

eular

CHARTER FOR WORK

CAMPAIGNING SUPPORT PACK

Charter for Work for people
with rheumatic diseases

LET'S
WORK
TOGETHER



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Top Tip!

Each page has top tips to help you make the most of this guide.

Top Tip!

You can use the processes described in this pack to help you develop other campaigns in the future.

Introduction

This support pack has been prepared to help you, the EULAR national organisations of PARE, make the best use of the EULAR Charter for Work as a campaigning tool in your countries.

The pack is based on the workshop held at the Alliance Against Arthritis (AAA) event in March 2009, with additional information and template materials.

The information in this pack is designed to be very flexible, so you can adapt it to suit the size, capacity, capabilities and budgets of your national organisation.

Even if you don't have the capacity, time or budget to launch the Charter for Work, there are many ways you can use it to support other campaigns / areas of your work.

For example, if you are campaigning around access issues you could include the clause in the Charter that relates to access to work / education to support your campaign and highlight this issue.

Alternatively, if you are campaigning for early diagnosis and early, aggressive treatment, you could use the Charter to highlight the importance of keeping people in work as another angle when engaging with physicians and policy makers.

You can use the worksheets and templates provided in this pack to help you plan and implement your campaign.

Top Tip!

Adapt this pack to suit the size, capacity, capabilities and budgets of your organisation.

Top Tip!

Use the worksheets and templates to help you plan and implement your campaign.

GUIDELINES 1

DEVELOPING A STRATEGY FOR A NATIONAL CAMPAIGN

1. THE ENVIRONMENT

Before you start, you need to understand the current situation in your country in terms of:

- Relevant laws and regulations
- Relevant campaigns and projects run by government bodies, other organisations etc.
- Employment trends, especially in light of the current economic downturn
- Any work-related matters affecting people with chronic conditions / disabilities

Most of this information can be found by conducting 'desk top' research, using a search engine like Google, or through library research.

You can also run a survey to find out the work experiences of your members or people with rheumatic diseases in the broader population.

There are a number of ways you can run a survey dependent on how much time and budget you have. If you are going to use the results of your survey to create news hooks for the media, you will need to have at least 100 people completing the survey, otherwise the statistics will not be considered sufficiently significant to be representative.

Some ways you could run a survey:

- A 'straw poll' survey
- A newsletter survey
- A social networking survey
- An omnibus survey
- An online survey

See Worksheet 1 to help you map the current environment and for explanations of each type of survey

Top Tip!

Find out what is in place or will soon be in place, what is being said in the media and what facts and figures are available.

Top Tip!

Surveys can be used to support your call to action and help influence policy makers

Survey results can help you campaign

Surveys can provide you with statistics to support your campaign. These statistics can be used to:

- **Create news hooks** – the announcement of survey results on World Arthritis Day gives you the opportunity to reach out to the media. Journalists are likely to be interested in news about rheumatic diseases around this date
- **Support your call to action** – gives rationale for what you would like to achieve through your campaign
- **Appeal to policy makers** – many policy decisions are influenced by statistics. ‘Calls to action’ supported by a significant number of responses are likely to resonate with your national policy makers

Top Tip!

Pick a battle you can win and make sure your objectives are SMART!

2. WHAT DO YOU WANT TO CHANGE / IMPROVE?

The key to a successful campaign is to identify and prioritise the key issues or challenges for people with rheumatic diseases in your country. There are bound to be many, but you need to list and prioritise them. Consider carefully:

- What is the most important issue or challenge?
- What is the situation now?
- What could be done to help fix the problem / improve the situation?

When you are prioritising, you need to be realistic and to pick a ‘battle’ you can win! Writing down the objectives for your campaign can help guide your thinking. Your objectives should be SMART:

Specific – *What do you want to achieve?*

Measurable – *How will you evaluate success?*

Achievable – *Is this something your organisation can undertake and achieve?*

Realistic – *Is this going to be realistic for your organisation in terms of resources?*

Timely – *Will your organisation be able to achieve your goals within a timeframe?*

See Worksheet 2 to help you work out what you want to change or improve

Top Tip!

If you are aiming your activity at a certain group of people, such as physicians or employers, involve them in the planning process.

3. WHO DO YOU NEED TO TARGET?

When considering who you need to communicate with, ask yourself the following questions:

- Who do you need to:
 - work with? Who can support your campaign?
 - inform? Who needs to know what you are doing?
 - influence? Change the way they think, feel or behave?
- What do you want each of these target audiences to think / say / do?
- Which target audience/s is / are the most important to my campaign?

Your **target audience/s** will be the people you need to communicate with to influence and persuade.

See the example in Worksheet 3 and then think about how the questions apply to your campaign

4. STAKEHOLDER MAPPING

Stakeholders are the wider audiences who influence and inform your target audience/s. You need to consider these and decide which, if any, you need to engage with. When identifying stakeholders consider not only those that will be supportive, but also those who might be negative, challenging or obstructive.

If you identify a stakeholder you are not familiar with, but you would like to engage with, it is advisable to find out a bit about them before you approach them. For example:

- Who do they influence?
- How much influence do they exert? Do they have a high profile? What is their reputation?
- What are their key activities?
- What other organisations are they linked with?
- Who are the key / appropriate contacts?

It may be worth approaching stakeholders that might be negative, challenging or obstructive to see if you can find out what their problem is and if you can do anything to address or neutralise it.

Top Tip!

*Consider the difference between what your target audience **CURRENTLY** thinks or does, with what you **WANT** them to think or do.*

Top Tip!

Consider stakeholders that may be negative, challenging or obstructive, as well as those that will be supportive.



If a topic is controversial, the media may approach both sides to develop their 'story'. Even if the other side won't change their perspective, at least you can say that you tried approaching them and that your door is always open...

See Worksheet 4 to help you identify and evaluate your potential stakeholders

5. ENGAGING WITH STAKEHOLDERS

You can communicate with your target audience / stakeholders DIRECTLY by writing to them or meeting them for example; or INDIRECTLY via the media, or both, etc.

For **direct communications**, consider how your target audience likes to be approached. For **indirect communications**, consider where your target audience get their information. When developing your communications, think how you will make your messages stand out.

See Worksheet 5 to help to you work out the best methods for engaging your stakeholders

6. KEY MESSAGE DEVELOPMENT

Key messages should be clear, simple and concise and use language appropriate to your target audience. To be effective, there should be no more than three key messages per audience. Key messages need repeating to ensure they are heard, understood and retained.

When developing key messages consider:

- Who are you targeting?
- What is important to them?
- What do you want them to think / feel / say / do differently?
- What will resonate with them? What will they respond to?

See Worksheet 6 to help you decide your key messages.

Top Tip!

Use the Charter for Work to engage stakeholders and start a dialogue with them.

Top Tip!

Key messages should be clear, simple and concise. They should also be repeated so they are heard, understood and retained.

7. LAUNCHING THE CHARTER

You may not have the resources to hold a launch event for the Charter for Work, but there are a number of ways you can use the Charter to support other campaigns you may be running, such as an access to buildings or transport campaign, or an access to treatment campaign that you could link to work / education.

First, you will need to translate the Charter for Work. Then you can consider:

- Who you might ask to endorse / sign the Charter in your country
- Whether a significant signing might provide a photo-opportunity for the media
- How you could use the Charter to help you enter into dialogue with stakeholders
- If there might be an opportunity to launch the Charter at an existing event

See Worksheets 7 and 8 for an example checklist and to help you plan and prepare your event

Top Tip!

The Charter for Work could be launched at an event, or you could use it to support a campaign you are already running.

GUIDELINES 2

USING THE CHARTER FOR WORK AS A LOBBYING TOOL

Lobbying campaigns

The Charter for Work for People with Rheumatic Diseases calls for:

- Greater **public** awareness and understanding of rheumatic diseases, acknowledgement of the contribution people with rheumatic diseases can make to the work force and the need to increase opportunities and choices at work for people with rheumatic diseases
- **Employers** to create an inclusive and flexible workplace where people with rheumatic diseases do not feel discriminated against
- Support from **healthcare providers** to help people with rheumatic diseases work, if they choose
- **Policy makers** to legislate for access to work by enforcing legislation requiring employers and planners to create an accessible environment and providing incentives to support and encourage the employment of people with rheumatic diseases

This section deals specifically with lobbying policy makers. As all countries' political systems will vary, this section provides some general guidelines and template materials you might adapt to use in a national lobbying campaign.

For the purpose of this guide the terms Policy Makers and Members of Parliament (MPs) cover:

- Government Ministers and high level officials working in their departments
- Elected representatives of Parliaments / Assemblies
- Opposition party elected members

Top Tip!

The Charter for Work provides a tool for approaching policy makers on issues around work and rheumatic diseases.

Top Tip!

Adapt the ideas and template materials in this guide to meet your needs and your country's political system.



1. THE ENVIRONMENT

Lobbying can be done at different levels:

These are generic examples, as countries will vary in the way they are structured:

Nationally: National Government departments covering health, employment and social security

Regionally: Regional governing bodies / assemblies that may be wholly or totally devolved, so they can make decisions within their region

Locally: Local MPs can be approached and asked to intervene directly on behalf of their constituents

The following questions might be helpful in identifying at what level you might want to engage in your country:

- Which level Government departments are responsible for rheumatic diseases / work?
- Do they or another department decide policy and fund policy?
- Do they implement and regulate policy relating to rheumatic diseases / work?
- Who sets healthcare / work related agendas and prioritises them?
- Which elected body debates, scrutinises and votes on Government policies relating to rheumatic diseases and work?
- What other initiatives exist that you could work with or link into?

2. SELECTING YOUR CAMPAIGN

As an organisation representing people with rheumatic diseases in your country, you will need to decide what is / are the key issue/s that policy makers can change.

You will need to set out your case clearly from the information you have gathered from your research; for example, it helps if you have data to support your case such as:

- The number of people with rheumatic diseases in your country and, if possible, the number of these that are of working age / currently unemployed etc.

Top Tip!

Be aware of legislation which already exists and legislation being planned.

Top Tip!

Make sure your call to action/s addresses an issue/s that policy makers can change.



You need to be aware of what legislation exists and how it is being implemented, such as:

- Any gaps in legislation, or legislation that is not being enforced
- Specific work / employment related problems faced by people with rheumatic diseases that could be addressed by a change in policy / law
- Any case studies / examples of people with rheumatic diseases that illustrate your point

The gap between your current situation and the desired situation gives you your 'call to action/s'.

From this and your research you will be able to:

- Develop a clear call to action – what do you want the policy maker / MP to do / say on your behalf?
- Decide how you will go about your lobbying campaign / get others involved

Everyone can become involved in campaigning for measures that will help people with rheumatic diseases have the possibility to work, if this is their choice.

Before you make an approach ensure you are clear what your key messages are:

- Make sure everyone representing you is aware of your key messages, so that you are all saying / asking for the same thing
- If you think there may be any difficult questions, think of these in advance and prepare agreed answers (a Q&A). Make sure everyone representing you has a copy of your Q&A document and sticks to your agreed answers – if in doubt about an answer it is better to say you don't know but will find out. Ensure you, or the appropriate person addresses the question as soon as possible

See Worksheets 2 and 6 to help you select your campaign

3. IDENTIFYING POLICY MAKERS / MPs WHO MIGHT BE INTERESTED IN SUPPORTING YOUR CAMPAIGN

Target:

- Government Ministries who cover Work / Pensions / Social Security / Health
- Opposition party spokespeople on Work / Pensions / Social Security / Health
- Senior non-Governmental elected representatives

Top Tip!

Be clear about what you want policy makers to do or say.

Keep to your key messages.

Top Tip!

Create a list or database of target policy makers/MPs as the basis for lobbying activities.



- Members of Work / Health related elected cross-party / assembly groups or societies
- Elected representatives who have asked questions on rheumatic diseases / chronic diseases / disabilities / work and disabilities / occupational health

Use the relevant Government / Assembly / party websites to identify policy makers / MPs who fit your criteria

- Create a list or database of target policy makers/MPs as the basis for lobbying activities

See Worksheet 4 to help you identify who might support your campaign

4. APPROACHING POLICY MAKERS / MPs

There are several ways policy makers / MPs might be approached:

- Your organisation can approach policy makers / MPs on behalf of your members
- Your organisation might co-ordinate and mobilise your members / other people with rheumatic diseases to lobby policy makers / MPs
- Your organisation might look at partnering / forming an alliance with other patient groups representing people with chronic diseases who share similar work-related problems
- Individuals with rheumatic diseases may want to support your campaign or have personal work-related issues they would like to address with their local policy maker / MP or council member

You could also use the Charter for Work for people with rheumatic diseases in your approach to:

- Gather signatures supporting the rights of people with rheumatic diseases to work
- Act as a focus when lobbying policy makers / MPs about a work related issue – this will be reinforced once you have collected signatures / support from other stakeholders
- Support a petition / ‘call to action’

The types of activities MPs / elected members can do to help you include:

- Asking questions in the Parliament / Assembly
- Writing to the appropriate Minister
- Arranging a meeting with the appropriate Minister
- Organising a debate in the Parliament / elected Assembly

See Worksheets 5 and 8 to help you decide and plan your approach

Top Tip!

Co-ordinate and mobilise your members or other partner groups to lobby for, and with you.

Top Tip!

Gathering signatures demonstrates the strength of support for your campaign.



Below are some approaches you, your members / people with rheumatic diseases could use with policy makers / MPs in your country.

WRITING A LETTER

- Always be polite – aim to persuade rather than to be confrontational
- Be clear WHY you are writing (state the problem you want addressed)
- Keep your letter short, but provide enough information for the reader to understand the situation
- Be factual – make sure the points you raise are correct and reasonable
- Explain the situation / any personal experience of the issue
- Clearly state:
 - what you would like to change / happen
 - what you would like the policy maker / MP to do / say
 - any specific deadlines / when you would like this to happen
 - if you would like to set up a meeting to discuss this further
- Request a response
- Keep a copy of all correspondence

Writing a letter from one individual might get a response, but if a policy maker/MP receives letters from ten or more people on the same subject, this will really make them take notice

See template letter in Appendix 2

HOLDING A MEETING WITH POLICY MAKERS / MPs

- Meeting with policy makers / MPs will be arranged through their offices, personal assistants (PAs) / diary secretaries
- Building a good relationship with the PA / secretary (gatekeeper) will help you access the policy maker / MP
- Familiarise yourself with the policy maker / MP's background
- Prepare and take a briefing document covering relevant facts and figures (with references) and the main discussion points you will raise in the meeting to leave with the policy maker / MP
- Be prepared to answer questions
- Most meetings will take place in the elected assembly buildings when Parliament / the Assembly is in session, or in the constituency or hometown of the policy maker / MP, so be prepared to travel

Top Tip!

Policy makers will start to take notice when they receive campaign letters from ten or more people – use the template letter and start writing now

Top Tip!

Prepare a briefing document to give to policy makers and MPs you meet with. It should cover your main discussion points and relevant facts and figures



HOLDING A MEETING WITH POLICY MAKERS / MPs (cont)

- It is always best to take one other campaigner with you when you have a meeting with a policy maker / MP
- It can be useful to provide information on your campaign in advance of your meeting, including the personal details of those attending for security reasons
- At the end of the meeting summarise what has been said and agreed – who will do what and by when
- Ensure someone is taking notes during telephone calls and meetings
- Even if someone else is taking notes, take your own notes to compare
- Notes from a call or a meeting should be shared as soon as possible afterwards to give participants a chance to add to, amend and/or agree the 'official' notes
- If agreed beforehand, the outcomes of meetings with policy makers / MPs / other stakeholders can become the focus of ongoing activity
- Keep policy makers / MPs informed and monitor the progress of any actions requested / promised

Top Tip!

Contact other stakeholders or organisations who may share your concerns and see if they will support your campaign. The more voices, the stronger the message.

INVOLVING OTHER STAKEHOLDERS

- The more people who lobby about a topic, the more powerful this will be
- Identify other stakeholders / organisations you think may have similar concerns and/or could support you, and approach them to ascertain their interest
- Decide how you would like to work together, who you will approach and how you will approach them
- Ask key stakeholders / stakeholder organisations to sign the Charter for Work

Top Tip!

The media can greatly extend the reach of your campaign. Make sure you approach the right media to reach your audience and adapt your messages for them.

INVOLVING THE MEDIA

- Involving the media can greatly extend the reach of your campaign. If you are going for mass coverage, aim for popular consumer newspapers, radio programmes or television channels
- If you are looking to target a certain group of people, find out the type of media they are most likely to read, listen to, watch or access online



INVOLVING THE MEDIA (cont)

- Adapt your key messages to each audience you are targeting; appeal to what's important to them and use appropriate language and terminology
- Policy makers / MPs will be particularly interested in coverage in their constituency's local media
- Policy makers / MPs also like being involved in photo-opportunities with the media, so knowing that the media will be at a certain event might encourage them to attend
- If there is an interesting photo-opportunity, remember to contact the picture editor on newspapers, as well as the news or features editors
- It is important that you have an interesting story to tell or 'news hook' to spark the media's interest. This could be an event that you plan such as a local launch of the charter, an interesting case study (for example a story of a person with rheumatic disease who has been unable to work because of a law that you want to change) or a surprising statistic that you've uncovered, for example from a survey that you have conducted

Letters to the Editor / publication

- Responding to a relevant news story or article provides a good opportunity to put your point across
- Keep letters short, to the point and polite
- If possible use a real example to illustrate your point/s
- If available, provide a link to where further information can be found
- Try to send the letter from a senior person in your organisation as this will add credibility to your letter and make it more appealing for the publication to include

BECOMING AN EXPERT SPOKESPERSON ON BEHALF OF PEOPLE WITH RHEUMATIC DISEASES

- There may be an opportunity for a 'patient representative' to sit on a national / regional / local Government, health service, or policy 'think tank', committee or forum
- Try and select an individual with the relevant experience to act as a patient representative on a committee or forum
- Use this opportunity to provide the perspective of people with rheumatic diseases, but try not to personalise everything to your own situation, where this is not relevant or representative to the issue/s under discussion

Top Tip!

Policy makers / MPs like being involved in photo-opportunities with the media. Knowing that the media will be at your event may encourage them to attend.

Top Tip!

A patient representative who can speak on behalf of people with rheumatic diseases can help bring issues to life and make an impact.

