



THE IMPACT OF PAIN ON MALTESE CITIZENS

Conference Proceedings

April 2018

Conference to present findings of research carried out through the
Impact of Pain on Maltese Citizens Survey (VOPS 25/2017)

[The project is supported by Grünenthal GmbH](#)

This project has been funded through the Voluntary Organisations Project Scheme managed by the Malta Council for the Voluntary Sector on behalf of the Parliamentary Secretary for Youth, Sport and Voluntary Organisations.

ADDRESS BY HOSTS



Gertrude A. Buttigieg
(Chairperson Malta Health Network)

Malta Health Network (MHN) was set up in 2007 to be a voice for patients. However on the event of presenting these research findings, MHN is being a voice for the patient not just to make noise but to come up with concrete findings and present these to the policy makers for appropriate action. The research on chronic pain was prompted following the question MHN was asked many times in relation to how many people suffer from chronic pain specifically in Malta rather than on an international level.

Holding the event on the 18th April was also significant since MHN is celebrating its' 10th year in promoting the Patients' Rights Day which is celebrated on this date on a European level.

When the Voluntary Organisations Projects Scheme (VOPs) 2017 scheme was launched, MHN approached the No Pain Foundation (NPF) and with the support from various others, the proposal for this project was submitted. This project made it for funding! It is with great pleasure that these findings are being shared to start paving the way to make a difference in the life of people with chronic pain and their families.

Special thanks for making this project possible goes to Voluntary Organisations Projects Scheme which is managed by the Malta Council for the Voluntary Sector on behalf of the Parliamentary Secretary for Youth, Sports and Voluntary Organisations which supported 80% of the funding and Grüenthal GmbH which supported with the outstanding amount.



Silvana Fanalista
(President No Pain Foundation)

When it comes to pain, our body is telling us something is wrong. Chronic pain is pain that last longer than 6 months, and which is hard and confusing to explain. The impact of pain extends to the family and the patient's social life, whilst also having an impact on the financial aspect. It is a difficult life journey and most people would be fighting this battle alone. There was no data for Malta on how many people are affected by chronic pain and in order to improve and recommend appropriate policies, there was an urgent need to explore this topic and how it impacts on people's lives.

Thanks to the collaboration between the Malta Health Network and No Pain Foundation, this research will help patients suffering from chronic pain. Something can be changed and improved. Although we have good service of medical care, we can do much more.

ADDRESS BY HON CLIFTON GRIMA (PARLIAMENTARY SECRETARY FOR YOUTHS, SPORTS AND VOLUNTARY ORGANISATIONS)



Clifton Grima
(Parliamentary Secretary for Youths, Sports and Voluntary Organisations)

This conference, organized to present the research results, is a celebration to highlight the study on the impact of chronic pain on Maltese citizens. It is a known fact that pain affects the life of people in various aspects - socially, at work and in other situations in everyday life.

This is a message to reaffirm our position of fully helping the voluntary organisations and promoting research by this sector. He thanked all involved for their work and dedication.



EXECUTIVE SUMMARY

The Impact of Pain on Maltese Citizens – facts and recommended actions

Pain indicates that something is wrong with our body. Pain is defined by the International Association for the Study of Pain (IASP)¹ as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage'.

International research defines chronic pain as pain that persists for more than 3 months. In this research on the impact of chronic pain in Maltese citizens, carried out in Malta in 2017, some people have reported persistent pain lasting for 2 years and more.

Data indicates that 20% of Malta's adult population experience chronic pain. Such pain is present in 1 in 10 persons aged 18-24 years, rising to 1 in 4 persons aged 45 years and over. Almost 40% of the younger cohort reported a higher level of impairment to their social activities due to their physical or emotional state.

Musculoskeletal diseases including arthritis, joint pains and fibromyalgia make up 75% of causes of chronic pain whilst 20% result from chronic headaches and migraine. The remaining balance is accounted for by cancer, vascular diseases, poor circulation or various injuries. People with chronic pain report that they are limited in their daily activities by varying degrees from lifting a bag with groceries to going up a flight of stairs. Pain can limit persons in basic activities such as washing and bathing, walking short distances, catching a bus or driving.

This impacts the quality of life of people, causing emotional distress and a sense of failure.

Chronic pain leads 86% of sufferers to be absent from work for at least 1 week a year. Some had to reduce working hours, others had to change jobs, whilst others left their employment or lost their jobs due to their health problems.

Pain may be invisible to the naked eye but it is very tangible to many in society. It is our duty to demand change through these recommendations:

- 1) Chronic Pain should be acknowledged as a disease in its own right.
- 2) A holistic policy should be drawn up to provide for chronic pain prevention where possible and for timely access to appropriate treatment, medicines and other therapeutic interventions, including rehabilitation.
- 3) Healthcare professionals should have adequate skills in diagnosing and managing pain effectively.
- 4) A National Pain Plan should be established to provide for inter-ministerial collaboration: pain is not only a health issue – it also represents a major contributing factor towards societal wellbeing.



PANEL 1 A RESEARCH STUDY ON THE QUALITY OF LIFE AND THE IMPACT OF PAIN ON MALTESE CITIZENS



Dr Christine Baluci
(Public Health Consultant)

Dr Christine Baluci introduced the audience into the area of pain as being commonly a major symptom in medical conditions or injuries. Pain is very often an initial indication of pathology and a reason for seeking medical assistance. The International Association for the Study of Pain (IASP, 2011)² defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'.

An alternative definition describes pain as 'whatever the experiencing person says it is and existing whenever the experiencing person say it does' (McCaffrey and Beebe, 1989)³. These definitions highlight that pain

is more than just tissue damage triggering a response from the nervous system and consequently, pain management involves more than simply treating the underlying disease. Research by Smith et al (2001)⁴ defined 'any chronic pain' as pain of at least 3 months' duration with 'significant' chronic pain as pain requiring treatment and professional advice and 'severe' chronic pain through reported intensity and pain-related disability. The Breivik Study (Breivik, 2006)⁵ looked at the prevalence, severity, treatment and impact of chronic pain in adults in 15 European countries and Israel. It was carried out via an initial large scale telephone survey followed by a more in-depth investigation. It showed that 19% of the 46,394 respondents experienced long term pain (defined as pain experienced for more than 6 months, pain experienced in the previous month, pain experienced at least 2 times per week and pain rated as at least 5 on the 10-point Numeric Rating Scale). The prevalence of pain reported in this study varied greatly between countries, ranging from 12% in Spain to 30% in Norway. Dr Baluci outlined available local data derived from the European health interview survey (EHIS)⁶ which was carried out between 2013 and 2015. The proportion of the respondents reporting moderate, severe or very severe bodily pain over the past 4 weeks was lowest in Latvia and Malta (just over 13.5% and 14%, respectively) and highest in Poland and Slovenia (between 31% and 32%).

1) IASP Taxonomy working Group (2011) Classification of Chronic Pain (Second Edition)

2) IASP Taxonomy working Group (2011) Classification of Chronic Pain (Second Edition)

3) McCaffery, M., Beebe, A., 1989. Pain: clinical manual for nursing practice. C.V. Mosby, St. Louis

4) Blair H Smith Alison M Elliott W Alastair Chambers W Cairns Smith Philip C Hannaford Kay Penny. Family Practice, Volume 18, Issue 3, 1 June 2001, Pages 292 - 299, <https://doi.org/10.1093/fampra/18.3.292>; <https://academic.oup.com/fampra/article/18/3/292/531630>

5) Breivik, H., et al. (2006) Survey of Chronic Pain in Europe Prevalence, Impact on Daily Life, and Treatment. European Journal of Pain, 10, 287-333

6) [http://ec.europa.eu/eurostat/statistics-explained/index.php/Glossary:European_health_interview_survey_\(EHIS\)](http://ec.europa.eu/eurostat/statistics-explained/index.php/Glossary:European_health_interview_survey_(EHIS))

	%	By Age (in years)						
		15-24	25-34	35-44	45-54	55-64	65-74	>75
EU	24.9	11.7	15.2	18.8	25.2	30.3	33.9	46.2
Malta	14.2	7.9		12.1	14.7	16.9	19.5	29.6

Table1: Percentage of persons aged 15 and over declaring moderate, severe or very severe bodily pain, 2014 or nearest year (%)



Ms Vanessa Bajada (Esprimi)

Ms Vanessa Bajada presented the methodology used in the research on chronic pain in Malta conducted through their agency on behalf of MHN and presented the key results.

Research Objectives

The main scope of the research was to collect data to provide insight about the extent of chronic pain in Malta and the impact that such pain has on the day-to-day activities of individuals including their social and economic activities. Moreover, a qualitative exercise was

carried out amongst a sample of people who indicated that they are suffering from chronic pain to understand:

- the experience of pain
- the management of pain and
- the support systems used people suffering chronic pain

The quantitative research exercise was carried out amongst a random sample of 1,100 members of the general public aged 18 and over representative of the Maltese population.

The survey was carried out using a mixed methodology approach. Interviewing was based on a quota sample based on variables of age and gender. It was also ensured that there was a geographical spread of regions as defined by the National Statistics Office (NSO).

30% of the interviews being carried out over the phone whilst 70% were conducted online. The quantitative research was carried out between December 2017 and January 2018 while the focus groups were carried out in February 2018.

Results of the Quantitative Survey

The survey has shown that the first point of contact of patients is frequently the general practitioner (GP) while pain specialists are consulted only to a minor extent. Respondents aged 35-44 were most likely to visit a GP at a private clinic both as a first point of contact for general health (83%) and also for pain related issues (73%). On the other hand, 7.4% would seek the advice of a specialist in either public or private sector for general health issues with an increase to 17.7%

in the case of pain. It is interesting to note that in the 65 year and over age group, 50% of respondents indicated that they would seek the help of a private GP in the case of pain while 30% would go straight to a specialist. Respondents in the lower socio-economic categories were less likely to visit a private GP than the respondents in the other socio-economic categories. When asked about their current health status only a very small percentage of people reported that their health state was poor.

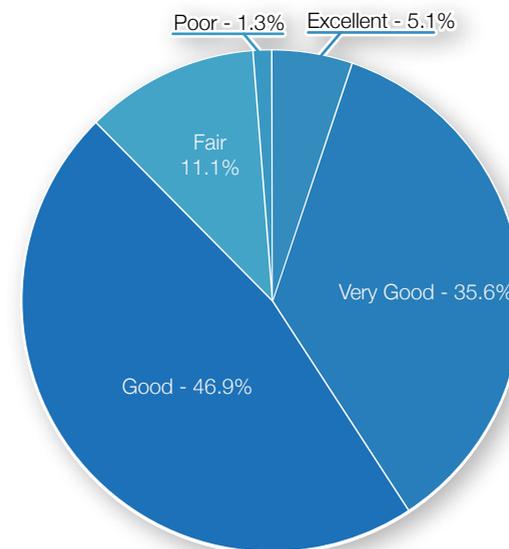


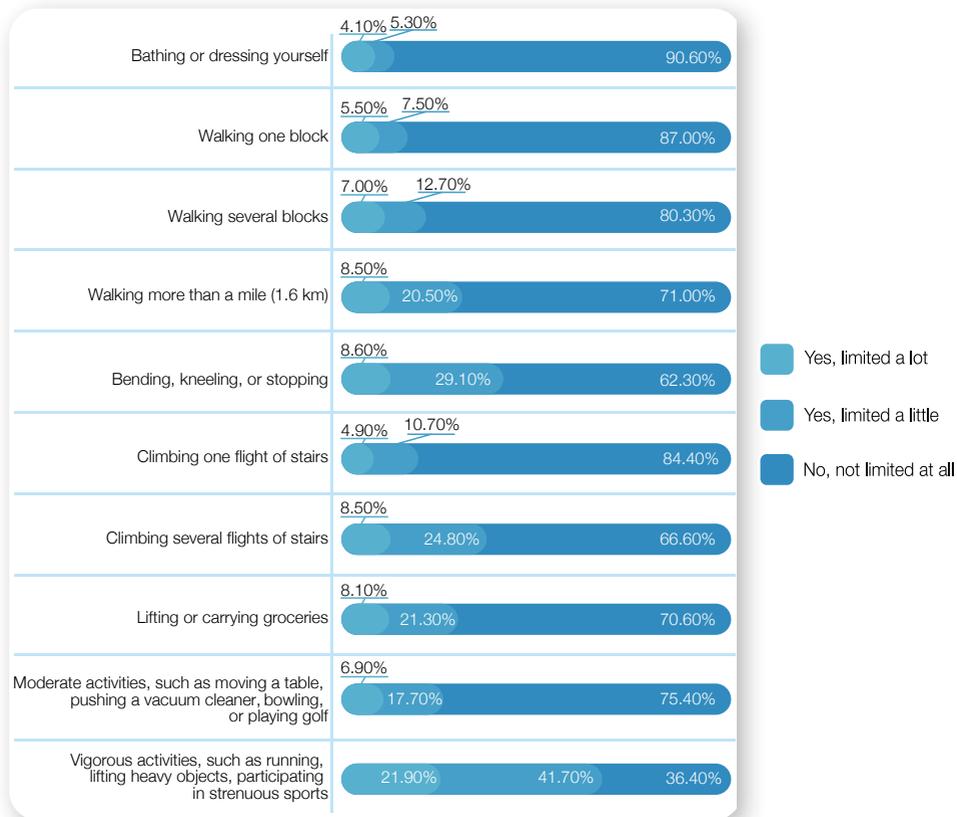
Chart 1: Share of persons as they reported on their health state

Generally, respondents across all ages reported their health to be in the same level as the previous year. The tendency to report some form of regression in general health over the past year seems to increase with age (somewhat worse than one year ago). It is worth noting that

very few respondents indicated being much worse health-wise than they were one year ago. In the age 18-64 year age cohort, 10-16% reported their health to be somewhat worse while in the 65 year plus age group, this increases to over 25%. There is also a tendency for respondents

in the skilled manual workers (C2) and unskilled workers and people living on benefits (D/E) categories to report being somewhat worse off than they were in the previous year, compared to respondents in the other categories. It was shown

that physical pain interferes with daily activities and leads to significant impact on absence from work. Most of the people experiencing pain claimed that they are not receiving any form of medication and 46% received even no treatment at all.



Commonly, the activity with the greatest level of limitation affected by the current state of health was vigorous activity including activities such as running, lifting heavy objects and participating in strenuous sports. This activity became

more problematic with age. Bending or stooping and climbing several flights of stairs are also activities which had significant levels of limitation compared to the other activities. Moderate activities such as moving a table, pushing a vacuum

cleaner or participating in an 'easy' sports activity were limited in almost 7% of participants.

It was indicated that pain has an impact on one's social activity. Respondents with severe and very severe experiences of pain tend to be more likely than other respondents to report some level of impact on their social activity.

The younger respondents showed a tendency to experience greater impact on their social activities as a result of their physical and/or emotional state (37.7% of respondents aged 18-24 years claimed that they felt their social activities were significantly affected by their physical and/or emotional state.)

	Positive Emotions				Negative Emotions					
	Did you feel enthusiastic and in a good mood?	Did you feel calm and peaceful?	Did you feel full of energy?	Did you feel like a happy person?	Did you feel like a very nervous person?	Did you feel so down in the dumps that nothing could cheer you up?	Did you feel downhearted and blue?	Did you feel worn out?	Did you feel tired?	
	Values in Percentage (%)									
None of the time	1.80	3.30	6.40	2.70	16.30	47.70	32.40	22.90	10.40	
A little of the time	7.60	13.30	14.00	8.50	29.50	26.20	33.50	31.20	23.30	
Some of the time	22.60	22.50	25.90	22.00	32.30	15.00	20.90	28.20	36.70	
A good bit of the time	28.40	25.50	29.80	25.50	11.70	6.30	8.40	10.10	17.60	
Most of the time	32.10	26.50	18.30	31.50	8.20	3.50	3.90	5.80	9.10	
All of the time	7.50	9.00	5.60	9.80	2.00	1.40	1.00	1.80	2.90	

Table 2: Respondents replies of the way they felt during the past 4 weeks and to what extent the statements presented included both positive and negative feelings experienced

In line with the main focus of this research, the participants were asked if they had experienced pain in the last 3 months. 52.4% indicated having experienced some pain in the last 3 months with 22% describing their pain as moderate to very severe. Interestingly respondents aged

45-54 were more likely to report moderate to very severe pain in the previous 3 months than respondents in the other age categories. However, taking in all reporting of pain including the very mild and mild the 65+ age group is tops as predicted.

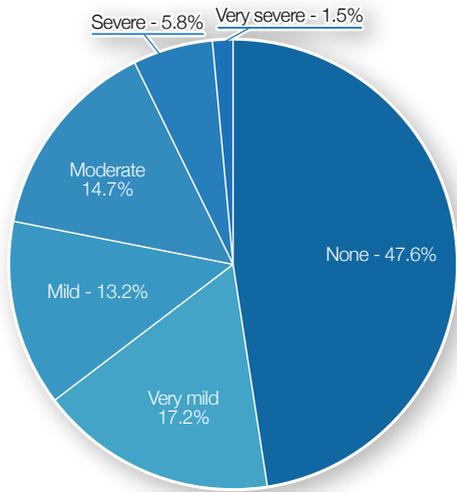


Chart 3: Share of persons as they reported on their experience of pain

For the scope of this survey, we proceeded to investigate only those cases where pain has been experienced for over 3 months. Half of the participants reported constant physical pain during the previous

3 months ranging from very mild to very severe. 38% of this subgroup reported experiencing this pain for more than 2 years.

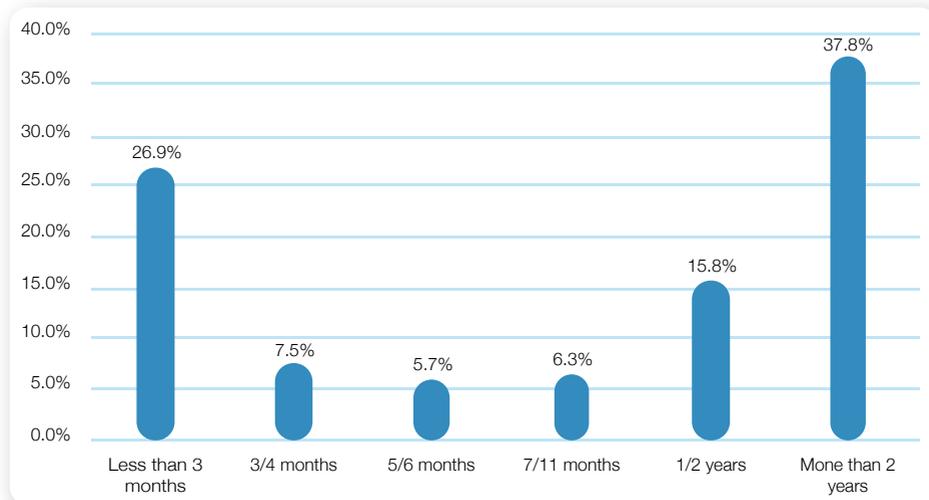


Chart 4: Percentages indicating duration of pain experienced

Data indicated that 20% of Malta's adult population experience chronic pain. Such pain is present in 1 in 10 persons aged 18 -24years rising up to 1 in 4 persons aged 45 years and over. Almost 40% of the younger cohort reported a higher level of impairment to their social activities due to their physical or emotional state. With regards to the most common causes of such chronic pain, musculoskeletal diseases including arthritis, joint pains and fibromyalgia make up 75% of chronic

pain whilst 20% is caused by chronic headaches and migraine. The remaining balance is accounted for by cancer, vascular diseases, poor circulation or various injuries. The majority of those experiencing pain and are in full or part-time employment indicated that they would take less than 1 week of leave due to their pain. 11.6% indicated taking more than a week of leave but less than a month of leave. The last part of the survey looked at

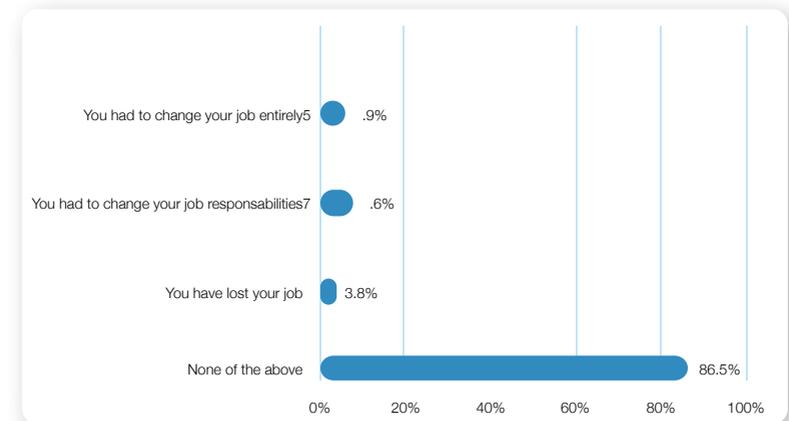


Chart 5: Percentages indicating consequences of chronic pain on work

treatment and satisfaction with treatment received. 35% of respondents who reported experiencing moderate to very severe pain in the previous 3 months were not receiving any form of treatment for their pain, 38.3% received medical treatment only, 10.7% received physical treatment only while 16% reported receiving both medical and physical treatment for their pain. Around 43% were satisfied or very satisfied with the treatment received for pain and 18.7% were either dissatisfied or very dissatisfied with the treatment received.

Ms Bajada then continued her report on the focus groups where 8 participants whose ages ranged between 28-72 years had the opportunity to tell their individual stories.

“ I feel that the pain is affecting my life extremely as I want to be active and I cannot. Before there wasn't an event I would miss.... ”

(Male - Age 68)

The participants reported that in most cases their immediate families were a good source of support with the issues they were facing. But later in the discussions it was also mentioned that due to the aging population and declining family size, the family may give less support in the future. Being part of the focus group was a positive experience and they all agreed that sharing experiences helps to ease the burden arising from chronic pain. Respondents claimed that pain has had a negative impact on their lives insofar as they would refrain from engaging in certain activities that they enjoy doing. They also indicated having to do things differently or plan ahead in order to manage and/or to avoid experiencing pain.

“ If I feel pain I take pain killers and keep going. I can no longer go to see football games or watch Juventus on TV due to pain and feeling depressed. ”
 (Male - Age 39 (non-working) suffers from regular headaches due to stress and depression)

Respondents in employment indicated that at some point they had to take time off work or change the way they do things because of their pain. Two of the respondents in the non-working group indicated that they had stopped doing the work they were previously doing as a result of pain. In cases where respondents indicated struggling with long standing musculoskeletal conditions such as arthritis, it was also mentioned that they had to learn to live with the pain. However, some form of medication was resorted to when the levels of pain were beyond the comfort zone. In these cases, professional

help from physiotherapists was commonly sought. A number of respondents also mentioned self-management and self-medication which they found helpful to lessen the pain experienced. In a couple of cases, respondents identified the need to lose weight in order to be able to manage the pain better.

“ I try and manage as much as possible and try to avoid taking medication. I try to ease the pain myself and sometimes it is the mental state that takes over. ”
 (Female - Age 75, non-working, Suffers from Chronic Migraines)

In some cases, surgical interventions were considered but often this option was not possible. Reasons included the respondent being too young to be able to do a knee replacement or the risks of the operation are perceived as outweighing the possible benefits of surgery. Professional medical advice is often sought relatively soon after the onset of pain. However, follow-up is often not sought as the cause of the problem is now known by the sufferer, and in most cases it is perceived that little can be done by professionals to help. In such cases, other than medication, respondents reported dealing with the pain namely through rest, hot/cold therapy, swimming or having a sauna.

“ I used to go to the gym... I need to lose weight too but it is difficult as I cannot do certain exercises. I can't walk for a long time or go down the stairs. ”
 (Female - Age 63 (non-working). Suffers from pain in knees)



Dr Mario Grixti
 (Specialist in Palliative Medicine and in Family Medicine)

Dr Mario Grixti reported that the GP is the first point of contact for more than 70% of the respondents with chronic

pain whereas less than 8% would opt for direct consultation with a pain specialist. This quantitative research on chronic pain has shown that Malta is comparable with other countries with regards to accessibility of healthcare professionals as the first point of contact, the cause of pain, the management of pain and the social impact of pain. Despite the complexity related with chronic pain, it is significant that the majority of patients seek community-based services for pain and this therefore raises the relevance of investment in GPs and multidisciplinary teams in primary care to provide a holistic approach in the management of pain.

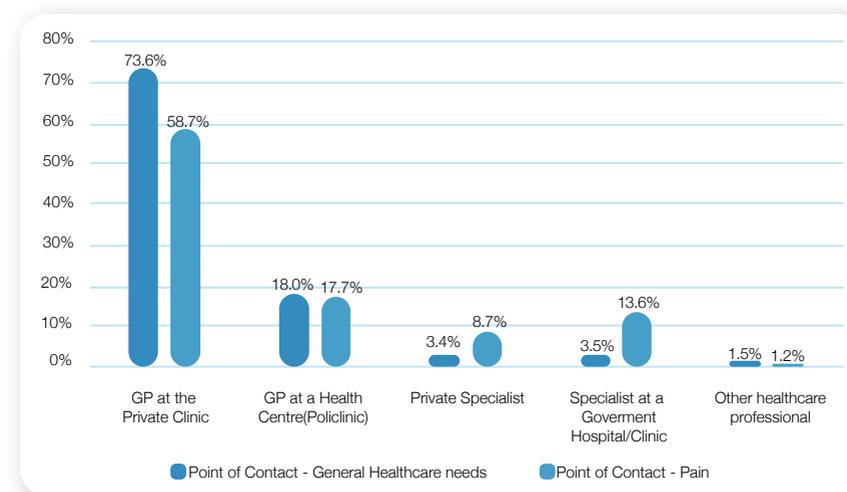


Chart 6 : Percentage of patients to Point of Contact for General Health Care and Pain

Females are more likely than males to report experiencing chronic pain and the prevalence of chronic pain increases with increasing age. With reported common causes of chronic pain ranging from musculoskeletal, such as in joints, limbs, in inflammatory

diseases, and chronic conditions such as diabetes mellitus and its co-morbidities as presenting causes of chronic pain, this is worth looking at in a wider context. In the diagnostic complexity of chronic pain there are other factors which are directly or indirectly contributing to the full clinical

picture of the patient with chronic pain such as the state of general health, the effect of physical and emotional factors, the impact of social activities and the economic impact of pain. This research has come up with interesting data to quantify the impact of these factors and variables on the overall suffering from chronic pain. Dr Gixti recommended further analysis of the data collected and presented so far.

Pain management seems to be more inclined to be medical through the use of oral medication rather than surgical and other hospital based interventions. For this reason, we have to invest in primary healthcare professionals in education on the use of opioid and non-opioid drugs while promoting other therapies which may be effective in managing chronic pain. It is essential to set up standards of care to plan for the future management of persons with chronic pain in the community.

This research has provided valuable data to healthcare policy makers in Malta for confirming that the development of structured pathways to deal with chronic pain management in primary care is a sustainable investment. Human resources are needed to provide holistic approach and specialised skills.

These should include physiotherapists, social workers, clinical pharmacists and specialised GP's in the use of diverse pain medications and therapies within structured pain protocols and referral pathways, to provide a framework for the support of structured pathways and the introduction of a variety of clinical management options which are evidence-based and well researched.

Co-operation with NGO groups involved in no-pain advocacy is also important in setting up such structured care pathways which give a more holistic and comprehensive approach to chronic pain management.



*Mr Christopher Vella
(Bioethicist)*

Mr Christopher Vella explained the relevance of bioethics in the issue of chronic pain. Chronic pain affects lives, usually directly by impacting on the quality of life of a person. It is therefore paramount a the ethical dimension of this problem is also taken into consideration. The first ethical issue mentioned is the need to have an ethically sound healthcare rationing system that respects the individuality and the dignity of everyone. Healthcare rationing is a reality; we are dealing with the distribution of a scarce resource, namely limited financial resources and specialized professionals.

It is ethically wrong to justify not providing a service due to financial constraints as one would be balancing the health of a person versus financial considerations, two factors which are irreconcilable.

The fact that policy makers are usually judged on their performance during the 5-year term in office might make them reluctant to embark on long term goals, and to favour instead something which maybe is not so serious but which gives quicker and more visible results. The reality of healthcare rationing in Malta is that, most often in a bid to maintain a sense of distributive justice, the latter example is adopted.

The research gave a clear picture of how many people (46%) are not receiving treatment for chronic pain, something which paradoxically contradicts the utilitarian rationale mentioned earlier. More in-depth research should explore the reasons why a number of persons experiencing chronic pain are not receiving any treatment for their pain especially since this research has shown that chronic pain has multiple direct and indirect biopsychosocial effects.



Mr Vella also explained how in ethics we hear about autonomy, which goes further than what we usually hear, that a patient has a right to refuse medical treatment. The positive right to have the full access to therapeutic and necessary treatment is therefore crucial. This positive right is highly dependent on the professionals, the policy makers and society. This is also relevant to another cardinal principle in medical ethics: justice, which can assume a lot of forms, both obvious and not so obvious.

A disservice to justice is discrimination, which may be due to several factors, for example the infrastructural and logistical set-up, the distance from certain areas, as well as cost of treatment if it is not offered on the National Health Service. If there is unjustifiable denial of access to certain therapeutic courses and if there are not adequately trained professionals to give the treatment, this creates further discrimination.

Since pain is subjective and not easily verifiable by a third person (as opposed to the case of medical disorders which are diagnosed by specific tests) there might be reluctance by policy makers to introduce certain measures due to potential abuse. There may also be certain concerns about abuse and dependency issues on using certain drugs.

The benefits of a long-term investment should be acknowledged. Educating professionals would be beneficial to address the problems mentioned, and this could have a positive impact on the workforce.

There are four key indicators we need to use to assess the current situation and

how this might be improved

- *Do persons with chronic pain have access to all medically approved treatment and in line with current medical knowledge?*
- *Are treatments given in the most cost-effective way?*
- *Are current policies preventing the worsening of chronic pain?*
- *Do current policies in pain management create discrimination?*



*Professor Julian Mamo
(Public Health Consultant and Specialist
in Family Medicine)*

In his discussion about the results of the survey, Professor Mamo identified the proportion of adult persons living with moderate, severe and very severe physical pain in the previous 3 months (22%). More importantly, those with severe pain impinging on their daily lives to the point of causing them loss of work, severe deterioration of their quality of life and a need among some to rely on others for support. The survey was also able to show that a large proportion of those living with such pain remained in pain after seeking help (more than 1 in 4). Such help was

sought predominantly from private family physicians but also from physiotherapists and others.

The diverse forms of support and other findings demonstrate that even self-help groups and support groups have a role to play when it comes to supporting those with chronic pain and that discussing issues related to the causes and the control of such pain was vital. Dealing with the psychological causes and the implications of pain were also important when understanding pain causation and

its relief and depressive illness was clearly linked to such chronic forms of pain. It was clear from the study that follow-up of pain was inadequately addressed even on the part of sufferers themselves. People get pain and stay in pain. Therefore such persons need to be followed up until symptoms improve (which is not always easy). The state facilities should facilitate inter-disciplinary primary care and promote better follow-up care, as sometimes the set-up of primary care does not support follow up.

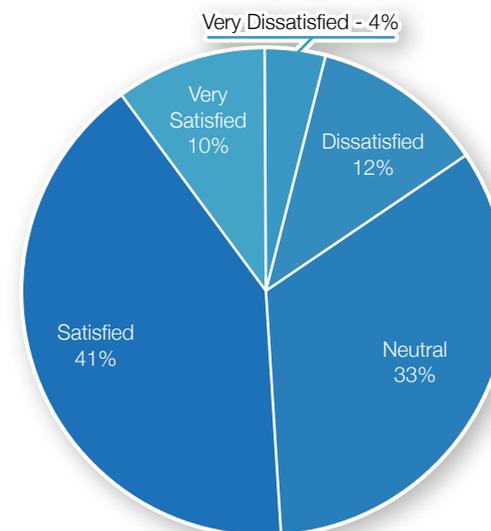


Chart 7: Percentage of patient satisfaction for treatment received

The findings have wide policy implications beyond those affecting health service practitioners and health policy makers. There are economic implications related to chronic pain – in terms of absence from work but also in terms of support

by carers, professionals and welfare services. The wider policy implications relate also to ongoing challenges faced by the adult population of Malta: ageing of the population means ever more chronic diseases, among which arthritis

and others causing even more pain. Daily activities are affected by chronic pain. Therefore, the evaluation of the community services is needed so that both persons experiencing chronic pain and their carers are given support (for example special leave, giving a number of benefits or including carers in the multidisciplinary team of care).

In the longer term, the serious epidemic of obesity and overweight now affecting more than two thirds of the population means that such painful conditions of joints and such non-communicable diseases will get even more frequent. Dealing with the root causes is important

and unless obesity and the ways in which adults in Malta continue to eat (and not exercise) are addressed, the health and indeed, the economic implications of such projections are very worrying indeed. Policy change is important to make better access to healthier food and diverse forms of exercise while considering fiscal and regulatory mechanisms to reduce the high energy intake, predominantly through sugars, that have become commonplace in our daily life.

Professor Mamo concluded by reiterating that the follow up on pain is essential although not always easy.



PANEL 2, COMPARISON WITH EUROPEAN DATA ON CHRONIC PAIN AND THE IMPACT OF PAIN ON PERSON, FAMILY AND SOCIETY



*Professor Ray Galea
(Vice Chairperson Malta Health Network)*

The chairperson for this panel Professor Ray Galea, started by explaining that such data gathering is useful but should not be an end to a means.

Gathered data reinforce an argument in order to promote changes necessary for the wellbeing of society. Having hard evidence means that arguments put forward are much stronger and authorities and policy makers can be positively convinced to make these changes.

Prof Galea then introduced the international speakers representing the European Societal Impact of Pain (SIP) platform.



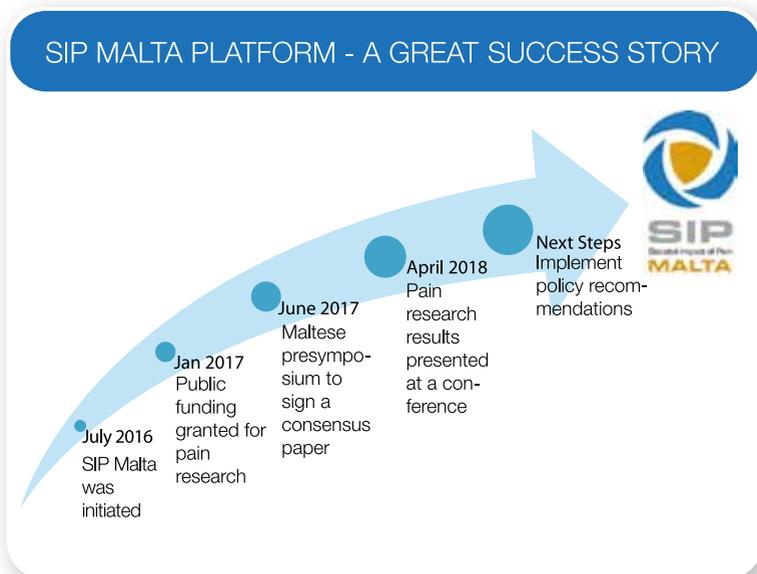
*Professor Bart Morlion
(President of the European Pain Federation EFIC
and Director of the Leuven Centre for Algology)*

Professor Marlion shared his views via a video message. He reminded the audience of the successful SIP 2017 Symposium in Malta held under the Maltese Presidency of the EU. He explained that one of the recommendations of this Symposium was to approach the various national health authorities to investigate the impact of pain in their countries. Professor Marlion explained that a decision was taken that

the SIP European Platform was going to focus more on the national needs. With this research and event, Malta can be used as an example whereby evidence by means of local data can be used to promote actions to reduce the impact of pain.

SIP Platform (Europe) will help to strengthen SIP Malta at a national level to shape the way forward on a national level. He expressed his wish to work further with MHN and NPF for the benefits of the Maltese and European society.

SIP MALTA PLATFORM - A GREAT SUCCESS STORY



*Mr Joop Van Griensven
(President of Pain Alliance Europe, PAE)*

Mr Van Griensven spoke about a survey carried out by PAE in 2017 in Europe on medical issues related to chronic pain, and another one this year on the effects of chronic pain on the economic and financial situation. The survey indicated that 70% of persons with chronic pain wait a year to get diagnosed. This has an impact on life and also affects the treatment outcomes since treatment is delayed. The results from the PAE survey 2017, indicated that 78% of respondents were not satisfied with the treatment received. In the case of the Maltese respondents to this survey,

this percentage was 21%. With regards to the recommended actions, Mr Van Griensven said that patients' representatives have to do work with patients and healthcare professionals to increase the rates of satisfaction with pain treatment. When proposing and developing policy, a holistic approach needs to be adopted with actions being taken by collective group rather than passing responsibility from one to another for action to be taken. Mr Van Griensven concluded by saying that the data presented from Malta confirmed the present situation and this can be used to compare issues with other countries and recommend policies. He presented 3 questions for consideration:

1. What about the experience of stigma in people with chronic pain? This was not considered in this event.
2. What about the psychological support needed by chronic pain patients?
3. Do we have a healthcare system or a healthsystem?



*Prof Dr Boaz Samolsky-Dekel
(Scientific Director, No Pain Foundation)*

Professor Boaz Samolsky-Dekel presented data from the literature with the results of a survey⁷ of 46,394 adults from 15 European countries in which 19% of respondents reported chronic pain. Out of these, 40% complained that their pain was inadequately managed. Chronic pain affects work and work efficiency, reduces quality and quantity of life and affects both the sufferer, his/her close contacts as well as society in general. Thus, chronic pain conditions can be a substantial socio-economic burden and, considering its societal impact, should be considered as a priority for policy makers. One of the major barriers to chronic pain sufferers is the appropriate management including appropriate referral. The management of chronic pain is complex; it requires evaluation, diagnosis and treatments. The latter may also necessitate concurrent psychological and physical therapy. Correct referral of patients to services is essential in the process of pain management and continuity of care and can affect clinical outcomes and costs. Inappropriate referral results in misuse of healthcare facilities, time and resources, accompanied by personal, societal and economic burden.

Professor Boaz Samolsky-Dekel commented that pain patients are often seen by healthcare professionals who are not adequately prepared to treat chronic pain conditions, or they are treated with inadequate therapies which do not help to alleviate the symptoms or treat underlying disorders possibly leading to increased patients' frustration. The GP should participate and collaborate with specialists in providing continuity of care. In 2010, in Italy, a state law (38/2010)⁸

7) Breivik, H., et al. (2006) Survey of Chronic Pain in Europe Prevalence, Impact on Daily Life, and Treatment. European Journal of Pain, 10, 287-333

8) http://www.salute.gov.it/portale/temi/p2_5.jsp?lingua=italiano&area=curePalliativeTerapiaDolore&enu=legge

was enacted so that all citizens in need have free access to palliative care and/or chronic pain therapy facilities.

Although the implementation of this law is still ongoing, this is a great example of how the state can provide the regulatory framework to improve management of chronic pain.

The Italian scenario foresees three care proficiency levels: low, intermediate and 'intense' treatment. Unfortunately, the 'referral issue' remains unsolved as there is no guidance as to which specific treatment level a particular patient should be referred to. A solution to this issue may come from an *ad hoc* assessment form which tries to classify the patients into high, intermediate and low pain chronicity. According to the operative hypothesis, patients diagnosed with 'low' level of pain are treated by the GP, those diagnosed with 'intermediate' pain are referred to a clinic with appropriate but limited pain treatment facilities while those with 'high' pain levels are sent to highly specialised pain treatment facilities. It was reported that when applying such an assessment instrument in an intermediate level facility, 30% of the treated patients could have been properly treated by the GP. This is a waste of healthcare resources. Another 30% of the screened patients would be deemed to require a higher level of treatment, thus for such patients time for proper treatment would have been lost while the inappropriate treatment would have been wasted.

Professor Boaz Samolsky-Dekel concluded that chronic pain is undertreated and because of its significant socio-economic burden to all stakeholders, it should be a priority to policy makers. Guidelines as to whom, where and when to refer the

right chronic pain patient for appropriate care are lacking. A stratified-based categorisation of chronic pain patients, based on prognosis/risk elements, may provide the best management plans for the right patient.



*Dr Gudula Petersen
(Governmental Affairs & Patient Centricity,
Grünenthal GmbH)*

Dr Gudula Petersen said that the presented data and comparison to EU data provided clear evidence that pain is a problem for society, the economy and especially for the patient. She congratulated the Maltese research group on the conclusion of this important study. Robust data is essential to convince policy makers to support improvement of pain management. If the politicians are shown the numbers, they would be better incentivised to improve ways to treat pain in a cost-effective manner. Thus all stakeholders involved in the pain issues should work to raise awareness and exchange information in a systematic way and develop policies and strategies.

In an overview of the work of the SIP Platform, Dr Petersen explained that SIP Platform is a multi-stakeholder initiative with more than 300 endorsing organisations including Maltese organisations. SIP has been founded in 2009 by Grünenthal and

European Pain Federation EFIC to ensure access to adequate pain treatment for all citizens and to unite all organisations and societies advocating better pain care to jointly address, define and foster pain policies. Other partners are the Pain Alliance Europe and Active Citizenship Network which represent patients and citizens on this platform. SIP has just been selected by the European Commission as one of only three thematic networks 2018. This is a fantastic opportunity to directly influence the European Commission's approach to health policy. Dr Peterson outlined what the SIP EU Platform has done since its setting up in 2009:

- o Working together and translation of what we learn into new solutions
- o Working with active citizens
- o Ensure access to care to all
- o Advocate for better pain management
- o It has been very active at lobbying with politicians since the first event in Brussels in 2011.

Following the successful event of SIP 2017 Symposium held in Malta, Dr Peterson explained that the platform is moving to another level by joining the EU Health Policy Platform. The strategy for 2018 consists of focusing on national platforms. Malta's activity as presented in today's conference is a good example to other countries. The achievements of the national SIP platforms will be shared in 2019 and SIP Malta is highly welcome to present its results there.

The conference then continued with the sharing of personal experiences by a chronic pain sufferer and a carer of a pain patient.



*Mrs Mary Vella
(Chairperson, Association for Rheumatoid
Arthritis Malta (ARAM) & member of SIP Malta)*

Mrs Mary Vella reported in a touching way her personal journey as a pain patient and how long it took her to get a correct diagnosis. Mrs Vella explained how she developed rheumatoid arthritis 16 years ago and how her initial experience of pain made her lose her energy and become dependent on others.

“ With support, life was not that difficult, but I felt like a burden to those around me. ”

Once the right medication was identified, her condition became stable and things started to improve. Whilst pain was still there, it became part of everyday life. She described how she learnt how to look well after herself, complimenting medication with self-help strategies. With such support, she manages to lead a satisfactory life while also actively helping others through ARAM.



Mr Mario Xuereb
(No Pain Foundation)

Another emotional story was told by Mr Mario Xuereb who takes care of his wife who suffers from severe chronic pain.

“ People do not remember her anymore ...she is a completely different person now. ”

He described his wife’s life as conditioned by pain, which subsides for a few days but the cycle starts again. Getting out of bed is sometimes a struggle and what many find to be normal simple things are difficult for her such as brushing her hair or holding a handbag on the shoulder. However, the bigger ‘pain’ is not being understood even by friends. On a positive note, finding the right doctors with the right approach including not being patronising as is the usual experience, made it a better experience.

Experiences from the floor:

Other participants were invited to share their experiences with chronic pain, especially severe pain such as in the cases of rheumatoid arthritis and cancer pain. Life becomes conditioned by pain, which may subside for a period only for the cycle

to start again. Most patients describe how the pain prevents them from maintaining the level of activity and energy enjoyed before the onset of pain, especially when this pain increases in its severity and distribution in the body. Normal simple activities are sometimes described as a struggle. Other effects such as sleeplessness, guilt over not functioning at the requested level and the feeling of being a burden to family members, significantly affect the lives of pain sufferers. Concern was also shown about how other persons do not understand the condition and do not empathise. Some individuals show remarkable courage in achieving their life aims despite the pain. Civil society organisations dedicated to painful medical conditions offer support to pain patients and this is felt to be very helpful.

Stigma experienced by pain patients, namely by being off work or not doing housework while appearing to be normal to other persons including family members was not explored in the survey. Stigma can be overcome by educating society to be more empathic of the situation of people suffering from chronic pain. Pain patients and carers feel that raising the awareness that chronic pain is a real issue is crucial as a first step and should start by education campaigns directed to both sufferers, carers and the general public. Pain sufferers, carers and also healthcare professionals feel that a multidisciplinary approach to the management of chronic pain is paramount but is presently lacking and not operating at an effective level. Multidisciplinary teams or facilities preferably in the primary care setting, should encompass a broad range of trained healthcare expertise

(primary care doctors, pain specialists, physiotherapists, nurses, social workers, psychologists, nutritionists, occupational therapists etc). They should also offer a variety of patient care services depending on the pain conditions treated and individual circumstances of the patient. Management pathways should span the diagnosis stage to return to full functionality. The traditional approach to treating and management of pain, especially chronic pain, is not always effective. Mindfulness

has also been advocated as a way of coping with pain. This is supported by research and may be a cost-effective tool that can help many throughout their life. Currently a patient has the right to refuse treatment, but one cannot demand a treatment option which is not available at the institution providing healthcare services. The more treatment or management options are available to patients, the more autonomy patients have in taking up the right treatment options.



PANEL 3: KEY POLICY PROPOSALS TO ADDRESS THE IMPACT OF PAIN IN MALTA.



Panel 3 was chaired by Mr. Christopher Vella (Hon Secretary, MHN) who highlighted the importance of having a clear and direct line of communication with the key policy makers, if we are to act on the findings of the survey and the data collected so far. He also remarked that according to medical law, one has the right to refuse treatment but cannot demand a different treatment which is not available at the institution giving the treatment. If more treatment options are available, the patients would be served better.



Ms Sina Bugeja
(CEO Special Projects Ministry for Health and ARAM representative)

Ms Sina Bugeja stressed the importance of promoting a more holistic approach when caring for patients. *'It is our business to improve the quality of life of patients'*. Ms Sina Bugeja explained how this study was a breakthrough when it comes to highlighting the problem of pain sufferers in Malta. Policy-makers need to act according to strict protocols, where they can only pursue in promoting policies which will have a positive effect on society and the community. Having such a study meant that for the first time the actual figures could be worked out, thus providing an objective scientific basis rather than just a personal recollection as justification to embark on a new policy. This is important since the usage of resources which are considered scarce need to be backed up by scientific data. The ramifications of such a policy would also need to have a wide inter-ministerial acceptance and collaboration agreements since it affects multiple facets of society. The need for investing in tools that can be utilised by the healthcare professionals is of prime importance. Ms Bugeja stressed on the importance of having consistency between healthcare professionals and on the need for the state to provide adequate and effective therapies.

On a personal note, Ms Bugeja, an expert in health promotion, remarked that this conference brought to mind the Ottawa Charter⁹ of 1986 which stresses on the need of 'building healthy public policies'. Building health public policies needs to be a joint venture between patients, significant others and policy makers.

9) http://www.euro.who.int/__data/assets/pdf_file/0004/129532/ottawa_charter



Dr John M Cachia
(Commissioner for Mental Health)

Dr John M Cachia raised the issue of chronic diseases like chronic pain and recommended to focus on solutions. Dr Cachia highlighted parallels with other chronic diseases like mental health and stated that joint initiatives may benefit more than one disorder. Dr Cachia offered insights from the perspective of a GP, Public Health Specialist and as the Commissioner for Mental Health. From the GP and Public Health Specialist's perspective, reinforcing the tools available to the GP as a front-liner is of paramount importance since he is the primary point of contact with chronic pain sufferers. Chronic pain may be the underlying reason for many conditions such as depression, nervous breakdowns, limitations on activities and burn-out syndrome. Because chronic pain also has a bio-psycho-social aspect, Dr Cachia argued that a significant number of persons with pain have added emotional issues due to cutting down on work and not doing what they should be doing because of limitations. From a Mental Health Commissioner's perspective, the psychosocial impact of pain leads to

mental health issues of a much bigger nature if pain is untreated. From a policy perspective, Dr Cachia explained that it is essential to empower patients, care givers and families and encourage them to look for help. He encouraged policy makers to empower GPs to understand pain better, to provide tools to measure and treat the psychosocial and psychological impact of pain. The importance of collaboration with the various NGOs was also stressed by Dr Cachia.



Hon Claudette Buttigieg
(Deputy Speaker)

Hon Claudette Buttigieg stressed that *'pain is a reality'* and clear evidence of this is given by the results presented at this conference. She explained that, although she is not a pain sufferer, she had personal knowledge of the effects that chronic pain has on an individual. This drives Hon. Buttigieg to concentrate on the personal experiences and effects of pain on a personal level of sufferers rather than to talk about statistics, policies and solutions. She stressed on

the importance of Parliament addressing the concerns of society, and explained that although the tools were in place, they are seldom used. The way NGOs can push an agenda forward is by asking for a Parliamentary Committee for pain and its' management on the national agenda. As Deputy Speaker of Parliament, Hon, Buttigieg remarked that unless an item is put on the agenda, it will rarely be discussed. Therefore NGOs need to communicate directly and relentlessly with Parliament. Hon Buttigieg stressed that having the Patients' Rights Charter entrenched in the Maltese Legislation is of paramount importance, since there are a lot of provisions in a Patients' Rights Charter which could be applied directly to chronic pain. Offering support to chronic pain sufferers is imperative for better outcomes.

All speakers have stressed the need for collaboration between the different authorities, entities and experts involved in the management of pain patients. The 'ego' of individual organisations should not be allowed to dictate and ruin the agenda. The extent of chronic pain and its impacts on society are too important to remain the remit of just one entity but needs everyone's commitment.



POLICY IMPLICATIONS

The survey on chronic pain and its impact on the Maltese population was prompted by the lack of data available – what is the prevalence of chronic pain and how does this affect everyday life, the social and financial situation of pain sufferers and what services do they access?

From the results of this survey and further discussions during the conference, the following outcomes are of note:

- Both evidence obtained from this research and other future surveys together with the sharing of personal experiences in such fora are important to highlight the significant impacts of pain on the individual and society. Policy makers require evidence for healthcare needs and cost effectiveness of measures to provide services.
- Approximately 90% of respondents identify the GP (at private clinics and health centres) as their first healthcare point of contact for general health while 76% identify the GP for pain related issues. This implies that if primary healthcare fails or is insufficient, these persons are referred to secondary care as first point of contact and possibly management. This would constitute an overload on the system with inefficient use. Therefore primary care is of prime importance and must be considered as a long term investment.
- Out of the 47% of respondents reporting pain during the previous 3 months including very mild, mild, moderate, severe and very severe pain, 35% reported moderate to very severe

pain but received no treatment for their reported pain. It would be interesting to know why these pain sufferers are not receiving treatment for their pain. Are they waiting for further consultations? Is there a lack of the knowledge on what services are available? Is it hesitation on the part of the healthcare professional to prescribe treatment or referral to more specialised care due to lack of skills?

- Nearly 38% of pain sufferers report being in pain for more than 2 years. People get pain and stay in pain.
- Ethical issues include issues of rationing of healthcare, inequalities resulting from accessibility due to the infrastructural and logistical set-up of services, costs of treatment and lack of resources including skilled human resources.
- Practical outcomes of treatment for pain might be different from the traditional clinical outcomes tied to general practice. For example, the ability to care for other family members or the ability to return to work are important outcomes for pain relief. Such outcomes may not be measured in treatment or services audits.
- A wider consideration of pain is the psychological and social elements. Depression is also an important aspect especially in chronic severe pain.
- An ageing population and the high prevalence of obesity in Malta play an important part in the prevalence and experience of pain, its causes and its management. Therefore we cannot consider pain in isolation.

- Resources are always limited, especially in the healthcare field. It may be necessary to put an economic argument derived from research data especially when dealing with policy makers and politicians.

- Policies related to pain are multifaceted and impinge on the remits of several ministries. It may be argued that some pain sufferers do not lack health but pain is impacting their daily living and this affects their general wellbeing, their employment and finally the economy of the country.



CONCLUSION

This conference, with its discussion of research results and personal experiences, highlighted several needs and gaps. This should lead us to consider actions required to improve the lives of persons with chronic pain. Research into local situations provide hard evidence to policy makers for investing in beneficial actions. We therefore set the following recommendations:

- Invest in the primary healthcare services through skilled human resources, education, facilities and equipment in order to improve the diagnosis, assessment, treatment and effective long-term management of chronic pain. Guidelines and resources must be made available to prevent shifting of patients that can be successfully managed at primary care level to the more expensive secondary care system.

- Multidisciplinary teams should encompass a broad range of healthcare expertise including primary care doctors, pain specialists, physiotherapists, nurses, social workers, psychologists, nutritionists, occupational therapists etc). Such teams should provide patient care services for a wide range of pain conditions and engage in educational and research activities, preferably in the primary care settings to manage pain patients from diagnosis stage until they return to full functionality.

- Different types of assessment and management strategies should be considered involving different healthcare professionals. Education and continued professional development is necessary and all the relevant professionals must be targeted.

- Management pathways must be developed, and their quality and effectiveness must be audited to ensure cost-effectiveness and patient satisfaction.

- Appropriate 'wait-times' must be determined for the various categories of pain. Acute painful conditions, such as pain related to trauma or surgery, should be treated immediately. Severe pain with the risk of deterioration or chronicity, such as pain in children or pain related to cancer or terminal or end-stage illness should be treated within 1 week. Severe undiagnosed or progressive pain with the risk of increasing functional impairment, generally of 6 months' duration or less, such as back pain that is not resolving or persistent postsurgical or post-traumatic pain, should be treated within 1 month

while persistent long-term pain without significant progression should be treated within 2 months.

- Pain needs to be followed up effectively to prevent patients having to cope with pain for extended periods of time.

- Equity in provision of services must be guaranteed by ensuring accessibility to and affordability of adequately skilled professionals and all medically approved treatment in line with current medical knowledge.

- Community services such as special leave, teleworking, appropriate transportation, amongst other services, must be considered to support both pain sufferers and their carers.

- Civil society organisations especially those organised around pain conditions must be supported to support their members in accessing medical care and in participating fully in their day to day living.

- Educate the general population on pain and its effects on the individuals and the wider society to prevent stigmatisation of pain sufferers.

- Encourage further research in pain related issues.



A MALTESE CONSENSUS PAPER FOR CHRONIC PAIN.

Preamble:

Maltese stakeholders with an interest in chronic pain led by Malta Health Network, No Pain Foundation and Societal Impact of Pain(SIP) Malta¹⁰ fully endorse the 'Societal Impact of Pain 2016 Policy Recommendations: Time for Action'¹¹ and 'The Societal Impact of Pain -A Road Map for Action'¹². These documents recognize that the successful implementation of the 8 Policy Recommendations is dependent on collaboration between EU member states.

The following text is being proposed by Malta Health Network, No Pain Foundation and Societal Impact of Pain(SIP) Malta.

Our recommendations are guided by five factors, namely:

- Ease of implementation
- Cost-effectiveness
- Urgency
- National priorities
- Major impact on patients.

The Maltese Stakeholders listed above are therefore making the following recommendations, in relation to the Maltese scene:

1. Chronic Pain should be included as an independent condition to facilitate the access of chronic pain sufferers to timely and effective treatment. Chronic pain

should be recognized as a disease in its own right and not only as a symptom of other diseases.

2. A national campaign should be run to raise awareness about chronic pain and its effects on the individual and society. Such a campaign should be conducted within a wide variety of settings and should target persons directly affected by chronic pain, their carers and healthcare professionals.

3. Pain management policies and services within our national hospital should be restructured and streamlined along European policies and guidelines.

4. Chronic pain should be duly recognized as a determinant of health and wellbeing. Relative research should be prioritized through appropriate funding.

5. Recognition of the wide-ranging implications of pain should be endorsed through closer inter-ministerial collaboration.

6. Pain should be included as a key indicator in the outcomes of medical and surgical interventions.

7. Appropriate facilities and funding should be established to facilitate specialization of healthcare professionals in the field of pain.

8. The Maltese authorities should enact and facilitate vocational retraining and integration of persons suffering from chronic pain into the workforce.

9. A National Pain Plan should be established and implemented by 2020.

10) <https://www.facebook.com/Societal-Impact-of-Pain-SIP-Malta-1633893960257388/>

11) https://www.sip-platform.eu/files/redakteur-bereich/Symposia/SIP%202016/Materials_Programm/SIP%202016%20compiled%20recommendations%20Final.pdf

12) [https://www.sip-platform.eu/files/redakteur-bereich/Assorted%20Photos/SIP%20related%20Pdfs/THE%20SOCIETAL%20IMPACT%20OF%20PAIN%20%20A%20ROAD%20MAP%20FOR%20ACTION_Abtract%20Booklet_%2026%20%20%20%20%20\(3\).pdf](https://www.sip-platform.eu/files/redakteur-bereich/Assorted%20Photos/SIP%20related%20Pdfs/THE%20SOCIETAL%20IMPACT%20OF%20PAIN%20%20A%20ROAD%20MAP%20FOR%20ACTION_Abtract%20Booklet_%2026%20%20%20%20%20(3).pdf)



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