

A national Danish pain plan.

The massive socioeconomic costs of chronic pain calls for interest and high priority by health professionals, politicians and governmental bodies. Nevertheless, chronic pain, historically has been neglected and treated as a byproduct. In 2018 something pivotal happened when the Danish government finally allocated funds to come up with a national pain plan.



Government allocates resources.

14.3 million DKK were allocated in the Danish finance act for the period of 2018-21. The goal in the first place was to uncover the shortcomings and best practices of chronic pain and come up with initiatives for long term advancements. Additionally with a focus on reducing the opioid consumption and the number of patients in risk of becoming dependent on this pain medicine. Eventually, the goal was to put together a national pain plan.

Even though, we in our patient organization would like to take credit for this long awaited health political initiative, more likely what got the ball rolling was the concern of an increasing high opioid consumption in the Danish population and regular epidemic in the US.

Uncovering the area of pain.

In the end of 2018, The National Health Authority appointed a working group of clinicians, researchers and patient representatives with expertise in chronic pain. Our patient organization - FAKS, The Danish Association of Chronic Pain Afflicted¹ participated with former president Pia Frederiksen and I.

Our first meeting in the working group took place in January 2019. It was followed shortly by a year long process of meetings, scientific literature reviewing and discussions. Unfortunately, the final report was delayed due to an national election and change of government. The report was finally issued in sep 2020 "Rundown of the pain area - professional proposal for a plan of action"². Then the all too familiar corona epidemic obstructed the further process of putting the recommendations into affect.

A national pain plan in the making.

Finally, in the spring of 2022 things began to stir again. Disappointingly, 10 million left of the initial 14,3 million allocated were no longer accessible due to the time frame of The Danish finance act of 2019-21 was exceeded. Moreover, no new funds were given to the national pain plan. Therefore, it needed to be within the existing economical budget of The Ministry of Health.

With this frame of reference, the ministry began conducting meetings about priorities with stakeholders in the field of chronic pain. I participated as spokesman of FAKS in a meeting together with our long term affiliate the interest organization SmerteSagen. We suggested focusing on the following objectives.

1. Implementation of programs and designated trajectories for assessment and management of chronic pain. This in accordance with the new nomenclature for chronic pain in ICD-11 where chronic pain can exist as chronic primary or secondary pain or both.
2. More education in chronic pain and modern pain science of healthcare professionals. Especially, with a focus on undergraduate medicine and the post graduate speciality of general practice.
3. Preventive and follow up measures and systematic treatment standards to reduce the risk of chronic post surgical and post traumatic pain.



¹ FAKS - Foreningen af Kroniske Smerteramte, [Link](#)

² sundhedsstyrelsen, "Afdækning af smerteområdet - Fagligt oplæg til en smertehandlingsplan" 2020, [Link](#)

Initiatives of the national pain plan.

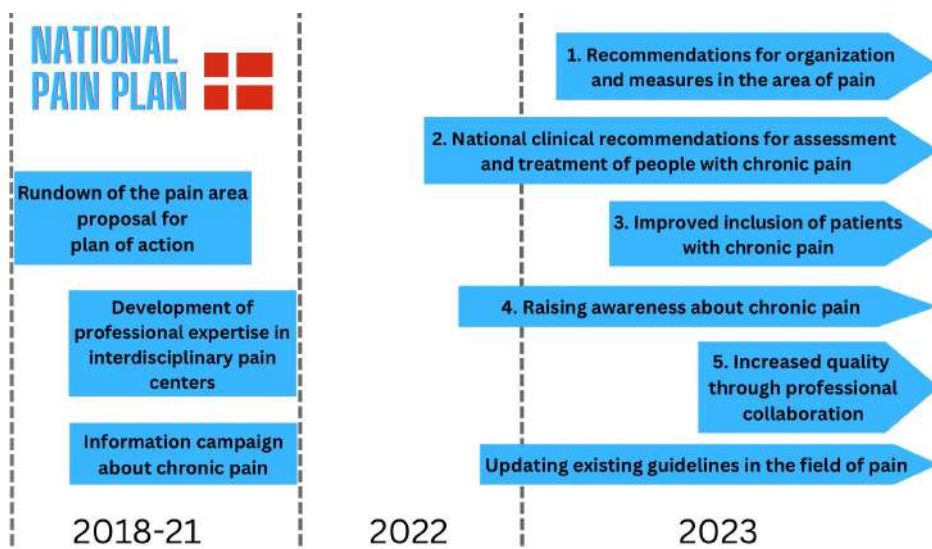
In July 2022, finally, The Ministry of Health issued the document “strategy for the pain area - a national strategy directed at people with chronic pain”³

The strategy contains five initiatives carried out from 2022 to 2023.

• Initiative 1.

“Recommendations for organization and measures in the area of pain”

Objective: To support early assessment and better organization of the collaboration between sectors. To support qualification of the assessment process to prevent unnecessarily long courses of assessment and the risk of chronification. In addition the recommendation should aim to prevent patients with planned surgery to develop avoidable chronic pain.



• Initiative 2. *“National clinical recommendations for assessment and treatment of people with chronic pain”*

Objective: To develop national clinical recommendations for specific interventions that support general practitioners in assessing and treating people with chronic pain better and faster. The recommendation will also be relevant for pain treatment after planned surgery to prevent addiction of opioids.

• Initiative 3. *“Improved inclusion of patients with chronic pain”*

Objective: To give patients a better bio psycho social insight to their own illness in order to facilitate more patient empowerment. Strengthen the dialogue between patients and health professionals. Secure a more uniform picture and approach to people with chronic pain between municipality and primary care.

In order to facilitate this, the initiative aims to develop a national PRO - patient reported outcome questionnaire. The PRO-questionnaire will be stored in the national questionnaire bank enabling all parties across the healthcare system to use and collect data from patients with chronic pain. The objective of registration and PRO-data is not only to qualify clinical work but also to be used in research.

• Initiative 4. *“Raising awareness about chronic pain”*

Objective: Increasing the well-being of people with chronic pain by preventing taboo and stigmatizing. The National Health Authority will carry out an awareness campaign. This will be building on the previous campaign from 2020 “Busting myths about chronic pain”

• Initiative 5. *“Increased quality through professional collaboration”*

Objective: To reinforce the propagation and implementation of the new recommendations. The National Health Authority will be conducting two workshops for people with key roles in healthcare and health professions, relevant authorities and organizations representing patients and relatives.

³ SUM, “strategi for smerteområdet en national handlingsplan målrettet mennesker med kroniske smerter” , [Link](#)

Initiatives set in motion.

- “National clinical recommendations for assessment and treatment of people with chronic pain”.

In September 2022 FAKS was appointed to participate in the 2nd initiative. My colleague Sanne Lydø and I began the process by taking a class in GRADE - Grading of Recommendations Assessment Development and Evaluation to understand and to assess the quality of scientific literature and research. We also wrote a pre-hearing document stating the most essential challenges and opportunities we experience in general practice for people with chronic pain⁴

From day one in the workgroup the general practitioners expressed concern about the population of the recommendations encompassing a large volume of all people with chronic pain. Also, they were not very fond of implementing a screening tool in general practice. We speculate that their reservations can be ascribed several factors. First and foremost, the expanding number of diagnoses and functions, tasks and shortage of time in general practice. Also, there is often a tug of war going on between GPs and the public authorities about tasks and fees.

I must admit that I am concerned about the Initiative being watered down resulting in something with no clinical value.

- “Raising awareness about chronic pain”

In november The National Authority of Health contacted FAKS about the 4th initiative.

They needed our patient perspective and quality assurance on material for an awareness campaign in progress. Two volunteers from our organization have been contributing, and the first video is in the pipeline.

- *“Recommendations for organization and measures in the area of pain”*

In January 2023, we were invited to join the 1st initiative that starts the 2nd of March.

With a focus on allocation of responsibility and transsectorial cooperation, we have high hopes for this initiative. Especially, as among the appointed are The National Board of Social Services, Danish Agency for Labor market and Recruitment, Danish regions, and KL-local Government Denmark. These public bodies have so far been very absent in the focus on chronic pain. Furthermore, I believe, we often miss the whole picture and potential of people with chronic pain, when focusing only on healthcare.

- *“Improved inclusion of patients with chronic pain”*

Most recently, I’ve had a meeting with The National Health Data Authority which is about to set up a commission on the 3rd initiative.

They wanted the input from a patients perspective on outcomes and screening tools. The initiative aims to develop a patient reported outcome questionnaire for primary care. This will most likely be a scale down version of the more extensive PRO-questionnaire already implemented in the interdisciplinary pain clinics in Denmark and registered in the database PainData.

I have been involved with the topic for some time. In 2021 FAKS participated in the development of value based healthcare in the interdisciplinary pain clinics. In the fall of 2022, I requested chronic pain to be included in The Danish Clinical Quality Program – National Clinical Registries (RKKP)⁵

- *“Updating existing guidelines in the field of pain”*

In addition to the 5 initiatives mentioned in the pain plan, The National Health Authority has been working on updating the existing guidelines in the field of pain. In the fall of 2022, 120 clinical guidelines were submitted for consultation. In December The National Health Authority held a workshop with various stakeholders in the field of pain attending including FAKS and myself. Emerging is a wish for fewer but more specific and up-to-date recommendations. Also expressed, was a wish for clinical recommendations for treatment and follow up on postoperative pain and treatment with opioids to prevent long-term use

⁴ “Prehørings svar – Faglig anbefaling for udredning af personer med smerter i almen praksis”, 27.10.24, [Link](#)

⁵ The Danish Clinical Quality Program, National Clinical Registries (RKKP), [Link](#)

Chronic pain - high impact, low priority.

Chronic pain is one of the most prevalent health conditions in Denmark and the world. Based on self-reported assessment an estimated 1,3 million of Danish people are affected by chronic pain⁴ - defined here as pain with a duration over 6 months. Same study shows that there have been an increase in the number of people with chronic pain in Denmark 2000 – 2017 (19.5%– 27.8%)⁶.

A large scale pan European telephone study carried out in 2003 involving 43,000 people in 15 European countries showed an average prevalence of 19% with chronic pain lasting 6 month or more⁷. This indicates that approximately 150 million people are experiencing chronic pain in Europe. More recent data from European countries shows a pooled mean of 30%⁸. However, the prevalence estimates are ranging from 8.7% to 64.4%. The high variance is probably due to inconsistencies of chronic pain definitions, variety of assessments methods and also to some extent dissimilarities of populations.



“a significant number of people are suffering from chronic pain with significant disability and distress”

Notwithstanding the fact that the condition chronic pain covers a wide continuum of severity, a significant number of people are suffering from chronic pain with significant disability and distress. This is also defined as chronic primary pain in accordance with the most recent definition by IASP (International Association for the Study of Pain) and WHO ICD-11 (International classification of diseases). The previously mentioned study from 15 European countries showed that in 2003, 6,33% were suffering from chronic pain of severe intensity⁹. More recent data shows that 8% of the US population are living with so called high impact chronic pain¹⁰. In the UK 1% - 6% of the population suffers from chronic primary pain estimated by National Institute for Health and Care Excellence - NICE¹¹.

Chronic complex/primary pain greatly impacts both functionality and quality of life of the people afflicted and their relatives. I can attest to that having lived with widespread pain over 25 years. Correspondingly, the costs for the health and social care system are substantial. The costs encompasses frequent consultations in primary care, hospitalizations and various kinds of social benefits, early retirement, and production loss etc. Also the indirect costs due to the strain exerted on relatives needs to be considered - more frequent sick days, taking time off work to care for the person with chronic pain etc.

It is also worth noting that the expenditure for chronic pain will only grow in the future due to an increasing aging population.

Consequently, with the high personal and societal impact of pain, one would think that chronic pain would be on top of the health political agenda and on the curriculum of every healthcare related curriculum. Disconcertingly, this is not the case, as I stated in the introductory.

⁶ “Increasing prevalence of chronic non-cancer pain in Denmark from 2000 to 2017: A population-based survey”, EUR J Pain, 08 November 2021.

⁷ Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. *European Journal of Pain*, 10, 287– 333. <https://doi.org/10.1016/j.ejpain.2005.06.009>

⁸ Steingrimsdóttir, Ó. A., Landmark, T., Macfarlane, G. J., & Nielsen, C. S. (2017). Defining chronic pain in epidemiological studies: A systematic review and meta-analysis. *Pain*, 158, 2092–2107. <https://doi.org/10.1097/j.pain.0000000000001009>

⁹ Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. *European Journal of Pain*, 10, 287– 333. <https://doi.org/10.1016/j.ejpain.2005.06.009>

¹⁰ Dahlhamer J, Lucas J, Zelaya C, Nahin R, Mackey S, DeBar L, et al. Prevalence of Chronic Pain and High-Impact Chronic Pain Among Adults - United States, 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67(36):1001-6.

¹¹ “Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain”, National Institute for Health and Care Excellence (NICE); 2021

Keeping up the momentum.

Despite that the Danish national pain plan is a step in the right direction, we must not forget that this initiative was dictated primarily by the fear of an opioid epidemic. It was not based on awareness and acknowledgment of chronic pain as a condition in its own right and a healthcare area.

It is also worth noticing, that the initiatives in the national pain plan fall under the legislation of healthcare. This entails that any recommendations and measures cannot incorporate rules and organizations of the social care system. Obviously, such vertical structure and silo thinking can result in sectors working against each other and measures in healthcare can be hampered by other incitements in the social sector. I hear the stories and experience the personal consequences of this disregard for chronic pain and disintegration of sectors.



*"It is not enough with fingers crossed,
we need initiatives in pain enforced"*

Besides providing services and activities for our members in our patient organization, we strive to take an active role in health professional work and health political advocacy. I do feel that we have made some headway in Denmark in the last 15 years I have been working as a volunteer in the field of pain. On an international level, things are slowly advancing too. The new nomenclature of chronic pain in ICD-11 e.g. is an important development that can help the documentation and visibility of chronic pain. Nonetheless, to keep the current moment, it is not enough with fingers crossed, we need initiatives in pain enforced.

As a small patient organization, we often experience running into a brick wall on various health professional and -political matters. It is difficult to break through these barriers as we rely solely on volunteers. Additionally, many of our volunteers are living with chronic pain themselves. Therefore, I think it is crucial to have professional organizations such as The European Pain Federation - EFIC and The international Association for the Study of Pain - IASP. However, these organizations are primarily representing the views and interests of health professionals and researchers in the field of pain. This is why we also need organizations such as Pain Alliance Europe - PAE that represents the voices of patient organizations and people living with chronic pain themselves. Last but not least, it is important that we as organizations and individual stakeholders respect and reach out and cooperate with each other. Stakeholder partnerships such as SIP - Societal Impact of Pain has an important role in this. Let us keep up the current moment. Much still has to be said and done to raise awareness of chronic pain and improve pain policies across countries.



This article has been written by Lars Bye Møller.

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Lars has been living with chronic pain (fibromyalgia) himself for 25 years.