

SOCIETAL IMPACT OF PAIN – EUROPEAN ROAD MAP MONITOR 2019

Bringing Pain Policy into the Next Decade



SIP
Societal Impact of Pain



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About the “Societal Impact of Pain” and the SIP platform

The burden that pain imposes on individuals and the enormous costs that society has to bear, not only by healthcare systems, but also related social, economic and employment costs, illustrate the urgency for European governments and the EU Institutions to act and put the societal impact of pain on their policy agenda. Basic and clinical sciences have demonstrated the feasibility of care pathways out of pain for many types of acute and chronic pain but healthcare systems frequently do not guarantee general access for patients to these. In order to address the societal impact of pain, different stakeholder groups joined forces in 2009.


SIP is an international multi-stakeholder platform aiming to:

- Raise awareness of the relevance of the impact that pain has on our societies, health and economic systems
- Exchange information and share best-practices across all member states of the European Union
- Develop and foster European-wide policy strategies & activities for an improved pain care in Europe (Pain Policy)

The scientific framework of the “Societal Impact of Pain” (SIP) platform is under the responsibility of the European Pain Federation EFiC®. Cooperation partners are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP symposia have been endorsed by more than 340 international and national pain advocacy groups, scientific organisations and authorities.

More information on events and publications by the SIP platform can be found at: www.sip-platform.eu.

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A stylized, light blue map of Europe is visible in the background, centered behind the text.

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Bringing Pain Policy into the Next Decade



SIP

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1. INTRODUCTION



Dear Reader,

Pain remains a major source of disability worldwide and is the main reason people seek healthcare, from general practice to emergency care (Eccleston et al., 2017). Across Europe, the number of people that will experience chronic persistent pain at some point in their lives is around 150 million - equivalent to the combined populations of Germany and France (Eccleston et al., 2017). As well as the immeasurable suffering that pain can cause individuals affected, it can also exert a significant burden on society. For example, the estimated direct and indirect healthcare cost for chronic pain disorders vary between two and three percent of GDP across the EU (Bevan et al., 2013) (Breivik et al., 2013). This would have been the equivalent of up to 478 billion Euros in 2018 (EuroStat GDP and main components – EU 28 Countries). To add to this, chronic pain:

- Is one of the major reasons why people exit the labour market prematurely and contributes significantly to disability retirement (Saastamoinen et al., 2012), undermining the Europe 2020 Strategy for smart, sustainable and inclusive growth.
- Undermines the European goal for healthy ageing, as expressed in the European Innovation Partnership on Action and Healthy Ageing.

Despite the significant burden, large health inequalities exist in the EU (Barnett, et al., 2012) and many people living with chronic pain do not have access to adequate treatment.

1. INTRODUCTION

In response to unmet needs that persist across Europe, in 2001, the European Pain Federation EFIC® published its Declaration on Pain (Annex 2, Ref.1) which called on national governments and EU Institutions to increase the level of awareness of the societal impact of pain. With limited EU policy action over the following 10 years, in 2009 the European Pain Federation EFIC® and Grünenthal GmbH set up the “Societal Impact of Pain” or SIP platform and later the co-operation partners Pain Alliance Europe and Active Citizenship Network joined, with the aim of:

- 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 EU Member States
- Developing and fostering European-wide policy strategies and activities for improved pain care in Europe

In 2011, the Societal Impact of Pain platform published their Road Map for Action (Annex 2, Ref. 4). This called on European governments and EU institutions to establish an EU platform to enable the exchange, comparison, and benchmarking of best practice between Member States on pain management and its impact on society; and use the platform to monitor trends and provide guidelines to ensure harmonisation across the EU.

To better understand the existing status of the priorities set out under the Road Map, gauge

progress, and provide evidence for policy makers, a questionnaire was designed to monitor the national implementation of the Societal Impact of Pain 2011 Road Map (Annex 2, Ref. 4), throughout Europe. The findings of the 2011 survey were gathered from opinions of local European Pain Federation EFIC® councillors, IASP® chapter presidents and Grünenthal managers from 26 countries and were launched at the 7th Congress of the European Pain Federation EFIC® in September 2011. The report reinforced the lack of national or regional policy action or prioritisation in many parts of Europe ten years on from the Declaration on Pain. It highlighted initial progress being made on establishing a pain platform; unmet needs of people living with chronic pain across Europe; and an inadequate level of knowledge and information about pain management. The exercise was repeated again in 2014 (Annex 2, Ref. 6).

For this latest 2019 survey, the Societal Impact of Pain Steering Committee recognised that a broader range of stakeholders, including healthcare professionals, patient organisations, and industry representatives involved in pain should be consulted. The survey was also evolved not only to look at the status of national guidelines and action plans, but to reflect on the status of policies supporting the updated priorities of the Societal Impact of Pain platform.

Key findings from 2019 show that while progress is being made across the region, there is still a long way to go to ensure that every country has some form of national guideline and action plan

for pain management in place and that it is being implemented. Findings also highlighted that key measures prioritised by the Societal Impact of Pain platform are still falling short, despite some progress being made in these areas. These measures include those which: support pain as a quality indicator; enable the collection and use of data to support evolving research; support people living with pain to maintain workability; and routinely encourage pain management education for healthcare professionals and patients.

That said, excellent progress has been made in some countries, the next step for the Societal Impact of Pain platform will be to support the roll-out of this progress to all other countries, enabling greater harmonisation across Europe.

The following pages outline the findings from our survey and the Societal Impact of Pain Steering Committee’s recommendations for achieving greater action towards the prioritisation of pain across Europe.

On behalf of the Societal Impact of Pain Platform Partners I wish you an interesting read.

Yours sincerely,



Professor Bart Morlion

President of the European Pain Federation EFIC®

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2. METHODOLOGY: EUROPEAN ROAD MAP MONITOR 2019

2.1. Objectives of the 2019 Survey

- To capture the status of implementation of policy priorities, identified in the 2018 Societal Impact of Pain Joint Statement (Annex 2, Ref. 2)
- To formulate evidence-based policy actions addressing the societal impact of pain

Societal Impact of Pain Policy Priorities

- Pain as a Quality Indicator
- Pain Research
- Pain in Employment
- Pain Education

Our priorities

- ✓ Indicators
- ✓ Employment
- ✓ Research
- ✓ Education

2.2 Development of the survey questions

The 2019 survey was designed by the Societal Impact of Pain project team in collaboration with experts in the field, to build on findings from previous years and meet the above objectives. The 2019 survey collected information on:

- General questions related to national pain networks
- Indicators related to the measurement and monitoring of pain
- Research, notably on funding of pain research
- Employment, with pain as the number one reason for absenteeism and disability
- Education, assessing whether pain is a dedicated subject for healthcare professional training, patient education and general public awareness

For a full list of questions please see ANNEX 1

2.3 Survey approach and analysis

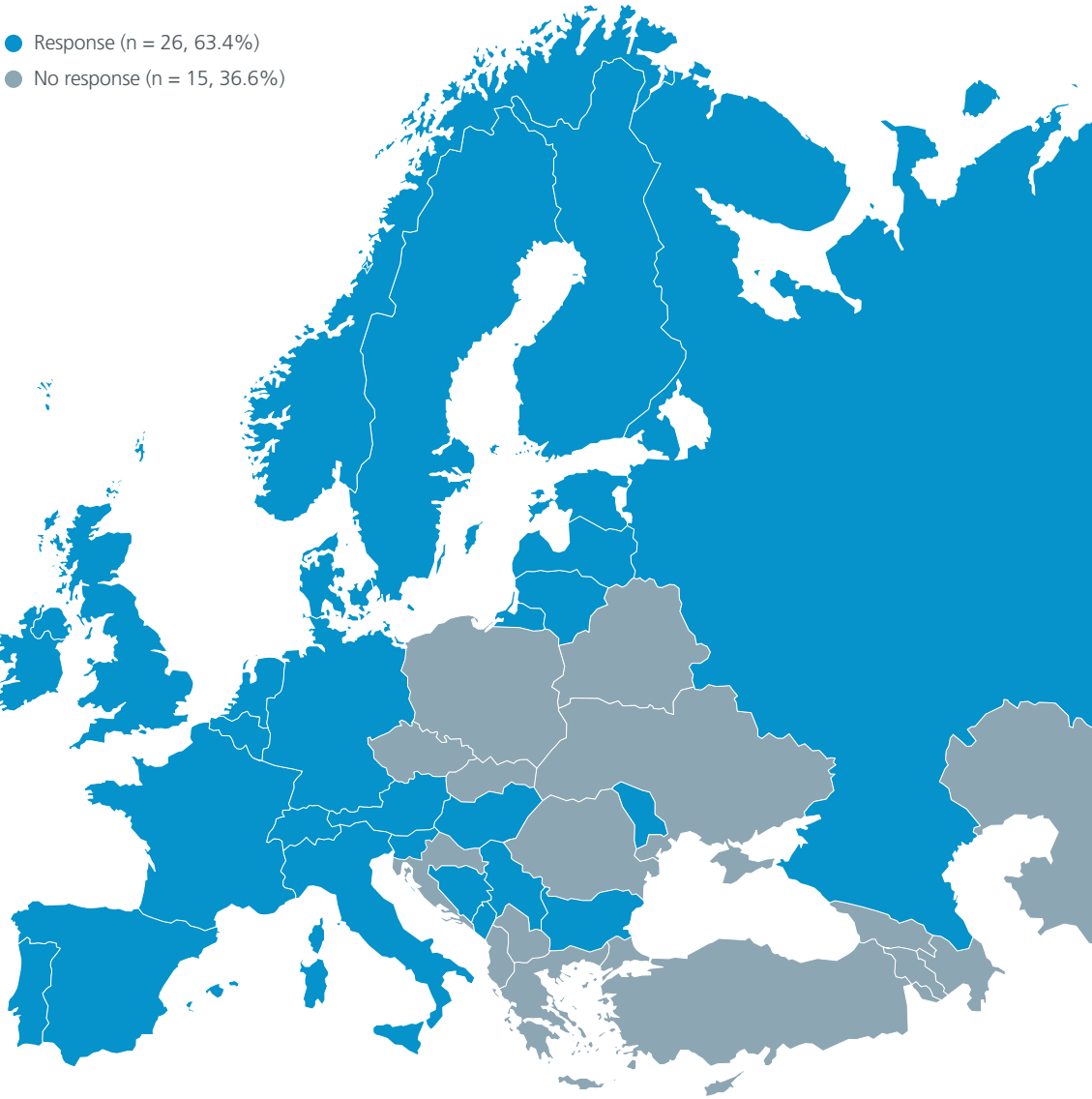
- **37** countries were requested to provide information, including:
 - European Pain Federation EFIC® representatives from their 37 Chapters
 - Pain Alliance Europe representatives from their 19 member countries
 - Grünenthal representatives from 15 countries
- The survey was directed at healthcare professionals (European Pain Federation EFIC®), patient organisations (Pain Alliance Europe) and industry representatives (Grünenthal) involved in pain
- Respondents from **26** countries provided data:
 - **64** individuals responded:
 - **13/64** responses were removed from the analysis because of incomplete, repetitive or missing answers
 - **51/64** responses were validated and analysed for this report
 - Healthcare professionals (**28**), patient organisations (**12**) and industry (**11**)
 - The highest rates of response were from Italy, UK, Spain, Austria and Finland

2. METHODOLOGY: EUROPEAN ROAD MAP MONITOR 2019

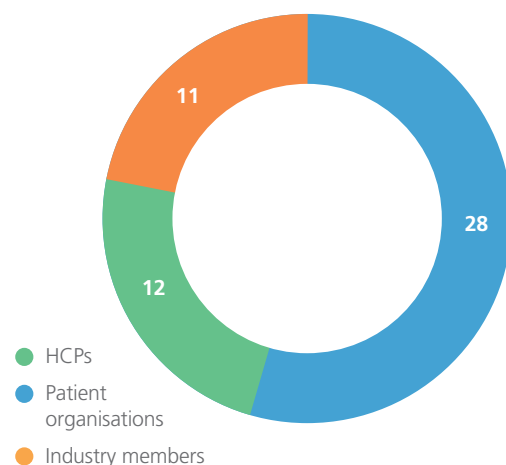
Participating countries and number of respondents

Country	# respon- dents	Country	# respon- dents	Country	# respon- dents
Italy	7	Bosnia and Herzegovina	1	Netherlands	1
UK	5	Bulgaria	1	Norway	1
Spain	5	Denmark	1	Portugal	1
Austria	4	France	1	Republic of Moldova	1
Finland	4	Hungary	1	Russian Federation	1
Germany	3	Ireland	1	Serbia	1
Switzerland	3	Kosovo	1	Slovenia	1
Estonia	2	Latvia	1	Sweden	1
Belgium	1	Lithuania	1		
TOTAL: 51 Responses, 26 Countries					

Responses for UK – most action against pain was being piloted through a programme in Scotland only. The action plan has not been evolved to cover the whole UK area at this time.



Profile of respondents (n=51)



Methodological notes

- Responses were analysed and validated against external sources where possible
- Where there was more than one response per country – responses were consolidated into one, prioritised by responses in the following order:
 1. Healthcare professionals (European Pain Federation EFIC®)
 2. Patient organisations (Pain Alliance Europe)
 3. Industry (Grünenthal)
- Respondents had the chance to answer “I do not know” if no information was available, or leave the answer blank – these results were not included in the percentage calculations
- Survey results are reported as (x /n (%)) to ensure transparency where number of countries included in response (n) is not 26

The preliminary results of the survey and their implications were presented at the Societal Impact of Pain 2019 Symposium on 7 November 2019, in Brussels, Belgium.

2.4 About this report of survey findings

This report provides background evidence and key findings that further substantiate the recommendations and commitments made within the Societal Impact of Pain's 2018 Thematic Network SIP Joint Statement, and outcomes from the ICD and ICF workshop on 6 November 2019 (Annex 2, Ref. 3). European Pain Federation EFIC® national chapters and Societal Impact of Pain representatives may use this information to further investigate and identify gaps in their national policy environments and inform policy makers around the Societal Impact of Pain's four policy priority areas.

3. SUMMARY OF KEY FINDINGS



3.1 Key Findings

- While progress has been made since the 2011 survey, there are still large discrepancies between European governments on the establishment and implementation of specific national pain plans, and limited legal structures are in place to enforce uptake of what is available.
- There is a lack of prioritisation across EU Member States for measuring and monitoring both pain as an outcome and pain as a quality indicator and more needs to be done to align to WHO directive and classification in these areas.
- Pain is not prioritised within national research strategies and best practice approaches such as the establishment of pain registries, collection of broad socioeconomic data, or inclusion of patients in research is not being closely followed.
- Policies are in place to try to maintain workability for those living with pain, although more needs to be done to ensure the support stays in place and that a holistic, centralised approach is established.

3. SUMMARY OF KEY FINDINGS

- Progress has been made with the incorporation of pain into undergraduate medical education in many countries but there are gaps in government initiated public education and resources for patients and caregivers on how to manage pain.

3.2 Call to Action

The Societal Impact of Pain platform calls on European governments and the EU Institutions to:

- Acknowledge the significant burden of pain on both individuals and society and increase prioritisation of pain within healthcare system frameworks, funding and policies
- We ask for the prioritisation of national and European funding to support the continued development and implementation of national guidelines, action plans and supporting legal frameworks to enable the prioritisation and uptake of better and more integrated services for pain management in every country across Europe.
- 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.
- 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 consider the propositions on pain research prioritisation from the civil society and scientific community.
- 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.
- Prioritise pain education for healthcare professionals, patients, policymakers, and the general public
 - We call for the sharing of best practice, identifying gaps, and proposing recommendations to foster education of healthcare professionals as well as awareness raising and education of patients, policymakers, and the general public on pain, across Europe.

4. THE RESULTS OF OUR SURVEY



4.1 National pain guidelines and national/ regional pain plans

The problem:

Despite the 2001 Declaration on Pain (Annex 2, Ref. 1) published nearly 20 years ago, there continues to be large discrepancies between European Member States and the extent to which their governments recognise adequate pain care as a citizen's right. The Societal Impact of Pain launched in 2009, has been making progress to improve the prioritisation of pain in Europe through the establishment of a European wide multi-stakeholder platform. Despite these efforts and progress in this area driven by the Societal Impact of Pain platform in the past 10 years, many countries still lack specific guidelines and significant disparity still exists in the prioritisation of pain by national governments and EU Institutions across Member States.

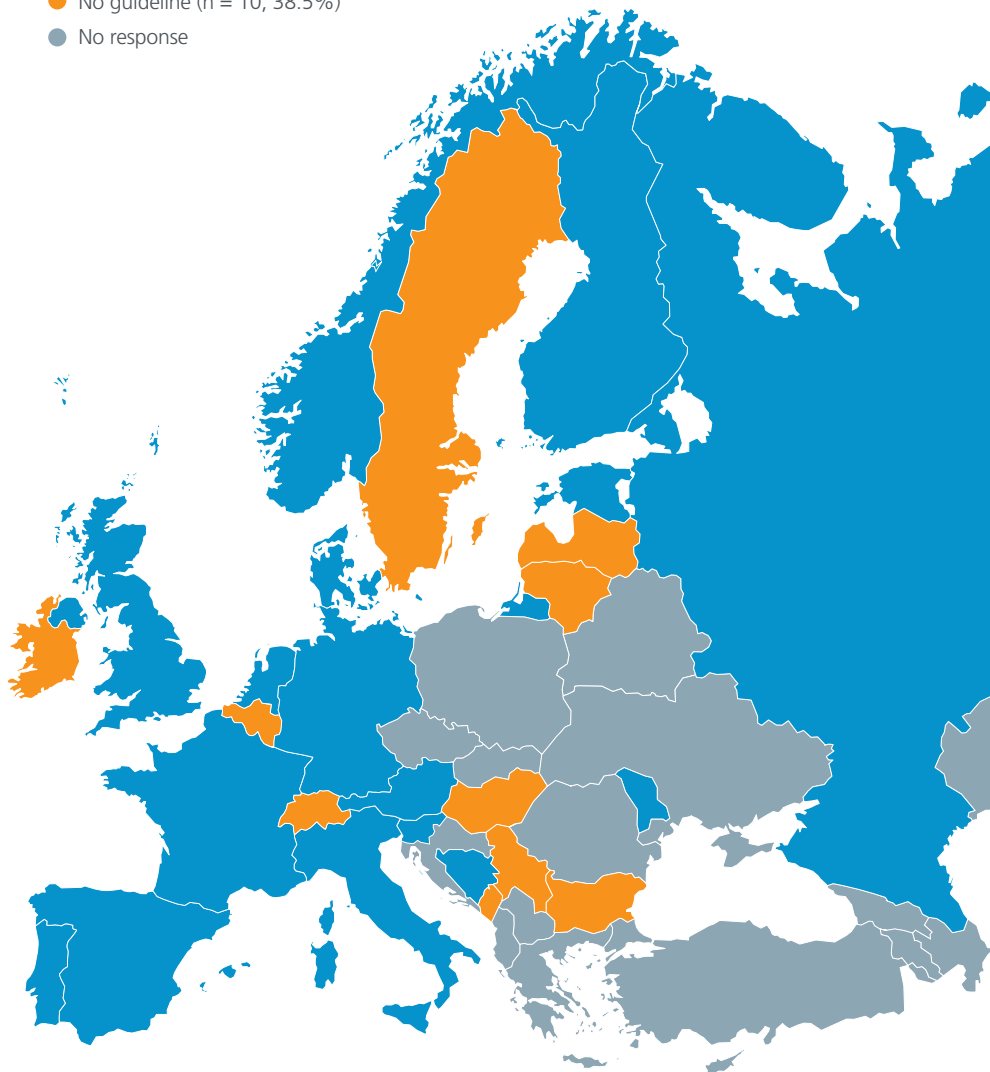
What the research found:

Nearly two-thirds (16/26 (62%)) of countries surveyed now report having national guidelines for pain management in place. Just over a third (11/26 (42%)) including Austria, Belgium, Bosnia and Herzegovina, Finland, France, Italy, Netherlands, Portugal, Russian Federation, Sweden, and UK (Scotland) have launched action plans most commonly covering both acute and chronic pain with national working groups set up to report on progress. However, only 4 countries reported that their action plan was implemented.

4. THE RESULTS OF OUR SURVEY

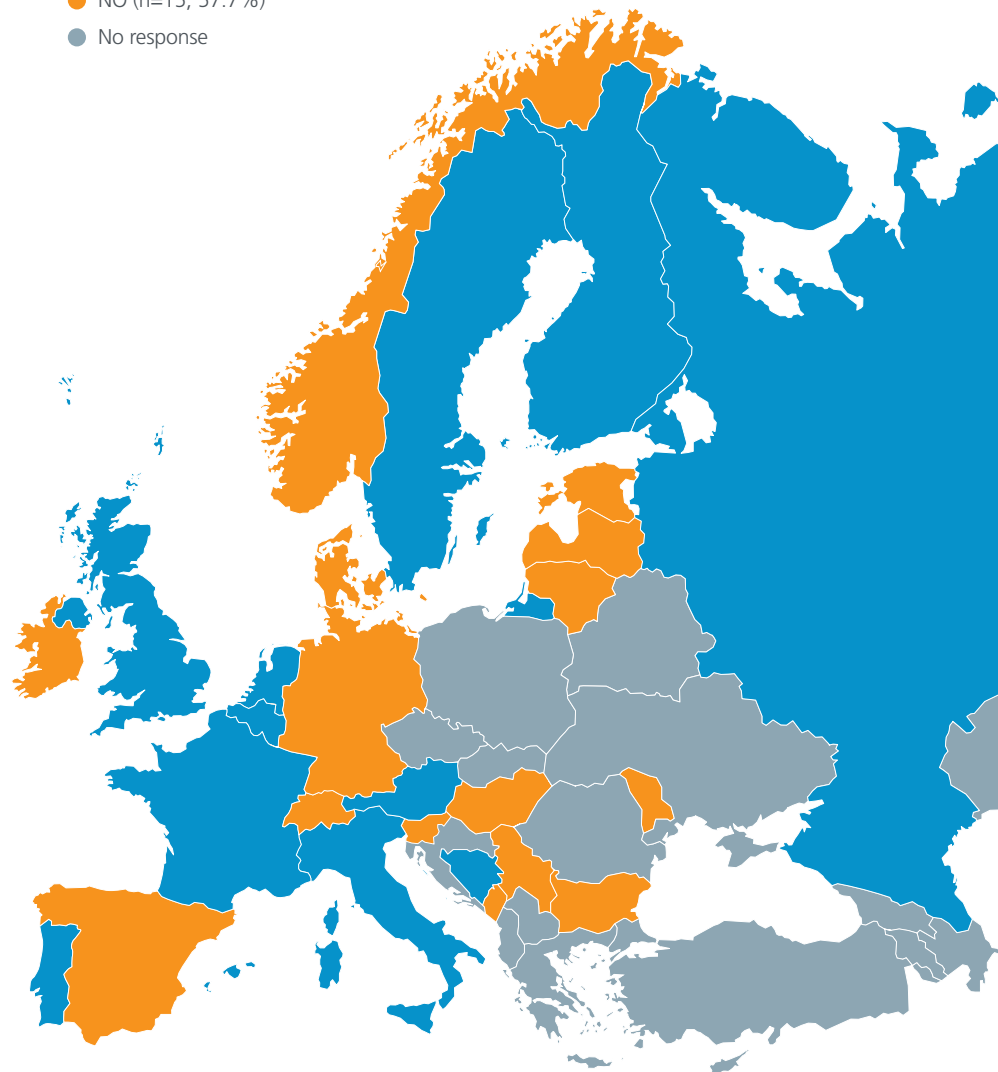
Countries with national guidelines for pain management

- Guideline available (n = 16; 61.5%)
- No guideline (n = 10; 38.5%)
- No response



Has a regional/national pain plan been launched?

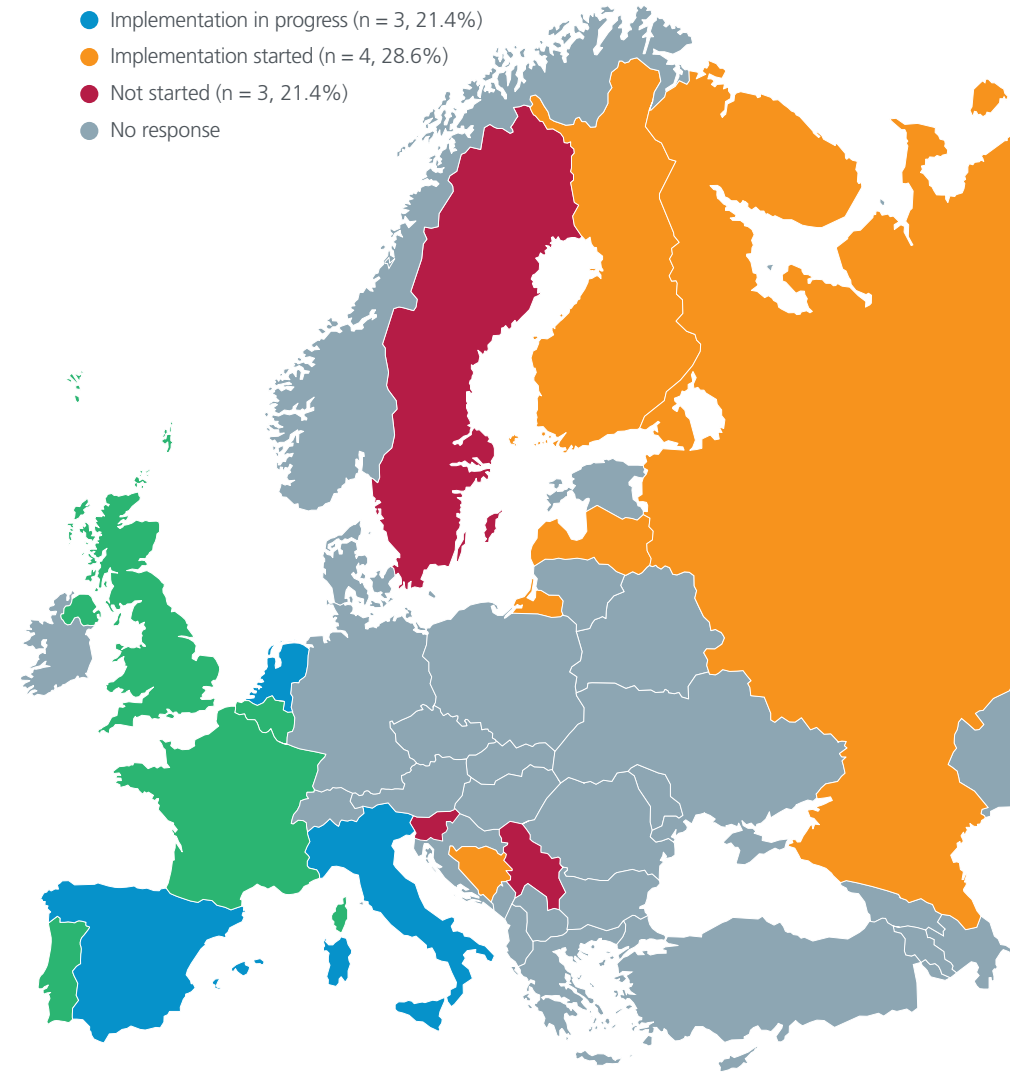
- YES (n=11; 42.3%)
- NO (n=15; 57.7%)
- No response



4. THE RESULTS OF OUR SURVEY

What is the status of implementation of the national/ regional pain plan?

- Implemented (n = 4, 28.6%)
- Implementation in progress (n = 3, 21.4%)
- Implementation started (n = 4, 28.6%)
- Not started (n = 3, 21.4%)
- No response



A possible reason for this could be that over half (15/26 (58%)) of the countries report not having a multi-stakeholder platform in place to represent the Societal Impact of Pain. However, over half (14/25 (56%)) do say they now have nationally agreed multidisciplinary teams that meet IASP criteria.

Countries with multi-stakeholder teams that meet the IASP criteria

Austria
Belgium
Denmark
Finland
Germany
Ireland
Italy
Latvia
Portugal
Russian Federation
Serbia
Spain
Switzerland
UK

That said, despite efforts in many countries, just over a third (9/25 (36%)) have acute pain services established in all their hospitals and less than a third (8/25 (32%)) have outpatient acute pain services established.

In addition, less than one third (7/25 (28%)) report knowing of specific laws or legally binding regulations to ensure pain plans are implemented.

Countries with specific laws or legally binding regulations on pain

Belgium
Denmark
Italy
Lithuania
Portugal
Serbia
Spain

What we conclude:

There are still large discrepancies between European countries on the establishment and implementation of specific national pain plans and limited legal structures are in place to enforce uptake of what is available.

Initiatives to support the better coordination and management of pain in countries across Europe are evolving and have improved since the inaugural Societal Impact of Pain Road Map Monitor in 2011 (Annex 2, Ref. 4). However, more must be done to ensure all countries have an established pain management plan in place and are encouraged to implement their national plans, to enable consistent delivery of better standards of care in pain management across Europe.

4.2 Pain as a Quality Indicator

The problem:

There are several EU initiatives that seek to address data collection on pain, through the establishment of indicators. Whilst some exist in theory, their implementation is not consistent (SIP Thematic Network: Pain as a health quality indicator - Annex 2, Ref. 8).

What the survey found:

Less than half the countries surveyed (11/25 (44%)) report having any national or regional standards available to measure chronic pain outcomes. Where there was something in place, these standards mostly measured pain intensity or frequency; and quality of life outcomes for example physical function, ability to perform activities of daily living, work and recreation. On top of this, of the 26 countries surveyed, only one (Bosnia and Herzegovina) was able to report having a system to actually monitor outcomes. Although from the United Kingdom, Scotland does intend to have a system for monitoring outcomes by mid-2020.

In terms of specific quality indicators, 20/25 (80%) countries could not report of knowing of any

national quality indicators for pain in their country, and like with the measurement of outcomes, only a quarter (4/16 (25%)) could report of a system being in place to monitor quality indicators for pain.

In fact, despite directive from the World Health Organisation (WHO) only a few countries are leading initiatives to implement the WHO's International Classification of Diseases 11th Revision (ICD) and International Classification of Functioning, Disability and Health (ICF). These frameworks have been set out to provide a foundation for consistent identification of health trends and statistics, including disability; and establish an international standard for reporting on diseases and health conditions, including pain. Of those countries surveyed that are implementing these frameworks, most will be launched within the next two years.

We need a consistent metrics for chronic pain across the EU.



4. THE RESULTS OF OUR SURVEY

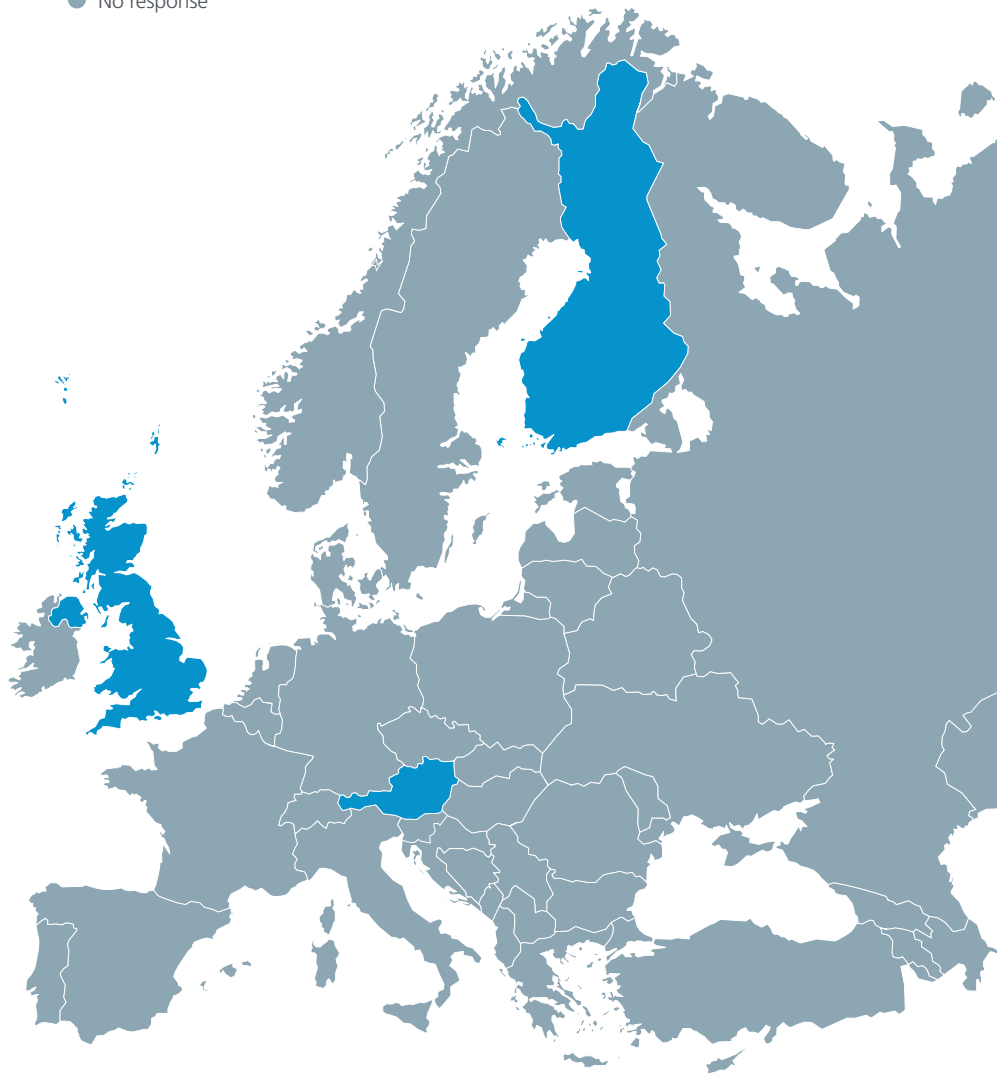
Are activities taking place for the implementation of ICD-11?

- YES (n = 11, 40.7%)
- No response



Are activities taking place for the implementation of ICF?

- YES (n=3, 11.5%)
- No response



What we conclude:

There is a lack of prioritisation across EU Member States for measuring and monitoring both pain as an outcome and pain as a quality indicator. More needs to be done to align with the WHO directive and classification in these areas.

The findings of the survey point to a distinct lack of prioritisation when it comes to having standard measures for chronic pain, both for pain outcomes in general and also pain as a quality indicator, and very little has been done so far to align to WHO's ICD and ICF classifications. In both cases, systems to monitor these standard outcomes and quality indicators seem relatively scarce. More needs to be done to prioritise all these elements both at the EU and Member State levels.

4.3 Pain Research

The problem:

While projects co-funded by the European Commission and Member States exist for pain research, funding is inconsistent, lacks coordination between systems and projects, and faces severe cuts. This places a burden on civil society partnerships to conduct and fund research programmes (SIP Thematic Network: Research on pain - Annex 2, Ref. 9).

What the survey found:

Respondents cite public bodies (14/47 (30%)), industry (11/47 (23%)) and medical societies (11/47 (23%)) as being the main funding bodies of pain research in their country. In terms of government led initiatives, while public bodies put forward funding for pain research in many countries; pain is not known to be mentioned in three quarters (19/25 (76%)) of respondent countries' national research strategies. When a pain research strategy is present most respondents (20/25 (80%)) report that implementation has not started yet.

Patient involvement is not mandatory in developing pain research projects in at least half (14/25 (56%)) of the countries surveyed. Where it is mandatory, some respondents report an "opportunistic" or "episodic" representation of patients. For example

to meet grant application criteria the inclusion of a patient might happen by chance.

On top of this, despite the guidance from WHO's International Classification of Diseases 11th Revision (ICD) just over a quarter (7/25 (28%)) of countries surveyed could confirm that they collect and document socioeconomic data on pain such as the impact of pain on medication costs, hospital-based services, disability compensation, days of work missed and early retirement. Less than a third (8/25 (32%)) report of there being national or regional pain registries or other databases in place to capture data for research.

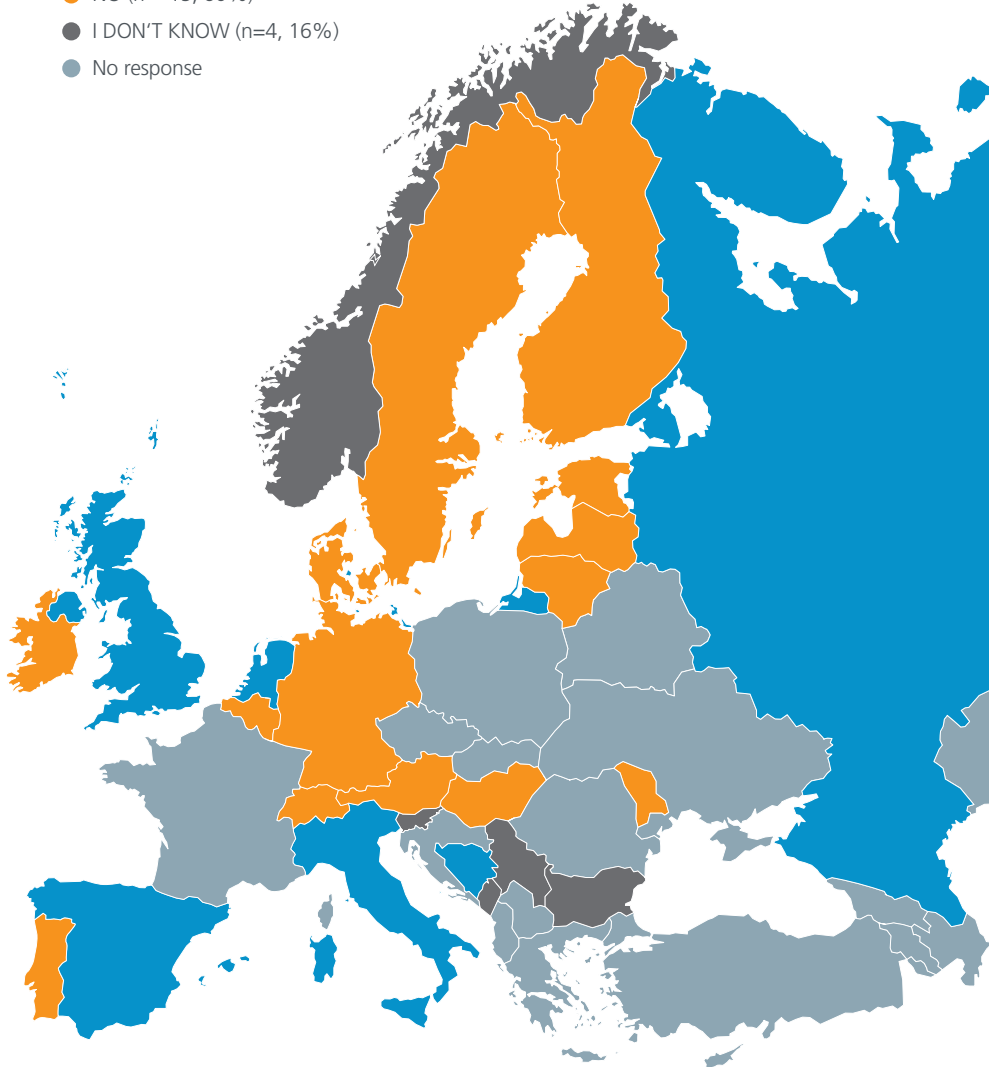
Over half (14/24 (58%)) countries that responded do however have publicly available national epidemiology data on chronic pain, most of which are available within scientific publications (8/22 (36%)) and policy papers (9/22 (41%)).



4. THE RESULTS OF OUR SURVEY

Is pain mentioned in national research strategies?

- YES (n=6, 40%)
- NO (n = 15, 60%)
- I DON'T KNOW (n=4, 16%)
- No response



What we conclude:

Pain is not prioritised within national research strategies. Best practice approaches such as the establishment of pain registries, collection of broad socioeconomic data, or inclusion of patients in research is not being closely followed.

While epidemiology data on pain is being collected across several countries and funding for pain research does exist in some form from various sources, gaps do exist and national strategy on pain seems not to be a priority for many nations. More needs to be done to identify and close the gaps on research funding for pain. Comprehensive registries should be established to collect multi-disciplinary data on the broad impacts of pain, including socioeconomic and scientific data with meaningful patient involvement. Overall improvements in these areas will help to improve the quality of data on pain care to support the national policy work.

4.4 Pain and Employment

The problem:

Chronic pain has a major impact on workforce participants and productivity and is not adequately acknowledged nor addressed (SIP Thematic Network: Pain as a factor in employment - Annex 2, Ref. 11). Pain-related conditions result in an increasing part of the workforce retiring too early. Musculoskeletal pain causes almost 50% of all absences from work lasting at least three days in the EU and 60% of permanent work incapacity (Breivik et al. 2013).

What the survey found:

There are few national or regional policies in place to incentivise people living with chronic pain to stay at work (8/25 (31%)) and to reintegrate those that have left work (7/25 (28%)). Where these policies are in place respondents report of discontinuity and a lack of a holistic centralised approach.

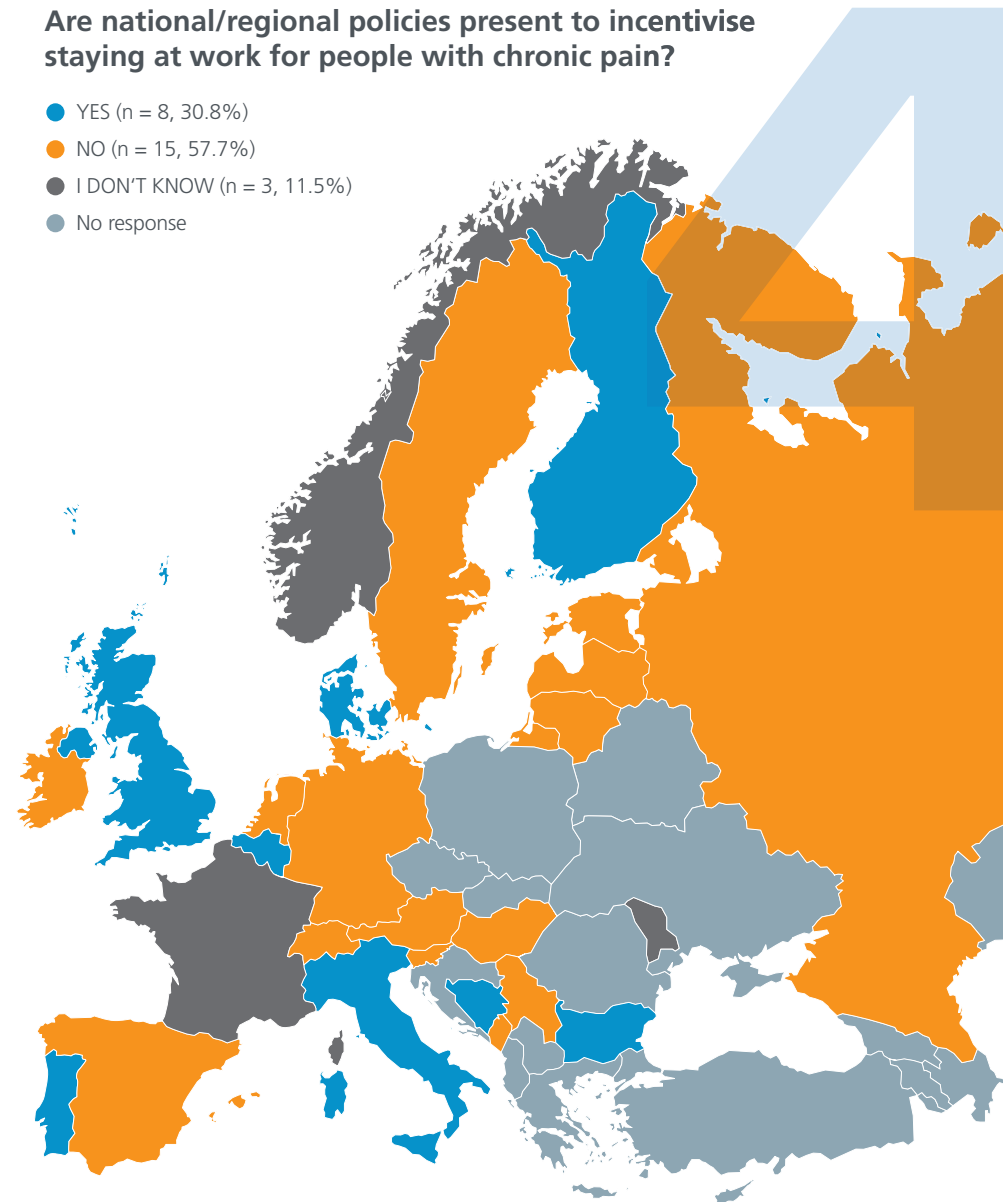
In terms of policies to support the vocational rehabilitation of people living with pain back into the workplace, there is an overall lack of awareness among countries ((8/25 (32%) said don't know), indicating a gap in knowledge on this topic and potentially strong variations among national policies.

Chronic pain has a major impact on workforce participation and productivity.



Are national/regional policies present to incentivise staying at work for people with chronic pain?

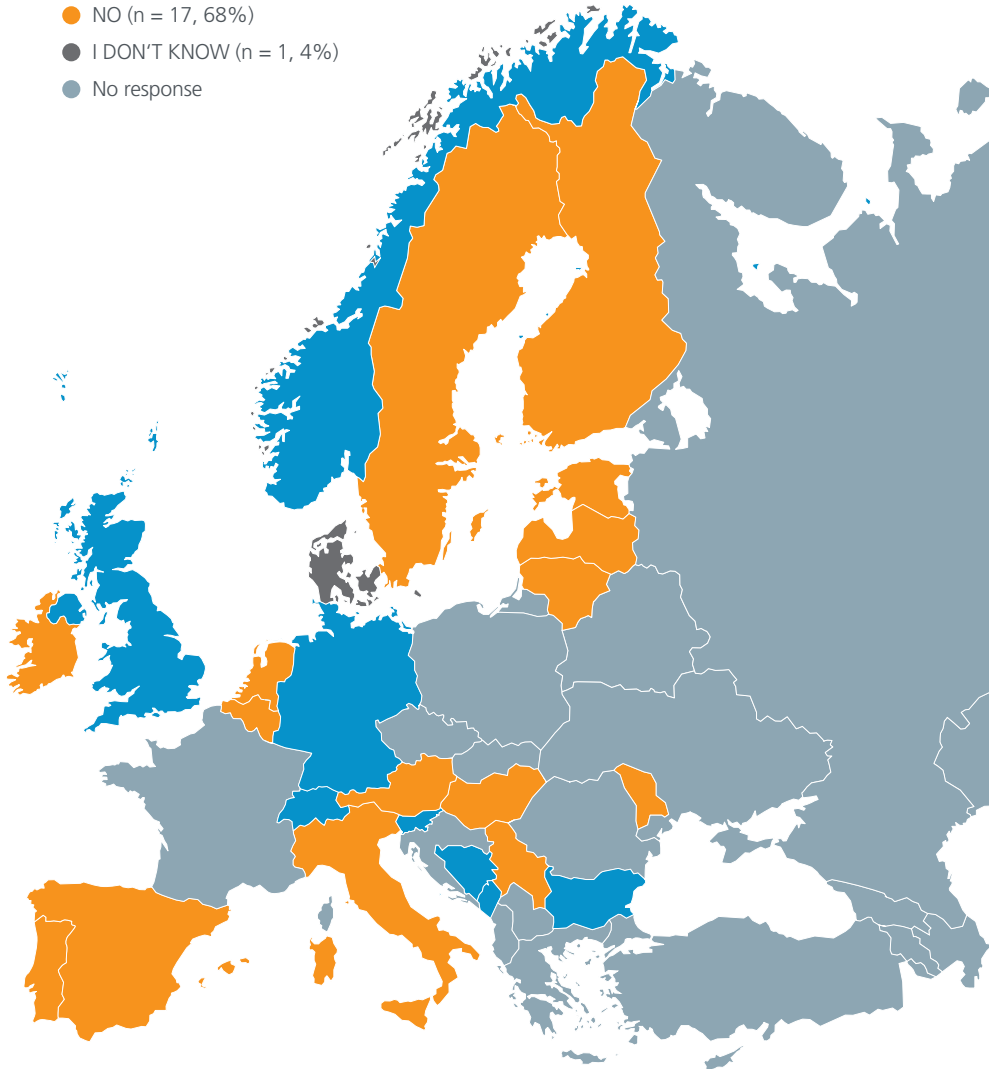
- YES (n = 8, 30.8%)
- NO (n = 15, 57.7%)
- I DON'T KNOW (n = 3, 11.5%)
- No response



4. THE RESULTS OF OUR SURVEY

Are national and/or regional regulations in place to reintegrate people with chronic pain into work?

- YES (7, 28%)
- NO (n = 17, 68%)
- I DON'T KNOW (n = 1, 4%)
- No response



What we conclude:

Policies exist to maintain workability for those living with pain, although more needs to be done to ensure the support stays in place and that a holistic centralised approach is established.

Policies to support workability for people living with pain exist in just a third of countries surveyed, suggesting that many countries are falling short in helping to keep people living with chronic pain in employment. This comes despite the socioeconomic and personal co-morbid implications that falling out of the workplace may have for many people affected. Where policies do exist, again, in many cases they don't seem to comprehensively support the patient journey, with patients in the survey citing discontinuity and lack of a holistic centralised approach. More needs to be done to establish and roll-out best practice policies in support of workability, that protect both the employer and the employee to enable workability to the degree to which the individual living with pain is willing and able to take on.

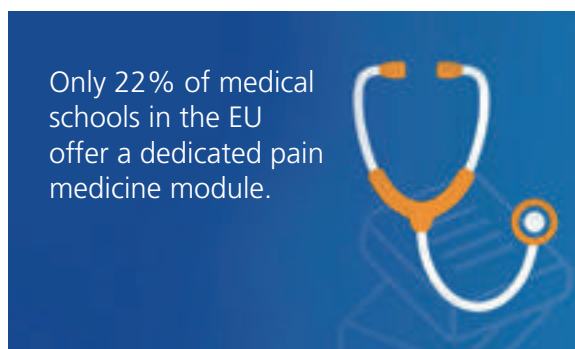
4.5 Pain Education

The problem:

Pain medicine is not taught as a dedicated unit in most European medical schools and there is a lack of awareness of the societal impact of pain in the broader community. Pain education within the medical curricula remains limited. In a study published in 2015, it found that even if pain was taught, it was not within a specific pain module. Alongside formal academic education, education of other stakeholders is of equal importance. There has been limited EU- or Member State-led activity in relation to specific pain-focused awareness raising activities. Most awareness raising activities have been conducted by civil society, aimed at the general public as well as to policymakers (SIP Thematic Network: Pain education - Annex 2, Ref. 10).

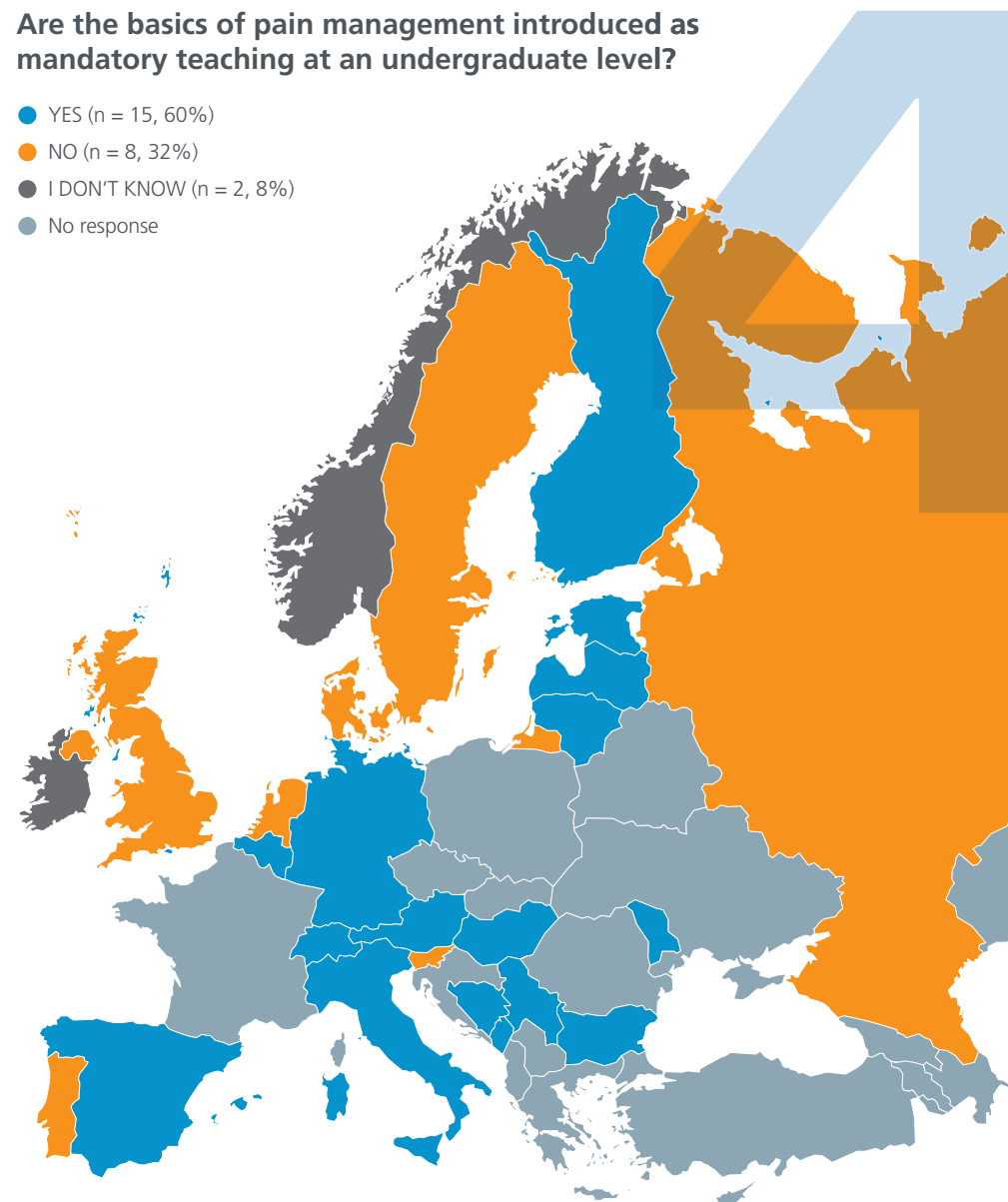
What the survey found:

The basics of pain management has now been introduced as mandatory in undergraduate teaching in nearly two thirds (15/25 (60%)) of surveyed countries, particularly for medical doctors, physiotherapists and nurses, with specialist training for physicians reported in over half (13/25 (52%)) of countries. That said, according to respondents' feedback the minimum mandatory requirement of hours for pain medicine teaching can vary significantly.



Are the basics of pain management introduced as mandatory teaching at an undergraduate level?

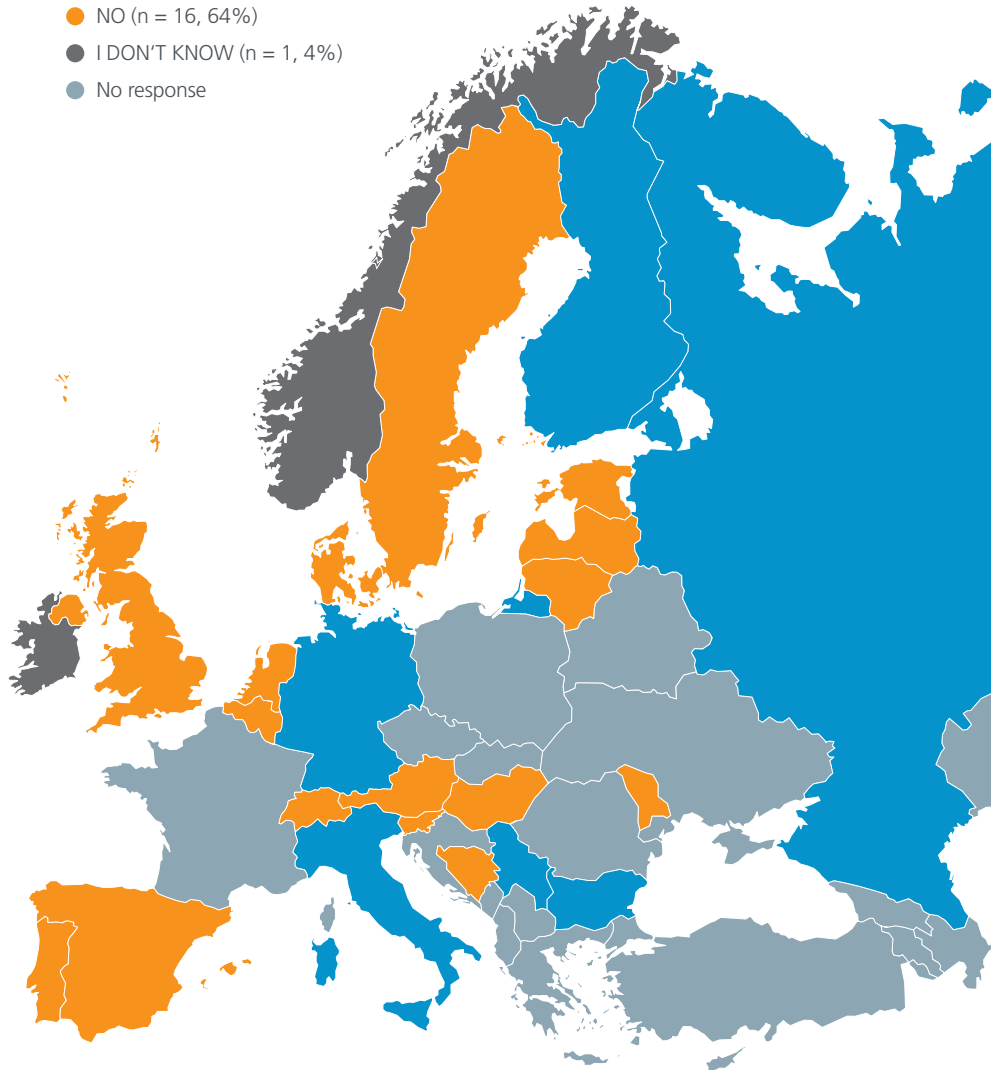
- YES (n = 15, 60%)
- NO (n = 8, 32%)
- I DON'T KNOW (n = 2, 8%)
- No response



4. THE RESULTS OF OUR SURVEY

Are national pain education programs available for the general public?

- YES (n = 8, 32%)
- NO (n = 16, 64%)
- I DON'T KNOW (n = 1, 4%)
- No response



On the other side, only 8/25 (32%) countries report there being national pain education programmes available for the general public, although in some cases, this gap is being filled by education led by charities and universities. These groups provide hospital-based pain management programmes and information and resources on 'learning to live with chronic pain'. Patient involvement in the development of these educational tools is not mandatory in nearly three quarters (17/24 (71%)) of countries and the quality of these tools is reported to be varied. In fact, only half the countries (12/24 (50%)) reported that healthcare professionals used these tools to help inform patients about pain and pain management.

What we conclude:

Progress has been made with the incorporation of pain into undergraduate medical education in many countries but there are gaps in government initiated public education and resources for patients and caregivers on how to manage pain.

More needs to be done to ensure greater consistency across EU Member States in relation to medical education on pain, with regards to a minimum requirement for each identified specialist group (medical doctors, physiotherapists, nurses etc). A basic level of information for the public on how to manage living with pain, should be provided by all national health services to ensure a certain standard of quality information to the public. This can then be supplemented with information provided by patient and/or healthcare professional organisations – which is already happening in many countries, although the quality of information seems to vary.

4.6 Reported challenges and achievements per country

Country	Achievements	Challenges
Belgium	National project for multidisciplinary pain centres Public-professional collaborations on pain	Funding Time Research
Bosnia and Herzegovina	In March 2017 the Ministry of Civil Affairs organised a meeting of Health Authority and Pain Association representatives, who agreed to draw up the Action Plan for pain control in Bosnia and Herzegovina and establish a working group to monitor progress	
Bulgaria	Improved pain education among doctors, residents in medicine and patients	Developing pain centres in as many hospitals as needed Determining approved protocols for pain management Obtaining financial support from the national health insurance fund for pain related procedures
Denmark	More discussion around pain than before but limited action so far	Not understanding that there are large inter-individual differences in response to pain treatment - it is not a one size fits all treatment
Finland	Collection of socioeconomic data on pain Improved knowledge how pain management should be organised	Funding for organising pain management Alignment from political parties on how to fund and organise Finland's healthcare system Parties not listening to pain management specialists
Germany	Interdisciplinary multimodal pain management for out-patient treatment is under development	National/political pain agenda Implementation of a National Research Strategy Development of Quality Indicators for Pain Lobbying of physicians who rarely accept opinion of other professionals in decision making processes Opinion/input missing from: psychologists, physiotherapists, social workers, occupational health therapists and patients
Hungary	Formal pain strategies and laws should be established soon	Government
Ireland	2014 was the year pain medicine was made a specialism in Ireland	Accurate data that is publicly available, which would inform a National Pain Strategy
Italy	Reducing chronic pain incidence Pain education Implementation of a hub and spoke pain network	Guidelines Culture on pain management Lack of financial funds, structural locations and professional equipment

4. THE RESULTS OF OUR SURVEY

Country	Achievements	Challenges
Kosovo	Hosting events for healthcare professionals from the National Pain Association Elective course in the Faculty of Medicine for pain management	Establishing services for the treatment of acute and chronic pain Establishing protocols for pain management Profiling doctors and nurses for pain management based on the EFIC® curriculum Creating patient booklets on knowledge and care of chronic pain Creation of national strategy for pain management
Latvia	Separate sub-speciality for pain (algologist)	
Lithuania	Pain management training programme for doctors	To engage policy stakeholders and public around pain
Netherlands	Development of an acute pain service Multidisciplinary collaboration with opioid taskforce – including the Pain Association and Ministry of Health	Knowledge on pain (physicians and general public) National standard for multidisciplinary pain management Chronic pain indicators
Portugal	Pain established as a fifth vital sign A pain consultation/unit in all public hospitals Guidelines for: Organising acute pain units in anaesthesiology departments Pain in obstetrics Launch of the national SIP platform Two universities with post-graduate pain courses Pain included as a competency by National College of Physicians	Pain education Undergraduate education for diverse professionals Lack of education for all professionals Education of patients and public Barriers with e-learning for older patients
Republic of Moldova	National Protocol on “Management of Cancer Pain” and creation of a working group Creation of a new speciality for medical students “Palliative care” (2017), with a textbook edition 2-3 educational one-day events per year for GPs about pain management, held by Moldovan Pain Society, supported by Menarini Foundation (around 500 participants)	Endemic corruption and loss of specialists Social harassment of medical workers, and their low social status Pain is not a priority for the Moldovan health system
Russian Federation	Regular postgraduate educational activities for doctors Discussions around the organisation of pain care at the Russian Parliament	Absence of pain within the approved state scientific research programme Organisation of chronic pain care
Slovenia	Decision to prioritise pain by the National Council Commission for Healthcare Discussions being held with the Secretary for Healthcare at Ministry for Health	Governmental changes

Country	Achievements	Challenges
Spain	Consensus document on a National Pain Strategy	Pain prioritised as a mandatory issue in Public Health Policies Effective pain units
Sweden	National Pain Working Group has started and will be followed by regional Working Groups on Pain	To establish mandatory education on pain for all stakeholders including politicians
Switzerland	Pain therapy is available to patients according to their needs	To achieve recognition of pain medicine as a speciality Chronic pain is still not seen as its own disease, but a symptom
UK	Multidisciplinary management of pain Access to highly specialised services	Timely access to services Funding restrictions on certain treatments

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5. CONCLUSIONS

The results described above reflect the knowledge of local European Pain Federation EFIC® Chapters, Pain Alliance Europe member organisations, and Grünenthal representatives from 26 countries. The findings of this report demonstrate the current status of national policies and guidelines related to the four key priorities of the SIP Joint Statement: pain as a quality indicator, and pain in research, education and employment.

Overall, we can report on some great examples of progress made in the countries surveyed. However, there is still a long way to go before all EU Member States, meet the standards for pain set out in the Road Map for Action. There is still work to be done to ensure that every country has some form of national guideline and action plan for pain management in place and that it is being implemented. In every area surveyed there were significant gaps in policies to support pain as a quality indicator; to enable the collection of data to support evolving research; to routinely encourage pain management education for healthcare professionals and patients; and to support people living with pain to maintain workability.

A diverse and growing stakeholder community is engaging on pain policies at the national level, enhanced by the launch of SIP national platforms to implement the requirements as defined in the SIP Roadmap for Action from 2011 (Annex 2, Ref. 4).

The SIP community remains committed to working across Europe to establish the foundations for a consistent standard of pain management, and from there work towards improving every aspect set out under our policy priorities - towards greater prioritisation of pain within European health system frameworks.

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ANNEX 1: THE 2019 SURVEY QUESTIONS

National health frameworks of pain

- Do you have a multi-stakeholder platform in place for representing the Societal Impact of Pain in your country?
 - If YES, does it involve (more than one answer possible)?
- Is there a law (or legally binding regulation) in your country specific to pain management and pain treatment in place?
- Is there any national guideline for pain management in place?
- Has a national/regional action plan against pain been launched?
 - If YES, please select all the statements applicable to the plan (multiple answers possible)
 - It covers acute pain
 - It covers chronic pain
 - The action plan is publicly available
 - A (national) working group on pain management been established to report on its progress
 - If YES, please tick the box reflecting the status of implementation in your country
 - Implementation completed
 - Implementation nearly completed
 - Implementation in progress
 - Implementation started
 - Implementation not started
- Do you have nationally agreed pain management multidisciplinary teams that meet IASP criteria?
- Are there acute pain services established in all hospitals?
- Are there outpatient acute pain services established?
- What are the major achievements in your country with regards to national pain strategies?
- What are the biggest or major challenges in your country with regards to pain strategies?

Pain as a Quality Indicators

- Are there national quality indicators for pain?
 - If YES, do you have a system to monitor the quality indicators for pain?
- Are there national and/ or regional standards available to measure chronic pain outcomes in your country?
 - If YES, please tick relevant box(es)
 - Outcome measure of pain intensity and/ or frequency
 - Quality of life outcomes (e.g. physical function, ability to perform activities of daily living, work, recreation)
 - Emotional wellbeing (e.g. depression, anxiety, anger, sleep disturbance)
 - Social consequences (e.g. marital/ family relations, sexual activity/ intimacy, social isolation)
 - Socioeconomic consequences (e.g. healthcare costs, disability, lost productivity)
 - If YES, is there a system to monitor the outcomes?
- Are there national or regional activities taking place to implement ICD-11 (the International Classification of Diseases 11th Revision)?
 - If YES, what is the expected timeline for implementation?
- Are there national or regional activities taking place to implement ICF (the International Classification of Functioning, Disability and Health)?
 - If YES, what is the expected timeline for implementation?

ANNEX 1: THE 2019 SURVEY QUESTIONS

Pain Research

- Do you collect and document socioeconomic data on pain (e.g. medication costs, hospital-based services, disability compensation, days of work missed, early retirement)?
- Are there national/ regional pain registries in your country or other databases?
- Is pain mentioned in the national research strategy of your country?
- Is a national research strategy for pain implemented in your country?
- Who is the main funding body for pain research in your country among the below?
 - Public bodies
 - Industry
 - Charities/ NGOs
 - Medical societies
- Is patient involvement mandatory in developing pain research projects?
- Do you have any publicly available national epidemiology data on chronic pain?
 - If YES, are those data publicly available through
 - Scientific publications
 - Policy papers
 - Grey literature

Pain in Employment

- Are there any national or regional policies in place to incentivise staying at work for people suffering from chronic pain?
- Are there any national or regional regulations to reintegrate people living with chronic pain into work?
- Is pain management included in vocational rehabilitation programmes?

Pain Education

- Are the basics of pain management introduced as mandatory teaching at an undergraduate level?
 - If YES, please specify for which profession (multiple answers possible):
 - Medical doctors
 - Physiotherapists
 - Nurses
 - Psychologists
 - Other
- Does formal, agreed, specialist pain training exist at national level for physicians?
 - If YES, what is the minimum mandatory requirement of hours for pain medicine teaching in your country?
- Are national pain education programmes available for the general public?
 - If YES, which of the following:
 - Pain management CDSMP (Chronic Disease Self-Management Programme) by Stanford
 - Health literacy on pain
 - National or regional e-health tools/ pain monitoring applications
 - Are the above tools used by healthcare professionals to inform patients about pain and pain management?
- Is it mandatory to have patients involved in the development of educational tools on pain?

Societal Impact for Pain resources

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