



SMALL THINGS MATTER

My Health Passport

Introduction and background

One of the key sessions at the Arthritis People On the Move (APOM) conference in November 2006, was a presentation and workshops on communication between doctors and patients and how this dialogue could be enhanced. One of the ideas that came out of the workshops was to develop a personalised tool – **'My Health Passport'** to help people with arthritis prepare for consultations with their doctor or other health providers. My Health Passport project is a part of World Arthritis Day (WAD) 2007/08, which this year has a theme of *"Small things matter"*.

My Health Passport provides an innovative way of improving the quality of consultation time and doctor/patient satisfaction by capturing information that is important to both patients and the doctors. For many patients it can be the small things that matter, but patients may not feel comfortable raising them, or they can be overlooked or forgotten at the time of the consultation.

The Passport empowers patients to take a more active and meaningful role in the ongoing management of their health, whilst providing doctors with a focused summary of information on which to base their medical assessments and treatment options. For people with a chronic condition like arthritis/rheumatism the consultation process is continuous and the passport helps to record and map any ongoing changes

Belgium was the first country to test the passport in both the Dutch and French speaking sectors, led by ReumaNet and CLAIR respectively. The results from pilot project in Belgium were featured at the European Leagues Against Rheumatism (EULAR) congress in Barcelona (13th -16th June 2007).

My Health Passport TEMPLATE and support materials

This guidance comes as a part of a package of **support materials** together with the **TEMPLATE of My Health Passport** developed by PARE Manifesto and supported by an educational grant from Wyeth Europa. This pack of information provides you with everything you will need to set up and run this project in your country.

Included with this package you will find the following materials:

- **My Health Passport** design template to be translated and adapted
- An introduction and instructions for people with arthritis/rheumatism to use the passport **(1)**
- A letter of introduction to the doctors of people who will be using the passport **(2)**
- This document which provides guidelines for the Social Leagues running the project

Important!!

Please ensure that these materials comply with your national regulations and codes of practice.

Please note all of these documents are generic for you to **adapt** and **translate**. You will find some places where instructions are bracketed and written in green capital letters, e.g. [NAME OF SOCIAL LEAGUE] or [NAME OF CONTACT]. This indicates where you need to fill in the appropriate information at this point and then delete the green writing.

Setting up and running the Health Passport project in your country

Listed here is a summary of the steps you will need to consider when setting up and running this project. To help you identify what is involved we have used simple symbols (*see below*).

Following this summary you will find a more detailed description of some of the activities.

Symbols code

 = **your time**

This symbol denotes actions your Social League will need to take.

 = **costs**







This symbol denotes costs, for example the cost of translating materials, photocopying and distributing materials etc.

 = **employing an agency or freelance person to help you**

Some of the activities can be time consuming and you may not have the capacity within your organisation to manage everything yourselves. In this case you may need to have outside support for some of the activities. Your sponsor may offer you support from their PR agency or a freelancer.

Involving your board / other members of your group / securing further support for the project

You may want to consider which other members of your group you will need to / want to involve in this project. If you think you would like to run this project in your country you will need to:

- Put the project to your board and secure their buy in
- Once agreed with your board, let PARE Manifesto Secretariat know you are interested in setting up the project by filling in the attached **application form**
- Decide how many copies of the passports you would like / will be able to produce and distribute. This will depend mainly of the funding and support available (*please see section below: distributing passports and support materials*)  / 
- **Secure funding** for the project and ascertain the level of support you will need (*see funding below*)  / 
- Allow time for meetings with your sponsor and their agency (*if applicable*)
- Consider which other members of your Social League you will need to / want to involve in this project
- Decide / confirm who will be the main point of contact for your Social League
- Identify a company to provide the translations and design  / 

- Decide who will need to review the translated materials
- Inform / brief those you want to involve about project 🕒
- Decide on deadlines. You may want to launch My Health Passport on a specific date (WAD, annual meeting of your organisation etc.)

Check	Action	Deadline
	▪ Discuss and agree the project and its scale with your board	
	▪ Decide who will be the main contact within your Social League	
	▪ Set up support / funding meetings	
	▪ Meet and brief agency (<i>if applicable</i>)	
	▪ Brief other members of your Social League	
	▪ Set deadlines and develop a time plan	

Steps to be taken / considerations

- You are provided with the Template of My Health Passport as well as templates for all the **support materials** you will need. These can be downloaded from the WAD website (www.worldarthritisdaily.org). The template of the passport and support materials come in English, so you will need to have them translated into your language 🕒/€/😊
- **Please note that the templates provided are generic and can be adapted by you as required. For example, when translating the materials the number of pages may be reduced / increased as necessary.**
- You need to decide about the period of time to be covered by diary pages in the Health Passport. As the passport will be filled in on a monthly basis you may decide to go for six month or 12 month periods depending on your capacity (more pages will increase production costs, you will also need to consider that removable part of the passport will need to be replaced) €
- You will need to check the **translations** and make any final amendments 🕒
- Decide how many people with arthritis/rheumatism you want to invite to the project and how you're going to approach them 🕒

Check	Action	Deadline
	▪ Translate the template and allow time for revising the translations	
	▪ Brief the designer on the Passport layout	
	▪ Arrange printing	

Recruiting people with arthritis/rheumatism to use the Health Passport

- Depending on the number of copies of My Health Passport that you produce (given the funding and support in place) consider the following ways of recruiting people for this project:
 - Through members of your organisation (during meetings) and through regional branches 🕒
 - Using existing relationships your organisation has with physicians/rheumatologists who could introduce the idea of the Health Passport to their patients 🕒
 - Through posting information about the project on your website
 - By reaching people with arthritis and encouraging them to use the Health Passport through information in the media (this will include preparing press release and selling it in to target media outlets) 😊 / 🕒

Check	Action	Deadline
	▪ Develop plan and timeline for recruiting people to the project	
	▪ Prepare necessary materials (copy for the website, press release, leaflets etc.)	

Distributing the passport

- Depending on the number of copies of My Health Passport that you decide to produce/capacity of your organisation in terms of resources and storage place consider different ways of storing and distributing packages and passports:
 - You will have to set up special email address for people to apply for My Health Passport / new removable part of the passport once the previous one has been filled up. You will also need to assign a special contact person to gather their details and coordinate distribution of packages containing My Health Passport and support materials 😊 / 🕒 / € **Please note that this will involve a considerable amount of time and resources!**
 - You, or the agency 😊 / 🕒 will need to photocopy all materials (€) and provide stamped addressed envelopes (€) to send materials and Passports out. For data protection you will need to personalise the letter, address the envelopes and send materials out from your organisation 🕒, but the materials can all be prepared for you by an agency or freelancer 😊 / 🕒 / € **Please make sure this procedure is in line with your national regulations regarding data protection!**
 - If the number of copies will be large you may want to hire special mail order handling house 😊 / € which will receive the requests from people interested in taking part in the project and distribute the passports together with support materials. They

can keep a record of the number of copies distributed/number of replaced removable parts of the Health Passport.

Check	Action	Deadline
	<ul style="list-style-type: none">▪ Develop plan/timeline for distributing packages with My Health Passport and support materials	
	<ul style="list-style-type: none">▪ Liaise with the agency/mail order handling house as appropriate	

Funding

Please let the PARE Secretariat know if you are interested in setting up this project. The PARE Secretariat will pass your interest on to Wyeth Europa who will inform their local affiliate and arrange a meeting with you.

If there is no Wyeth affiliate in your country, please still make your application to the PARE Secretariat before seeking funding from another sponsor.

My Health Passport is a World Arthritis Day project supported by an educational grant from [WYETH / COUNTRY] as part of their Touchpoints programme

Wyeth



APPLICATION FORM

Please complete this form if your association or Social League would be interested in taking part in the World Arthritis Day My Health Passport project in your country.

Please type or print your details

Name:

Association or Social League:

Country:

Contact details:

Email:

Telephone:

Please tick the applicable box:

- We would be interested in setting up the My Health Passport project in our country
- We would like to have the contact name and details for our local Wyeth company with a view to discussing support for this project
- We would also be interested in learning more about setting up the Video Diaries project in our country

Please return this form to:

Birte Glüsing, PARE Manifesto Secretariat.

Email: secretariat@paremanifesto.org

Fax: +49 228 962 1284

We look forward to hearing from you soon!