

More participation, for a better health

ELSA MATEUS



SIP
Societal Impact of Pain







Liga Portuguesa
Contra as Doenças Reumáticas

1. Evidence on the impact of pain



RMDs in Portugal

			
64.1%	47.1%	Low back pain* is the most common RMD in the female population (26.4% of women)	<p>56%</p> <p>5,6 million</p> <p>[107 rheumatologists at National Health System, in 2015]</p>
6 out of 10 Portuguese	4 out of 10 Portuguese	Low back pain* is the most common RMD in the male population (22.8% of men)	

**Followed by periarticular pathology (15,8%), knee osteoarthritis (12,4%) and osteoporosis (10,2%).
EpiReumaPt data – 2014.*

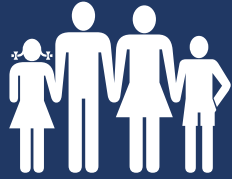
RMDs in Portugal

			
45,1 %	Portuguese population with ages between 50 and 64 years old were not employed (2005-2006). *	3 million	€ 910 million 0,5% national GDP
43,4 %	RMD were more prevalent among those out of work (vs. 32.1%; p<0.001).*		
29,9 %	Portuguese population with ages between 50 and 64 were retired (2011-2013). **		
3,9 %	Self-reporting retirement due to RMD.**		

* INS 2005-2006.

** EpiReumaPt data – 2014. Laires, P., abstract presented at the EULAR Annual Conference of PARE 2017.

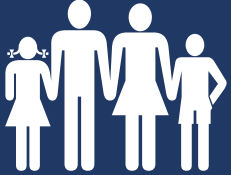



Chronic Pain in Portugal



13%	Patients with early retirement because of the pain
17%	Patients diagnosed with depression associated with chronic pain
35%	Dissatisfaction with the treatment of chronic pain
20%	Patients with chronic pain followed by a specialist

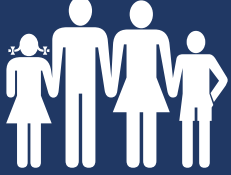


* FMUP 2007

Chronic Pain in Portugal

			
30%	Prevalence of Chronic Pain*	3 million	2,7% national GDP
16%	Pain Prevalence of chronic moderate to severe		
50%	Patients with moderate or severe impact of Chronic Pain in domestic or activities		
4%	Patients with job loss associated with chronic pain		

* *FMUP 2014*

Pain in Portugal

		
61%	People experience body pain at least once a week*	€ 381 million [last 12 months]
1,4	Working days loss due to body pain	
50%	Work regularly feeling pain, which directly impacts their productivity and performance	

* *Global Pain Index 2017*

2. Addressing the problem



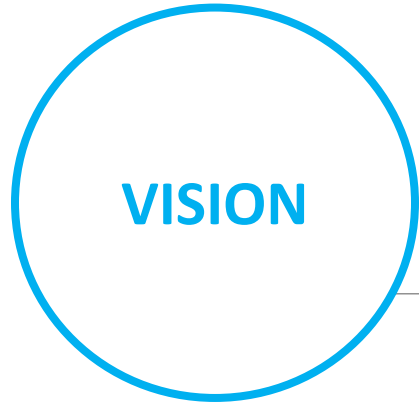


Share experiences and effective self-strategies

Learn to live with pain (functional capacity + emotional + behavioral skills)

Define priorities and reset beliefs, values, attitudes, behavior and skills

Disclose, inform, raise public awareness and call to action



**SOCIAL
RESPONSIBILITY
OF PATIENTS**

STEP IN

ADVOCATE

READJUST

REINVENT

TAKE PART

LEARN

COMPROMISE

INVOLVE

SHARE



**ACTION
PLAN
2014**



Photo Contest "Chronicles of Pain"

“Chronicles of Pain“

Exhibitions

National Association of Pharmacies

XVII Forum for Support to the Rheumatic Patient,
Lisbon, October 2014

FNAC – Alfragide Shopping Center

Lisbon, November 2014 - February 2015

Art & Pain Colloquium

Rectorate of the New University of Lisbon,
organized by the NOVA Medical School
and the Faculty of Social and Human Sciences,
26 e 27 November 2015.





3. More participation, for a better health





**MAIS
PARTICIPAÇÃO
melhor saúde**

**MORE PARTICIPATION, BETTER HEALTH –
PROMOTING PUBLIC INVOLVEMENT IN HEALTH**

Background: The Public Participation Gap



- National Health Plan – since 2004
 - Public participation is key to achieve better health outcomes
 - Participation at individual, institutional and political levels
- WHO (2010)
 - Involvement of health stakeholders is insufficient and selective
- International support and engagement for greater and meaningful public participation
 - EPF, IAPO, PARE, European Commission, EMA, NICE, FDA, European Pain Federation EFIC

The Goal



- To develop a Charter for Public Participation in Health that:
 - Is widely accepted and recognized by patient organisations and other health stakeholders (including decision-makers)
 - Can be used to promote public involvement in health decision-making
 - Is approved by the Portuguese Parliament

Working Team



MAIS PARTICIPAÇÃO
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Membro da Coligação Internacional Sida

Working Together



- Participatory action research methodology
- Whole-of-society-approach



Charter for Public Participation in Health



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**Carta para a Participação
Pública em Saúde**

Maio 2017
www.participacaosaude.com

- Signed by 82 CSOs and 30 individuals
 - Mostly patient organisations
 - Current and former MPs
 - Former MoHs
 - Health care professionals
 - University professors and researchers – both from the public participation and health fields)
- Constitutional and policy framework
- Best international practices
- Principles and objectives
- Priorities, practices and guidelines
- Communication tool

Forum MORE PARTICIPATION, better health



- Portuguese Parliament
- Activists, MPs, MoH representative, National health Plan Director, SS of Administrative Modernisation, health professionals, media, public



Petition for Public Participation in Health



4000 signatures => discussion in the Plenary session with all Members of the Parliament

The screenshot shows a web browser displaying the 'Petição Pública' website. The page title is 'Solicita que seja instituída a "Carta para a Participação Pública em Saúde"'. The petition is addressed to the President of the Portuguese Republic. It features the 'MAIS PARTICIPAÇÃO melhor saúde' logo and a green 'Assinar Petição' button. The number of signatures is 3.103. The page also includes social media sharing options and a list of related links.

Petição Pública Criar Petição Login ou Registrar

Pesquise Petições procurar

Apoie esta Petição. Assine e divulgue. O seu apoio é muito importante.

Solicita que seja instituída a "Carta para a Participação Pública em Saúde"

Para: Ex.mo Senhor Presidente da Assembleia da República,

Assinaram a petição
3.103 PESSOAS

Assinar Petição

O seu apoio é muito importante. Apoie esta causa. Assine a Petição.

Algunas razões para assinar:
O que dizem os outros signatários

Tem um blog ou site? Adicione este módulo. Participe na divulgação.

Links Relacionados:

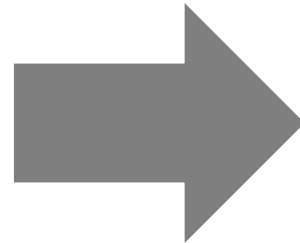
- Carta para a Participação Pública em Saúde
- Sobre o projeto MAIS PARTICIPAÇÃO, melhor saúde
- MAIS PARTICIPAÇÃO, melhor saúde

A aguardar por www.facebook.com... ganizações representativas permite ainda adequar os cuidados de saúde



**MAIS
PARTICIPAÇÃO**
melhor saúde

Charter
+
Forum
+
Petition



- Public discussion
- Political commitment
- New legislation (?)

By promoting public involvement in health, so that the patients' perspectives can be taken in account, we believe we can contribute to enhance the general quality of our healthcare system.





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