



Driving musculoskeletal
health for Europe

**EUMUSC.NET project
Work Package 7
2012-2013**

**D16 Report on barriers and facilitators to the implementation of
the standards of care**

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Introduction

Musculoskeletal diseases (MSD) are the largest cause of physical disability in the EU and one of the most frequent reasons for long term treatment (Lim et al. 2004-60;The global burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Murray CJL, Lopez.A.D., editors. 1996. Cambridge (MA): Harvard School of Public Health on behalf of the World Health Organization and The World Bank.). The burden of MSD is expected to increase due to the increasing proportion of elderly in the society (Woolf and Pfleger 646-56). To treat people with MSD efficiently there is a need for evidence-based knowledge about their assessment and management (Woolf and Pfleger 646-56), this knowledge is urgently needed to manage the increasing amount of people diagnosed with MSD (Murray et al. 2004-223).

Evidence-based management implies using the best currently available research-based evidence in the decisions about patient care (1), and is dependent on many factors. Especially how general physicians, other health professionals (2), and patient's (Brand and Cox 170-79) adhere with research-based evidence and guidelines. Non-optimal adherence to recommendations for OA management (Denoeud et al. 70-74) is frequent among health professionals. GP's and specialists adhere with guidelines to a varying degree, and patient's information needs are often not met (Chard et al. 1208-10;Rosemann et al. 48). Many patients do not receive recommended interventions. For example only one out of four patients receive disease specific information for their OA complaints, and less than 50% receive recommended exercise interventions (3).

A lack of information about the disease can influence adherence to treatment (4). Research has suggested that patients with OA use treatments that lack scientific evidence (5). Clinicians are asking for summaries of evidence supporting recommendations (Brand and Cox 170-79) while many clinical practice guidelines already exist. An overview of clinical guidelines for osteoarthritis in 2008 detected 34 publications between 1993 and 2005, many of them overlapping in content (Misso et al. 394-99), so the authors suggested resources be used implementing these rather than developing new guidelines. On the other hand the correctness of a guideline gradually decline over the years due to new knowledge (6). It is suggested that only about 90% of a guideline's content remains correct after three years (7).

Patients and clinicians within rheumatology care agree with the treatment recommendations at varying degrees, both between and within these groups (van der Goes et al. 1015-21). Factors influencing adherence in rheumatology care can be access to optimal care (8), communication (9) and personal characteristics (Gignac et al. 905-12). Patients often lack a correct perception about their disease (10).

To identify the effective components of care in long lasting MSDs, the parts that have been discovered effective must be integrated into a whole treatment system, because having effective components of care is not sufficient in diseases where there is no curative treatment. This way treatment in MSDs is complex and multifaceted, and to successfully integrate the effective components of care and tailor the care to the patients needs require patient involvement and some times a multidisciplinary treatment team (11). It is suggested that multidisciplinary care can improve adherence, health status and patient satisfaction (12).

A systematic search on facilitators for adherence to recommendations in osteoarthritis (OA) or Rheumatoid Arthritis (RA) care up until June 2012 detected following relevant scientific

papers: An educational programme in the format of case workshops on diagnoses and treatment in OA and treatment in RA for general practitioners (GP's) in Canada increased self reported improvements in practice and satisfaction (13). Focus groups with patients, GP's and physical therapists (PT's) have been conducted according to recommendations for knee OA. Several barriers to overcome for these groups were identified. Among other factors, several GP's were uninterested in OA due to a perceived little impact on the course of the disease, patients felt that many GP's were uninterested in their disease, but PT's felt they had the knowledge to treat OA. Comparing attitudes towards recommendations GP's should i.e. be educated about effective non-pharmacological treatments, PT's should be educated in benefits of the use of pharmacological approaches, and GP's and patients were ambivalent towards the positive effects of reducing overweight and should be educated on this (Poitras et al. 458-65).

A clinical pathway for patients with hip and knee OA has been attempted implemented in Australia to facilitate implementation of recommendations into practice. A major barrier to the success of this system is the change in evidence and recommendations over time (14). The EULAR recommendations for knee OA were to a great extent agreed with among GP's in France, Spain, Belgium, Switzerland and Italy (Denoeud et al. 70-74; Mazieres et al. 1158-64).

It is recently suggested that postgraduate education for PTs may increase adherence to guidelines for treating patients with OA compared to no postgraduate education (Peter et al. 368-75; Grol et al. 217-19; Harting et al. 221-32; Bero et al. 465-68).

Standards of Care in OA and RA are subject to facilitators and barriers in different European countries. Equity in health care provision can only be achieved by enhancing facilitators and overcoming modifiable barriers across Europe. The eumusc.net project consists of a multidisciplinary group of researchers from many different European countries. The current work package (WP-7) in the eumusc.net project examines facilitators for implementing the Standards of Care for OA and RA in health care systems across European countries.

Standards of Care

The Standards of Care (SOC) (Appendix 1, 2) were developed and served as basis for the recommendations used in the WP7. The EUMUSC.NET work package 7 decided and agreed on testing the SOC by selecting the most important ones to the newly diagnosed patient following the principles of a 'patient journey', where diagnoses, assessment, and management should be included. It was also decided on using a wording that was simplified compared to the original SOC, but still capturing the same core content. The detailed descriptions of these are called recommendations and are presented in the next two paragraphs.

The WP7-group also decided after a comprehensive literature search, to assess facilitators for the implementation of the SOC to capture important modifiable factors. This way the barriers could be considered known, while the way of asking for facilitators could stimulate problem-solving by the responders. Additionally, when sending the survey throughout Europe it could create awareness about what needs to happen in the different health care settings to enable the implementation of the SOC's. The survey was sent to patients, health professionals and policy makers in all European countries.

OA recommendations

1. People with symptomatic osteoarthritis should have access to a clinician able to make a differential diagnosis
2. People with symptomatic osteoarthritis should be assessed regularly
3. People with osteoarthritis should have evidence-based non-pharmacological treatment as needed
4. People with osteoarthritis should have evidence-based pharmacological treatment as needed
5. People with osteoarthritis should have evidence-based surgical treatment as needed

RA recommendations

6. People with rheumatoid arthritis should have timely access to a clinician making a differential diagnosis
7. People with rheumatoid arthritis should be assessed formally and regularly to ensure disease control.
8. People with rheumatoid arthritis should have evidence-based pharmacological treatment like synthetic or biologic drugs as needed
9. People with rheumatoid arthritis should have evidence-based non-pharmacological treatment as needed

The WP-7 working group

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Work Package meeting 7a, Oslo 6-7th February 2012.

The EUMUSC.NET work package 7 decided and agreed on testing the SOC by selecting the most important ones to the newly diagnosed patient following the principles of a 'patient journey' where diagnoses, assessment and management should be included. It was also decided on using a wording should be simplified compared to the SOC but still capturing the

same content. Due to a lack of knowledge about facilitators in the literature, the group decided on focusing on exploring these.

Work Package meeting 7b, Oslo 10-11th September 2012.

The EUMUSC.NET work package 7 emphasized that the results from the survey were only hypothesis generating, and it was necessary to explore the facilitators for implementing the SOC further. Relatively low response rates from Eastern European countries complicated comparisons between regions. The complexity of the questions asked, and lack of translations could be reasons for this.

To explore the facilitators for implementing good clinical practice in different countries focus groups were planned, and the group started working on a protocol for these. Each focus group was to be held at a national level, except from one international meeting at the PARE conference where several nations were represented. Group numbers were ideally aimed at being between 8-12 participants. The moderator should be skilled in group dynamics and interactions. A workshop on focus-groups was given in Oslo.

It was further decided that a focus group protocol needed to be developed to ensure that all WP7 delegates were undertaking similar procedures during group data collection. The Norwegian team together with Francis Guillemin and Maarten de Wit provided a detailed description of the focus groups (Appendix 3) for use in locally or nationally organized focus group meetings.

Facilitators and barriers

Identifying barriers and facilitators to meeting Standards of Care and Health Care Quality Indicators were conducted through a web-based questionnaire and qualitative interviews.

Evidence from the literature search

A facilitator list for use in the survey was derived from a consensus process during the WP7a meeting based on a literature search. The facilitator list used in the survey was primarily based on the framework by Cabana et al (15). The following facilitators were chosen:

- Accessibility of recommendation (easy to find)
- Knowledge (education to understand content and importance of recommendation)
- Agreement with the content of the recommendation
- Cultural background (shared attitudes, values, goals, religion)
- Personal attitude towards recommendation
- Motivation (personal effort, drive, willingness to get engaged)
- Organization (support of patient, professional, health care organization)
- Environmental factors (facilities and equipment)
- Time resources
- Economical resources
- Outcome expectancy (belief that recommendation will be used)

Evidence from the European Survey

The EUMUSC.NET study aimed at asking patients, health care professionals, and policy makers how to get Europe to use the recommendations for treating patients with OA and RA. Surveys are often used as systems for collecting information to describe, compare and make

assumptions about attitudes, values knowledge and behaviour and rely on valid and reliable information from participants. The aim of this survey was thus to explore facilitators for the implementation of Standards of Care in OA and RA.

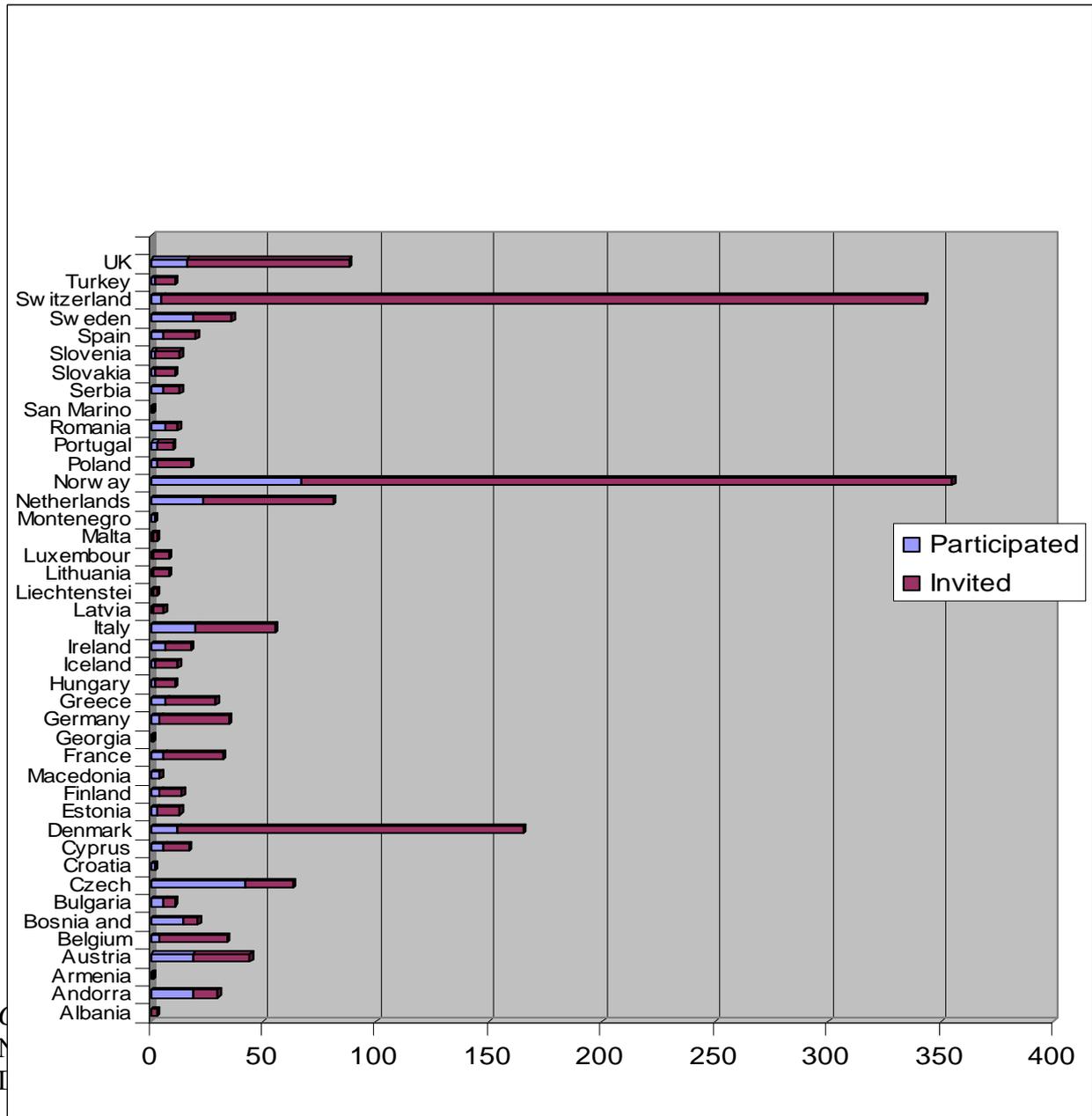
The EUMUSC.NET survey was performed using Quest Back (license by Diakonhjemmet Hospital). A pilot questionnaire was distributed in January 2012, and the final survey database was opened on the 23th of March and closed on the 8th of August. The WP-7 group chose an open direct personal approach by mailing group contacts within health care, patient organizations and rheumatology in Europe, PARE, collaborating partners, and EULAR. Additionally a personal recruitment at the EULAR conference was undertaken (iPAD at EUMUSC.NET stand assisted by K.E. and B.A. from the WP7 group). N=1610 were invited, and N=282 finally participated in the survey after two reminder rounds.

Table 1. Respondents to the survey

Variable	Mean (SD) n=282
<i>Age</i>	48.12 (11.48)
<i>Gender</i>	
Male (%)	101 (36%)
Female (%)	181 (64%)
<i>Years professional/patient experience (%)</i>	
<15 years	106 (38%)
15- <30 years	103 (36%)
30≤ years	73 (26%)
<i>Position (%)</i>	
Health Professional	199 (71%)
Patient	74 (26%)
Health Care Administrator	9 (3%)

Roughly 2/3 of the responders to the survey were health professionals. 67 Rheumatologists, 48 Physical therapists, 26 medical doctors, 14 nurses, 22 occupational therapists, surgeons, social workers, psychologists and health professionals with other occupations answered the survey.

Figure 1. Number of individuals invited and responding to survey per country



Questions for the explorative analyses:

Which facilitators are rated most/least important? Which facilitators are endorsed across European countries? Are facilitators for using recommendations in RA is rated higher than OA? Does country, age, gender, position or experience influence the facilitators for using the recommendations?

Results:

There were few differences between countries on how participants answered the questions. Cultural factors were rated least important and is also rated 'I don't know' more frequently than the other factors. The more experienced the participants were, the slightly more important all facilitators were scored both for RA and OA.

Motivation, agreement and knowledge were rated most frequently very much or of much importance both for both OA and RA (Figure 2). The facilitators were generally confirmed by the participants across the different European countries.

For the implementation of the SOCs for OA the facilitators motivation, agreement and personal attitude was considered most important. For implementing the SOCs for RA, the most important facilitators were agreement, knowledge and motivation.

Figure 2. Importance of the different facilitators for implementing the Standards of Care for OA and RA in the different countries

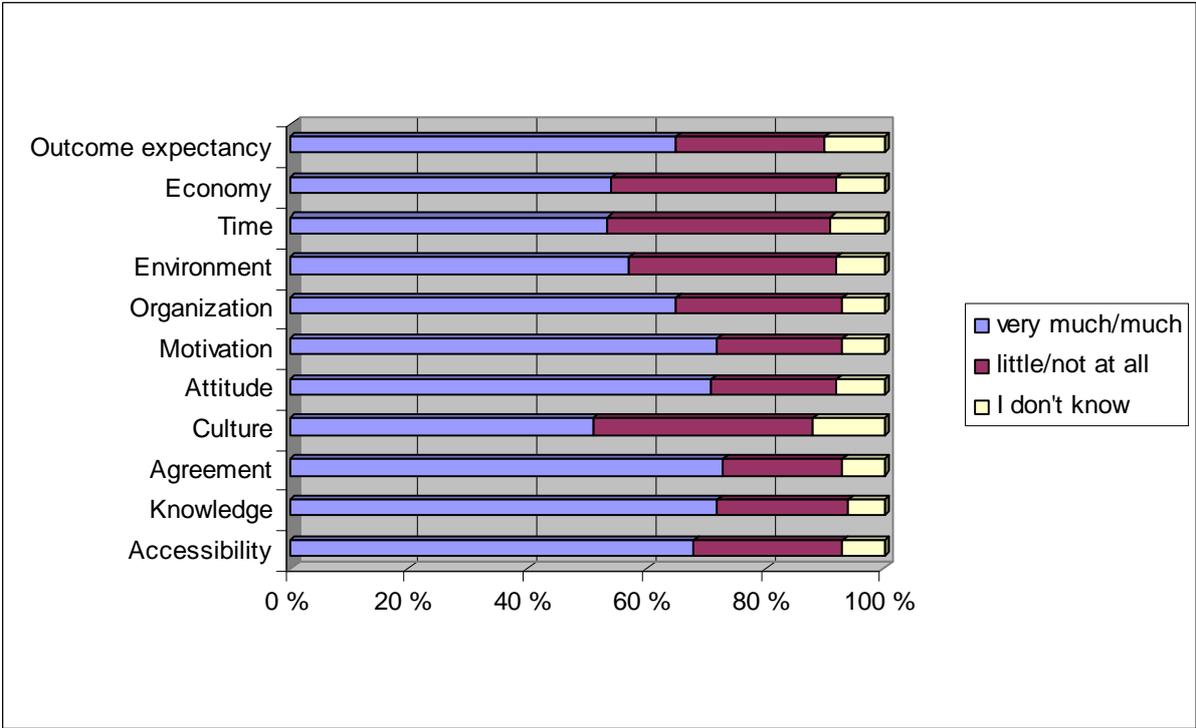


Figure 3. Agreement (percentage x 10) with the OA facilitators

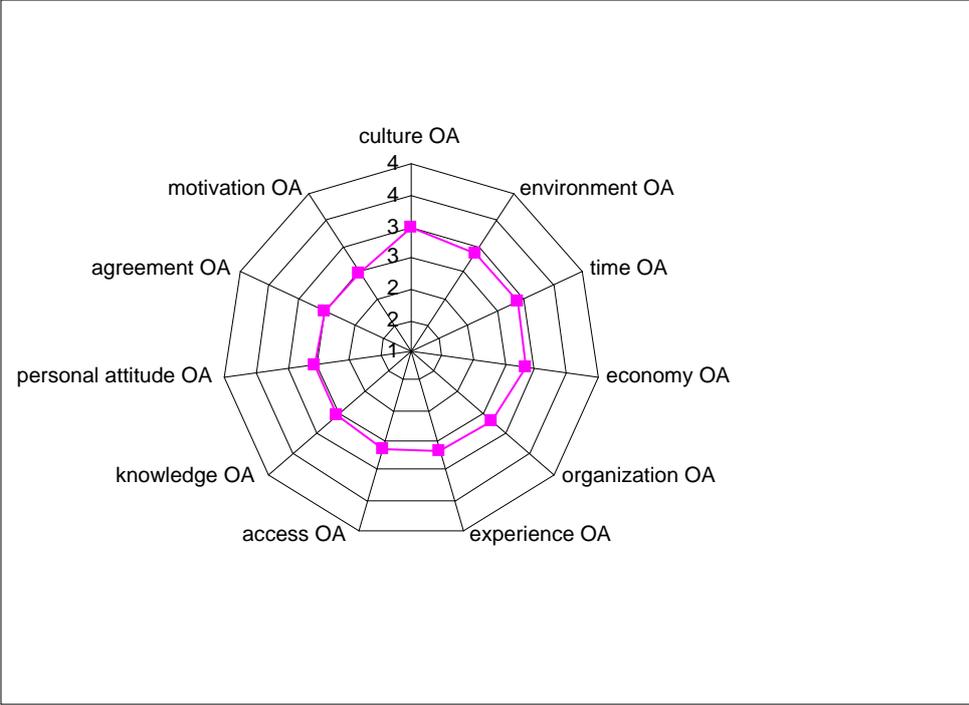


Figure 4. Agreement (percentage x 10) with the RA facilitators

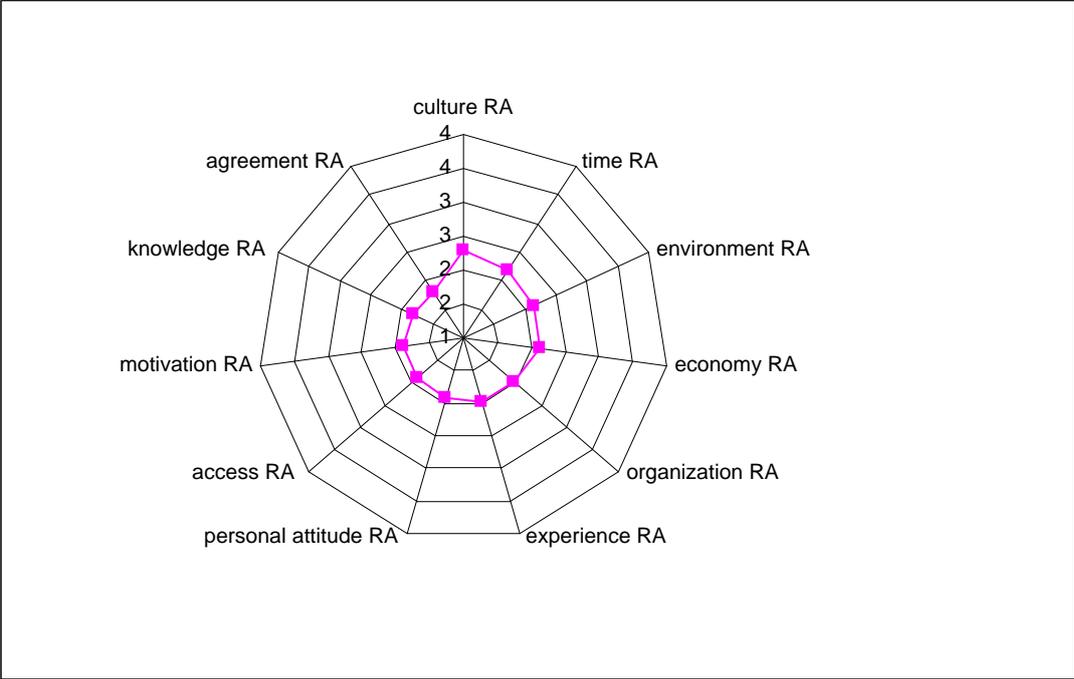
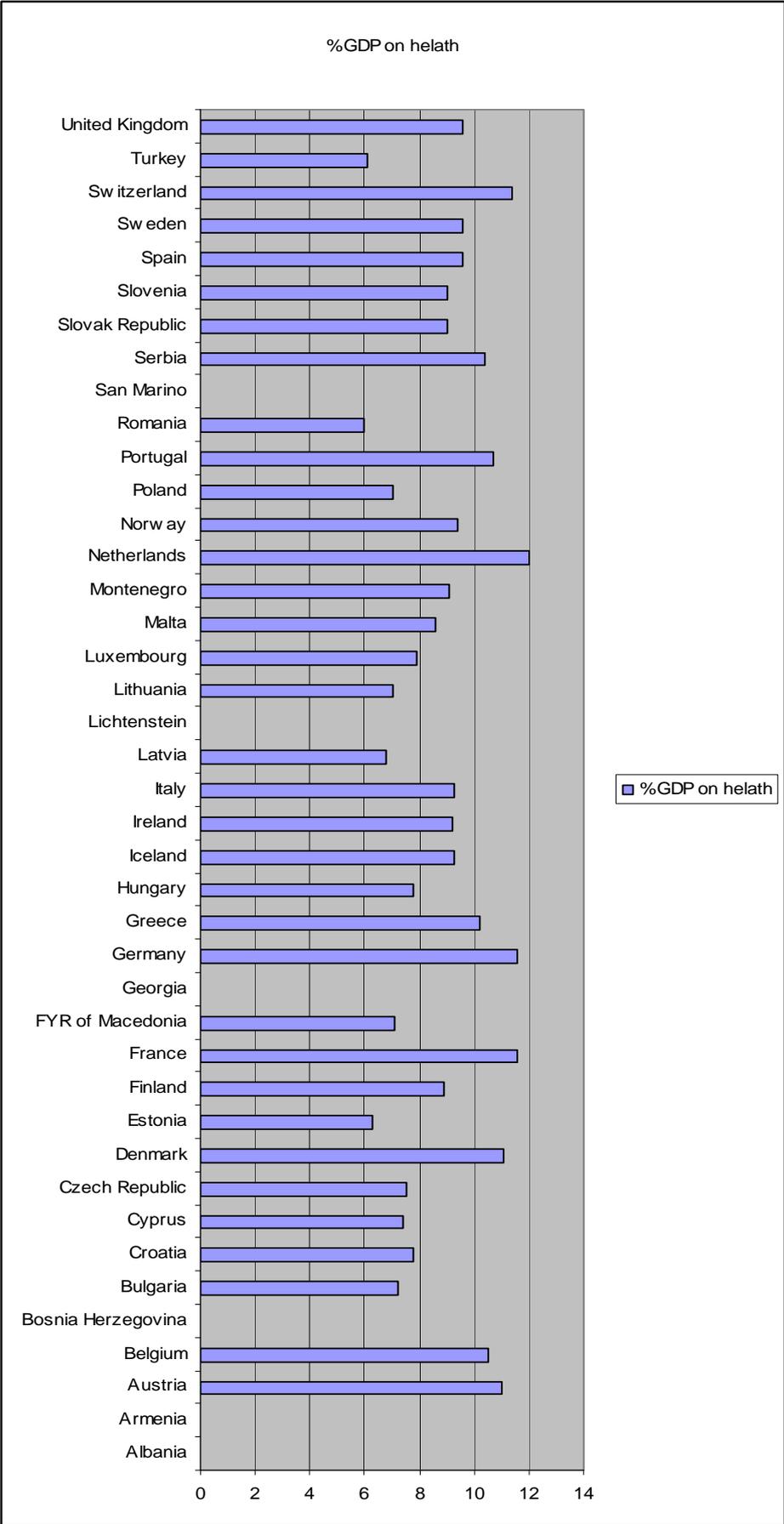


Figure 5. Health care spending in % GDP in Europe in 2010



(16)

According to the OECD, numbers on Gross Domestic Product (GDP) in Europe from 2010 indicate that Romania used 6% of their GDP on health care, while France and Germany used 11.6%, Sweden 9.6% and Norway 9.4% (17). This gap may be a reason for the inequality mentioned in the focus groups, for example the lack of multidisciplinary resources available to capture the challenges of OA and RA in line with the recommendations. Income, living conditions and health care spending depend on various factors and are currently rapidly changing in Europe. This also affects the possibilities of implementing the SOC's.

Comments by survey participants

Free text comments by the survey-participants were grouped into three categories:

1. "I do not understand":

I have not been able to interpret and answer any of your questions as I do not understand whose accessibility, knowledge, agreement, background and attitude you are asking for - mine or the patients'?

I do really have problems with understanding the questions!

PS - I don't know if I will have the chance to say this later but I found the questions difficult to understand and so hope I have answered correctly

I do really have problems with understanding the questions, so that is why I answer like this!

2. "I miss the following":

Importance of the climate

Macro-economical factors and administrative barriers limit the access to biological treatment

Cost of drugs seems to limit use in some cases

More team working, financial incentives

Training of primary care physicians to make diagnosis= incentives

Knowledge about why the recommendations are not followed

Multidisciplinary approach - to maximise efficiency in recommendations in the prevention stage (primary, secondary and tertiary)

Better understanding of policy makers and or Health insurance companies

Informing, support, claim for patients with RMD & promotion of research into understanding and facing rheumatic illnesses

3. "Other important factors":

There are not enough rheumatologists to do the differential diagnosis (probably there shouldn't be), but family doctors are not trained enough in rheumatology.

Rheumatology is not thought enough in medical schools and rotation in rheumatology for family doc.

I do not treat OA (paediatrician)

Very dependable on which doc one is referred to at the health centre

OA is a condition that is mainly treated in primary care in Sweden! In specialist clinics it is a condition that is concurrent with another rheumatic disease.

Evidence from focus groups

The participants in WP7 had a workshop by Francis Guillemin on EUMUSC focus-groups in September 2012. Based on the preliminary findings it was decided to aim at having focus groups in at least 5 different countries to explore the findings from the survey further.

The main theme of the focus groups was: *"What is important to enable successful implementation of the Standards of Care for OA and RA?"* Focus groups were held in different countries with different health care systems; Norway, Sweden, Germany, France and

Romania; however the results were more similar across countries than expected. An important finding from the focus groups with patients and clinicians were that the recommendations were endorsed and the facilitators confirmed. Description of focus group participants are presented in table 2.

Table 2. Participants in the focus groups

Country	Health professionals (n)	Patients (n)
Norway	6	2
Romania	8	0
Sweden OA	0	10
Sweden RA	0	8
Germany	0	10
France	7	1

Data from the focus groups emphasized that educating clinicians, health professionals and patients about the Standards of Care is needed. Access to national guidelines or standards translated to the local language may help implement them. Information and improved communication between different levels of health care was also mentioned as important. The focus groups showed that multidisciplinary teams needed to be strengthened, and that reimbursing patient education may be an important incentive to meet the Standards of Care. Access to care can be a challenge in rural areas, and some health economic systems need to be changed to avoid inequity of care. Communication between different levels of health care, or between the different health professionals treating or examining the patient is not optimal as emphasized by the German focus group. The focus group from Romania demonstrated the complicated gap between accepting and agreeing with the SOC and access to the recommended care.

Osteoarthritis

Improving health professional and patients' knowledge and attitude can help implement the recommendations for OA; motivation can move organizations to help provide time, facilities and economical resources for this. Clinicians need to take OA symptoms more seriously; some clinicians view the disease as a pure degenerative ageing condition, even though there is evidence that it is not a pure degenerative disease. More competent clinicians and health professionals are needed to meet the challenges of OA and implement the recommendations. The focus group from Sweden suggested: "The patient should have a well educated contact person in the health care system that is available on the phone". Educating health professionals is an important facilitator, and increasing patients' awareness about the disease, as well as the importance of assessments and physical activity was emphasized by the focus groups. Multidisciplinary and multifaceted assessments are needed when the patient is examined or diagnosed. Information and treatment advice should be given independent of the background (or economic incentives for specific treatments) of the specialist they are seeing. High quality treatment plans may be difficult to achieve due to a lack of knowledge about therapeutic options.

Rheumatoid Arthritis

Successful implementation is dependent on early referral systems, better understanding in primary care and faster referral to specialist care. This is overall being implemented. Patients need availability of educational materials. Access to care and treatment can be influenced by personal motivation and attitude, and organization protocols, etc. Improved knowledge and organizational support may help optimize health care. Access to a specialized health

professional is a challenge where health professionals with a speciality are lacking in the health care system and where there is a lack of multidisciplinary teams. Specialists and health professionals with specialized skills are needed to implement some of the Standards. Time, education and strengthened multidisciplinary teams are needed to assess, treat and monitor the individual patient.

Patient organizations contributions

Starting points for implementing the standards were discussed internationally with patient organizations at the PARE conference. Patient organizations could contribute being the connection between local stakeholders, attempt to influence politicians and health care administrators, educate patients, exchange knowledge, and translate available written materials. The patient organizations within EULAR further thought the EULAR could contribute with stimulating to exchange information and education by training health professionals and patients, help translate materials, make information accessible on the web and in print, work at a EU level (together), launch the standards for Europe as a whole, not as optional for the different countries, arrange workshops for ministers of Health in Europe to increase awareness about MSD and their treatment. PARE delegated sincerely suggested to provide and recommend a short version of the standards for patients so they know what to ask their clinicians, health professionals and health care administrators for.

Focus group Norway

Results from a structured group interview with health professionals and patients in Norway March 5th, 2012.

Patients and health professionals from a specialist hospital, a patient board and primary care were invited to an interview to explore factors to help promote (facilitators) the implementation of the treatment recommendations for OA and RA in clinical practice based on the EUMUSC Standards of Care.

Present at the interview were two local leaders in rheumatology care, two professional patients, two nurses, an occupational therapist and a physiotherapist. The interview lasted for one hour. All informants received oral and written information about the treatment recommendations for OA and RA prior to the interview. One researcher moderated the interview (RHM), another (CØ) took notes during the meeting.

The results are summed up for each of the EUMUSC recommendations. The participants generally agreed with the recommendations.

Recommendations for osteoarthritis:

People with symptomatic osteoarthritis should have access to a clinician able to make differential diagnosis.

The clinician and patients' attitude and knowledge may help implement this recommendation. It is dependent on availability of different equipment (i.e. Ultrasound). Cooperation and information between the different levels of health care is important. Updating systems and strategies for health professionals could also help implement this recommendation.

People with symptomatic osteoarthritis should be assessed regularly.

Information on why this is important would help implementation; and it is easier to motivate patients and health professionals if assessments are a part of a project.

People with osteoarthritis should have evidence-based surgical treatment as needed.

Good, updated knowledge and communication skills would help make this recommendation happen.

People with osteoarthritis should have evidence-based pharmacological treatment as needed
The clinician and patient attitude and knowledge may help implement this recommendation. Easy access to a pharmacy /stores would help in the rural areas. Patients must be informed and willing to make an effort to get evidence based recommended pharmacological treatment, some patients are negative towards taking medication...how to overcome this barrier?

People with osteoarthritis should have evidence-based non-pharmacological treatment as needed.

Information about what types of treatment should be made available for patients and health professionals. Educating the stakeholders about OA and treatment and increase knowledge would help. Patients and health professionals' interest in making an effort would play an important role.

Recommendations for rheumatoid arthritis:

People with rheumatoid arthritis should have timely access to a clinician making a differential diagnosis.

Early and effective referrals from GPs to specialist care would help, and good capacity of physicians and rheumatologists could facilitate this. Templates of how references should be made so that enough information about the patient is given during referral would ease this.

People with rheumatoid arthritis should be assessed formally and regularly to ensure disease control.

Research and ongoing research projects facilitates the use of assessments. Patients' motivation and information about the importance of assessments is important. Communication between the patient and health professional is crucial here.

People with rheumatoid arthritis should have evidence-based pharmacological treatment like synthetic or biologic drugs as needed.

Knowledge and specialist expertise would help the recommendation happen, so would good information about medications and side effects. Health professionals and patients attitudes towards pharmacological treatments influence the success of the implementation of this recommendation.

People with rheumatoid arthritis should have evidence-based non-pharmacological treatment as needed.

The success of implementing this recommendation is dependent on Health professionals' knowledge and availability. There should be enough health professionals to take care of non-pharmacological care; the knowledge would have to be better transferred into the community. Patients and health professionals motivation for updating is important, in addition to access to and distance to the professionals, pools, rooms, and equipment.

Participant quotes: "Patients' motivation and information about the importance of assessments is important", "Educating the stakeholders about OA and treatment effects, and increase knowledge would help" (about non-pharmacological treatment), "Early and effective referrals from GPs to specialist care would help, and good capacity of physicians and rheumatologists could facilitate this" (timely differential RA diagnosis).

Focus groups Romania

Focus group performed in a Clinical Hospital “Dr I Cantacuzino” regarding the implementation of EUMUSC.NET Standards of Care for OA in Romania. Dr Gabriela Udrea Bucharest, Romania.

The group consists of one moderator, one note keeper and 8 participants: 4 seniors in rheumatology and 4 specialists in rheumatology, all of them were females, mean age 43 years old, mean years experience in rheumatology 8, 5. The moderator asked the main question about the implementation of Standards of Care. Participants individually answered the main question. The moderator identified areas where the participants agreed or disagreed. When dissensus was identified the moderator tried to clarify.

FOR SOC OA1: People with symptoms of OA should have access to a health professional competent in making a (differential) diagnosis. All the participants found the recommendation accessible, agreed with the content of the recommendation, each of them are positive toward implementation and outlined the importance of professional organisation support (education) in implementation. They also agreed that recommendation will be implemented without time and economical resources.

FOR SOC OA2: People with symptoms of OA should be assessed at diagnosis and upon significant worsening for: Pain, Function, Physical activity, BMI, Ability to do their tasks and work. The participants agreed with the recommendation, the importance of the recommendation was well-known and thought the implementation will be not influenced by cultural background, environmental factors, time and economical resources. They also believed the recommendation will be used but function, evaluation of physical activity, BMI and ability to do their tasks and work should be done by the rheumatology nurse as a part of the consultation and for this required support of the professional and health care organization and education.

FOR SOC OA3: People with OA should receive a treatment plan with a shared treatment target set up between them and a health professional. The participants agreed with the content of recommendation, it's importance was well-known and thought the implementation will be not influenced by cultural background, environmental factors, time and economical resources but will be influenced by specialist attitude regarding the patient. There is not need for education, for professional and patient organization support. They also believed the recommendation will be used.

FOR SOC OA4: 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.

The participants understand and agreed with the content and importance of the recommendation but don't believe the recommendation will be implemented due to the fact that in many rheumatology care settings the management of the musculoskeletal disorders is not performed in a multidisciplinary team. Many maybe even all of them don't have dietician, rheumatology nurse, occupational therapist, psychologists and social workers. They believed that only motivation of patient, professional and health care organizations will move the authorities towards organization rheumatology health care in multidisciplinary teams. There is also need for time and economical resources and also facilities.

FOR SOC OA5: People with OA should achieve optimal pain control using pharmacological and non-pharmacological means. All the participants found the recommendation accessible, agreed with the content of the recommendation, each of them are positive toward implementation and outlined the importance of patient, professional and health care organisations support (education) in implementation. They also agreed that recommendation

will be implemented without time and economical resources and will not be influenced by cultural background.

FOR SOC OA6: People with OA should achieve optimal function using pharmacological and non-pharmacological means. There was consensus between participants .All the participants found the recommendation accessible, agreed with the content of the recommendation, each of them are positive toward implementation and outlined the importance of professional and health care organisations support (education) in implementation. They also agreed that recommendation will be implemented without time and economical resources and will not be influenced by cultural background.

FOR SOC OA7: People with OA receiving NSAID or aspirin therapy should be assessed for GI bleeding risk, CVD risks and renal risks. There was consensus between participants .All the participants found the recommendation accessible, agreed with the content of the recommendation, each of them are positive toward implementation and outlined the importance of,professional and health care organisations support (education) in implementation. They also agreed that recommendation will be implemented without time and economical resources and will not be influenced by cultural background.

FOR SOC OA8: People with OA should receive information tailored to their needs within 3 months of diagnosis by health professionals about

Their disease and all aspects of living with and managing their OA, in written form and in a format suited and tailored to the individual, in a timely fashion appropriate to their needs.

The benefit of exercises and physical activity and should be instructed to exercise appropriately. Aids, devices and other products for environmental adaptations.

On ergonomic principles and activity-based methods to enhance functioning in daily life and participation in social roles. The importance of an ideal body weight, the role of analgesics – their potential benefits and risks, a healthy lifestyle (such as discontinuation of all types of tobacco use, balanced use of alcohol, physical activity, healthy diet, management of sleep disturbance if necessary), Prevention of accidents and injuries, support groups and patient organisations, when to think about surgery, additional treatment options provided some people might find useful. The participants understand and agreed with the content and importance of the recommendation but don't believe the recommendation will be implemented due to the fact that in many rheumatology care settings the management of the musculoskeletal disorders is not performed in a multidisciplinary team. Many maybe even all of them don't have dietician, rheumatology nurse, occupational therapist, psychologists and social workers, physiotherapist or rehabilitation physician .They believed that only motivation of patient, professional and health care organizations will move the authorities towards organization rheumatology health care in multidisciplinary teams. The patient organizations will support the action by brochures and website information about these aspects. There is also need for time and economical resources and also facilities.

FOR SOC OA9: People with OA should receive information about weight reduction if necessary. There was consensus between participants .All the participants found the recommendation accessible, agreed with the content of the recommendation, each of them are positive toward implementation. They also agreed that recommendation will be implemented without time and economical resources and will not be influenced by cultural background.

FOR SOC OA10: People with OA failing to respond to pharmacological and non-pharmacological therapy should be considered for surgical intervention. If referred, they should be seen by an orthopaedic surgeon within a reasonable time. There was consensus between participants .All the participants found the recommendation accessible, agreed with the content of the recommendation, each of them are positive toward implementation. They also agreed that recommendation will be implemented without time and economical resources and will not be influenced by cultural background.

Focus group performed in a Clinical Hospital “ Dr I Cantacuzino” regarding the implementation of EUMUSC.NET Standards of Care for RA in Romania. Dr Gabriela Udrea, Bucharest, Romania.

The group consists of one moderator, one note keeper and 8 participants : 4 seniors in rheumatology and 4 specialists in rheumatology, all of them was females, mean age 43 years old, mean years experience in rheumatology 8,5. The moderator asked the main question about the implementation of Standards of Care . Participants individually answered the main question. The moderator identified areas where the participants agreed or disagreed. When dissensus was identified the moderator tried to clarify.

SOC RA1: People with symptoms of RA should have timely access (6 weeks according to EULAR recommendations) to a clinician/ health professional competent in making a (differential) diagnosis. All the participants found the recommendation easy to find, agreed with the content of the recommendation, each of them are positive toward implementation and outlined the importance of professional and patient organisation support in implementation. There was dissensus regarding the education of specialists in order to understand the importance of the recommendation and their disponibility to have more unpaid and time consuming consultations (outlined the importance of professional organisation). Another disagreement was regarding the cultural background of the patient (low educational level, low income, low access to medical care, low expectations- but all agreed that general practitioner could be key point in solving this problem using educational brochures). All of them believe that recommendation will be used.

For SOC RA2: People with RA should be given relevant information and education about Their disease, Its management. All aspects of living with and managing their RA, in written form and in a format suited and tailored to the individual, in a timely fashion appropriate to their needs. All participants agreed with the content of the recommendation and believed that recommendation will be used. They mentioned the importance of the patient organisation in providing the educational support (brochures in every rheumatology care setting, meetings between patients and specialists) and also the role of rheumatology nurse. The participants outlined that patient organisations have an important role in pressuring on professional organisations in order to implement this recommendation. The duration of consultation is already short and this activity is time consuming.

For SOC RA3: People with RA should receive a treatment plan individually developed between them and their clinician at each visit. All participants agreed with the content of the recommendation and had a positive attitude towards recommendation and believed that recommendation will be used but pointed out on: the need for education of specialists and authorities about the importance of psychosocial aspects, pain management needs, vocational issues, relationships, family, work issues, sleep disturbance, managing anxiety and depression induced by the disease and development of the multidisciplinary team including occupational therapist, psychologist, or social services if appropriate. Implementation of this recommendation require education and willingness to get engaged in implementation, time resources and economical resources (for education of specialists working in the field, to employ these specialists in order to work in a multidisciplinary team with rheumatologist and rheumatology nurse for patients with RA).

For SOC RA4: At the start of any disease specific treatment, people with RA should be fully educated about the expected benefits and any potential risks fully evaluated to assess both clinical status and safety aspects. All participants agreed with the content of the

recommendation and are positive toward recommendation and believed it will be used. The discussions revealed that there is a need for specialised nurse in rheumatology trained in scoring disease activity, evaluating HAQ, participation, work status, depression scales. (NB: in Romania there are not nurses specialised in rheumatology and all the educational activities with the patient are performed by the rheumatologist). The implementation of this recommendation call for education, time, economical resources and awareness of the professional organisations.

For SOC RA5: People with RA should be fully assessed for symptoms, disease activity, damage, co-morbidity and function at diagnosis; these assessments should also be done annually; if disease not within target, clinical assessment should be done at least 3 monthly (all clinical variables) and possibly more frequently upon significant worsening. There was agreement between participants regarding the content, accessibility, belief that recommendation will be used. They also agreed that implementation of this standard of care require educational activities for specialists, patients and time and economical resources.

For SOC RA6: People with RA should have rapid access to care when they experience significant worsening of the disease. The participants agreed with the content, accessibility and believed in positive outcome expectancy for the recommendation. They thought that cultural background will not influence the implementation but require: educational and organisational activities in every medical team, personal effort, support of local and national professional and patient organisation and economical resources (protocols).

For SOC RA7: People with RA should be treated with a disease modifying anti-rheumatic drug (DMARD strategy) as soon as the diagnosis is made. The participants agreed on recommendation and considered there are not barriers for implementation other than education.

For SOC RA8: If the target of low disease activity or remission is not achieved using a synthetic DMARD (usually being methotrexate), treatment should be reevaluated at least every 3 months. Agreement between participants for accessibility, content, positive outcome of the implementation. Personal attitudes towards recommendation were positive. All of them outlined the support of the professional and patient organisations in education of the

For SOC RA9: People with RA should be evaluated for pain, and relief of pain associated with RA should be considered. Agreement between participants for accessibility, content, positive outcome of the implementation. Personal attitudes towards recommendation were positive.

For SOC RA10: People with RA who have residual joint problems despite state-of-art pharmacological (including intraarticular) and non-pharmacological therapy should be assessed by an orthopaedic surgeon within 3 months if there is joint damage/ soft tissue problems that can probably be solved by surgery. There was agreement between participants. They found recommendation easy to find, were positive towards it, didn't require time and economical resources but professional organisation support and education to understand the importance of the recommendation (meetings rheumatologists/orthopaedists)

For SOC RA11: People with RA should have access to evidence based pharmacological and non-pharmacological treatment. There was agreement between participants. They found recommendation easy to find, were positive towards it but implementation requires time resources and motivation.

For SOC RA12: People with RA should have access to a specialised health professional to receive assessment, advice and training in all matters related to their disease. At this point there was disagreement between the participants. They were sceptical regarding the implementation because they thought we don't have specialists in the field (podiatrists), orthoses prescription is unusual between rheumatologists, orthopaedists, rehabilitation

physicians. There is a need for understanding the recommendation, for education, for support from professional and patient organisations.

For SOC RA13: People with RA should understand the benefit of exercises and physical activity and should be advised to exercise appropriately. There was agreement between participants. They found recommendation easy to find, were positive towards it, but require professional and patient organisation support and education to understand the importance of the recommendation (meetings rheumatologists/patient organisations/ rehabilitation physicians/ physical therapist, working in a multidisciplinary team)

For SOC RA14: 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. They should receive information, advice and training on splints, aids, devices and other products for environmental adaptations. The participants found the recommendation useful, accessible and believed it will be used outlining the support of the patient organisations (personal effort, willingness to get engaged in the educational projects, brochures), the support of rheumatology nurses and needs for economical resources. They also emphasized the importance of occupational therapists in a multidisciplinary team (education, support of the professional organisation for training), and economical resources (feedback from health assurance company in order to reimburse splints, aids)

For SOC RA15: People with RA should receive information and advice about A healthy lifestyle (such as discontinuation of all types of tobacco use, balanced use of alcohol, physical activity, healthy diet, management of sleep disturbance if necessary)

Prevention of accidents and injuries,

Support groups and patient organisations, when to think about surgery and additional treatment options provided some people might find useful. The participants found the recommendation useful, accessible and believed it will be used outlining the support of the patient organisations (personal effort, willingness to get engaged in the educational projects, brochures), the support of rheumatology nurses.

For SOC RA16: People with RA who wish to try alternative therapies that some people found symptomatically beneficial, should be informed about the limited evidence. The participants found the recommendation useful, accessible and believed it will be used outlining the support of the patient organisations (personal effort, willingness to get engaged in the educational projects, brochures), the support of rheumatology nurses and needs for economical resources.

Focus groups Sweden

Report from the Swedish Rheumatism Association concerning our Focus group on OA 27 November 2012. Stockholm 30 Nov -12, Rolf Greiff, The Swedish Rheumatism Association.

The Focus group consisted of 10 patients, 8 women and 2 men. Their age span was from 54 to 75 years of age. 9 had been diagnosed with OA and 1 suspected that she/he had OA. They have had diagnosed OA between 10 to 30 year, suspected OA for 20 years. Their OA history was one we recognise, from quick diagnose, good treatment and appropriate care, to a long period of visits to primary care and extremely bad and disrespectful treatment before they finally got a referral to a specialist.

Focus group question:

”What is important to enable successful implementation of Standards of Care for OA?”

The patient should go to a doctor who can make differential diagnosis and have a holistic perspective. The doctor should take the patient's descriptions of symptoms and possible concerns seriously.

Patients should be informed about various treatment options and possible side effects of medication.

Patients should be informed about the importance of regular physical therapy and training and be offered the opportunity to do so. Medical personnel should motivate the patient to both exercise and ways to lose weight if needed.

Patients should meet with an occupational therapist and receive information about technical aids.

Patients should be offered participation in an OA Management Course.

Clinicians should inform you that there is a patient organization and how to get in touch with it.

Finally, the Focus group agreed fully on these.

What this means for you and your OA ... 9. If my BMI is > 27, have I been informed about weight reduction? 10. Have I been informed about when surgery should be considered, what it involves, its benefits and risks?

Report from the Swedish Rheumatism Association concerning our Focus group on RA 20. November 2012. Stockholm 26 nov -12, Rolf Greiff, The Swedish Rheumatism Association.

The Focus group consisted of 8 patients, 7 women and 1 man. Their age span was from 35 to 77 years of age. 7 had been diagnosed with RA and 1 suspected that she/he had OA. They have had diagnosed RA between 1 to 27 year, suspected OA for 30 years. Their RA history was one we recognise, from quick diagnose and appropriate care to a long period of visits to primary care before they finally got a referral to a specialist/ rheumatologist.

Focus group question:

“What is important to enable successful implementation of Standards of Care for RA”

Patients should quickly get a referral and get access to a specialist - within six weeks. Visiting hours should be flexible in time, depending on what issues the patient wants to address. It is important to discuss all kinds of questions from the test results, concern for other diseases, family relations, etc.

More resources are needed throughout rheumatism care, from primary care to specialist clinics.

Care should have a holistic approach to patients including the opportunity to meet paramedic skills.

The patient should have a well educated contact person in the health care system that is available on the phone.

In primary care they need a better understanding of musculoskeletal / rheumatic diseases.

Information to the patient about status and treatment proposals should be given repeatedly.

Focus group Germany

Focus Group Germany, Hünxe/Bonn, 28/11/2012, Time: 21st November, 2012 – 14.00 – 15.45, Moderator: Dieter Wiek, Deutsche Rheuma-Liga, Note Keeper: Dr. Cornelia Sander, Deutsche Rheuma-Liga, Participants: All participants were patients with various MSDs, members of Deutsche Rheuma-Liga NRW, concerning SOC OA and RA.

Focus group question:

“What is important to enable successful implementation of Standards of Care for OA and/or RA”

RA – 2nd round: First response of all participants

Statements:

More rheumatologists needed; it would shorten the waiting time to have access to a rheumatologist. We need more specialists, who have to cooperate better, especially with therapists; doctors have budget problems. Patients need more therapeutically and psychological support, more help concerning joint protection and shoe supply, more information concerning side effects of drugs. Only prescribed drugs are paid by the health insurance, but no reimbursement for drugs that patients need but needn't be prescribed any more. This means high costs for patients. More and better information is needed. GPs should react faster and refer patients to specialists, as patients need a better access to specialists. Patients' knowledge of existing structures should be improved. An early arthritis consultation should be the rule everywhere. Doctors should point out to patient organizations. Increase the number of rheumatologists. Very satisfied with the medical care. Her GP and rheumatologist cooperate well. Patients need their diagnosis earlier. The information about the treatment has to be improved. There should be a sufficient coverage of medical supply, some regions do not have enough specialists (uneven distribution). GPs have to be trained more and better. We need a network of care.

Rheumatoid Arthritis

1. Medical Care:

Patients need more rheumatologists, an even regional distribution of rheumatologists, faster access to rheumatologists without long waiting lists, and this should not depend on your health insurance membership. Faster assessment if conditions are serious and/or worsen. Integrated care: The system should be one where doctors, therapists and items of health aid (e.g. wheelchairs) can be chosen freely independently of contracts made by health insurers. The individual needs of patients have to be considered and no fixed rules put down by the health insurers. The drug treatment (especially when changing the drug treatment) should depend on the individual treatment plan and not on the contracts of the health insurance company. There should be more information on side effects, risks of drugs, co- morbidities.

2. Non-Medical Care

We need more information about rheumatic diseases for patients but also in society in general, so that people with RMDs are more accepted. The parts in the health system have to be educated and trained to deal better with people with RMDs. The exchange of information between GPs, rheumatologists, physiotherapists and others have to be done better to improve the patient's care.

If patients do not get the sickness benefits or assistance, they should be able to contact an independent institution for support. This point was a controversial issue as some participants

believe we should establish a new institution, whereas others think the existing structures are sufficient.

Patients require more psychological help and support. It is regarded as better for in-patients, but there is no adequate care for out-patients. Both parts (inpatient and outpatient care) have to be linked. A team of therapists should support patients to cope with their illness and their daily life (multidisciplinary approach). Patients should get more information about their social rights and should be supported if they want to achieve these rights (e.g. workplace, consultancy). Patient organizations, self-help groups and self-management courses have to be promoted. A network of care would enable better care.

Osteoarthritis statements by the focus group

The overall aim should be to manage OA without an operation alternative: prescription for exercise, being more receptive to patient's pain condition, put emphasis on non-pharmacological treatment, aim: quality of life without pain; Support with coping with complication in every day life. Patients are not taken seriously. It is considered necessary to clarify who has the competence to treat OA. More information about OA in the light of an aging society, more physicians are needed. Poor medical care, patients are completely at the mercy of physician, superficial diagnostic evaluation in a hurry. Physicians are interested in selling treatments that patients have to pay for out of their own pockets (IGEL- Leistungen), this is an inhibition threshold for consulting physicians. Problems with treatment only occur with severe pain, then treatment necessary aim: diagnostic evaluation in an early stage of OA with appropriate therapeutic interventions, treatment depends on medical specialist: orthopaedic specialists tend to operate even if operation is not the only option. OA: problems with health care. Preferable: orthopaedic rheumatologists, more help with pharmacological treatment and operations. National treatment guidelines do not exist, in case of a primary inflammatory rheumatic disease question: which specialist covers secondary OA?

OA - Debate

1. Medical Care

Patients need qualitatively optimized care (number of orthopaedic specialists is sufficient) - for OA as a secondary illness - orthopaedic rheumatologists who cover their medical care, because they are able to consider the interrelations between inflammatory rheumatic diseases and OA and the consequences for treatment-choices. Orthopaedic specialists who consider the interrelations of different joints when treating a condition. the implementation of quality standards for surgeons/hospitals for operative procedures (number of operations is not a criterion for quality). Clinical decision making about a clinic choice should be based on what is best for the patient. Bonuses should not guide which clinic is chosen to treat a patient. a decision making about possible treatment options that is guided by what is best for the patient. Operational procedures should not be conducted for economical reasons. If operational procedures are necessary – a decision - making process that is independent from their membership to a certain health insurance company should be undertaken. Information should be available for both about non-operational treatment options. Doctors who do not base their treatment choice on their budget (prescribing an operation rather than exercise therapy).

2. Non-Medical Care

Better interacting between patient and physician to come to a favourable agreement (patient as a partner). Better support for patients' dealing with complications in every day life. Advertise the existence of patient/self help organisation to orthopaedic specialists, orthopaedic

specialists should tell their rheumatic patients about patient organizations. Patients should be motivated to exchange experiences about their illness. “Barrier-free” is not a known concept for a lot of orthopaedic specialists. Based on their knowledge, patients hold the view that orthopaedic specialists are a dying species.

Focus group France

Facilitators and barriers to implementation of Standards of Care for OA
5 mars 2013 Nancy (France)

Present: one general practitioner, one patient with knee OA, one medical research assistant, one rheumatologist-epidemiologist, one physiotherapist, one physical rehabilitation doctor, one rheumatologist-epidemiologist (notes and reporter), one animator (public health). Invited apologized: one surgeon, one general practitioner, one rheumatologist (academic)

Standards of Care for OA, translated in French, were delivered to the participants 10 days in advance. This focus group was conducted according to rules given by the EUMUSC.net group. It started with a general round table where each participant could express their first reactions suggested by Standards of Care. Then more open exchange between participants has been conducted, notes were taken on a paperboard. By the end, notes were read by the group and approved. Duration of the meeting: 2 hours.

I- General reflections of the Standards of Care

Facilitators:

Therapeutic solutions exist and are known to many people (examples: surgery, joint infiltration).

Barriers:

OA is not always considered as a disease or merely as ageing disease.

OA is extremely banal to physician and to patients.

Sometimes the rheumatologist is powerless.

Known someone who therapeutic failure is a strong barrier to further use of health care.

II- Contribution to each single standard

Facilitators:

Standard n°1:

The French health care system has set the system of gatekeeper physician (treating physician) for 10 years and allows in 95% of cases access to GP is very easy and very well reimbursed.

Access to specialist is equally easy (rheumatologist, radiologist).

The complementary cover by CMU (universal disease covering, by social security) makes access easier to most deprived persons.

Standard n°2:

Training to assessment tools.

Integrating assessment in professional performance contract with health insurance

Standard n°3:

To disseminate information on many therapeutic options among professionals since they are frequently known only to rheumatologists.

Standard n°4:

Physiotherapists are numerous in France.

Physiotherapy is well reimbursed.

Some multiprofessionals health houses are rarer but are facilitating comprehensive care.

It would be a must to have better recognition and identification of proficiencies of many professionals (like physiotherapists)

Standard n°5:

Education of patients through therapeutic education.

A national health care policy to better control pain has been since implemented years ago and is a real success.

Standard n°6:

idem

National health care policy to develop programs of adapted physical activity would be useful.

Standard n°7:

Therapeutic education would limit self-medication especially for NSAIDs.

The pharmacist may play an important role.

Standard n°8:

A dedicated time with payment is necessary.

This could be announcement, therapeutic education consultation.

Supports like flyers, website or others media.

Education of medical auxiliaries.

Standard n°9:

To identify the best time to speak about losing weight.

It requires knowing the criteria to determine such best time and to catch the opportunity.

Standard n°10:

Waiting lists to surgery are short in France; this needs to be maintained.

III – Barriers

Standard n°1:

Believes of professionals to access other professionals.

Existence of priority co-morbidity or multiple diseases.

Standard n°2:

Medical time is limited.

Simply tools are not well known.

Spontaneous use is not present.

Standard n°3:

Chronic disease phenomenon and its banalisation.
Insufficient knowledge of the individual evolution limits practitioners in predicting the future to patients.

Standard n°4:

Occupational therapists are few and their care is not well reimbursed in ambulatory care.
Physiotherapists insufficiently exchange with general practitioners or between professionals.
Reimbursement is limited.
Access to physiotherapists in a rural area is difficult (transportation problem).

Standard n°5:

Negative beliefs for pharmacological (example: morphine) and non pharmacological treatments.
A negative image of using technical aids in France (crutches, cane, wheelchair)

Standard n°6:

Functional capacity is less a priority than pain.

Standard n°7:

Banalisation of treatments like NSAIDs induces an underestimation of their associated risks.

Standard n°8:

No specific payment of such dedicated time.
No self health group or OA association in France.

Standard n°9:

No methods exist for easy implementation.
Belief that such objectives are unreachable.

Standard n°10:

To determine the good time lacks recommendation and it depends on relation between patients and doctor.
High costs of surgery.

PARE workshop (International)

by Rikke Helene Moe (moderator) and Babette Anhalt (note-taker) Zurich, 2. November 2012. Duration 70 minutes. 19 international participants with various rheumatic diseases.

Facilitators and barriers:

The theme of the workshop was on facilitators (and barriers) to implementing the Standards of Care (SOC)

The list of facilitators were discussed, and agreed on; the following were considered very important by the participants:

Access to care, and to recommendations

Knowledge

Economical resources: can be a lack of money but also can be a lack of efficient use of current economical resources

Implementation

Attitude (positive)

The group suggested what national organisations could do to help implement the SOC: Be the connections between local/national stakeholders, influence politicians, educate patients, stimulate patient power, exchange knowledge, and translate available written educational materials.

The group suggested what the EULAR organization could do to help implement the SOC: Stimulate exchange of information and education, training health professionals and patients, have a special effort on educating young (er) people on their terms, translate materials, put information on the web and in print, work at a EU level (together) and launch the SOC's for Europe as a whole, arrange workshops for ministers of Health in Europe to increase awareness, provide short uncomplicated versions of the recommendations for patients so they know what to ask their clinicians for.

Dissemination

The EUMUSC.NET has been presented at the EULAR congress in Berlin 2012, at PARE in Zurich in November 2012, at EUMUSC.NET webpage, in EULAR HP Newsletter 2012, A scientific article has been published (18), information has been sent to patients, health professionals and health care administrators, the EULAR and the EUMUSC partners in all European countries related to the survey performed in 2012.

Examples of good practice (case studies) will be disseminated to all target groups, such as health practitioners, patients associations, advocates, NGOs, policy makers, using all means of dissemination to raise Standards of Care, such as brochures, websites, press releases, and press conferences.

Acknowledgements

The WP 7 group acknowledges all patients, health professionals and health care administrators who participated in the survey and the qualitative interviews. A special thank to Østvik C, Anhalt B, Wiek D, Sander C, Greiff R, Udrea G, Guillemin F for conducting the qualitative interviews.

We also acknowledge all participants in the focus group including the participants in the French focus group: Anne-Christine Rat, Guy Vançon, Nadine Valentin, Robert Boini, Cédric Baumann, Alain Aubrège, Francine Mangin.

Appendix 1. Osteoarthritis Standard of Care

SOC Number	SOC	Subtext	Patient checklist
SOC OA 1	People with symptoms of OA should have access to a health professional competent in making a (differential) diagnosis.		Was my OA diagnosed by a competent health professional?
SOC OA 2	People with symptoms of OA should be assessed at diagnosis and upon significant worsening for <ul style="list-style-type: none"> • Pain • Function • Physical activity • BMI • Ability to do their tasks and work 	Functioning in daily life includes people's capacity to carry out activities related to their work, hobbies or social activities.	Do I have regular assessment concerning my symptoms and functioning in daily life?
SOC OA 3	People with OA should receive a treatment plan with a shared treatment target set up between them and a health professional.	The treatment plan should be developed in partnership between the health professional and the person with OA. The treatment plan should include at least: <ul style="list-style-type: none"> • information about the disease • an individualised activity and exercise program • if the persons BMI > 27 information on weight management should be given and a referral to a weight management program should be offered comorbidities have to be taken into account in the development of the treatment plan.	Do I have a treatment target and a corresponding treatment plan?
SOC OA 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.		Do I have the opportunity to receive support if needed from health professionals such as rheumatologist, dietician, general practitioner, nurse, occupational therapist, physiotherapist, psychologist and social worker?
SOC OA 5	People with OA should achieve optimal pain control using pharmacological and non-pharmacological means.	<ul style="list-style-type: none"> • Maybe it is not possible to reach the status of being completely painfree but people should achieve satisfactory pain control. • People should be informed about pharmacological and non-pharmacological treatment options, what can be expected from them and their risks and benefits. 	Do I know how to control pain associated with OA?
SOC OA 6	People with OA should achieve optimal function using pharmacological and non-pharmacological means.	If a patient is diagnosed with symptomatic OA and has functional limitation then an improvement of his/her functional ability by 20% on a patient reported outcome measure should be reached within three months after initiation/change of pharmacological/non	Do I know how to maximise my physical function despite having OA?

		pharmacological treatment. (Measured by visit or telephone contact or letter)	
SOC OA 7	People with OA receiving NSAID or aspirin therapy should be assessed for GI bleeding risk, CVD risks and renal risks.		
SOC OA 8	<p>People with OA should receive information tailored to their needs within 3 months of diagnosis by health professionals about</p> <ul style="list-style-type: none"> • Their disease and all aspects of living with and managing their OA, in written form and in a format suited and tailored to the individual, in a timely fashion appropriate to their needs. • The benefit of exercises and physical activity and should be instructed to exercise appropriately. • Aids, devices and other products for environmental adaptations. • On ergonomic principles and activity-based methods to enhance functioning in daily life and participation in social roles. • The importance of an ideal body weight • The role of analgesics – their potential benefits and risks • A healthy lifestyle (such as discontinuation of all types of tobacco use, balanced use of alcohol, physical activity, healthy diet, management of sleep disturbance if necessary) • Prevention of accidents and injuries • Support groups and patient organisations • When to think about surgery • Additional treatment options provided some people might find useful 	The individualized exercise program should include advice for physical activity, range of motion-, muscle strengthening- and aerobic exercises.	<p>Do I understand my disease and my role in its management?</p> <p>Have I been offered information in different formats and/ or education about my disease?</p> <p>Have I been informed about living with and managing my OA?</p> <p>Have I been informed about a healthy lifestyle?</p> <p>Have I been informed about exercises specific for me?</p> <p>Have I been informed about pain relieving medication – the benefits and potential risks?</p> <p>Do I know what benefit I can have from my exercise program?</p> <p>Have I been informed and did I receive advice and training on aids, devices and ergonomic principles to enhance function in daily life and participation in social roles?</p>
SOC OA 9	People with OA should receive information about weight reduction if necessary.	People with OA with an BMI > 27 should receive information on weight management and should be offered a referral to a	If my BMI is > 27: Have I been informed about weight reduction?

		weight management program.	
SOC OA 10	People with OA failing to respond to pharmacological and non-pharmacological therapy should be considered for surgical intervention. If referred, they should be seen by an orthopaedic surgeon within a reasonable time.	People with OA considered for surgical intervention should be offered a presurgical assessment along with information about of the procedure, the risk and benefits, post- operative care and individualised discharge plan.	Have I been informed about when surgery should be considered, what it involves, its benefits and risks?

Appendix 2. Rheumatoid Arthritis Standard of Care

SOC Number	SOC	Subtext	Patient checklist
SOC RA 1	People with symptoms of RA should have timely access (6 weeks according to EULAR recommendations) to a clinician/ health professional competent in making a (differential) diagnosis.		Was my RA diagnosed by a specialised health professional within 6 weeks of onset of symptoms?
SOC RA 2	<p>People with RA should be given relevant information and education about</p> <ul style="list-style-type: none"> • Their disease, • Its management • And all aspects of living with and managing their RA, <p>in written form and in a format suited and tailored to the individual, in a timely fashion appropriate to their needs.</p>	<p>For people with RA there should be the opportunity (if required) to</p> <ul style="list-style-type: none"> • have time to talk to someone face to face about the concerns at the clinical visit • gain information and education at all stages of the patient journey • discuss the care package and to know what to expect from it and when • get information and self-management support at the right time • discuss the emotional and psychological impact of the disease on life, for example as part of the annual review • discuss work issues, provided with appropriate support to enable to remain at work or get back to work when this is desired 	<p>Do I understand my disease, my role in its management and the role of health professionals?</p> <p>Have I been given information in different formats and/ or education about my disease?</p> <p>Have I been given information and / or education about treatments, their benefits and risks?</p> <p>Have I been given information and education relevant to my needs i.e. pain/flare management, drug reactions?</p> <p>Have I been given information about, and given contact details of, relevant patient charities and organisations which are considered to be trusted sources of evidence based information?</p>
SOC RA 3	People with RA should receive a treatment plan individually developed between them and their clinician at each visit.	<p><i>The treatment plan should include at least:</i></p> <ul style="list-style-type: none"> • Diagnosis, physical examination and follow-up evaluations • Assessment of signs and symptoms of the disease and its sequels: general health, functioning, psychosocial aspects, pain management needs, vocational issues, relationships, family, work issues, sleep disturbance, managing anxiety and depression including referral to occupational therapy or social services if appropriate. Family and carers should be involved where appropriate • Goals: defined by person with RA and health professionals together • Communication plan: e.g. contact detail of expert care in case of worsening of the disease • Monitoring plan: at least one annual review should be done • Education plan: access to 	Have I received a treatment plan which includes explanation of my management, expected outcomes and important contact details?

		personalized education programmes developed by health professionals, means to increase self management and information (e.g. patient organizations, trusted sources of evidence based information)	
SOC RA 4	<p>At the start of any disease specific treatment, people with RA should be</p> <ul style="list-style-type: none"> Fully educated about the expected benefits and any potential risks Fully evaluated to assess both clinical status and safety aspects. 	<p><i>The assessment for clinical status and safety aspects should include at least:</i></p> <ul style="list-style-type: none"> Clinical status appraisal should include at least : <ul style="list-style-type: none"> A measure of disease activity such as composite scores like DAS or any of its variants, CDAI or SDAI; individual components like joint counts, global assessment of disease activity by the person with RA and the clinician or health professional A measure of functioning (such as HAQ, participation, work status, or an ICF- based instrument) A baseline evaluation of the structural damage by X-rays (may be scored globally by any available system or just checked for structural joint damage); MRI or ultrasonography may provide additional insights (but should not replace x-ray). Based on clinical status, person with RA and clinician/health professional should state an individual shared target that should be realistic and relevant; such treatment target should be expressed in terms of status to be achieved and time to reach it. Assessment for comorbidities may lead to deviations from conventional or alterations of agreed treatment plans for RA, since some comorbidities constitute risk factors for developing specific adverse events, like COPD for infections; others may limit the dose, like renal function impairment; others may contraindicate some treatments, like active infections. Given the immunosuppressive nature of most therapies in RA and the high rate of infections in this population, it is very important that the vaccination status is reviewed and that the person is protected against avoidable infectious diseases in accordance with national vaccination plans. 	<p>Was I informed about expected benefits and potential risks of treatment? Was I assessed for clinical status and safety before the treatment was started?</p> <p>Was I informed about vaccination?</p>
SOC RA 5	<p>People with RA should be fully assessed for symptoms, disease activity, damage, comorbidity and function at diagnosis; these assessments should also be done annually; if disease not within target, clinical assessment should be done at least 3 monthly (all clinical variables) and possibly more frequently upon significant worsening.</p>	<p>Depending on the disease activity and status of the therapy and/ or person with RA, these intervals may range from few days or weeks to several months.</p> <ul style="list-style-type: none"> People with RA in remission should be re-appraised at least once a year; People with RA not in remission should be scheduled at a rheumatologist within 3 months Clinical target should be reviewed by evaluating the change in disease activity measures. Safety should be evaluated by a complete work-up with laboratory examinations, review of possible adverse events, new co-morbidities, complications of RA, and re- 	<p>Have I received a regular assessment schedule?</p>

		<p>evaluation of protection against infections</p> <p><i>Additionally the annual review/ assessment should also include:</i></p> <ul style="list-style-type: none"> • Persons participation in activities that are important to him or her, work capacity, functional status, CV risk and special needs. • Progression of structural joint changes; since progression is usually faster in the first two years, the clinician/health professional may decide for less frequent intervals of x-ray assessment in situations of stable low disease activity or remission. When joint surgery is planned, imaging is mandatory. • Non- pharmacological treatments require periodic reviews. 	
SOC RA 6	<p>People with RA should have rapid access to care when they experience significant worsening of the disease.</p>	<p>Notwithstanding regular monitoring schemes, people with RA may need acute care at unpredictable time points; this should be warranted irrespective of other planned visits and the time-points for regular follow-up should generally not be affected by such emergency access to the team:</p> <ul style="list-style-type: none"> • Adverse event reporting should not be postponed until the next scheduled visit: therefore, a fast-track system should exist (i.e. telephone, rapid access slots or protocols developed in collaboration with the rheumatology team) • Access in case of flares. • It is advised to maintain regular check-ups despite in between visits, otherwise target may be lost, and some important safety aspects may be under-evaluated 	<p>Have I been informed when, how, and who I can contact in case my disease is worsening?</p>
SOC RA 7	<p>People with RA should be treated with a disease modifying anti-rheumatic drug (DMARD strategy) as soon as the diagnosis is made.</p>	<p>Glucocorticoid may be needed in addition to DMARD treatment (lowest dose for the shortest period of time).</p>	<p>Am I receiving a disease modifying anti-rheumatic drug, and if not, do I understand why not?</p>
SOC RA 8	<p>If the target of low disease activity or remission is not achieved using a synthetic DMARD (usually being methotrexate), treatment should be reevaluated at least every 3 months.</p>	<ul style="list-style-type: none"> • If treatment target is not achieved with the first or combination DMARD strategy, addition of biological DMARD should be considered especially when poor prognostic markers are present (i.e. for bad outcome of physical disability or structural damage); when poor prognostic predictors are absent, switching to or adding another synthetic DMARD should be considered (as defined by appropriate guidelines). • In people with RA lacking predictors for severe disease another synthetic DMARD monotherapy (or in combination with methotrexate) may be employed. • If a biological agent has failed, another TNF inhibitor, abatacept, rituximab or tocilizumab is indicated, sequencing according to local protocols. • In people with RA in persistent remission, tapering of biological agent should be considered and in long-term remission a careful 	<p>If my target of low disease activity or remission is not achieved, is my treatment reappraised at least every 3 months?</p>

		titration of synthetic DMARD dose.	
SOC RA 9	People with RA should be evaluated for pain, and relief of pain associated with RA should be considered.	<ul style="list-style-type: none"> • Nonsteroidal anti-inflammatory drugs (NSAIDs) have to be considered in symptomatic people with established RA and early arthritis after evaluation for gastrointestinal, renal, and cardiovascular risk. • Replacement of conventional NSAIDs by COX-2 selective drugs, or the addition of gastroprotective agents to classical NSAIDs should be prescribed in persons at increased risk for NSAID GI toxicity (as defined by appropriate guidelines). • Analgesics should be prescribed if NSAIDs are contraindicated or if NSAIDs convey inadequate pain relief. 	Do I know how to control pain associated with RA?
SOC RA 10	People with RA who have residual joint problems despite state-of-art pharmacological (including intraarticular) and non-pharmacological therapy should be assessed by an orthopaedic surgeon within 3 months if there is joint damage/ soft tissue problems that can probably be solved by surgery.	People with RA should be offered a presurgical assessment along with information on the procedure, the risk and benefits, post-operative care and an individualised discharge plan.	Have I been informed about the options of surgery?
SOC RA 11	People with RA should have access to evidence based pharmacological and non-pharmacological treatment.	People with RA should receive information about expected effects, benefits and possible risks of any pharmacological or non-pharmacological treatment that may be instituted or started by the person.	Do I have access to pharmacological and non-pharmacological treatments according to my clinical need?
SOC RA 12	People with RA should have access to a specialised health professional to receive assessment, advice and training in all matters related to their disease.	<ul style="list-style-type: none"> • People with RA should be encouraged to carry out regular physical activities. • People with RA should receive professional advice on exercises (aerobic and strengthening) specific to their joint involvement and adapted to the person's general health. • Information should be given on the positive effect of exercises on general and cardiovascular health, as well as maintenance of mobility and prevention of muscle wasting. • Information and education on joint protection should be given, tailored to the person's needs. • People with RA should be assessed for the need (and the acceptance) of splints and should have access to a health professional providing them. • The need for adapting the environment at home/ at work should be assessed and an experienced health professional advice should be available. • People with RA should receive expert advice on assistive devices to 	<p>Do I have the opportunity to receive support if needed from health professionals such as rheumatologist, dietician, general practitioner, nurse, occupational therapist, physiotherapist, psychologist and social worker?</p> <p>Have I been offered information about how, why and when to contact different members of the multi-disciplinary team as soon as possible after my diagnosis was made?</p>

		<p>improve/ maintain the ability to carry out activities of daily living.</p> <ul style="list-style-type: none"> • The psychological and social impact of the disease should be taken into account and appropriate interventions should be offered. • In the treatment of people with RA attention should be given to foot problems and information provided on foot care, foot wear and orthoses / insoles. 	
SOC RA 13	<p>People with RA should understand the benefit of exercises and physical activity and should be advised to exercise appropriately.</p>		<p>Have I been informed about physical activity and exercises specific for me?</p>
SOC RA 14	<p>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. They should receive information, advice and training on splints, aids, devices and other products for environmental adaptations.</p>		<p>Have I received information and if necessary advice and training on aids, devices and ergonomic principles to enhance function in daily life and participation in social roles?</p>
SOC RA 15	<p>People with RA should receive information and advice about</p> <ul style="list-style-type: none"> • A healthy lifestyle (such as discontinuation of all types of tobacco use, balanced use of alcohol, physical activity, healthy diet, management of sleep disturbance if necessary) • Prevention of accidents and injuries, • Support groups and patient organisations, • When to think about surgery and • Additional treatment options provided some people might find useful. 	<p>Reliable information based on a person's status assessment and best available knowledge should include material on:</p> <ul style="list-style-type: none"> • Discontinuation of all types of tobacco use • Balanced use of alcohol • Physical activity • Diet: Advice regarding a balanced diet in order to control weight and on the need to supplement vitamins and minerals, even if there is current lack of scientific evidence on the impact of such measures on disease activity and course <ul style="list-style-type: none"> - avoidance of diets deficient in dairy products (contain calcium), - following a Mediterranean diet could be encouraged (fish) - minerals, vitamin C and D, calcium, fish oil and folic acid can be supplemented (and folic acid must be supplemented with use of MTX) • Sleep: early management of sleep disturbances as a factor improving quality of life. 	<p>Have I been informed about a healthy lifestyle?</p>
SOC RA 16	<p>People with RA who wish to try alternative therapies that some people found symptomatically beneficial, should be informed about the limited evidence.</p>		<p>Have I been informed about alternative therapies and the limited evidence available?</p>

Appendix 3. Protocol EUMUSC focus groups

Developed in cooperation with Francis Guillemin and Maarten de Wit: Focus group question “What is important to enable successful implementation of Standards of Care for OA and/or RA”

Task: The EUMUSC.NET decided to use a simple focus group approach (no tape recording or transcribing mandatory). All wp7 members are challenged to perform at least one focus group in their own setting. If possible health care administrators and politicians should be prioritized; if they cannot be gathered for the purpose of a focus group, individual interview(s) might be an alternative. Mixed or patient groups are also welcome. Please be aware of the selection of informants, whether groups can be mixed, and whether there are homogenous or heterogeneous groups. EUMUEC.NET would need the results of the focus-groups by 1. December

You need: One moderator, one note keeper, a room with table and chairs, one blackboard or presentation-board and 8-12 participants. Focus group interviews should be between 1 and 2 hours. Consider the need for ethical approval, depending on the formal rules that apply in your country.

General attitude: All comments are valuable, no comments are bad, and every theme brought up is enriching.

Format:

We want to explore new ideas, the participants should not hold back on their comments

1. Written information should be handed out ahead of the focus-group (the EUMUSC Standards of Care for RA and/or OA).
2. Other variables to be collected on the group level: position (HP, Patient, Health care administrator). Years experience with the position. Age? Gender?
3. Moderator starts asking the main (broad) question about the implementation of Standards of Care. Participants individually answer the main question. Then, the moderator asks focal questions in a structured manner and participants are encouraged to talk and interact with each other.

Task and role of the moderator:

- Introduce yourself, clarify your own role and background, introduce the note keeper, and clarify his task and role.
- Ask for permission of recording/note keeping. Explain the purpose of the meeting. Explain the procedure (time frame) and the rules. Announce that all participants will receive the report of the meeting and the opportunity to respond to the report for accuracy (responder check).
- 1st round - Short introduction by the participants.
- 2nd round - Gather a first response of all participants on the main question. Focus on listening and learning from the participants. Your role as moderator is only to stimulate discussion by asking open questions aiming to explore and clarify all perspectives in the group. Be reluctant in expressing agreement or disagreement with participants. Use probes to obtain and understand the arguments and ideas of all participants; for instance: “do I understand correctly...” or “May I try to summarize...”

- Make sure that all participants contribute actively in the discussion. Interrupt dominant participants by asking politely: "allow me to summarize your point briefly", or "May I ask you to be concise in your answers?"
- End the first explorative round by summarizing your first impression of opinions that seemed to be shared by most of the participants, and opinions that are different. The note keeper might write topics down on a flip chart when mentioned more than once. Check whether your summary is accepted by all participants, if not: ask for clarification. Stay closely to the words and formulation of the participants. Don't cluster topics together nor rephrase the topics in your own (scientific or professional) language.
- 3rd round - Propose to discuss the subsequent topics or opinions one by one. Now the moderator might want to explore differences in opinions, or group topics together when relevant. Check every step you make with the participants. For instance, ask: "what is the difference between 'giving more information' and 'communicate better?'"
- Stimulate the exchange of multiple viewpoints and responses. This will result in more in-depth discussions. When consensus does not exist, the moderator should employ a systematic process to identify the sources of dissent. Don't force to get consensus that is not the aim of this focus group.
- Try to allocate enough time to each topic that is written down on the flip chart. Avoid spending too much time on the first topic, which might not be the most important topic.
- Make sure that the focus group does not get drawn into a discussion of the philosophy of the task and process.
- Observe the interactions among group members.

*The moderator must be skilled in group process and interviewing techniques.

Task and role of the note keeper:

- The main responsibility is to give an accurate report of the diversity of opinions and ideas regarding the main question of the focus group. It is important to identify areas where participants agree and areas where no consensus exists. This need to be reported by the note keeper by making sure discussions are adequately recorded (you could use one or two voice recorders) or by writing down the arguments and discussions.
- The note keeper helps the moderator only when needed, but should keep in mind that he only plays "the second violin" in the moderation. This means that the moderator steers the focus group and the note keeper only interferes when the moderator misses an important remark by one of the participants or when something is not clear to him.
- The note keeper might keep an eye on the time keeping. He might signal the moderator that it is time to go to the next step or to the next topic.
- During the explorative phase (2nd round): write the occurring topics down on a flip chart. These topics might structure the second part (3rd round) of the focus group.
- Observe the interactions among group members.

Reference List

- (1) Guyatt G. Evidence-based medicine in everyday practice. *Cleve Clin J Med* 1999 Sep;66(8):461-4.
- (2) Brand C. Translating evidence into practice for people with osteoarthritis of the hip and knee. *Clin Rheumatol* 2007 Sep;26(9):1411-20.
- (3) Pencharz JN, Grigoriadis E, Jansz GF, Bombardier C. A critical appraisal of clinical practice guidelines for the treatment of lower-limb osteoarthritis. *Arthritis Res* 2002;4(1):36-44.
- (4) Mitchell HL, Hurley MV. Management of chronic knee pain: a survey of patient preferences and treatment received. *BMC Musculoskelet Disord* 2008;9:123.
- (5) Li LC, Maetzel A, Pencharz JN, Maguire L, Bombardier C. Use of mainstream nonpharmacologic treatment by patients with arthritis. *Arthritis Rheum* 2004 Apr 15;51(2):203-9.
- (6) Shekelle PG, Ortiz E, Rhodes S, Morton SC, Eccles MP, Grimshaw JM, et al. Validity of the Agency for Healthcare Research and Quality clinical practice guidelines: how quickly do guidelines become outdated? *JAMA* 2001 Sep 26;286(12):1461-7.
- (7) Shekelle PG, Ortiz E, Rhodes S, Morton SC, Eccles MP, Grimshaw JM, et al. Validity of the Agency for Healthcare Research and Quality clinical practice guidelines: how quickly do guidelines become outdated? *JAMA* 2001 Sep 26;286(12):1461-7.
- (8) Lacaille D, Anis AH, Guh DP, Esdaile JM. Gaps in care for rheumatoid arthritis: a population study. *Arthritis Rheum* 2005 Apr 15;53(2):241-8.
- (9) Li LC, Sayre EC, Kopec JA, Esdaile JM, Bar S, Cibere J. Quality of Nonpharmacological Care in the Community for People with Knee and Hip Osteoarthritis. *J Rheumatol* 2011 Aug 1.
- (10) March LM, Schwarz JM, Carfrae BH, Bagge E. Clinical validation of self-reported osteoarthritis. *Osteoarthritis Cartilage* 1998 Mar;6(2):87-93.
- (11) Walker J. Rheumatoid arthritis: role of the nurse and multidisciplinary team. *Br J Nurs* 2012 Mar 22;21(6):334, 336-4, 339.
- (12) Wagner EH. The role of patient care teams in chronic disease management. *BMJ* 2000 Feb 26;320(7234):569-72.
- (13) Petrella RJ, Davis P. Improving management of musculoskeletal disorders in primary care: the Joint Adventures Program. *Clin Rheumatol* 2007 Jul;26(7):1061-6.
- (14) Brand C. Translating evidence into practice for people with osteoarthritis of the hip and knee. *Clin Rheumatol* 2007 Sep;26(9):1411-20.
- (15) Cabana MD, Rand CS, Powe NR, Wu AW, Wilson MH, Abboud PA, et al. Why don't physicians follow clinical practice guidelines? A framework for improvement. *JAMA* 1999 Oct 20;282(15):1458-65.

- (16) *OECD Health Data 2012*. Eurostat Statistics Database; WHO Global Health Expenditure Database 2013
- (17) *OECD Health Data 2012*. Eurostat Statistics Database; WHO Global Health Expenditure Database 2013
- (18) Strombeck B, Petersson IF, Vliet Vlieland TP. Health care quality indicators on the management of rheumatoid arthritis and osteoarthritis: a literature review. *Rheumatology (Oxford)* 2012 Oct 29.