The Societal Impact of Pain – A Road Map for Action

European Road Map Monitor 2011

Pilot Project - Preliminary Results

Publisher:

Authors:
Rolf-Detlef Treede, Medical Faculty Mannheim, Heidelberg University, Germany
Norbert van Rooij, Governmental Affairs & Health Policy, Grünenthal GmbH

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Dear Reader,

Chronic pain poses a substantial burden on the individual but also on society, including an enormous economic burden on health care systems. A structured programme of EU institutions targeting these challenges and the long-term consequences of chronic pain is thus needed:

- Chronic pain is one of the major reasons for early retirement and individuals to leave the labour market, which undermines the Europe 2020 Strategy for smart, sustainable and inclusive growth.
- Chronic pain also undermines the European goal for healthy ageing, as expressed in the European Innovation Partnership Action and Healthy Ageing.
- Chronic pain directly affects sufferers and their quality of life and should be addressed by a common, horizontal approach according to a resolution on non-communicable diseases recently adopted by the European Parliament.

EFIC® is a multidisciplinary, professional organisation in the field of pain science and medicine, representing 35 national European pain societies (IASP® chapters) with a total of some 20,000 scientists, physicians, nurses, physiotherapists, psychologists and other healthcare professionals across Europe, who study pain or treat patients suffering from pain. EFIC® is registered as a non-profit organisation in Belgium and has organised two international symposia on the Societal Impact of Pain (SIP) in Brussels in 2010 and 2011.

The European Federation of IASP® Chapters (EFIC*) was responsible for the scientific framework of SIP 2011 and this was endorsed by a number of patient advocacy and scientific organisations. The pharmaceutical company Grünenthal GmbH was responsible for logistical support, preparation and the organisation of this international event. The purpose of the SIP symposia is to create a platform for discussion among all stakeholders with the aim to raise awareness of the relevance of the impact that pain has on our societies, health and economic systems, to exchange information and to share best practices across all members states of the EU, as well as to develop and foster European-wide policy strategies and activities for improved pain management in Europe.

An important outcome of SIP 2011 was the Road Map for Action, which outlines the key issues on how the EU institutions and member states could effectively address the societal impact of pain at both EU and national levels. The Road Map has been endorsed by more than 55 organisations with various interests across Europe, which reflects the broad relevance this document has for the European Union.

The ‘Road Map for Action’ outlines seven key policy dimensions on how EU institutions and member states can effectively address the societal impact of pain at EU level. It aims to provide politicians and health care decision-makers with a benchmark on national policy in pain care throughout Europe. Recognising the need for an improved pain care agenda, the European Road Map Monitor 2011, which is based on the ‘Road Map for Action’, has been developed to understand the key issues that need to be addressed to effectively tackle the societal impact of pain.

Preliminary results from this first European Road Map Monitor into pain care were presented in Hamburg (21-24 September) at the 7th Congress of the European Federation of the IASP® Chapters (EFIC®). These early findings offer a snapshot of how countries have addressed and implemented, nationally and internationally, the “Road Map for Action” for improved pain care in Europe. The study looked at the extent to which pain was recognised as a specific health condition. There were also questions about the status of mandatory teaching programmes on pain care and the existence of local stakeholder platforms sharing best-practice policies.

The preliminary findings from the European Road Map Monitor 2011 have reinforced many of the ongoing issues relating to the societal impact of pain. Although the majority of countries in Europe reported to be in the process of establishing some form of pain platform, the research revealed some of the unmet needs of chronic pain patients. It also showed there was inadequate knowledge and information about pain management and ten years on from the EFIC® Declaration of Pain, national and EU policy action had been very limited and was not adequately prioritised with governments and health providers in many parts of Europe.

On behalf of EFIC® I wish you an interesting read,

Yours sincerely,

[Signature]

Prof. Hans G. Kress, MD, PhD
President of EFIC®
The Societal Impact of Pain
“A Road Map for Action”

We call on European governments and the EU Institutions to:

1. Acknowledge that pain is an important factor limiting the quality of life and should be put on the top of the priority list 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 has 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.

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.

Management Summary
European Road Map Monitor 2011

The European Road Map Monitor 2011 is an evaluation based on the EU policy document ‘A Road Map for Action’, which was finalised and presented at the symposium, ‘Societal Impact of Pain 2011’, at the European Parliament in Brussels in May 2011. It outlines seven concrete steps on how national governments and EU institutions can effectively address the societal impact of pain in Europe.

The preliminary data from the Road Map Monitor 2011 give an initial overview of how the Road Map for Action, and its national and international implementation, is developing across the EU and its Member States. The research tool was established by EFIC® to provide politicians and health care decision-makers with a benchmark on national policy in pain care throughout Europe.

The early findings from the European Road Map Monitor 2011 have reinforced many of the on-going issues relating to the societal impact of pain. Although the majority of countries reported to be in the process of establishing some form of national pain policy platform, the research revealed some of the challenges facing countries in establishing their own chronic pain policy.
The societal impact of pain and chronic pain is a major issue affecting the health, well-being, and productivity of citizens throughout Europe. A network within the health system for pain management has been installed to ensure that pain care is a top priority for the national statutory health authorities on pain care and its impact on society has been established. The quality of care and services provided for patients, their family, care-givers, employers, and the general public (“pain is real”) has been launched.

An educational programme on pain pathophysiology for psychologists, nurses, and other health care professionals has been established. Pain medicine and care has been introduced as a mandatory teaching subject in curricula for physicians, nurses, pharmacists, and other healthcare professionals, notably through further education (in-service or postgraduate), continuing education (refresher courses, seminars, symposiums, courses, workshops, etc.), and via self-learning (reading, internet, courses, etc.).

Pain care is a top priority for the national statutory health care authorities. Adequate financing (early diagnosis and secondary prevention) have been implemented. Comparison and benchmarking of best practices between regional health authorities on pain care and its impact on society has been established. A network within the national health system for pain management to improve the quality of life of European citizens.

The Roadmap Monitor 2011 was finalised in workshop 2 at the symposium “The Societal Impact of Pain.” As such it has been available as possible. Information was gathered from 19 EFIC® chapters and 14 Grünenthal affiliates. EFIC® data was used where both organisations responded.

The results were first presented at the symposium “The Societal Impact of Pain in Europe” during the EFIC® Congress in Hamburg on 23 September 2011.

Methodology
European Road Map Monitor 2011

A 3-page questionnaire was designed by EFIC® board members to establish a tool to monitor annually the implementation of the road map at a national level throughout Europe. Moreover, additional questions referring to major achievements or major problems a country has encountered implementing its “Road Map for Action” have also been included.

The questionnaire was distributed to all 35 EFIC® chapters as well as representatives of Grünenthal national affiliates, in order to establish the validity of the survey as a useful tool. 35 countries were invited to participate in this initial survey. 26 nations provided data for this inaugural version of the European Road Map Monitor 2011. The purpose of this preliminary phase was to compare as much information available as possible. Information was gathered from 19 EFIC® chapters and 14 Grünenthal affiliates. EFIC® data was used where both organisations responded.

Additional Questions:

- Where are you in the process of implementing the Roadmap Monitor 2011?
- Have you had major achievements or major problems in your country?
- Have you developed a platform for representing SIP including other stakeholders?
- Is there a platform in place for representing SIP including all national organisations representing pain (e.g. EFORT, OARSI, EAPC etc.)
- Is there a platform in place for representing SIP including patient organisations?
- Is there a platform in place for representing SIP including pharmaceutical industry?
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- Is there a platform in place for representing SIP including patient organisations?
This early result from the European Road Map Monitor 2011 highlights several key messages. Although these are preliminary findings, it becomes apparent the majority of countries in Europe are in the process of establishing some form of platform representing the societal impact of pain. Patient organisations are represented in the central regions of Europe and the results show pain physician organisations are evident on pain platforms in most European countries.

The study also reveals many countries are making progress in including statutory health authorities on their pain policy platforms. These early results show Portugal and Belgium are leading the way with a National Action Plan on the societal impact of pain.

However, there are large discrepancies between European member states and the extent to which their governments recognise adequate pain care as a citizen’s right. The report also revealed some of Europe’s largest economies have a big challenge ahead installing a pain management network. In addition, a lot of work still needs to be done to ensure satisfactory patient access to pain care (diagnosis, treatment, medication).

These preliminary research findings also show governments in Europe lack the commitment to strengthen and prioritise pain research to address the societal impact of pain on the health, social, and employment sectors. It would seem some of these European governments are struggling to raise the profile of pain care in their national health care policies.
Large discrepancies between governments and the extent to which they recognise adequate pain care as a citizen’s right

Finland, France, Italy, Portugal and Sweden have each stated their governments endorse fully the right of every citizen to have access to adequate pain care. The Czech Republic and Spain have almost completed this process. Many countries, e.g. Croatia, Poland, Slovenia and the UK, are making good progress in this area. The remaining countries, shown in orange, report the authorities in their countries have started to recognise the right of every citizen to have access to adequate pain care.

**Analysis**

According to this study, all authorities in the countries reported, recognise as or are in the process of recognising the right of every citizen to have access to adequate pain care. Two-thirds of the nations that responded to the survey see the task ahead either as “work-in-progress” or they consider their governments to be in the early stages of recognising the right of every citizen to have access to adequate pain care. Finland, France, Italy, Portugal and Sweden could report 100% support by their governments for pain care to be seen as a citizen’s right. This may be considered a positive move forward for some. However, as there are varying degrees of understanding and large discrepancies between the nations as to how much the right of a citizen is recognised by the authorities, some may consider this a poor result.

There are still large discrepancies between European governments and the extent to which they recognise adequate pain care as a citizen’s human right.

Portugal and Belgium lead the way with their National Action Plans

Belgium and Portugal have launched their National Action Plan against pain; France has nearly achieved this. The UK, Germany and Italy are amongst the handful of nations making progress in launching their National Action Plan. The rest of the countries in Europe that took part in this study, which include Poland, Scandinavia, Spain and the Ukraine, have either started the process of launching an action plan or they are yet to get it off the ground.

**Analysis**

Research findings show Belgium and Portugal are leading the way having already launched their National Action Plan. Portugal’s National Programme for Pain Control testifies to the intention of health authorities to ensure the best practice in terms of pain treatment. From this study, France appears the next country in line to adopt its own National Action Plan. This would be France’s fourth national plan, as the country has reportedly already launched three action plans for pain since 1996. The UK is reportedly progressing well to create a fully-operational National Action Plan. In England, parliamentary questions have been raised on pain, while Scotland and Wales have already recognised pain as a disease in its own right.

The results from this question could be seen as a major achievement, as the majority of countries are reportedly in the process of establishing a National Action Plan for the improvement of pain management.
A network within the national health system for pain management has been installed in Finland, France and Sweden. These countries have completed the installation of pain management networks within their national health services. Slovenia has nearly completed this task, while neighboring Balkan state Serbia seems to be moving in the right direction, as does Belgium, Hungary, Latvia and the Netherlands. Bulgaria, Estonia, Poland, Slovakia, the Ukraine and the UK report to have started the process of establishing a national healthcare network for pain management. All other nations, which include Denmark, Germany, Italy, Ireland, Norway, Portugal and Spain, have no form of network in place.

**Analysis**

The large areas of orange and red in this map show the majority of nations in Europe have either just started or are yet to start establishing a network within their national health systems for pain management. This means European states Bulgaria, Estonia, Poland, Slovakia, the Ukraine or the UK have only made moves to establish this network, while Denmark, Germany, Italy, Ireland, Norway, Spain and Portugal are yet to start these measures. However, there are positive signs that networks are being installed in the Eurozone. This survey shows Finland, France and Sweden have a fully-functioning network for pain management within their national health system and Slovenia appears to have almost achieved this. A handful of Europe’s smaller nations, e.g. Belgium, the Netherlands and Hungary, which appear on this map in yellow, are reportedly making progress in establishing a pain management network within their health systems.

France, Italy and Portugal reported that pain care is a top priority for their national statutory health care authorities. Belgium and Croatia, which are marked in blue, claim to have almost achieved this, while health authorities in Czech Republic, Finland, Slovenia and Sweden are making good progress to prioritise pain care. All other nations that responded to the questionnaire have only just started or are yet to start prioritising pain care within their national health care authorities.

**Majority of European states struggle to make pain care a top priority**

France, Italy and Portugal reported that pain care is a top priority for their national statutory health care authorities. Belgium and Croatia, which are marked in blue, claim to have almost achieved this, while health authorities in Czech Republic, Finland, Slovenia and Sweden are making good progress to prioritise pain care. All other nations that responded to the questionnaire have only just started or are yet to start prioritising pain care within their national health care authorities.

**Analysis**

National statutory health care authorities in Italy, France and Portugal have the highest regard for pain care. Belgium and Croatia agree to a certain extent, but these findings show there is still work to be done to make it a top priority. The Czech Republic, Finland, Slovenia and Sweden seem confident they are moving in the right direction. On the other hand, Germany and its Scandinavian neighbours Denmark and Norway believe pain care has not been prioritised at all in their respective countries. The UK, Ireland, Spain and the bulk of former Eastern European countries report their national health care authorities have only made early moves to prioritise pain care.

**Europe is struggling to make pain care a top priority**

There is evidence of a gulf between the few countries (France, Italy and Portugal) that claim their health care systems treat pain care as a top priority and the rest of Europe.
Patient access to pain care (diagnosis, treatment, medication) is sufficiently ensured

According to the findings, the majority of countries in Europe consider themselves to be around the halfway point of ensuring patient access to pain care. Portugal is the only country that reports to have completed this process. Austria, Belgium and Bulgaria, marked in blue, consider themselves close to sufficiently ensuring patients have access to pain care. Germany, Ireland, Portugal, and the UK, have reportedly made a start at guaranteeing this access, while in Bosnia & Herzegovina, Denmark and the Netherlands, the process of ensuring patient access to pain care has not yet started.

Analysis
The research shows only patients in Portugal can confidently expect to be ensured access to pain care. Austria, Belgium and Bulgaria seem to be close to achieving this. These findings could be seen as a positive sign for pain patients in Europe, as the majority of countries that responded to this question claim to be making some form of progress to achieve the goal of sufficiently ensuring patient access to pain care. It should also be noted that some nations could be making better progress than they have admitted in the survey, as a large percentage of nations are in the yellow zone. It is unclear whether these countries are nearer the completion phase or starting point of their access agenda. Interestingly, fewer countries took part in this particular section of the survey, which could mean they may either not know the full status of patient access to pain care or there is no data available or there is no data available.

Results from this study show France and Slovakia have introduced pain medicine and care as a compulsory teaching subject. Austria, Bulgaria, the Czech Republic, Finland and Serbia, which are marked in blue, are close to completing the process. The majority of other countries are, to varying degrees, taking measures to introduce pain medicine and care as a fixed part of the teaching curriculum. Bosnia & Herzegovina, Denmark, Norway, Portugal, Spain and the Ukraine are amongst the few countries that reported to have no mandatory teaching in this area.

Analysis
The response to this question shows that progress is being made to introduce pain medicine and care as a compulsory subject in the education programme of health professionals. According to reports, pain medicine is mandatory in more than half of German medical schools and the curriculum was designed by the country’s IASP® chapter. It is also an add-on subject for those with direct patient contact. In the Czech Republic, pain care is a separate discipline with its own education programme. Although these examples show the medical profession is moving in the right direction to introduce a mandatory pain education curriculum, there is reportedly still a lack of fully-qualified pain experts.

Europe is moving steadily towards sufficiently ensuring patient access to pain care. More than half of the respondents seem confident they are moving in the right direction to achieve their goal of ensuring sufficient pain care.
An educational programme on pain pathophysiology for the general public ("pain is real") has been launched.

The survey shows Spain has completed the launch of its public educational programme on pain pathophysiology, "pain is real". Austria's campaign is near to completion. Germany, the Ukraine and some smaller, former Eastern European countries are in the midst of preparations for their launch. The UK and France are amongst a handful of nations that have just started the process to launch the public education project. However, there are still a large number of countries in Europe that do not appear to have started preparations for a programme launch.

Analysis
It is clear from the results of this section of the study that Europe is starting to understand the importance of educating the public on pain matters, as well as the medical profession. Spain appears to be leading the way with its pain pathophysiology education programme. The majority of nations placed themselves in the yellow zone, which means they consider themselves to be in the middle of preparations to launch their own public "pain is real" education project. However, it is unclear if preparations are closer to the completion end of the spectrum or are at the starting point of the project.

Austria revealed it had come the furthest in strengthening its commitment to pain research as the map shows activities in this area are near completion. Governments in the Czech Republic, France, the UK, Finland and some former Eastern European countries are in the process of achieving this. Germany and the Ukraine are the largest states to admit their governments have only just started the process of implementing procedures to strengthen pain research in their national road maps addressing the societal impact of pain. Spain and Portugal, the rest of Scandinavia and Ireland are amongst those nations whose authorities have made no moves to prioritise pain research.

Analysis
It is clear from this map that no government in Europe has completely backed a policy to prioritise and strengthen pain research. Austria seems to be the sole nation close to achieving a commitment from the authorities to implement procedures to strengthen and prioritise pain research.
Europe lacks a fully-fledged chronic pain care plan with focus on wait times and financing of early diagnosis and secondary prevention

Finland is the only country which reports to have implemented chronic pain care plans focusing on both wait times and financing of early diagnosis and secondary prevention. Austria, the Czech Republic and Portugal are close to achieving a chronic pain care plan. France, Italy and Belgium are the only other nations in the western region of Europe that are in the process of implementing such a plan. Belgium, Norway, the Netherlands, Sweden and a couple of Baltic States have started the process of establishing this chronic pain care plan. Denmark, Germany, Spain and the UK are amongst those Western European countries that have reportedly no plan in place.

Analysis
This study reveals that some of Europe’s largest nations have no chronic pain care plan in place with its focus on sufficient wait times and financing of early diagnosis and secondary prevention. The UK, which stated it is in the middle of implementing a chronic pain policy on this matter, has reportedly not started the implementation of the plan. This implies there could be a large discrepancy between implementing a chronic care policy and rolling it out as a fully-fledged plan.

Results from this study show Belgium, the Czech Republic and Italy have all established a high-level working group on pain care to monitor progress. Croatia and France are close to completing the process, while Austria, Portugal and the UK are in the process of instituting such a group. Ireland, Norway, Spain and Sweden and the majority of former Eastern European nations have reportedly not started the process to establish high-level pain care working groups.

Analysis
This diagram shows that although some countries have made substantial moves forward to establish a fully-operational high-level working group to monitor the progress of pain care in Europe, there is an equal amount of nations that have failed to start the process. This raises an important question as to how the progress of pain care is actually being monitored in different nations. It is also possible each respondent has a different interpretation of what “high-level” actually means. There could be perfectly adequate working groups monitoring the progress of pain care across Europe who do not consider themselves to be a high-level set up.

With the exception of Finland, Europe lacks a fully-fledged chronic pain care plan with its focus on waiting times and the financing of early diagnosis and secondary prevention. According to this study, some of Europe’s largest and most influential nations have yet to embark on implementing such a plan.

Many European countries appear to be lacking the impetus to install high-level working groups to monitor the progress of pain care. Belgium, the Czech Republic and Italy are the only countries to have reported a fully-operational, high-level working group on pain care.
According to the survey, Portugal and Italy have completed the installation of a policy to monitor outcomes of pain care policy. The Czech Republic is close to achieving this, while Austria, France, Slovenia and the UK are making progress with this agenda. The rest of the countries that took part in this survey have either just started or have yet to start the process of installing such a policy.

Analysis

This research shows that although some countries might have made noticeable advances to install a policy to monitor outcomes of pain care, there are still large red and orange areas on this map, which implies the majority of countries have not started an installation programme.

Although Italy and Portugal have fully installed a policy to monitor outcomes of pain care policy, there is little evidence in the rest of Europe, apart from the Czech Republic, that other nations are close to achieving this.

Conclusions

The results described above are the preliminary findings to the first European Road Map Monitor 2011. At this initial stage, responses reflect the knowledge of local EFIC® councillors, IASP® chapter presidents and Grünenthal managers from 26 countries.

The preliminary findings from the European Road Map Monitor 2011 have reinforced many of the ongoing issues relating to the societal impact of pain. Although the majority of countries in Europe reported to be in the process of establishing some form of pain platform, the research revealed some of the unmet needs of chronic pain patients. It also showed there was inadequate knowledge and information about pain management and that ten years on from the EFIC® Declaration of Pain, national and EU policy action had been very limited and was not a priority with governments and health providers in many parts of Europe.

In future, a consensus finding process will be required on a local level to integrate all stakeholders represented in the SIP platform at EU level (e.g. IASP® chapters, professional organisations, patient advocacy groups and all other stakeholder representatives involved in pain care). Some questions can still be refined to encourage more accurate responses (e.g. a question which asks whether a policy to monitor outcomes of pain care policy has been installed, could include supplementary questions to find out whether advocacy groups had requested this procedure or whether it had been initiated by health authorities).

It will be important to cross-validate the findings and continue to monitor the progress in the EU member states on pain policies. All findings should be communicated to national and EU governments to improve policy-making regarding the societal impact of pain in Europe.

Next steps

European Road Map Monitor 2011

These preliminary results from the European Road Map Monitor 2011 were first presented at the symposium ‘The Societal Impact of Pain in Europe’ during the EFIC® Congress in Hamburg on 23 September, 2011. Following this initial publication, the next steps are as follows:

- Fill in the gaps
- Include all endorsing partner organisations
- Cross validate data
- Publish current state
- Monitor progress
- Communicate the findings to national and EU governments to improve policy making regarding the societal impact of pain in Europe

Prof. Dr. med. Rolf-Detlef Treede, Medical Faculty Mannheim, Heidelberg University, Germany

SIP

Societal Impact of Pain

Completed

Nearly completed

In progress

Started

Not started

Slow progress in installation of monitoring systems

Little evidence of progress in Europe to install a policy to monitor outcomes of pain care policy

A policy to monitor outcomes of pain care policy has been installed

Completed

Nearly completed

In progress

Started

Not started

Slow progress in installation of monitoring systems

According to the survey, Portugal and Italy have completed the installation of a policy to monitor outcomes of pain care policy. The Czech Republic is close to achieving this, while Austria, France, Slovenia and the UK are making progress with this agenda. The rest of the countries that took part in this survey have either just started or have yet to start the process of installing such a policy.