2021 EULAR points to consider to support people with rheumatic and musculoskeletal diseases to participate in healthy and sustainable paid work

Annelies Boonen 1,2, Casper Webers 1,2, Maarten Butink 1,3, Birgit Barten 4, Neil Betteridge 5, Dame Carol Black 6,7, Ann Bremander 8,9, Boryana Boteva 4,10, Olga Brzezińska 4, Lina Chauhan 11, Sarah Copsey 12, Vera Guimarães 13, Monique Gignac 14,15, Jennifer Glaysher 16, Frans Green 17, Jan L Hoving 18, Mary Lucy Marques 19,20, Hana Smucrova 1,21, Tanja A Stamm 1,22, Dieter Wiek 4, Ross Wilkie 23, Anthony D Woolf 24, Gerd R Burmester 1,25, Johannes W Bijlsma 1,26, Suzanne M M Verstappen 27,28,29

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ABSTRACT

Aim As part of its strategic objectives for 2023, EULAR aims to improve the work participation of people with rheumatic and musculoskeletal diseases (RMDs). One strategic initiative focused on the development of overarching points to consider (PtC) to support people with RMDs in healthy and sustainable paid work participation.

Methods EULAR’s standardised operating procedures were followed. A steering group identified six research areas on paid work participation. Three systematic literature reviews, several non-systematic reviews and two surveys were conducted. A multidisciplinary taskforce of 25 experts from 10 European countries and Canada formulated overarching principles and PtC after discussion of the results of literature reviews and surveys. Consensus was obtained through voting, with levels of agreement obtained anonymously.

Results Three overarching principles and 11 PtC were formulated. The PtC recognise various stakeholders are important to improving work participation. Five PtC emphasise shared responsibilities (eg, obligation to provide active support) (PtC 1, 2, 3, 5, 6). One encourages people with RMDs to discuss work limitations when necessary at each phase of their working life (PtC 4) and two focus on the role of interventions by healthcare providers or employers (PtC 7, 8). Employers are encouraged to create inclusive and flexible workplaces (PtC 10) and policymakers to make necessary changes in social and labour policies (PtC 9, 11). A research agenda highlights the necessity for stronger evidence aimed at personalising work-related support to the diverse needs of people with RMDs.

Conclusion Implementation of these EULAR PtC will improve healthy and sustainable work participation of people with RMDs.

INTRODUCTION

In nearly all European countries, the work participation gap between people with chronic diseases, especially those with rheumatic and musculoskeletal diseases (RMDs), and the general population persists, varying between 10% and 15%.1 Moreover, RMDs account for up to 60% of prolonged sickness absence and work disability in the European Union and consistently rank first or second in causes of work disability across countries.2 Being age-related diseases, this burden will likely increase over the coming decades. Multiple reasons have been identified to explain the persistent work participation gap. First, despite medical advances, cure of RMDs remains elusive for most patients, and pain remains the most common symptom hampering activities and participation. Second, with population ageing, welfare systems focus on inclusive and longer participation in the workforce, posing challenges to people with chronic diseases. Third, the nature of work has changed over time with more emphasis on efficiency and productivity, and little attention for vulnerable persons in society.3

To bridge the work participation gap, EULAR included in its strategic objectives that ‘By 2023, EULAR’s activities and related advocacy will have increased participation in work by people with RMDs.’4 As part of these activities, a taskforce was assembled to formulate points to consider (PtC) to support healthy and sustainable paid work participation for people with RMDs. The target audiences comprise (organisations of) people with RMDs and healthcare professionals, as well as employers, trade unions, occupational health and safety organisations, policymakers, researchers and others involved in durable work participation for people with chronic diseases such as RMDs.

METHODS

The steering committee (GRB, JWB, NB) of EULAR’s Campaign on RMDs and Work convened physically in January 2020 with experts (AB, SMMV, TAS, TW) in the field and a patients’ representative (DW) and decided on the protocol for the PtC. In line with the updated EULAR standardised operating procedures, two convenors (SMMV, AB), two fellows (MB, CW) and a methodologist (TAS) were appointed.5 This extended steering group identified six research areas where evidence would be required to inform the formulation of the PtC:

1. Is work relevant for (clinical) outcome?
2. What are barriers and facilitators to enter, maintain or return to work?
surveys, data extraction/analyses and data synthesis. The three

5. How do work participation rates in people with RMDs compare with those in the general population?

6. What should employers do (or not do) to facilitate people with RMDs entering, maintaining returning to work?

The RMDs considered were inflammatory arthritis (IA) including juvenile idiopathic arthritis (JIA), osteoarthritis (OA), systemic diseases, crystal arthritis, regional or generalised musculoskeletal pain (see online supplemental appendix 1 for details). Studies on (work-related) musculoskeletal injuries and chronic low back pain were excluded, as these persons are not under chronic care of rheumatologists in most countries. After scanning the published literature, it was decided to conduct three new systematic literature reviews (SLRs). The first aimed to identify facilitators and barriers for work outcomes (research area 2), the second addressed prospective studies assessing non-pharmacological interventions (research area 3), and the third concerned studies comparing work participation outcomes in people with RMDs with the general population (research area 5). Additionally, the extended steering group decided on two surveys. The first was distributed among professional and patient organisations in rheumatology to identify recommendations/guidelines or activities (eg, self-management courses, guidelines) aiming to support work participation for people with RMDs (research area 3). The second survey was among large companies on available policies or programmes to support people with chronic diseases, specifically those with RMDs (research area 6). For remaining areas (research areas 1 and 4), non-systematic searches were the source of evidence. Online supplemental appendix 1 provides an overview of sources of evidence for each research area including the types of RMDs actually addressed in these sources, and table 1 explains key terminology. Convenors and fellows were responsible for the literature searches and surveys, data extraction/analyses and data synthesis. The three SLRs will be submitted for publication.

**Recommendation**

3. What is the effectiveness of pharmacological and non-pharmacological interventions on work participation outcome?

4. Which characteristics of the social security system are effective in entering, maintaining or returning to work?

5. How do work participation rates in people with RMDs compare with those in the general population?

6. What should employers do (or not do) to facilitate people with RMDs entering, maintaining returning to work?

The extended steering group convened four times to discuss intermediate results. The entire taskforce (n=25) was invited for a virtual meeting in May 2021, and included persons from 10 European countries and Canada. A wide range of stakeholders were invited including: health professionals, researchers, epidemiologists, patient representatives, consultants in management and policy communication, a politician and a representative of the European Agency for Safety and Health at Work. Participants formulated the PtC following a process of discussion and voting based on evidence from the existing and new (systematic) literature reviews and survey results (online supplemental appendices 2–3 for sources of evidence and unpublished results). Consensus was reached if >75% of the members voted in favour of a PtC in the first (or >66% and >50% in a second and third, if applicable) round. After the meeting, the level of evidence and strength of recommendation were added to each of the statements. Finally, taskforce members anonymously indicated the level of agreement (LoA) via an online survey (numerical rating scale ranging from 0=‘do not agree at all’ to 10=‘fully agree’) emailed to participants after the taskforce meeting. The mean and SD of the LoA as well as the percentage of taskforce members with an agreement ≥8 are presented. Taskforce members could refrain from voting if a statement was outside their professional expertise. Based on the gaps in evidence and issues of controversy, a research agenda was formulated. The final manuscript was approved by the EULAR Council.

**RESULTS**

The taskforce developed and endorsed 3 overarching principles and 11 PtC (table 2).

**Overarching principles**

Participation in good work increases self-worth and self-esteem, economic independence and social inclusion, which generally translates into better health and well-being

Substantial causal evidence indicates that not having paid work is a predictor of comorbidities, social exclusion and mortality. Consensus exists across various disciplines that paid work

### Table 1 Clarity of words as used in this manuscript

<table>
<thead>
<tr>
<th>Construct</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid work participation</td>
<td>The act of taking part/being involved in paid work. Comprises having (or not having) paid work but sick leave and presenteeism.</td>
</tr>
<tr>
<td>Work participation outcomes</td>
<td>Work status: Having paid work (employee or self-employed) and reasons for not having paid work (eg, work disability).</td>
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<td></td>
<td>Sick leave or sickness absence: Not performing/attending work due to illness while having an employment contract.</td>
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<tr>
<td></td>
<td>Presenteeism: (a) The behaviour of attending (paid) work while being ill, and/or (b) the level of productivity loss, or (c) difficulty reduced ability to work when being at work with health problems.</td>
</tr>
<tr>
<td>Adverse work outcome</td>
<td>(Partial) unemployment (eg, work disability) and/or sick leave and/or presenteeism due to health issues.</td>
</tr>
<tr>
<td>Work participation gap*</td>
<td>The difference in work participation outcomes between between patients with RMDs and the general population.</td>
</tr>
<tr>
<td>Good work (decent work)</td>
<td>Work that is engaging, gives people a voice, treats them fairly, provides job security, helps them to progress and is accommodating for specific health and mental needs.</td>
</tr>
<tr>
<td>Work sustainability intervention (stay at work)</td>
<td>Intervention that aims to prevent unwanted/adverse work outcome and focuses on persons having a paid job.</td>
</tr>
<tr>
<td>Return to work intervention</td>
<td>Intervention that aims for return to paid work of persons currently on sick leave, work disabled or unemployed.</td>
</tr>
<tr>
<td>Work-related support</td>
<td>Any support contributing to work participation of people with a (chronic) disease.</td>
</tr>
<tr>
<td>Pharmacological intervention</td>
<td>Intervention with focus on effects of drugs/medicines.</td>
</tr>
<tr>
<td>Non-pharmacological intervention*</td>
<td>Intervention that does not contain pharmacological or surgical components.</td>
</tr>
<tr>
<td>Workplace intervention*</td>
<td>Intervention mainly executed at the workplace.</td>
</tr>
<tr>
<td>Healthcare intervention*</td>
<td>Intervention mainly executed in a healthcare setting.</td>
</tr>
<tr>
<td>Intersectionality</td>
<td>Framework for conceptualising a person, group of people or social problem as affected by a number of discrimination and disadvantages. It takes into account people’s overlapping identities (eg, gender, race, sexual orientation, education, obesity) and experiences (social exclusion, stigmatisation) in order to understand the complexity of prejudices they face.</td>
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</table>

*Definition specific for the current PtC.

PtC, points to consider; RMDs, rheumatic and musculoskeletal diseases.

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positively contributes to mental and physical health of people with RMDs. Evidence of specific work activities having an adverse impact on health is scarce, methodologically challenging and mainly limited to OA. However, it should be recognised that performing paid work might aggravate symptoms of RMDs, and for some individuals specific circumstances might preclude healthy work participation. The taskforce emphasised the importance of ‘good work’, referring to work that is engaging, gives people a voice, treats them fairly and inclusive, provides job security and equal opportunities, helps them to progress and is accommodating for specific health and mental needs.

The aim of work-related support for people with RMDs is to optimise working life and to ensure best physical and mental health. The taskforce asserted work-related support has a dual aim: (1) to support people with RMDs to sustain their ability to remain employed and, if needed, to return to work after absence, and (2) to safeguard health. Work participation should not be imposed at the expense of physical or mental health. Also, after being informed about benefits and drawbacks, not participating in paid work can be a personal (informed) choice.

It is a shared responsibility of all members of the society to support people with RMDs to participate in healthy and sustainable work. Work participation is a complex outcome, influenced by multiple factors at the individual, social, societal and environmental level that are interconnected and that involve different people and professionals. To improve the sustainability of work participation, it is essential to recognise persons at risk, including intersectionality that considers multiple aspects of a person’s identities and experiences that can make some individuals at greater risk of discrimination and disadvantage. It is also critical to ensure that all relevant persons and organisations collaborate. Support can vary from appreciation of a person’s work commitment to informal help or formal policies and practices to accommodate healthy work.

### Points to consider

Throughout their working life, people with RMDs should be supported and encouraged to enter, sustain and/or return to work. It is a shared responsibility of all members of the society to support people with RMDs to participate in healthy and sustainable work.

**Overarching principles**

A. Participation in good work increases self-worth and self-esteem, economic independence and social inclusion, which generally translates into better health and well-being. B. The aim of work-related support for people with RMDs is to optimise working life and to ensure best physical and mental health. C. It is a shared responsibility of all members of the society to support people with RMDs to participate in healthy and sustainable work.

**Points to consider**

1. Throughout their working life, people with RMDs should be supported and encouraged to enter, sustain and/or return to work.
2. People with RMDs should have timely access to health and job support to promote sustained work ability and productivity, and to prevent long-term absence.
3. Health professional organisations, policymakers, patient organisations and employers should collaborate to minimise the employment gap and optimise employment opportunities among people with RMDs.
4. People with RMDs should be supported (in the decision whether) to discuss their work-related challenges with their employer and healthcare providers.
5. Presenteeism and sickness absence can be signals for future adverse work outcomes.
6. All aspects of the biopsychosocial framework of health have to be considered when addressing the work participation needs of people with RMDs.
7. Disease-modifying interventions for inflammatory rheumatic diseases have a beneficial effect on work participation and are recommended to be started as early as possible.
8. Non-pharmacological interventions should be considered for people with RMDs to reduce or prevent sickness absence and possibly improve work ability.
9. Actors in the social security systems should develop and implement policies and practices to promote work sustainability and return-to-work efforts, with respect to the rights of people with RMDs.
10. Healthy workplaces and supportive attitudes of employers, managers and colleagues are essential for people with RMDs to acquire and maintain work.
11. Employers should develop and implement policies and practices to promote a workplace culture of inclusivity, flexibility and support.

**Table 2 Overarching principles and points to consider**

<table>
<thead>
<tr>
<th>Overarching principles</th>
<th>LoE (1–5)</th>
<th>SoR</th>
<th>LoA (0–10)</th>
<th>Mean (SD)</th>
<th>% with score ≥8</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Participation in good work increases self-worth and self-esteem, economic independence and social inclusion, which generally translates into better health and well-being.</td>
<td>9.5 (2.0)</td>
<td>91</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. The aim of work-related support for people with RMDs is to optimise working life and to ensure best physical and mental health.</td>
<td>9.6 (0.7)</td>
<td>100</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. It is a shared responsibility of all members of the society to support people with RMDs to participate in healthy and sustainable work.</td>
<td>9.1 (1.7)</td>
<td>82</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Evidence of effectiveness of disease modification comes from RA, axSpA and PsA, evidence of benefits of early versus late stems from indirect comparisons of RCTs in RA or cohorts in SpA. axSpA, axial spondyloarthritis; LoA, level of agreement; LoE, level of evidence; PsA, psoriatic arthritis; RA, rheumatoid arthritis; RCTs, randomised controlled trials; RMDs, rheumatic and musculoskeletal diseases; SoR, strength of recommendation; SpA, spondyloarthritis.*

People with RMDs should have timely access to health and job support to promote sustained work ability and productivity, and to prevent long-term absence.

People with RMDs on long-term sickness absence or on work disability benefits have lower chances of successful return to work. It is thus important to promote work participation and support work ability while still in paid work. This requires early identification of persons at risk followed by support tailored to the person’s needs. While this is a shared responsibility of several stakeholders, healthcare providers could play a more active role in screening for those at risk and initiating timely support. Current management recommendations and standards of care in RMDs overall lack too often explicit statements on the need for work-oriented care in clinical practice (online supplemental appendix 3.1).

Health professional organisations, policymakers, patient organisations and employers should collaborate to minimise the employment gap and optimise employment opportunities among people with RMDs.

Collaboration among stakeholders is essential to increase employment opportunities for people with RMDs. Relevant parties should (1) agree on common goals and principles regarding ‘healthy and sustainable work’, and define the specific responsibilities of each stakeholder; (2) consider national as well as local context (healthcare, social security, employment systems and labour market); and (3) monitor effectiveness and safety of practices and interventions in order to increase knowledge on effective and efficient work-related support.

People with RMDs should be supported (in the decision whether) to discuss their work-related challenges with their employer and healthcare providers. People with RMDs are best positioned to recognise when sustainable work participation is at risk. However, they might need encouragement/guidance (a) in their decisions whether and when to share information—for example, disclose their disease with their workplace leader (eg, supervisor, human resource manager) - in the context of legislation on this issue and (b) how to formulate their needs to any relevant stakeholders. Healthcare providers can play an important role in this process. If needed, interactions among patients, healthcare providers and employer groups should be facilitated, allowing a shared decision and actionable treatment plan. It is essential patients feel safe to communicate.

Presenteeism and sickness absence can be signals for future adverse work outcomes. There is accumulating evidence that presenteeism and/or recent sickness absence are strong predictors of long-term sick leave and that long-term sick leave is a strong predictor of future work disability. Both predictors should be an indicator—also in clinical care—to start support processes to maintain healthy and sustainable work participation.

All aspects of the biopsychosocial framework of health have to be considered when addressing the work participation needs of people with RMDs.

Consistent with the biopsychosocial model of human functioning, factors associated with work outcomes comprise not only physical and mental health impairments, but also personal and environmental factors. These contextual factors can be barriers as well as facilitators, and are of special interest if they are modifiable. To facilitate a comprehensive needs assessment of patients in relation to work outcomes, the International Classification of Functioning and Health for Vocational Rehabilitation can be considered. In people with RMDs, limited physical function (and/or disease activity in case of IA) is the strongest disease-related predictor of adverse work outcomes. Lower education, higher age, female gender and work-related factors (such as physically demanding jobs, job autonomy and social security system) are contextual factors that have repeatedly been associated with adverse work outcomes.

Disease-modifying interventions for inflammatory rheumatic diseases have a beneficial effect on work participation and are recommended to be started as early as possible.

In IA, there is high-level evidence that disease-modifying drugs have moderate to large beneficial effects on sick leave and presenteeism. In people with established rheumatoid arthritis (RA) and axial spondyloarthritis (axSpA), the majority of people who are work disabled will not return to work. However, among patients with early RA and axSpA, some data indicate early remission translates in employment rates that come closer to the general population. While this latter evidence comes exclusively from recent studies in RA and axSpA, the taskforce was in agreement that timely disease modification could have similar beneficial effects on work outcome in patients with other RMDs.

Non-pharmacological interventions should be considered for people with RMDs to reduce or prevent sickness absence and possibly improve work ability.

Clinical and methodological heterogeneity in non-pharmacological studies hamper clear conclusions about the effectiveness of non-pharmacological interventions for work sustainability and return to work in case of absence/sick leave. Our literature review showed small but significant beneficial pooled effect sizes of non-pharmacological interventions for work status, sick leave and presenteeism. Effects seemed somewhat stronger in people with RMDs compared with persons with unspecified pain disorders, especially for sick leave. Beneficial effects have been observed for both single-component (eg, information/education) or multiple-component (eg, education/information combined with physical exercise training and workplace visits/adaptations) interventions, in populations with or without risk factors for adverse outcome at baseline and for interventions executed at the workplace, in a healthcare setting or in a combined healthcare–workplace setting. Heterogeneity suggests tailoring of non-pharmacological work-related support to the individual’s needs, with an essential role of context.

Actors in the social security systems should develop and implement policies and practices to promote work sustainability and return-to-work efforts, with respect to the rights of people with RMDs. Compared with people with RMDs living in high-income countries, those living in countries with lower healthcare expenditures and lower economic prosperity (gross domestic
people with chronic diseases.50–53 Of note, persons with RMDs granting work disability have higher employment rates among people with chronic diseases.50–53 Some evidence suggests that systems requiring vocational rehabilitation before granting work disability have higher employment rates among people with chronic diseases.50–53 Of note, persons with RMDs who face long-term sickness absence or work disability often feel stigmatised along the process towards recognition of work disability. This is less so for persons within Scandinavian social security systems.52 54 Taken together, the findings call for system changes at different strands and various executive levels of the social security system, with priorities that can differ by region/country.

Healthy workplaces and supportive attitudes of employers, managers and colleagues are essential for people with RMDs to acquire and maintain work

Qualitative and quantitative research among people with RMDs provides substantial evidence on the facilitating role of attitudes of colleagues, supervisors and employers in healthy and sustainable work.53 Therefore, the taskforce calls upon all persons working with people with RMDs to adopt an understanding attitude and to implement active support for persons with RMDs in periods or circumstances when support is needed. Ensuring ‘good work’ is an essential basis for a culture of inclusiveness.

Employers should develop and implement policies and practices to promote a workplace culture of inclusivity, flexibility and support

To achieve impactful improvement in career perspectives and sustainable work participation of people with RMDs, the taskforce highlighted the need for workplaces that are inclusive for people with chronic disease and are flexible in accommodating to the needs of people with RMDs. These needs typically differ between individuals and across jobs and may vary over time. Employers have the legal duty to ensure safety and equality at work. To develop and implement desired policies and practices, employers and their organisations should align with other stakeholders such as unions and disability managers/occupational physicians, and account for national and regional needs, opportunities and regulations.

Research agenda

Several knowledge gaps emerged during evidence collection in the six research areas and were reinforced in the final taskforce meeting. Gaps pertained to defining and measuring ‘healthy and sustainable’ work participation, defining and measuring ‘good work’, dealing with intersectionality, methodological issues of designing work intervention studies, the need for high-quality evidence on (cost-)effectiveness of work interventions and policies, and the need for clear implementation strategies (table 3).

**DISCUSSION**

Finding paid work, maintaining sustainable work, pursuing a career and if applicable re-entering the labour market are as relevant for people with RMDs as for those in the general population. A taskforce of 25 experts in the field of work participation formulated 11 statements with the ultimate aim to close the persistent work participation gap of people with RMDs compared with the general population and optimise working life for people with RMDs. Not providing people with RMDs the support to gainfully participate in the labour market will result in socioeconomic exclusion of this population, potentially resulting in poor health and inequities.56

Though some of the statements are based on evidence of systematic review of scientific papers (PtC 7 and 8), other statements have a low level of evidence and rely on expert opinion (PtC 1–4). Therefore, the guidance statements have been formulated as ‘points to consider’ rather than recommendations. Statements with lowest level of evidence (1–4 and 9–11) received still a high level of agreement and inspired the research agenda, specifically on the question what constitutes ‘good work’ for people with RMDs, what is the role of healthcare professional in supporting work and which specific policies and practices for social security systems and employers are successful in achieving sustainable work. Also, response to our surveys was low and likely those with attention for work participation were more likely to respond. Initiatives revealed through the survey can be inspirational for other societies/companies. Researchers should engage in evaluation of such practices.

The PtC recognise the complexity of work participation, as people’s background, health impairments and experiences interact with cultures, institutions, and systems. To enhance healthy and sustainable work, the actors involved—from people with RMDs and their healthcare providers to policymakers—are called upon to take responsibility to enable the right for paid work and the right for just and favourable conditions of work.57 Importantly, staying in work should never be at the expense of disease control. The PtC further emphasise the role of prevention (eg, acting upon early signs that work support is needed, designing healthy workplaces), the need to consider health as well as context, and alignment of care and support for individual people with RMDs across the settings (healthcare, employers and labour organisations, social security). The key to success is implementation of policies and practices that have shown to be safe and effective for each part of the work participation chain.

A vast amount of research evidence points to the decisive role of the workplace in sustainable work for vulnerable persons. While several terms and definitions have been proposed on what constitutes ‘good work’, a generally agreed upon and (wherever possible) evidence-based working definition is highly needed. Overall, work that helps people to progress, treats them fairly, provides job security, and has the culture and resources to be accommodating and flexible for specific health and mental needs has been identified as good work.9 10

A limitation of this project was the sparse literature in some specific RMDs. However, the general principles as revealed from the frequently studied diseases (RA, SpA, systemic lupus erythematosus) are likely generalisable to other RMDs, with an exception for the role of disease modification where evidence comes exclusively from IA. When specific evidence for types of RMDs will become available in the future, updates of the current PtC could be considered. However, such evidence should also become part of the disease-specific management recommendation. Second, although the PtC were not externally validated, the participants constituted experts in the field of work participation at the national and international level. Finally, participants could abstain from voting if they felt a statement was outside their professional expertise.

### Recommendation

Table 3  Research agenda originating from knowledge gaps identified during the literature searches and confirmed by the discussion among members of the taskforce

<table>
<thead>
<tr>
<th>Research topic</th>
<th>Justification</th>
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<tbody>
<tr>
<td><strong>Healthcare</strong></td>
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</tr>
<tr>
<td>How to train/guide persons with RMDs to start a conversation with HCP, supervisor or employer to discuss health-related problems at work?</td>
<td>Employers and healthcare professionals might not always be aware of a person’s specific work limitations. Communication might be a first step towards problem recognition and solutions, but requires thoughtful preparation.</td>
</tr>
<tr>
<td>How can healthcare professionals accurately identify persons with RMDs at risk of adverse work outcomes?</td>
<td>Prediction and risk stratification tools for adverse work outcome have been developed in general working populations, but have not been validated in people with RMDs.</td>
</tr>
<tr>
<td>Which non-pharmacological interventions are effective in (subgroups of) persons with RMDs?</td>
<td>Current evidence on effectiveness of non-pharmacological interventions (including workplace and community interventions) showed high heterogeneity. Efficiency of interventions will benefit from more accurate inclusion/stratification.</td>
</tr>
<tr>
<td>How can we implement (and finance) work-oriented care in clinical practice? Should work-related care be a quality indicator?</td>
<td>Screening, risk stratification, interventions and monitoring of work participation should be implemented by general practitioners, medical specialists and other healthcare professionals. Limited resources for prevention should not hinder timely work-oriented care.</td>
</tr>
<tr>
<td><strong>Workplace</strong></td>
<td></td>
</tr>
<tr>
<td>Which features of work constitute a healthy workplace for people with RMDs, and which features are harmful for RMD-related health outcomes?</td>
<td>Features of work can comprise type of work, tasks within a job (including autonomy and flexibility), physical environment, regulations (including salary, job and social security) and culture of workplaces (eg, support from colleagues, accommodations).</td>
</tr>
<tr>
<td>What are the needs (eg, policies, financial) and responsibilities of employers to support people with RMDs in healthy and sustainable work?</td>
<td>Most employers don’t have specific knowledge and skill to support people with RMDs and limited finances are in place to encourage employers to implement limited policies on this issue.</td>
</tr>
<tr>
<td><strong>Outcome assessment and monitoring</strong></td>
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<tr>
<td>How do we define ‘healthy and sustainable work’ and how can we measure this?</td>
<td>How can we combine different perspectives on work participation outcomes (patient, caregivers, workplace and societal)? Are short-term measures appropriate surrogates for long-term outcomes? Clearly, continuation of work should not go at the expense of health.</td>
</tr>
<tr>
<td>How can we improve real-world data collection of work outcomes of persons with RMDs?</td>
<td>Measures of work participation should be routinely collected as part of (1) clinical data/information and (2) research projects which include working-age adults. Encourage the development of ‘big data’ that integrate data variables at level of the patients, their working and living environment, healthcare and social security system and national policies are required to fully understand efficiency of intervention.</td>
</tr>
<tr>
<td><strong>Policies on healthcare, social security and labour organisation</strong></td>
<td></td>
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<tr>
<td>What is the role of intersectionality in (closing) the work participation gap?</td>
<td>Individuals in a society experience discrimination and disadvantage on the basis of a multitude of factors. Social inequality in employment occurs along several axes that intersect and need to be studied and acted upon appropriately.</td>
</tr>
<tr>
<td>Which policies support sustainable work for patients with RMDs?</td>
<td>Governments are interested in policies to enhance sustainable and healthy work participation, especially in an ageing population. Evidence on this issue is scarce, and methodologically challenging to generate.</td>
</tr>
<tr>
<td>What is the cost-effectiveness of various interventions that could help to close the work participation gap?</td>
<td>High-quality care is not only effective but also efficient. As one of the aims of work-related care is to reduce the financial burden of health-related productivity costs, work-oriented policies and care should be affordable. What is the return on investment of interventions including policies?</td>
</tr>
<tr>
<td>How can work policies be financed?</td>
<td>Silos in budgets between healthcare and labour policies should not hinder health-oriented policies at the workplace.</td>
</tr>
<tr>
<td><strong>Collaboration</strong></td>
<td></td>
</tr>
<tr>
<td>How can we improve collaboration between professional organisations, policymakers, patient organisations and employers?</td>
<td>Shared goals, consistent communication and aligned policies/systems are essential to achieve optimal work participation.</td>
</tr>
<tr>
<td>How can we implement evidence-based practices, interventions and policies?</td>
<td>If practices/interventions have proven to be effective, (de-)implementation will be the key to achieve impact in individuals and society.</td>
</tr>
<tr>
<td>HCP, healthcare provider; RMDs, rheumatic and musculoskeletal diseases.</td>
<td></td>
</tr>
</tbody>
</table>

In conclusion, considering and implementing these EULAR PtC are a shared responsibility and should improve healthy and sustainable work participation of people with RMDs.

### Author affiliations

1. Internal Medicine, Division of Rheumatology, Maastricht University Medical Centre+, Maastricht, The Netherlands
2. Care and Public Health Research Institute (Caphri), Maastricht University, Maastricht, The Netherlands
3. Social Medicine, Maastricht University, Maastricht, The Netherlands
4. EULAR Research Partner, EULAR RARE, Zurich, Switzerland
8. Department of Regional Health Research, University of Southern Denmark, Odense, Denmark
9. Department of Clinical Sciences, Lund University, Lund, Sweden
10. Bulgarian Organisation for People with Rheumatic Diseases (BOPRD), Sofia, Bulgaria
11. British Airways, London, UK
12. European Agency for Safety and Health at Work (EU-OSHA), Bilbao, Spain
13. Liga Portuguesa Contra as Doenças Reumáticas, Lisboa, Portugal
14. Institute for Work & Health, Toronto, Ontario, Canada
15. Dalla Lana School for Public Health, University of Toronto, Toronto, Ontario, Canada
REFERENCES

Recommendation


57 Universal Declaration of human rights, article 23 1948.
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 erythematoses (SLE)
- Systemic sclerosis (SSc)
- ANCA associated vasculitis (AVAS)
- Crystal arthritis: gout
- Calcium-pyrophosphate 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
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 the search and addressed in the sources by the final were linked to specific Overarching Principles (OP) and/or Points to Consider (PtC).

<table>
<thead>
<tr>
<th>Research area</th>
<th>Source of evidence</th>
<th>(a) RMDs considered in search/survey (b) RMDs actually addressed in contributing documents (papers/reviews/chapters etc)</th>
<th>Contribution to specific OP/PtC</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is work relevant for (clinical) outcome?</td>
<td>Scoping review</td>
<td>Scoping review on benefits of work for physical and mental health in chronic diseases, including RMDs [1]</td>
<td>(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)</td>
</tr>
<tr>
<td></td>
<td>Systematic literature review (new)</td>
<td>SLR on work participation as predictor of progression of RMD [2]</td>
<td>(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%).</td>
</tr>
<tr>
<td></td>
<td>Non-systematic search (new)</td>
<td>Work as an outcome domain in EULAR management recommendations (Online appendix 3.1)</td>
<td>(a) All RMDs (b) 9/21 recommendations addressed work participation of which 4 IA, 2 OA and 1</td>
</tr>
</tbody>
</table>
| 2. What are barriers and facilitators to enter, stay or re-integrate in work? | Systematic literature review *(new)* | (a) All RMDs  
(b) SLRs were available for RA, axSpA and PsA | Ptc 7 |
|---|---|---|---|
| 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 |
<table>
<thead>
<tr>
<th>4. Which characteristics of the social security system are effective in entering, staying or re-integrating in work?</th>
<th><strong>Systematic literature review (new)</strong>&lt;br&gt;SLR on barriers and facilitators to gain, maintain and return to paid work</th>
<th>longitudinal observational studies in all RMDs (n=1)</th>
<th>(a) All RMDs&lt;br&gt;(b) Most papers addressed inflammatory arthritis and SLE</th>
<th>PTC 9</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-systematic search</strong>&lt;br&gt;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</td>
<td></td>
<td></td>
<td>(a) General population or any RMD&lt;br&gt;(b) When RMDs were studied, this concerned mainly RMDs in general or IA</td>
<td>PTC 9</td>
</tr>
<tr>
<td>5. How is the cycle of working life in persons with RMDs compared to that in the general population?</td>
<td><strong>Systematic literature review (new)</strong>&lt;br&gt;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]</td>
<td></td>
<td>a) All RMDs considered&lt;br&gt;(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%)</td>
<td>PTC 1</td>
</tr>
<tr>
<td>6. What (not) to do by employers to facilitate entering, staying and re-integrating in work?</td>
<td><strong>Survey (new)</strong>&lt;br&gt;Survey among employers to explore initiatives to support people with RMDs or chronic diseases in general</td>
<td></td>
<td>(a) All RMDs considered&lt;br&gt;(b) No distinction between RMDs was made</td>
<td>PTC 11</td>
</tr>
</tbody>
</table>

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 erythematoses; 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].

<table>
<thead>
<tr>
<th>Recommendation (type)</th>
<th>Sections (italic) and specific text in the recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendations regarding lifestyle behaviours and work participation to prevent progression of rheumatic and musculoskeletal diseases (under review)</td>
<td>- <em>Statement 1 (work)</em>: Work participation may have beneficial effects on health outcomes of people with RMDs and therefore should receive attention within healthcare consultations</td>
</tr>
<tr>
<td>Recommendations of the role of nurses in the management of inflammatory arthritis (2020).[14]</td>
<td>- <em>Research agenda (Box 1)</em>: To study the nursing contribution to patients’ employment status and social participation.</td>
</tr>
<tr>
<td></td>
<td>- <em>Discussion</em>: Studies reporting nursing interventions that focus on healthy lifestyle and work participation were rare. The research agenda aims to examine these areas.</td>
</tr>
<tr>
<td>Recommendation for the management of hand osteoarthritis (2019).[15]</td>
<td>- <em>Overarching principle A</em>: The primary goal of managing hand OA is to optimize hand function, in order to maximise activity and participation.</td>
</tr>
<tr>
<td>Recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying anti-rheumatic drugs: 2019 update (2019).[16]</td>
<td>- <em>Overarching principle E</em>: RA incurs high individual, medical and societal costs, all of which should be considered in its management by the treating rheumatologist. &quot;The economic burden includes not only the medical costs, but also the costs due to sick leave, work disability, or premature retirement.&quot;</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis (2017). [18]</td>
<td>Overarching principle 5: &quot;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.”</td>
</tr>
<tr>
<td>Recommendations for the non-pharmacological core management of hip and knee osteoarthritis (2016). [19]</td>
<td>Recommendation 1: &quot;The recommendation on the initial assessment included the following elements: the person's physical status, activities of daily living, participation.” Recommendation 2: &quot;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: &quot;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.”</td>
</tr>
<tr>
<td>Standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases (2017).[21]</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>
| - **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) |
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.

<table>
<thead>
<tr>
<th>Standard of care/quality indicator (type)</th>
<th>Sections (italic) and relevant phrase in standard/indicator</th>
</tr>
</thead>
</table>
| Development of patient-centred standards of care for rheumatoid arthritis in Europe: the eumusc.net project (2014).[35] | 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] | 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] | 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 [...].” |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Text Content</th>
</tr>
</thead>
</table>
| 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] | - **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.

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

<table>
<thead>
<tr>
<th>Outcome Domain set</th>
<th>Study Setting</th>
<th>Place in the Core Set</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myositis[53]</td>
<td></td>
<td>-Research Agenda: Ability to work</td>
</tr>
<tr>
<td>Juvenile Idiopathic Arthritis[54]</td>
<td></td>
<td>-Important but optional: Participation</td>
</tr>
<tr>
<td>Shoulder disorders[55]</td>
<td>Clinical trials</td>
<td>-Important but optional: Participation</td>
</tr>
<tr>
<td>Flare in Rheumatoid Arthritis[56]</td>
<td></td>
<td>-Important but optional: Participation</td>
</tr>
<tr>
<td>Psoriatic Arthritis[57]</td>
<td>Randomized controlled trials and longitudinal observational studies</td>
<td>-Important but optional: Participation</td>
</tr>
<tr>
<td>Hip and Knee OA[58]</td>
<td>Clinical trials</td>
<td>-Important but optional: Participation</td>
</tr>
<tr>
<td>Chronic gout[59]</td>
<td></td>
<td>-Important but optional: Participation</td>
</tr>
<tr>
<td>Acute gout[59]</td>
<td></td>
<td>-Important but optional: Work disability</td>
</tr>
<tr>
<td>Axial Spondyloarthritis[60]</td>
<td>Clinical trials and observational studies</td>
<td>-Important but optional: Work and Employment</td>
</tr>
<tr>
<td>Systemic Lupus erythematoses[61]</td>
<td>Randomized controlled trials and longitudinal observational studies</td>
<td>-Research Agenda Work Status</td>
</tr>
<tr>
<td>Polymyalgia Rheumatica[62]</td>
<td></td>
<td>-Research Agenda Participation</td>
</tr>
<tr>
<td>Longitudinal observations studies [63]</td>
<td>-Mandatory: Participation (including work)</td>
<td></td>
</tr>
</tbody>
</table>
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.
Table 1. Background of the 20 organisations responding to the survey

<table>
<thead>
<tr>
<th>Type of organisation</th>
<th>Country</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient organisations</td>
<td>Belgium, Denmark, Finland, Germany, Greece, Israel, Poland, Portugal, United Kingdom</td>
<td>9</td>
</tr>
<tr>
<td>Health professional organisations</td>
<td>Georgia, Greece, Hungary, Italy, The Netherlands, Portugal and Spain (n=3)</td>
<td>9</td>
</tr>
<tr>
<td>Combined patient and health professional organisation</td>
<td>Norway</td>
<td>1</td>
</tr>
<tr>
<td>Research group</td>
<td>Belgium</td>
<td>1</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Organisation type</th>
<th>Number of positive answers</th>
<th>Open text clarification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability of guidelines, recommendations and information materials</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability of guidelines or recommendations for treatment/management of RMDs, in which work participation is included</td>
<td>Patient</td>
<td>5/9</td>
<td>- report to promote professional re-integration of persons with chronic rheumatic diseases</td>
</tr>
<tr>
<td></td>
<td>Professional</td>
<td>3/9</td>
<td>- guideline on RA and work participation</td>
</tr>
<tr>
<td>Providing information (materials) for either patients, health professionals or employers on how to support people with RMDs in work</td>
<td>Patient</td>
<td>7/9</td>
<td>- brochures or websites regarding working and having a RMD (both in English or non-English)</td>
</tr>
<tr>
<td></td>
<td>Professional</td>
<td>3/9</td>
<td>/</td>
</tr>
<tr>
<td></td>
<td>Combined</td>
<td>1/1</td>
<td>/</td>
</tr>
<tr>
<td>Providing support to people with RMDs or healthcare professionals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presence of a dedicated person or working group focusing on work participation of persons with RMDs</td>
<td>Patient</td>
<td>4/9</td>
<td>- 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</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 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 |

**Establishing contact with employers/employer organisations, policy makers or governmental bodies**
| Professional | 2/9 | / |

| 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.
References in online appendices 2 and 3


