



Towards the development of a definition of independence for individuals diagnosed with rheumatoid arthritis in remission: an 'OMERACT remission in rheumatoid arthritis patient perspective' special interest group report

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ABSTRACT

Aims: To discuss and refine the preliminary definition of “independence” from the patient’s perspective in RA remission.

Methods: Data from a scoping review and international focus groups were presented at the OMERACT Remission in RA Patient Perspective Special Interest Group (SIG) meeting in February 2024. The SIG included 40 delegates from diverse geographic regions who discussed the findings and potential refinements of the preliminary definition of independence from the patient’s perspective in the context of RA remission.

Results: Drawing together findings from the scoping review and focus groups, the following preliminary definition of “independence” was presented for discussion: “Being able to do what you want, when you want, in the way you want to do it.” Delegates emphasized the importance of capturing all aspects of independence, adjustments to the proposed preliminary definition were suggested, and some delegates requested more specificity before taking the preliminary definition forward for use in the next research stage. Issues were raised on whether cultural variation on concepts of independence was adequately captured in the qualitative work so far. For example, some cultures may value receiving support from others as a reaffirmation of social belonging and interdependence, rather than a contradiction of independence. This will need addressing in our future work to ensure cross-cultural differences in definitions of independence are not missed. The majority of delegates voted in favour of continuing the work toward defining targeted sub-domains, which will allow the group to develop an instrument to assess independence in RA remission from the patient’s perspective.

Conclusion: Consensus was reached in favour of continuing the work towards defining targeted sub-domains, which will allow the group to develop an instrument to assess independence in RA remission from the patient’s perspective. However, suggestions were made to refine and improve the current definition. The next steps include refining the definition, followed by identifying and/or developing instruments to create an outcome measure for independence in RA remission.

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Introduction

Remission is now a realistic outcome of the treatment of rheumatoid arthritis (RA) because of advanced treatments. Although the remission criteria of the American College of Rheumatology/European Alliance of Associations for Rheumatology (ACR/EULAR) include the Patient Global Assessment (PtGA) [1], there are concerns that this may not sufficiently capture the patient's perspective [2]. Thus, the OMERACT 'Remission in RA: Patient Perspective' Working Group was formed in 2010 to explore what additional components patients consider essential criteria for describing remission and how this differs from the remission criteria used by ACR/EULAR in RA [2].

A previous international focus group in 2015 and survey studies in 2017 by this OMERACT Working Group identified pain, fatigue, and independence as the top three most important domains to patients for measuring remission in RA [3,4]. This Working Group then conducted a longitudinal cohort study of RA patients with low disease activity or in patient-perceived remission to identify candidate instruments for these three domains and to explore their value in assessing RA remission. Validated instruments were used to measure pain and fatigue; these were found to work well for both stable disease and to detect changes in disease activity [5].

For independence, no validated scale was found. Therefore, to measure independence, working group leaders developed a question in 2021: *"Over the last week, have you been able to do things as and when you want, without needing any kind of assistance?"* scored from 0, meaning no assistance to 10 needing a lot of assistance [5]. However, while the new independent NRS (Numerical Rating Scale) worked well with stable disease activity, it did not perform well in predicting change [5]. Thus, the independence domain needs further exploration, and a validated measure needs to be developed.

The role of the PtGA in determining remission in RA has been widely discussed in the literature [6–10]. Patient delegates at the Remission in RA: Patient perspective special interest group (SIG) meeting at OMERACT 2020 expressed uncertainty about which aspects of their condition to focus on when completing the PtGA, noting their focus changed each time they completed it. It was proposed that patient-reported pain, fatigue, and/or independence measures may be considered to replace or augment the PtGA criterion in the current remission criteria. A first step towards this is to explore whether pain, fatigue, and independence cover the PtGA in remission or whether patients feel that something will be left out [10].

At the 2020 SIG meeting, delegates voted in favour of further research into independence (90 % all delegates; 94 % patient delegates) [10]. Informing the development or selection of a validated patient-reported outcome measure for independence requires an initial understanding of how patients define and interpret independence. An OMERACT SIG meeting of the 'Remission in RA: Patient Perspective' Working Group was held in February 2024 to review progress toward this objective and to discuss next steps."

Our group conducted a scoping review, presented in the SIG meeting, which aimed to explore how the concept of independence is represented in the RA literature and to identify any descriptions or definitions in the context of remission [11]. Relevant databases were systematically searched to identify publications that discussed independence or the related concept of "autonomy" as a measure of disease activity, a descriptor of remission, or an outcome of treatment. A total of fifty-eight publications were included in the final analysis, ten of which specifically referenced remission. The review revealed that independence in RA extends beyond physical and cognitive functioning to encompass broader dimensions such as employment, social engagement, autonomy in healthcare decisions, and domestic responsibilities. Four major themes were identified as central to the conceptualization of independence: 1. A return to a state before arthritis, 2. Being physically and functionally able, 3. A sense of freedom without needing to rely on others, 4. Having control over the organization of one's life. A graphic

abstract summarizing the review's methods and key findings is provided in Supplementary Figure 1.

In this manuscript, we aim to present patients' perspectives on what independence means in the context of remission and to summarize the group's feedback on the SIG's previous research findings.

Focus groups

The SIG meeting was informed by data from the scoping literature review (discussed above) and focus groups [11,12].

Focus group methods

Focus groups with patients from three continents (Europe (UK), Australasia (Australia), and North America (USA and Canada)) aimed to understand how patients use and define the concept of independence in the context of RA remission [12]. Patients with RA aged over 18 years who had experienced remission at least once since diagnosis were invited to participate in online focus groups. Participants were recruited by a clinical team member in hospitals and through adverts on social media (Twitter, Facebook). The detailed methodology has been reported elsewhere [12]. Focus groups were held on Microsoft Teams, lasted approximately one hour, and were digitally recorded and transcribed verbatim. Transcripts were anonymised with participants given pseudonyms. Written informed consent was obtained prior to each focus group through an online form.

The complete dataset was analyzed using reflexive thematic analysis following Braun & Clarke's six steps [13], and the findings are reported elsewhere [12]. We were also interested in participants' responses to specific questions to understand their views on independence as the term for the domain under scrutiny, the NRS created for the longitudinal study, and the potential of the PtGA to measure independence. The data for these questions were analysed using directed qualitative content analysis, with data coded to address these predetermined questions [14]. These results and a preliminary definition of independence that arose from the focus group deliberations have not been published previously.

Five focus groups were held with three to five participants each, and an additional interview was conducted with one participant who could not attend a focus group. To ensure maximum participation, focus groups combined participants across continents.

Focus group results

Is independence the right term?

We asked participants if they were happy with independence being the correct term for this domain. Other suggestions were autonomy, having choices, control, function, living with RA, and being self-sufficient. However, the majority of participants were happy with independence:

Caitlin: I like it [10].

Maria: I do too, I do too. Just, yeah, I don't see anything wrong with it for that actual word, er, you know, being able to do what we can when we can.

Participant feedback on previous independence NRS

We asked participants what they thought about the NRS created for the longitudinal survey to measure independence: *"Over the last week, have you been able to do things as and when you want, without needing any kind of assistance?"* scored from 0, meaning no assistance to 10 needing a lot of assistance. No participants were completely satisfied with this measure in its current form. The key areas of concern were issues with assistance, NRS wording, and the timeline.

Issues with assistance

Assistance is complicated, and this is discussed more fully elsewhere [12]. Many participants were dissatisfied with the importance given to assistance in the NRS:

Rebecca: *Because it makes it sound like if you have assistance, then you're not independent.*

Participants also commented on the term assistance being subjective, with interpretations being too broad to measure remission usefully:

Josie: *Yeah. I think that's – I don't like the without needing any kind of assistance because assistance could mean somebody else helping you or it could be using a walking stick.*

Some participants thought assistance was important to include, but should not be the only focus for a measure of independence:

Cara: *I guess that question to me is kind of skewed. It's, it definitely can't stand alone*

NRS wording

Participants also raised issues with the overall wording of the NRS, with many participants considering it too broad or too vague to unpick Independence:

Eve: *It definitely needs more specific, um, things like what things are they – what – what do we need help with or not need – or – you know, either need help with or not need help with, either or, um, different ailments of different things.*

Some participants liked the first part of the NRS (doing things as and when you want to):

Lauren: *Because you can, you can still do stuff without assistance but maybe not when you want to do it or the way you want to do it.*

Timeline

There was no overall agreement on the timeline of the NRS even within each focus group, with some participants being happy with the one-week period, and others preferring longer or a more individualized timescale:

Caitlin: *I was almost thinking to be more open-ended, like eliminate the week completely, or the timeframe and just be like, you know, how frequently do you need any kind of assistance?*

Participant feedback on the patient global assessment in the context of remission

Overall, patients were not keen on the PtGA as a measure of disease activity/remission. They again raised issues relating to the timeline with views ranging from a measure should focus on a few hours up to a month, and felt the PtGA was too vague:

Claudia: *What do you mean 'well'? Emotionally, physically..?*

Participants had mixed responses on how they complete the PtGA, with some focusing only on pain or physical aspects of RA, others including their emotional well-being, and some focusing on whatever bothered them most at the time of completion:

James: *I think it probably comes down to what's – what's affecting you most at that point, whether it's pain or it's brain fog.*

However, the majority of participants reported that independence is not a consideration when completing the PtGA:

Emma: *I don't think I really put independence in my mind when I was filling these out.*

Reflexive thematic analysis of focus groups

The complete reflexive thematic analysis has been presented elsewhere [12]. In summary, the analysis identified five distinct but interconnected themes and related subthemes that define how patients perceive independence in the context of RA remission: "I can't get myself dressed": Physically and functionally able (subthemes: 1- Activities of daily living, 2-Meeting responsibilities, 3-Valued activities); "Something more substantial": Participation beyond function (1-Being

beyond present, 2-Confidence to make future plans, 3-Not having to pace, 4-Being 'normal' but what is 'normal'?); "It's a mind battle": Cognitive independence (1- Not having to think ahead, 2-Not thinking about RA management, 3-Forgetting about RA); "Somebody's going to have to define assistance": Assistance is complicated (1-Assistance is subjective, 2-Everyone needs help sometimes, 3-Not reliant on anyone or anything); and "a degree of personal autonomy": Having or taking control (1-Choices not dictated by RA, 2-Independence regardless of RA). We considered these to be targeted sub-domains or components of independence. These components were underpinned by the construct "stages of independence," which acknowledges that independence may mean different things to different patients, and there may be other factors beyond disease activity that hold patients in each of these stages. These data have previously been published by our group and were presented with a corresponding visual diagram [12].

These new findings indicate that an ideal definition of independence involves fully engaging in activities without needing to adjust for or be affected by disease activity, as well as mental freedom from thoughts about RA. Achieving independence in the context of RA remission is a multifaceted concept. The next step involves reaching a consensus between patients and professionals on the key issues identified in focus groups, which will guide the development of a tool to measure independence from the patient's perspective in RA remission.

Preliminary definition of "independence"

Drawing together findings from the scoping review and focus groups, the following preliminary definition of "independence" was presented for discussion:

"Being able to do what you want, when you want, in the way you want to do it."

This preliminary definition of independence was developed by the remission working group, through discussions of the findings from the systematic literature review and qualitative research. The wording was taken from patient quotes in the qualitative work.

Special interest Group(SIG)

SIG methods

SP summarised the group's research to date, and the scoping literature review and focus groups were presented in more detail by TK and CF (respectively). Delegates contributed to [group discussions](#) verbally or in a text chat stream, running simultaneously throughout the meeting. At the end, a series of questions was posed to the attendees with the teleconferencing polling function used for voting (yes/no) ([Table 1](#))

In OMERACT, consensus refers to an evidence-informed agreement among diverse stakeholders—patients, clinicians, and researchers—typically determined through structured discussion and voting, with at least 70 % agreement indicating endorsement of a proposed concept, domain, or instrument [15].

SIG results

SIG participants

Forty delegates attended the virtual SIG on 26th Feb 2024. Of these, 14 were patient research partners (PRPs) and carers, 17 were principal investigators, 8 were healthcare providers, and one was "other." The meeting included attendees from 14 countries, with the highest representation from the USA (7 attendees), followed by Australia, Canada, and the UK (5 attendees each). Other participants were from Portugal and the Netherlands (3 each), Lebanon [2], and one attendee each from Brazil, Denmark, France, Japan, Mexico, Morocco, and Nigeria.

Table 1
Delegate voting results from virtual OMERACT 2024 SIG Meeting.

Question	Yes N/total (%)	No N/total (%)	Unsure N/total (%)
Question 1: "Do you endorse the proposed definition of independence in the context of remission in rheumatoid arthritis as presented, believing it accurately reflects patient experiences and needs and is clinically relevant and feasible for application in medical practice? " "If you voted unsure, please provide comments"	29/40 (72 %)	3/40 (8 %)	10/40 (20 %)
	"being able does not take into account the internal feeling of the patient, only their physical capability. I would suggest being and feeling." "I think it is a great starting point for ongoing work and see if you can address some of the uncertainties. Great work. Go forward." "I think the word "normality" may be somewhat confusing depending on the culture, patient history, and age." "I think we need to capture/diminish the subjectivity by splitting or exploring (more) the difference between physical and cognitive independence" "I'm not quite certain how this is different from what is already being measured by HAQ. If a patient has a HAQ score of 0, that person is functionally independent." "In general, the formulation was ok, but my concern is how we define the various items we discussed, such as contextual factors (gender, geography, disconnect between provider and patient goals, etc.)" "I think it is too generic, but I didn't feel strongly enough to vote no." "We need to better define/refine independence rather than take the excellent work so far as a final definition."		
Question 2: "Given the work we have done, the current definition is sufficient for us to continue the work toward defining targeted sub-domains which will allow us to develop an instrument for this concept."	32/34 (94 %)	2/34 (6 %)	0

SIG discussions

Normality in rheumatoid arthritis: A complex concept

One of the components from the 'Participation beyond function' theme presented to delegates was 'Being normal, but what is normal?'. In agreement with the focus group participants, delegates discussed the challenges of defining "normality". They highlighted the subjective nature of the concept and emphasized its potential to differ among individuals and evolve over time. One PRP stressed the significance of prioritizing personal independence and satisfaction with ongoing treatments over engaging in comparisons with other patients. Delegates suggested that measuring "normality" might not yield helpful insights.

Is independence the right label?

Participants and researchers recognized that no standardized measures or definitions currently exist to capture "independence" specifically within the context of RA. Given the importance of understanding

this concept for assessing patient well-being, the group emphasized the need to refine the preliminary definition to include the components identified from the scoping review and the focus groups. The team agreed that these insights might support creating a more structured approach to measuring and understanding independence from the patient perspective in RA studies.

The complex nature of independence was highlighted, and it was suggested that the term 'autonomy' might offer a more nuanced representation. Ultimately, participants concluded that independence entails the freedom to pursue one's desires without impediments stemming from pain and health-related challenges. Consensus needed to be greater regarding the optimal timeframe for assessing independence since it can vary with disease duration.

Although participants suggested "autonomy" as a possible label, "independence" emerged as the preferred term among the majority of the group members, reflecting the patients' perspective on how they wish to define and label their experiences with RA. The group noted that differences in meaning between "independence" and "autonomy" could hold relevance for RA patients, with "independence" seemingly resonating more broadly as the global concept. Also, in later discussions, it was suggested that autonomy has wider connotations wherein limitations are placed on one's life by external factors, e.g., societal factors, authorities and regulations. To clarify and validate this preference, further investigation is anticipated in the quantitative phases of the study, such as during instrument selection and validation.

Scalability and validation

One delegate expressed concerns about the scalability of the work to other inflammatory and musculoskeletal diseases. It was clarified that a measure of independence in the context of RA may apply to conditions and diseases other than remission in RA. However, the work to inform the resulting instrument has only focused on independence in the context of RA remission. Further qualitative work would be needed to broaden the scope at the next stage. There is potential for further development and testing to adapt a resulting measure across multiple conditions.

Culture, illness, and independence: A complex dialogue

The SIG delegates discussed the subjective nature of independence, noting how it is shaped by factors such as disease stage, age, and cultural influences. They highlighted the importance of understanding cultural and geographical differences in the language and the meaning of independence for patients. The group acknowledged that external perceptions and cultural norms might shape feelings of independence, particularly in societies where dependency is more common. One member pointed out that, in some countries, limited access to therapy, including medication, could further affect how patients perceive and experience independence. Gathering input from patients from a broader range of countries could provide valuable perspectives on this component.

The team engaged in an in-depth exploration of how illness and cultural contexts influence the concept of independence, emphasizing the need for further research. They identified the need for additional research on how independence intersects with cultural factors, gender dynamics, and family structures. They noted that these aspects were not fully captured in previous qualitative work and may offer important insights for developing a more inclusive understanding of independence in patient care.

Physical and cognitive independence

The distinction between physical and cognitive independence was underscored, emphasizing the potential ease of measuring physical independence relative to cognitive aspects. This was highlighted as a good

example of why a more comprehensive preliminary definition of independence, ensuring each construct or component is effectively captured, would be necessary before advancing to instrument selection.

The need for clarification in defining each of the components was acknowledged, as different measurement tools may be required to address the unique elements within each component of independence.

Discussion on assistance

The team explored the nuances of assistance and its role in shaping perceptions of independence, emphasizing the subjective nature of this experience. They debated the impact of different types of assistance, such as instrumental or assistive devices, versus person-to-person support, noting that each person's needs and preferences for assistance might uniquely shape their interpretation of independence. Some participants highlighted that assistive tools offer a type of "freedom" distinct from human support, potentially enabling a sense of independence by allowing individuals to live autonomously without relying on others for physical help. This distinction underscored the importance of defining independence to account for both self-reliance and the empowering potential of tools or devices.

Poll results and terminology discussion

Question as displayed in Table 1 was asked to participants to approve the preliminary definition of independence. The SIG voted on Question Version 1 in Table 1, with 29 out of 40 members (72 %) voting "yes," 3 out of 40 (8 %) voting "no," and 20 % remain uncertain, which was insufficient for consensus. With 20 % of delegates voting 'uncertain' the discussion resulted in suggesting that they were not opposed to the preliminary definition as a working definition but suggested it needed more specificity for adopting as the final definition. Thus, delegates suggested reflecting this in a new voting question: "Given the work we have done, the current definition is sufficient for us to continue the work toward defining targeted sub-domains which will allow us to develop an instrument for this concept." (Question 2, Table-1).

In voting on question 2, delegates reached a consensus, with 32 of 34 (94 %) delegates voting in favour. However, it is worth noting that the number of overall votes reduced by 6 in the second round so these delegates may still have been unsure. Including these as unsure would still result in a consensus agreement outcome ($32/40 = 76\%$) but highlights the importance of clarifying and refining the definition of independence in our next steps.

Participants who voted "unsure" offered a range of feedback on the definition of independence (Table-1). One participant highlighted the importance of assessing not only whether patients can perform an activity ("being able") but also their confidence in doing so, suggesting the phrase "feeling able" be added. One delegate suggested further clarity was needed on the difference between physical and cognitive independence. One delegate raised the variability in meaning across patients of terms like "normality". However, this was addressed in the presented work as a complex term and not included in the definition presented for this reason. One participant questioned how a new measure of independence would differ from existing assessments of function like the HAQ. However, this was addressed in data presented from SIG group's previous work, both the scoping review and qualitative research findings, highlighting that patients define independence as much more multifaceted than physical function. Concerns were raised over whether cultural variation on concepts of independence was adequately captured, and one delegate highlighted the importance of defining contextual factors, including gender and geography in any future work. Finally, both the discussion and comments emphasised the need for continued refinement of the definition before considering it complete.

Since the preliminary definition was not sufficiently precise, the group agreed to proceed by developing definitions for the sub-domains of independence, as previously outlined. Our next steps will be to refine

the definition of independence further, ensuring it encapsulates individual differences through a prioritization survey. A clear definition will enable us to move towards instrument selection and/or development and testing.

Discussion

The scoping review [11] and focus groups [12] suggest independence is a complex and multifaceted concept, with further discussion around the difficulty of capturing and measuring this concept raised in the SIG. The discussions of the current meeting underscored that cultural and societal factors, including norms around dependency and access to care, significantly influence how patients experience and define independence. The group emphasized that collecting perspectives from patients in diverse regions will be essential to understand and represent the global variation in this concept fully. Furthermore, in depth discussions pointed out that the concept of independence is multifaceted and varies according to both disease stage and individual experience. Delegates observed that while validated instruments for assessing physical function are readily available, greater conceptual and methodological clarity is required to evaluate the broader dimensions of independence. The polling results supported the agreement in favour of continuing to define targeted sub-domains to assess independence in RA remission from the patient's perspective. However, it has been suggested that there is a need for a more precise definition of independence.

Our next steps will be to further refine the definition of independence in the context of RA remission to ensure it encapsulates individual differences. The SIG Working group will identify whether a single or composite measure best captures this. A clear definition will enable us to move towards instrument selection and/or development for subsequent testing.

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Declaration of competing interest

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.semarthrit.2026.152948](https://doi.org/10.1016/j.semarthrit.2026.152948).

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