VIEWPOINT

Developing a framework for the implementation of recommendations for lifestyle factors for people with RMDs across Europe: assessment of current materials and implementation needs

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ABSTRACT

Lifestyle factors (such as diet, physical activity or smoking habits, among others) are known to influence the progression of rheumatic and musculoskeletal diseases (RMDs). Despite contemporary improvements in RMD care, the management of lifestyle factors is suboptimal. In the context of a recent European Alliance of Associations for Rheumatology (EULAR) task force, existing informative materials regarding lifestyle factors for people with RMDs were collected from national organisations across European countries. Current materials show important limitations in terms of coverage, literature support and access, which may make the implementation of successful interventions difficult. In the present viewpoint, a roadmap to cover these gaps at the European level with the recent EULAR recommendations on lifestyle factors is discussed from an implementation perspective. This analysis may pave the ground for future implementation endeavours at the European level related to non-pharmacological interventions that may also be applicable beyond rheumatology.

BACKGROUND

Rheumatic and musculoskeletal diseases (RMDs) are the largest contributor to disability in Europe,[1 2] thus accounting for important economic and societal costs.[3 4] The burden of RMDs has been recognised in the WHO Europe Plan for the Prevention and Control of Non-Communicable Diseases, where actions to promote and improve musculoskeletal health were urged.[5 6]

The management of RMDs has experienced major breakthroughs in recent decades, mostly due to better clinical instruments and the development of effective pharmacological approaches. However, there are several other areas where promotion of specific actions may mitigate the progression of RMDs and thus, their associated comorbidity and disability. Most of these areas relate to lifestyle factors, such as diet, physical activity and smoking habit, among others. Moreover, certain lifestyle factors (smoking, healthy weight, physical activity and certain dietary components) have been reported to promote progression from preclinical stages, so lifestyle counselling may be also applicable in the prevention setting,[7–9] where there is an urgent need for effective interventions. Nevertheless, overall the application of non-pharmacological interventions has received little attention, and important knowledge and clinical gaps exist in this field.

Recently, the European Alliance of Associations for Rheumatology (EULAR) task force recommendations on lifestyle behaviours to prevent the progression of RMDs were published,[10] after systematically reviewing the evidence of the effect of diet, body weight, physical activity, smoking, alcohol consumption and work participation in a group of prevalent RMDs (osteoarthritis (OA), rheumatoid arthritis (RA), axial spondyloarthritis, psoriatic arthritis, systemic sclerosis, systemic lupus erythematosus and gout).[11–14] However, beyond generating evidence-based statements, for recommendations to be of clinical value and promote behavioural change, implementation science methods and techniques should be used to ensure the recommendations influence clinical practice.[15] Then, after the dissemination of these

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documents through academic and scientific channels, their implementation represents the next goal.

In an effort to enable successful implementation, the task force performed an initial evaluation of the current situation pertaining to lifestyle recommendations across Europe. The aims of the present viewpoint were to evaluate the existing materials about lifestyle factors for people with RMDs across European countries, to assess their limitations and implementation needs, as well as to propose a framework for the uptake of the recent EULAR recommendations on lifestyle factors to overcome these gaps.

COLLECTING INFORMATIVE MATERIALS ACROSS EUROPEAN COUNTRIES

A protocol to search for materials related to lifestyle factors for people with RMDs was designed by three members of the task force (JR-C, GC and SMMV). Informative materials were defined as any information support provided to patients and/or professionals regarding any lifestyle factor. A standardised letter was distributed through three channels: (1) the national societies of rheumatology were contacted via the Emerging EULAR Network (EMEUNET) country liaisons, (2) the health professionals in rheumatology (HPR) associations were contacted by task force members using the EULAR database and (3) national patient associations were contacted by patient representatives through People with Arthritis and Rheumatism in Europe (PARE) network. Only national organisations affiliated with EULAR were contacted. The obtained materials were assessed in terms of formats, extension, design, coverage and accessibility parameters. Finally, an assessment of the implementation needs according to different implementation theoretical approaches[15] was performed, including process model, determinants and evaluation. In brief, process models describe and guide the process of translating research into practice. The ACE (Academic Centre for Evidence-Based Practice) Star Model of Knowledge Transformation was used in this analysis.[16] Next, the determinant framework relates to the identification and overcoming of barriers/usages of facilitators, in order to understand what influences the implementation outcomes. To evaluate the determinants, the PARIHS (Promoting Action on Research Implementation in Health Services) instrument was used.[17] Finally, the evaluation framework aims at specifying and assessing the aspects of implementation that could be evaluated to determine the implementation success. Evaluation was assessed through the RE-AIM (Reach, Effectiveness, Adoption, Implementation and Maintenance) tool.[18]

ANALYSING EXISTING INFORMATIVE MATERIALS ON LIFESTYLE FACTORS FOR RMDS

A total of 38 materials from 11 countries were obtained (table 1), including north, south and central European regions. Most of the materials were in the form of documents (22 (57.8%)) or leaflets (12 (31.5%)). The factor most reported was diet (23 (60.5%)) followed by physical activity (17 (44.7%)), whereas information on work participation was scarce (2 (5.2%)). The materials were mostly focused on RA (8 (21.0%)), although it was common to observe documents for people with RMDs in general (12 (31.5%)). Only 8 (21.0%) materials included scientific references. Although 23 (60.5%) materials contained some kinds of recommendations, only 2 were evidence-based, whereas the rest contained general statements (not specific, not based on literature discussion or lacking appraisal of the strength of the evidence). With only one exception, the materials were only available in the official national language, and 16 (42.1%) were accessible on the internet, whereas no information on accessibility or reach was obtained for the rest. The accessibility, understanding and application of some of these documents may be reduced for individuals with limited health literacy due to (1) the presence of complex terms/concepts, (2) lack of simplicity and (3) the need of information on health infrastructure or knowledge of the healthcare system,[19] in addition to an overall lack of specific recommendations and information on accessibility.

Our search revealed that materials focused on lifestyle factors for people with RMDs were not always available at the national level in Europe, despite the general interest expressed in this area. Among current materials, there is an important lack of consistency in terms of formats, layouts, content, literature support and access. Furthermore, target populations also varied across countries, and not all RMDs and lifestyle factors were represented. Importantly, the involvement of patient representatives and approaches to include patient preferences were mostly absent or not clearly reported. Of note, lack of consistency in existing materials related to key methodological areas such as literature support, lifestyle factors and RMD coverage as well as patient involvement, which cannot be attributed to local adaptations or cultural context.

Next, the existing materials were evaluated for their completeness on several implementation domains (online supplemental table 1). Overall, the informative materials showed important implementation flaws in elements of the process model, especially due to methodological and dissemination issues. Similarly, extensive gaps were detected among determinants, especially due to the absence of patient involvement steps, solid methodology and strategy plans, although this information was limited in some cases. Moreover, evaluation practices, especially regarding effectiveness and adoption, were mostly absent, which may also account, at least in part, for the reduced evidence on successful lifestyle implementation activities in the literature.

A good example of implementation practices in this scenario is the GLA:D International Network.[20] This initiative is based on a multilevel intervention (health professional training, patient education and clinical care)

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Table 1 Summary of the materials focused on lifestyle factors for people with RMDs retrieved from national associations

Country	Type of material (extension)	Developed by	Target population	Factors covered	RMDs covered	Literature support (includes references?)	Recommendations	Access
Austria	Paper (6 pages)	National society	Patients and clinicians	Diet	Gout (and hyperuricaemia)	Yes	Yes (evidence-based)	Online (journal article)
	Leaflet (2 pages)	National society	Patients	Diet	Gout (and hyperuricaemia)	Yes	Yes (evidence-based)	Online
Croatia	Document (40 pages)	Patient association	Patients	Diet	SSc	No	No	Unclear
	Document (20 pages)	Patient association and national association	Patients	Diet	OA	No	No	Online
	Document (20 pages)	Patient association and national association	Patients	Diet	RA, gout	No	No	Online
Italy	Leaflet (12 pages)	National association	Patients	Diet	RMDs in general	No	No	Unclear
Lithuania	Document (28 pages)	National association	Patients	Diet, weight	Gout	No	No	Unclear
	Document (13 pages)	National association	Patients	Diet, physical activity	SLE	No	No	Unclear
	Leaflet (2 pages)	National association	Patients	Smoking, alcohol, weight, diet, physical activity	RMDs in general	No	Yes (general statements)	Online/unclear
Moldova	Document (33 pages)	Ministry of health	Clinicians	Lifestyle (in general)	Gout	Yes	Yes (general statements)	Online
	Document (34 pages)	Ministry of health	Clinicians	Lifestyle (in general)	PsA	Yes	Yes (general statements)	Online
	Document (52 pages)	Ministry of health	Clinicians	Lifestyle (in general)	RA	Yes	Yes (general statements)	Online
	Document (29 pages)	Ministry of health	Clinicians	Lifestyle (in general)	SSc	Yes	Yes (general statements)	Online
	Document (2 pages)	Ministry of health	Clinicians	Lifestyle (in general)	SLE	Yes	No	Online
	Document (47 pages)	Ministry of health	Clinicians	Lifestyle (in general)	SpA	Yes	Yes (general statements)	Online
Norway	Document (2 pages)	Patient association and health professionals association	Patients	Lifestyle (in general)	RMDs (in general)	No	No	Unclear

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Table 1 Continued

Country	Type of material (extension)	Developed by	Target population	Factors covered	RMDs covered	Literature support (includes references?)	Recommendations	Access
Portugal	Document (28 pages)	National society and health professionals association	Patients	Diet, smoking, alcohol, physical activity	PsA	No	No	Unclear
	Document (28 pages)	National society and health professionals association	Patients	Diet, smoking, physical activity	SpA	No	No	Unclear
	Document (25 pages)	National society and health professionals association	Patients	Diet, physical activity	JIA	No	No	Unclear
	Document (28 pages)	National society and health professionals association	Patients	Diet, weight, physical activity	RA	No	No	Unclear
	Document (19 pages)	National society and health professionals association	Patients	Diet (related to specific clinical features), physical activity	SSc	No	No	Unclear
	Document (28 pages)	National society and health professionals association	Patients	Diet, smoking, alcohol, physical activity	SLE	No	No	Unclear
	Document (28 pages)	National society and health professionals association	Patients	Diet, alcohol, physical activity, work adaptations	SS	No	No	Unclear
Slovenia	Leaflet (2 pages)	Health professionals association	Patients	Physical activity (various sports)	RMDs in general	No	Yes (general statements)	Unclear
	Leaflet (2 pages)	Health professionals association	Patients	Lifestyle (in general)	RMDs in general	No	Yes (general statements)	Unclear
	Leaflet (2 pages)	Health professionals association	Patients	Diet, weight	RMDs in general	No	Yes (general statements)	Unclear
	Leaflet (27 pages)	Health professionals association	Patients	Diet, weight, physical activity, smoking, alcohol	SpA	No	Yes (general statements)	Unclear
	Leaflet (21 pages)	Health professionals association	Patients	Diet, weight, physical activity, smoking, alcohol	PsA	No	Yes (general statements)	Unclear
	Leaflet (25 pages)	Health professionals association	Patients	Diet, weight, physical activity, smoking, alcohol	RA	No	Yes (general statements)	Unclear

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Table 1 Continued

Country	Type of material (extension)	Developed by	Target population	Factors covered	RMDs covered	Literature support (includes references?)	Recommendations	Access
Spain	Video booklet (2 min)	Regional association	Patients	Weight, smoking, alcohol, physical activity	RA	No	Yes (general statements)	Online
	Document (62 pages)	Regional society and patient association	Patients	Weight, diet, physical activity, smoking, work adaptations	RA	No	Yes (general statements)	Unclear
	Website	National society and patient association	Patients	Lifestyle factors (in general)	SLE, RA, gout, SSc, PsA (up to 24 RMDs)	No	Yes (general statements)	Online
Sweden	Leaflet (4 pages) Video (11 min)	National society	Patients	Diet	RMDs in general	No	Yes (general statements)	Online
	Leaflet (4 pages) Video (9 min)	National society	Patients	Smoking	RMDs in general	No	Yes (general statements)	Online
	Leaflet (4 pages) Video (9 min)	National society	Patients	Physical activity	RMDs in general	No	Yes (general statements)	Online
	Leaflet (4 pages) Video (10 min)	National society	Patients	Diet	RMDs in general	No	Yes (general statements)	Online
Turkey	Document (288 pages)	National society	Patients	Physical activity	RMDs in general	No	Yes (general statements)	Unclear
	Document (20 pages)	National society	Patients	Diet	RA	No	Yes (general statements)	Unclear

Countries are listed in alphabetical order.
JIA, juvenile idiopathic arthritis; OA, osteoarthritis; PsA, psoriatic arthritis; RA, rheumatoid arthritis; RMDs, rheumatic and musculoskeletal diseases; SLE, systemic lupus erythematosus; SpA, spondyloarthritis; SS, Sjögren syndrome; SSc, systemic sclerosis.

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for people with OA, which has been adopted across the globe.[20 21] Solid evaluation practices, including a patient registry, a set of outcome measures and a regular reporting policy, are an integral part of this initiative.[22] Moreover, substantial efforts were made at the identification of local barriers and facilitators in different contexts.[23] Strategies to ensure access, a broad stakeholder strategy (from patients and practitioners to academic and insurance/regulatory bodies) and compulsory training were also important hallmarks of this programme. Although strategies for patient involvement in the implementation were unclear, shared decision process and patient perspectives play a role as outcomes of the initiative.[20–22]

Taken together, all these points highlight that the current materials are far from being optimal to promote changes in lifestyle behaviours in people with RMDs, thus being of limited value to significantly impact healthcare and healthcare systems in Europe. This may account for the suboptimal situation of lifestyle management intervention on RMDs, although contemporary evidence has demonstrated that implementation can be feasible. This assessment has helped to understand possible causes underlying this situation and unmet needs detected for these elements, which may guide further research efforts on this topic and guide the implementation pipeline.

CREATING A FRAMEWORK TO IMPLEMENT RECOMMENDATIONS ON LIFESTYLE: UPCOMING STEPS AND PERSPECTIVES

Compared with the existing informative materials, the recent EULAR task force documents have important advantages on several elements of process models, mostly due to the solid methodology and the involvement of patient representatives from the very early steps of the project and spanning the whole project lifecycle. However, as these documents stand in the phase of scientific papers, further work is needed to close the gap between evidence-based research and real-world end product implementation (figure 1). Based on the current analysis and implementation science needs, several factors will be key to ensure an optimal implementation phase, which relate to the implementation object, the context and organisational variables (figure 1). Of note, this roadmap was conceived as a general scheme so that it can be adapted to similar implementation activities, even beyond the field of rheumatology. Hence, the adoption of some of these elements could be tailored (and potentially expandable) depending on the specific needs of a given project.

A special focus should be paid to the translation domain in order to develop a broad stakeholder strategy, with an emphasis on the multilevel organisation of rheumatology care, from rheumatologists to HPR and primary care levels. A deep analysis of the diversity of the roles of HPR (especially nurses) will be instrumental in ensuring the uptake of the recommendations as well as in maximising the likelihood of success for the implementation phase. Similarly, important unmet needs relate to the integration element, in order to ensure an optimal and multilevel dissemination and uptake of these recommendations into international and national guidelines. The integration into education and training schemes should also be considered. The existence of public health interventions and/or campaigns at the national level also need to be screened in order to gain understanding of local barriers and facilitators (see next paragraph), and to design adaptations to guide implementation efforts. The fact that these recommendations were developed in the context of a EULAR task force also represents an important advantage in this regard with considerable promise to gain recognition and enable adaptation across Europe.

An appropriate management of the contextual determinants will be crucial to ensure the success of the implementation of these recommendations. The identification of local barriers and facilitators (cultural, language, socioeconomic, health literacy or ethnical-related characteristics) of different end-users and contexts (healthcare systems, health workforce and public health policies) poses a major challenge. Therefore, both a solid, predefined and systematic strategy (focused at macro-levels, meso-levels and micro-levels), and a wide network of partners and representatives are mandatory to cover this need. Again, the solid practices of EULAR projects and the multilevel network of the EULAR structure represent strategic systems that may facilitate these steps. Additionally, these observations strengthen the need of setting the involvement of patient research partners at the centre of these endeavours, also to inform specific actions to improve health literacy.

Finally, information on evaluating practices was overall absent for the current materials. The design of an evaluation roadmap with predefined objectives, equipped with predefined indices to evaluate access, uptake and representativeness of the target audiences as well as the whole implementation process are mandatory. Due to their relevance, an appropriate allocation of resources (including funding and materials) must be planned. Furthermore, how to convert lifestyle behaviour into quality indicators/measures may be challenging in some areas (diet, weight, etc), although more specific efforts have been developed in others (work participation). This may add another layer of complexity, but it gives an outstanding opportunity to expand the set of quality indicators in rheumatology to other, less attended areas of health. How to integrate these metrics into rheumatology care reinforces again the need for a global approach combining the rheumatology workforce, attending levels and healthcare organisations.

The completion of these unmet needs will not only cover the existing gaps but will also cover all the stages of implementation of the clinical recommendations proposed by EULAR.[24]

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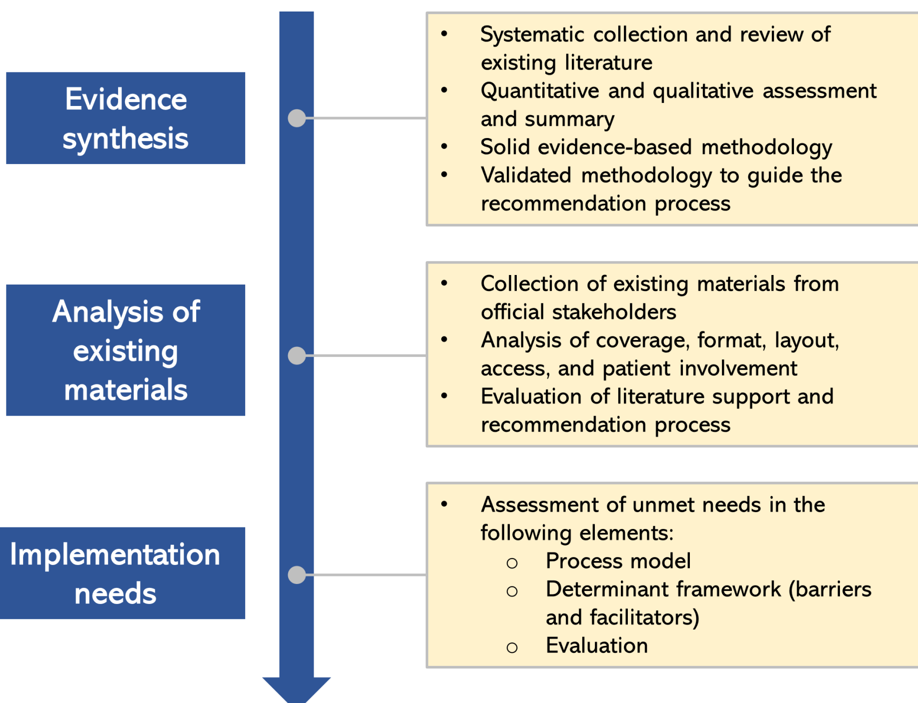

Implementation phase

	Actions	*Responsible(s)*	*Level of action*
Object	Develop a solid literature support	Taskforce	
Object	Create a practice document to guide translation, dissemination and access	Implementation team + local stakeholders	Macrolevel + Mesolevel
Object	Produce instructions (tool box) to guide integration	Implementation team	Macrolevel + Mesolevel
Object	Develop an evaluation framework (including outcome mesures for impact, adoption and maintenance, and a strategy)	Implementation team	Macrolevel
Context	Evaluate the characteristics of users/adopters (health professionals, and care levels)	Implementation team	Meso/ Microlevel
Context	Evaluation of the characteristics of end users (patient needs and preferences)	Local stakeholders	Microlevel
Context	Asses the characteristics of the context (organizational, leadership, social context, information systems, and resources)	Implementation team + local stakeholders	Macro/ Mesolevel
Organization	Assemble a multidisciplinary implementation team	Taskforce/steering group	Macrolevel
Organization	Build or search a multi-level network of stakeholders	Taskforce/steering group	Macro + Mesolevel
Organization	Plan a sustainable allocation of resources (financial and human)	Taskforce/steering group	Macrolevel

Figure 1 Roadmap for the implementation of materials focused on lifestyle factors for people with rheumatic and musculoskeletal diseases. This figure covers all the steps from generating evidence to end product implementation. Yellow blocks summarise the steps already achieved. According to general implementation science and the analysis of unmet needs in existing materials, several factors judged to be essential to allow successful implementation and to promote change were selected and grouped into related to implementation object, context or organisational variables. The roadmap was conceived as a general scheme that could serve as a guide for a spectrum of implementation projects based on lifestyle factors. Specific adaptations may be considered for each element). For each item, the responsible actor and the level of action is indicated. Macro-level refers to supranational or international structures (international research teams/task forces, international associations, etc); meso-level refers to regional and institutional structures or actors (national societies/associations, national patient associations, policymakers, health systems, etc); whereas micro-level refers to front-line individuals (clinicians, health professionals, patients, etc).

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CONCLUSION

Despite the role of lifestyle factors for the progression of RMDs, their current management is largely insufficient due to the sparsity of appropriate materials. Instruments to implement and disseminate recommendations are much awaited. Existing materials in European countries are hallmarked by an important lack of consistency, coverage, literature support and access. Involvement of patient representatives, accessibility and a focus on the target populations represent additional weaknesses, which represent important limitations for their implementation. Addressing these unmet needs in the context of the recent EULAR recommendations for lifestyle improvements will facilitate their uptake and adherence too. Additionally, this will facilitate a framework for future implementation endeavours at the European level related to non-pharmacological interventions that may also be applicable to other areas beyond rheumatology.

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