

**A practical guide to disseminate
EULAR recommendations
to patients**

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Preface

Patients are becoming more actively involved in the management of their own disease and the healthcare decisions that have to be made. This is called shared decision making: decisions about potential treatments are made on the basis of information given by the health professional and on the preferences of the patient. To make a well-informed decision, it is necessary for the patient to be provided with up-to-date information about treatment options. This includes the benefits and risks of taking or rejecting a particular treatment.

It is because of this increasing need for reliable and easy to access information that EULAR develops disease management recommendations. EULAR, and in particular the EULAR Standing Committee of PARE (People with Arthritis/Rheumatism in Europe), considers it important that these recommendations reach patients as well as health professionals. EULAR has therefore made the dissemination of recommendations a priority for the coming years.

Patients should be aware of the EULAR recommendations and where to find them. However, the traditional, scientific wording of the recommendations is often difficult for lay people to understand. It is important, therefore, to adapt the recommendations to the language of the patient. Moreover, it is sometimes necessary to adjust recommendations to the context of a particular country. EULAR wants to promote this process by providing English lay versions. EULAR furthermore encourages its member organisations to translate the lay versions into other languages and to disseminate these versions to patients in their own country. Also in countries that have developed national guidelines or recommendations, patient organisations should develop lay summaries and disseminate these to patients. High quality and up-to-date patient versions are needed to ensure that all people with rheumatic and musculoskeletal diseases (RMDs) in Europe are aware of the existing recommendations, and can understand them.

This booklet provides practical guidance for the dissemination of recommendations to patients. The standard operating procedure (SOP), the steps to develop patient versions are summarised on page 20 (Fig1). The guide as a whole contains suggestions, tips, examples, and helpful checklists complementing the core SOP's. We hope that not only European patient organisations but all supporters of EULAR find this guide useful in their daily work to improve health care for people with RMDs.

Marios Kouloumas, EULAR vice-president representing PARE

Gerd Burmester, EULAR president

Introduction

Over the years the *European League Against Rheumatism* (EULAR)¹ has developed many recommendations for disease management (1;2). These recommendations are primarily developed and published to inform practicing health professionals and to improve their daily treatment routines. However, in many countries up-to-date and understandable information for patients is lacking. Readable, patient friendly information is needed to make appropriate health decisions and to follow treatment instructions. Not only people with lower health literacy, but many patients have problems with reading and understanding the often scientific terminology of medical professionals. As a result, many patients lack adequate information and do not have enough understanding of their disease and possible treatment options. This can lead to suboptimal decisions, low trust in health professionals and low compliance. A substantial number of patients seek help in alternative or complementary medicine. Lack of knowledge is an important cause of unsatisfying disease outcomes and low quality of life.

Priorities of EULAR

Improving patients' knowledge about the management of their disease can be enhanced by patient education. EULAR has recognised that the dissemination of recommendations is an important priority. This priority is reflected in the revised Standardised Operating Procedures (SOPs)* for developing management recommendations that were published in 2014 (2). In this new version, the role of patients is emphasised as well as the importance of early planning of the dissemination and implementation process

Because patient organisations represent the users of health care, they are key in this dissemination process. For this reason the EULAR Standing Committee of PARE initiated the development of a practical guide on the dissemination of recommendations to patients. This guide is in the first place meant for national patient organisations. Because we expect that in many cases patient organisations and health professionals will work together, we think the guide will also be useful for health professionals with an interest in promoting patient education.

Methods

This guide is based on a systematic literature review (SLR), a Delphi method* and two face-to-face meetings in Amsterdam with the members of the Task Force². The Task Force* consisted of a mixed group of patient representatives, health professionals and an implementation specialist. The Task Force reviewed the outcomes of the SLR, developed recommendations for dissemination and assisted in the development of this guide.

The literature review showed that there is not much known about effective dissemination strategies to patients. Most of what we know is from studies about dissemination of guidelines among health care professionals. And the level of evidence that was found in the literature was relatively low: level 3 or 4. This means that conclusions were based on

¹ Concepts indicated with an asterisk (*) are explained in the glossary.

² The SLR will be published elsewhere.

single case studies (level 3) or on expert opinion (level 4). For this reason the Task Force developed a set of *principles* for dissemination. Depending on the context and the disease, approaches for dissemination to patients may vary. The literature review gave insights into good examples of dissemination and practical suggestions for a strategic approach. It also provided an overview of tips, options and potential problems.

Terminology

In this guide we use the following definitions of translation, adaptation, dissemination and implementation.

Adaptation and translation

The adaptation of recommendations is a three-step process. First, translating the scientific wording of the original recommendations into an English lay-version. It is important that in the translation the content of the recommendations is not changed. The translation stays as close to the original version as possible. Second, translating this English lay version into another language and subsequently adapting the content to the country-specific context and information needs of patients.

Dissemination

Dissemination is the process of raising awareness about the recommendations. It gives insight in the existence of recommendations and where to find them.

Implementation

Implementation is the process of promoting the application of recommendations. This leads to more (structural) use of the recommendations or guidelines in clinical practice.

Principles for disseminating recommendations to patients

Overarching principles

- A) Patient organisations, rheumatologists and other health professionals play a pivotal role in the dissemination of EULAR recommendations to patients.
- B) Patients should be involved during the whole process of recommendations development, adaptation and dissemination according to the EULAR recommendations for the inclusion of patient representatives.

Development

- 1. A dissemination plan should be part of the recommendations project protocol, formulated at the start of the development or updating of the EULAR recommendations.
- 2. The dissemination plan should include identifying target audiences, their information needs and the strategies for dissemination of the EULAR recommendations, as well as suggestions for evaluating the dissemination process.

Adaptation and translation

- 3. An English lay version should be developed for all EULAR recommendations.
- 4. The English lay version should fulfil the following general principles: being short; understandable, and clear; using active voice, present tense, short sentences (maximum 15 words) and short paragraphs (maximal 10 lines).
- 5. For non-English speaking countries the lay version should be translated into the national language and adapted to the country-specific situation. Preferably, the national patient organisation should take this initiative.

Dissemination

- 6. The original version, English lay version and country specific versions of the EULAR recommendations should be easily accessible for patients.
- 7. For dissemination of the national lay versions to patients a combination of traditional as well as innovative tools should be considered.
- 8. The national patient organisations should use specific opportunities and events to present the EULAR recommendations.

The principles explained

Overarching principles

- A. *Patient organisations, rheumatologists and other health professionals play a pivotal role in the dissemination of EULAR recommendations to patients.*

Dissemination of management recommendations is a priority for EULAR. EULAR recognizes that dissemination can only be successful in close collaboration with all stakeholders. EULAR therefore acknowledges the important role of national patient organisations and health professionals in initiating the translation and dissemination of the EULAR recommendations to health professionals and patients. As described in the overarching principle, collaboration with health professionals is necessary because they are in close contact with patients and have extended insights into the needs and concerns of patients. By health professionals we mean all people working with people with a rheumatic or musculoskeletal disease. This includes rheumatologists, nurses, orthopaedics, physiotherapists, occupational therapists, psychologists, physicians and general practitioners.

A description of the process and responsibilities is provided in a flow chart (figure 1).

Collaboration to overcome different perspectives

In 2007 EULAR published recommendations on the management of glucocorticoid therapy (GC) in rheumatic diseases (3). The implementation of these recommendations was hindered by uncertainty about the actual benefit-risk ratio of these drugs. Research showed that patients and health professionals have different perspectives on glucocorticoids (6). Patients tend to overestimate the risks. This may be reflected in serious concerns about adverse effects or even refusal to take GC treatment. Also among medical doctors no consensus exists regarding their optimal use, which makes the recommendations controversial and difficult to implement.

A joint strategy to address the lack of consensus

To address the problem of under use of the recommendations and a lack of consensus, EULAR decided in 2014 to facilitate an additional implementation project in which a group of experts collaborated with patients to ensure right from the beginning both practical relevance and high implementation potential. The project aims to develop consensus and subsequently develop the best way for disseminating and implementing the existing recommendations to professionals and patients with rheumatic conditions. As soon as an important hurdle has been removed and the group has achieved consensus about the conditions under which glucocorticoids have a good benefit-risk ratio, an effective innovative dissemination strategy can be developed, aimed at people with rheumatic conditions and rheumatologists/clinical doctors.

- B. *Patients should be involved during the whole process of recommendations development, adaptation and dissemination according to the EULAR recommendations for the inclusion of patient representatives.*

Patient participation in the establishment of recommendations ensures a broad view on the relevance of the recommendations and increases quality, validity and usability. Their involvement can also improve the dissemination to patients. In 2011 EULAR formulated eight recommendations for the inclusion of patient representatives in scientific projects (box 2). Future development, adaptation and dissemination of recommendations should live up to these recommendations.



Reference cards

In 2013 EULAR evaluated the dissemination and implementation of the recommendations for patient involvement (4). After interviewing EULAR Task Force leaders and a survey to patient research partners it became apparent that both groups considered these recommendations extremely helpful. However, they reported that the recommendations were not easy to find and that they found it difficult to explain the concept of patient participation to colleagues and other stakeholders. For this reason EULAR developed a set of reference cards. These cards help patients as well as research team members to start new collaborative relationships. The reference cards were accompanied by a practical guide for researchers and patient research partners (“Patient involvement in research; a way to success”). The guide explains the eight recommendations in more details and shows how patients can be best included in scientific projects. The reference cards and the guide were provided in printed version as well as online through the EULAR website.

Recommendations for the inclusion of patient representatives

1. Participation of patient research partners is strongly recommended for clinical research projects and for the development of recommendations and guidelines, and should be considered for all other research projects.
2. Participation of patient research partners should be considered in all phases of the project to provide experiential knowledge, with the aim of improving the relevance, quality and validity of the research process.
3. A minimum of two patient research partners should be involved in each project.
4. Identification of potential patient research partners should be supported by a clear description of expected contributions.
5. The selection process of patient research partners should take into account communication skills, motivation and constructive assertiveness in a team setting.
6. The principal investigator must facilitate and encourage the contribution of patient research partners, and consider their specific needs.
7. The principal investigator must ensure that patient research partners receive information and training appropriate to their roles.
8. The contribution of patient research partners to projects should be appropriately recognised, including co-authorship when eligible.

Development

1. *A dissemination plan should be part of the recommendations project protocol, formulated at the start of the development or updating of the EULAR recommendations.*

The aim of a dissemination plan is to consider how the recommendations can be spread to different audiences using different tools and strategies. It is beneficial to develop a dissemination plan at the beginning of a project. It increases the chance that the information will effectively reach the different target audiences. It also enables an early start to the preparation of the dissemination, for instance by raising funds, contacting potential partners, starting a Facebook page or LinkedIn group and approaching relevant stakeholders such as conference organizers, publishers, editorial boards and the EULAR member organisations. More information about the development of a dissemination plan is given in checklist 1.

EULAR vision

In 2014, EULAR updated the Standardised Operating Procedures for EULAR-endorsed recommendations (2). The following bullet points are taken from the official EULAR document and emphasize the importance of dissemination:

- Implementation starts with knowledge about the recommendations. Therefore, dissemination is the crucial first step.
- A strategy for dissemination should be part of the original proposal.
- The minimum dissemination that is required is the submission of an abstract to the EULAR annual Congress and the submission of a manuscript to the Annals of Rheumatic Diseases, the EULAR journal, for consideration of publication.
- Although the content of the recommendations will not vary, the presentation, dissemination and implementation may need to be adjusted for the various target audiences (for instance lay versions of recommendations for patients).
- For dissemination purposes it is important to present the recommendations in an easy to understand way.
- A special consideration is the development of a lay version of the recommendations for patients. Ideally, this would be part of the original project, but frequently this can only be completed as a separate project afterwards with involvement of a larger group of patients.
- Another dissemination option is to send the recommendations to a high number of the intended end users, for example, rheumatologists in various countries in case of management recommendations. The rheumatologists can be asked about their agreement with each recommendation in a similar way as described for the task force members. In addition, they can be asked to indicate whether the specific recommendation will change their practice, and if it will not change their practice, is this because they disagree or because they already apply this in clinical practice. Finally, expected or actual barriers to the implementation can be listed. This will provide essential information to develop an implementation project.
- Other ways of dissemination are presentation by key opinion leaders, the inclusion in national recommendations, and continuing education programmes.

- 2. The dissemination plan should include identifying target audiences, their information needs and the strategies for dissemination of the EULAR recommendations, as well as suggestions for evaluating the dissemination process.*

EULAR Task Force leaders, as well as patient organisations, are responsible for developing a dissemination plan and should take the initiative. The primary target group for a patient versions are the individual persons with a rheumatic or musculoskeletal disease. A lay version is important to inform patients about what they may expect when they are receiving rheumatology care as described in the EULAR recommendations. Rheumatologists, health professionals, general practitioners and national and international patient organisations may be included as secondary target audiences for the lay versions. The goal of dissemination to these different targets group may vary. An overview of optional components of the dissemination plan is described in checklist 1.

The dissemination plan should consider the financial implication of dissemination strategies; every strategy needs a budget. Acquiring funding at an early stage results in a greater chance that the dissemination strategy will succeed. Sometimes it is beneficial to engage with third parties who might have an interest in the dissemination process. In that case opportunities for co-financing should be explored. Checklist 2 illustrates things to consider when acquiring funding.

Adaptation

3. An English lay version should be developed for all EULAR recommendations.

All recommendations have to be translated into an English lay version. There are various ways of producing English lay versions. The Annals of the Rheumatic Diseases started in 2014 to produce lay summaries of scientific papers. These summaries are written by a medical writer and reviewed by members of the PARE network of Patient Research Partners. Checklist 5 provides some examples of translations into lay language. Ideally, this lay version is published together with the original manuscript.

In 2015 EULAR decided to follow the same procedure for each EULAR recommendation. EULAR has developed Standard Operating Procedures for this process. The final version needs to be agreed by the Task Force leader.

In the past, a few English lay summaries have been developed at stand-alone events. Here, expert patients from different European countries were invited for a one-day meeting, often initiated and facilitated by health professionals. Below we describe the first initiative to develop an English lay version by the ASAS group. On page 16 we report the efforts of the Belgium Reumanet to translate and develop lay versions in Dutch. Checklist 3 contains an outline of basic information that is considered relevant for patients.

The first lay summary

The Assessment of SpondyloArthritis international Society (ASAS) developed an English lay version of its recommendations for the management of Ankylosing Spondylitis (AS) (5). A consensus meeting with participants of various countries was held with the aim of creating a lay summary that could be understood by patients. To achieve this, the main task was to simplify the wording and to explain the original text by adding comment. However, it was stated at the beginning of the meeting that modification of the meaning of the original recommendations was not allowed.

In general, common speech was preferred as a translation of Latin terms in the expert's version (e.g. 'other diseases' instead of 'comorbidity', 'medication' instead of 'concomitant drugs'). But not all medical language can be rendered in lay terms. In some instances translation of words did not contribute to a better understanding of the patient-adapted version. Therefore, some words were deleted, such as "structural" and "persistently", or explained in more detail, for instance for the word "Cox-2 inhibitor". The most important experience in this meeting was that it was not a great problem to agree on this patient-adapted version to a rather mixed group of AS patients from 10 different European countries. The involvement of patients with many different native tongues enhances the likelihood that the resulting language version can be easily understood by many patients, and also easily translated into various languages, as specific English wording is avoided.

In some cases the patients' vote on the translation was influenced by disagreement about the content of the recommendations. One of the controversial issues for patients was the role of self-management and that of patient organisations. In the future, this difficulty can be reduced by allowing AS patients to participate in the development of recommendations at an earlier stage.

4. *The English lay version should fulfil the following general principles: being short, understandable, and clear; using active voice, present tense, short sentences (maximal 15 words) and short paragraphs (maximal 10 lines).*

The English lay version should meet the demands and needs of patients. It should be simple, up-to-date, understandable and readable for a wide range of people. Preferably, therefore, it should be developed or checked on readability by non-native English speakers from different countries. Providing a high quality lay version of recommendations might be time consuming and requires expertise. At the end, the (medical) information should be checked for accuracy and consistency with the original recommendations.

A good patient version takes the general principles for a clear text into account:

- 1) Be as short as possible. Avoid unnecessary information.
- 2) Use familiar/layman wording instead of jargon.
- 3) Explain medical terms if these cannot be avoided.
- 4) Use words of one or two syllables.
- 5) Present clear and consistent (unambiguous) information.
- 6) Use active voice in the present tense, for example, 'Brush your teeth after every meal' instead of 'Your teeth should be brushed after every meal'.
- 7) Use short sentences of 15 words or less.
- 8) Use short paragraphs of ten lines or less.
- 9) Be aware that the language of patients is not similar to the language spoken by professionals.

"I keep constantly the target audience in mind. I always try to write a text that a person of 14 or 15 years old can understand. I am conscious not to use any jargon and to keep sentences as short as possible."

Nele Caeyers

Electronic testing of readability

These principles should not be handled as strict, mandatory guidelines, but as a rule of thumb. To improve the quality of lay texts, software has been developed to check texts on readability using for instance the criteria of Flesch Reading Ease, the Evaluative Linguistic Framework or other formulas. This software analyses the characteristics of a text such as the average length of a sentence and the average number of syllables per word. The result is an objective assessment of the readability of the text.

Lay versions to support Health Democracy in France

In 2014, the French Society of Rheumatology (FSR) developed management recommendations for rheumatoid arthritis and arthritis spondylitis. On the initiative of two national French patient associations (ANDAR – rheumatoid arthritis; and AFLAR – rheumatisms) two working groups were established to develop patient versions of these recommendations. Each working group comprised members of the initial working group and patients identified by the patient organization to achieve a balance in numbers.

Both groups translated the recommendations in lay language and achieved consensus without distorting the medical meaning of the initial recommendations. The groups followed a standardized process to reword the recommendations in a language accessible to all. This process included a physical meeting continued by exchanges of emails. The last step comprised a survey to a wider group of patients to ensure broad understanding and acceptability. This survey revealed high levels of satisfaction and was also useful for dissemination and implementation of the recommendations.

For the FSR, active patient participation is an example of health democracy. It helps to make good lay versions that are understandable for the entire patient population. At the same time, far from being passive recipients of health care, it gave patients the opportunity to have an active role in the improvement of the disease management of their peers. By including patient organisations in the dissemination of these recommendations, patients will be empowered to become partners with their doctors through the dynamic of shared decision-making.

More information about the French initiative can be found through the EULAR Congress book 2015.

5. *For non-English speaking countries the English lay version should be translated into the national language and adapted to the country-specific situation. The national patient organisation preferably should take this initiative.*

The English lay version of recommendations must be translated into the national language of each country. This is important to make the recommendations accessible for a wider audience. The translation of the recommendations must stay close to the original English lay version. This will avoid differences between the lay versions in different countries and prevent new recommendations being developed that are not based on evidence or expert consensus. If possible, the translation should be done by a professional medical writer, following the principle of “forward and backward translation”*. Collaboration with the national society for rheumatologists may increase the chance to obtain funding.

The lay version should then be checked by patients for relevance and readability.

Country specific

The national versions of the recommendations have to be country specific. This means that there should be information about the use of the recommendations for that specific country. This information can be given in a separate text box. It has to explain which adaptations have been made to make the recommendations applicable in the national context.

EULAR name and logo

All English lay summaries, commissioned by EULAR and approved by the Task Force leader, carry the EULAR name and logo. Translated and country specific lay versions, that are based on the EULAR recommendations cannot have the EULAR logo. However, if the translated version is approved by the EULAR scientific society of that country, and if it has a web-link to the original and English lay version, it may carry the title, for instance: “German translation of the EULAR management recommendations for etc.”

Checklists

Checklist 4 describes the process of translating the English lay version into national lay versions. It also explains how to adapt the English lay version into a suitable version for the country-specific situation. This checklist gives practical pointers about the use of logos and the quality-check of the translation. Checklist 5 gives more information about which steps should be taken to translate the English version into other languages. Both checklists can be followed with as well as without the involvement of a medical writer.

Reumanet translates EULAR recommendations

The Belgium patient organisation Reumanet took the initiative to translate existing English lay versions into Dutch. Where there was no English version, a national Dutch lay version was developed on the basis of the original EULAR recommendations. The steps of both scenarios are described separately below.

If a EULAR lay version exists...

The first Dutch lay version was translated from the existing English lay version of the 'EULAR recommendation for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2013 update'. According to Nele Caeyers, responsible for developing the lay versions, the translation into Dutch was not difficult and required hardly any adaptations. The amount of time to make the first translation took not more than 1,5 day.

The translated version was sent to members of the Belgium network of patient research partners. They checked the translation for readability and content. Then something interesting happened. One of the patient research partners noticed that the recommendations were slightly different from what recently had been concluded in a national study. As a consequence the translated lay version was forwarded to the involved rheumatologist to check the accuracy of the content of this lay version. The rheumatologist concluded that the recommendations were much in line with his findings, except for one aspect. This aspect was added to the national lay version with an asterisk and a footnote. This made the national lay version more specific, as the particular findings were also included. It was then checked with patient research partners whether this addition of information was understandable and clear. Once this was agreed upon, the final national lay version was published on the Reumanet website (Reumanet.be) and in several magazines of Reumanet member organizations. Patients and professionals were very enthusiastic about this national lay version.

If no EULAR lay version exists...

The development of national lay versions where there are no English versions is much more difficult and more time consuming. In this case the first step should be reading the scientific manuscript and summarizing and translating the parts that are relevant for patients. Reumanet started this process by again involving the members of the Belgium network of patient research partners. It is the experience of Reumanet that this scenario takes much more time, up to a couple of weeks. It also requires more energy and resources. For example, more attention should be given to the collaboration with stakeholders, preferably from an early stage to align the different expectations and possibilities.

Dissemination

6. *The original version, the English lay version and the country specific version of the EULAR recommendations should be easily accessible for patients.*

It is important that patients have access to all versions of the EULAR recommendations. All available versions of the EULAR recommendations can be accessed through the EULAR website: www.eular.org. Also, when sent to the EULAR secretariat, the translated versions that have been approved by the EULAR scientific society of that country will be made available through the EULAR website.

The patient organisations have to make the country specific version easily accessible on their websites and include a link to the original and the English lay version. Beside the use of the websites, other ways of spreading recommendations are encouraged (see recommendations 7 and 8 and checklist 7).

ARD lay summaries for patients and non-clinicians

In 2014 the British Medical Journal (BMJ) started to develop lay versions of some of the EULAR recommendations and other scientific publications that might be of special interest to patients. The lay versions are written by a professional medical writer. The BMJ collaborates with EULAR in the review of the lay versions, and improving the layout and accessibility. This task has been undertaken by the members of the PARE network of patient research partners. They regularly read draft lay versions and send their feedback to the BMJ. Their comments have already resulted in substantial adaptations in the layout of the lay versions and in improving accessibility by open access* through the BMJ and EULAR websites. Because not all original manuscripts are open access, there are technical and legal obstacles to making the accompanying lay versions open access. We hope the obstacles will be solved in the near future to give patient organisations and all individual people with RMDs the opportunity to download the lay versions for free.

The lay versions can be accessed through:

http://ard.bmj.com/collections/ard_lay_summaries

7. *For dissemination of the national lay versions to patients a combination of traditional as well as innovative tools should be considered.*

To disseminate the EULAR recommendations successfully to patients, patient organisations and health professionals, a variety of strategies should be used (see checklist 1 and 7). More traditional methods are dissemination via internet, presentations, self-management courses or leaflets. Innovative ways to spread recommendations might, for example, use social media or videos. Patients and patient organisations could explain their publicity campaigns. Their experiences might be used as good/bad practice examples for future campaigns to disseminate recommendations.

Survey as dissemination strategy

In 2011, the Standing Committee of Health Professionals published recommendations for the role of the nurse in the management of chronic inflammatory arthritis (7). The authors were aware of the fact that the recommendations might be difficult to disseminate, particularly in countries that are not familiar with the concept of an arthritis nurse practitioner. However, many health professionals thought that the recommendations could be a strong lobbying tool in the hands of health professionals and patients if they were better informed about the existence and content of the recommendations.

The Task Force members came with an innovative idea to promote the dissemination of the recommendations by organising an international survey in Europe and the United States of America. This web-based survey asked respondents to:

- a) Assess their level of agreement with the recommendations;
- b) Assess the application of the recommendations in their own country;
- c) Indicate potential barriers for implementation of the EULAR recommendations in their own country.

The survey was a great success, gathering the opinions of 967 nurses, 548 rheumatologists and 2034 patients from 23 countries. The results of the survey were published (8) and show significant differences between the different target groups:

The most commonly reported reasons for incomplete agreement were 'too many responsibilities' (nurses), 'doubts about knowledge of the nurse' (rheumatologists) and 'fear of losing contact with the rheumatologist' (patients). The most commonly reported barriers to the application were time constraints and unavailability of service.

This example shows the benefits of a large scale survey: it not only improved the awareness of many health professionals and patients about the existence of the recommendations, it also gave insights into some important barriers to the implementation of these recommendations.

8. *The national patient organisations should use specific opportunities and events to present the EULAR recommendations.*

There are frequent events where groups of patients come together. These events are ideal to present the content of the recommendations and to explain why it is important for patients to know about them. These events can be symposia, patient meetings, self-management programmes or the general assembly of an organisation. In some countries, ambassadors play a key role in the dissemination of recommendations. This is described in the best practice below.

Using meetings that are already organized is an efficient and effective strategy to reach a group of patients at the same time. For this reason it is sometimes less costly and less time-consuming to wait until an existing meeting rather than organizing a separate event. The use of combined strategies and repetition of key messages are the most effective. Other suggestions for dissemination strategies are given in checklist 7.

Swiss ambassadors raise awareness

The use of ambassadors for sensitisation has become more common in European countries. A project of the Swiss Rheumaliga used ambassadors to raise awareness of rheumatic diseases and preventative measures. Brief, clear messages were formulated to target people affected by rheumatic diseases, their relatives, health professionals and the wider public.

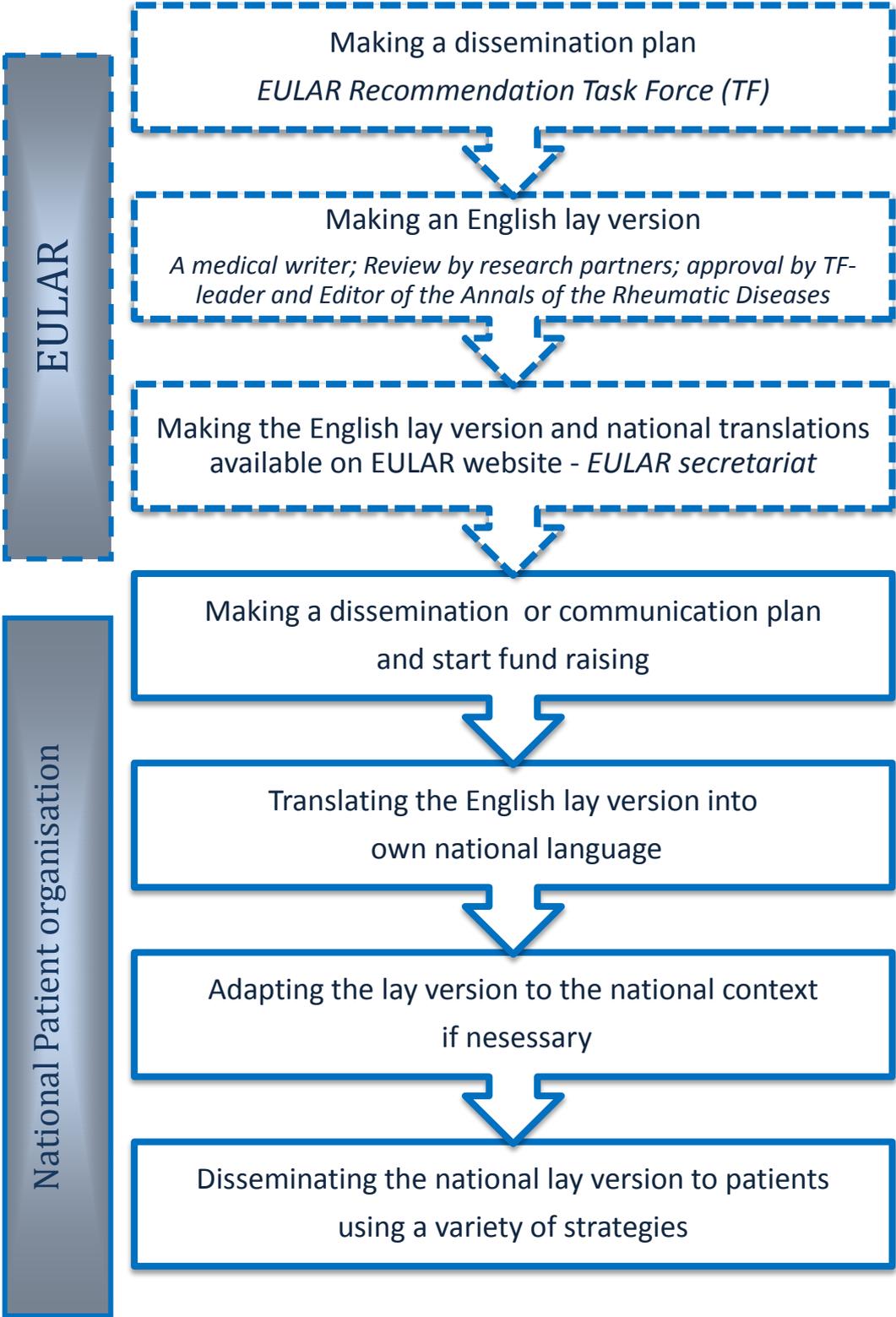
Although the aim of this campaign was to create broader awareness and sensitisation and prevention, different components of this strategy are relevant for the dissemination of recommendations, particularly the use of ambassadors.

This campaign showed the value of using existing public events as platforms for disseminating information. By joining these events, a large audience was reached. To enlarge the attention of the wider public and the media, the Swiss league worked with prominent ambassadors. They had a special interest in the themes of the campaign and could facilitate media activities. This helped to remove the taboos surrounding rheumatic diseases. Together with the Swiss league they formulated concise statements to be used in all media activities. The ambassadors explained, for instance, the conditions under which a person should visit a doctor in order to get an appropriate assessment of the symptoms. To provide more in-depth information to those affected by rheumatic diseases, the league organized health conferences throughout Switzerland with presentations by specialists. All these activities were supported by a web dossier, web videos, publications, members' magazines, print and online media. Success of the campaign was seen in the increased number of people downloading web content, a higher number of requests for brochures and an increasing level of media presence.

More information about this campaign can be found through the EULAR Congress book 2015.

Figures and checklists

Figure 1. Standard operating procedures (SOP) for translating, adapting and disseminating EULAR recommendations to patients



Checklist 1. Making a dissemination plan

This table shows different actions that can be taken for dissemination of recommendations to patients.

What is needed for dissemination?	Examples of ways to do this (actions)	Strategy
Making the EULAR recommendations available	<ul style="list-style-type: none"> <input type="checkbox"/> Check for the availability of an English lay version. <input type="checkbox"/> Translating the English lay version in your own language (see the French case study on page 14 and the Belgium case study on page 16) <input type="checkbox"/> Developing a country specific lay version (adaptation) <input type="checkbox"/> 	ORGANISATION
Making the EULAR recommendation accessible for patients	<ul style="list-style-type: none"> <input type="checkbox"/> Publishing the national lay version on the website of national organisations <input type="checkbox"/> Providing a link on your website to the original and the English lay version of the EULAR website <input type="checkbox"/> Patient leaflets and patient magazines <input type="checkbox"/> Reference cards and background information (see case study on page 8) <input type="checkbox"/> 	
Making individual patients aware of the existence of lay versions of the EULAR recommendations	<ul style="list-style-type: none"> <input type="checkbox"/> Including EULAR recommendations in existing patient information materials <input type="checkbox"/> Patient leaflets <input type="checkbox"/> Article in patient journals <input type="checkbox"/> Incorporating the lay versions in self-management courses, programs or work books <input type="checkbox"/> Message on television screens in waiting rooms <input type="checkbox"/> Posters in waiting rooms of rheumatologists/orthopaedic surgeons <input type="checkbox"/> Social media such as LinkedIn and Facebook Groups <input type="checkbox"/> Organising a survey among members (see case study on page 18) <input type="checkbox"/> Tweets <input type="checkbox"/> 	INFORMATION

<p>Making patient organisation and individual patients interested in the EULAR recommendations</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Involving patient representatives in the Recommendation Task Force (see page 9) <input type="checkbox"/> Personal communication <input type="checkbox"/> Organising a meeting <input type="checkbox"/> Recruiting key persons/Opinion leaders (ambassadors: see Swiss case study on page 19) <input type="checkbox"/> Invitational conference <input type="checkbox"/> Workshop at PARE conference or national events <input type="checkbox"/> 	<p>MOTIVATION</p>
<p>Making individual patients capable to understand the recommendations.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Developing an English lay version if this is not available (see the ASAS case study on page 14) <input type="checkbox"/> Involving a professional, medical writer (see case study page 17) <input type="checkbox"/> Developing E-learning module or program <input type="checkbox"/> Education, guidance and support by other patients <input type="checkbox"/> 	<p>EDUCATION</p>
<p>Evaluating the effectiveness of the dissemination</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Determine indicators for availability, accessibility, awareness, and understanding <input type="checkbox"/> Conducting evaluation studies <input type="checkbox"/> 	<p>EVALUATION</p>

Checklist 2. Budget items to consider

In order to develop a dissemination strategy, funding is necessary.

This checklist provides budget points to consider, but is not exhaustive.

- Staff (coordinator)
- Translation (medical writer, or the forward and backward translation* procedure)
- Expenses for patient participants
- Travel allowance (for volunteers and/or staff members)
- Layout and design
- Printing costs of materials: leaflets, brochures, posters
- Event costs (accommodation, banners, videos, a booth)
- Costs of advertisements
- Producing instruction or promotion film
- Producing an App

Checklist 3. Outline basic information of a lay summary *

Disease, condition

- What is the disease?
- What are the symptoms?
- How is the diagnosis made? By whom?

Explanation about the disease and about how the body normally functions.

A reference to the self test (if available)

- How many people have this disease?
- How does the disease develop?

Self-management, what can I do?

- What can I do to reduce the symptoms?
- What can I do to prevent the symptoms or worsening of the disease?

A reference to tools that support self-management (if available), for instance a disease diary or medication app.

Treatment

- What is the treatment?
 - What treatments are possible (treatment options)
 - What is the expected result?
 - What are potential risks and complications?
 - Who is taking care of the treatment (general practitioner, specialist, health professional)
- A reference to a decision aid about different treatments (if available)*
- What kind of research is needed to evaluate the effectiveness of the treatment?
 - What is the procedure if the symptoms do not disappear?
 - Which medical tests are needed? By whom (specialist, specialized nurse, general practitioner)? How often?
 - In case of which symptoms should a patient (immediately) contact a doctor? (signal information)

Limitation and disability

- What do the symptoms and any limitation mean for daily living?
- What are the consequences for living, work, income, social participation, relationships, sexuality, leisure time (social life)?
- Where can I find support for coping with the impact of the disease?
- *A reference to websites of patient organisations and other national (independent) organisations that provide education or support.*

* Source: "Patient information based on recommendations", Dutch Federation of Patients and Consumers, 2012.

Checklist 4. Translating and adapting English lay versions into a national lay version

- ☑ Translate the text of the English lay version into the national language
- ☑ The translation should preferably be done by a professional translator.
- ☑ Stay close to the text of the English lay version
- ☑ Use the advice mentioned under recommendation 4 to make the text readable
- ☑ Ensure the accuracy of the translation by using the principle of forward and backward translation*
- ☑ Let patients check whether the translated version is readable and understandable (use the technique of cognitive interviewing*)
- ☑ Add a paragraph with an explanation about the country specific context of the recommendations at the end of the translated version
(For example, if the recommendation advises the use of nurse practitioners, but in the your country this kind of nurse does not exist, it should be explained who can do the job instead)
- ☑ Complement the national lay version with
 - a paragraph about the applicability of the recommendations
 - a paragraph about the feasibility of the recommendations
 - a paragraph that highlights the differences from previous recommendations
 - a reference to the source of the original recommendation as well as the English lay version (EULAR website)
- ☑ The EULAR scientific society of your country should approve the final lay version
- ☑ Send the translated and approved lay version to the EULAR secretariat to be added to the EULAR website

Checklist 5. Steps of forward and backward translation*

Translation of the lay version into European languages requires a process of forward-backward translation in 5 steps.

Step 1	Two or three persons (at least 1 rheumatologist and 1 teacher of English, all as bilingual as possible, but of whom at least one must be fully bilingual, and wherever possible also a patient research partner) – translate <u>independently</u> the English version into the target language.
Step 2	A single preliminary lay version is obtained during a <u>simple consensus meeting</u> with the 2 to 3 translators. Please keep in mind at this phase that the final wording needs to be understood by lay people, including people with low health literacy.
Step 3	<u>Backward translation</u> is then performed by an independent bilingual native English speaker, blinded to the English original version.
Step 4	A <u>multidisciplinary consensus committee</u> then meets, including the initial 2-3 translators, at least 2 rheumatologists (who may also be part of the translator group), one person very familiar with cross-cultural adaptation, and at least one patient fluent in English. The group will compare the initial version and the back-translation and will discuss the phrasing of the target-language version, and by consensus will produce a final version. The committee has to ensure that the translation is fully comprehensive and to verify cross-cultural equivalence of the source and final versions. Please keep in mind <u>again</u> at this phase that the final wording needs to be understood by lay people including people with low health literacy.
Step 5	The final version is <u>pre-tested</u> with 5 target-language-native patients. These patients read the lay version in the presence of one of the members of the translation team to check whether it is fully understood for all recommendations and whether the patients have problems with the formulation. Patients' comments are collected and the initial translators may need to go back to the translation and modify it, if comments are frequent and consistent.

Courtesy of Prof. dr. L. Gossec

Checklist 6. Examples of translations into lay language

This table provides examples of translations of 7 original recommendations into lay language. They derive from the “EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2013 update.” This table shows that adaptations are sometimes minimal (1). In other cases actors are introduced (2: doctors and patients), recommendations are simplified (3), sentences are shortened by splitting into two sentences (4), shortened by explaining terms in an additional introduction (5) or sentences are explained by adding information (6) or by describing difficult terms (7).

ORIGINAL	LAY SUMMARY
1. Therapy with DMARDs should be started as soon as the diagnosis of RA is made.	1. Patients should start taking DMARDs as soon as they are diagnosed with RA.
2. Monitoring should be frequent in active disease (every 1–3 months); if there is no improvement by at most 3 months after the start of treatment or the target has not been reached by 6 months, therapy should be adjusted.	2. Doctors should monitor patients every one to three months when their RA is active. If a patient has not improved enough after three or did not reach an agreed therapeutic target at six months, their treatment should be adjusted.
3. In cases of MTX contraindications (or early intolerance), sulfasalazine or leflunomide should be considered as part of the (first) treatment strategy.	4. If a patient can't take methotrexate, sulfasalazine and leflunomide are other preferred options.
4. Low-dose glucocorticoids should be considered as part of the initial treatment strategy (in combination with one or more csDMARDs) for up to 6 months, but should be tapered as rapidly as clinically feasible.	5. Patients and doctors can consider using corticosteroids called glucocorticoids at low doses, as part of the patient's initial treatment (along with DMARDs). But these drugs should be reduced and stopped as soon as possible.
6. In patients responding insufficiently to MTX and/or other csDMARD strategies, with or without glucocorticoids, bDMARDs (TNF inhibitors, abatacept or tocilizumab, and, under certain circumstances, rituximab) should be commenced with MTX.	5. Biological DMARDs are usually used along with methotrexate.

<p>6. Tofacitinib may be considered after biological treatment has failed</p>	<p>6. If biological DMARDs haven't helped, a DMARD called tofacitinib can be considered in countries that have approved this drug (currently not approved in the EU region due to questions on the benefit-risk ratio).</p>
<p>7. When therapy needs to be adjusted, factors apart from disease activity, such as progression of structural damage, comorbidities and safety issues, should be taken into account</p>	<p>7. When treatment needs to be adjusted, other things need to be taken into account along with a patient's disease activity. These things include any other illnesses the patient may have, the possible side effects of current or previous treatment, and the development of joint damage over time.</p>

Checklist 7. The use of social media and innovative tools

Combining different strategies for dissemination strengthens the effectiveness of your efforts.

However, information on which strategies are most successful is lacking. The following strategies can be used, depending on the available resources:

- Publications on paper
 - Journal publications.
 - Paper newsletters of patient organisations.
 - Books
 - Advertisements in magazines and newspapers
 - Advertisements on relevant products (e.g. milk cartons) or medication boxes

- Education
 - Interactive internet-based lectures
 - Developing a variety of learning tools like posters, summaries, hand-outs, pocket cards, slide sets etc for patients and professionals
 - Interactive group education materials

- Internet/ICT:
 - E-guidelines
 - Other ICT channels (eg, MSN Messenger, AOL Instant Messenger)
 - Use of virtual guides to direct people to the website (eg, in chat boxes)
 - Forums on the Internet
 - Automatic new information and resources for professionals and patients who have signed up for updates
 - Links on other websites
 - Publications on Facebook, LinkedIn etc
 - Publications on websites of patient organisations
 - E-mail
 - Banners on other websites
 - Online counselling of patient organisations
 - Advertising
 - Advertisements on websites visited by the target group

- Oral presentations and interviews:
 - At meetings
 - At conferences
 - On television and radio

- Other media:
 - DVDs
 - Making a video, for inspiration or for instruction.

- ☑ Network
 - Face-to-face contact
 - Word of mouth (e.g. by friends and family)

- ☑ Phone
 - Telephone calls
 - SMS
 - Whatsapp

- ☑ Persons
 - ‘Knowledge brokers’, people whose role it is purely to disseminate knowledge. They would need an understanding of both the research and the target audience
 - Ambassadors (prominent people)
 - Recruit national contact persons
 - Activation of a network of local key opinion leaders as messengers and educators
 - Recruitment of clinical champions/community champions.

- ☑ Flyers/leaflets/posters
 - Distribution of flyers at exhibitions and other public events
 - Distribution of flyers door-to-door
 - Posters
 - Personalised leaflets for patients

Appendices

Glossary

Forward-backward translation - Translation of the lay version into European languages requires a process of back and forward translation. This means that the lay version is first translated into the target language. Then the translated version is again translated into English. The second English version is then compared with the first version. The differences need to be discussed (see checklist 5).

Cognitive Debriefing Interview – Cognitive debriefing is a form of pilot testing to find out whether (the intention of) a recommendation is understandable, acceptable and relevant to patients. Cognitive debriefing is done by asking a small number of respondents to read the lay version aloud and say whatever they think or feel. This can be recorded and analysed at a later stage.

Delphi-process – The Delphi-process is a method to reach consensus through a structured consultation of different people. It is important to include people with different perspectives, such as patients, rheumatologists and nurses. This method is particularly useful where there is little or no published information on the subject. Unlike other methods, the Delphi-process does not need participants to physically meet together. Besides, there is no limit on how many people can be involved. Since the process is anonymous, it avoids ‘power struggles’. People can change their minds without losing face. The process also enables a combination of many opinions into a group response. Another benefit is that it can be completed in a short period of time.

EULAR – The European League Against Rheumatism (EULAR) is the organisation which represents the patient, health professional and scientific societies of rheumatology of all the European nations. EULAR tries to stimulate, and support the research, prevention, treatment, and rehabilitation of rheumatic diseases. EULAR is a truly multi-European organisation fostering a multitude of activities in areas of research, patient care, and education. To manage its goals effectively, EULAR has set up committees and managerial bodies. The General Assembly is the highest authority of EULAR. It is composed of the members of the Executive Committee and delegates of the regular member organisations and corporate members. The General Assembly meets once a year on the occasion of the Annual European Congress of Rheumatology.

G-I-N is a global network that supports evidence-based health care and improved health outcomes by reducing inappropriate variation throughout the world. Its mission is to lead, strengthen and support collaboration and work within the guideline development, adaptation and implementation community.

OPEN ACCESS – Open access means that scientific articles are freely available through the internet. It stands for unrestricted online access to peer-reviewed academic articles as opposed to articles for which a fee is required to access or download.

SOP – EULAR develops Standardised Operating Procedures (SOPs). These help to evaluate, disseminate and implement recommendations. Their objective is to maintain a high level of intrinsic quality and comparability of EULAR studies. To achieve this, the definition and publication of these standardised procedures might be a good starting point. These SOPs are not mandatory in themselves but can be used flexibly. Obviously these SOPs should not be a barrier to acceptance of a project if not all points are satisfied but might be important to consider before starting a project.

TASK FORCE – A Task Force is a temporary group of people (experts) formed to carry out a specific project that often requires a multidisciplinary approach. In EULAR, Task Forces comprise representatives from the scientific societies, health professionals and patients.

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