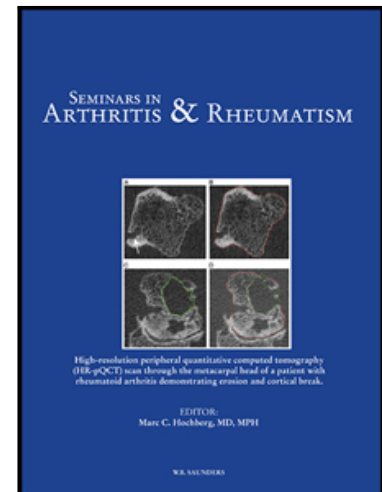


“It means almost forgetting that you’ve got a disease”: An OMERACT study to define independence in the context of rheumatoid arthritis remission from the patient perspective

Caroline A. Flurey , Bethan Jones , Ummugulsum Gazel ,
Chikosolu Uzoka , Kate Rosser , Thomas Khoo ,
Marieke Voshaar , Wijnanda Hoogland , Beverley Shea ,
Lynn March , Dorcas Beaton , Peter Tugwell ,
Susanna Proudman , on behalf of the OMERACT remission in RA:
Patient perspective working group



PII: S0049-0172(24)00166-5
DOI: <https://doi.org/10.1016/j.semarthrit.2024.152526>
Reference: YSARH 152526

To appear in: *Seminars in Arthritis & Rheumatism*

Please cite this article as: Caroline A. Flurey , Bethan Jones , Ummugulsum Gazel , Chikosolu Uzoka , Kate Rosser , Thomas Khoo , Marieke Voshaar , Wijnanda Hoogland , Beverley Shea , Lynn March , Dorcas Beaton , Peter Tugwell , Susanna Proudman , on behalf of the OMERACT remission in RA: Patient perspective working group, “It means almost forgetting that you’ve got a disease”: An OMERACT study to define independence in the context of rheumatoid arthritis remission from the patient perspective, *Seminars in Arthritis & Rheumatism* (2024), doi: <https://doi.org/10.1016/j.semarthrit.2024.152526>

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Highlights:

- Independence in the context of rheumatoid arthritis (RA) remission is complex and multifaceted.
- Independence goes beyond being physically and functionally able, to include full active participation without the need to pace and plan around RA.
- Independence includes a cognitive component, meaning freedom from having to think about and plan for RA.
- Assistance (both from other people or devices) means different things to different patients with no agreement on whether it is an aid or barrier to independence, making it complex to include in a measure of independence.

“It means almost forgetting that you’ve got a disease”: An OMERACT study to define independence in the context of rheumatoid arthritis remission from the patient perspective

Authors:

Caroline A. Flurey¹, Bethan Jones¹, Ummugulsum Gazel², Chikosolu Uzoka¹, Kate Rosser¹, Thomas Khoo³, Marieke Voshaar^{4,5}, Wijnanda Hoogland⁴, Beverley Shea², Lynn March⁶, Dorcas Beaton⁷, Peter Tugwell⁸, Susanna Proudman³ on behalf of the OMERACT remission in RA: Patient perspective working group.

Affiliations:

¹College of Health, Science and Society, University of the West of England, Bristol, UK

²University of Ottawa Rheumatology Dept, Ottawa, Canada

³Discipline of Medicine, University of Adelaide and Rheumatology Unit, Royal Adelaide Hospital, Adelaide, Australia

⁴OMERACT patient research partner, The Netherlands

⁵Department of Pharmacy, Sint Maartenskliniek, Department of Pharmacy, Radboudumc, Nijmegen, The Netherlands.

⁶Florance and Cope Professorial Dept of Rheumatology, Royal North Shore Hospital and Kolling Institute, Sydney MSK, Faculty of Medicine and Health, University of Sydney, Australia.

⁷Institute for Work & Health, Toronto, ON Canada

⁸University of Ottawa Dept of Medicine and School of Epidemiology and Public Health, Bruyere Research Institute, Ottawa Hospital Research Institute, Ottawa, Canada

Corresponding author:

Dr Caroline Flurey

caroline2.flurey@uwe.ac.uk

University of the West of England, Frenchay Campus, Colhardbour Lane, Bristol, BS16 1QY, UK

Word count: 4,522

Keywords: OMERACT, rheumatoid arthritis, remission, independence, qualitative

Abstract

Aims: Our previous work identified pain, fatigue, and independence as missing from the ACR/EULAR rheumatoid arthritis (RA) remission criteria from the patient perspective.

Validated measures exist for pain and fatigue, but not for independence. As a first step towards developing such a measure, this study aimed to understand ‘Independence’ in the context of RA remission from the patient perspective.

Methods: International qualitative research study comprising five focus groups of 19 participants with RA. Data were analysed using reflexive thematic analysis.

Results: Five overarching themes were identified, underpinned by a construct of “stages of independence”. Independence means at least being ‘physically and functionally able’ but may go beyond this and enable ‘participation beyond function’, ‘cognitive independence’, and ‘having or taking control’. There was no agreement on whether assistance is an aid to independence or undermines ability to achieve independence (‘assistance is complicated’). The construct “Stages of independence” 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.

Conclusion: These novel data suggest a desirable definition of independence includes full active participation without the need to consider or work around disease activity, and cognitive independence from thoughts of RA. Independence in RA remission is a complex concept and next steps will be to seek patient and professional agreement on the most important issues raised in these focus groups to take forward to developing a measure for independence in the context of RA remission from the patient perspective.

Introduction

Rheumatoid arthritis (RA) is a systemic, inflammatory condition causing synovitis and pain in multiple joints, which can result in permanent disability with accompanying emotional, social, financial, and societal burden. Remission (a state of ‘disease activity as good as gone’) (1) is the desired outcome in RA treatment. However, the current American College of Rheumatology/European Alliance of Associations for Rheumatology (ACR/EULAR)

remission criteria (2) have been criticised for not adequately incorporating the patient perspective (3).

The Outcome Measures in Rheumatology (OMERACT) (4) 'Remission in RA: Patient Perspective' Working Group found that remission domains most frequently prioritised by RA participants were pain, fatigue, and independence (1,5). A longitudinal cohort study of RA patients with low disease activity or in patient-perceived remission aimed to identify candidate instruments for these three domains in RA remission (6). Validated instruments were used to measure pain and fatigue, and a non-validated numerical rating scale (NRS) was created to measure independence. The pain and fatigue measures performed well overall, whilst the new independence NRS worked well for construct validity and discriminative capacity but was not sensitive to change (6). These results indicate 'Independence' is worthy of further exploration, but a validated patient reported outcome measure is needed. To inform the development of this, we need to understand how patients are using and defining 'Independence' in the context of RA remission.

A qualitative systematic literature review (which included the initial focus group study from this working group) (1) found mentions of Independence could be organised into themes of: 'A return to state before arthritis'; 'Being physically and functionally able'; 'A sense of freedom without needing to rely on others'; and 'Having control over the organisation of one's life' (7). However, no studies asked patients to focus on independence, and could therefore be missing key information. Thus, we aimed to understand independence in the context of RA remission from the patient perspective.

Methods

Design: Focus groups were conducted to elicit a broad range of perspectives on what independence means to patients in the context of remission, and promote discussion between participants (8). A topic guide (Table 1) was developed based on themes identified

by a systematic literature review (7) and discussions with the multidisciplinary study team, including patient research partners. These followed an iterative process (9) with new concepts raised by participants explored in subsequent focus groups.

Participants: Patients with RA aged over 18 years who self-reported having experienced remission at least once since diagnosis were invited to participate in online focus groups. Patients did not have to be currently in remission to participate. Participants were recruited from Europe (UK), Australasia (Australia), and North America (USA and Canada) by a member of their clinical team, and through adverts on social media (Twitter, Facebook). Data collection continued until additional focus groups no longer generated new themes (10).

Process: A pre-study questionnaire captured demographic and clinical data (Table 2). Focus groups were conducted by the first author (CF), held on Microsoft Teams, lasted approximately one hour, digitally recorded, and transcribed verbatim. Transcripts were anonymised with participants given pseudonyms. Ethics approval was granted by the University of the West of England, Bristol: HAS.21.12.042 with local approvals obtained at participating hospitals. Written informed consent was obtained prior to each focus group through an online form.

Analysis: Data were analysed using reflexive thematic analysis following Braun and Clarke's six steps (11). Analysis was inductive (data-driven), primarily semantic (focusing on explicit meaning), experiential (focusing on participants' own perspectives and understandings), and realist (capturing truth and reality as expressed by participants). The first author (CF) identified potential areas of analytic interest through repeated reading of the transcripts and checking against digital recordings. Micro-level code labels were applied to all data and managed using NVivo 12. (12) One coder is good practice in reflexive thematic analysis for consistency in 'meaning making' across the data (11). Codes were clustered together into broader patterns of meaning, then all data related to each theme were collated

across the full data set. The full study team reviewed the themes, and contributed to refining, defining, and naming them.

Results

19 RA patients from North America (n=9), Europe (n=5), and Australasia (n=5) participated with a mean age of 53.9 years (range 31-67); disease duration 16 years (range 3-31years); patient global assessment 2.80 (SD: 2.76). The majority of participants were female (84%), white (95%), and working either full or part time (53%) (Table 2).

Five focus groups were conducted with three to five participants in each. One participant was interviewed due to being unable to make a scheduled focus group. Participants were combined across continents to maximise participation. Five distinct but interconnected themes were identified reflecting how patients use and define Independence in the context of RA remission: Physically and functionally able, Participation beyond function, Cognitive independence, Assistance is complicated, Having or taking control. These were all underpinned by the concept of Stages of independence (Figure 1).

Theme 1: “I can get myself dressed”: Physically and functionally able

Independence included being physically and functionally able to do the things participants wanted. The physical ability to carry out activities of daily living was discussed as the minimum requirement for independence. However, depending on the level of independence participants were aiming for this also included being physically and functionally able to meet their responsibilities, and engage in valued activities.

“So, if the function you want isn’t there, then it’s really impeding your independence”
(Emma/31yrs/Australia)

Activities of daily living

To most participants, independence meant at the very least being able to do personal care tasks for themselves (*“when you don’t need someone to dress you”* Anita/41yrs/UK). For some, independence to do these daily tasks was more important than eliminating pain to their experience of remission:

“Even if there’s a tiny bit of pain, that’d be all right because it’s – just used to it and it’s not that big a deal, just to be able, yeah, just to be able to do my activities of daily living comfortably” (Rebecca/47yrs/USA)

Meeting responsibilities

Having the ability to meet responsibilities was important to participants as a measure of independence. For many, this meant being able to run errands without needing help from others, and some highlighted the importance of being able to get in and out of a car to enable them to fulfil responsibilities without help from others. For those still working, this included being able to continue working and carry out all their work-related tasks:

“Being able to go to work. Work a whole day [...] you’re on your feet all day. And being able to do that, and then drive home is being independent for me as well.” (Josie/61yrs/UK)

Valued activities

Participants discussed the importance of being physically and functionally able to participate in valued activities pointing towards a definition of independence going beyond fulfilling day-to-day activities. Quality time with family and friends was particularly valued and having the physical ability to participate in social activities was seen as an important aspect to include in a measure of independence:

“So, for me, the independence is about being able to play with my grandchildren, being able to walk my dog [...] I could accept not being able to go back to running and spinning and – you know – sort of those high intense sports, um, as long as I can still get out for walks and enjoy myself and do my baking and um, meet my friends when I want to.” (Claire/61yrs/UK)

“Are you attending more social events now than you were, um, when your disease activity was high? Are you doing more now than when your disease activity was high? Those would be the kind of measures I would use” (Stuart/64yrs/USA)

Discussion around valued activities included the physical ability take part in active hobbies and pursuits that may be particularly physically demanding:

"I dragon boat race. I ride my bike. I was a teacher, 40-odd years. And it got under control very quickly with all the drugs, so I got my independence back very quickly. And I feel like I can lift mountains at the moment." (Cara/67yrs/Canada)

"I love travelling but it's really, really hard for me physically, um, especially like all of the walking and being on my feet and kind of the same thing with like going to concerts and fairs and festivals and that kind of thing where you have to be again walking a lot and standing." (Lauren/62yrs/UK)

Theme 2: "Something more substantial": Participation beyond function

Participants emphasised that independence involves participation beyond being physically and functionally able to carry out physical tasks or take part in chosen activities.

Beyond being present

Some participants explained that when not in remission they exerted independence through pushing themselves. However, an important distinction was made that independence in the context of remission meant going beyond being able to attend events or carry out tasks.

Participants reported needing to feel productive and explained the importance of not having to struggle to do the things they wanted to. Being independent meant going beyond presenteeism to full engagement with the activity they had chosen:

"I was thinking like, doing your hobbies, but not just getting around to reading like a chapter of a book, but maybe even participating in a book club or an online forum. Like not just your hobbies, but being engaged with your hobbies" (Caitlin/31yrs/USA)

To some participants, being independent meant being able to do all components of a task (for example in the workplace) rather than needing help with certain aspects. Participants were concerned about the impact on other people of having to do parts of a task for them that they were unable to do themselves:

“Oh, I can’t use the stapler today. Could you do it for me? Or I can’t do this today. Can you – or I can’t reach the top shelf today. Could you get something down for me? You just feel a nuisance.” (Josie/61yrs/UK)

Confidence to make future plans

Participants discussed the importance of being able to make future plans without worrying whether they would be well enough. Being able to be relied upon by others was an important aspect of independence, and participants discussed feelings of guilt and frustration at having to cancel plans. Cancelling plans was cited as a clear sign that they were not in remission:

“What really makes the difference though, for me, is, er, whether or not I have to start cancelling things. You know, if I – if I get up, um, in the morning and say I – I just can’t do this, then I know that I’m not in – I’m no longer in remission” (Stuart/64yrs/USA)

Not having to pace

Pacing and planning is an important aspect of RA self-management. To some participants, independence meant being free of having to consider pacing themselves to conserve strength and energy. Independence meant not only being able to do the things they wanted to, but to have something left afterwards without having to consider planning recovery time:

“Sometimes you get asked questions about, are you able to go work? Are you able to complete a day’s work? Yes I am, but then I’ve got nothing left [...] So, because I need to work to pay my bills, work will be my priority. So, I will go to work, and then when I come home, I perhaps can’t stand and cook.” (Josie/61yrs/UK)

Some participants explained that being able to do things without having to pace was an important distinction between pushing themselves to be independent despite disease activity, and being independent in the context of RA remission:

“It’s a lot more of a fight to be independent when your disease is active than it – when it’s in remission [...] Everything I do has to be very well planned out, ‘cause I have to um, economise my movements and what I do to maintain a level of energy to get through what I need to accomplish in a day. So I have to be very strategic when I’m doing things.” (Anita/41yrs/UK)

Being 'normal', but what is 'normal'?

For many participants independence meant being 'normal' (although not all: "*normal's boring*", James/36yrs/Australia) but there was no consensus to what 'normal' meant. To some participants this meant returning to a pre-RA state, whilst others highlighted independence may have been lost due to ageing. For some normality meant being as independent as a healthy person, keeping up with their peers, or fitting in with societal expectations of participation:

"What society kind of dictates is what I kind of picture as normal. Like, can you stand in the grocery line in the checkout; that's something a normal person would do."
(Caitlin/31yrs/USA)

Theme 3: "It's a mind battle": Cognitive independence

Most participants explained independence is not just being physically but mentally independent of RA:

"For someone who is used to just doing things without thinking, when you have that taken away, it's a real battle. It's a mind battle. It's horrible." (Cara/67yrs/Canada)

Not having to think ahead

Participants discussed the mental exhaustion of having to think ahead to accommodate RA disease activity. The ability to be spontaneous without needing back-up plans was an important component of independence:

"Being in remission means I don't have to think about that. I don't have to think about kind of running out of fuel partway through the day." (Josie/61yrs/UK)

Not thinking about RA management

Participants discussed the mental load of having to plan their life around hospital appointments and medication. To many participants, defining independence meant being free of all the aspects of disease management that remind them of having RA:

“To me, it means, um, it means having less life interruptions, as I live my life. It means, um, it means friction in my life, as a result of RA. And, er, when I’m not in remission, I see my doctor more. I have a tendency to get to physical therapy more. Er, I do things that make me focus on RA.” (Stuart/64yrs/USA)

Whilst some participants were satisfied that they could be independent whilst still on medication, for others true independence meant also being free of having to think about drug regimens or worry about the related side effects. Anita compares this to other people’s experience, relating back to a desire for ‘normality’:

“I know it’s [taking medication] a small hassle, but other people don’t think about that hassle, do they?” (Anita/41yrs/UK)

Forgetting about RA

The most desirable form of independence was being so well controlled they would be able to forget about RA completely:

“For me it means almost forgetting that you’ve got a disease. So much so that you might forget to take your tablets in the morning because you feel so well.” (Josie/61yrs/UK)

Theme 4: “Somebody’s going to have to define assistance”: Assistance is complicated

There were mixed views among participants concerning whether independence could include receiving assistance or whether a definition of independence meant doing things without assistance: *“I guess somebody’s going to have to define assistance” (Rebecca/47yrs/USA).*

Assistance is subjective

A key concern among participants about including assistance in a measure of independence was that assistance means different things to different people. The focus groups provoked much discussion on what counts as assistance, with it seen as a broad-spectrum concept including help from another person, walking aids, or use of a jar opener. This made it difficult

for participants to understand what a generic measure of assistance might refer to.

Participants highlighted a difference between *needing* assistance from another person and accepting assistance because another person happens to be with you. Participants flagged that people without RA may still benefit from some forms of assistance:

"I think the help that I get is just what I would have had anyway – with or without the illness, so sometimes I can't open a jar, so my husband will do that for me. But that's not to say he would [sic] have done that anyway" (Vanessa/52yrs/Australia)

For some participants, context was important for accepting assistance, with having to accept help seen as a challenge to independence when it was due to RA, but acceptable when in remission:

"I'm pig-headed when it comes to the things that I – I don't want to give that up. I don't want to give up the simple function of opening a jar, um, but when I'm in remission I have no problem with that – go, could you open that please? Because I just don't want to do it, not because I can't do it." (Cara/67yrs/Canada)

Participants noted that assistance may have a complicated relationship with independence. Some patients may still consider themselves independent when receiving assistance; and lack of assistance may not be an accurate indication of remission as patients may have made adjustments and adapted their lives to work around the need for assistance:

"I think it's pretty much about, ah, intention. If you want to be in some sort of relationship or partnership with the help of that other person, then it's beautiful. You can be independent and still be dependent on them. But, if it's something you don't want, or you don't like the person, but you need them to help you do something, then – yeah, that – that would not feel like independence at all to me." (Emma/31yrs/Australia)

"I don't need assistance, but I've made the adjustments." (Sophia/44yrs/UK)

Everyone needs help sometimes

To many participants medication, tools, and devices were seen as an aid rather than challenge to independence. Some participants embraced assistance as part of life

regardless of having RA, noting that everyone needs assistance to some extent, and found it difficult to clarify where assistance was needed specifically due to RA:

"I sometimes rely on tools to do certain things, not because I'm not independent; it's just that, you know, it's easier. I'm sure that a lot of people who don't have any conditions still rely on things to do certain things." (Maria/55yrs/USA)

Not reliant on anyone or anything

For some participants, independence meant being completely free of any help from either people or devices. Some highlighted that the need for assistance tended to be a sign their RA was worsening. Independence from having to be reliant on others also meant independence from feeling like a burden:

"For me, it's almost like literal independence, that's remission. I don't need someone else around to help out with anything. Um, you know, even opening stuff or, um, like for me in the winter shovelling snow kind of a thing." (Caitlin/31yrs/USA)

Theme 5: "A degree of personal autonomy": Having or taking control

To many participants, independence meant having control over their lives and decisions. Some discussed taking back control through pushing for independence regardless of RA symptoms.

Choices not dictated by RA

An important wider element of independence was being able to make decisions without considering RA. This ranged from everyday decisions, such as which clothes to buy, to important life decisions such as being able to plan for a family without needing to consider medication or discussing with their clinical team: Participants valued autonomy, which seemed to be the gold standard for independence:

"It's about a degree of personal autonomy that you can make those decisions for yourself and go about your day and carry out those tasks that you want to do without, you know, consulting someone else or asking someone else to come along with you." (Rebecca/47yrs/USA)

Independence regardless of RA

In creating a measure of independence in the context of RA remission, it is important to note that some participants reported finding ways to be independent despite RA

“You find different ways to make yourself independent within the context of what you’re living in” (Eve/42yrs/Australia)

Some prioritised independence over pain or joint damage and pushed themselves to their limits:

“I could still be independent because that’s the way I am, and I’ll battle through it.”
(Cara/67yrs/Canada)

Underpinning theme: Stages of independence

Underpinning these findings is the idea that independence *“would probably be a bit different for everyone”* (Emma/31yrs/Australia). Participants suggested *“there are stages of independence”* (Clare/61yrs/UK), and there may be other factors beyond disease activity that hold patients in each of these stages, such as disability, personal circumstances, and intrinsic motivation.

Patients could be ‘practically independent’: not having full functional abilities but pushing past limitations and using adaptations to enable them to do things they want (aligned with subtheme: being independent regardless of RA):

“It might not be what everybody else does but for you that’s how you do it”.
(Rebecca/47yrs/USA)

The next stages are ‘functionally independent’: functionally able to take part in the things they want to (aligned with Theme 1); ‘socially independent’: beyond presenteeism, and

without the need to pace (aligned with Theme 2); ‘cognitively independent’: not having to plan ahead, think or worry about RA (aligned with Theme 3):

“I can get up, I can get myself dressed, I can go to the toilet – toilet by myself...I can sort of manage to feed myself even if I can’t maybe open all the jars I want to or whatever. Like all of those basic things” (Claire/61yrs/UK)

“You should be independent to do all of the things that you need to do - working, daily activities, you know, social things, fun things” (Lauren/62yrs/UK)

“You don’t think about it, ‘cause you can do it”. (Cara/67yrs/Canada)

Finally, full autonomy (aligned with Theme 5) was seen as the gold standard for independence, being in control of all aspects of life without having to consider RA:

“Owning myself as a social being [...] giving me the choice to do what I wish to do, and not giving the disease the choice.” (Lauren/62yrs/UK)

Discussion

These focus groups found independence to be a complex multi-faceted concept. Participants reported independence is at minimum being ‘physically and functionally able’. For many, independence in the context of RA remission goes beyond this and enables ‘participation beyond function’, ‘cognitive independence’, and ‘having or taking control’. There was no agreement on whether assistance is an aid to independence or undermines ability to achieve independence (‘assistance is complicated’). Our findings align with our previous systematic literature review (7). However, the current study identified important additional considerations.

Whilst a return to ‘normality’ was important, patients were not certain nor agreed on what ‘normality’ means, which supports previous interviews with RA patients that found six

typologies of 'normality' exist, with multiple 'normalities' present in individuals' narratives (13). For some participants, independence in the context of RA remission included being independent from taking medication, whilst for others medication supported them to be independent. This supports previous qualitative work that found patients varied in their opinions on the role of medication in defining remission (1). However, to inform a measure of independence for clinical trials or clinical practice, the focus would be on remission with medication. Self-management is key to adapting to life with RA, with patients previously reporting a need to micro-manage symptoms daily (14). However, participants in this study defined independence as being free of the cognitive drain of self-management. This supports previous research in ankle reconstruction, which found high vigilance for ongoing symptoms was related to increased stress and mental exhaustion (15).

Some elements of independence may overlap with other domains. For example, being able to make plans without worrying about consequences could be captured by a measure of pain or fatigue. Thus, it will be important to test whether a measure of independence can detect additional meaningful change in disease activity.

Our findings indicate a complicated relationship between independence and assistance with individual differences in interpretation of assistance, and no agreement on whether independence is conditional on being free of assistance. This may help explain why the NRS for independence previously created by this working group was not sensitive to change (6). Qualitative research is designed to elicit a range of views, not determine consensus. Thus, agreement on how to treat assistance in a measure of independence will need to be sought in a future quantitative study.

In developing a measure of independence, a composite measure may be needed to take into account the multiple components highlighted through the current study. This is the approach taken by the Bristol Rheumatoid Arthritis Fatigue Multi-Dimensional Questionnaire, which includes multiple domains (physical fatigue, living with fatigue, cognitive fatigue,

emotional fatigue) and demonstrates the value of a multi-dimensional approach to a complex issue (16). Acknowledging individual differences through anchoring a question based on whether patients feel more or less independent than a previous time point could be considered. However, this would make it difficult to compare scores between patients.

Finally, our findings highlighted different levels or stages of independence with some patients self-identifying as independent through pushing themselves beyond limitations, and others seeking a level of independence they are unsure is achievable due to existing joint damage or other limiting factors such as personal circumstances or intrinsic motivation. Thus, it will be crucial to ensure a measure of independence accounts for these different perceptions, and to ensure there is a clear cut off for the level of acceptable independence associated with remission.

This study may have limitations in missing the voices of participants who were unable to take part in scheduled focus groups. However, participants were combined cross-continent to enable groups to be scheduled at multiple time points with morning, afternoon, and evening slots available for each time-zone. This study is also limited by the majority of participants being white and female, and the focus groups being limited to English language speakers. How patients define independence is likely to be influenced by cultural context such as, cultural norms around the family structure and expectations of support. Some of these differences were captured in our OMERACT Special Interest Group discussion, which will be reported in a subsequent paper. We will develop a recruitment strategy to increase participant diversity in the next stage of this research, and ensure participants have the ability to add to the items generated by our focus groups in the prioritisation stage.

Definitions of independence may also differ according to socio-economic status, but these data were not collected. However, participants included a range of demographic and clinical characteristics from three continents reflecting a range of disease experiences, care pathways, and family and social circumstances. Focus groups can be criticised for producing

consensus opinion or favouring the most dominant members of the group.(17). However, they were chosen for potential for group discussion to elicit ideas that may not arise from one-to-one interviews.(18) One interview was conducted for logistical reasons, which provided rich data with particular depth on personal experiences but missed the dynamic idea generation of the groups. This is the first qualitative study to focus on independence in the context of RA remission from the patient perspective.

Our novel findings suggest that a desirable definition of independence includes full active participation without the need to consider or work around disease activity, and cognitive independence from thoughts of RA. Independence in RA remission is a complex concept that may require a more sophisticated measure than a single scale to take into account the multi-dimensional nature of Independence. Next steps will be to seek patient and professional agreement on the most important issues raised in these focus groups to be taken forward to developing a measure for independence in the context of RA remission.

Declarations of competing interests:

Dr Flurey reports grants to her institution from Arthritis Australia in relation to the submitted work; grants to her institution from Lupus UK and Economic and Social Research Council, and consulting fees from Pearson Global, outside the submitted work. Prof March reports grants to her institution from Australian Government, Janssen Australia, and CLEARbridge Foundation. Prof Tugwell reports board participation for UCB Biopharma GmbH & SPRL, Parexel International, Prahealth Sciences; and contributions to OMERACT from Abbvie, Astra Zenaca, Aurinia, BMS, Centrexion, GSK, Horizon Pharma Inc , Janssen, Novartis, Pfizer & Sparrow. Prof Proudman reports grants to her institution from Arthritis Australia in relation to the submitted work; grants to her institution and personal fees from Boeringer-Ingelheim and Janssen, outside the submitted work. The remaining authors declare no conflicts of interest.

Funding: Arthritis Australia

Acknowledgements: The authors would like to thank the patients who participated in this study; Arthritis Australia for funding this work; National Rheumatoid Arthritis Society for advertising this study; Kim Griggs for study set up and recruitment support; the members of the OMERACT Remission in RA: Patient Perspective Working Group who have contributed to the continual development of this work; and the OMERACT executive and secretariat for their ongoing support of this work, particularly Shawna Grosskleg for administrative support.

References

1. Van Tuyl LHD, Hewlett S, Sadlonova M, Davis B, Flurey C, Hoogland W, et al. The patient perspective on remission in rheumatoid arthritis: "You've got limits, but you're back to being you again." *Ann Rheum Dis*. 2015 Jun 1;74(6):1004–10.
2. Felson DT, Smolen JS, Wells G, Zhang B, Van Tuyl LHD, Funovits J, et al. American college of rheumatology/European league against rheumatism provisional definition of remission in rheumatoid arthritis for clinical trials. *Arthritis Rheum*. 2011 Mar 1;63(3):573–86.
3. Van Tuyl LHD, Smolen JS, Wells GA, Scholte-Voshaar M, Hoogland W, Boers M. Patient perspective on remission in rheumatoid arthritis. *Journal of Rheumatology*. 2011;38(8):1735–8.
4. Beaton D, Maxwell L, Grosskleg S, Shea B, Tugwell P, editors. The OMERACT Handbook Version 2.1 [updated April 2021] [Internet]. Available from: <https://omeract.org/handbook/>
5. Van Tuyl LHD, Sadlonova M, Hewlett S, Davis B, Flurey C, Goel N, et al. The patient perspective on absence of disease activity in rheumatoid arthritis: A survey to identify key domains of patient-perceived remission. *Ann Rheum Dis*. 2017 May 1;76(5):855–61.
6. Rasch L, Boers M, Lems W, van Schaardenburg D, Proudman S, Hill CL, et al. Patient perspective on remission in rheumatoid arthritis: Validation of patient reported outcome instruments to measure absence of disease activity. *Semin Arthritis Rheum*. 2021;51(6):1360–9.
7. Khoo T, Jones B, Chin A, Terrett A, Voshaar M, Hoogland W, et al. Defining independence: A scoping review by the OMERACT patient perspective of remission in rheumatoid arthritis group. *Semin Arthritis Rheum*. 2023 Feb 1;58:152152.
8. Braun V, Clarke V. Successful qualitative research. London: SAGE; 2013.
9. Ritchie J, Lewis J. Qualitative research practice: a guide for social science students and researchers. London: SAGE; 2003.

10. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health*. 2021;13(2):201–16.
11. Braun V, Clarke V. *Thematic Analysis: A practical guide*. London: SAGE; 2021.
12. International Q. NVivo 12. 2018.
13. Sanderson T, Calnan M, Morris M, Richards P, Hewlett S. Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociol Health Illn*. 2011;33(4):618–33.
14. Flurey C, Morris M, Richards P, Hughes R, Hewlett S. “It’s like a juggling act”: Rheumatoid Arthritis patient perspectives on daily life and flare whilst on current treatment regimes. *Rheumatology*. 2014;53(4):696–703.
15. Pinsker EB, Sale JEM, Gignac MAM, Daniels TR, Beaton DE. “I don’t have to think about watching the ground”: A qualitative study exploring the concept of vigilance as an important outcome for ankle reconstruction. *Arthritis Care Res (Hoboken)*. 2020;72(10):1367–73.
16. Nicklin J, Cramp F, Kirwan J, Greenwood R, Urban M, Hewlett S. Measuring fatigue in rheumatoid arthritis: A cross-sectional study to evaluate the Bristol Rheumatoid Arthritis Fatigue Multi-Dimensional questionnaire, visual analog scales, and numerical rating scales. *Arthritis Care Res (Hoboken)*. 62(11):1559–68.
17. Sim J. Collecting and analysing qualitative data: issues raised by the focus group. *J Adv Nurs*. 1998;28(2):345–52.
18. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ*. 1995 Jul 29;311(7000):299–302.
19. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005 Nov;15(9):1277–88.

Table 1: Focus group topic guide

Brief introduction to explain the work so far – explain that patients have rated pain, fatigue and independence as important in defining remission but while we have measures for pain and fatigue we don't have a good understanding of what independence means to patients

1. Keeping in mind the context of your disease activity being as good as gone, what would it mean to you to be independent?
2. Can you still be independent if you need help? (*Prompts: From someone else? From tools/devices? From medication?*)
3. Can you tell the difference between independence being affected by your disease activity compared with joint damage? (*Prompts: How is it different? How could we capture that difference in a measure?*)
4. At the moment, the criteria for your disease activity being as good as gone includes a measure for function. Does that cover independence, or is independence more than function? (*Prompts: How is it different?*)
5. Based on all the things we've discussed so far, do you think independence is the right word for these concepts, would something else work better?
6. If we measured independence (/other word participants come up with) what would you like to see included?
7. †In the questionnaire you completed before this focus group, you will have seen the patient global question: 'considering all the ways your disease affects you...'. [*share screen to show**] This is currently the only way that the patient perspective of remission/disease as good as gone is taken into account. Some researchers have suggested that question isn't helpful. How would you feel about it being replaced with separate measures for pain, fatigue and independence? Do you think something important about your experience of RA would be missed if we only use these three?
8. †What do you keep in mind when completing this [*patient global – on screen**]?
9. Do you think this [*patient global – on screen*] is enough to capture your independence in the context of your disease being as good as gone?
10. †This is one of the possibilities of how to measure independence. Do you think it is an accurate question or do you have suggestions to improve measuring independence? [*A slide showing the below shared on screen*]

Over the last week, have you been able to do things as and when you want, without needing any kind of assistance?

No assistance 0 1 2 3 4 5 6 7 8 9 10 A lot of assistance

11. Is there anything else you want to tell me / anything I haven't asked about?

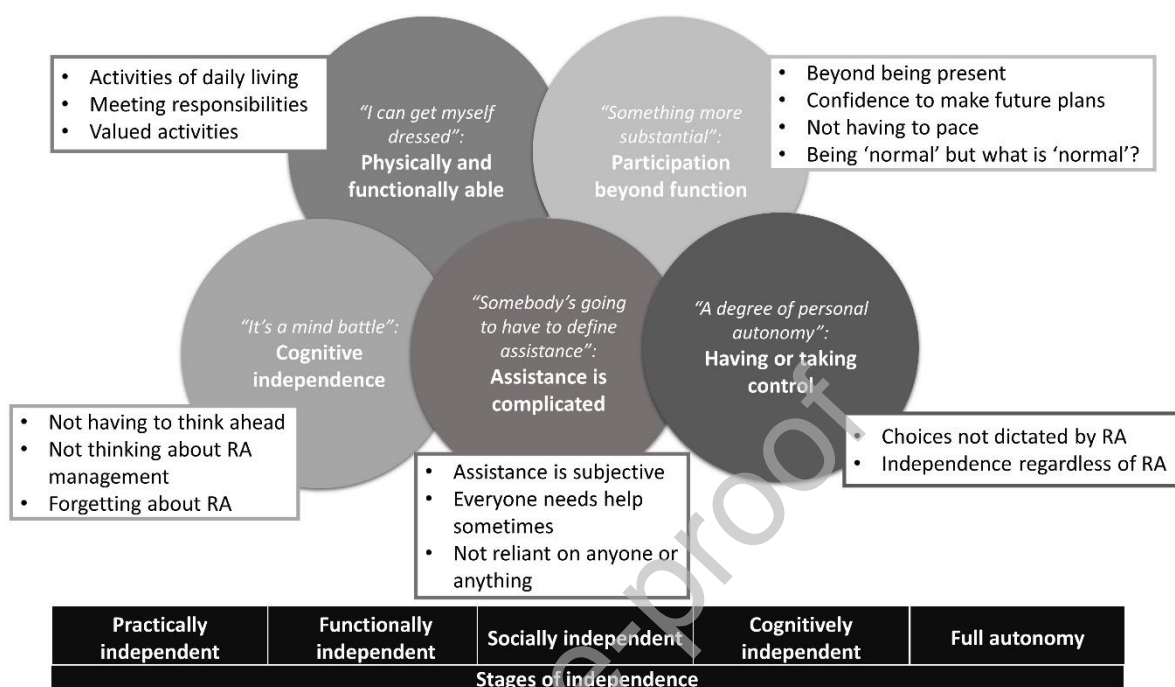
**Shared on screen was a slide showing: "Considering all the ways your disease affects you, how well are you doing today?" With a Visual Analogue Scale anchored "very well" to "very badly"*

†Directed qualitative content analysis (19) was used to specifically address participants' views on the patient global assessment and the NRS created for the longitudinal study for measuring independence (questions 7-10), which will be reported in a subsequent paper.

Table 2: Participant characteristics

Participants, n	19
Age in years, mean (min-max)	53 (31-67)
Disease duration in years, mean (min-max)	16 (4-31)
Patient Global Score, mean (sd)	2.93 (2.76)
Gender, n <i>Female, Male</i>	16, 3
Continent, n <i>North America, Europe, Australasia</i>	9, 5, 5
Ethnicity, n <i>White, Hispanic</i>	18, 1
Employment status, n <i>Full time, Part time, Retired, Not working, prefer not to say</i>	5, 5, 5, 3, 1
Marital Status, n <i>Married, Single, Widowed, Living with partner</i>	13, 1, 2, 3

Figure 1: Thematic diagram



Declaration of interests

☐ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☒ The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Caroline Flurey and Susanna Proudman reports financial support was provided by Arthritis Australia. Caroline Flurey reports a relationship with LUPUS UK that includes: funding grants. Caroline Flurey reports a relationship with Pearson Global that includes: consulting or advisory. Caroline Flurey reports a relationship with Men and Boys Coalition that includes: board membership. Lynn March reports a relationship with OMERACT that includes: board membership. Lynn March reports a relationship with Australian Government medical research grants that includes: funding grants. Lynn March reports a relationship with Janssen Australia Pty Ltd that includes: funding grants. Lynn March reports a relationship with CLEARbridge Foundation that includes: funding grants. Lynn

March reports a relationship with Northern Sydney Local Health District that includes: travel reimbursement. Lynn March reports a relationship with Australian Rheumatology Association that includes: board membership. Lynn March reports a relationship with Australian Arthritis & Autoimmune Biobank Collaborative that includes: board membership. Dorcas Beaton reports a relationship with OMERACT that includes: board membership. Beverley Shea reports a relationship with OMERACT that includes: board membership. Susanna Proudman reports a relationship with Boehringer-Ingelheim that includes: board membership, funding grants, and speaking and lecture fees. Susanna Proudman reports a relationship with Janssen Pharmaceuticals Inc that includes: funding grants and speaking and lecture fees. Peter Tugwell reports a relationship with Reformulary Group that includes: consulting or advisory. Peter Tugwell reports a relationship with OMERACT that includes: board membership. Peter Tugwell reports a relationship with UCB Biopharma GmbH & SPRL that includes: board membership. Peter Tugwell reports a relationship with Parexel International that includes: board membership. Peter Tugwell reports a relationship with Prahealth Sciences that includes: board membership. Peter Tugwell reports a relationship with AbbVie Inc that includes: funding grants. Peter Tugwell reports a relationship with AstraZeneca Pharmaceuticals LP that includes: funding grants. Peter Tugwell reports a relationship with Aurinia that includes: funding grants. Peter Tugwell reports a relationship with Bristol Myers Squibb Co that includes: funding grants. Peter Tugwell reports a relationship with Centrexion that includes: funding grants. Peter Tugwell reports a relationship with GSK that includes: funding grants. Peter Tugwell reports a relationship with Horizon Pharmaceuticals Inc that includes: funding grants. Peter Tugwell reports a relationship with Janssen Pharmaceuticals Inc that includes: funding grants. Peter Tugwell reports a relationship with Novartis that includes: funding grants. Peter Tugwell reports a relationship with Pfizer Inc that includes: funding grants. Peter Tugwell reports a relationship with Sparrow Pharmaceuticals Inc that includes: funding grants. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.