Online appendices

Online appendix 1. Rheumatic and musculoskeletal diseases considered in the current Points to Consider (PtC)

EULAR definition of RMDs

Rheumatic and musculoskeletal diseases (RMDs) are a diverse group of diseases that commonly affect the joints, but can also affect the muscles, other tissues and internal organs. There are more than 200 different RMDs, affecting both children and adults. They are usually caused by problems of the immune system, inflammation, infections or gradual deterioration of joints, muscle and bones. Many of these diseases are long term and worsen over time. They are typically painful and limit function. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and life expectancy.

Disease/conditions included in current PtC

- Inflammatory arthritis (IA): rheumatoid arthritis (RA)
  axial spondyloarthritis (axSpA),
  peripheral spondyloarthritis (pSpA) including psoriatic arthritis (PsA)
  juvenile idiopathic arthritis (JIA))
- Osteoarthritis (OA): mono-, oligo or generalized osteoarthritis (OA)
- Systemic diseases: systemic lupus erythematodes (SLE)
  systemic sclerosis (SScl)
  ANCA associated vasculitis (AVAS)
- Crystal arthritis: gout
  Calcium-pyrophospate disease (CPPD)
- Regional or generalized musculoskeletal pain:
  fibromyalgia (FM)
  complaints of arm, neck, shoulder (CANS)
  chronic widespread pain (CWP)

Diseases/conditions excluded:

- work related musculoskeletal injuries
- (acute and chronic) low back pain

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Online appendix 2. Sources of evidence, RMDs considered/addressed and contribution to specific Overarching Principles / Points to Consider per research area.

Per research area, the sources of evidence (in order of level of evidence) and disease considered in the search and addressed by the sources are presented. Additionally, the sources of evidence, RMDs considered in te search and addressed in the sources by the final were linked to specific Overarching Principles (OP) and/or Points to Consider (PtC).

Research area	Source of evidence	(a) RMDs considered in search/survey (b)RMDs actually addressed in contributing documents (papers/reviews/chapters etc)	Contribution to specific OP/PtC
1. Is work relevant for (clinical) outcome?	*Scoping review*		
	Scoping review on benefits of work for physical and mental health in chronic diseases, including RMDs [1]	(a) All RMDs (b) General population and 5 major chronic diseases, including musculoskeletal diseases. The latter included 40 studies (SLRs, NR, guideline) addressing LBP or occupational injuries (n=20) , a mix of musculoskeletal conditions (n=15) and inflammatory arthritis (n=5)	OP A
	*Systematic literature review **(new)***		
	SLR on work participation as predictor of progression of RMD [2]	(a) All RMDs (b) Two SLRs were identified (one in SSc and in inflammatory arthritis and SLE). Another in 23 original studies addressed RA (10/23; 43%), OA (6/23; 26%), axSpAS (2/23; 8.7%) and PsA (1/23; 4.3%).	OP A PtC 6
	*Non-systematic search **(new)***		
	Work as an outcome domain in EULAR management recommendations (Online appendix 3.1)	(a) All RMDs (b) 9/21 recommendations addressed work participation of which 4 IA, 2 OA and 1	PtC 2

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		RMDs in general and one RA and OA	
	Work as an outcome domain in standards of care/quality indicators in RMDs (Online appendix 3.2)	(a) All RMDs (b) 8 out of 15 standards addressed work participation, of which 6 concerned IA, one OA and one chronic pain	PtC 2
	Work as an outcome domain in standard sets of the International Consortium for Health Outcome Measurement (ICHOM) (Online appendix 3.3)	(a) All RMDs (b) 3 standards addressing IA, OA and wrist pain	PtC 2
2. What are barriers and facilitators to enter, stay or re-integrate in work?	*Systematic literature review* ***(new)***		
	SLR on facilitators/barriers to get a job, stay in work and return to work while having a RMD (see research area 2)	(a) All RMDs (b)Most papers addressed inflammatory arthritis and SLE	PtC 5, 6, 10
3. What is the effectiveness of pharmacological and non-pharmacological interventions?	*Systematic literature review*		
	SLR on the effect of pharmacological interventions on work participation [3-5]	(a) Limited to inflammatory arthritis (b) SLRs were available for RA, axSpA and PsA	PtC 7
	SLR on the effect of non-pharmacological interventions on work participation ***(new)***	(a) All RMDs (b) 64 studies of which 39% addressed pain disorders and 61% all other types of RMDs.	PtC 8
	Survey ***(new)***		
	Survey among health professional and patient societies to collect initiatives to support people with RMDs (Online appendix 5.1)	(a) All RMDs (b) No distinction among type of RMDs was made	PtC 10
	Non-systematic search ***(new)***		
	Work as an outcome domain in Core Domain Sets of Outcome Measurers in Rheumatology (OMERACT) (Online appendix 4)	(a) All RMDs (b) 11/21 Core Sets addressed work participation *in trials* for IA (n=4) , crystal arthritis (n=2), OA (n=1), systemic disease/vasculitis (n=2), shoulder disorders(n=1), and in	PtC 3, 7, 8

		longitudinal observational studies in all RMDs (n=1)	
4. Which characteristics of the social security system are effective in entering, staying or re-integrating in work?	*Systematic literature review **(new)***		
	SLR on barriers and facilitators to gain, maintain and return to paid work	(a) All RMDs (b) Most papers addressed inflammatory arthritis and SLE	PtC 9
	Non-systematic search		
	Non-systematic studies to describe the disability employment gap in Europe among persons with chronic diseases [6] and with RMDs [7] and to evaluate the impact of regulations [8], policies [9] or system characteristics [10-13] to get or keep people at work	(a) General population or any RMD (b) When RMDs were studied, this concerned mainly RMDs in general or IA	PtC 9
5. How is the cycle of working life in persons with RMDs compared to that in the general population?	*Systematic literature review **(new)***		
	SLR on rates of work participation (e.g. employment status, absenteeism, presenteeism, return to work), in people with RMDs compared to the general population/control population [7]	a) All RMDs considered (b) 65 articles addressing RA (26.2%), OA (15.4%), SLE (15.4%), AxSpA (12.3%), FM (9.2%), mixed population (7.7%), JIA (7.7%), PsA (3.1%), SSc (1.5%), and gout (1.5%)	PtC 1
6. What (not) to do by employers to facilitate entering, staying and re-integrating in work?	*Survey **(new)***		
	Survey among employers to explore initiatives to support people with RMDs or chronic diseases in general (Online appendix 4)	(a) All RMDs considered (b) No distinction between RMDs was made	PtC 11

RMD: rheumatic ad musculoskeletal diseases (for definition in this manuscript: see Online appendix 1); SLR: systematic literature review; NR: narrative review; LBP: low back pain; SSc: systemic sclerosis; SLE: systemic lupus erythematodes; IA: inflammatory arthritis; axSpA: axial Spondyloarthritis; OA: osteoarthritis; JIA: juvenile idiopathic arthritis

Online appendix 3.1 (Supporting research area 1)

Aim
To assess whether work participation is included in the EULAR management recommendations [14-34]

Result
EULAR management recommendations were found for 21 conditions/clinical settings. Work was addressed in 9 out of 21 EULAR recommendations. However, work was mainly as part of the background, overarching principles or research agenda and more rarely as a recommendation (goal for management) (see Table). The Recommendations retrieved but not mentioning work include: recommendation for management of psoriatic arthritis [22], systemic sclerosis [23], gout [24], calcium pyrophosphate crystal deposition [25], large vessel vasculitis [26], fibromyalgia [27], rheumatic and musculoskeletal diseases [28], ANCA-associated vasculitis [29], Behçet's syndrome [30], Sjögren's syndrome [31], anti-phospholipidic syndrome [32], lupus nephritis [33], and recommendations for patient education for people with inflammatory arthritis [34].

Recommendation (type)	**Sections *(italic)* and specific text in the recommendation**
Recommendations regarding lifestyle behaviours and work participation to prevent progression of rheumatic and musculoskeletal diseases (under review)	***-****Statement 1 (work)****:*** "Work participation may have beneficial effects on health outcomes of people with RMDs and therefore should receive attention within healthcare consultations"
Recommendations of the role of nurses in the management of inflammatory arthritis (2020).[14]	*-Research agenda (Box 1):* "To study the nursing contribution to patients' employment status and social participation." *-Discussion:* "Studies reporting nursing interventions that focus on healthy lifestyle and work participation were rare. The research agenda aims to examine these areas."
Recommendation for the management of hand osteoarthritis (2019).[15]	*-Overarching principle A:* "The primary goal of managing hand OA is to optimize hand function, in order to maximise activity and participation."
Recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying anti-rheumatic drugs: 2019 update (2019).[16]	*-Overarching principle E:* "RA incurs high individual, medical and societal costs, all of which should be considered in its management by the treating rheumatologist." "The economic burden includes not only the medical costs, but also the costs due to sick leave, work disability, or premature retirement."

Recommendations on the health professional's approach to pain management in inflammatory arthritis and osteoarthritis (2018).[17]	*-Overarching principle (Box 1):* "The disease encompasses multiple biological, psychological and social factors, […] work and support." *-Recommendation 2:* "The patient should receive a personalised management plan with the aim of reducing pain and pain-related distress and improving pain-related function and participation in daily life."
2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis (2017).[18]	*-Overarching principle 5:* -"When assessing the financial burden for society, the direct medical costs as well as indirect costs due to work productivity loss should be taken into account."
Recommendations for the non-pharmacological core management of hip and knee osteoarthritis (2016).[19]	*-Recommendation 1:* "The recommendation on the initial assessment included the following elements: the person's physical status, activities of daily living, participation." *-Recommendation 2:* "Treatment of hip and/or knee OA should be individualised according to the wishes and expectations of the individual, localisation of OA, risk factors […], presence of inflammation, severity of structural change, level of pain and restriction of daily activities, societal participation and quality of life." *-Recommendation 11:* "Patients with hip or knee OA at risk of work disability or those who want to return to work should have access to vocational rehabilitation such as changing work tasks, work hours, workplace modification."
Recommendations for the management of early arthritis (2017).[20]	*-Recommendation 12:* "Education programmes aim at letting patients cope with disability maintenance of ability to work and participation in life."

Standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases (2017).[21]	*-Aspects considered as part of holistic care (Box 1):* Educational and vocational aspects: ‣addressing future career perspectives ‣support in preparing for work readiness […] ‣addressing work experience and encouraging young people to gain relevant experience […] ‣informing about rights and obligations, benefits and opportunities to adapt working (place, time)

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Online appendix 3.2. (Supporting research area 1)

Aim
To assess whether work participation included in Standards of Care (SOCs), Quality Standards (QS) or quality indicators (QI) [35-49]. [14-34]

Result
Work participation was addressed in 8 out of 15 SoC/QIs that were published in peer review literature (table)[35-49] and were screened for work outcome domains. SoC/QIs for rheumatoid arthritis [43, 44], psoriatic arthritis [45-47], juvenile localized scleroderma [48], and juvenile idiopathic arthritis [49] did not mention work.

Standard of care/quality indicator (type)	**Sections (italic) and relevant phrase in standard/indicator**
Development of patient-centred standards of care for rheumatoid arthritis in Europe: the eumusc.net project (2014).[35] eumusc.net	*-SoC 14:* "People with RA should receive information, advice and training on joint protection and ergonomic principles as well as activity-based methods to enhance functioning in daily life and participation in social roles."
Development of healthcare quality indicators for rheumatoid arthritis in Europe: the eumusc.net project (2014).[36] eumusc.net	*-Health Care Quality Indicators for rheumatoid arthritis 6:* "If a patient is diagnosed with RA, then a rheumatologist and/or relevant health professionals from the multidisciplinary team should assess and document the following variables: (1) …, (2)…, (3) …, (4) labor force participation. The assessment and documentation should occur at baseline and thereafter at appropriate time intervals, at least annually for 1, 3 and 4."
BSR guidelines on standards of care for persons with rheumatoid arthritis (2005).[37] *BSR, broadly endorsed by other relevant organisations*	*-SoC 2: Empowering persons with rheumatoid arthritis:* "This management should take into account not only the goal of controlling the activity of the disease, […] but also the psychological, employment and educational opportunities, family and social impact of the disease." *-SoC 5: Annual review:* "All persons with rheumatoid arthritis should have a formal annual assessment of […] employment status […].

Development of ASAS quality standards to improve the quality of health and care services for patients with axial spondyloarthritis (2020).[38]	*-Quality Standard 9 for axial spondyloarthritis, management:* "The annual review provides a regular opportunity to assess the patient in terms of current disease management, and any further support they may need in the future, in order to enable them to maximise their health, participation in society and life satisfaction. Focus should not only be on clinical symptoms and severity of disease but also on comorbidities like CV risk management or osteoporosis, employment, psychological factors, and life-style including physical activity."
Quality standard for the management of patients with psoriatic arthritis: QUANTUM project. (2018).[39]	*-Quality standard 20 to optimise management of the disease:* "Medical records must include family history, tobacco and alcohol consumption, frequency of physical exercise (type and approximate number of hours per week), employment situation, comorbidities and periodic updating (at least weekly) of the treatment that patients are receiving during the consultation."
Development of patient-centred standards of care for osteoarthritis in Europe: the eumusc.net-project (2015).[40] eumusc.net	*-SoC 2:* "People with symptoms of OA should be assessed at diagnosis and upon significant worsening for ‣ […] Ability to do their tasks and work" *-SoC 4:* "People with OA should have access to different health professionals such as occupational therapist and physiotherapist if needed to treat their symptoms and achieve optimal possible functioning in daily life and participation in social roles (including paid work)." *-SoC 8:* "People with OA should receive information tailored to their needs within 3 months of diagnosis by health professionals about ‣ […] ergonomic principles and activity-based methods to enhance functioning in daily life and participation in social roles;"
Australian Paediatric Rheumatology Group standards of care for the management of juvenile idiopathic arthritis (2014).[41]	*-SoC 11: Transition to adult services (11.2):* "Adolescent patients should have access to career counselling and vocational planning."
Standards of care for acute and chronic musculoskeletal pain: the Bone and Joint Decade (2008).[42]	*-Preventions: At place of work:* "Minimize workplace exposure to at risk activities, such as vibration, repetitive tasks, inappropriate lifting, etc."

Online appendix 3.3 (Supporting research area 1)

Aim
To investigate whether work participation was an outcome domain in the Standard sets for RMDs of the International Consortium for Health Outcome Measurement (ICHOM)[50-52].

Result
Work was included in all three standard sets for RMDs.

Standard set (type)	**Domain description**
Standard set for inflammatory arthritis[50]	Work/school/housework ability and productivity (as part of domains related to functioning)
Standard set for hand and knee osteoarthritis[51]	Work status (as part of the domains reflecting s patient reported health status)
Standard set for hand and wrist conditions[52]	Return to work (to be assessed in all tracks)

Online appendix 4 (Supporting research 3)

Aim

To assess whether work participation was included an outcome domain included in the disease specific Core Domain Sets of Outcome Measures in Rheumatology (OMERACT) [53-69].

Result

Work participation was addressed in 12 out of 18 OMERACT Core Outcome Domain Sets, usually as an important but optional core domain [53-63, 65-69]. Six Core Outcome Domain Sets did not mention work participation: hand osteoarthritis [64], ANCA-associated vasculitis [65], fibromyalgia [66], osteoporosis [67], connective tissue disease-associated interstitial lung diseases [68], and Behçet's syndrome [69].

Outcome Domain set	**Study Setting**	**Place in the Core Set**
Myositis[53]		*-Research Agenda:* Ability to work
Juvenile Idiopathic Arthritis[54]		*-Important but optional:* Participation restrictions
Shoulder disorders[55]	Clinical trials	*-Important but optional*: Participation (recreation/work)
Flare in Rheumatoid Arthritis[56]		*-Important but optional*: Participation
Psoriatic Arthritis[57]	Randomized controlled trials and longitudinal observational studies	*-Important but optional*: Participation
Hip and Knee OA[58]	Clinical trials	-Important but optional Participation
Chronic gout[59]		*-Important but optional:* Participation restrictions Work disability
Acute gout[59]		*-Important but optional:* Work disability
Axial Spondyloarthritis[60]	Clinical trials and observational studies	*-Important but optional:* Work and Employment
Systemic Lupus erythematodes [61]	Randomized controlled trials and longitudinal observational studies	*-Research Agenda* Work Status
Polymyalgia Rheumatica[62]		*-Research Agenda* Participation

Longitudinal observations studies[63]		-*Mandatory:* Participation (including work)

Online appendix 5.1

Survey 1 (Supporting research area 3)
Survey among health professional and patient societies for initiatives to support people with RMDs in work participation

Aim
To collect information (materials) developed or used by health professionals' and patient organisations in Europe to support and promote healthy and sustainable work participation for people with RMDs.

Methods
Participants
140 health professional and patient organisations were contacted by EULAR's Advocacy department to fill in an online survey (Qualtrics). One reminder was sent after two weeks. Additionally, the invitation was included in the EULAR newsletter. The survey closed after four weeks (May 19th, 2021).

Survey
The survey comprised 7 questions addressing: (1) guidelines or recommendations including work participation, (2) presence of a dedicated person or working group focusing on work participation, (3) information materials for patients, health professionals or employers on how to support people with RMDs in work, (4) courses/sessions how to deal with work related problems, (5) training for health professionals to facilitate inclusion of work as a treatment goal, (6) contact with employers/employer organisations. (7) contact with policy makers/ Questions could be answered as yes/no. In case of a positive answer, details could be provided in an open textbox.

Results
After the closing date, 20 organisations (14%) from 16 European countries had responded (Table 1). Nine patient organisations, nine professional organisations, one combined patient/professional organisation and one research group participated. Four of the health professionals' organisations represented rheumatologists as well as allied health professionals, one general practitioners, two rheumatologists only, one allied health professionals in rheumatology and one primary care physicians. Information and education were the most frequent types of practices implemented. Evaluation of initiatives was scarce (and considered challenging). Several patient societies also have contact at the policy level or with employer organisations.

Conclusion
Despite reminders, few organisations responded. Notwithstanding, information from societies of 16 European countries was obtained. Non-responders had likely no initiatives or no dedicated person in place, and the examples from the current surveys can serve as inspiration but should be evaluated more systematically.

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Table 1. Background of the 20 organisations responding to the survey

Type of organisation	**Country**	**n**
Patient organisations	Belgium, Denmark, Finland, Germany, Greece, Israel, Poland, Portugal, United Kingdom	9
Health professional organisations	Georgia, Greece, Hungary, Italy, The Netherlands, Portugal and Spain (n=3)	9
Combined patient and health professional organisation	Norway	1
Research group	Belgium	1

Overall, patient organisations seemed to be more active compared to organisations for healthcare professionals/rheumatologists, especially in organizing events and contact with employers and policy makers.

Table 2. Responses per question by type of organisation

Question	**Organisation type**	**Number of positive answers**	**Open text clarification**
Availability of guidelines, recommendations and information materials			
Availability of guidelines or recommendations for treatment/management of RMDs, in which work participation is included	Patient	5/9	- report to promote professional re-integration of persons with chronic rheumatic diseases
	Professional	3/9	- guideline on RA and work participation
Providing information (materials) for either patients, health professionals or employers on how to support people with RMDs in work	Patient	7/9	- brochures or websites regarding working and having a RMD (both in English or non-English)
	Professional	3/9	/
	Combined	1/1	/
Providing support to people with RMDs or healthcare professionals			
Presence of a dedicated person or working group focusing on work participation of persons with RMDs	Patient	4/9	- social workers are employed at the telephone counsel line and other staff members are also involved in issues around work - to assist patients with knowledge regarding their rights at work and in social services

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	Professional	3/9	- nursing work group dedicated to accompanying and helping the patient in different aspects - working group to promote early diagnosis and treatment, in order to prevent work disability
	Combined	1/1	/
Organizing events, courses or sessions for people with RMDs to address possible problems they may face at work	Patient	8/9	- information sessions for patients on social rights - information sessions and personal coaching about working with RMDs - telephone counsel line, website, local events - support groups for patients
	Professional	5/9	- topic discussed at meetings with patient organisations
	Combined	1/1	- network conference, including topic of work
Organizing training or courses to educate health professionals working in the field of rheumatology to facilitate work as treatment goal for patients	Professional	2/9	/
Establishing contact with employers/employer organisations, policy makers or governmental bodies			
Contact with employers or employer organisations to provide guidance on how to support people with RMDs in the workplace	Patient	4/9	- collaboration with employment confederation to develop resources for employers
Contact with policy makers or other governmental bodies to discuss policies and to promote the importance of work participation in people with RMDs	Patient	8/9	- Meetings with stakeholders - Round tables with politicians
	Professional	3/9	- participating in steering committees
	Combined	1/1	/

Note: As the focus of the survey was on (evaluation of) real world initiatives and not on research, answers by the Research Group were not included in the narrative summary.

Online appendix 5.2

Survey 2 (Supporting research area 6)
Survey among employers to explore initiatives to support people with RMDs

Aim
To gain an understanding if organisations developed specific policies and/or wellbeing programmes to employ and support people with RMD complaints or chronic disease in general in the workplace.

Methods
Organisations: Thirteen large companies or employer organisations (mainly UK) were identified through personal links or through searches on the website. A letter to request information on policies or wellbeing programmes was emailed to these organisations. Email addresses of companies searched via the website included those working in human resources, recruitment or disability office. Only three organisations replied. A virtual meeting was held to gain an understanding about the support in place for people with RMDs. In addition, an interview was held with one of the participants (Group Ergonomic, Musculoskeletal and Wellbeing Specialist at BT).
Questions addressed during the interview included amongst others: Has your organisation developed specific policies and/or wellbeing programmes to employ and support persons with RMD complaints or chronic diseases in general?; What are these policies and/or wellbeing programmes?: If people experience any problems due to ill health at work, who are the people within the organisation to contact (e.g. line manager, occupational therapist).

Results
All responding companies had general policies in place to support employees in the workplace with health problems as per legal requirements. Policies mainly depend on local and national guidelines. Support and possible requirements to adjust the working environment were discussed with the line manager, occupational therapist (if available) and sometimes the employer. One company specifically mentioned interventions for people with RMDs. To promote a healthy lifestyle, wellbeing programmes were initiated and included: access to physiotherapist/fitness provider, access to local gyms. However, some of these wellbeing programmes are restricted by funding.

Discussion
Few companies responded, which might reflect absence of dedicated persons/departments addressing health at work. It seems legal requirement on healthy workplaces are effective in ensuring practices are available. Quality and efficacy of such policies requires evaluation.

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