Event Report

Pain in the International Classification of Diseases (ICD-11): A SIP Event

On 29th November 2022, the Societal Impact of Pain (SIP) Platform, hosted a virtual event with over 130 registrants entitled "Pain in the International Classification of Diseases (ICD-11)".

This event covered a broad and engaging discussion of the benefits and the challenges of implementing ICD-11. Alongside speakers from WHO Europe, national representatives gave insight into their countries or regions progress and findings. The event also presented the SIP Road Map Monitor 2022, launched the same day and available to read online.

I. Introduction

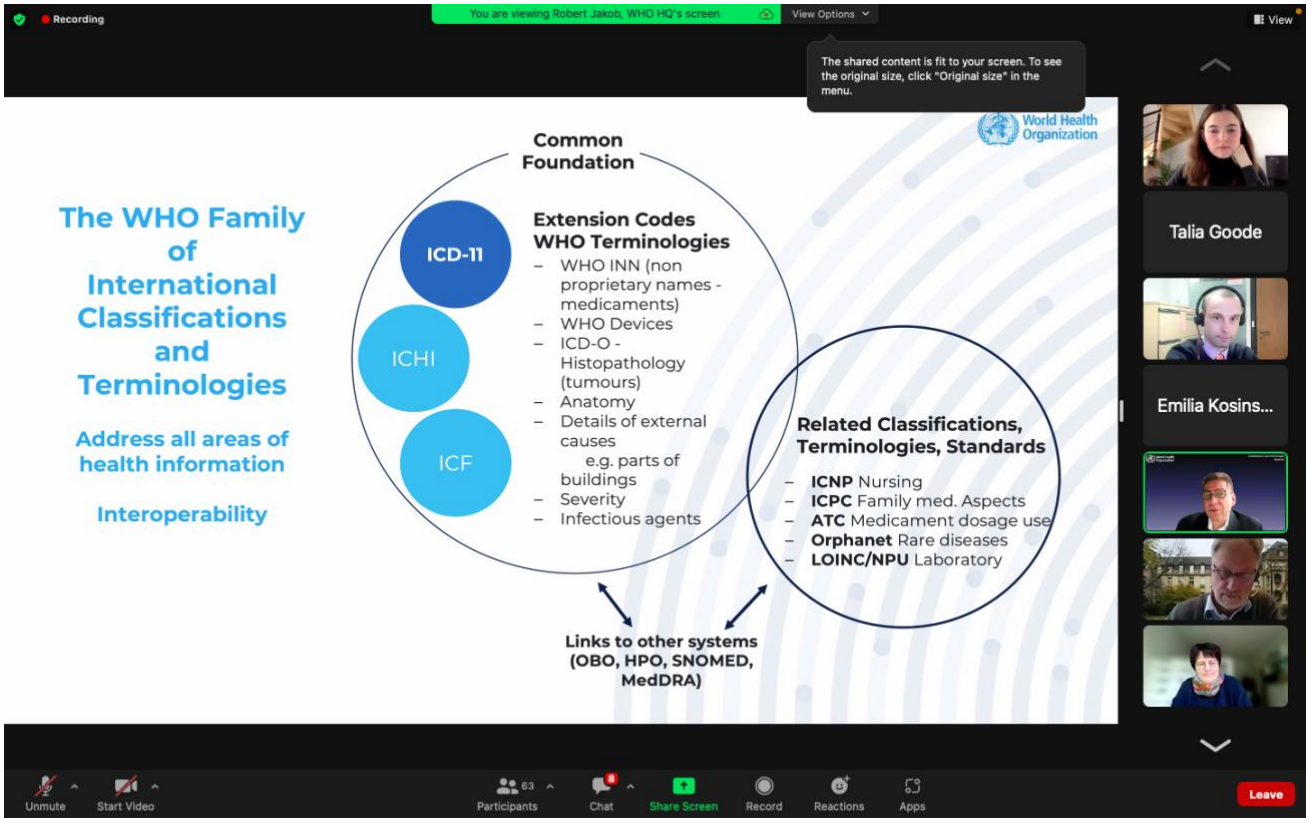
Angela Cano Palomares, Project Manager of SIP, opened the event welcoming the audience and speakers and outlining the structure of the event.

Sam Kynman, Executive Director of the European Pain Federation EFIC, gave background information on SIP. A collaboration between EFIC and PAE (Pain Alliance Europe), representing allied health professionals and patients to achieve advocacy goals and influence policy change relevant to pain management. Sponsorship from Grünenthal declared.

Patrice Forget, Chair of SIP, introduced himself and welcomed everyone to the event. Apologies given for absence of **Deidre Ryan**, President of PAE. ICD-11 has a potential large impact on our lives in terms of development of services as well as recognition of the issues and conditions that people living with pain have. ICD-11 has potential impact in terms of education of professionals, for classifying pain better, for harmonising terminology and communicating with patients living with pain. It will also have implications on researchers and how they conduct research projects. It also ties into one of SIP's priorities which is 'Pain and

Employment.' We need greater recognition of pain problems and prevention and consequences of pain in the workplace.

II. Technical Implementation of ICD-11 – World Health Organization (WHO) Perspective



Robert Jakob, Team Leader Classifications and Terminologies at WHO-Headquarters, explained that ICD-11 is a legally mandated health data standard since January 2022 for reporting mortality and morbidity information. ICD-11 is both independent of language and culture and clinically relevant and scientifically updated, bringing greater detail to ICD-10. Terminology and classification have been integrated into one structure.

ICD-11 has multiple uses including:

- Cause of death
- Clinical terms, records, surveillance
- Functioning assessment
- Primary care
- Prevention research
- Patient safety, drug safety, device safety
- Casemix, costing resources, DRG
- Cancer registration

ICD-11 is not alone. It comes with the ICHI and the ICF. Using all three together widens what you can do with recording patient data.

Stem codes for the classification go beyond just a diagnosis and allow for external reasons or causes to be recorded and recognised, while 'traditional medicine conditions' is still an option.

The terminology extension codes allow for greater detail of patient symptoms and data recording.

Example given of viewing a Chronic cancer pain in ICD-11. Structure allows for adding information such as severity of pain, alternative severity (mental), temporal pattern, onset.

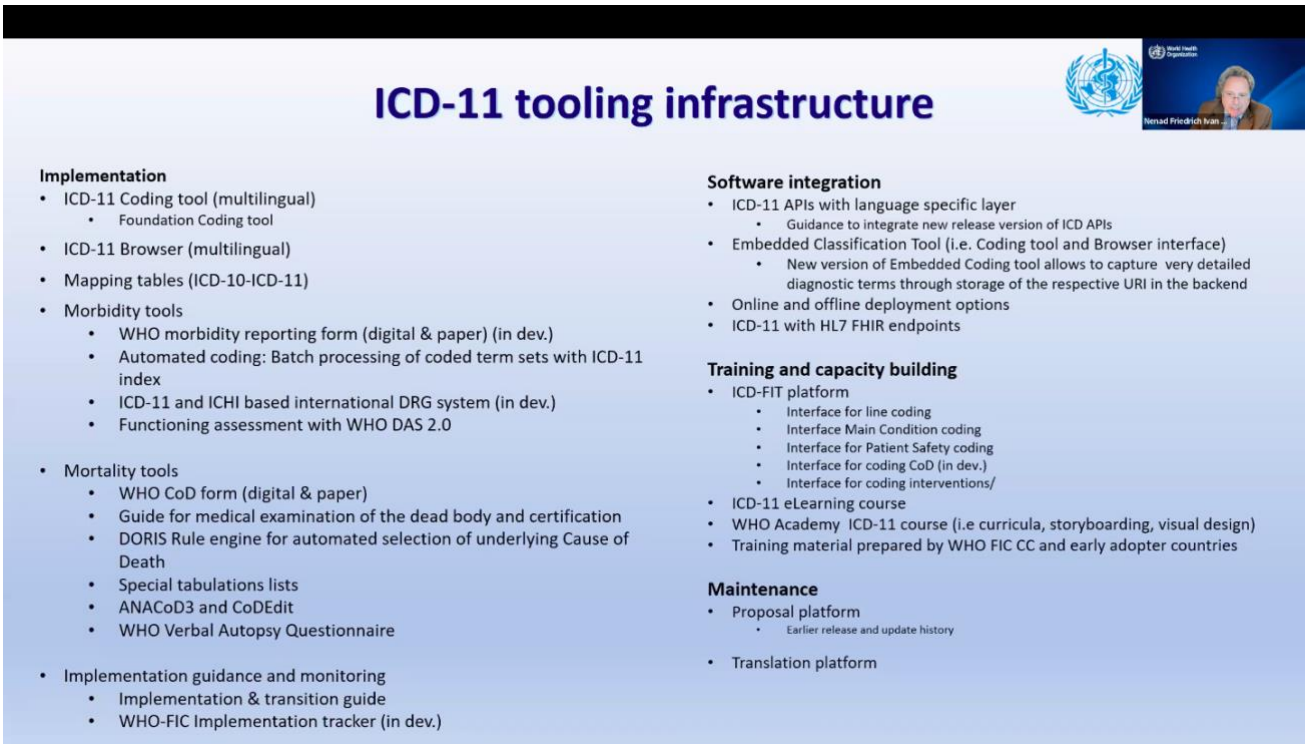
ICD-11 coding tool easily codes a great level of detail and is multilingual. It is currently available in 29 languages, covering most of Europe. Example of coding tool given, like a Google search you can type in the diagnosis and the Coding tool finds the best match including the code combination (post coordination) information for left or right (laterally).

In terms of implementation, there is an application programme interface replacing software. It allows software to communicate with the system and a search engine. This is advantageous to a dropdown list which limits search options. This is available from WHO services and can be used online like a Cloud system. It is scalable and reliable. An alternative is to download this to be able to use locally and offline.

Information for implementation can be found online ***icd.who.int***
Here you will also find a 'be involved' section which, once registered, you can suggest amendments to the classification system.

ICD-11 is already being used in 2022 in the following scenarios:

- Health records in primary, secondary and tertiary care
- Death certificates
- Publications
- Reimbursement
- Vaccination certificate
- Traditional medicine
- Essential medicines
- UHC Menu



Nenad Friedrich Ivan Kostanjsek, Technical Officer at WHO-Headquarters, used national examples of ICD-11 implementation to demonstrate ICD-11's tooling infrastructure (summarised above) which ranges from implementation tools to software integration tools amongst others. This is a key additional feature of ICD-11, which builds upon ICD-10.

Example from Kenya and Colombia given of ICD-11 being using in routing Health Information Systems (RHIS) for death certification and electronic recording. Example from Kuwait of integrating and updating their own Electronic Medical Record System. By searching for a word in the search box, the ICD-11 code is then generated. Example from India of combination of ICD-11 and ICHI in the context of service packages.

The development of natural language processing capacity is in progress. It needs addition of accurate clinical terms for continuous enhancement of ICD-11 index.

Key considerations for ICD-11 implementation:

- Carry out a Health Information System ecosystem analysis and review
- Specify the value proposition of ICD-11 (e.g., faster, easier, more accurate coding) from the country perspective
- Specify opportunities and challenges for ICD-11 implementation in the country
- Specify and carry out a step-wise transition process including:
    - Integration and piloting of ICD-11 APIs in software applications
    - Training and capacity building of coding workforce
    - Scaling up of ICD-11 pilots and training
    - Preparing system-wide implementation
    - Routine reporting with ICD-11

Malaysia implementation transition plan given as an example. Top-down approach where ICD-11 is already implemented in data warehouse, recording data already at national level with ICD-11 and next year they will start systematically rolling out the piloting and subsequent implementation of primary data capturing with ICD-11 across hospitals. Other countries have taken bottom-up approach.

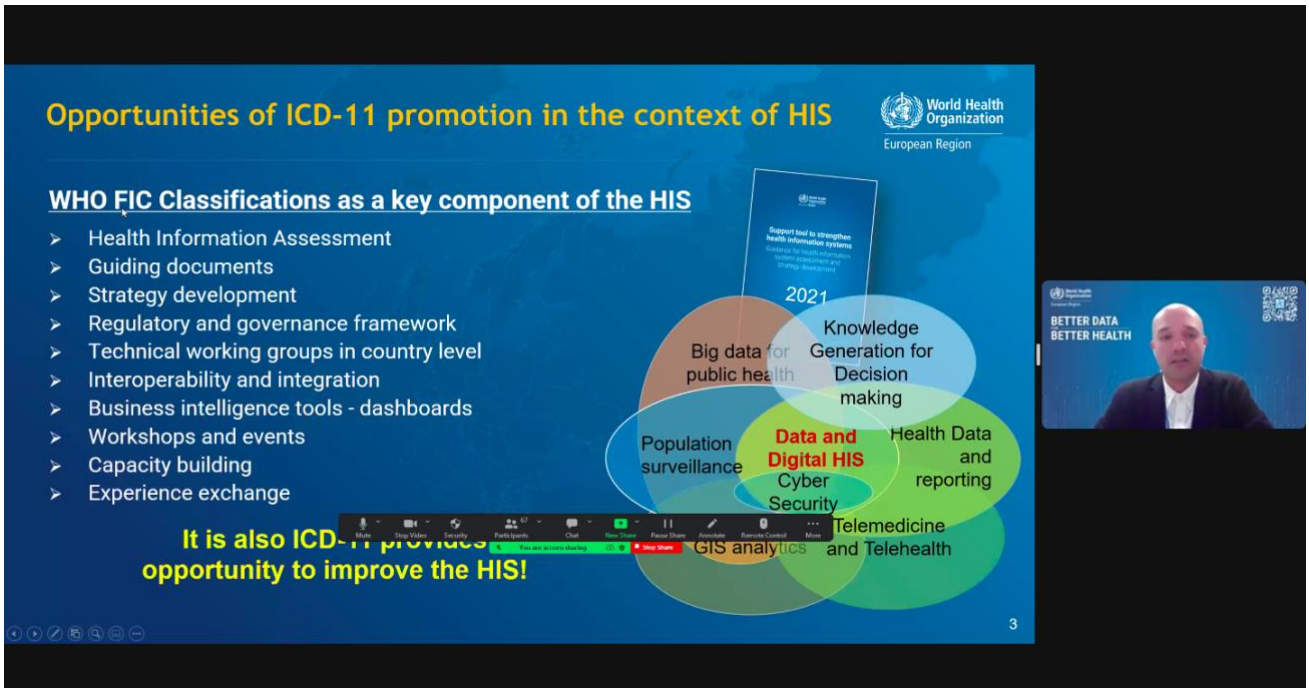
Key points to highlight are that ICD-11 is not a drop-down list like ICD-10, the google search style feature should be used. To leverage from the benefits of ICD-11, it is important that the ICD-11 based electronic health record system includes the following data in the data form entry:

- A data entry field to indicate the diagnostic
- Statement in free text
- A command field which activates the smart search with the ICD-11 coding tool
- One data field which records the ICD-11 code(s) and another data field which documents the ICD-11 code title as rendered and selected by the user in the ICD-11 coding tool
- A mechanism which stores the respective ICD-11 URI of the selected ICD-11 entity in the backend

ICD Training also needs rethinking. Some principles to consider when training personnel:

- Competency based and target group oriented
- Inside out approach (i.e., build more competencies around core by adding gradually increasing levels of complexity) instead of bottom-up
- Problem based learning through stories and practical exercises
- Give learners a sense of 'benefit/gain'
- Leverage technology
- Use different media e.g., YouTube

It is essential to bring people onboard so that everyone recognises the benefits of ICD-11 and how it will impact them. Promote the benefits as you learn and go along – example given from Kuwait of physicians outlining the benefits for other physicians.



Karapet Daytyan, Data and Digital Health Unit, Division of Country Health Policies and Systems, WHO Regional Office for Europe, presented opportunities and efforts for ICD-11 implementation within the WHO European Region (EURO).

The EURO includes 53 member states or recognised territories and covers approximately 1 billion people.

ICD-11 promotion is related to the Health Information System and digital health because it is a priority of WHO EURO. Data and digital health information system are also highlighted in the WHO action plan.

In the context of opportunities of ICD-11 promotion in the context of HIS, WHO are supporting many actions:

- Health Information System Assessment and giving recommendations to always incorporate ICD-11
- Guiding documents for ICD-11 implementation
- Strategy development for member states
- Regulatory and governance framework development
- Establishing technical working groups at national level
- Interoperability and integration
- Business intelligence tools
- Workshops and events
- Capacity building
- Experience exchange

One thing to highlight is that the WHO's work is encouraging ICD-11 to be an additional tool for improving and strengthening Health Information Systems.

The digital health action plan for the WHO EURO 2023-2030:

- The individual at the centre of care
- Health system challenges and citizen needs
- Data-driven policy and decision making
- The future of health systems
- Long-term commitment

During 72nd Session of WHO Regional Committee for Europe in September 2022, the main WHO health related even for Europe, all member states approved the digital health action plan, which demonstrates that digital health and Health Information Systems are becoming higher priority.

ICD-11 implementation efforts in the EURO:

- Promotion and introduction
- Workshops and webinars
- Capacity building
- Translation
- Coordination for implementation
- Established WHO FIC European network

Why establish WHO-FIC European Network?

- Lack of coordination in implementing classifications in the region
- Lack of promotional activities
- Lack of capacity building
- Emerging ICD-11 implementation
- ICF and ICHI and other classifications related requests – less well known

The WHO-FIC European Network includes:

- 47 members
- 21 countries
- 8 network meetings
- Members looking for expansion to involve all stakeholders

The WHO-FIC European Network seeks to support the development, implementation, and maintenance of WHO-FIC across the EURO through:

- The Global WHO-FIC Network
- Cooperation and collaboration
- Exchange of good practices
- Capacity building for WHO-FIC
- Ongoing situation analysis

Ongoing or implemented ICD-11 support in EURO:

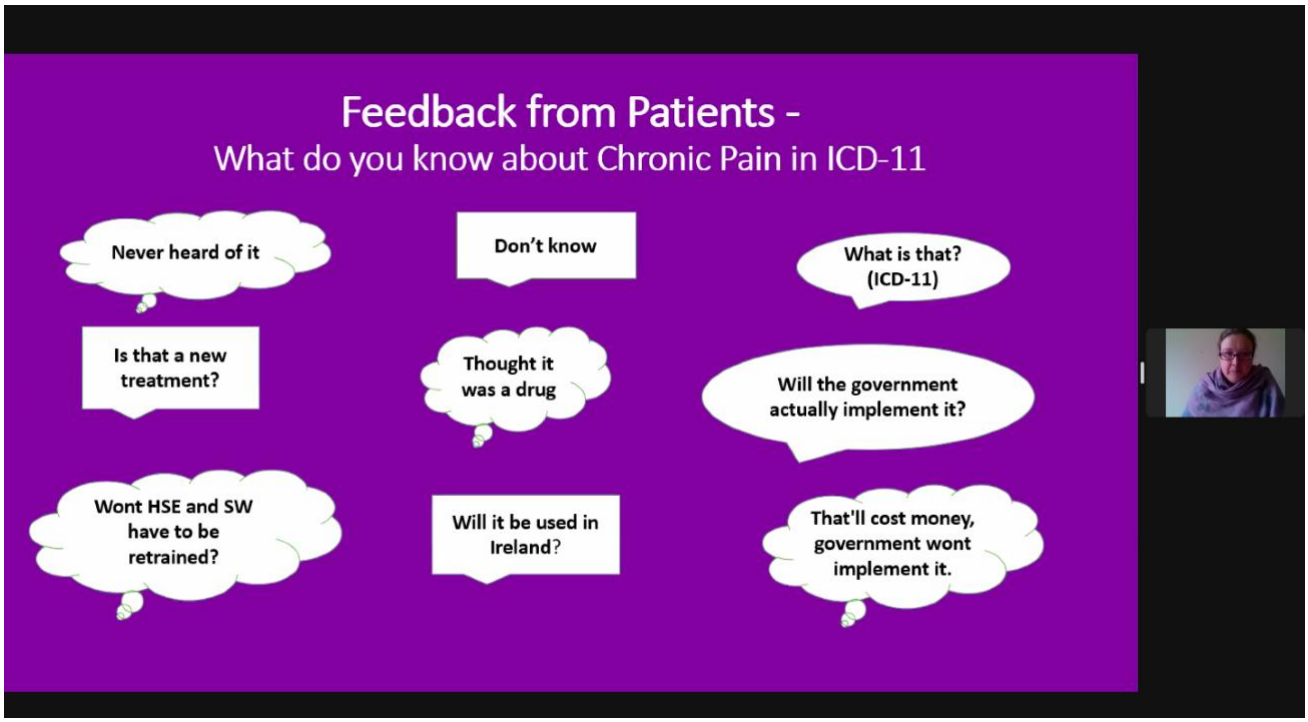
- 14 WHO collaborating centres for the WHO-FIC, across 9 countries: *Norway, Czech Republic, France (3), Germany, Ireland, Italy, Netherlands, Norway, Switzerland, UK (3)*
- 25 countries participated in ICD-11 introduction and implementation preparation training
- 29 languages translation and/or preparation for translation in WHO Europe
- Guidance development for digitalisation of Health Information Systems

Regional priorities include:

- WHO-FIC European Network expansion – to include all stakeholders
- Situation analyses – develop regional database for WHO-FIC status and progress reporting and develop regional roadmap for WHO-FIC/ICD-11 implementation to

identify regional priorities and gaps
- Overcome ICD-11 implementation challenges in EURO region – lack of digital infrastructure, translation issues, funding for capacity building, training, and promotion

III. ICD-11: A Patient's Perspective



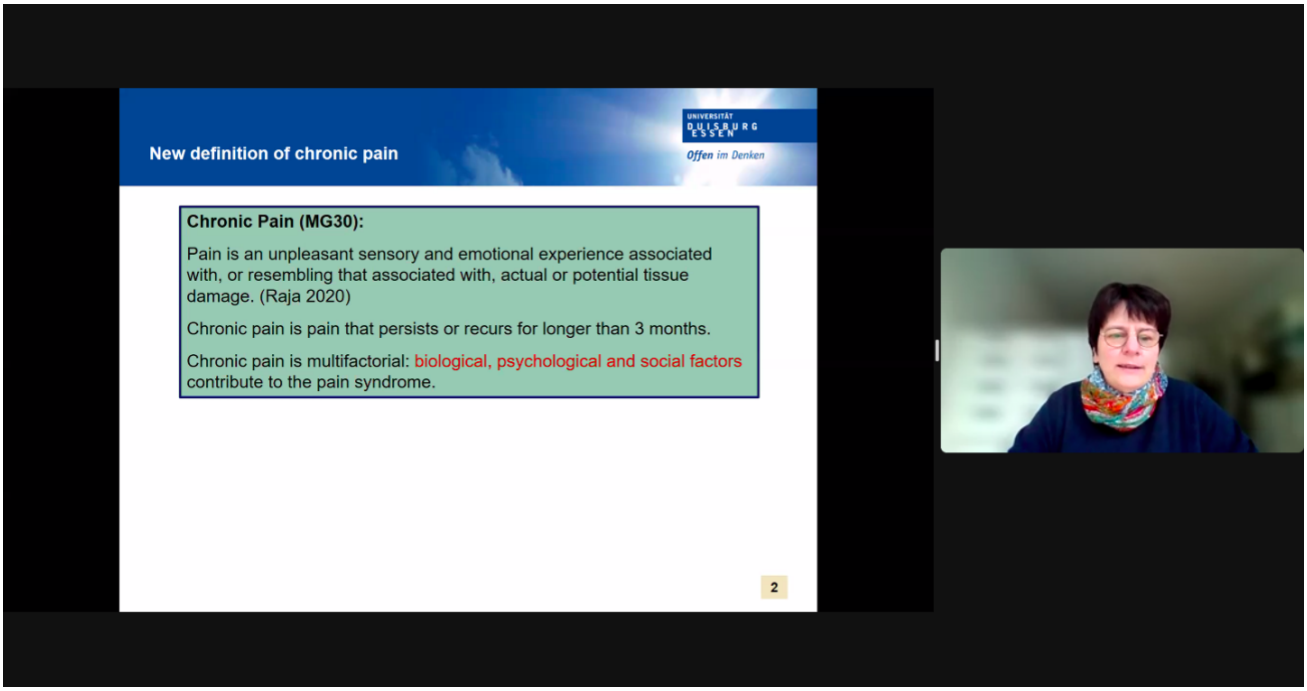
Martina Phelan, Chairperson, Chronic Pain Ireland, shared the patient perspective on how patients view ICD-11 and how they can benefit from ICD-11.

See the various responses from patients about their knowledge and perspective of ICD-11. It was very common that patients did not know what ICD-11 was as well as negative responses about the realistic implementation of ICD-11.

Education and training patients about what ICD-11 is and its direct benefits for them is needed to have the support of patients before approaching governing bodies to implement ICD-11.

The benefits for patients include:
- Reduced stigma and anxiety for patients as conditions are officially recognised
- Recognised condition across health care providers and personnel
- Guaranteed referral and treatment options
- Everyone has the same understanding of pain conditions, less misunderstanding when receiving or seeking treatment in multiple centres, national or international
- Guaranteed payments for treatments by health insurance companies
- Recognised condition across Social Welfare Departments and payments issued for existing conditions not currently recognised e.g., fibromyalgia.

IV. ICD-11: Improving pain management



Prof. Dr. Antonia Barke, University of Essen, discussed the impact of ICD-11 on pain management.

Shortcomings of the previous classification of chronic pain in the ICD:
ICD does not include a definition of pain, there is no biopsychosocial model of pain, and it fails to reflect the internationally accepted definition of pain. There were also some missing diagnoses in ICD-10 such as chronic pain related to cancer and its treatment, chronic postsurgical pain, chronic neuropathic pain. Clear definitions and criteria were lacking, such as the pain classification not including detail such as 'chronic.' Finally, diagnoses were scattered throughout the ICD, which meant a lack of a unified response for researchers and from healthcare professionals.

ICD-11 classification of chronic pain has been adapted to the current internationally recognised definition:
Chronic Pain (MG30) – Pain is an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissues damage. (Raja 2020). Chronic pain is a pain that persists or recurs for longer than 3 months. Chronic pain is multifactorial: biological, psychological, and social factors contribute to the pain syndrome.

How will this improve pain management?

- Dualism between mind and body is replaced by unified biopsychosocial model
- Whole person with their living context will be in focus
- Multidisciplinary treatment would be a natural consequence and is recommended in the ICD-11
- Additional extension codes will allow to code biopsychosocial aspects of pain in an individual case, benefitting individual patients

Chronic Pain (MG30) has the following subsections with their own classification codes:
MG30.0 – Chronic primary pain is chronic pain in one or more anatomical regions that is characterised by significant emotional distress (anxiety, anger/frustration, or depressed mood) or functional disability (interference in daily life activities and reduced participation in social

roles). This diagnosis is appropriate independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms.

IMPORTANT to note: biological factors are NOT forbidden, and psychological factors are NOT required.

How will this improve pain management?

- Multifactorial nature means patients should be able to receive multidisciplinary treatment
- It is descriptive and free of etiological assumptions
- Chronic primary pain is classified in one place
- Grouping should stimulate the research into differences and similarities
- It would be compatible with new developments such as 'nociplastic' pain accounting for neuroplasticity contributing to the chronic pain syndrome

MG30.1 – Chronic cancer-related pain (new to ICD-11)
MG30.2 – Chronic postsurgical and post traumatic pain (new to ICD-11)
MG30.3 – Chronic secondary musculoskeletal pain
MG30.4 – Chronic secondary visceral pain
MG30.5 – Chronic neuropathic pain (new to ICD-11)
MG30.6 – Chronic secondary headache or orofacial pain

How do these subsections and inclusion of new diagnoses improve pain management?

- Having diagnostic categories that can inform treatment
- Provide the basis for reimbursement
- In the long-term, it will make the diagnoses visible and bring them on the policy and research agenda

Example given from Thailand of classification of pain according to ICD-10 – 29% classified as 'other chronic pain' – unspecified.
ICD-11 with the same data, provides much greater detail leading to better patient treatment and patient information.

Extension codes: This feature allows to code for pain severity, temporal features, and evidence for psychosocial factors, these can be combined with all chronic pain codes.
Pain severity: combination of intensity, pain-related interference, and pain-related emotional distress with a 11-point numerical rating of the patient. All assessed separately then converted into WHO categories as previously shown.

How will this improve pain management?

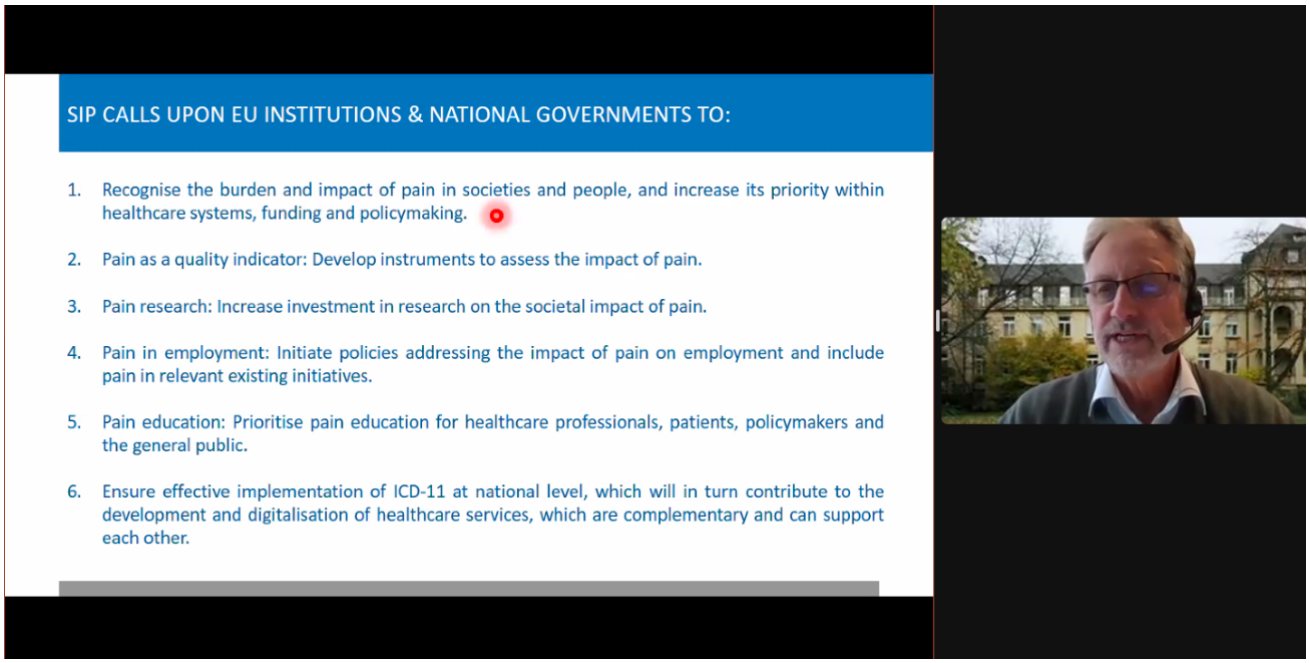
- Interference and distress are important for patient quality of life
- The person providing treatment will have to ask the patient about it
- It will then be part of the diagnostic code
- It will make the interference and distress more visible in the system
- It will inform other treatment providers
- It will allow monitoring of the pain over time and treatments
- It may improve research and make it easier to compare study samples
- It may stimulate discussions between patient and treatment provider

The same is true for the code for psychosocial factors. Presence of cognitive, emotional behavioural and/or social factors that accompany the chronic pain. The extension code is appropriate if:

- There is positive evidence that:
    - Psychosocial factors contribute to:
        - The cause
        - The maintenance and/or the
        - Exacerbation of pain and/or associated disability and/or when the chronic pain results in negative psychobehavioural consequences (e.g., demoralization, hopelessness, withdrawal)

This code can be combined with ANY primary and secondary diagnosis of chronic pain.

V. Presentation of the 2022 SIP Road Map Monitor



Rolf-Detlef Treede, Medical Faculty Mannheim of Heidelberg University, presented the SIP Road Map Monitor from 2022, which revisited the previous version in 2019, to understand how national guidelines, action plans and the status of policies supporting the updated priorities of SIP have evolved in the last few years, especially in the post-pandemic context.

Objectives:

1. Capture the status of implementation of long-term policy priorities, previously identified in the 2018 Societal Impact of Pain Joint Statement
2. Formulate evidence-based policy actions addressing the societal impact of pain

Development of the survey questions:
Building on the 2019 survey, the 2022 survey collected information on general questions related to:

1. National Health Frameworks of Pain
2. Pain as a Quality Indicator
3. Pain Research
4. Pain in Employment
5. Pain Education

Survey approach and analysis:

Respondents from 13 countries provided data. 16 countries responded however 3 were discounted due to incomplete/missing answers.
39 countries were invited to provide information, including 38 European Pain Federation EFIC chapters, 7 national representatives from Pain Alliance Europe PAE and all 12 SIP National Platforms.

2022 SIP Road Map Monitor Results:

National Health Frameworks of Pain

- 62% have a national guideline for pain management while 37% do not
- 46% have launched an action plain against pain, 3 of which cover acute pain and 2 do not. 4 of them cover chronic pain and 1 does not. 1 country did not specify if their plan covered acute or chronic pain

Although many have national guidelines plans, less have an active action plan which calls for further action.

Pain as a Quality Indicator

- 31% have activities to discuss or implement ICD-11, while 38% do not and 31% do not know
- 16% have activities to discuss or implement ICF, while 38% do not and 46% do not know

Pain is being ignored and not on the discussion table to be implemented later.

Pain Research

- None of the countries stated that they have a national research strategy for pain implemented in their country
- None of the countries stated that patient/public involvement is mandatory in their country when developing pain research projects in publicly funded calls

Pain is not being recognised as a research topic on its own. Whereas in America there is large funding for pain research. Health topics must compete against each other for EU funding as opposed to topics having their own budget.

Pain in Employment

- 23% have regulation to reintegrate people with chronic pain into work, while 62% do not and 15% do not know

Pain Education

- 46% have national pain education resources available for the general public, while 54% do not
- 62% stated that the basics of pain management are mandatory teaching at undergraduate level, while 38% do not have the same mandate
- 62% have specialist pain training for medical doctors at a postgraduate level. 15% have specialist pain training for nurses at postgraduate level. 23% have specialist pain training for physiotherapists at a postgraduate level. 8% have specialist pain training for psychologists at a postgraduate level

Common understanding of pain is important, including educating the general public as well as healthcare professionals in all disciplines.

Key findings:

1. Development and implementation of specific national pain plans is largely missing

European governments should learn from each other

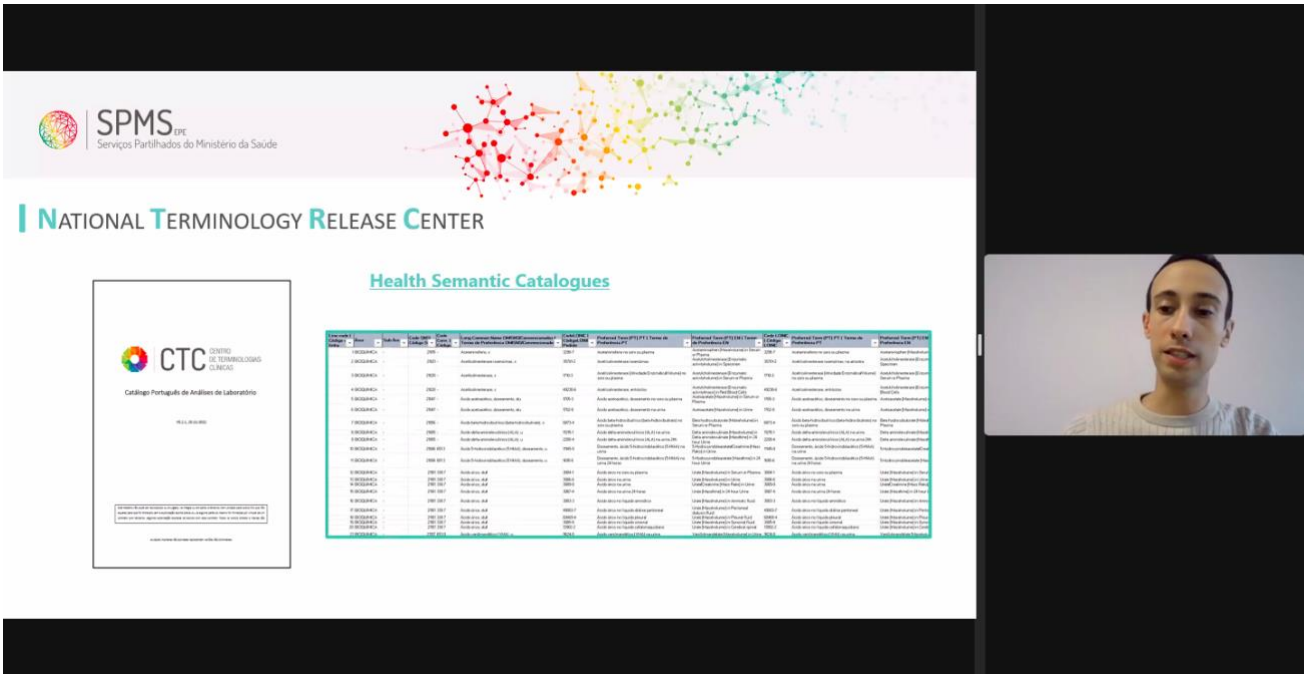
2. There is a lack of prioritisation of pain in Europe. Action is needed to reach the standard of the WHO directive and classification in these areas
3. The establishment of pain registries, collection of broad socioeconomic data and patient involvement within pain research projects are key areas for improvement
4. More needs to be done to ensure a holistic patient-centred approach is established for adaptation of workplaces and reintegration into the workplace
5. There are large discrepancies across Europe in pain education at both undergraduate and postgraduate level and major gaps in patient involvement in the development of educational tools for pain management; both are key areas for improvement

SIP calls upon EU Institutions & National Governments to:

1. Recognise the burden and impact of pain in societies and people, and increase its priority within healthcare systems, funding, and policymaking
2. Pain as a quality indicator: Develop instruments to assess the impact of pain
3. Pain research: Increase investment in research on the societal impact of pain
4. Pain in employment: Initiate policies addressing the impact of pain on employment and include pain in relevant existing initiatives
5. Pain education: Prioritise pain education for healthcare professionals, patients, policymakers, and the general public
6. Ensure effective implementation of ICD-11 at national level, which will contribute to the development and digitalisation of healthcare services, which are complementary and can support each other

Read the full 2022 SIP Road Map Monitor **here**.

VI. Semantic Interoperability: Perspectives from a governmental agency



Filipe Mealha, Coordinator for Planning, Architecture, Compliance and Engineering, introduced himself as working for the Shared Services of the Portuguese Ministry of Health (SPMS). The SPMS is a public enterprise created in 2020 functioning under the guardianship of the Ministries of Health in Finance. It aims to provide shared services to organisations operating specifically

around health, to 'centralise, optimise and rationalize' the procurement of goods and services within national health systems in the following areas:

- Purchasing and logistics
- Financial services
- Human resources
- Telehealth

Portuguese landscape:

- 10 million citizens
- 54 public hospitals
- 359 primary care units
- 90% of these public hospitals or primary care units are using SPMS ICT solution software

To extract value from health data, there are 4 main layers:

- Legal
- Organisational
- Semantic
- Technical

Today's focus is on the semantic layer, ensuring that information is registered and received in the same manner across the whole ecosystem.

For this, Portugal created a national structure, called the National Terminology Release Centre, a result of a cooperation protocol between the SPMS, DGS (clinical guidance) and ACSS (financial services).

Approaches for releasing reference data. Started using national codes and map them to classifications or terminologies. Additionally, they also provide full release of classifications which is true in the case of ICD-10, CM and PCD, adopted nationwide in Portugal. Also provide context specific value sets from classification and terminology. They also help hospitals with their local codes and be able to map them with international classifications and terminologies. This makes it possible to extract useful information from health data and an exchange of information between health providers and health care provision.

Health Semantic Catalogues: this is the approach of mapping national codes to international classification/terminologies and to context specific value sets from classification and terminology. This approach takes international standards and models the context to see which concepts are relevant to the context then which listing of values are relevant to each concept to come up with tables. The tables show what information systems will upload and use for health data. This approach allows old and new systems to use this reference data. These catalogues power the exchange of information.

Structuring these catalogues includes public consultation for transparency mechanisms. Consensus is needed when producing the structures, public consultation gives people the chance to express agreement or disagreement with the reference data being produced. Another key moment is the identification of clinical experts who support national health programmes.

Top tips:

- Have regular meetings with people who will be using these structures in reality – healthcare providers and software vendors. Use their feedback, and get the backing of everyone involved, will dramatically help the implementation of these structures

- Ensure that you are working for the right opportunity. It is very time consuming to produce reference data, so ensure there is a will for change, and it is needed

This links to the currently discussed regulation of the European Health Data Space. This regulation, from the Commission is a market regulation, which talks about 2 uses of data:

- Primary use – using health data to provide direct patient care. Certain pieces of health data will be mandatory to exchange amongst all Member States
- Secondary use – exchange of data to be better at policymaking, regulation, research, and development

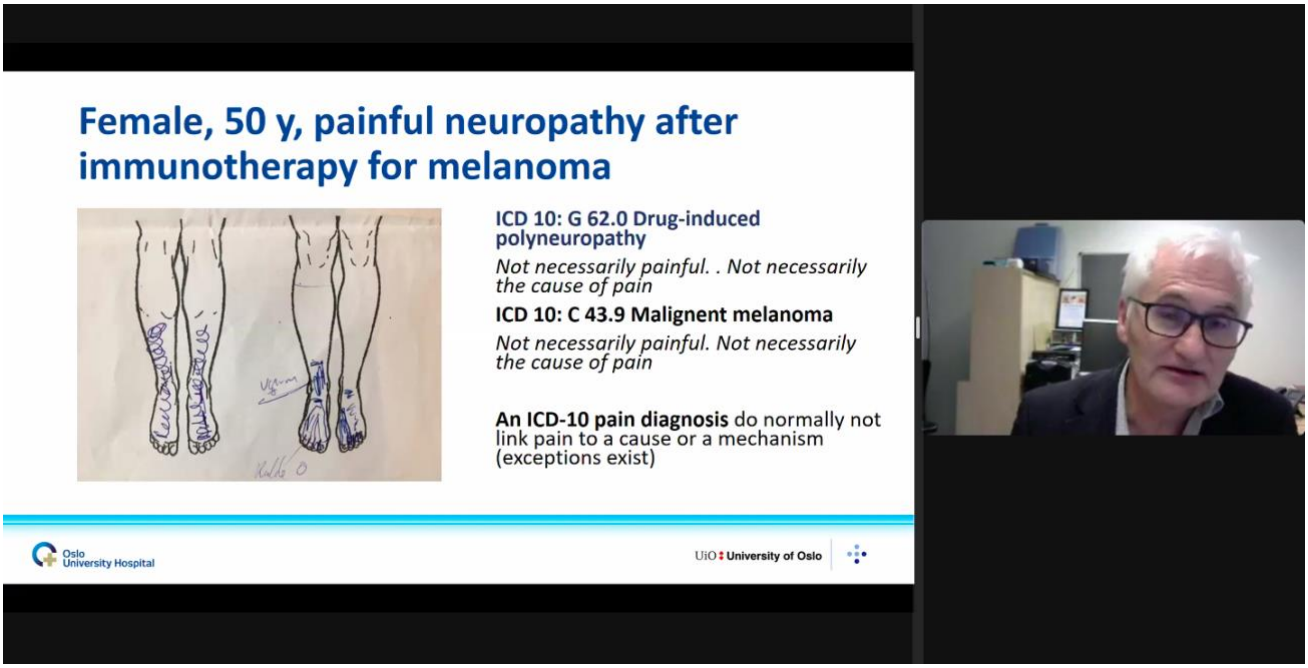
In both cases, the SPMS have created work groups to involve private and public sector. Communicating with these different organisations helps reach agreement on normalised interfaces and then SPMS will bridge the gap between Portugal and the other Member States. Three reference instruments needed to do so:

1. Specific guidelines from the European Commission
2. Semantic reference structures
3. Technical interoperability specifications needed to allow information to freely flow

Data strategy to establish a standardised data chain management:

1. Standardise values and definitions used in reporting systems to allow uniform understanding of data stored in the NHS information systems
2. Publish an integrated, accurate and consistent set of master data for use by other applications
3. Create metadata standards for Health Information Systems
4. Enforce compliance with metadata quality requirements in national Health Information Systems
5. Builds a standard data repository and distribution system where standardization occurs at the source

VII. The Use of ICD-11 for Chronic Pain in a Multidisciplinary University Pain Clinic



Audun Stubhaug, Professor at University of Oslo and Head of Department of Pain Management and Research at Oslo University Hospital and Institute of Clinical Medicine, University of Oslo.

Why did we start using ICD-11 chronic pain classification in our pain clinic?
Reasons against it included the fact that ICD-11 is not yet implemented in Norway by national health authorities and that the ICD-11 is not translated into Norwegian.

In favour, we needed a classification system that classifies the patients main pain problem in a reliable way and the ICD-10 is not an alternative due to pain not being classified. English is well understood by all medical doctors and the ICD-11 was easy to implement in the electronic patient register.

The Pain Clinic (Dept of pain management and research – Oslo University Hospital)

- Secondary and tertiary care – university clinic
- Multidisciplinary clinic
    - 12 medical specialists (anaesthesiology, neurology, rehabilitation medicine, gynaecology)
    - Psychologists
    - Physical therapists
    - Nurses
- 'All' treatment modalities available
- Electronic register already established
- ICD-11 and ICD-10 used for all patients

How we use it in the pain clinic:

- ICD-11 is integrated with their electronic patient register
- The healthcare professional must choose ICD-11 code from a pull-down menu at the very first consultation
- The second level of ICD-11 and the health care professional chooses the next code (which is more detailed)
- The third screen provides a list of suggested ICD-10 diagnoses based on ICD-11 classification

By following the algorithm, the pain problem will be well categorised, and single, double, or triple parenting is allowed. One main ICD-11 diagnosis must be chosen. Example given.

ICD-11 results of first level primary diagnosis from patients in Dept of Pain Management and Research Oslo pain clinic:

- Chronic primary pain 31%
- Cancer-related pain 3%
- Postsurgical/posttraumatic 16%
- Secondary musculoskeletal 13%
- Secondary visceral 6%
- Neuropathic pain 24%
- Secondary headache/orofacial pain 1%
- Other 3%

All patients get a pain diagnosis.

ICD-11 diagnoses are integrated in the patient registry. Patients complete web-based questionnaires at home before and during treatment as well as after as a long-term follow-up including the following:

- Demography
- Bodily symptoms
- Sleep
- Coping
- Expectations etc.

Results are made available for the clinician.

This data can help with new findings, such as: coping expectations, pain intensity and pain-related disability appear similar across the novel 1st level chronic pain classifications. There was large individual variation, therefore the take home message is that we need individualisation for patients in all pain categories.

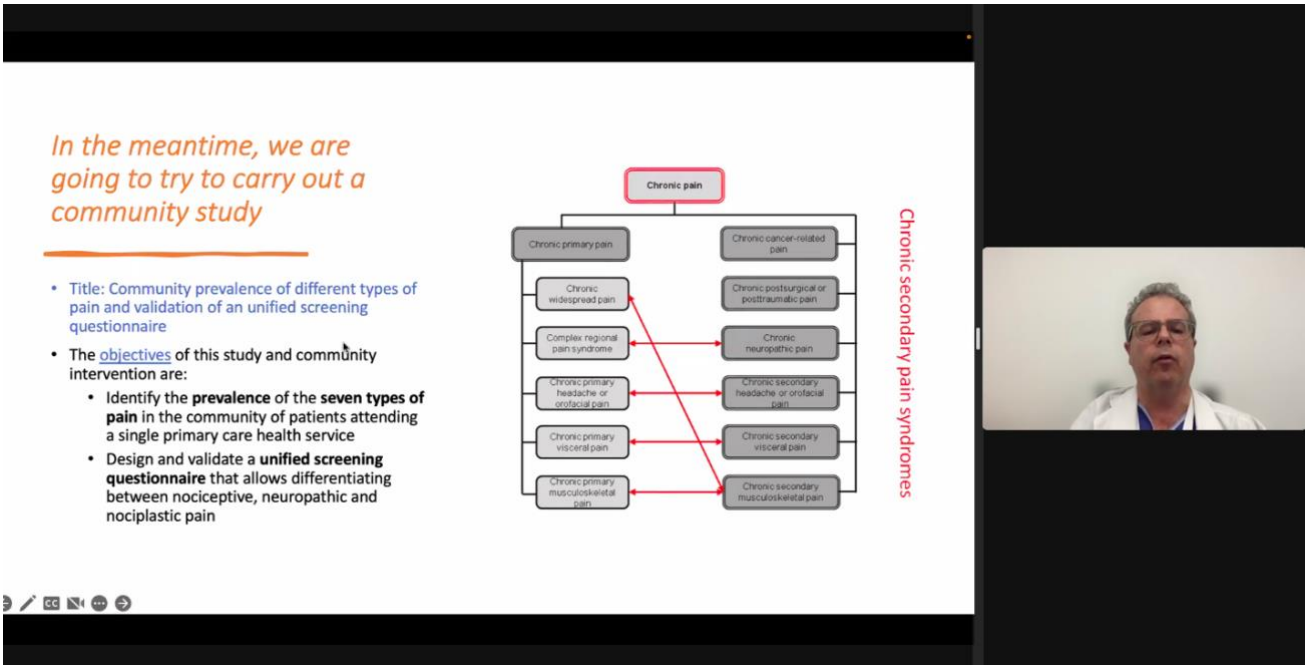
Benefits of using ICD-11 in the clinic:
- All chronic pain patients get a pain diagnosis
- Common diagnostic system describes the pain problem

Challenges of using ICD-11 in the clinic:
- The transition from a secondary pain diagnosis to a primary pain diagnosis and vice versa
- How to secure uniform practice
- Training healthcare professionals how to use the system

What are future perspectives?
The pain specific register can be combined with specialist care register, prescriptions register, sick leave and pension database. This helps to calculate Quality of Adjusted Life years and calculate the cost-effectiveness of treatment.

Take home message:
ICD-11 chronic pain classification can be implemented in pain clinics even if not implemented in country via health authorities. Do not have to wait for them. The pain field needs ICD-11 now and the common diagnostic system will start benefitting the field of pain now.

VIII. ICD-11 in Spain



Victor Mayoral Rojals, previous President of the Spanish Pain Society.

ICD-11 provides a great opportunity to standardise coding for chronic pain across health care systems, but there have been large delays. In 2015, ICD-10 was legally adopted by Spain, 5 years later than when WHO released it. In 2018, discussion about the update/release of ICD-11 began, but Spain was not ready because they were still working on implementing and understanding ICD-10. The Spanish Ministry of Health, as recent as November 2022 have decided to not yet adopt IC-11, but instead to update ICD-10 to the 2022 4th edition. They expect to move to ICD-11 in 5 years, which means to work with ICD-11, pain clinics need to do so alone.

In the meantime, they are conducting a community double study titled 'Community prevalence of different types of pain and validation of a unified screening questionnaire.' The objectives are:

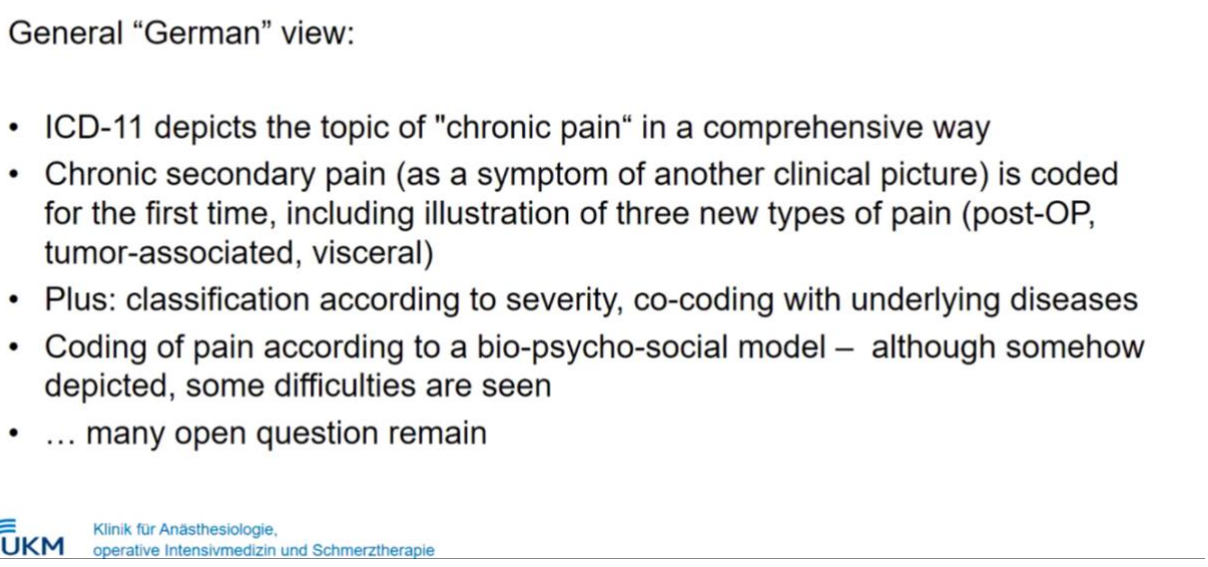
- Identify the prevalence of the 7 types of pain in the community of patients attending a single primary care health service
- Design and validate a unified screening questionnaire that allows differentiating between nociceptive, neuropathic and nociplastic pain

There will be focus on chronic primary pain as it is perceived as the most important new code.

Stages of the study:

1. One week of recruitment and then subsequent ordinary visits
2. Hold a training lecture to facilitate and unify a correct codification for all physicians in a primary care centre
3. Online CRD including factors such as age, sex, time with pain, main diagnosis etc. A second code will also be available for cases of secondary problems diagnoses.
4. One in ten patients will be invited to complete the unified pain questionnaire which will be based on pain detection

IX. ICD-11: German Perspective



Esther Pogatzki-Zahn, Anaesthesiologist, and pain specialist, in the Council of IASP and Councillor from the German Pain Society.

German context:

- 23 million German citizens (28% of the population) report chronic pain, 95% of which is chronic pain not related to cancer
- 6 million patients meet the criteria of chronic, non—cancer, debilitating pain
- 2.2 million patients meet the criteria of chronic, non-cancer-related pain with severe impairment and associated mental impairments (pain disease)
- Satisfaction values of current pain therapy are insufficient: 24.2% of participants surveyed with chronic pain in pain treatment were (very) dissatisfied

In Germany, the Federal Institution for Drugs and Medical Devices (BfArM) is responsible for all ICD-11 issues.

Several activities related to ICD-11 and pain were organised within the German Pain Society and coordinated by the research committee of the German Pain Society, in cooperation with BfArM, including:

- Two-day workshop on ICD-11 and Pain in 2019 (Cologne)
- Workshops in 2021 and 2022 (ICD-11)
- Translation of ICD-11 coding and description
- ICHI workshop in 2022 which German Pain Society participated in and gave impressions on pain related to ICHI

General German view:

- ICD-11 depicts the topic of chronic pain in a comprehensive way
- Chronic secondary pain (as a symptom of another clinical picture) is coded for the first time (which is very much needed), including illustration of three new types of pain (post-op, tumour-associated, visceral)
- Classification according to severity, co-coding with underlying diseases is a great benefit
- A potential problem is the bio-psychosocial model in ICD-11, it needs to be carefully investigated because it is not an automatic coding system, it needs co-coding which might be difficult to implement

Germany already has its own F coding system. F45.41 is the code for chronic pain disorder with somatic and psychological factors. This code directly goes to the multimodal pain management system, because psychological and somatic pain factors are included here. F45.41 in ICD-10 is currently very relevant for Germany and an exact illustration of how ICD-11 will work is necessary. F45.41 is only available in ICD-10 in Germany.

From ICD-10-ICD-11 in Germany:

- Projects with double coding (ICD-10 + ICD-11) are required
- Validation of the 3-month time criterion (e.g., group comparisons of pain duration)
- Differentiation of coding recommendation with mandatory coding of severity
    - For primary care
    - For other specialists
- Examination of severity definitions in other disease groups
    - In Germany
    - Internationally
- User-friendliness in connection with coding must be checked to ensure it is practical to use in the clinic
- Some areas are underrepresented (children, bio-psycho-social, disease specific etc.)

X. Q&A Discussion

Sam Kynman (SK) raised the question of the European Health Data Space (EHDS) and the distinction between terminology questions about functional integration of information for a health or research purpose and the practical implementation of data sharing. SIP is focusing on pain and digital medicine as well as ICD-11 and SK asked the speakers if the rollout of ICD-11 should be an aim in the context of greater European integration of healthcare systems and health data sharing.

Rolf-Detlef Treede (RDT) explained the regional office in Copenhagen is dedicated to this and digitalisation due to the EHDS. Europe and the European Union can really make a difference here at moving this along after many delays due to the elaborate systems already in place. It is estimated to take 5 years for a health system to undergo dramatic changes. Digital health must be leveraged in Europe, so what is the status of this and how can SIP play a role in accelerating this?

Karapet Davtyan (KD) added that the digital health action plan, accepted by the Regional Committee, also says that leveraging digital health in Europe is one of the priorities. ICD-11 is not presented as the tool for improving interoperability or integration rather it is a tool for improving medical language to ensure medical societies talk in the same language.

Rolf-Detlef Treede (RDT), linked this to Filipe Mealha's presentation which highlighted that ICD-11 could be useful at the semantic level. KD agreed.

Lars Bye Moller (LBM), in Denmark, is participating in a work group by the National Health Ministry, conducting a national clinical recommendation assessment of chronic pain in primary care. Since most patients suffering from chronic pain will interact with primary care, he asked how ICD-11 translates into ICPC, the system which GPs use.

Robert Jakob (RJ) confirmed that they have worked closely with primary care group to ensure that the conceptualisation matches the need in primary care and all the primary care content can be coded with ICD-11.

Antonia Barke (AB) explained the hope that primary care professionals might use the top level 7 categories, because they should be able to distinguish between those 7 categories and then ensure continuity if patients then have a specialised treatment. Although this would be up to individual countries, a certain compatibility should be there.

Robert Jakob (RJ) gave an example of a low-middle income environment, where 6 million people are successfully dealt with using ICD-11 and there is no need for a separate system for primary care because of the variable levels of detail is available in ICD-11, which makes the ICPC unnecessary except for analytical purposes.

Rolf-Detlef Treede (RDT) explained that the ICPC could be linearization of foundations of ICD-11. He suggested data analysis in primary care. In some instances, data quality coding is not good enough to analyse chronic pain coding. Denmark could use the opportunity to provide this data, because ICD-11 is a living system which is data driven and evidence based. Denmark could provide good quality up to date primary care data which would be useful for everyone.

Lars Bye Moller (LBM), the National Health Authorities in Denmark, for the past 6 years, have been working on a national health plan where a report has recently been issued stating that the current guideline for assessment of chronic pain in primary care will implement a tool to capture

the data from the patients. This tool will give better and more systematic data on patients in primary care for the future. This system is only being used systematically in interdisciplinary pain clinics.

Rolf-Detlef Treede (RDT) reiterated that this move to the primary care level is needed and its very important for patients. He suggested looking into how pain patients have been treated, diagnosed, and managed through primary care in Denmark in the past. If you find insufficiencies in the past and then find ways to improve the system this way.

Gunilla Göran (GG), offered an answer to LBM. For 3 years, Sweden has been working on guidelines for caring for pain patients and they are now ready with the work. The group of 15 different professionals and 2 pain representatives continue to work for a further 3 years to implement the general guidelines. This is taking place on the regional and the local level and mostly focusing on primary care level, for GPs to implement these guidelines. In the past, there has not been a quality register for GPs pain patients, but it is now in place. This work is underway because, globally, patients have been lacking good quality care in GPs work. Hopefully, results can be shared on this from Sweden.

Lars Bye Moller (LBM) explained that their work asks GPs to use a screening tool with patient reported outcomes, it can be short but with quantitative numbers and qualitative covering quality of life and functioning for patients in primary care. This tool should not only serve as a tool for researchers in data, but also for the GP and for patients so that they can understand the biopsychosocial issues of chronic pain because one of the biggest issues that GPs face in their daily interaction with patients is that they are in different worlds. Patients request certain treatments or surgery, but they need to reach a common understanding of the complexity of chronic pain. Therefore, implementing a screening tool is high priority.

Gunilla Göran (GG) confirmed Sweden are also trying to implement a similar tool.

XI. Synopsis and Conclusions

Patrice Forget, Chair of SIP, offered a summary of the important future and consequences of the implementation of ICD-11, which keeps the discussion alive for years to come. The take home message is that harmonised terminology needs to be centred and the process can be both top-down or bottom-up which means countries can use different approaches as mentioned today by different country perspectives and experience of ICD-11. Harmonising the language will make it easier to share best practices placing patients and people living with pain at the centre, which is essential in terms of recognition and acknowledgement of conditions. This helps to reduce stigma and provide better care. There is also great potential for professional education by using harmonised terminology. This has not existed in this way before. With ICD-11 we can integrate the multifactorial nature of pain, the biopsychosocial model, the need to inform and improve treatment into national pain plans. We have seen it is possible to use ICD-11 in our pain clinics and conduct research projects using ICD-11 but we must continue to work on this and to understand better how to implement it and improve its implementation.

Reminder of SIP's position paper is full of resources and recommendations about implementing digital health and ICD-11. **Available on SIP's website here.**

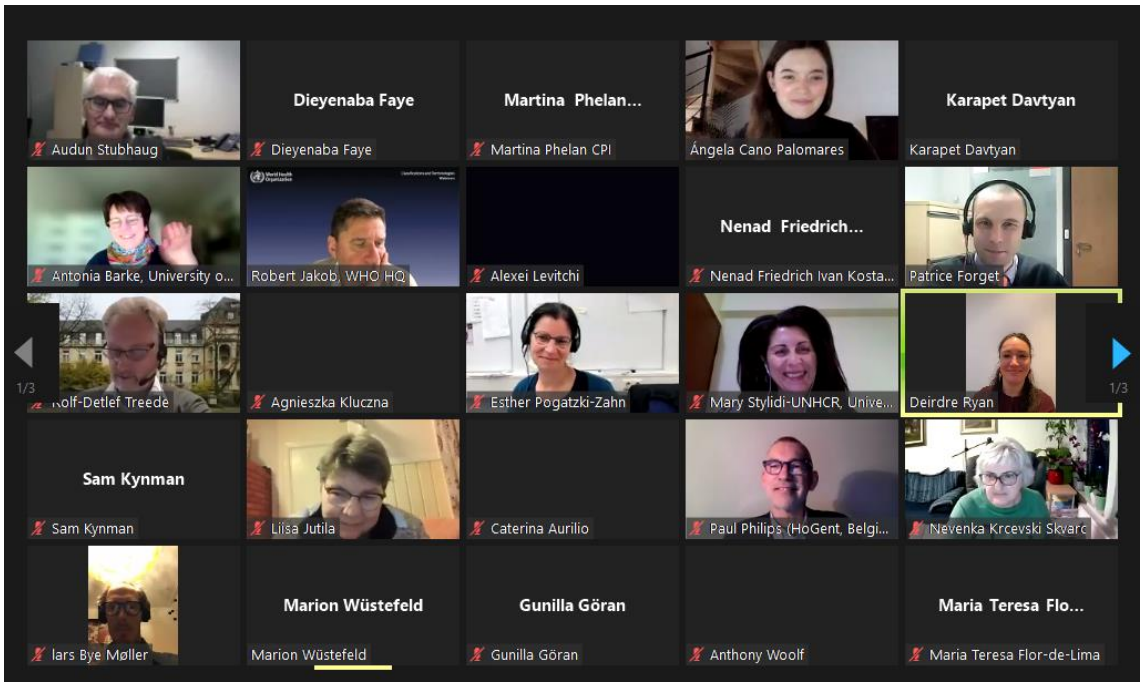
XII. Next Steps

Deirdre Ryan, Co-Chair of SIP and President of Pain Alliance Europe (PAE), thanked the speakers for their presentations and for explaining national perspectives of concrete efforts and sharing

best practices. Due to the complexity of the topic, as a next step, it is important that the discussion continues at the SIP national platform level, and we take home the messages and examples shared today. We know that ICD-11 needs to be implemented but focus is needed on how to do this and add the best value for patients at the national level that fits within the national health system.

SIP is preparing materials for next year and are preparing a workshop which will be submitted for the EFIC 2023 Congress in Budapest in September. The workshop will demonstrate live coding of ICD-11 to show how to use the new coding system. This will be useful for basic scientists, clinicians, and researchers. Everyone will leave with a solid understanding of what the new ICD-11 coding looks like, why it is important and we will show the gaps of previous versions.

Materials to support this will be ICD-11 and ICF infographics which will be updated from 2019 versions with new learnings. Results from the Road Map Monitor Survey will be produced into an overview sheet to distribute at EFIC's congress as well as for engagement plans for 2023, including the MEP level to see if there will be an indicator from the Commission or Council that this is an EU-supported overarching idea. SIP will also develop the ICD-11 position paper and perhaps develop a case study specific to a country. SIP will reach out to all for help in translation and asking input in the development of these materials to ensure they are applicable and approachable for everybody.



The Zoom Chat

Sahar Ezz-Elarab: Sahar Ezzelarab WHO Country Office, Egypt.

Anthony Woolf: Hi, Tony Woolf, Global Alliance for Musculoskeletal Health.

Mohammed Khalid: Mohammed Neurologist and Pain interventionist from Baghdad.

Mary Stylidi: Mary Stylidi, UNHCR, University of Western Macedonia, Greece

Agnieszka Kluczna: Hi, Agnieszka Kluczna, palliative care specialist, assistant palliative care department of Opole, Poland.

Jane Meijlink: Different countries appear to be using different versions of ICD-11. How does this work?

Rolf-Detlef Treede: There usually are transition tables, and one for ICD-10 to ICD-11 is in preparation.

Mary Stylidi: Question – Addressing people with chronic pain in disaster filed or conflict environments can be very challenging. What could be the best way to offer them health care services under these peculiar circumstances?

Alexei Levitchi: Hello! I would like to ask at which level introduction of socioeconomic data (Z codes) impacted or will impact the difficulty of patient's data collection? This is also to avoid stigmatization of the patients, but also to avoid misuse of such information e.g., by insurance companies.

Jane Meijlink: Patient advocates tend to think that ICD-11 doesn't concern patient organisations! We really need very simple explanations of what it is and how it works.

Atonia Barke: We did an English education video (5 mins) – I would be happy to share this with SIP to help with this if it is deemed useful.

Alexei Levitchi: Martina – great mention of fibromyalgia as many such patients are not supported by insurances.

Iars Bye Moller: What is the process for translating ICD-11 to ICPC-2 which is used by GPs in primary care?

Jane Meijlink: Antonia – this sounds very useful.

Sharon B: As a person who has been diagnosed with fibromyalgia in Ireland, I completely agree with Martina. Too many times, I've been told to 'compartmentalize and move on' 'it's in your head' 'not many people in my country or the east have it must be something about the women here' and 100s of other disgusting careless comments. The implementation of ICD-11 and general education to doctors about chronic pain is beyond needed.

Jane Meijlink: In my field (IC/BPS) some of the definitions and terminology are out of date and/or based on theories rather than reality.

Martin Phelan CPIL: Jane Meijlink, I agree we need to educate and get more advocate

organisations on board.

Rolf-Detlef Treede: Dear Jane, thanks to your initiative we had a first TC on IC-BPS, and this process should be continued.

Jane Meijlink: If anyone, including patients/advocates/ organisations, spot inaccuracies in definitions, terminologies, links or whatever in ICD-11, how can they communicate this to the right people?

Rolf-Detlef Treede: WHO-FIC has a proposal platform. Individuals can make proposals, but Group proposals based on evidence and Consensus are more useful.

Jane Meijlink: R-D T: Patients should be able to point out a possible error without being expected to produce scientific details. If an error is suspected, it is then up to the scientific/medical sector to investigate it.

Sharon B: I agree with Jane.

Rolf-Detlef Treede: Jane, Problem: a single person's judgement alone does not define an error, some Consensus process is also needed on the Patient side.

Maria Teresa Flor-de-Lima: To Dr. Filipe Mealha Do you think that Pain Codes can be introduced in your Health Semantic Catalogues?

Sharon B: @jane @ Rolf; Sure, but dismissing all the individual reports, lessens the recognition of multiple error reports. In Ireland, for a fibro diagnosis, the first port of call is to treat the condition with SSRIs. After that doesn't work, they shrug and suggest O.T.C paracetamol. This seems like a very serious course of treatment, rewiring your brain for an uncertain outcome. There is little research into the benefit of an abundance of serotonin in the brain as a course of treatment for Fibro. Fibro seems to be a huge umbrella term for an illness that has many possible causes, treatments, and irritants. Does the ICD-11 list SSRIs as an initial treatment? If so, can that be changed? It seems to me that there needs to be far more scientific tests done first before SSRIs are prescribed (i.e., hormonal levels tested, general health tested, brain scan etc.) Patients need a space to log a complaint so that multiple complaints can accumulate.

Rolf-Detlef Treede: Dear Sharon, please contact Deirdre Ryan About the Status of a Project that we have with the European Brain Council that includes Treatment pathways for FMS patients. Analysis is ongoing, results will be presented to Policy makers by PAE among others.

Gunilla Göran: thank you Rolf-Detlef ENFA is taking part in this research, and we hope for good results.

Jane Meijlink: Esther: great talk. I finally understand the concept of secondary pain a lot better! Thanks!

Nenad Friedrich Ivan Kostanjsek: @Lars: for functioning assessment you may consider use of WHO DAS 2.0 which is also embedded in ICD-11 functioning section.

Gunilla Göran: Lars, how can I contact you?