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## New galaxies in the universe of shared decision making and rheumatoid arthritis

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### Abstract

**Purpose of review:** Implementing shared decision making (SDM) is a top international priority to improve care for persons living with rheumatoid arthritis. Using SDM tools such as decision aids improve patients' knowledge and support communication with their clinicians on treatment benefits and risks. Despite calls for SDM in treat-to-target, studies demonstrating effective SDM strategies in rheumatology clinical practice are scarce. Our objective was to identify recent and relevant literature on SDM in rheumatoid arthritis.

**Recent findings:** We found a burgeoning literature on SDM in rheumatoid arthritis that tackles issues of implementation. Studies have evaluated the SDM process within clinical consultations and found that uptake is suboptimal. Trials of newly developed patient decision aids follow high methodological standards, but large-scale implementation is lacking. Innovative SDM strategies such as shared goals and preference phenotypes may improve implementation of treat-to-target approach. Research and patient engagement are standardizing measures of SDM for clinical uses.

**Summary:** Uptake of SDM in rheumatoid arthritis holds promise in wider clinicians' and patients' awareness, availability of decision aids, and broader treat-to-target implementation strategies such as the learning collaborative. Focused attention is needed on facilitating SDM among diverse populations and those at risk of poorer outcomes and barriers to communication.

### Keywords

Shared decision making; rheumatoid arthritis; patient decision aid; outcome measure; treat-to-target

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## Introduction

Implementing shared decision making (SDM) is a priority outlined in international guidelines to improve quality of care for persons living with rheumatoid arthritis (1, 2). SDM is a process by which rheumatologists collaborate with patients to provide high-quality care based on best available evidence and eliciting patient's values and preferences (3–5). SDM is important in all aspects of care, from appropriately informing patients of the rheumatoid arthritis diagnosis to generating a personalized treatment target and management plan (3).

One of the key current challenges to managing rheumatoid arthritis is fully implementing the treat-to-target approach (6, 7). Early, intensive and rapid control of the disease prevents accelerated joint damage, loss of function and cardiovascular morbidity (6–8). The treat-to-target approach involves choosing a shared goal for treatment, assessing progress and making decisions to escalate treatments to reach a target (6, 9). SDM is an overarching principle to help navigate the treat-to-target approach (6).

Many barriers have been identified to using SDM in rheumatoid arthritis care. Clinicians perceived patients' preferences and knowledge concerning medication to act as limiting factor to the treat-to-target approach (8–10). Patients also often disagree with key treat-to-target recommendations such as short-term treatment adjustments or targeting of low disease activity and remission, instead favor quality of life and pain as targets (11). Of particular concern, deliberation and SDM about the best treatment choices to reach patient goals was sidetracked by third-party insurance providers that can approve or deny authorized medication (8). This situation reflects the obstacles posed by a broken funding model in the US-health care system to fully realize SDM when caring for patients.

Despite the emphasis on SDM to guide treatment choices, studies in rheumatoid arthritis were underrepresented in a 2017 Cochrane review of 105 studies of decision aids with only one published trial and two ongoing studies (12). Another Cochrane review on strategies to increase use of SDM by health professionals identified only one trial on a decision aid for rheumatoid arthritis that enhanced knowledge and reduced decisional conflict (13, 14). A recent systematic review of interventions to support SDM in treatment decisions in long-term conditions included 23 studies, none of rheumatoid arthritis (15).

An evidence gap is evident between the proposed principles by large organizations in rheumatology and what occurs in real-world practice. Patients' experience of SDM is suboptimal, particularly for persons with communication barriers such as limited health literacy (14, 16). We explore the universe of SDM and reflect upon the most significant recent advances for persons living with rheumatoid arthritis.

### 1. Is shared decision making happening in clinical consultations?

Designing strategies to foster SDM in clinical practice requires an understanding of whether and how decision-making processes happen in clinical consultations (17, 18). This is the starting point of both the *Ottawa Decision Support Framework* and the Mayo Clinic's method of direct observation of consultations during the design of decision aids (17, 18).

This evidence is limited for many decision-making processes happening in clinical consultations for rheumatoid arthritis.

*Mathijssen et al.* recorded 168 clinical consultations with rheumatoid arthritis patients in two centers in the Netherlands to investigate if and how SDM occurred in clinical practice (19). The authors audio-recorded consultations and assessed them using the “observing patient involvement in decision making” (OPTION) scale, a 5-item tool that measures SDM from an observer perspective. OPTION was scored between 0 and 100, with a higher score representing higher level of SDM. The authors found a mean OPTION score of 28.3, and a range from 0 to 75, which they interpreted as representative of substantial variability and low to moderate levels of SDM when deciding on rheumatoid arthritis treatments. The authors found that a longer consultation time of 10 minutes was associated with slightly higher SDM score, and that decisions to make changes to a patient’s treatment (e.g. stopping medication) required more SDM.

We consider this article highly relevant to the field. Data collection happened between 2015 and 2017, coinciding with the publication of international guidelines calling for SDM in rheumatoid arthritis. This study provides a clear picture of usual clinical practice because participants were not aware that they would be assessed for SDM during data collection. The suboptimal level of SDM underscores the need to develop tools and strategies to foster SDM in clinical consultations. Future studies should assess if and how SDM occurs in order to map the diversity of decisions that happen in rheumatoid arthritis care and allow for carefully designed interventions to facilitate uptake.

**Key messages:** SDM is not yet embedded in clinical consultations for rheumatoid arthritis. There is a need to develop and test effective strategies and tools to foster SDM in clinical practice.

## 2. Designing Innovative Strategies to Foster Shared Decision Making

Recent literature highlights teams who are designing innovative strategies to foster SDM in clinical practice. In this section, we delineate SDM innovations as 1- decision aids, 2- goal sharing strategies and 3- identification of preference phenotypes.

**2.1 Advances in decision aids**—Decisions aids are one of the best known and effective strategies to foster SDM in clinical practice, but are rarely used in rheumatoid arthritis (12, 20). *Li et al.* conducted a mixed-methods study to assess the impact of an interactive online patient decision aid (ANSWER-2) on patients’ decisional conflict, medication-related knowledge and self-management capacity (7). In fifty patients with a median disease duration of 5 years, using the decision aid significantly improved the proportion of patients with a decisional conflict score lower than 25 (20% before and 52% after the intervention,  $p < 0.001$ ), which is associated with a higher likelihood of following through on a decision.

*Li et al.* followed high quality standards for the design of decision aids including working with knowledge users (e.g. rheumatologists and patients) (7). The decision aid targeted the decision to begin or switch to a new biologic or small-molecule agent. SDM in rheumatoid

arthritis involves specifying the context for the decision with SDM being most relevant after patients have had an inadequate response to methotrexate monotherapy. ANSWER-2 uses a web-based format and multi-level adaptive design that progressively provides relevant information to patients. This is an important step forward for rheumatoid arthritis care where many options with complex benefits and risks occur.

However, this study showed that some patients expressed mixed reactions to the usefulness of the decision aid (7). Some found it helpful in improving knowledge while others stated it was “*the rheumatologist’s job*” to describe medication attributes: “[...] *I really think it’s a waste of time. [...] It’s the rheumatologist’s job, if he’s going to do his job properly, to relay this information to the patient.*” This contrast highlights a key point in SDM : tools cannot replace the conversation and collaboration between patient/family and clinician. Tools can support and facilitate SDM. This patient’s response underscores the importance of eliciting patient preferences for involvement, and tailor knowledge transfer and decision making processes to each individual patient/clinical context who faces their own unique situation (21).

In another trial, *Pablos et al.* developed and tested a decision aid to support treatment decisions among patients in Spain with moderate to severe rheumatoid arthritis who didn’t achieve therapeutic goals with their current treatment (22). In their beta testing with 54 patients and 6 rheumatologists, the authors showed that using the decision aid reduced decisional conflict score by 8.6 points.

In contrast to many decision aids developed in the United States, for use mainly in a private healthcare system, this trial focused on a European population. Implementing SDM in other healthcare systems and cultures will likely require developing new or adapting decision aids in contexts where options and costs may differ significantly. Also, there may be variation across cultures regarding expectations of healthcare, the patient-clinician dynamic, and thus require interventions to help raise awareness and train clinicians to implement SDM.

We observe that decision aids for rheumatoid arthritis focus solely on medication treatment choices. Newer decision aids should consider incorporating other treatment options. *Sepucha et al.* published the DECIDE-OA trial comparing two decision aids for helping patients with osteoarthritis decide about surgical options. This choice is relevant for a subset of patients with rheumatoid arthritis (23, 24). Our patients also benefit from rehabilitation interventions early during their disease and it will be fundamental to discuss these options in future SDM conversations.

Most decision aids for rheumatoid arthritis are at the pilot trial stage. We have yet to see a large-scale randomized trial that assesses longer-term outcomes such as adherence to treatment sequences, healthcare utilization and improvement in health outcomes (25). The SUNDAE reporting guidelines for trials of decision aids will likely guide researchers in their implementation and trial initiatives (26, 27).

**2.2 Shared goals to foster SDM**—Many current SDM frameworks skate over the goal-setting phase of the decision making process (28). Setting goals is a key aspect of

rheumatoid arthritis care, including the start of the treat-to-target approach when choosing targets (6, 9, 11). A recent systematic review identified over 400 patient goals and expectations in rheumatoid arthritis (29). Patients expressed a diversity of goals such as improving pain, lowering stress, increasing well-being, having better peer support and education about the disease, access to services and tools to communicate with healthcare providers (29). The goal setting phase of rheumatoid arthritis care is vital to patients' lives and goes beyond composite measures of disease activity targets.

Shared goals between patients and clinicians are far from being achieved: a recent survey found that half of patients with rheumatoid arthritis are uncomfortable raising concerns or fears with their physicians, while the latter wished patients would discuss more their goals (30). *Barton et al.* examined goal conceptualization in a qualitative study with 19 rheumatoid arthritis patients and 18 rheumatology clinicians (31). The authors identified two overarching domains of shared goals: knowledge and stress (31). Knowledge was important for making informed decisions for patients, and ensured adherence and medication safety was key for clinicians. Stress impacted patients' experience with healthcare and their treatment choices. The authors found a misalignment between patients' and clinicians' view on shared goals in rheumatoid arthritis.

This study is highly relevant to implementing SDM in a treat-to-target approach to reach concordance in goal setting. Direct quotes from patients and clinicians show that we are not addressing clear mechanisms of the SDM process in rheumatoid arthritis care, including knowledge and alignment with value and preferences. Thus, if a clinician and a patient can't agree on shared goals, the SDM process cannot occur, nor can they effectively follow a treat-to-target approach. The authors are designing a tool to improve goal elicitation and alignment of shared goals in rheumatoid arthritis management.

Integration of patient-reported outcomes into clinical encounters may also facilitate communication about goals and expectations (32). In one study, patients completed Patient-Reported Outcomes Measurement Information System (PROMIS) measures before consultation with a rheumatologist (33). Using PROMIS improved communication and facilitated SDM about treatment options by better understanding the patient's symptoms, behaviours, lifestyle and preferences for treatment. Teams aim to implement patient outcome measures in real time using an electronic dashboard, which will make it easier to integrate in rheumatology clinics (34).

**2.3 Identifying preference phenotypes**—Eliciting patients' values and preferences is a central aspect of SDM, yet a complex endeavour in rheumatoid arthritis due to the uncertainty of the disease trajectory. *Fraenkel et al.* assessed preference phenotypes to facilitate the SDM process (35). Among 1273 participants with rheumatoid arthritis who failed methotrexate monotherapy, the authors identified five preference phenotypes that would likely have the strongest impact on their subsequent treatment decisions. Most patients' decisions would be impacted by the cost of medication, followed by the risk of bothersome side effects, risk of rare side effects, mode of administration of medication, onset of action and risk of serious infections (35). Simplifying preference phenotypes before

clinic visits is an innovation in SDM that has the potential to make it easier for clinicians to acknowledge, elicit, and address patients' preferences.

Guided by the preference phenotypes, *Hsiao et al* designed a value clarification tool to support SDM for treatment escalation decisions (36). The tool differs from traditional decision aids: it anchors the process on preference phenotypes likely to impact subsequent treatment decisions based on their values and goals. Ninety-six clinician-patient dyads used the tool which resulted in more medication choices offered to patients and a higher number of visits in which medication characteristics and costs were discussed. More patients expressed their values and preferences concerning treatment escalation decisions and these decisions were more likely to be concordant with what mattered most to patients (36).

**Key messages:** New trials of decision support tools showed effectiveness to improve SDM process concerning treatment options in rheumatoid arthritis. Innovative SDM strategies including setting shared goals and phenotyping patients' preferences are being leveraged to guide treatment decisions and support the treat-to-target approach. Large-scale trials that implement SDM tools and strategies in clinical practice are needed along with rigorous standardization of SDM measures of impact.

### 3. OMERACT Core Outcome Domains to Measure SDM in Rheumatology

A barrier to implementing SDM in clinical practice is deciding whether SDM occurred and how to measure its impact. In 2015, *OMERACT (Outcome Measures in Rheumatology)* created a working group on SDM to identify core outcome domains to be used in trials of SDM interventions in rheumatology (37, 38). The group published a white paper outlining a 6-step process for SDM and five Core Outcome Domains (39). The proposed five Core Outcome Domains to measure the impact of SDM include:

1. Knowledge: does the patient know more about treatment options and benefits and risks after being exposed to a SDM intervention?
2. Alignment with values and preferences: does the SDM tool help the patient choose the treatment that has the characteristics that matter most to them?
3. Confidence: does the patient feel that they made the best decision?
4. Satisfaction: is the patient satisfied about the decision-making process?
5. Adherence: did the patient follow through with the chosen option?

The working group will publish concise whiteboard videos early in 2020 to describe their process and outline the proposed domains. After establishing consensus on core domains, the group will then identify a core set of measurement tools for SDM in clinical practice. Several tools already exist to measure SDM, but mainly for research purposes (40). A recent paper focused on the comparison of three short SDM measures (SDM Process\_4, CollaboRATE and SURE) and found these measures to have valid psychometric properties (41), however broad use of the measures in rheumatology is lacking. These measures are easy to use and could be implemented in clinical care for rheumatoid arthritis.



**Key messages:** Collaborative efforts to identify and standardize core domains to assess the impact of SDM interventions on patients with rheumatoid arthritis are actively underway. The next phase will be to identify best current and practical tools for measuring SDM in clinical practice and develop new ones if required.

## Conclusion

Our understanding of SDM in rheumatoid arthritis is in its infancy but expanding rapidly. Current evidence addresses barriers to the implementation of SDM that may serve other fields of medicine. The rheumatology community must define the best ways to foster meaningful SDM in clinical consultations, unravel innovative SDM interventions and measure SDM in clinical practice. We need to design multifaceted implementation strategies that combine clinician training and SDM tools to fully realize SDM in practice. We propose a set of research priorities and unanswered questions that will improve our understanding of SDM (Table). Ongoing exploration of this expanding universe must continue.

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## References

1. Singh JA, Saag KG, Bridges SL Jr., Akl EA, Bannuru RR, Sullivan MC, et al. 2015 American College of Rheumatology Guideline for the Treatment of Rheumatoid Arthritis. *Arthritis care & research*. 2016;68(1):1–25. [PubMed: 26545825]
2. Smolen JS, Landewe R, Bijlsma J, Burmester G, Chatzidionysiou K, Dougados M, et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update. *Annals of the rheumatic diseases*. 2017;76(6):960–77. [PubMed: 28264816]
3. Legare F, Labrecque M, Cauchon M, Castel J, Turcotte S, Grimshaw J. Training family physicians in shared decision-making to reduce the overuse of antibiotics in acute respiratory infections: a cluster randomized trial. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*. 2012;184(13):E726–34.
4. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, et al. A three-talk model for shared decision making: multistage consultation process. *Bmj*. 2017;359:j4891. [PubMed: 29109079]
5. McCormack J, Elwyn G. Shared decision is the only outcome that matters when it comes to evaluating evidence-based practice. *BMJ Evid Based Med*. 2018.
6. van Vollenhoven R Treat-to-target in rheumatoid arthritis - are we there yet? *Nat Rev Rheumatol*. 2019;15(3):180–6. [PubMed: 30700865] \* This paper describes the history and key challenges of implementing the treat-to-target approach in rheumatoid arthritis.
7. Li LC, Shaw CD, Lacaille D, Yacyshyn E, Jones CA, Koehn C, et al. Effects of a Web-Based Patient Decision Aid on Biologic and Small-Molecule Agents for Rheumatoid Arthritis: Results From a Proof-of-Concept Study. *Arthritis care & research*. 2018;70(3):343–52. [PubMed: 28544648] \* This study assessed the impact of an online adaptive decision aid to reduce decisional conflict concerning the choice of biological or small molecule agents. The decision aid is co-designed following high quality standards.
8. Binder-Finnema P, Dzurilla K, Hsiao B, Fraenkel L. Qualitative Exploration of Triangulated, Shared Decision-Making in Rheumatoid Arthritis. *Arthritis care & research*. 2019;71(12):1576–82. [PubMed: 30369071]

9. Falzer PR. Treat-to-target and shared decision making in rheumatoid arthritis treatment: Is it feasible? *Int J Rheum Dis*. 2019;22(9):1706–13. [PubMed: 31359630]
10. Zak A, Corrigan C, Yu Z, Bitton A, Fraenkel L, Harrold L, et al. Barriers to treatment adjustment within a treat to target strategy in rheumatoid arthritis: a secondary analysis of the TRACTION trial. *Rheumatology*. 2018;57(11):1933–7. [PubMed: 29982720]
11. Benham H, Rutherford M, Kirby S, Stebbings S, White D, Sim D, et al. Treat-to-target in rheumatoid arthritis: Evaluating the patient perspective using the Patient Opinion Real-Time Anonymous Liaison system: The RA T2T PORTAL study. *Int J Rheum Dis*. 2019;22(5):874–9. [PubMed: 30793870]
12. Stacey D, Legare F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane database of systematic reviews*. 2017;4:CD001431.
13. Legare F, Adekpedjou R, Stacey D, Turcotte S, Kryworuchko J, Graham ID, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *The Cochrane database of systematic reviews*. 2018;7:CD006732.
14. Barton JL, Trupin L, Schillinger D, Evans-Young G, Imboden J, Montori VM, et al. Use of Low-Literacy Decision Aid to Enhance Knowledge and Reduce Decisional Conflict Among a Diverse Population of Adults With Rheumatoid Arthritis: Results of a Pilot Study. *Arthritis care & research*. 2016;68(7):889–98. [PubMed: 26605752]
15. Mathijssen EGE, van den Bemt BJJ, van den Hoogen FHJ, Popa CD, Vriesekolk JE. Interventions to support shared decision making for medication therapy in long term conditions: A systematic review. *Patient Educ Couns*. 2019.
16. Barton JL, Koenig CJ, Evans-Young G, Trupin L, Anderson J, Ragouzeos D, et al. The design of a low literacy decision aid about rheumatoid arthritis medications developed in three languages for use during the clinical encounter. *BMC Med Inform Decis Mak*. 2014;14:104. [PubMed: 25649726]
17. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, van der Weijden T. A systematic development process for patient decision aids. *BMC Med Inform Decis Mak*. 2013;13 Suppl 2:S2.
18. Joseph-Williams N, Newcombe R, Politi M, Durand MA, Sivell S, Stacey D, et al. Toward Minimum Standards for Certifying Patient Decision Aids: A Modified Delphi Consensus Process. *Medical decision making : an international journal of the Society for Medical Decision Making*. 2014;34(6):699–710. [PubMed: 23963501]
19. Mathijssen EGE, Vriesekolk JE, Popa CD, van den Bemt BJJ. Shared decision making in routine clinical care of patients with rheumatoid arthritis: an assessment of audio-recorded consultations. *Annals of the rheumatic diseases*. 2019.\*\* This study analyzed SDM from an observer perspective in routine consultations for rheumatoid arthritis. The authors found low to moderate scores of SDM indicating an important potential to develop SDM tools and interventions.
20. Legare F, Shemilt M, Stacey D. Can shared decision making increase the uptake of evidence in clinical practice? *Frontline Gastroenterol*. 2011;2(3):176–81. [PubMed: 28839605]
21. Hargraves IG, Montori VM, Brito JP, Kunneman M, Shaw K, LaVecchia C, et al. Purposeful SDM: A problem-based approach to caring for patients with shared decision making. *Patient Educ Couns*. 2019;102(10):1786–92. [PubMed: 31353170]
22. Pablos JL, Jover JA, Roman-Ivorra JA, Inciarte-Mundo J, Dilla T, Sacristan JA, et al. Patient Decision Aid (PDA) for Patients with Rheumatoid Arthritis Reduces Decisional Conflict and Improves Readiness for Treatment Decision Making. *Patient*. 2019\* This study assessed a decision aid to support treatment decision in European population. Adapting decision aids to other cultures than United States is required to benefit all patients.
23. Ishikawa H, Abe A, Kojima T, Kojima M, Ishiguro N, Nomura Y, et al. Overall benefits provided by orthopedic surgical intervention in patients with rheumatoid arthritis. *Modern rheumatology / the Japan Rheumatism Association*. 2019;29(2):335–43.
24. Kobayashi S, Niki Y, Harato K, Nagura T, Nakamura M, Matsumoto M. Rheumatoid Arthritis Patients Achieve Better Satisfaction but Lower Functional Activities as Compared to Osteoarthritis Patients After Total Knee Arthroplasty. *J Arthroplasty*. 2019;34(3):478–82 e1. [PubMed: 30514640]



25. Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. *Implementation science* : IS. 2016;11:114. [PubMed: 27502770]
26. Hoffman AS, Sepucha KR, Abhyankar P, Sheridan S, Bekker H, LeBlanc A, et al. Explanation and elaboration of the Standards for UNiversal reporting of patient Decision Aid Evaluations (SUNDAE) guidelines: examples of reporting SUNDAE items from patient decision aid evaluation literature. *BMJ quality & safety*. 2018;27(5):389–412.
27. Sepucha KR, Abhyankar P, Hoffman AS, Bekker HL, LeBlanc A, Levin CA, et al. Standards for UNiversal reporting of patient Decision Aid Evaluation studies: the development of SUNDAE Checklist. *BMJ quality & safety*. 2018;27(5):380–8.
28. Elwyn G, Vermunt NPCA. Goal-Based Shared Decision-Making: Developing an Integrated Model. *Journal of Patient Experience*.0(0):2374373519878604.
29. Hulen E, Ervin A, Schue A, Evans-Young G, Saha S, Yelin EH, et al. Patient goals in rheumatoid arthritis care: A systematic review and qualitative synthesis. *Musculoskeletal Care*. 2017;15(4):295–303. [PubMed: 27976535]
30. Gibofsky A, Galloway J, Kekow J, Zerbini C, de la Vega M, Lee G, et al. Comparison of patient and physician perspectives in the management of rheumatoid arthritis: results from global physician- and patient-based surveys. *Health Qual Life Outcomes*. 2018;16(1):211. [PubMed: 30413162]
31. Barton JL, Hulen E, Schue A, Yelin EH, Ono SS, Tuepker A, et al. Experience and Context Shape Patient and Clinician Goals For Treatment of Rheumatoid Arthritis: A Qualitative Study. *Arthritis care & research*. 2018;70(11):1614–20. [PubMed: 29438606] \* This study is among the few to assess the concept of shared goals as a strategy to foster SDM in clinical practice. This has important implications for addressing rehabilitation options in rheumatoid arthritis.
32. Fautrel B, Alten R, Kirkham B, de la Torre I, Durand F, Barry J, et al. Call for action: how to improve use of patient-reported outcomes to guide clinical decision making in rheumatoid arthritis. *Rheumatol Int*. 2018;38(6):935–47. [PubMed: 29564549]
33. Bartlett SJ, De Leon E, Orbai AM, Haque UJ, Manno RL, Ruffing V, et al. Patient-reported outcomes in RA care improve patient communication, decision-making, satisfaction and confidence: qualitative results. *Rheumatology*. 2019.
34. Ragouzeos D, Gandrup J, Berrean B, Li J, Murphy M, Trupin L, et al. “Am I OK?” using human centered design to empower rheumatoid arthritis patients through patient reported outcomes. *Patient Educ Couns*. 2019;102(3):503–10. [PubMed: 30446358]
35. Fraenkel L, Nowell WB, Michel G, Wiedmeyer C. Preference phenotypes to facilitate shared decision-making in rheumatoid arthritis. *Annals of the rheumatic diseases*. 2018;77(5):678–83. [PubMed: 29247126]
36. Hsiao B, Binder-Finnema P, Nowell WB, Michel G, Wiedmeyer C, Fraenkel L. Preference Phenotypes in Support of Shared Decision-Making at Point-of-Care for Patients With Rheumatoid Arthritis: A Proof-of-Concept Study. *Arthritis care & research*. 2019;71(5):629–37. [PubMed: 29953733] \*\* This study assessed the impact of a decision aid targeting treatment escalation decisions. It differs from traditional SDM approaches by anchoring the process on preference phenotypes likely to impact subsequent treatment decisions. This study demonstrates that using SDM strategies in the context of treat-to-target decisions is feasible and likely to have positive impact on the process of care.
37. Toupin-April K, Barton J, Fraenkel L, Li L, Grandpierre V, Guillemin F, et al. Development of a Draft Core Set of Domains for Measuring Shared Decision Making in Osteoarthritis: An OMERACT Working Group on Shared Decision Making. *J Rheumatol*. 2015;42(12):2442–7. [PubMed: 25877502]
38. Toupin-April K, Barton J, Fraenkel L, Li LC, Brooks P, De Wit M, et al. Toward the Development of a Core Set of Outcome Domains to Assess Shared Decision-making Interventions in Rheumatology: Results from an OMERACT Delphi Survey and Consensus Meeting. *J Rheumatol*. 2017;44(10):1544–50. [PubMed: 28765239]
39. Toupin-April K, Barton JL, Fraenkel L, Meara A, Li LC, Brooks P, et al. OMERACT Development of a Core Domain Set of Outcomes for Shared Decision-making Interventions. *J Rheumatol*. 2019.\*\* This study describes the development process of OMERACT Core Domain Set for SDM

interventions in rheumatology. It will likely lead to a standardization of measures in SDM trials for rheumatoid arthritis which will help better understand the impact of SDM interventions.

40. Gartner FR, Bomhof-Roordink H, Smith IP, Scholl I, Stiggelbout AM, Pieterse AH. The quality of instruments to assess the process of shared decision making: A systematic review. *PloS one*. 2018;13(2):e0191747.
41. Brodney S, Fowler FJ Jr., Barry MJ, Chang Y, Sepucha K. Comparison of Three Measures of Shared Decision Making: SDM Process\_4, CollaboRATE, and SURE Scales. *Medical decision making : an international journal of the Society for Medical Decision Making*. 2019;39(6):673–80. [PubMed: 31226911]

**Key points**

- Shared decision making is not yet embedded in clinical consultations for rheumatoid arthritis.
- New trials of decision aids improved patient knowledge and reduced decisional conflict concerning treatment options, but large-scale trials are lacking.
- Innovative strategies including shared goals and preference phenotypes support implementation of SDM in a treat-to-target approach.
- Core outcome domains are being identified to measure the impact of incorporating shared decision making in clinical practice which may spur research on training or easy-to-use tools.

**TABLE.**

Proposed research priorities and research questions to improve our understanding of SDM in rheumatoid arthritis.

Research components	Research priorities	Research questions
1. Shared decision making process at the level of clinical consultation	<ul style="list-style-type: none"> <li>Assess if and how shared decision making happens in diverse clinical consultations for rheumatoid arthritis.</li> </ul>	<ul style="list-style-type: none"> <li>What are the different decisions facing patients with rheumatoid arthritis at the different steps of their care process?</li> </ul>
2. Strategies to foster shared decision making in rheumatoid arthritis.	<ul style="list-style-type: none"> <li>Pursue development of new decision aids using adaptative and computer-assisted designs.</li> <li>Pursue large-scale pragmatic randomized trials of decision aids and/or clinician training to determine their effectiveness.</li> <li>Expand innovative SDM strategies such as shared goals and preference phenotypes.</li> </ul>	<ul style="list-style-type: none"> <li>Are there more effective implementation strategies beyond the learning collaborative to support uptake of SDM in clinical practice?</li> <li>Is there a differential effect of SDM tools among persons with limited health literacy?</li> </ul>
3. Measuring SDM and its impact in clinical practice	<ul style="list-style-type: none"> <li>Following consensus on Core Outcome Domains for SDM, identify valid, reliable and easy-to-use tools to measure the impact of SDM in clinical practice.</li> </ul>	<ul style="list-style-type: none"> <li>Does SDM improve rheumatoid arthritis outcomes (e.g. disease activity, quality of life)?</li> <li>Can SDM reduce disparities in health outcomes in rheumatoid arthritis?</li> </ul>