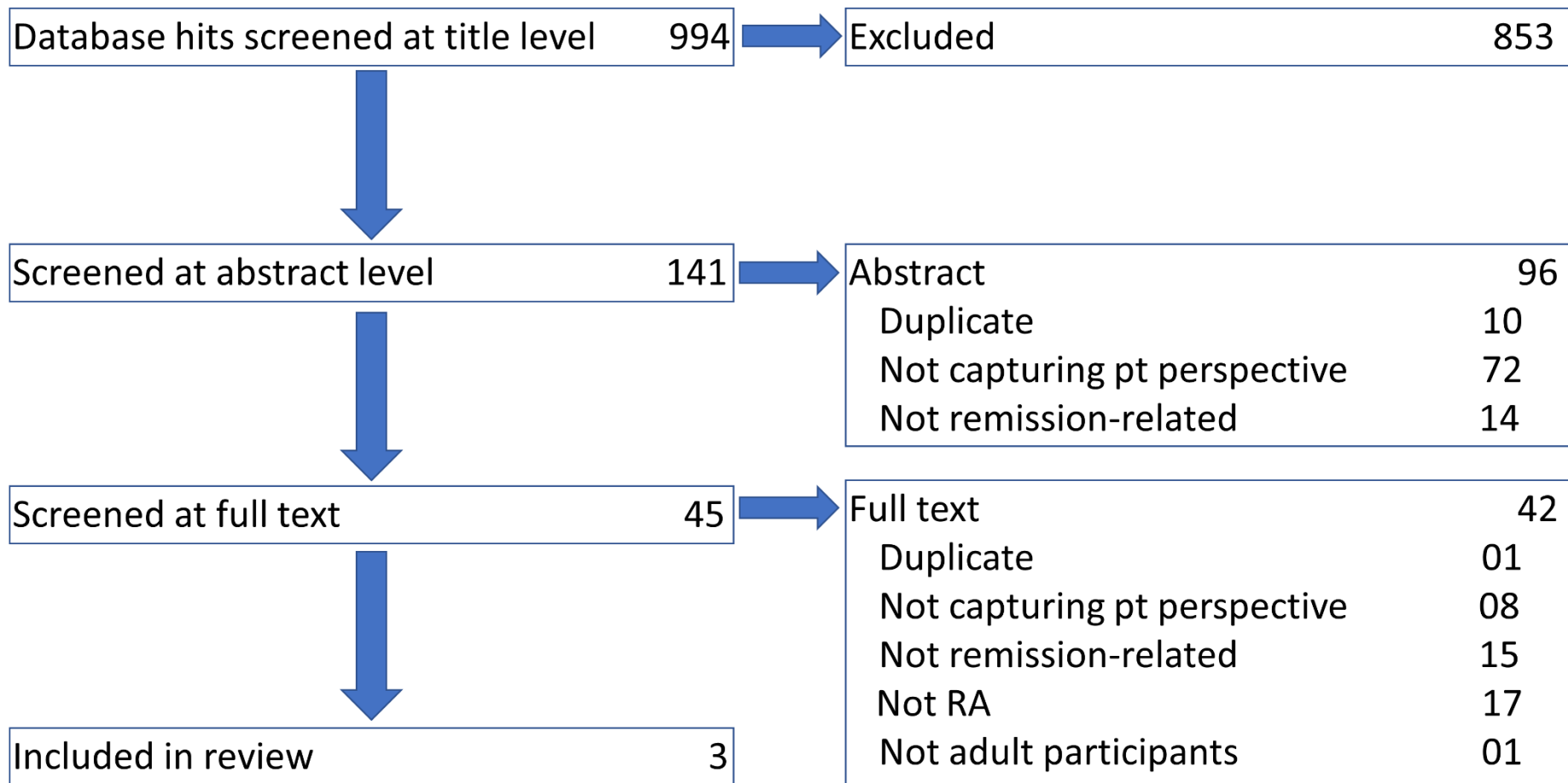


Figure 2: CONSORT diagram for Search One: Patient perspective of RA remission

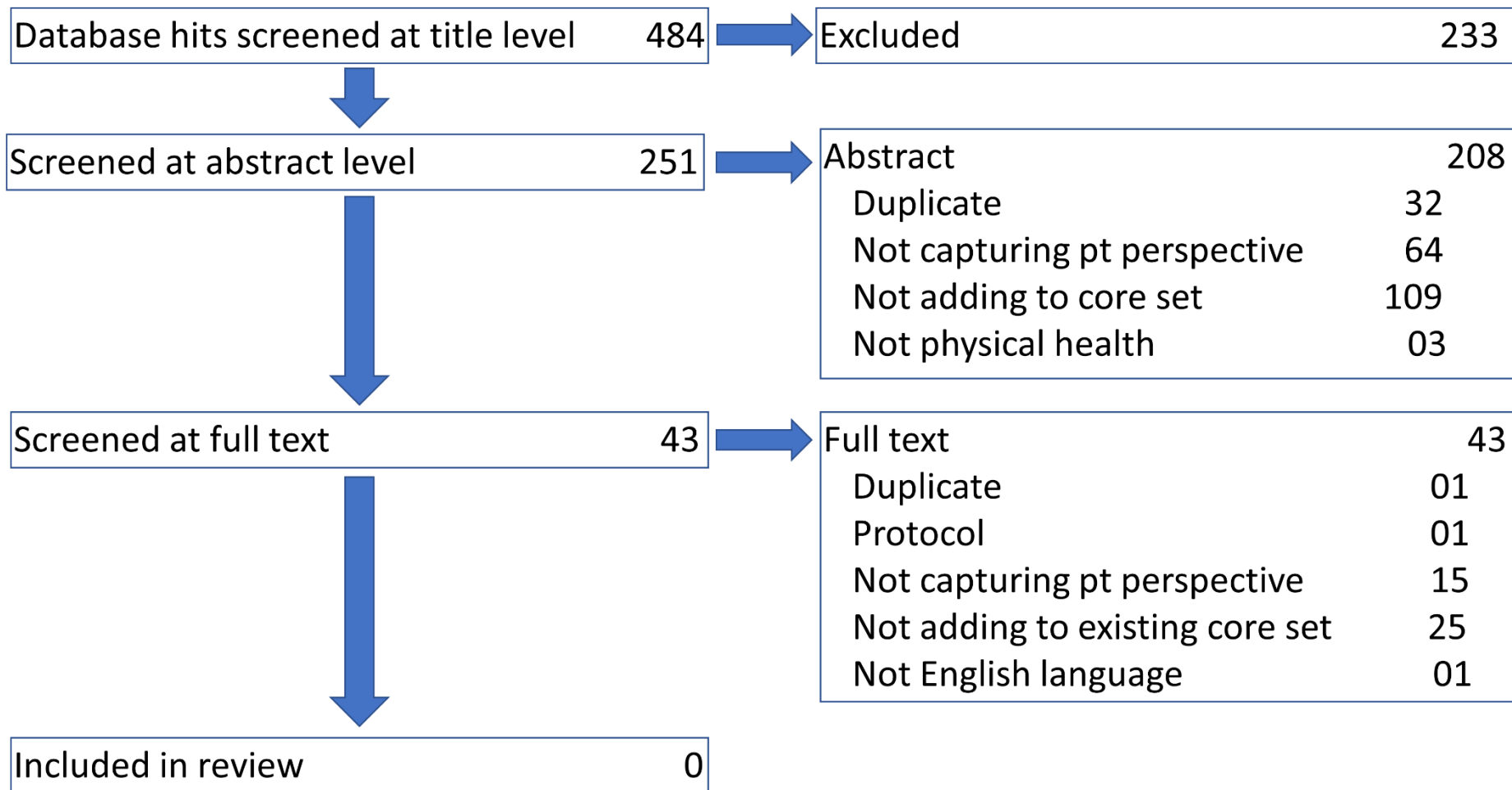


Figure 3: CONSORT diagram for Search Two: Incorporating the patient perspective into an existing core set

Supplementary material

Supplementary Table 1: Papers excluded at full text screening for Search 1

Author	Date	Title	Reason for exclusion
Bartlett S.J.	2018	Lifestyle and MTX use are the strongest predictors of not achieving remission in the first year of rheumatoid arthritis: Results from the Canadian early arthritis cohort (CATCH).	Not capturing patient perspective
Bingham et al.	2011	Identifying preliminary domains to detect and measure rheumatoid arthritis flares: report of the OMERACT 10 RA Flare Workshop.	Not remission specific
Bubb et al.	2018	Incorporation of patient reported outcomes data in the care of us veterans with rheumatoid arthritis: A randomized, controlled trial.	Not remission specific
Buhkari	2019	Is remission achievable in most patients with rheumatoid arthritis? Results suggest not.	Not capturing patient perspective
Bykerk et al.	2014	Flares in Rheumatoid Arthritis: Frequency and Management. A Report from the BRASS Registry.	Not remission specific
Byrne	2019	Increasing the impact of behavior change intervention research: Is there a role for stakeholder engagement?	Not remission specific
Castrejon et al.	2013	Can remission in rheumatoid arthritis be assessed without laboratory tests or a formal joint count? Possible remission criteria based on a self-report RAPID3 score and careful joint examination in the ESPOIR cohort.	Not capturing patient perspective
Cheung P.,	2019	The patient acceptable symptom state (PASS) in Asian rheumatoid arthritis (RA) patients.	Not remission specific
De Wit et al.	2016	Feasibility and added value of meaningful patient involvement in the development of a core outcome set for psoriatic arthritis.	Not RA specific
De Wit et al.	2016	Meaningful involvement of patients in the development of a core outcome set for psoriatic arthritis.	Not RA specific

Felson	2012	Defining remission in rheumatoid arthritis.	Not capturing patient perspective
Felson et al.	2011	American college of rheumatology/European league against rheumatism provisional definition of remission in rheumatoid arthritis for clinical trials.	Not capturing patient perspective
Ferreira et al.	2017	Drivers of patient global assessment in patients with rheumatoid arthritis who are close to remission: An analysis of 1588 patients.	Not capturing patient perspective
Gossec et al.	2018	Phrasing of the patient global assessment in the rheumatoid arthritis ACR/EULAR remission criteria: an analysis of 967 patients from two databases of early and established rheumatoid arthritis patients.	Not capturing patient perspective
Gudu et al.	2017	Definition of remission and minimal disease activity in psoriatic arthritis: A systematic literature review.	Not RA specific
Hatemi, Gulen;	2017	Developing a Core Set of Outcome Measures for Behçet Disease: Report from OMERACT 2016.	Not RA specific
Heiberg et al.	2008	Identification of disease activity and health status cut-off points for the symptom state acceptable to patients with rheumatoid arthritis	Not remission-related
Hewlett S.,	2019	Dose reduction of biologic therapy in inflammatory arthritis: A qualitative study of patients' perceptions and needs.	Not remission-related
Højgaard et al.	2018	A systematic review of measurement properties of patient reported outcome measures in psoriatic arthritis: A GRAPPA-OMERACT initiative.	Not RA specific
Holland et al.	2018	Applicability of the PSAID12 questionnaire as a core outcome measurement in psa clinical trials: An evaluation using omeract filter 2.1 instrument selection criteria.	Not RA specific
Horta-Baas et al.	2017	Evaluation of the activity of rheumatoid arthritis in clinical	Not RA specific

		practice. Agreement between self-rated clinimetric evaluation and clinical evaluation with activity indexes: DAS28, CDAI and SDAI. <Evaluacion de la actividad de la artritis reumatoide en la atencion clinica habitual. Concordancia entre la autoclinimetria y la evaluacion clinica con los indices de actividad: DAS28, CDAI y SDAI.>	
Hsaio et al.	2017	Incorporating the patient's perspective in outcomes research.	Not remission specific
Idzerda et al.	2014	Can we decide which outcomes should be measured in every clinical trial? A scoping review of the existing conceptual frameworks and processes to develop core outcome sets.	Not remission-related
Kapadia et al.	2015	Development of a core set of outcomes in children with severe neurodisability and feeding tube dependency: A systematic review.	Not adults
Kloppenburg et al.	2015	Report from the OMERACT Hand Osteoarthritis Working Group: Set of Core Domains and Preliminary Set of Instruments for Use in Clinical Trials and Observational Studies.	Not RA specific
Leung A.M.H.,	2016	Defining criteria for rheumatoid arthritis patient derived disease activity score that correspond to Disease Activity Score 28 and Clinical Disease Activity Index based disease states and response criteria.	Not capturing patient perspective
Macefield et al.	2014	Developing core outcomes sets: methods for identifying and including patient-reported outcomes (PROs).	Not remission-related
Merkel et al.	2011	The OMERACT core set of outcome measures for use in clinical trials of ANCA-associated vasculitis.	Not RA specific
Miedany et al.	2013	Treat to target of psoriatic arthritis: Core set criteria of minimal disease activity.	Not RA specific
Orbai	2017	Ensuring representativeness of the patients' perspectives in the final	Not remission-related

Orbai et al.	2016	results generated from clinical research-challenges from the perspective of researchers. Report of the GRAPPA-OMERACT psoriatic arthritis working group from the GRAPPA 2015 Annual Meeting.	Not RA specific
Ow et al	2011	Domains of health-related quality of life important and relevant to multiethnic english-speaking asian systemic lupus erythematosus patients: A focus group study.	Not RA specific
Paanalahti et al.	2014	Validation of the Comprehensive ICF Core Set for stroke by exploring the patient's perspective on functioning in everyday life: a qualitative study.	Not RA specific
Sanderson et al	2012	The development of the rheumatoid arthritis patient priorities in pharmacological intervention outcome measures.	Not remission-related
smith et al.	2018	A Core Outcome Set for Multimorbidity Research (COSmm).	Not RA specific
Tillet et al.	2014	Enhanced patient involvement and the need to revise the core set - Report from the psoriatic arthritis working group at OMERACT 2014.	Not RA specific
Tillet et al.	2015	Review of the psoriatic arthritis working group at OMERACT 12: A report from the GRAPPA 2014 annual meeting.	Not RA specific
Tillet et al.	2015	Review of the psoriatic arthritis working group at OMERACT 12: A report from the GRAPPA 2014 annual meeting.	Duplicate study
Tunis et al.	2017	Engaging Stakeholders and Promoting Uptake of OMERACT Core Outcome Instrument Sets.	Not remission-related
Van Tuyl	2014	Measurement of stiffness in patients with rheumatoid arthritis in low disease activity or remission: a systematic review.	Not remission-related
Weigl and Wild	2018	European validation of The Comprehensive International Classification of Functioning, Disability and Health Core Set for Osteoarthritis from the perspective	Not RA specific

Zogala et al.

2018

of patients with osteoarthritis of the knee or hip.
Patient-reported outcome measures used in rheumatoid arthritis cohorts and registries around the world: An environmental scan from the outcome measures in rheumatology critical outcomes in longitudinal observational studies working group.

Not remission-related

Supplementary Table 2: Papers excluded at full text screening for Search 2

Author	Date	Title	Reason for exclusion
Aggarwal et al.	2017	2016 American College of Rheumatology/European League Against Rheumatism criteria for minimal, moderate, and major clinical response in adult dermatomyositis and polymyositis: An International Myositis Assessment and Clinical Studies Group/Paediatric Rheumatology International Trials Organisation Collaborative Initiative.	Not capturing patient perspective
Aggarwal et al.	2017	2016 American College of Rheumatology/European League Against Rheumatism criteria for minimal, moderate, and major clinical response in adult dermatomyositis and polymyositis: An International Myositis Assessment and Clinical Studies Group/Paediatric Rheumatology International Trials Organisation Collaborative Initiative.	Duplicate
Aiachini et l.	2016	Validation of the ICF Core Set for Vocational Rehabilitation from the perspective of patients with spinal cord injury using focus groups...International Classification of Functioning	Not adding to existing core set
Aydin et al.	2019	Update on Outcome Measure Development in Large-vessel Vasculitis: Report from OMERACT 2018.	Not adding to existing core set
Aydin, Sibel Zehra et al	2015	Update on Outcome Measure Development for Large Vessel Vasculitis: Report from OMERACT 12.	Not adding to existing core set
Baker K. et al	2015	Restoring or threatening a normal life: Withdrawing medication from patients with rheumatoid arthritis in remission.	Not adding to existing core set
Barlett et al.	2013	Preliminary data supporting the feasibility and construct validity of promis fatigue scale and RA core set variables in an academic rheumatoid arthritis clinic.	Not adding to existing core set
Benham H.	2019	Treat-to-target in rheumatoid arthritis: Evaluating the patient perspective using the Patient Opinion Real-Time Anonymous Liaison system: The RA T2T PORTAL study.	Not adding to existing core set

Christalle et al.	2018	Assessment of patient centredness through patient-reported experience measures (ASPIRED): protocol of a mixed-methods study.	Protocol
Contreras-Yáñez	2017	Patient's perspective of sustained remission in rheumatoid arthritis.	Not adding to existing core set
Curtis et al.	2013	Patient perspectives on achieving treat-to-target goals: A critical examination of patient-reported outcomes.	Not adding to existing core set
Dinglas et al.	2018	Understanding patient-important outcomes after critical illness: A synthesis of recent qualitative, empirical, and consensus-related studies.	Not adding to existing core set
Direskeneli et al.	2011	Development of outcome measures for large-vessel vasculitis for use in clinical trials: opportunities, challenges, and research agenda.	Not adding to existing core set
Falahee M., et al	2019	Preferences of Patients and At-risk Individuals for Preventive Approaches to Rheumatoid Arthritis.	Not adding to existing core set
Felson	2012	Defining remission in rheumatoid arthritis.	Not capturing patient perspective
Ferreira et al.	2018	The impact of patient global assessment in the definition of remission as a predictor of long-term radiographic damage in patients with rheumatoid arthritis: protocol for an individual patient data meta-analysis	Not capturing patient perspective
Gaujoux-Viala	2012	What are the reasons of discrepancies between patients and physicians in their perceptions of rheumatoid arthritis disease activity and what is the impact of this discordance on remission, function and structure at 1 year?.	Not adding to existing core set
Gossec et al.	2014	Doctor, will my fatigue be better if I'm in remission? An exploratory analysis of 1284 Rheumatoid Arthritis (RA) patients indicates fatigue is the only aspect of patient-perceived impact to remain significant in ACR/EULAR boolean remission.	Not adding to existing core set
Gromnica-Ihle and Rink	2011	Treat-to-target from the patient perspective. <Treat-to-Target aus Sicht der Betroffenen.>	Not English language
Hirsh et al.	2019	Limited Health Literacy and Patient Confusion About Rheumatoid Arthritis	Not adding to existing core set

		Patient Global Assessments and Model Disease States.	
Hush et al.	2012	Standardized measurement of recovery from nonspecific back pain.	Not adding to existing core set
Ishiguro N et al.	2018	Relationship between disease activity and patient-reported outcomes in rheumatoid arthritis: Post hoc analyses of overall and Japanese results from two phase 3 clinical trials.	Not adding to existing core set
Katikaneni M.,	2018	Which is the best measure for rheumatoid arthritis disease activity? a head to head comparison of the six american college of rheumatology recommended disease activity measures.	Not capturing patient perspective
Kojima et al.	2017	Patient-reported outcomes as assessment tools and predictors of long-term prognosis: a 7-year follow-up study of patients with rheumatoid arthritis.	Not capturing patient perspective
Kuusalo et al.	2017	Patient-reported outcomes as predictors of remission in early rheumatoid arthritis patients treated with tight control treat-to-target approach.	Not capturing patient perspective
Lee et al.	2011	Pain persists in DAS28 rheumatoid arthritis remission but not in ACR/EULAR remission: a longitudinal observational study.	Not capturing patient perspective
Munters et al.	2011	Patient preference of disability in rheumatoid arthritis.	Not adding to existing core set
Olsen et al.	2016	Predictors of Fatigue in Rheumatoid Arthritis Patients in Remission or in a Low Disease Activity State.	Not capturing patient perspective
Orbai et al.	2017	Updating the psoriatic arthritis (PsA) core domain set: A report from the PsA workshop at OMERACT 2016.	Not adding to existing core set
Pietrogrande et al.	2011	Recommendations for the management of mixed cryoglobulinemia syndrome in hepatitis C virus-infected patients.	Not adding to existing core set
Rasch et al.	2017	Validating Rheumatoid Arthritis Remission Using the Patients' Perspective: Results from a Special Interest Group at OMERACT 2016.	Not adding to existing core set
Robson et al.	2017	OMERACT endorsement of patient-reported outcome instruments in antineutrophil cytoplasmic antibody-associated vasculitis.	Not capturing patient perspective
Saketkoo et al.	2014	Reconciling healthcare professional and patient perspectives in the development	Not adding to existing core set

		of disease activity and response criteria in connective tissue disease-related interstitial lung diseases.	
Smith et al.	2018	A Core Outcome Set for Multimorbidity Research (COSmm).	Not adding to existing core set
Steunebrink et al.	2016	Recently diagnosed rheumatoid arthritis patients benefit from a treat-to-target strategy: results from the DREAM registry.	Not capturing patient perspective
Terwee et al.	2016	Content validity of the Dutch Rheumatoid Arthritis Impact of Disease (RAID) score: Results of focus group discussions in established rheumatoid arthritis patients and comparison with the International Classification of Functioning, Disability and Health core set for rheumatoid arthritis.	Not adding to existing core set
Tunis et al.	2017	Engaging Stakeholders and Promoting Uptake of OMERACT Core Outcome Instrument Sets.	Not adding to existing core set
Turk et al.	2018	Pain, sleep and emotional well-being explain the lack of agreement between physician- and patient-perceived remission in early rheumatoid arthritis.	Not capturing patient perspective
van der Ven et al.	2017	No clear association between ultrasound remission and health status in rheumatoid arthritis patients in clinical remission.	Not capturing patient perspective
Van Tuyl et al.	2013	Patient-reported Remission in rheumatoid arthritis.	Not capturing patient perspective
Van Tuyl et al.	2018	The controversy of using PGA to define remission in RA.	Not capturing patient perspective
Van Tuyl et al.	2012	Patient-Reported Outcomes in Rheumatoid Arthritis.	Not adding to existing core set
Ward et al.	2015	Measures of arthritis activity associated with patient-reported improvement in rheumatoid arthritis when assessed prospectively versus retrospectively.	Not capturing patient perspective