

Patient Perspective of Remission in Rheumatoid Arthritis Domain Definition Report

Population: Patients with rheumatoid arthritis	Intervention(s): Any	Control(s): Placebo/Drug	Context: Remission
Target Domain: Independence Not part of a broader domain			
Definition:	<p>"Being able to do what you want, when you want, in the way you want to do it" in the context of RA remission. It is not equivalent to remission.</p> <p>Independence is separate from pain, fatigue, and function but these all overlap and influence each other.</p> <p>It is a multi-attribute domain with broad themes including: Being Physically and Functionally Able, Participation Beyond Function, Cognitive Independence and Having Control over Life, Work and Needs.</p> <p>Important contextual factors that influence independence include physical, cognitive & emotional factors.</p>		
Core Area:	Life impact		
Scoping Review Findings:	<p>"Defining independence: A scoping review by the OMERACT patient perspective of remission in rheumatoid arthritis group." Khoo T, Jones B, Chin A, Terrett A, Voshaar M, Hoogland W, March L, Beaton D, Gazel U, Shea B, Tugwell P, Flurey C-A, Proudman S. <i>Seminars Arthritis Rheum</i> 2023;58:152152</p> <p>Main themes identified describing independence from this scoping review.</p> <ol style="list-style-type: none"> A return to a state before arthritis <p>"...one ultimate outcome: a quality of existence comparable to a status before start of their disease"[. 1](Van der Elst K et al. THU0574 Outcomes Important to Patients with Early Rheumatoid Arthritis. A Qualitative Interview Study. <i>Annals of the Rheumatic Diseases</i>. 2013)</p> <ol style="list-style-type: none"> Being physically and functionally able <p>"...independence seems mainly related to physical functioning, that is, 'the ability to do things you have to do and not have to ask others to do things for you'." [2]Van Tuyl LHD et al. Validating rheumatoid arthritis remission using the patients' perspective: Results from a special interest group at OMERACT 2016. <i>Journal of Rheumatology</i>. 2017</p> <ol style="list-style-type: none"> A sense of freedom without needing to rely on others. <p>being independent was spoken of as a conception of freedom, a physical feeling of maintaining independence without bodily symptoms." [3] (Malm K et al. Quality of life in patient with established rheumatoid arthritis: A qualitative study. <i>Annals of the Rheumatic Diseases</i>. 2016)</p> <ol style="list-style-type: none"> Having control over the organisation of one's life, work, and needs. <p>informants felt independent because they received assistance only when and in a way, they needed during their engagement. In this way, the informants felt that they [...] had control over their occupations." [4]. Nyman A, Lund ML. Influences of the social environment on engagement in occupations: the experience of persons with rheumatoid arthritis. <i>Scand J Occup Ther</i>. 2007</p>		
Focus Group Findings:	<p>"Being able to do what you want, when you want, in the way you want to do it: An OMERACT Study to Define Independence in the Context of Rheumatoid Arthritis Remission from the Patient Perspective." Flurey CA, Jones B, Gazel U, Uzoka C, Rosser K, Khoo T, Voshaar M, Hoogland W, Shea B, March L, Beaton D, Tugwell P, Proudman S. "It Means Almost Forgetting that You've Got a Disease". Available at SSRN: https://ssrn.com/abstract=4701130 or http://dx.doi.org/10.2139/ssrn.4701130</p> <p>Main themes identified describing independence from this qualitative work:</p> <ul style="list-style-type: none"> Independence in the context of rheumatoid arthritis remission is complex and multifaceted. Five overarching themes were identified, underpinned by a construct of "stages of independence". Independence means. <ol style="list-style-type: none"> being 'Physically and Functionally Able' but may go beyond this and enable: 'Participation Beyond Function' (without the need to pace and plan around RA), 'Cognitive Independence' (meaning freedom from having to think about and plan for RA) 'Having or Taking Control'. 'Assistance is Complicated' (meaning there was no agreement on whether assistance is an aid to independence or undermines ability to achieve independence) 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. 		
Contextual Factors:	<p>Assistance is a qualifier of independence (be it person to person or aids).</p> <p>Assistance is complicated so need to better define assistance, having or taking control.</p>		