

Supplemental Table S1. Domain discussion and assignment to core, outer circle, research agenda, contextual factors or adverse events during the nominal group technique consensus meeting with patients and physicians

	Domains	Initial bin	Summary of discussion points	Final position
1	Anxiety	C	Placed under Emotional wellbeing – not a required individual element	IC Emotional well-being out
2	Cognitive function	C	Discarded	
3	Coping	C	Important but a contextual factor that relates to how patients may answer questions on instruments for example	CF
4	Daily activities including housework	A	Encompassed within Physical function or Participation. The model for this rationale was the ICF distinction between activities and participation (see above in text). This was felt to be better measured in these categories because physical function refers to whether or not you can do the activity and participation refers to whether or not you do the activity.	IC Physical function, Participation
5	Dactylitis	A	Placed under MSK disease activity	IC MSK disease activity
6	Depressive mood	C	Important: eventually placed under Emotional well-being but this was discussed as a potential separate core domain or as a required element to be measured in Emotional well-being or as an outer core measure. However, it was felt that it is sufficiently encompassed within Emotional well-being.	IC Emotional well-being
7	Discomfort	C	This was felt to be sufficiently encompassed within Pain and Patient Global and not needing a separate domain	out
8	Disease activity	A	There was a great deal of discussion around disease activity and how this was to be operationalized. It was decided that disease activity includes MSK, Psoriasis and Systemic inflammation. Additionally the Patient global is also potentially overlapping with disease activity although there was a great deal of contention around this concept and Patient global was maintained as a separate domain (see below)	IC MSK disease activity
9	Embarrassment	C	While important, it was subsumed under Emotional well-being.	IC Emotional well-being
10	Emotional support	B	Emotional support was felt to be a contextual factor that may influence how a patient does on therapy or how they	CF

may respond to questionnaires.

11	Emotional well-being	B	Moved into the Core Domain Set. There was a great deal of discussion around what this means. There are instruments available to measure emotional wellbeing, validating the concept that this could be included as a core domain. Additionally, there was a large amount of discussion around whether the items specified following emotional wellbeing should be made mandatory or optional. After much discussion, it was decided that the domain would be specified as “emotional well-being (e.g. anxiety, depressive mood, frustration, stress, embarrassment, and self-worth)”	IC Emotional well-being
12	Employment/work	A	This was voted as important by >70% of patients and clinicians in the Delphi. All agreed that it was very important. Discussion was centered on: a) whether it should be a separate entity or combined under participation, or b) whether it should refer to the individual, society or both. Work was also discussed in the context of work for which you get paid for (employment) and work at home. The low rate of employment among patients in clinical trials was discussed and the need to think more broadly about the concept of “work” was raised. Given its importance and the multifaceted exploration of this item, it was decided that this item belongs both under Participation and in the outer core (important but not required in all clinical trials) as measurement of the societal impact. We termed the societal impact aspect of Employment/work as “Economic Cost” and placed it in the outer core (see below).	IC Participation
13	Enthesitis	A	Included as a subdomain under MSK disease activity.	IC MSK disease activity
14	Family roles	C	To the patients, “family roles” meant the ability to be what they wanted to be to their family members and to take on the roles they wanted to assume. There was a notation that not all will find this a mandatory domain as not all patients are concerned about family roles. This was felt to be best positioned under Participation.	IC Participation
15	Fatigue	A	Important to both patients and physicians and was maintained with full agreement in the inner core. It was felt to represent both life impact and pathophysiology.	IC Fatigue
16	Financial impact	C	There was a great deal of discussion of financial impact because this was a domain that had a relatively broad definition. It was felt that Work/employment and Participation capture this to some degree. Societal	OC Economic cost

			financial impact is captured by “Economic cost” in the outer circle. Additionally, this was felt to be a contextual factor as cost of therapies and cost of care will be different by country, health care system, and insurance/health care delivery model.	
17	Frustration	C	Placed under Emotional well-being. As with the other components of Emotional well-being, it was felt to be important to measure but in the end we decided to list it as one of the examples of things that could be measured under Emotional well-being.	IC Emotional well-being
18	Global health/Patient Global	A	More than 70% of both physicians and patients rated this as important. There was a great deal of discussion about the meaning and placement of this item, e.g., is global health about the totality of the patients’ health? We discussed that when patients and clinicians rated this it was anchored in the survey in the context of having PsA. Clinicians think of this in terms of the patient global health assessment. “In all the ways your disease affects you, how are you doing . . .” Patients didn’t think of it this way, but rather as disease related health status a whole. Note was made by both patients and clinicians that you can’t totally separate PsA and other aspects of health when you ask this question. However, patients do understand the concept of asking the question and when asked how they respond to the question, they do try to answer it in the way it is stated, in terms of their disease activity. Multiple patients stated that when asked this question, they first try to remember how they answered it the last time. It was additionally noted that this is an important question as it is often used for an anchor against which other decisions or assessments are made. A point was raised that we ask this question in terms of disease activity but there was disagreement on this. It was recommended that we place this under disease activity as a measure of patient reported disease activity but this was not agreed upon. Instead, we left it as its own individual domain. Multiple names for this were discussed but we finally agreed on “Patient Global” with an asterisk to define this in terms of the patient’s global assessment of “in all the ways your disease affects you, ...” Prior to renaming this, there were discussions about whether this domain was better represented by HRQoL*. See that discussion below.	IC Patient global
19	Independence	B	This was very highly rated by patients (82% said it was important) but not as highly rated by physicians. Patients and clinicians agree this is important but did not necessarily agree on what this means or how you would measure it. To many patients it meant the ability to accomplish what you want to do without having to ask for	RA

			help (as in the original definition). It was noted that this includes activities of daily living, physical function, and participation, but it's also something more. There was agreement that this should be better studied and for this reason it was placed in the Research Agenda.	
20	Intimacy and sexual relations	C	Comment was made that it may not be important enough or an issue for all patients so that is why it was not supported for inclusion and thus dropped.	out
21	Leisure activities	C	Combined into Participation.	IC Participation
22	Medication side effects	A	This is covered under Adverse Events in Filter 2.0 and thus was not maintained as a separate core item.	AE
23	Nail psoriasis	B	Clinicians felt this was important but patients were less committed to it. It was discussed that this is generally collected under psoriasis measures but not necessarily. Nail psoriasis can cause a significant amount of embarrassment, disfigurement and pain and may respond differently to therapies than other manifestations. Thus, it was grouped into Skin disease activity.	IC Skin disease activity
24	Pain	A	This was rated as important by >70% of patients and clinicians. There was little discussion of this item given the high level of agreement.	IC Pain
25	Participation in social activities	B	Bin B; This was changed to "Participation" as a separate entity and social activities were then subsumed under Participation (and as noted above so were family roles, leisure activities, and work).	IC Participation
26	Physical function	A	More than 70% of physicians and patients said this was important. There was not a great deal of discussion around this as there was generally agreement that it should be included.	IC Physical function
27	Psoriasis symptoms	A	Renamed as "Skin disease activity" and this includes both Psoriasis and Nail psoriasis.	IC Skin disease activity
28	Self-management	B	Contextual factor rather than a core domain. The ability of a patient to self-manage may reflect their engagement and desire to participate in their own care and may then reflect how well they will do with therapy in the long run. Patients saw this slightly differently initially – they thought of this as the need to use other therapies or other methods of management in order to control their disease not controlled by their standing therapy. It was discussed that this is maybe better represented in the concept of flare and thus	CF

			doesn't fit here.	
29	Self-worth	C	Combined under Emotional well-being. Like the other factors in that group, patients felt that this was very important and initially considered this as a separate domain. It was noted that patients in the focus groups were also very strongly describing this concept of self-worth.	IC Emotional well-being
30	Sleep quality	C	Initially this was dropped but then resurrected when it was discussed that we don't know exactly what this means and what influences it but that it is important to patients. Results of a recent abstract were reported to suggest that even patients with PsA who had disease that was controlled had worse sleep than controls and patients with psoriasis. Sleep tracked with joint swelling and disease activity as well as anxiety. Because we want to know more about sleep and how this may respond to therapy, this was placed in the Research Agenda. Of note, it was also discussed that changes in sleep are captured (or should be captured) within adverse events if it occurs within a clinical trial.	RA
31	Social support	C	Discussed to be a contextual factor rather than something that actually changes with therapy.	CF
32	Spine symptoms	A	This was changed to spondylitis and included under "MSK Disease Activity"	IC MSK disease activity
33	Stiffness	B	Initially was grouped under MSK disease activity. It is included in a number of measures for arthritis and spondylitis. However, it was noted that it's not clear if this is really a good measure of disease activity, what we're measuring when we ask about stiffness and whether it's better to ask about length of time or presence, etc. Thus, because the concept is not well understood and despite many years of experience with this domain, we don't exactly know how to use it, so we included it instead in the research agenda.	RA
34	Stress	C	Placed under Emotional well-being; similarly, felt to be important and was initially suggested for inclusion as a "must measure" but instead included in the list of "e.g."	IC Emotional well-being
35	Structural joint damage	A	Discussions revealed this to be important by both groups but it was debated whether or not this should be in the inner circle or the outer circle. The discussions were focused on the following: 1) ultimately, we want to be able to prevent structural damage, 2) ideally a new therapy will prevent structural damage and this should be measured at	IC Structural joint damage*

			some point in the development of a drug, 3) this is hard to measure and takes large sample sizes and is costly (feasibility and cost may be prohibitive and this is not ideal for short term studies), 4) not all trials or observational studies need to do this but as noted previously, at some point in the development of a drug, this should be collected. The final decision (after two votes) was to keep it in the core domain but to include an asterisk that states that this is not mandatory for all RCTs and LOS but should be included at some point in drug development. The reasons for the asterisk designation in the inner core was relevance to smaller/shorter RCTs and LOS and financial cost.	
36	Swelling	A	Renamed as peripheral arthritis (or dactylitis) and included under MSK disease activity.	IC
37	Systemic inflammation	B	This was initially rated highly by clinicians but not as high by patients. This was moved to category A after explaining the meaning of this item to patients. It was discussed that systemic inflammation is the target of many therapies, though we don't have great tests right now (e.g. C reactive protein and erythrocyte sedimentation rate are not elevated in all patients with active disease), future biomarkers may be better, systemic inflammation may lead to the development of comorbidities and ultimately death.	IC Systemic inflammation
38	Treatment burden	C	Treatment burden is of great importance to patients; both those in the room for the discussion and in the focus groups. For example, the amount of work it takes to get the therapy or to take the therapy or the side effects of the therapy, not being able to drink alcohol, limiting your activities, sitting for an infusion, etc. Ultimately, it may be important to compare the burden of one therapy to another. Thus, treatment burden was included on the research agenda as it was not yet well defined.	RA
39	Unpredictability of disease activity	B	This was important to patients and was noted in all focus group studies. However, it was noted that this is captured under disease activity domains and Anxiety/Emotional well-being. Additionally, clinicians noted that this is just the nature of the disease: it's unpredictable.	out

* Health Related Quality of Life (HRQoL): This concept has been traditionally included in Core Domains. There was discussion about whether to include HRQoL. Some feelings were centered on the need to collect measures such as EQ5D and SF36 in order to have a standard, comparable understanding of what it means to have the disease, what a response looks like, and to establish utilities for these health states. However, patients instead favored the more specific terms included in the Core Domains that speak to quality of life: patient global, participation, fatigue, pain, emotional wellbeing. Thus, the final decision was not to add a separate domain for HRQoL. **Abbreviations:** IC: inner core; out: the domain was excluded; CF: contextual factor; AE: adverse event; RA: research agenda.