

“It may help you to know...”: The Early-phase Qualitative Development of a Rheumatoid Arthritis Goal Elicitation Tool

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ABSTRACT. *Objective.* Treatment guidelines for rheumatoid arthritis (RA) include a patient-centered approach and shared decision making, which includes a discussion of patient goals. We describe the iterative early development of a structured goal elicitation tool to facilitate goal communication for persons with RA and their clinicians.

Methods. Tool development occurred in 3 phases: (1) clinician feedback on the initial prototype during a communication training session; (2) semistructured interviews with RA patients; and (3) community stakeholder feedback on elements of the goal elicitation tool in a group setting and electronically. Feedback was dynamically incorporated into the tool.

Results. Clinicians (n = 15) and patients (n = 10) provided feedback on the tool prototypes. Clinicians preferred a shorter tool deemphasizing goals outside of their perceived treatment domain or available resources; they highlighted the benefits of the tool to facilitate conversation but raised concerns regarding current constraints of the clinic visit. Patients endorsed the utility of such a tool to support agenda setting and preparing for a visit. Clinicians, patients, and community stakeholders reported the tool was useful but identified barriers to implementation that the tool could itself resolve.

Conclusion. A goal elicitation tool for persons with RA and their clinicians was iteratively developed with feedback from multiple stakeholders. The tool can provide a structured way to communicate patient goals within a clinic visit and help overcome reported barriers such as time constraints. Incorporating a structured communication tool to enhance goal communication and foster shared decision making may lead to improved outcomes and higher-quality care in RA.

Key Indexing Terms: goal elicitation, qualitative methods, quality of care, rheumatoid arthritis, shared decision making

The international treat-to-target guidelines for rheumatoid arthritis (RA) outline treatment goals for disease activity¹ and emphasize patient involvement in goal setting.² With a focus on disease activity targets, rheumatologists often fail to elicit patient goals and, historically, patients tend to defer to the clinician's agenda during the clinic visit.³ Alignment or agreement of

goals between patient and clinician, or goal concordance, has been studied in other chronic conditions such as diabetes⁴ and end-of-life care.⁵ Studies have identified a positive relationship between goal concordance and improved clinical outcomes, and conversely, between discordant goals and poor adherence.^{6,7}

Rheumatology studies over the past decades documented conflicting clinician–patient priorities and values; there is also nonrheumatology literature showing that discordant patient–clinician health goals were associated with poor outcomes.^{8,9,10} A previous qualitative study found that patients with RA and clinicians approach treatment goals differently, in part due to different knowledge bases and competing priorities.¹¹ Use of a discussion aid in the primary care setting to enable conversations about patient “workload, capacity and treatment burden” demonstrated feasibility and no increase in visit length.¹²

Communication barriers that limit the elicitation or understanding of patient-identified goals may contribute to poor patient experience and negative health outcomes in chronic disease management. Suboptimal patient-centered communication in RA has been reported among persons with communication barriers such as limited health literacy, limited English-language proficiency, and lower trust in physicians.¹³ Communication tools to foster shared decision making have

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been developed in RA.^{13,14,15,16} Goals commonly identified by patients with RA in the literature relate to aspects of normal daily life, physical capacity, independence, and well-being.^{17,18} With limited time for follow-up visits and a focus on treating to a disease activity target, clinicians may not discuss disease education or lifestyle factors with patients, despite formal recommendations to do so.^{19,20} The quality of patient–clinician communication in the management of rheumatologic conditions has a strong connection to the patient’s health-related quality of life (QOL).²¹ Identifying patient preferences for important health and symptom status outcomes can aid in medical and therapeutic intervention planning, and increase patient satisfaction and adherence.^{13,22}

Given prior studies that underscored the importance of patient–clinician goal concordance in chronic diseases such as diabetes, and the divergent goals of patients with RA and clinicians uncovered in our qualitative work, the objective of this study was to design a goal elicitation tool using an iterative process that included feedback from multiple stakeholders, including patients with RA and clinicians.

METHODS

Overview. Data from an extensive literature review,¹⁸ multiple focus groups with RA patients and clinicians,¹¹ and community stakeholder feedback led to the creation of a goals measure for persons with RA,²³ which provided pilot data to inform the initial goal elicitation tool prototype in the current study. With the intent to generate a more balanced conversation between patients and clinicians around patient goals, available tools not specific to rheumatology were reviewed, and common elements to foster conversation were included in the prototypes with permission.^{24,25} The research protocol for this study was approved by the joint institutional review board (IRB) of these 2 academic medical centers (IRB Number 15851). Written informed consent was waived.

Participants. Patient participants were recruited from 2 rheumatology clinics at 2 large medical centers, one a Veterans Affairs (VA) hospital clinic and the other a university hospital clinic. Eligible patients met the American College of Rheumatology 2010 criteria for RA, were aged ≥ 18 years, spoke English, and had been seen by a rheumatology clinician at least once in the prior 12 months. Eligible patients were mailed a recruitment letter 2 weeks before an upcoming rheumatology appointment. On the day of the appointment, patients were approached in the waiting room by research staff to ask if they were willing to provide feedback on a communication tool. Interested patients were enrolled. Out of 25 patients who were mailed an invitation, 10 attended their scheduled clinic visit and agreed to participate (40%). Clinician participants included rheumatology faculty, fellows, and advance practice partners from the 2 clinics; a total of 15 clinicians provided feedback on the goal tool.

The initial goal elicitation tool prototype. Representative RA patient-identified goals from the original goals measure were included in the first iteration of the goal elicitation tool and displayed in a circle or wheel (Figure 1). Instructions for the goal tool prompted patients to identify their 3 top goals for treatment. Placing the goals in a circle was meant to avoid imposing a hierarchy onto individual patient priorities. The 8 goals included the following: have less pain, work regularly, do daily activities, improve mood, feel less tired, improve sleep, avoid side effects, and other. To capture the nuanced lifestyle and illness experience of patients, open-ended questions such as, “Anything else on your mind?” were included, with space allotted for the patient to write important information to discuss with the clinician. Additionally, to include broader QOL factors, open-ended questions of “Where do you find the most joy in life?” and “What are you doing to

manage your pain and/or stress?” as well as sentence stems to help the patient start a conversation in the visit were included on the second page of the tool. These more general questions were adapted from the ICAN Discussion Aid and from materials developed by the Patient Revolution.^{12,24,25}

Phase 1: Clinician feedback. Rheumatology specialists attended a 1.5-hour, in-person clinician training session on communication and were introduced to the initial goal tool prototype developed by the research team. The tool was presented to the local division of rheumatology attending physicians, fellows, and advanced practice partners; the majority attended. Food was provided. Clinicians provided written and verbal input on the content and organization of the tool, and reflected on how it may fit into the flow of a clinical encounter.

Phase 2: Usability testing—cognitive interviews with RA patients. Based on the clinician feedback, 2 subsequent prototypes of the goal tool (where order of presentation varied with the goal circle at the top of the page in 1 version and at the bottom in a second) were presented in random order to consecutively recruited RA patients (Figure 1). Iterative usability testing involved administering the 2 prototypes to patients who evaluated the goal tool for clarity, completeness, redundancy, and format. The first 5 RA patient participants were asked to provide feedback on these 2 iterations of the goal tool (Figure 1, Tool A and Tool B) in a 30-minute semistructured cognitive interview. Questions assessed ease of understanding the content of the tool and elicited feedback on wording or design elements that should be changed, kept, removed, or were missing.

Unstructured questions assessed participant opinions of feedback received during prior testing to better understand generalizability of suggested changes to the tool. In the refinement-development portion of phase 2, the second half of the patient sample ($n = 5$) was asked to provide feedback on later iterations of the tool (Tool C) based on the incorporated clinician feedback and feedback from the first half of the patient participants. Tool C included the addition of color pictures of the goals, black-and-white icons of the goals, and variations of questions on pain, stress, medication, and mobility or function (Supplementary Figure 1, available with the online version of this article). This dynamic testing process further refined the goal tool by eliminating redundancies and emphasizing the key elements most effective in goal communication while using the clearest and most visually appealing format. A research assistant wrote down verbatim quotes and nonverbal observations during all interviews. Participants received a \$25 gift card for their participation. The research assistant and interviewer debriefed the tool development research team at regular meetings throughout this process. The team then collectively decided how to make changes to the tool in real-time based on the most commonly endorsed changes suggested by patients.

Phase 3: Written feedback from the community stakeholder group. The Veteran Engagement Group (VEG) is a group of volunteer veteran stakeholders who provide feedback to researchers in the local Veterans Health Administration. They meet monthly to give feedback on research projects regarding understanding, usability, and feasibility. VEG participants were invited to provide written feedback on the iteration of the goal tool that incorporated all clinician and patient feedback (Tool C). No one on this panel of stakeholders disclosed a diagnosis of RA but were experienced in usability evaluation and highly engaged in the healthcare system. This VEG feedback validated the final prototype iteration (Figure 2).

Analysis. Qualitative themes were identified during each stage of testing and development, then used to redesign the tool for subsequent usability evaluation. The initial feedback from the 5 patients with RA was analyzed in parallel to the interviews and incorporated in the Tool C prototype. The second group of 5 patients with RA then provided feedback to refine the tool for ease of use, architecture, task flow, and concordance with user needs to create the final Tool C version. A pragmatic, explanatory approach based on grounded theory²⁶ was used for content analysis: patterns and themes were induced from clinician and patient feedback until saturation was reached. Written and verbatim qualitative feedback on implementing the

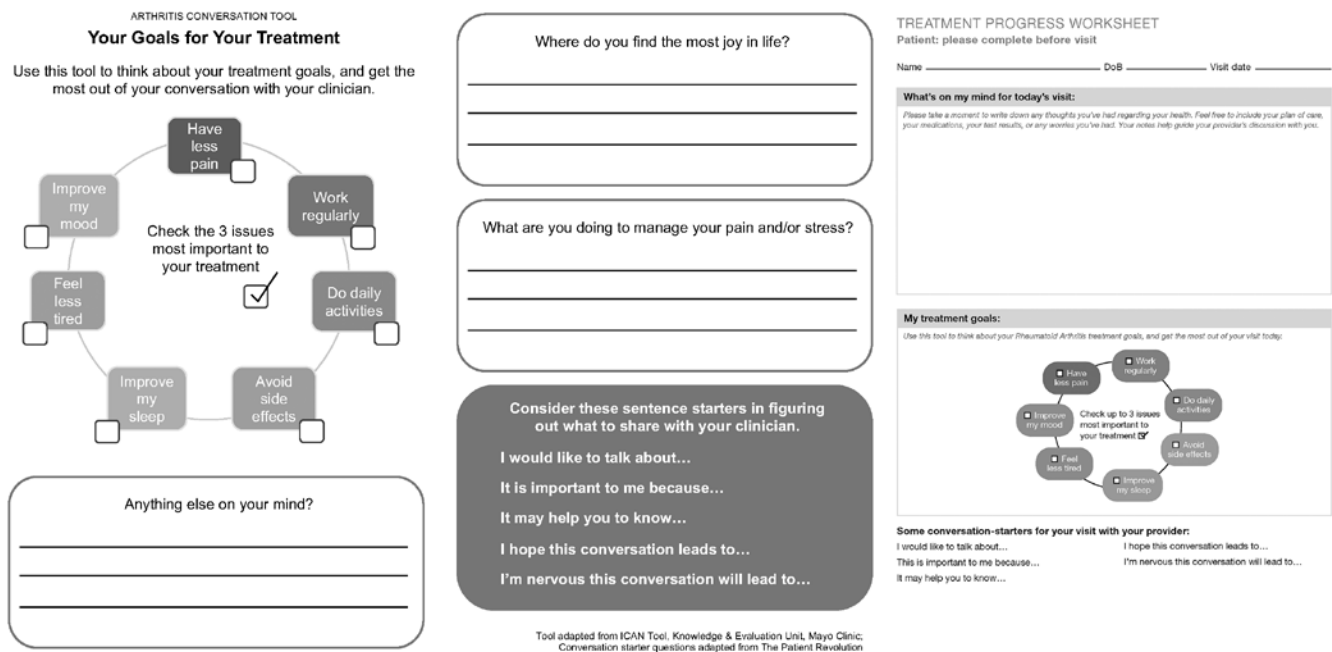


Figure 1. The goals identified from prior studies were incorporated as wheels into 2 iterations of the tools, Tools A and B, along with open-ended prompts. Sentence stems were used on the reverse side of Tool A and on the front side of Tool B.

goal elicitation tool is presented in the Results section. Decisions about the final goal prototype format were based on these common themes.

RESULTS

Participant demographics. Fifteen rheumatology clinicians attended the communication training during phase 1. The majority were MDs and 6 were female. In phase 2, a total of 10 patients with RA agreed to participate; 4 were female. Six patients were recruited from the VA clinic, and 4 from the university clinic. Most interviews took place immediately before a clinic visit, and 2 were conducted afterwards. The mean age of patients with RA was 63 years (SD 8.24, range 47–74 yrs). Six patients resided in urban areas, and 4 in rural areas. In phase 3, written feedback on the final prototype of the tool was provided by 4 veteran stakeholders (2 female, 1 retired, 2 students, and 1 employed).

Phase 1 results: Clinician feedback (presented with a 2-sided version of the tool; Figure 1, Tool A). Overall, clinicians acknowledged communication challenges and goal misalignment, and they endorsed the utility of a structured goal tool, especially the sentence stems to aid in communication. Clinicians identified high caseload burden and time limitations during a rheumatology visit as barriers to a goal discussion or use of the goal tool. Other barriers included the perception that several of the goals listed on the tool were outside of one’s practice scope. Lack of systemic support or referral resources were also cited as barriers despite recognition that patients often bring up these concerns during the appointment. Alternately, a majority of clinicians endorsed the utility of goal communication, patient empowerment, and long-term benefits to reduce administrative burden and improve treatment outcomes (see Table 1 for clinician quotations and qualitative themes).

In phase 1, clinicians expressed a preference for a shorter tool that deemphasized goals they deemed outside of their treatment domain or available resources.

Phase 2 results: Patient feedback on iterative tool versions.

- **Patterns of feedback differed by individual characteristics and past experiences.** The majority of the patients with RA endorsed the utility of the goal tool to align patient and clinician needs. However, patients’ prior experiences with the medical system and individual clinician communication style influenced patient perceptions of the tool’s acceptability. Some patients felt their agenda was overlooked, which made them less likely to communicate goals: “The doctor does not listen, he has his own agenda—his way or no way—he does not care about my agenda. There’s [*sic*] only so many times I get bulldozed before I give up” (Patient 2).

- **Patient reactions to the format of the goal tool.** Preferences for the original tool prototype layout (Tool A) were most prominent. It was described as clear and easy to understand. Most patients found the writing prompt, “Anything else on your mind?” useful; however, others were either uncomfortable writing personal information or had physical barriers that impaired their ability to complete the tool. “Those with RA would find it too difficult to complete due to arthritis in the hand” (Patient 4).

- **Sentence stem conversation starters.** Response to the sentence stem conversation starters was unanimously positive. A few patients voiced concern over the phrase, “I am nervous about...” and preferred it be removed in order to avoid discussing anything negative with their clinician. In contrast, 1 participant stated that having the nervousness prompt validated her nervousness and made it more acceptable to discuss uncomfortable topics that may be embarrassing: “To see it written means it’s okay

Goals for Treatment

Check your **3 most important goals** for today's visit:

Check your **3 most important goals**

Anything else on your mind for today's visit?

What are you doing to manage pain and/or stress?

- | | |
|---|---|
| <input type="checkbox"/> Take a walk | <input type="checkbox"/> Take a warm bath or shower |
| <input type="checkbox"/> Spend time with family | <input type="checkbox"/> Read a good book or watch a movie |
| <input type="checkbox"/> Work on a hobby | <input type="checkbox"/> Meditate or pray |
| <input type="checkbox"/> Listen to music | <input type="checkbox"/> Do a crossword puzzle or play a game |
| <input type="checkbox"/> Time with pets | <input type="checkbox"/> Other: _____ |

Consider these sentence starters in deciding what to share with your clinician.

I would like to talk about...
 It's important because...
 It may help you to know...

Tool adapted from ICAN Tool, Knowledge & Evaluation Unit, Mayo Clinic;
 Conversation starter questions adapted from The Patient Revolution

Figure 2. Final goal elicitation tool, which includes black-and-white icons, space for writing thoughts for the visit, strategies for pain and stress management, and sentence starters.

Table 1. Clinician feedback on goal tool (phase 1).

Positive reactions to learning about enhancing communication with patients
<p>“Reinforces need to address what the patient expects/would like to achieve in a visit.”</p> <p>“I was not aware that embarrassment was an emotion experienced at a physician visit. I will be cognizant of this in my future practice.”</p> <p>“Even though the patient says, ‘I’ll do what you say, doc,’ go further and work on further eliciting goals of care more directly.”</p> <p>“Sentence starters might be helpful if they have worries or expectations; it helps them get them out.”</p> <p>“This [tool] cuts down on follow-up calls about things patients were not able to talk about in the clinic.”</p> <p>“Often, these thoughts come out only at the very end; it would be fabulous if they did this at the beginning.”</p>
Medical complexity and prior experiences obscure goal communication
<p>“I would love more ways to help patients understand what is a realistic goal for a rheumatology visit. At [the] optometrist or dentist, most people go in knowing what they can/can’t expect but medical visits, especially RA, are vague and there isn’t a clear idea of what we can/can’t do for them.”</p> <p>“Anxiety in the medical room does go back to prior physician experiences. It seems three-quarters of the time is spent getting anxiety down so that you can get to communicating, which usually only occurs until later at the end of the session.”</p>
Limited time and resources to explore patient treatment goals
<p>“It’s [using the tool] challenging but doable; the currency is time. It’s not just this patient but all patients behind them. Always have to consider how long you can spend with patients, since you have to take that time away from someone else.”</p> <p>“A new patient visit...is an opportunity,” and the questions might “empower the patient to feel okay bringing up certain topics. I’d like to know why they’re here, what hopes [they] have to accomplish today. The visit is time-limited; I’m not going to be able to touch on everything, but giving them the chance to bring it up can help them fulfill their agenda.”</p> <p>“Essentially there is only time for some information gathering of what the problem might be, physical examination, then discussing the plan and doctor documentation, order writing, prescription refill orders.”</p> <p>“I’m worried that these are not things I can realistically help with. Need a tool that focuses on things that are more reasonably approached.”</p> <p>“Mental health is important but beyond the scope of the appointment.”</p>
Systemic constraints interfere with goal discussions
<p>“This is only 1 focus of communication but there are bigger problems with our medical culture that are interfering with doctor–patient interaction.”</p> <p>“The tool would set up expectations that I would treat but (1) there is not enough time to treat mood; (2) outside scope of practice; and (3) no referral resources available from leadership and no time to connect patients with referrals/do case management.”</p>

to say it. I can talk to my doctor about something I’m nervous about, or acknowledging that you’re nervous about the appointment” (Patient 7). The number of sentence stems were reduced in the final version of the tool in order to keep all text on 1 page and included the following: (1) “I would like to talk about...”; (2) “This is important to me because...”; and (3) “It may help you to know...”

• *Patient responses to goal wheel.* Patients agreed that the goals listed on the tool were representative. Without prompting, half rated 3 goals they wanted to discuss for that day’s visit. With regard to specific goals that resonated with patients, mood was mentioned by all. Half of the patients found utility in retaining “mood” on the goal wheel, whereas the other half thought it unrelated to RA or that the rheumatologist would be unable to help with mood. Patients described how all the goals were in fact interrelated, each contributing to symptoms that affect daily life. One patient noted: “Goals are interrelated—‘if you feel better, you’ll sleep better.’ If you’re able to do normal activities throughout the day, you’ll be tired, and be able to sleep. When my pain is worse, I’m in a worse mood, and my spouse and I don’t get along as well” (Patient 3).

Final stage of development: Refinement using Tool C iterations. The refinement stage tested Tool A against variants of Tool C, the dynamic prototype of the final version. Tool C ultimately became the final prototype. Tool C was edited down to a single page to include only elements the consensus agreed would provide the most utility in guiding the goal conversation. By dynamically incorporating minor differences in formatting and wording of questions, each variant was presented and assessed for patient preference on the second half of the patient sample.

Different versions of Tool C varied in presentation using the following: (1) color pictures vs icons of the goals; (2) presentation of a goal wheel, vs list, vs square; and (3) variations of wording for the stress and pain management question prompt. Icons of the goals were preferred and elicited the most positive response from patients: “Keeping icons associated with the goals lends a more modern appearance and can be helpful for people who visually process information” (Patient 9). Black-and-white icons were preferred over no icons and over color pictures. At times, if the picture or icon was not an exact match to the goal, patients were confused and exasperated, reporting that it took too long to understand or complete the tool. Color pictures introduced too much visual noise and made it too difficult to quickly grasp goal concepts. When individual question prompts about pain, function, and medications were added, responses were negative: “Tool C is not as simplistic as Tool A” (Patient 10). Stress management strategies in checkbox form were ultimately included in the final version.

Cross-cutting themes from patient and clinician feedback.

• *Acknowledgment of system limitations.* Patients and clinicians acknowledged constraints on communication, especially for more complex cases. Viewed as an important but brief appointment, both wanted the clinic visit to be efficient and focused on RA-related topics. However, patients were unsure which symptoms were relevant and which should be prioritized.

• *Differences in goal focus.* Patient and clinician goals differed: clinicians focused on medical and administrative tasks whereas patients focused on daily QOL problems due to RA symptoms. Notably, clinicians emphasized information gathering, physical exams, and administrative goals; patients emphasized

maintaining an acceptable QOL in the face of limited function in order to continue doing valued activities such as going to church, fishing, walking, and being with family. Outcomes were defined differently from the perspective of clinicians vs that of patients (Table 2).

Phase 3: Written feedback from the VEG. Veteran stakeholders were presented with the final iteration of the goal tool, after feedback from patients and clinicians had been incorporated. Stakeholders reported that the goal tool was “very fast to fill out” and useful to prioritize patients’ needs to discuss with the clinician. One stakeholder wrote: “Great tool that is simple, self-explanatory, and easy to use as a conversation starter”.

DISCUSSION

A novel goal elicitation tool for persons with RA and their rheumatology clinician was iteratively developed by dynamically incorporating qualitative feedback from patients, clinicians, and a veteran stakeholder group. This is the first communication tool to support a discussion of goals for RA treatment developed with, and for, patients with RA. Iterative usability testing of the tool prototype assessed patient and clinician feedback to arrive at a final version of the tool for use during rheumatology appointments. This tool is intended to improve patient–clinician communication in RA. The overwhelming majority of patients endorsed

the utility of the tool for enhancing communication regarding the patient’s goals. It was rated as acceptable and useful, accurately capturing patient-identified needs in a structured way to facilitate communication.

To our knowledge, this is the first goal elicitation conversation aid developed for RA. Notably, both patients and clinicians acknowledged that a structured goal tool would be beneficial; however, concerns about its use due to system barriers of time and resources were voiced. Medical training and insufficient institutional resources become paradoxical barriers to diagnosing problems with communication.^{27,28} Suboptimal patient–clinician communication, specifically around shared decision making, has been reported in RA.^{29,30} Tools to support elicitation of goals and shared decision making are needed. In a 2018 international survey of patients with RA, 61% of patients felt uncomfortable raising concerns or fears with their clinician, and 68% of clinicians wished they had more goals discussions with their patients.²¹

Differences in patient- and clinician-identified goals in our study exemplify the conflicting values in priorities.³¹ Clinicians focused on targeting the underlying clinical problem that most urgently needs to be treated while fulfilling requests for consultative services from the referring provider, and patients focused on individual priorities rooted in their own individual

Table 2. RA patient and stakeholder feedback on goal tool iterations.

Patient feedback	
General themes regarding usability in an RA visit, with RA patients endorsing the value of the goal tool	
	“This tool is so important, because patients can list their goals in the beginning of the visit, that’s what really on their mind, and want to get on the same page as their doctor. Anticipating what they’re going to cover, but unsure about how it will come about with doctor. Gives patient a chance to get their thoughts aligned before meeting with doctor” (Patient 3).
	“This goal tool would be helpful [for] every appointment to help sort out and organize all of the different things they’d like to discuss with the doctor, because during the appointment it gets lost or tend to forget because the doctor has an agenda and is direct and it goes quickly” (Patient 7).
Presentation and preferences for Tool A (goal wheel at top) vs Tool B (open space at top, goal wheel at bottom)	
	“Tool A would help the doctor zero in on your needs and what you want addressed” (Patient 10).
	“I really like this [Tool A] layout. I wouldn’t have known to flip it over if I hadn’t seen the lines on the back as I was holding up the tool. Either have an indicator to flip to side 2, or keep as 1 page” (Patient 7).
	“Having the goals presented first is a lot easier to understand; my eyes know where to go” (Patient 3).
	“There is a lot of writing. Because of the pain in my hands, I’m going to minimize what I write...” (Patient 4).
Reaction to tool as influenced by established communication patterns	
	Patients who reported good communication with their clinician reacted positively to the tool, with 1 patient stating they did not require the tool because of good communication and “close relationship” (Patient 9) with the clinician.
	“Too much to discuss in 1 visit; not enough time; these goals are not focused on main issue” (Patient 6).
	“I would be very wary of who would see the tool and how it would be used: I don’t even know if the provider may even look at the tool and would like a verbal confirmation that it was seen. I would want to protect who saw it” (Patient 10).
Identification of other clinicians, such as the PCP, as the primary contact for treatment goal discussions	
	“I discuss mood, life goals, quality of life, etc... with someone other than the rheumatologist; [I] would rather discuss mood and pain management with a primary care doctor” (Patient 5).
	“I just talk with my PCP about my goals instead of my rheumatologist” (Patient 2).
Stakeholder feedback on the final iteration of the tool	
	“I think would be easy to use as it is a way to get you thinking of what you want to tell your doctor. This way the appointment is guided by your wants and needs. I feel it is a great use of time for all. It does beat writing something down on a paper at home and then trying to talk about it. It makes everyone on the same page and using the same terminology.”
	“If I was the patient and it was up to me to integrate this tool into the appointments, I would appreciate having this tool to start the conversation. With multiple symptoms, it could be overwhelming to attempt to explain them all in an appointment and could otherwise become unorganized. This tool would help me prioritize and organize my thoughts.”

PCP: primary care provider; RA: rheumatoid arthritis.

situations, often feeling helpless while coping with chronic disease. Clinicians also expressed feeling helpless to address the multifaceted and holistic goals of patients and highlighted the dearth of referral resources available. Patients want “to be seen” and “to be believed” about their pain and suffering.³² Our findings were consistent with prior research in that patients want to be experts of themselves and want clinicians to be experts on RA disease course and treatment, yet still desire goals to be considered within the patient’s life context.¹⁷

Despite the novel, iterative tool development and multistakeholder involvement, our study is not without limitations. First, generalizability is limited outside of an academic medical center setting. Second, the lack of inclusion of non-English language patients also limits generalizability. Third, while the tool can be used at either an initial rheumatology visit or follow-up, we interviewed established patients in order to obtain a better sense of what would be most useful to foster goal conversations with the clinician.

Identifying patient priorities for important health and symptom status outcomes can help direct medical intervention, increasing patient satisfaction and adherence. The patient’s own experience with illness is shaped by preferences, behaviors, and sociocultural contexts.³³ The clinician–patient interaction can have the most negative effect on people without “health capital,” who are often already members of marginalized groups.³⁴ The RA goal elicitation tool described here may help decrease defensiveness and anxiety, due to its structured format. It validates the patient role in choosing priorities and discussing health goals, rebalancing power dynamics for more successful communication.³⁵ Interestingly, the clinicians were largely unaware of the influence of power dynamics overall, but especially their effect on patient willingness to disclose important information. The tool can redress this power hierarchy by reframing perspectives surrounding the long-term time efficiency gains through structuring patient concerns into measurable goals; this can resolve the major concerns identified as barriers for both parties. Stakeholder participants who provided feedback outside of this medical power dynamic touted the tool’s utility to align patient and clinician goals, terminology, and expectations.

Goals of care evolve throughout treatment,³³ and the goal elicitation tool must be studied at various stages of disease progression.³⁴ Treatment guidelines highlight the need for a “negotiated position” for both patient and clinician; this RA goal elicitation tool can help structure these complex and nuanced negotiations, especially for persons with barriers to communication.^{11,13} Changes to communication dynamics by using the tool also have the potential to reduce clinician workload by more evenly distributing the responsibility of chronic disease management by decreasing follow-up calls and empowering the patient to self-advocate and seek out necessary referrals. Along with heterogeneity of patient goals, the patient’s capacity for self-management also varies from individual to individual. Future work will include a pilot study of the effectiveness and feasibility of implementing the goal tool in daily clinical practice across distinct populations, and its effect on communication and treatment outcomes.

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ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

REFERENCES

1. Smolen JS, Breedveld FC, Burmester GR, et al. Treating rheumatoid arthritis to target: 2014 update of the recommendations of an international task force. *Ann Rheum Dis* 2016;75:3-15.
2. Tymms K, Zochling J, Scott J, et al. Barriers to optimal disease control for rheumatoid arthritis patients with moderate and high disease activity. *Arthritis Care Res* 2014;66:190-6.
3. Kwok CK, Ibrahim SA. Rheumatology patient and physician concordance with respect to important health and symptom status outcomes. *Arthritis Rheum* 2001;45:372-7.
4. Lafata JE, Morris HL, Dobie E, Heisler M, Werner RM, Dumenci L. Patient-reported use of collaborative goal setting and glycemic control among patients with diabetes. *Patient Educ Couns* 2013;92:94-9.
5. Paladino J, Bernacki R, Neville BA, et al. Evaluating an intervention to improve communication between oncology clinicians and patients with life-limiting cancer: a cluster randomized clinical trial of the serious illness care program. *JAMA Oncol* 2019;5:801-9.
6. Gavigan K, Nowell WB, Serna MS, Stark JL, Yassine M, Curtis JR. Barriers to treatment optimization and achievement of patients’ goals: perspectives from people living with rheumatoid arthritis enrolled in the ArthritisPower registry. *Arthritis Res Ther* 2020;22:4.
7. Kirwan JR, Hewlett SE, Heiberg T, et al. Incorporating the patient perspective into outcome assessment in rheumatoid arthritis—progress at OMERACT 7. *J Rheumatol* 2005;32:2250-6.
8. Carr AJ. Margaret Holroyd Prize Essay. A patient-centred approach to evaluation and treatment in rheumatoid arthritis: the development of a clinical tool to measure patient-perceived handicap. *Br J Rheumatol* 1996;35:921-32.
9. Hewlett SA. Patients and clinicians have different perspectives on outcomes in arthritis. *J Rheumatol* 2003;30:877-9.
10. Samuelsson A, Ahlmen M, Sullivan M. The rheumatic patient’s early needs and expectations. *Patient Educ Couns* 1993;20:77-91.
11. Barton JL, Hulen E, Schue A, et al. Experience and context shape patient and clinician goals for treatment of rheumatoid arthritis: a qualitative study. *Arthritis Care Res* 2018;70:1614-20.
12. Boehmer KR, Dobler CC, Thota A, et al. Changing conversations in primary care for patients living with chronic conditions: pilot and feasibility study of the ICAN Discussion Aid. *BMJ Open* 2019;9:e029105.
13. Barton JL, Koenig CJ, Evans-Young G, 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.
14. Fraenkel L, Matzko CK, Webb DE, et al. Use of decision support for improved knowledge, values clarification, and informed choice in patients with rheumatoid arthritis. *Arthritis Care Res* 2015;67:1496-502.
15. Li LC, Adam P, Townsend AF, et al. Improving healthcare consumer effectiveness: an Animated, Self-serve, Web-based Research Tool

- (ANSWER) for people with early rheumatoid arthritis. *BMC Med Inform Decis Mak* 2009;9:40.
16. Nota I, Drossaert CH, Taal E, Vonkeman HE, Haagsma CJ, van de Laar MA. Evaluation of a patient decision aid for initiating disease modifying anti-rheumatic drugs. *Arthritis Res Ther* 2016;18:252.
 17. Ahlmen M, Nordenskiöld U, Archenholtz B, et al. Rheumatology outcomes: the patient's perspective. A multicentre focus group interview study of Swedish rheumatoid arthritis patients. *Rheumatology* 2005;44:105-10.
 18. Hulen E, Ervin A, Schue A, et al. Patient goals in rheumatoid arthritis care: a systematic review and qualitative synthesis. *Musculoskeletal Care* 2017;15:295-303.
 19. Roddy E, Zhang W, Doherty M. Concordance of the management of chronic gout in a UK primary-care population with the EULAR gout recommendations. *Ann Rheum Dis* 2007;66:1311-5.
 20. Yun H, Chen L, Xie F, et al. Do patients with moderate or high disease activity escalate rheumatoid arthritis therapy according to treat-to-target principles? Results from the Rheumatology Informatics System for Effectiveness registry of the American College of Rheumatology. *Arthritis Care Res* 2020;72:166-75.
 21. Gibofsky A, Galloway J, Kekow J, et al; RA NarRAtive global advisory panel. 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;16:211.
 22. Lim AY, Ellis C, Brooksby A, Gaffney K. Patient satisfaction with rheumatology practitioner clinics: can we achieve concordance by meeting patients' information needs and encouraging participatory decision making? *Ann Acad Med Singap* 2007;36:110-4.
 23. Barton JL, Markwardt S, Schue A, Saha S, Yelin EH. Goal concordance in rheumatoid arthritis: beyond pain reduction, is there agreement? [abstract] *Arthritis Rheum* 2018;70.
 24. The Patient Revolution. Tools for the visit. [Internet. Accessed June 24, 2021.] Available from: <https://patientrevolution.org/visit-tools>
 25. Boehmer KR, Hargraves IG, Allen SV, Matthews MR, Maher C, Montori VM. Meaningful conversations in living with and treating chronic conditions: development of the ICAN discussion aid. *BMC Health Serv Res* 2016;16:514.
 26. Glaser BG, Strauss AL. *Discovery of grounded theory: Strategies for qualitative research*. Routledge; 2017.
 27. Heisler M, Vijan S, Anderson RM, Ubel PA, Bernstein SJ, Hofer TP. When do patients and their physicians agree on diabetes treatment goals and strategies, and what difference does it make? *J Gen Intern Med* 2003;18:893-902.
 28. Nimmon L, Stenfors-Hayes T. The "handling" of power in the physician-patient encounter: perceptions from experienced physicians. *BMC Med Educ* 2016;16:114.
 29. Barton JL, Trupin L, Tonner C, et al. English language proficiency, health literacy, and trust in physician are associated with shared decision making in rheumatoid arthritis. *J Rheumatol* 2014;41:1290-7.
 30. Mathijssen EGE, Vriezckolk JE, Popa CD, van den Bemt BJE. Shared decision making in routine clinical care of patients with rheumatoid arthritis: an assessment of audio-recorded consultations. *Ann Rheum Dis* 2020;79:170-5.
 31. Silvers IJ, Hovell MF, Weisman MH, Mueller MR. Assessing physician/patient perceptions in rheumatoid arthritis. A vital component in patient education. *Arthritis Rheum* 1985;28:300-7.
 32. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. *Patient Educ Couns* 2006;60:102-14.
 33. Dager TN, Kjekken I, Berdal G, et al. Rehabilitation for patients with rheumatic diseases: patient experiences of a structured goal planning and tailored follow-up programme. *SAGE Open Med* 2017;5:2050312117739786.
 34. Berdal G, Sand-Svartrud AL, Bo I, et al. Aiming for a healthier life: a qualitative content analysis of rehabilitation goals in patients with rheumatic diseases. *Disabil Rehabil* 2018;40:765-78.
 35. Georgopoulou S, Prothero L, D'Cruz DP. Physician-patient communication in rheumatology: a systematic review. *Rheumatol Int* 2018;38:763-75.