

## Thematic Network on the Societal Impact of Pain Framing Paper

Version 4 – 12 September 2018

### Preamble

This paper presents the common position of stakeholders from the health, social, and employment sectors in Europe on the issue of the status of pain in the European Union. It presents existing policies that are and can be relevant to pain and lays them out into four categories: **health indicators, research, employment, and education.**

Further, this paper highlights where there are gaps in relation to addressing pain and offers recommendations to action to policy makers and all other stakeholders to address these identified challenges. Our goal is to achieve improved care and pain management across the EU to reduce the societal impact of the disease, which touches upon all aspects of life.

This Framing Document and the associated Call to Action were developed by the Societal Impact of Pain (SIP)<sup>1</sup>, in partnership with stakeholders and members of the EU Health Policy Platform (a full list of contributing organisations is available at the end of the paper).

### 1. Burden of pain

In Europe<sup>2</sup>, there are approximately 740 million people<sup>3</sup>, most of whom experience an episode of severe pain at some point in their life. For approximately 20 percent, that pain is chronic – episodic, persistent, or variable. In other words, today there are 150 million people experiencing pain. That number is approximately equal to the populations of Germany and France combined.

#### *What is pain?*

Pain is an *“unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.”*<sup>4</sup>

Acute pain is pain of recent onset and limited duration due to injuries, illness, or as a result of surgical interventions, e.g. post-operative pain, acute headaches, strain trauma and burns, fractures, activated arthrosis, and dental pain<sup>5</sup>.

However, acute pain which persists for longer than three months, is generally classified as **chronic pain**<sup>6</sup>. The process of which is known as ‘*chronification*’. *“Biologic factors involved in this transition include central sensitization, neuroplastic changes, altered pain modulation, and changes to the “neuromatrix.” Chronic pain may involve irreversible pathophysiologic changes, so interrupting the cascade of events that allows acute pain to advance to chronic pain is of crucial importance.”*<sup>7</sup>

<sup>1</sup> The “**Societal Impact of Pain**” (SIP) is an international platform created as a joint initiative of the European Pain Federation EFIC and the pharmaceutical company Grünenthal GmbH. The scientific framework of the SIP platform is under the responsibility of the European Pain Federation EFIC®. Co-operation partners for SIP are Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support.

<sup>2</sup> Note: data taking from 37 countries, absent in Andorra, Armenia, Azerbaijan, Belarus, Georgia, Iceland, Liechtenstein, Luxemburg, Malta, Monaco, and the Vatican City.

<sup>3</sup> Eccleston, C., Wells, C., & Morlion, B. (2017). European Pain Management. Oxford, UK: Oxford University Press, ISBN: 9780198785750

<sup>4</sup> <http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698#Pain>

<sup>5</sup> [http://www.change-pain.com/grt-change-pain-portal/change\\_pain\\_home/acute\\_pain/pain\\_basics/definition\\_of\\_pain/pain\\_is.../en\\_EN/318500008.jsp](http://www.change-pain.com/grt-change-pain-portal/change_pain_home/acute_pain/pain_basics/definition_of_pain/pain_is.../en_EN/318500008.jsp)

<sup>6</sup> <https://medlineplus.gov/magazine/issues/spring11/articles/spring11pg5-6.html>

<sup>7</sup> <https://www.sciencedirect.com/science/article/pii/S1524904212000926>

Pain can also arise due to other illnesses (known as “co-morbidity”) and can result in palliative care. Further, pain is commonly connected with numerous chronic health conditions, such as cancer and musculoskeletal diseases (Roberto, et al., 2016) (Majithia, Loprinzi, & Smith, 2016) (IASP, 2009) (Mieritz, Forman, Mieritz, Hartvigsen, & Christensen, 2016). Indeed, chronic pain is one of the most common co-morbidities of other long-term illnesses (Barnett, et al., 2012).

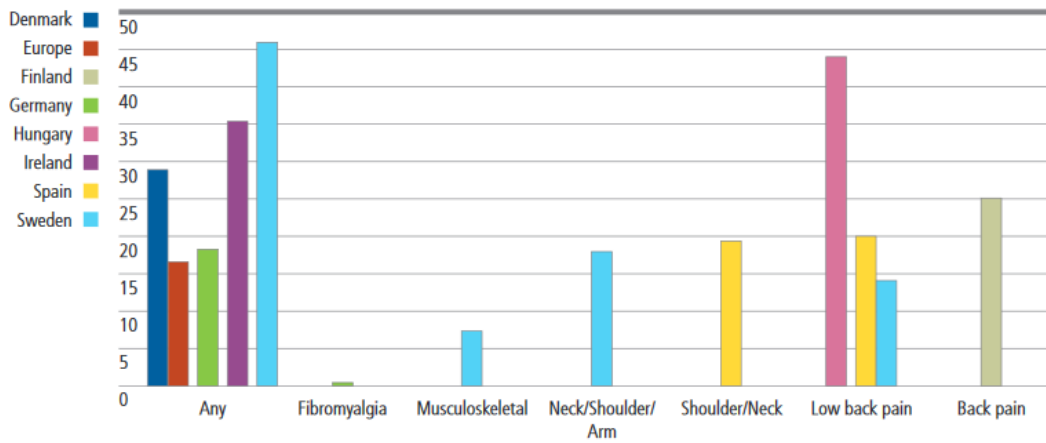


Figure 3 % prevalence of chronic pain in general adult population by type of pain

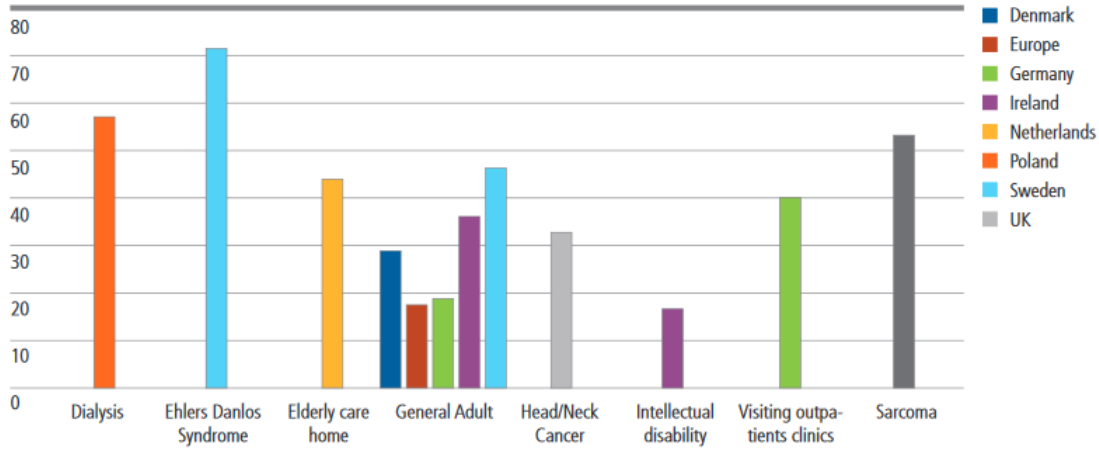


Figure 1 Percentage of chronic pain within some other chronic diseases and certain settings

Source: Road Map for Action 2014 Road Map Monitor<sup>8</sup>

### The impact of pain on the individual and society

Pain can interfere with a person's quality of life and general functioning. People in pain can experience impairments in attention, control, working memory, mental flexibility, problem solving and information processing speed (Hart, Wade, & Martelli, 2003). In the presence of chronic pain,

<sup>8</sup> [https://www.sip-platform.eu/files/structure\\_until\\_2016/Home/ReflectionProcess\\_screen.pdf](https://www.sip-platform.eu/files/structure_until_2016/Home/ReflectionProcess_screen.pdf)

other dimensions of health (physical, psychological, social) are severely reduced (Elliott, Smith, Penny, Chambers, & Smith, 1999) (Smith, et al., 2001). Additionally, pain is associated with increased depression, anxiety, fear, and anger (Bruehl, Burns, Chung, & Chont, 2009).

Pain complaints cause a large proportion of physician visits (Gureje, Simon, & Von Korff, 2001) (Mäntyselkä, et al., 2001) (Koleva, 2005), placing a large burden on clinics and healthcare professionals to treat the increase number of patients in an appropriate manner. As a result, pain places an enormous economic burden to healthcare systems (Eccleston, Wells, & Morlion, 2017).

Pain related conditions result in an increasing part of the workforce retiring too early. With more than 500 million sick days per year in Europe, musculoskeletal pain causes almost 50 percent of all absences from work lasting at least three days in the EU and 60 percent of permanent work incapacity (Bevan, Reducing Temporary Work Absence Through Early Intervention: The case of MSDs in the EU, 2013). Unsurprisingly chronic pain is one of the major reasons why people exit the labour market prematurely and it contributes significantly to disability retirement (Saastamoinen, et al., 2012).

## ADVOCACY MAP

### Societal Impact of Pain (SIP)<sup>9</sup>

- The "Societal Impact of Pain" (SIP) is an international platform created in 2009 and aims to raise awareness of the relevance of the impact that pain has on society, health, and economic systems; exchange information and sharing of best practice across EU Member States; and develop and foster European-wide policy strategies and activities for an improved pain care in Europe (Pain Policy).
- The platform provides opportunities for discussion for healthcare professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators, and budget holders.
- SIP seeks to: 1. Ensure access to adequate pain treatment for all citizens; and 2. Unite all organisations and societies advocating better pain care to jointly address, define and foster pain policies
- SIP supports national stakeholders in developing national platforms to advocate and raise awareness of the societal impact of pain, by providing trainings, advice, and exchange of best practice.
- National SIP Network platforms have already been established in Malta and in France. Other platforms currently in development are in Belgium, Portugal, Slovenia, and The Netherlands.

### French White Book on Pain

- In France, in October 2017, stakeholders representing national medical, academic, and patient organisations published an open letter<sup>10</sup> to the then President-elect, Emmanuel Macron, calling on his future government to urgently development concrete measures to address pain.
- The authors further developed a comprehensive document, known as the *White Book*<sup>11</sup>. The Book calls for the maintenance of existing specialised pain centres; the strengthening of HCP training in pain management; valuing the patient care pathway for chronic pain; improving pain management in emergency and outpatient settings; the development of pain prevention

<sup>9</sup> <https://www.sip-platform.eu/>

<sup>10</sup> [https://www.lemonde.fr/sciences/article/2016/10/31/il-faut-ecrire-un-nouveau-chapitre-de-la-lutte-contre-la-douleur\\_5023175\\_1650684.html](https://www.lemonde.fr/sciences/article/2016/10/31/il-faut-ecrire-un-nouveau-chapitre-de-la-lutte-contre-la-douleur_5023175_1650684.html)

<sup>11</sup> <https://www.amazon.fr/douleur-men-sors-Comprendre-agir/dp/2848354232>

campaigns in the workplace as well as in surgery settings or during care procedures; developing recognition and support for non-drug and complementary approaches to pain; and improve pain management for the most vulnerable populations.

- SIP France has used the momentum created by the discussions that have arisen as a result of the White Book to continue its work in France.

#### **Pain Alliance Europe (PAE) Survey on Chronic Pain 2017: Diagnosis, Treatment, and Impact of Pain<sup>12</sup>**

- An online survey that was performed in 17 countries, with 3,500 respondents.
- The survey found that 95 million people across Europe live with chronic pain.<sup>13</sup>
- As a result, *“the total cost of the consequences of chronic pain is estimated to be as high as €300 billion.”<sup>14,15</sup>*
- The findings show that there is a gap in treatment in many European countries, mainly due to a lack of early diagnosis and timely intervention, which is further worsened by inadequate treatment.
- The report recommends that the needs and treatment preferences of patients should be further investigated for better insights.

#### **European Federation of IASP Chapters (EFIC): Reflection process on chronic diseases - the role of chronic pain, May 2012<sup>16</sup>**

- Systematic literature review on the impact of chronic pain, developed in May 2012, for the consideration of the 2013 final report by the European Commission on the reflection process on chronic diseases<sup>17</sup>.
- Provides insights into the interrelation of chronic pain and chronic diseases, and the effect chronic pain has on healthcare and economic systems.
- Calls for chronic pain to be considered and integrated into the European Commission’s reflection process as **a chronic disease is its own right**.

#### *Key Findings:*

1. The overall impact of pain measured in terms of prevalence and cost is high.
2. Chronic pain is most prevalent in those patients with other chronic diseases.
3. Chronic pain can be considered as a very common and costly chronic disease in its own right.
4. There is a strong link between increasing age and prevalence of chronic pain.
5. Chronic pain is not adequately prioritised within policies and budgets

<sup>12</sup> <http://www.pae-eu.eu/wp-content/uploads/2017/12/PAE-Survey-on-Chronic-Pain-June-2017.pdf>

<sup>13</sup> <http://appsso.eurostat.ec.europa.eu/nui/show.do>

<sup>14</sup> [https://www.dgss.org/fileadmin/pdf/Pain\\_Proposal\\_European\\_Consensus\\_Report.pdf](https://www.dgss.org/fileadmin/pdf/Pain_Proposal_European_Consensus_Report.pdf)

<sup>15</sup> <http://www.pae-eu.eu/wp-content/uploads/2017/12/PAE-Survey-on-Chronic-Pain-June-2017.pdf>

<sup>16</sup> [https://www.sip-platform.eu/files/structure\\_until\\_2016/Home/ReflectionProcess\\_screen.pdf](https://www.sip-platform.eu/files/structure_until_2016/Home/ReflectionProcess_screen.pdf)

<sup>17</sup> [https://ec.europa.eu/health/sites/health/files/major\\_chronic\\_diseases/docs/reflection\\_process\\_cd\\_final\\_report\\_en.pdf](https://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/reflection_process_cd_final_report_en.pdf)

## 2. Existing policies relevant to pain

Multiple existing policies demonstrate that pain poses a serious societal problem in Europe.

The EU has included reference to pain in its position ahead of the **UN high-level meeting on the prevention and control of non-communicable diseases**, which was launched in 2011<sup>18</sup>, with a review in July 2014<sup>19</sup>, and another upcoming in late 2018<sup>20</sup>. The EU's position and commitment of the high-level meetings was made especially clear in a European Parliament Resolution ahead of the launch of the UN initiative, in September 2011<sup>21</sup>, when a reference on pain was made for the first time. Namely, *“the majority of NCDs have common symptoms, such as chronic pain and mental health problems, which directly affect sufferers and their quality of life and should be addressed by means of a common, horizontal approach, so that healthcare systems can tackle these diseases more cost-effectively.”*

Article 8(5) of the **EU Directive on the application of patients' rights in cross-border healthcare** (2011/24/EU)<sup>22</sup> foresees that an objective assessment of *‘the degree of the patient's pain’* must be used to assess the right to cross-border healthcare. Indicators are therefore needed in Member States to set criteria for granting access to cross-border healthcare and to compare the quality of healthcare services available to citizens, consumers, and patients. The implementation of the Directive is now under review by the European Commission, thus opening up the debate on the implementation of Article 8(5). Thus far, the transposition of the Article has not been discussed in the successive reports on the implementation of the Directive. This opens a window of opportunity to raise debate within the EU Institutions and expert organisations on the need to develop indicators for pain measurement as part of the implementation of the Directive.

The **informal Conclusions of the EU Health Ministers** meeting in 2014, under the auspices of the Italian Presidency, pledged to further promote the use of palliative care and pain therapy in the EU member states.<sup>23</sup> The seed for this initiative was the leadership of the Italian Government which already has specific legislation on pain – **Legge 38**<sup>24</sup> – aimed at establishing two integrated networks: palliative and pain medicine. It states that pain and palliative care are priority areas within national health plans. The law states that *“access to pain management is a fundamental human right.”*<sup>25</sup>

The **2017 Council Conclusions on ‘Encouraging Member States-driven Voluntary Cooperation between Health Systems’**<sup>26</sup> called to evaluate access to treatment for patients with chronic pain, while recognising the need to maintain the balance between innovation, availability, accessibility, and affordability.

### ADVOCACY MAP

#### SIP Road Map for Action and Implementation Monitor

- The Societal Impact of Pain – A Road Map For Action<sup>27</sup> was launched in 2011, with a survey conducted to monitor its implementation (known as the Road Map Monitor) in 2011 and 2014.

<sup>18</sup> [http://www.who.int/nmh/events/un\\_ncd\\_summit2011/en/](http://www.who.int/nmh/events/un_ncd_summit2011/en/)

<sup>19</sup> [http://www.un.org/en/ga/president/68/pdf/882014FINAL\\_Summary%20of%20the%20high-level%20meeting%20on%20NCDs.pdf](http://www.un.org/en/ga/president/68/pdf/882014FINAL_Summary%20of%20the%20high-level%20meeting%20on%20NCDs.pdf)

<sup>20</sup> <http://www.who.int/ncds/governance/third-un-meeting/en/>

<sup>21</sup> <http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7-TA-2011-0390&language=EN&ring=B7-2011-0489>

<sup>22</sup> <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32011L0024>

<sup>23</sup> [http://www.salute.gov.it/portale/news/p3\\_2\\_4\\_1\\_1\\_stampa.jsp?id=4355](http://www.salute.gov.it/portale/news/p3_2_4_1_1_stampa.jsp?id=4355)

<sup>24</sup> <http://www.parlamento.it/parlam/leggi/10038l.htm>

<sup>25</sup> <https://www.sip-platform.eu/pain-resources/initiatives/italy>

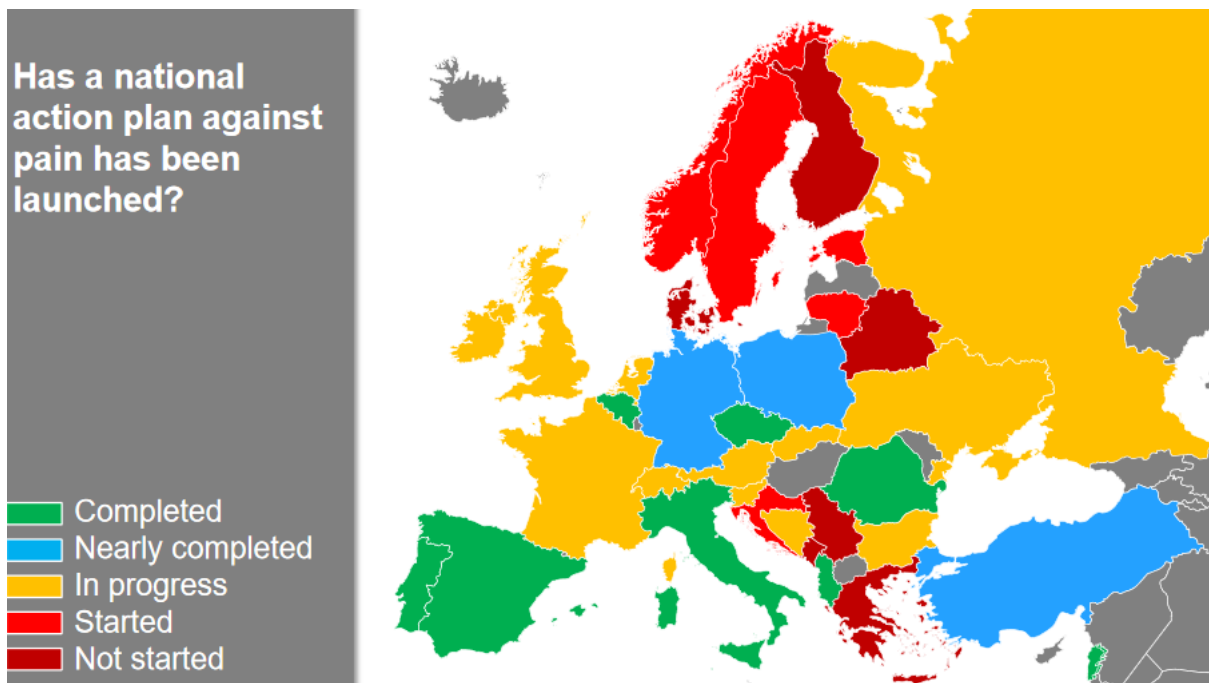
<sup>26</sup> <http://data.consilium.europa.eu/doc/document/ST-9978-2017-REV-1/en/pdf>

<sup>27</sup> [https://www.sip-platform.eu/files/structure\\_until\\_2016/Home/Final\\_SIP%20Road%20Map%20Monitor%20Booklet%202011\\_06.02.2012.pdf](https://www.sip-platform.eu/files/structure_until_2016/Home/Final_SIP%20Road%20Map%20Monitor%20Booklet%202011_06.02.2012.pdf)

➤ The Road Map called on EU Governments and Institutions to:

1. **Acknowledge** that pain is an important factor limiting the quality of life and should be a top priority of the national health care system;
2. **Activate** patients, their family, relatives, and care-givers through the availability of information and access to pain diagnosis and management;
3. **Raise awareness** of the medical, financial and social impact that pain and its management have on the patients, their family, care-givers, employers, and the healthcare system;
4. **Raise awareness** of the importance of prevention, diagnosis, and management of pain amongst all healthcare professionals, notably through further education;
5. **Strengthen pain research** (basic science, clinical, epidemiological) as a priority in EU framework programme and in equivalent research road maps at national and EU level, addressing the societal impact of pain and the burden of chronic pain on the health, social, and employment sectors;
6. **Establish an EU platform** for the exchange, comparison, and benchmarking of best practices between member states on pain management and its impact on society, and
7. **Use the EU platform** to monitor trends in pain management, services, and outcomes and provide guidelines to harmonize effective levels of pain management to improve the quality of life of European Citizens.

➤ As part of the Road Map Monitor, the status of the **implementation of national pain plans** are mapped. The 2014 findings were presented at the 2016 SIP Symposium:<sup>28</sup>



**Active Citizenship Network MEP Interest Group on Patients' Rights and Cross-border Healthcare<sup>29</sup>**

<sup>28</sup>[https://www.sip-platform.eu/files/structure\\_until\\_2016/Events/2016/Plenary%2024%20May/PDF/01.%20SIP%202016%20-%20Presentation%20Chris%20Wells.pdf](https://www.sip-platform.eu/files/structure_until_2016/Events/2016/Plenary%2024%20May/PDF/01.%20SIP%202016%20-%20Presentation%20Chris%20Wells.pdf)

<sup>29</sup> <http://www.interestgroup.activecitizenship.net/>

- The Active Citizenship Network (ACN) is a flexible network of over 80 civic societies and patient organisations from across Europe. It aims to encourage active participation of citizens in European-policy making<sup>30</sup>. It hosts the annual European Patients' Rights Day in the European Parliament as one of its many activities focused on civic, patient, and consumer rights.
- Launched in 2015, ACN also organises the MEP Interest Group on Patients' Rights and Cross-border Healthcare. The aims of the Group are to strengthen the protection of patients' rights in European legislation, promote initiatives to encourage and ensure the appropriate implementation of European legislation on patient safety (notably with the Cross-border healthcare Directive), to actively support European Patients' Rights Day and collaborate with the associations involved at national and European level, and seek to establish a European year of Patients' Rights.<sup>31</sup>

## 2.1. Health indicators

When considering the societal impact of pain, EU sources of information already exist.

The **BRIDGE-HEALTH project** has provided a **definition for the 37<sup>th</sup> indicator on 'General musculoskeletal pain'**, which falls under 'Diseases and Mental Health' in terms of policy areas and more specifically, into (Preventable) Burden of Disease (BoD) and health threats, communicable diseases.<sup>32</sup> However, this indicator is still under development and no data is available in international databases.<sup>33</sup> Therefore, further work has to be developed and the Joint Action on Health Information (InfAct), which had its kick-off meeting in March 2018<sup>34</sup>, is expected to tackle the issue, as it aims to provide *"sustainable solid infrastructure on EU Health Information to improve availability of comparable, robust and policy-relevant health status data and health system performance information."*<sup>35</sup>

**The preferred source of ECHI – identified by BRIDGE Health – is the European Health Interview Survey (EHIS).**<sup>36</sup> In the context of EHIS, *"all EU Member States are obliged to collect data on the health status, the provision of healthcare, health determinants, and socio-economic conditions of their populations."*<sup>37</sup> **As the frequency of data collection of EHIS is every 5 years, the next round is planned for 2019.** *"The second wave (EHIS wave 2 or EHIS round 2014) was conducted between 2013 and 2015 in all EU Member States, Iceland and Norway."*<sup>38</sup> This wave collects data on the 'Severity of bodily pain by sex, age, and educational attainment level'.<sup>39</sup> Although, this data does not fit directly for the 37<sup>th</sup> ECHI indicator on musculoskeletal pain but it can provide a trend on pain by socio-economic status which is very relevant for the societal impact of pain.

<sup>30</sup> <http://www.activecitizenship.net/about-us.html>

<sup>31</sup> <http://www.interestgroup.activecitizenship.net/106-launched-the-meps-interest-group-on-european-patients-rights-and-cross-border-healthcare.html>

<sup>32</sup> [https://ec.europa.eu/health/sites/health/files/indicators/docs/echi\\_shortlist\\_by\\_policy\\_area\\_en.pdf](https://ec.europa.eu/health/sites/health/files/indicators/docs/echi_shortlist_by_policy_area_en.pdf)

<sup>33</sup> <https://www.volksgezondheidenzorg.info/echi-indicators/self-assessed-health-status#node-general-musculoskeletal-pain>

<sup>34</sup> <http://ec.europa.eu/chafea/news/news577.html>

<sup>35</sup> [https://ec.europa.eu/health/sites/health/files/indicators/docs/ev\\_20171206\\_co01\\_en.pdf](https://ec.europa.eu/health/sites/health/files/indicators/docs/ev_20171206_co01_en.pdf)

<sup>36</sup> [http://ec.europa.eu/eurostat/statistics-explained/index.php?title=Glossary:European\\_health\\_interview\\_survey\\_\(EHIS\)](http://ec.europa.eu/eurostat/statistics-explained/index.php?title=Glossary:European_health_interview_survey_(EHIS))

<sup>37</sup> <https://edoc.rki.de/bitstream/handle/176904/2595/239ufPuDm2rO.pdf?sequence=1&isAllowed=y>

<sup>38</sup> [http://ec.europa.eu/eurostat/cache/metadata/en/hlth\\_det\\_esms.htm](http://ec.europa.eu/eurostat/cache/metadata/en/hlth_det_esms.htm)

<sup>39</sup> Distribution of the population according to the severity of bodily pain using modalities 'None, Very mild, Mild, Moderate, Severe or Very severe'.

**The State of Health in the EU**, a separate, two-year initiative between the European Commission and the OECD provides policy makers, interest groups, and health practitioners with factual, comparative data and insights into health and health systems in EU countries.

This initiative covers a multi-stage process:

The first, the report *Health at a Glance: Europe* gauges the progress towards effective, accessible, and resilient health systems across the EU, every two years. The latest report, published in November 2016<sup>40</sup>, states that “people with musculoskeletal diseases generally have lower employment rates and are more likely to leave employment early compared to people without such musculoskeletal problems.” (p.22.) Despite the scarcity of data on **musculoskeletal pain**, this report is backed by a UK study showing that one third of people with symptoms of arthritis left work due to ill health (Oxford Economics, 2010<sup>41</sup>)<sup>42</sup>. The *Health at a Glance* report also stresses that “musculoskeletal diseases are associated with lower productivity.” (p.26.) In the UK alone, 30.6 million days are lost as a result of musculoskeletal problems, representing nearly one quarter of the total days lost due to sickness absences in 2013 (Office for National Statistics, 2014).<sup>43</sup>

The second and third stages of the State of Health in the EU initiative are the 28 Country Health Profiles and the *State of Health in the EU Companion Report 2017*, respectively. **The latter mentions pain in relation to patient-reported outcomes.** Specifically, it describes how patients undergoing certain surgeries and procedures under the English National Health Service (NHS) are invited to provide feedback by filling in questionnaires on their outcomes, which includes reporting about the existence of pain or discomfort they might experience before/after the procedure(s). The answers are then converted into a ‘health gain’ score which can contribute to evaluating the effectiveness of these treatments. **These Patient Reported Outcome Measures (PROMs) are very valuable as they reflect the patients’ perspective, including on pain. (p.37.)** The *Companion report* further mentions that the Commission is planning to co-fund the OECD’s new *Patient Reported Indicators Survey (PaRIS)*, which “will focus on patient-reported outcomes such as whether a treatment reduced pain or enabled a person to live more independently.” (p.39.)<sup>44</sup>

The **2007 Eurobarometer**<sup>45</sup> also used pain as an indicator. The 2007 Eurobarometer identified that “one in four have experienced chronic pain of a magnitude sufficient to restrict daily activities” and “the problem of chronic pain, as with many other health problems, is reported more by women than by men (28% vs. 22%)”<sup>46</sup>.

Chronic pain, along with several other types of pain, is included in the 11<sup>th</sup> revision of the **International Classification of Diseases (ICD-11)**<sup>47</sup>, as revised in June 2018. The previous revision was in 2010. ICD-11 describes chronic primary pain as multifactorial, capturing its persistence and disruptive nature, without making assumptions about etiology.<sup>48,49</sup> The updated Classification is expected to be

<sup>40</sup> [https://ec.europa.eu/health/state/summary\\_en](https://ec.europa.eu/health/state/summary_en)

<sup>41</sup> “The economic costs of arthritis for the UK economy” (Oxford Economics, 2010) <https://www.oxfordeconomics.com/my-oxford/projects/128882>

<sup>42</sup> [https://ec.europa.eu/health/sites/health/files/state/docs/health\\_glance\\_2016\\_rep\\_en.pdf](https://ec.europa.eu/health/sites/health/files/state/docs/health_glance_2016_rep_en.pdf) (pg. 22)

<sup>43</sup> [https://ec.europa.eu/health/sites/health/files/state/docs/health\\_glance\\_2016\\_rep\\_en.pdf](https://ec.europa.eu/health/sites/health/files/state/docs/health_glance_2016_rep_en.pdf)

<sup>44</sup> [https://ec.europa.eu/health/sites/health/files/state/docs/2017\\_companion\\_en.pdf](https://ec.europa.eu/health/sites/health/files/state/docs/2017_companion_en.pdf)

<sup>45</sup> The Eurobarometer “examines the effects of health problems on the day-to-day lives of EU citizens” looking at the impact of poor health as whole, the incidence of restricted activity due to muscle, joint, and back pain, as well as the impact of chronic pain.

<sup>46</sup> [http://ec.europa.eu/health/ph\\_publication/eb\\_health\\_en.pdf](http://ec.europa.eu/health/ph_publication/eb_health_en.pdf)

<sup>47</sup> Published 18 June 2018, <https://icd.who.int/browse11/l-m/en>

<sup>48</sup> <https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2f2fid%2f2fenty%2f1581976053>

<sup>49</sup> <https://www.sip->

[platform.eu/files/editor/media/sip2017/Presentations%20for%20SIP%20website\\_Plenary%20I/6.%20Plenary%20Session%20I\\_Treede.pdf](platform.eu/files/editor/media/sip2017/Presentations%20for%20SIP%20website_Plenary%20I/6.%20Plenary%20Session%20I_Treede.pdf)



discussed and implemented at the General Assembly meeting in 2019. However, its implementation in all Member States will take time.<sup>50</sup>

## ADVOCACY MAP

### Malta Consensus Paper for Chronic Pain<sup>51</sup>

- The Maltese Consensus paper for chronic pain was adopted in 2017 by the Malta Health Network, No Pain Foundation, and SIP Malta. It provides nine recommendations, including that *“pain should be included as a key indicator in the outcomes of medical and surgical interventions.”*
- *“Investing EU funds in the development of pain as a quality indicator will be of paramount importance to measure the impact of mission-oriented research.”*

### Survey of Pain Measurement in Dutch Hospitals

- In the Netherlands, the Dutch National Patient Safety Programme developed indicators to measure pain in post-operative patients in hospital<sup>52</sup>. The measurement is conducted via a survey whereby patients give a pain-score measurements and notably highlights the importance of addressing of those with a pain-score above 7 in the first 72 hours after the operation.
- In a study to analyse the data<sup>53</sup>, however, despite 99 percent of hospitals implementing the programme, it found that only 56 percent of the post-operative patients were subjected to standardised pain measurements (i.e. more than once a day) during the first three days following surgery. Of the 3,895 patients surveyed, only 12 percent were measured three times a day. The reason for this was believed to be that the programme was regarded solely for external justification purposes and that pain was still considered an “uninteresting” side effect of treatment.

## 2.2. Research and Pain

The European Commission 7<sup>th</sup> Framework Programme for Research and Technological Development (FP7) funded the EuroPain project (2009-2015). EuroPain focused on understanding chronic pain and improving its treatment.<sup>54</sup> The subsequent and current European research framework programme, **Horizon 2020**, also includes projects related to pain, such as the RELIEF project<sup>55</sup>, a Pre-Commercial Procurement (PCP) project which sets out to improve chronic pain relief through *“information and communication technologies”* (ICT) self-management solutions.<sup>56</sup>

At the 2017 SIP Symposium, an official speaking on behalf of DG Research and Innovation highlighted the Commission’s investment in pain research over the past ten years. For example, the collaborative

<sup>50</sup> <https://ec.europa.eu/cefdigital/wiki/display/EHSEMANTIC/ICD-11%3A+The+11th+Revision+of+the+International+Classification+of+Diseases>

<sup>51</sup> <https://www.maltahealthnetwork.org/wp-content/uploads/2017/08/Pain-roadmap-MT-3-clean-May2017.pdf>

<sup>52</sup> [https://issuu.com/vms\\_veiligheidsprogramma/docs/2009.0109\\_praktijkgids\\_pijn](https://issuu.com/vms_veiligheidsprogramma/docs/2009.0109_praktijkgids_pijn)

<sup>53</sup> <https://www.ncbi.nlm.nih.gov/pubmed/27614250>

<sup>54</sup> [https://cordis.europa.eu/project/rcn/203679\\_en.html](https://cordis.europa.eu/project/rcn/203679_en.html)

<sup>55</sup> <http://relief-chronicpain.eu/index.html>

<sup>56</sup> <https://ec.europa.eu/digital-single-market/en/news/new-project-launched-innovation-chronic-pain-self-management>

research project, DOLORisk, which addresses personalised medicine and the better stratification of the patient to develop a risk model for neuropathic pain<sup>57</sup>.

The Commission has submitted a proposal for the 9<sup>th</sup> Framework Programme for Research (**Horizon Europe**) under the next Multi-Annual Financial Framework (MFF), which was presented in May 2019, and following consultation, is expected to be launched in January 2021.

## ADVOCACY MAP

### Brain, Mind, and Pain Patient-Centred Innovation Grant<sup>58</sup>

- The Brain, Mind, and Pain Patient-Centred Innovation Grant has been initiated by Pain Alliance Europe and financially supported by Grünenthal Group, with the aim of encouraging patient-centred innovation which, in turn, results in the improvement of the life conditions of pain.
- The biennial grant addresses individual applicants as well as different organisations' initiatives and partnerships, invited to present their innovation projects or ideas with direct impact on brain, mind, and pain patients' quality of life. The jury is composed of patient representatives, led by Pain Alliance Europe (PAE).
- In 2018, 19 applicants from 8 European countries applied for the grant. The three winners of the grant were: *Master Your Pain* by Groningen University, an e-health platform to help patients with rheumatic pain self-manage their symptoms; ASPERGA Association for their prototype auditory aid that aims to reduce sensory pain in people with autism spectrum disorder; and *MyBrainNet* by Dystonia Europe, a central platform for neurological brain diseases, providing information to patient groups and patients to help improve their quality of life.<sup>59</sup>

### European Brain Council Value of Treatment Study<sup>60</sup>

- In June 2017, the European Brain Council (EBC) published the findings of a two-year research project on *The Value of Treatment* (VoT), building on a previous EBC Report on "The Economic Costs of Brain Disorders in Europe", published in 2005 (Balak N and Elmaci I 2007) and updated in 2010 (Gustavson A et al. 2011, Olesen J et al. 2012, Di Luca M et al, 2014).
- The project focused on nine therapeutic areas: schizophrenia, Alzheimer's Disease, epilepsy, headaches, Normal Pressure Hydrocephalus, Parkinson's Disease, Multiple Sclerosis, Restless Legs Syndrome, and stroke. Due to the fact that there is a considerable gap in terms of diagnosis and treatment across Europe, although effective treatment exists. The study research framework included the testing of an integrated care model and the development of a series of qualitative and quantitative benchmarks to identify treatment gaps and causal factors along the continuum of care in patient care pathway analysis. The study also estimated the socio-economic impact and health gains of best practice healthcare interventions with an economic evaluation. The VoT study also promoted a biopsychosocial approach and looked at possible new research developments in early intervention to improve primary and secondary prevention and treatment.
- The conclusions highlight the need for more research, early, if possible prodromal, diagnosis and intervention, integrated seamless care underpinning timely care pathways by illustrating best

<sup>57</sup> [https://www.sip-platform.eu/files/editor/media/sip2017/Proceedings/SIP\\_Proceedings\\_2017\\_v2.0.pdf](https://www.sip-platform.eu/files/editor/media/sip2017/Proceedings/SIP_Proceedings_2017_v2.0.pdf)

<sup>58</sup> <http://bmp-grant.eu/>

<sup>59</sup> <http://bmp-grant.eu/2018/06/21/winners-announced-for-patient-driven-pain-grant/>

<sup>60</sup> <http://www.braincouncil.eu/activities/projects/the-value-of-treatment>

practice healthcare interventions to address fragmentation in the healthcare sector in Europe, and access to the best treatments available.

- More specifically, the VoT Working Group on Headaches concluded that the implementation of good headache healthcare is likely to be cost-saving. Tension-type headache, migraine, and medication-overuse headache affects half of the European population. Headaches are treatable but are still significantly under-diagnosed and wrongly treated in the population. Education of primary care practitioners and pharmacists can play a key role in increasing diagnosis, proper treatment, and appropriate referral to tertiary level of care for the most complex cases. Implementation of structured headache services (usually a three-tier model, but always based in primary care) is a good way to achieve higher population coverage. Such intervention needs support by educational initiatives aimed at both patients and healthcare providers to achieve better adherence.

### **EULAR RheumaMap**

- The European League Against Rheumatism (EULAR)<sup>61</sup> “Research Roadmap to transform the lives of people with Rheumatic and Musculoskeletal Diseases” (also known as the RheumaMap)<sup>62</sup> was launched in 2017 by the European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs).
- Put together by drawing on the expertise of the European RMD community, from scientific societies to health professional and patient organisations, the RheumaMap aims to inform policy makers, funding institutions, the broad scientific community and stakeholders about the challenges and opportunities in RMD research.
- More specifically, it identifies the priorities and main challenges in RMD research and innovation for a number of individual diseases. It addresses the need for the prevention of the onset of RMDs, promote higher levels of early diagnosis of RMDs, to promote higher levels of secondary prevention (or mitigation of impact once established) of RMDs, to optimise care of people with existing RMDs, reduce morbidity and mortality in people with RMDs, and to address the reintegration of individuals into society.
- With specific regard to pain, the RheumaMap outlines recommended research focus areas for pain in general as well as specifically highlighting recommendations for mechanical back and neck disorders, foot pain, shoulder pain, carpal tunnel / wrist pain, and Fibromyalgia.<sup>63</sup>

### **Innovative Medicines Initiative (IMI)**

- Since 2008, the Innovative Medicines Initiative (IMI) has been working towards advancing medical research to overcome societal challenges. This EU public-private partnership has funded specific research on pain, “**IMI Pain Care**”, to deliver on the project ‘Improving the care of patients suffering from acute or chronic pain’<sup>64</sup>.
- The project has been put forward by the Pain Group of IMI2, which includes Bayer, Novartis, Lilly, and TEVA, and co-led by Grünenthal and Esteve.

<sup>61</sup> <https://www.eular.org/>

<sup>62</sup> <https://www.eular.org/myUploadData/files/RheumaMap.pdf>

<sup>63</sup> <https://www.eular.org/myUploadData/files/RheumaMap.pdf>, (p. 24)

<sup>64</sup> <http://ec.europa.eu/research/participants/portal/desktop/en/opportunities/h2020/topics/imi2-2016-10-03.html>

- The project sets out to address three specific scientific challenges: *“Use of Patient Reported Outcome Measures for patient – health care professional contacts in acute and chronic pain management; improving translatability of functional biomarkers in pain pathways; and improving translation in chronic pelvic pain.”*<sup>65</sup>

### **Mission-oriented research under *Horizon Europe***

- Pain research is the ideal candidate for a mission-oriented approach that the Commission plans to adopt in the upcoming *Horizon Europe* (FP9). Given its crosscutting nature, pain should be considered as a quality indicator for the achievement of many health missions such as increase of healthy lifespan and life quality of cancer survivors. Pain management plays a crucial role in tackling musculoskeletal diseases, nervous system diseases, and noncommunicable diseases more broadly.
- The SIP partners submitted their response to the Commission’s public consultation on mission-oriented research<sup>66</sup>. In their response<sup>67</sup>, they stress that a focus on mission-oriented research should focus on a reduction in sick leave days by 50 percent since chronic pain is one of the major reasons why people exit the labour market, shorten by 80 percent the time until diagnosis for chronic pain patients by 2030 as most patients have to wait from one to 12 years for a diagnosis, half the number of chronic pain patients by ensuring early diagnosis at the first visit to avoid pain chronification, and increase treatment satisfaction to 90 percent by 2030 and find sustainable solutions to improve patient involvement in their treatment choice.
- On specific recommendations for action, the SIP partners propose concrete examples in their submission on how to strengthen pain research within *Horizon Europe*, under the headings of epidemiology, creation of registries, clinical research, development of screening tools, e-health (including m-health) in pain, behavioural research, systems level research, cellular and molecular research, development of precision medicine, and prevention.<sup>68</sup>

### **2.3. Employment and pain**

Over 40 million EU workers have musculoskeletal disorders caused by their work. This, in turn, causes almost 50 percent of all absences from work lasting three days or longer in the EU and 60 percent of permanent work incapacity. The direct and indirect costs are estimated to be €240 billion a year, up to two percent of GDP across the EU (Bevan, 2013<sup>69</sup>). By addressing pain in activities and policies related to pain, could have a large impact on working days and costs to the labour sector.

The **EU Strategic Framework on Health and Safety at Work 2014–2020**<sup>70</sup> identified challenges and objectives for Member States, including improvements to health and safety rules, prevention of

<sup>65</sup> [https://www.europeanpainfederation.eu/wp-content/uploads/2018/04/EFIC\\_Newsletter\\_2018.pdf](https://www.europeanpainfederation.eu/wp-content/uploads/2018/04/EFIC_Newsletter_2018.pdf)

<sup>66</sup> Submitted on 4 April 2018, [https://ec.europa.eu/info/designing-next-research-and-innovation-framework-programme/what-shapes-next-framework-programme\\_en](https://ec.europa.eu/info/designing-next-research-and-innovation-framework-programme/what-shapes-next-framework-programme_en)

<sup>67</sup> <https://www.sip-platform.eu/files/editor/media/EU%20Initiatives/SIP%20Position%20Paper%20on%20the%209th%20Framework%20Programme.pdf>

<sup>68</sup> <https://www.sip-platform.eu/files/editor/media/EU%20Initiatives/SIP%20Position%20Paper%20on%20the%209th%20Framework%20Programme.pdf>

<sup>69</sup> <https://www.bl.uk/britishlibrary/~media/bl/global/business-and-management/pdfs/non-secure/r/e/d/reducing-temporary-work-absence-through-early-intervention-the-case-of-msds-in-the-eu.pdf>

<sup>70</sup> <http://ec.europa.eu/social/main.jsp?catId=151&langId=en>

occupational diseases and issues relating to the ageing workforce. As part of this, the identification of work-related ailments and how to prevent them, is key.

The **European Union Information Agency for Occupational Safety and Health (EU-OSHA)** states that *“musculoskeletal disorders (MSDs) are one of the most common work-related ailments. Throughout Europe they affect millions of workers and cost employers billions of euros. Tackling MSDs helps improve the lives of workers, but it also makes good business sense.”*<sup>71</sup>

Speaking at the 2017 SIP Symposium, a representative from **EU-OSHA** highlighted the EU-OSHA Swedish country report<sup>72</sup>, *“where there is a system of joint budgeting across the disciplines that are involved in an individual’s return to work following illness.”* This example showed improvements in rates of those employees with MSDs returning to work.<sup>73</sup>

As musculoskeletal disorders are often work-related, Eurostat (ESTAT) and other EU bodies collect data or report information on this issue. Under the heading of “Health and well-being at work”, the European Foundation for the Improvement of Living and Working Conditions (Eurofound)<sup>74</sup> has developed the **European Working Conditions Survey (EWCS)** *“which collects information on job quality and its correlation with the health and well-being of different groups of workers.”* The 2017 survey investigated *“associations between working conditions and the physical and mental health of workers and absenteeism and presenteeism”*.

The key findings of the survey included:

- *“musculoskeletal disorders are one of the most common work-related complaints, affecting millions of workers and costing billions of euros to employers.”* (p.42.);
- *“the most widely reported health problem by workers is backache (reported by 43%), followed by muscular pains in the arms (41%), headache and eyestrain, and overall fatigue (both 35%).”* (p.124.); and
- *“presenteeism is the phenomenon whereby a worker, although contending with a physical or psychological health problem, still comes to work. There is increasing awareness of the costs of presenteeism; not least, it is associated with lower productivity”* (p.112) (Sainsbury Centre for Mental Health, 2007)<sup>75</sup>.

In June 2018, the **European Parliament Committee on Employment and Social Affairs unanimously adopted an own-initiative report on “Pathways for the reintegration of workers recovering from injury and illness into quality employment”**<sup>76</sup>. The report sets out measures that the European Commission and Member States should address to retain and reintegrate workers into the workplace who suffer from chronic conditions or injuries. In addition to the personal improvements in quality of life and mental health, the report also stresses the economic benefits, such as reducing costs for companies and making pensions and social security systems more sustainable for future generations.<sup>77</sup> It calls for improvement on how sickness absences are managed; make workplaces more adaptable to chronic conditions and disabilities by modifying tasks, equipment, and working time; raise awareness of and address potential psychological barriers to return to work (e.g. stress or stigma); develop and implement systematic monitoring and support affected by psychosocial risks

<sup>71</sup> <https://osha.europa.eu/en/themes/musculoskeletal-disorders>

<sup>72</sup> <https://osha.europa.eu/en/tools-and-publications/publications/country-report-sweden-worker-participation-management>

<sup>73</sup> [https://www.sip-platform.eu/files/editor/media/sip2017/Proceedings/SIP\\_Proceedings\\_2017\\_v2.0.pdf](https://www.sip-platform.eu/files/editor/media/sip2017/Proceedings/SIP_Proceedings_2017_v2.0.pdf) (p.110-111)

<sup>74</sup> <https://www.eurofound.europa.eu/topic/health-and-well-being-at-work>

<sup>75</sup> [https://www.eurofound.europa.eu/sites/default/files/ef\\_publication/field\\_ef\\_document/ef1634en.pdf](https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1634en.pdf)

<sup>76</sup> [http://www.europarl.europa.eu/oeil/popups/ficheprocedure.do?lang=&reference=2017/2277\(INI\)](http://www.europarl.europa.eu/oeil/popups/ficheprocedure.do?lang=&reference=2017/2277(INI))

<sup>77</sup> <http://www.europarl.europa.eu/news/en/press-room/20180607IPRO5237/employment-committee-meps-set-out-measures-against-long-term-work-absence>

(e.g. depression or burnout); and use evidence-based policy to support return-to-work approaches. The report was adopted in Plenary on 11 September 2018.

To address the issue on a broader level, the **European Pillar of Social Rights** was formally established by the European Commission in November 2017. The Pillar *“reflects a joint commitment to providing a healthy, safe and well-adapted work environment for workers in the EU. It includes provisions on protection of workers’ health and safety at work, as well as adapting the working environment to enable longer participation in the labour market.”*<sup>78</sup> The Pillar is structured around three categories: 1. Equal opportunities and access to the labour market, 2. fair working conditions, and 3. social protection and inclusion. It builds on 20 key principles, including Principle 12 on social protection and Principle 13 on unemployment benefits.<sup>79</sup> In May 2018, the European Commission presented its Country-Specific Recommendations (CSRs) which have a specific focus to social challenges, guided by the European Pillar of Social Rights.<sup>80</sup>

## ADVOCACY MAP

### PATHWAYS Project

- A three-year EU project that *“contributes to the development of innovative approaches to promote the professional integration and reintegration of people with chronic diseases and improve their employability.”*<sup>81</sup>
- Identifies *“integration and reintegration to work strategies for persons with chronic diseases and mental disorders in Europe”*<sup>82</sup> and consists of an extensive mapping report<sup>83</sup> as well as ten country reports.<sup>84</sup>
- Evaluates the effectiveness of these strategies<sup>85</sup> and assesses *“specific employment related needs of persons with chronic diseases and mental disorders.”*<sup>86</sup>
- The main findings of the mapping report show that the current European and national policy frameworks on employment activation are not adequately targeted to help persons with chronic diseases. They rather target *“broader categories, such as persons with disabilities, long-term unemployed, vulnerable groups, etc.”* However, *“strategies targeting persons with disabilities do not necessarily address the needs of patients with chronic diseases and mental health issues since the employment needs of these two groups are not the same.”*<sup>87</sup>

### CHRODIS PLUS<sup>88</sup>

<sup>78</sup> <https://www.eurofound.europa.eu/topic/health-and-well-being-at-work>

<sup>79</sup> [https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles\\_en](https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en)

<sup>80</sup> <http://ec.europa.eu/social/main.jsp?langId=en&catId=1226&newsId=9110&furtherNews=yes>

<sup>81</sup> <https://www.path-ways.eu/>

<sup>82</sup> <https://www.path-ways.eu/>

<sup>83</sup> [https://www.path-ways.eu/wp-content/uploads/pathways\\_report\\_identify.pdf](https://www.path-ways.eu/wp-content/uploads/pathways_report_identify.pdf)

<sup>84</sup> <https://www.path-ways.eu/publication-dissemination/professional-integration-and-reintegration-strategies-for-persons-with-chronic-diseases-and-mental-health-disorders/country-reports/>

<sup>85</sup> [https://www.path-ways.eu/wp-content/uploads/pathways\\_report\\_evaluate.pdf](https://www.path-ways.eu/wp-content/uploads/pathways_report_evaluate.pdf)

<sup>86</sup> [https://www.path-ways.eu/wp-content/uploads/pathways\\_report\\_assess.pdf](https://www.path-ways.eu/wp-content/uploads/pathways_report_assess.pdf)

<sup>87</sup> <https://www.path-ways.eu/publication-dissemination/professional-integration-and-reintegration-strategies-for-persons-with-chronic-diseases-and-mental-health-disorders/>

<sup>88</sup> <http://chrodis.eu/>

- CHRODIS PLUS, a three-year European initiative (2017-2020), has been launched to address ways of improving working conditions and supporting employers to ensure a healthy workforce.
- Under Work Package 8 “Chronic Diseases and Employment”, three main tasks were agreed: 1. developing a training tool for employers and the employment sector, 2. developing a toolkit for adaptation of the work place for access, prevention, and maintenance of chronic diseases at the workplace, and 3. developing policy recommendations for health promotion and disease prevention in the workplace for people with chronic disease<sup>89</sup>.

### **Pain Alliance Europe (PAE) Survey on Chronic Pain 2018: Pain and your work life<sup>90</sup>**

- Developed by PAE in collaboration with national patient organisations, the PAE 2018 Survey on Chronic Pain was built based on information from literature and existing questionnaires. The survey consisted of 28 questions which addressed topics, including: diagnosis, situation at work and impact of chronic pain on the financial situation of the respondent. Performed in 17 European countries, the survey collected 4,588 replies.
- The findings show some important aspects of the impact that chronic pain generates on patients in relation with their work life:
  - As a result of chronic pain, about 50 percent of the respondents are prevented from doing their work; only about 35 percent worked full time and 27 percent worked part-time, as a result of the pain condition.
  - The survey results found that 40 percent of the respondents needed to change their employer because they developed chronic pain
  - Survey respondents reported that only a minority of employers (30 percent) made special adaptations to facilitate people with chronic pain in their work; in almost 60 percent of the reported special adaptations, these were made on the basis of a personal request.
  - Two thirds of the chronic pain patients taking the survey had their income diminished as a result of the chronic pain condition, affecting their life; more than 10 percent of them currently only receive 10 percent of their initial revenue.

### **European Pillar of Social Rights**

- The MEP Interest Group on Brain, Mind and Pain (BMP)<sup>91</sup>, coordinated by the patient organisations, European Federation of Neurological Associations (EFNA) and Pain Alliance Europe (PAE), hosted a number of meetings and discussions on the health in the workplace and access to employment. Specifically, they hosted an Interest Group meeting in March 2017, in response to the launch of the consultation on the European Pillar of Social Rights.<sup>92</sup>
- As a follow on from its Call To Action #makeworkwork<sup>93</sup> campaign and the launch of the European Pillar of Social Rights, EFNA and PAE submitted a joint response to this consultation.<sup>94</sup>

<sup>89</sup> <http://chrodis.eu/08-employment/>

<sup>90</sup> <http://www.pae-eu.eu/wp-content/uploads/2017/12/PAE-Survey-on-Chronic-Pain-June-2017.pdf>

<sup>91</sup> <http://www.brainmindpain.eu/>

<sup>92</sup> <http://www.brainmindpain.eu/optimising-the-european-social-pillar-to-makeworkwork-for-those-affected-by-brain-mind-and-pain-conditions-2/>

<sup>93</sup> <http://www.brainmindpain.eu/written-declaration-access-to-employment/>

<sup>94</sup> <http://efna.net/wp-content/uploads/2017/05/EFNA-Consultation-on-the-European-Pillar-of-Social-Rights.pdf>

- In the joint response, the organisations note: *“we feel that overall the priority must be on the implementation of existing legislation, rather than the creation of new legislative texts. This will not only benefit patients, but wider society from a socio-economic perspective. Therefore, we suggest the use of the EU Semester’s country-specific recommendations to encourage Member States to implement cost-effective retention, reintegration and rehabilitation actions.”*<sup>95</sup>

#### **Migraine at Work Survey**<sup>96</sup>

- The European Migraine and Headache Alliance (EMHA) launched a pan-European survey in May 2018 to better understand the current situation of workers in companies who experience migraines. It seeks to serve as a starting point for subsequent improvement initiatives, notably with *“the implementation of preventive measures and the optimum integration of the worker with migraine within companies with common benefit both at personal/health and at business level.”*
- The study was designed with the Spanish Association of Specialists in Occupational Medicine (AEEMT) and is being conducted in Spain, Ireland, England, Italy, Germany, and France. The sample size for each participating country is expected to be a minimum of 500 workers but ideally 1,000 workers. The survey will close in November 2018.

#### **European Patients’ Forum on Equality for Patients at Work and in Education**<sup>97</sup>

- The European Patients’ Forum (EPF) published a position paper on *“Equal treatment for patients in Education and Employment”* which highlights the difficulties patients with chronic diseases have when seeking and education as well as in the workplace.
- In the workplace, it notes that patients can face challenges, either when they return to work (e.g. the employer is misinformed about their capacity to remain at work) or when finding a new job, resulting in stigma and discriminatory attitudes. Further, there is a lack of clarity as to the definition of *“disability”* in a number of member states and whether patients with chronic diseases fall under this definition. *“Adequate legislation to protect and support patients are not always in place and lack recognition by the relevant stakeholders.”*<sup>98</sup>
- The paper stresses that *“with appropriate support, many patients are able to work, resulting in a hugely improved quality of life that also reduces the negative financial impact of chronic illness and the risk of social exclusion. Retaining people with chronic conditions in employment can be beneficial for the employee, the employers, and society. For employers, the benefits of hiring and keeping employees with chronic conditions are multiple: it shows the employer values experience, diversity and inclusion, which are part of a well-functioning company.”*<sup>99</sup>

## **2.4. Education**

<sup>95</sup> <http://efna.net/wp-content/uploads/2017/05/EFNA-Consultation-on-the-European-Pillar-of-Social-Rights.pdf>

<sup>96</sup> <https://www.europeanheadachealliance.org/project/migraine-at-work/>

<sup>97</sup> [http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper\\_equal-treatment-in-education-and-employment.pdf](http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper_equal-treatment-in-education-and-employment.pdf)

<sup>98</sup> <http://www.eu-patient.eu/News/News/epf-calls-for-equal-treatment-for-patients-in-education-and-employment/>

<sup>99</sup> <http://www.eu-patient.eu/News/News/epf-calls-for-equal-treatment-for-patients-in-education-and-employment/>



Pain education can be divided into two areas: **1. Formal academic education** of healthcare professionals, and **2. Awareness raising and wider stakeholder education.**

### *Formal academic education*

Pain education within the medical curricula remains limited. In a study published in 2015<sup>100</sup>, it found that even if pain was taught, it was not within a specific pain module. France was found to be the leader in teaching dedicated pain modules (87 percent of schools). However, the rest of the countries lagged, with only 22 percent of schools providing a dedicated pain module, whilst only 9 percent made them compulsory. Seven percent of schools showed no evidence of pain teaching at all. The study concludes, *“Documented pain teaching in many European medical schools falls far short of what might be expected given the prevalence and public health burden of pain.”*

Speaking at the 2017 SIP Symposium<sup>101</sup>, one of the authors of the study, Andreas Kopf from the Charité University Hospital in Berlin, Germany, stated that ***“the key to success in pain management would be to integrate pain medicine in undergraduate and postgraduate education. Pain assessment and management therefore should be an essential part of curricula of medical faculties and of postgraduate residency programmes.”***

Further, to identify the gap and address the educational needs of the health workforce (i.e. healthcare professionals), the **Joint Action on Health Workforce Planning and Forecasting** (EU JAHWF)<sup>102</sup> launched a three-year project to *“map existing activities in the areas of workforce planning and forecasting and create a compilation of good practices as a reference point for the introduction and improvement of planning mechanisms at national level.”* In its final conference in 2016, the Joint Action published *“a handbook on health workforce planning methodologies that describes and analyses the planning practices developed in selected EU countries.”*<sup>103</sup> The outcome of the Joint Action is the establishment of the **health workforce planning and forecasting expert network**. Their aim will be to establish a platform to exchange knowledge and address the challenges identified, map national workforce policies across the EU Member States, facilitate exchange of knowledge and best practice via European workshops, and provide country-specific support on the national implementation of health workforce planning.

The expert network launched a tender in September 2017. It consists of five work packages, of which the first will *“organise expert networking to structure and exchange knowledge in the area of health workforce planning and forecasting and provide a forum to address health workforce challenges”*.<sup>104</sup>

The European Commission and OECD 2016 report ***Health at a Glance*** further acknowledges that *“With appropriate training and on-going support from primary care practitioners, nurses have been found to provide as high-quality care as primary care doctors in the provision of care for acute and chronic conditions, and with higher patient satisfaction (Maier et al., forthcoming). An expanded scope of practice for nurses already exists in several European countries. In Sweden and Finland for example, additional training was developed for nurses to be involved in post-discharge protocol, patient education and chronic disease management. Expanding the role of community pharmacists is another avenue to renew the focus on preventive health care.”*<sup>105</sup>

<sup>100</sup> <http://bmjopen.bmj.com/content/5/8/e006984>

<sup>101</sup> [https://www.sip-platform.eu/files/editor/media/sip2017/Proceedings/SIP\\_Proceedings\\_2017v1.0\\_with%20links.pdf](https://www.sip-platform.eu/files/editor/media/sip2017/Proceedings/SIP_Proceedings_2017v1.0_with%20links.pdf) (p.70-71)

<sup>102</sup> <https://www.cpme.eu/joint-action-on-health-workforce-planning-and-forecasting/>

<sup>103</sup> <http://www.euro.who.int/en/health-topics/Health-systems/health-workforce/news/news/2016/06/completion-of-the-eu-joint-action-on-health-workforce-planning-and-forecasting>

<sup>104</sup> <http://healthworkforce.eu/about-us/>

<sup>105</sup> [https://ec.europa.eu/health/sites/health/files/state/docs/health\\_glance\\_2016\\_rep\\_en.pdf](https://ec.europa.eu/health/sites/health/files/state/docs/health_glance_2016_rep_en.pdf) (p. 49)

## ADVOCACY MAP

### Addressing the gaps in pain education

- Given the abovementioned gaps in pain education, one of the objectives of the European Pain Federation (EFIC) is to promote healthcare professional education in the field of pain.
- Issues that EFIC focuses on include the recognition of differences in therapeutic strategies and pain education within Europe, the harmonisation of such differences, and the review of existing curricula and plans for training of pain specialists (it might be desirable to develop a European academy to accredit pain specialists, possibly by examination)<sup>106</sup>.
- EFIC offers curricula and examinations on pain medicine, such as a voluntary certification which takes place annually: **Examination for the European Diploma in Pain Medicine (EDPM)**<sup>107</sup> and the **Examination for the European Diploma in Pain Physiotherapy (EDPP)**<sup>108</sup>.

### European Pain Management book<sup>109</sup>

- The European Pain Management book offers a comprehensive overview of pain education across Europe. The data published in the book seeks to serve to highlight best practice examples as well as existing gaps in chronic pain management education.
- The book aims to support national advocacy activities to promote and improve chronic pain management education.
- The book contains national chapter reports, including a focus on the importance of pain education. For example, the book finds inadequate training in Greece, with HCPs having to travel to other countries for further pain education. In Belgium, several universities offer a module on the pathophysiology of pain and pain treatment, with specialised pain education programmes for nurses. The Association for Pain Therapy-Bosnia Herzegovina (APT-B&H) will offer further education as per the European Pain Federation curricula. The Czech Republic has established a three-year educational scheme; whilst Scandinavian countries have joined forces to educate future pain specialists, with the Scandinavian Society of Anaesthesiology and Intensive Care (SSAI) has developed a two-year course on advanced pain treatment.

<sup>106</sup> <https://www.europeanpainfederation.eu/about-efic/mission-statement/>

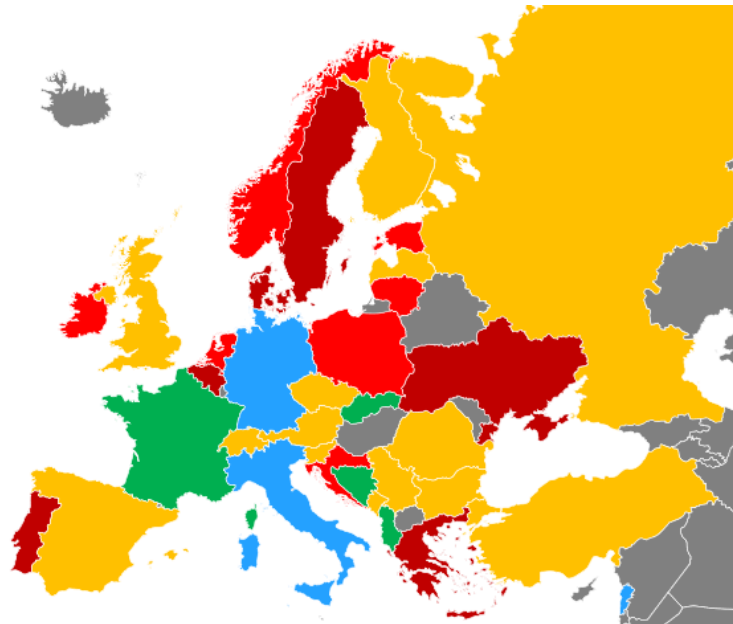
<sup>107</sup> <https://www.europeanpainfederation.eu/core-curriculum/diploma-in-pain-medicine/>

<sup>108</sup> <https://www.europeanpainfederation.eu/diploma-in-pain-physiotherapy/>

<sup>109</sup> Eccleston, C., Wells, C., & Morlion, B. (2017). European Pain Management. Oxford, UK: Oxford University Press, ISBN: 9780198785750

Are the basics of pain medicine and care being taught in residency programs for all medical specialties?

- Completed
- Nearly completed
- In progress
- Started
- Not started



Road Map for Action 2014 Road Map Monitor<sup>110</sup>

#### EU Civic Prize on Chronic Pain: Collecting good practices

- Currently in its second edition<sup>111</sup>, the EU Civic Prize on Chronic Pain is run by Active Citizenship Network (ACN) to highlight best practice examples to raise awareness and address the societal impact of pain. Four prizes are given under the categories 1. Patient Empowerment, 2. Innovation, 3. Clinical Practices, and 4. Professional Education.
- In its first edition, the project received 30 best practice examples, from 11 different countries.<sup>112</sup>
- Under the *Professional Education* category, **‘Patients as Teachers in Health Professional Education’**<sup>113</sup> by the Pelvic Pain Support Network (PPSN), UK won the award for Professional Education. As part of the undergraduate curriculum in selected UK universities, PPSN and patients with teaching backgrounds give lectures to students on the patient’s experience and perspective of long-term pain and their experiences with healthcare professionals.
- The application process<sup>114</sup> for submissions of best practice examples under the four categories for the second edition of the Prize is open until 31 December 2018.

#### Awareness raising and wider stakeholder education

Alongside formal academic education, education of other stakeholders is of equal importance. These most notably include policymakers, patients, healthcare management, and employers/ employment organisations and unions. Such education should, furthermore, be tailored to the specific audiences,

<sup>110</sup> [https://www.sip-platform.eu/files/structure\\_until\\_2016/Events/2016/Plenary%2024%20May/PDF/01.%20SIP%202016%20-%20Presentation%20Chris%20Wells.pdf](https://www.sip-platform.eu/files/structure_until_2016/Events/2016/Plenary%2024%20May/PDF/01.%20SIP%202016%20-%20Presentation%20Chris%20Wells.pdf)

<sup>111</sup> <http://www.activecitizenship.net/patients-rights/projects/261-european-civic-prize-on-chronic-pain-collecting-good-practices-second-edition-2018-2019.html>

<sup>112</sup> <http://www.activecitizenship.net/press-releases/241-4-best-practices-against-pain-awarded-today-in-malta.html>

<sup>113</sup> <http://www.activecitizenship.net/patients-rights/projects/204-european-civic-prize-on-chronic-pain-collecting-good-practices.html>

<sup>114</sup> <http://www.activecitizenship.net/bp/2018/form/new.php>

their level of health and pain literacy, and take into account their respective cultural and social backgrounds.

In 2014, the European Commission funded the **EMPATHiE** (Empowering patients in the management of chronic diseases)<sup>115</sup> study which sought to contribute to EU knowledge and facilitate the development of patient-centred healthcare policies, whilst also contributing to the then-reflection process on chronic disease management. The study looked at four different working packages: 1. Identification of best practice models for patient empowerment, 2. Analysis of these models and identify advantages and barriers to empowering patients, 3. Develop a methodology to validate the transferability of good practice, and 4. Develop scenarios for future EU collaboration regarding patient empowerment.

## ADVOCACY MAP

### European Patients' Forum Empowerment Campaign<sup>116</sup>

- In response to the EMPATHiE study, the European Patients' Forum (EPF) launched the Empowerment Campaign, which ran between 2015 and 2016. The Campaign sought to raise awareness of the role patients must play in the decision-making process, with regard to chronic diseases, and promote what patient empowerment is from the patient's perspective. As part of the Campaign, a Charter on Patient Empowerment<sup>117</sup> and a RoadMap for Action<sup>118</sup> was launched.
- The Campaign tagline, "Patients prescribe E5 for sustainable health systems", sought to demonstrate that patients are active people who can, if supported and according to their individual capabilities and situation, make a difference for the sustainability of healthcare systems. The five "E" of Empowerment stand for: Education (patients can make informed decisions about their health), Expertise (self-management of their condition means they have a unique expertise), Equality (patients need support to become equal partners with HCPs in managing their condition), Experience (individual patients working with patient organisations and exchange of experiences and acting as a collective voice), and Engagement (patients need to be involved and designing more effective healthcare, research and services).

### EFNA Survey of Young People with Neurological Conditions<sup>119</sup>

- Acknowledging the underrepresentation of young people with neurological conditions, notably with regard to the additional burdens of comorbidity and chronic illnesses, the European Federation of Neurological Associations (EFNA)<sup>120</sup> conducted a survey of young people with neurological conditions.
- The survey was conducted between March and May 2018 and received 1368 responses from 39 countries and launched on 22 July 2018, to mark World Brain Day 2018. Almost 80 percent of the respondents were female, with the majority of the responses coming from those living with Multiple Sclerosis, Myalgic Encephalomyelitis, Chronic Pain, and Migraine<sup>121</sup>. 66 percent of

<sup>115</sup> [https://ec.europa.eu/health/sites/health/files/patient\\_safety/docs/empathie\\_frep\\_en.pdf](https://ec.europa.eu/health/sites/health/files/patient_safety/docs/empathie_frep_en.pdf)

<sup>116</sup> <http://www.eu-patient.eu/campaign/PatientsprescribE/>

<sup>117</sup> <http://www.eu-patient.eu/campaign/PatientsprescribE/charter-on-patient-empowerment/>

<sup>118</sup> [http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/roadmap/roadmap\\_patient-empowerment\\_epf\\_2017.pdf](http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/roadmap/roadmap_patient-empowerment_epf_2017.pdf)

<sup>119</sup> <https://www.efna.net/wp-content/uploads/2018/07/EFNAYoungPeopleSurvey.pdf>

<sup>120</sup> <https://www.efna.net/>

<sup>121</sup> <https://www.sip-platform.eu/media/details/efna-survey-of-young-europeans-with-neurological-conditions>

respondents of Myalgic Encephalomyelitis and forty percent of respondents with migraine expressed that they have chronic pain.<sup>122</sup>

- About a quarter of those surveyed across all disease areas were unemployed and not seeking work. However, for those who list chronic pain as their primary condition, this number rises to more than 50 percent<sup>123</sup>.
- The survey found that the highest concern for respondents was access to medication/ treatment, followed by isolation, and stigma.<sup>124</sup>

### Awareness Raising towards Policymakers

- The education and awareness raising towards and by policymakers is a vital step in the overall approach to addressing the societal impact of pain. Without knowledge and action aim at and from policymakers, be it at local, national, or European level, many activities and proposals for policy would not be possible.
- A key undertaking by the **Societal Impact of Pain Platform** is the **annual Symposium**. Since 2010, the aim of these Symposiums is to act as a meeting point for education and knowledge on all issues concerning pain – from grass-roots to national and European policy. It to bring together EU and national policymakers, patients and patient organisations, healthcare professionals, academics and anyone interested in the societal impact of pain to discuss the latest topics and advances in pain policies, research, healthcare management, as well as identify holistic approaches and exchange of best practice examples to ensure a sustainable approach to pain diagnosis, treatment, and care. Discussants during these meetings included senior European Commission officials, MEPs, as well as eminent academics, and influential patient organisation representatives.
- The **European Parliament Brain, Mind, and Pain (BMP) Interest Group**<sup>125</sup> is another platform where policymakers and other interested stakeholders raise key issues as well as provide an opportunity to exchange best practice on specific activities and policies. The group explores issues of common interest to those affected by neurological and chronic pain disorders, including stigma, quality of life, research, and patient involvement. For example, recent meeting discussions have focused on pain with regard to employment, the European Social Pillar, and optimising Patient Relevant Outcome Measures for sustainable healthcare systems.

### International Pain Awareness Month

- September was officially recognised as International Pain Awareness Month at the 70th World Health Assembly in 2016<sup>126</sup>. The campaign seeks to raise awareness of pain with patients, policymakers, healthcare professionals, as well as the general public.
- As part of this annual campaign, the American Chronic Pain Association, the International Pain Management Network, and the International Alliance of Patient Organizations (IAPO) develop toolkits, tailored to major geographic regions, that will provide information for working collaboratively with healthcare professionals, consumer and professional organizations,

<sup>122</sup> [https://www.efna.net/wp-content/uploads/2018/07/Data\\_ChronicPain\\_180704.pdf](https://www.efna.net/wp-content/uploads/2018/07/Data_ChronicPain_180704.pdf)

<sup>123</sup> [https://www.efna.net/wp-content/uploads/2018/07/Data\\_ChronicPain\\_180704.pdf](https://www.efna.net/wp-content/uploads/2018/07/Data_ChronicPain_180704.pdf)

<sup>124</sup> <https://www.efna.net/wp-content/uploads/2018/07/EFNAYoungPeopleSurvey.pdf> (p. 3)

<sup>125</sup> <http://www.brainmindpain.eu/>

<sup>126</sup> <https://www.iapo.org.uk/events/international-pain-awareness-month>

journalists, community leaders, and public officials. These will be provided to all participating organisations<sup>127</sup>.

### **Pain Toolkit**

- The Pain Toolkit outlines pain management skills that can enable patients to become their active self-manager, thereby allowing them to be less dependent on their healthcare professional.<sup>128</sup>
- The first edition of the Toolkit was developed in 2002 by Pete Moore, a pain patient himself, whilst writing an article on pain self-management for healthcare professionals.
- These tools include self-acceptance of the condition, how to ensure a good quality of life, as well as how to address any set-backs. The Toolkit also offers a support community and information on how to set up and/or attend pain management workshops.

## **3. Recommendations for policy action**

### **1. Pain as an indicator: *Develop instruments to assess the societal impact of pain (pain as a quality indicator)***

We ask to explore opportunities to build on existing instruments which are available to define, establish and/or use pain as an indicator in the assessment of healthcare systems' quality and thus contribute to assessing the societal impact of pain and build on existing initiatives and opportunities to fill the data gap on the societal impact of pain.

We call on the European Commission to:

- Work on addressing the gap in the European Core Healthcare Indicators project, leveraging the inclusion of chronic pain in the 11th Revision of the International Classification of Diseases (ICD-11) and promote implementation of ICD-11 at national level
- Assess the possibility to include work on a European Core Healthcare Indicator on Pain in existing projects such as the Joint Action on Health Information
- Together with the OECD, present pain as a key indicator of health and health systems and analyse the links between population health and labour market outcomes in *Health at a Glance: Europe 2020*
- Together with civil society, to repeat and broaden the 2006 Health Eurobarometer which included musculoskeletal pain and consult civil society for survey expertise

We call on Member States to:

- Establish quality indicators to set criteria for granting access to cross-border healthcare and ensuring comprehensive electronic health records
- Ensure proper implementation of the ICD-11 so that data on chronic pain will be available to build European Core Healthcare Indicator on Pain
- Ensure the implementation Article 8.5 of the European Commission Directive on cross-border healthcare for pain patients

<sup>127</sup> <http://www.theacpa.org/wp-content/uploads/2017/08/INTERNATIONAL-PAIN-AWARENESS-MONTH-Short.pdf>

<sup>128</sup> <https://www.paintoolkit.org/about>

## **2. Pain education: *Prioritise pain education for health care professionals, patients, policymakers, and the general public***

We call for the sharing of best practice, identifying gaps, and proposing recommendations to foster the formal education of healthcare professionals as well as awareness raising and education of patients, policymakers, and the general public on pain, across Europe.

We call on the European Commission to:

- Support national governments in the coordination and sharing of best practice (e.g. patient and healthcare education programmes) and further expand on the existing best practice portal to foster information exchange and cross-fertilisation among European health systems on the societal impact of pain, with all relevant stakeholders
- Support awareness raising activities and information campaigns aimed at educating the wider stakeholder environment to address the societal impact of pain on a holistic level.
- Take into account in its work on health workforce planning (such as the Joint Action on Health Workforce Planning and Forecasting), whether Member States have access to the necessary education and training resources to establish the integrated models of care, and interdisciplinary teams required for the treatment of conditions such as chronic pain

We call on Member States to:

- Initiate patient education programmes and information campaigns in order to create public awareness of the short and long-term consequences of inadequate access to pain treatment for pain symptoms
- Promote wider access to pain education within healthcare professions, especially to all those involved with assessing and treating pain

We further call on civil society to disseminate policies and best practice developed by Member States and European Institutions, connect with their policymakers, and work with their respective network to collect and share relevant best practices and raise awareness of the importance of pain education for healthcare professionals, patients, and the general public.

## **3. Pain in employment: *Initiate policies addressing the impact of pain on employment and include pain in relevant existing initiatives***

We ask for reasonable, flexible workplace adjustments by employers which can help individuals with chronic pain to stay in work or reintegrate into the workforce.

We call on the European Commission to:

- Work together with national authorities to promote policies that reflect the link between pain management/care and employment
- Support projects such as CHRODIS-Plus and its participating organisations for the inclusion of pain into all of its proposed training tools as well as the development of any policies and recommendations, as tasked under Work Group 8.
- Take into account the recommendations from the PATHWAYS project report when reviewing current strategies and broaden them to address the needs of patients with chronic diseases and mental health issues in relation to employment policies.

#### **4. Pain research: *Increase investment in research on the societal impact of pain***

We ask to identify and analyse gaps in national and European funding for research (basic science, clinical, epidemiological) on the societal impact of pain and drafting recommendations on how future EU framework programmes can fill these gaps. Such analysis should take into account the propositions on pain research prioritisation from the civil society and scientific community.

We call on the European Commission to:

- Propose further investment in research (basic science, clinical, epidemiological) on the societal impact of pain as a priority in future EU framework programmes as well as in employment and health policy.
- Support the development of pain centres of excellence across the EU and encourage a network for these centres to provide for better understanding of pain and offer better pain management
- Include pain as a topic for its mission-oriented research and under its research and innovation programmes, such as *Horizon Europe*. These could include models for effective pain treatment within research programmes, the development of screening tools, e- and m-health platforms, behavioural research, systems-level research, cellular and molecular research, and the development of precision medicine. Given the holistic approach to the social impact of pain, representatives from social science should also be involved.

We call on Member States to allocate further investment in research (basic science, clinical, epidemiological) on the societal impact of pain as a priority in future EU framework programmes and make funds available through employment and health policy and research and innovation programmes.



## ANNEX I

SIP lead on the development of this Framing Document and Joint Statement, in collaboration with various organisations and members of the EU Health Policy Platform. The list of signatories is presented below.

### **About SIP**

The "**Societal Impact of Pain**" (SIP) is an international platform created as a joint initiative of the European Pain Federation EFIC and the pharmaceutical company Grünenthal GmbH and aims for:

- raising awareness of the relevance of the impact that pain has on our societies, health and economic systems
- exchanging information and sharing best-practices across all member states of the European Union
- developing and fostering European-wide policy strategies & activities for an improved pain care in Europe (Pain Policy).

The platform provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators and budget holders.

The scientific framework of the SIP platform is under the responsibility of the European Pain Federation EFIC®. Co-operation partners for SIP are Pain Alliance Europe and Active Citizenship Network. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support.

### **List of Endorsers**