



WELCOME!

Ensuring Europe's Beating Cancer Plan (EBCP) addresses cancer pain in quality of life, survivorship, and palliative care

# \*\*Recommendations on slide 35\*\*



The 'Societal Impact of Pain' (SIP) platform is a multi-stakeholder partnership led by the European Pain Federation EFIC and Pain Alliance Europe (PAE), which aims to raise awareness of pain and change pain policies. The scientific framework of the SIP platform is under the responsibility of EFIC and the strategic direction of the project is defined by both partners. The pharmaceutical companies Grünenthal GmbH and Pfizer are the main sponsors of the Societal Impact of Pain (SIP) platform.



Societal Impact of Pain

# Patrice Forget Chair of the Societal Impact of Pain (SIP)

# Brona Fullen President, European Pain Federation (EFIC)



14h00-14h05: Welcome and introduction

# **Mike Bennett**

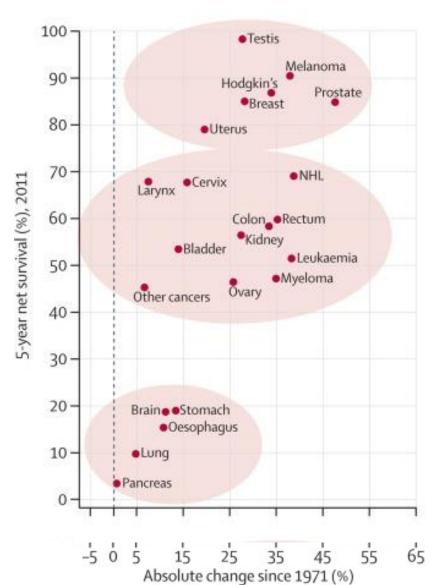
# Cancer Pain Task Force Co-Chair, EFIC Professor of Palliative Medicine, University of Leeds, UK



# **1. INCREASED CANCER SURVIVAL**

Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries

Claudia Allemani, Tomohiro Matsuda, Veronica Di Carlo, Rhea Harewood, Melissa Matz, Maja Nikšić, Audrey Bonaventure, Mikhail Valkov, Christopher J Johnson, Jacques Estève, Olufemi J Ogunbiyi, Gulnar Azevedo e Silva, Wan-Qing Chen, Sultan Eser, Gerda Engholm, Charles A Stiller, Alain Monnereau, Ryan R Woods, Otto Visser, Gek Hsiang Lim, Joanne Aitken, Hannah K Weir, Michel P Coleman, CONCORD Working Group\*



Net survival 2010–11, and absolute change since 1971, in England



## 1. INCREASED CANCER SURVIVAL Pain from cancer treatment

VOLUME 32 · NUMBER 16 · JUNE 1 2014

JOURNAL OF CLINICAL ONCOLOGY

REVIEW ARTICLE

#### Pain in Cancer Survivors

Paul A. Glare, Pamela S. Davies, Esmé Finlay, Amitabh Gulati, Dawn Lemanne, Natalie Moryl, Kevin C. Oeffinger, Judith A. Paice, Michael D. Stubblefield, and Karen L. Syrjala

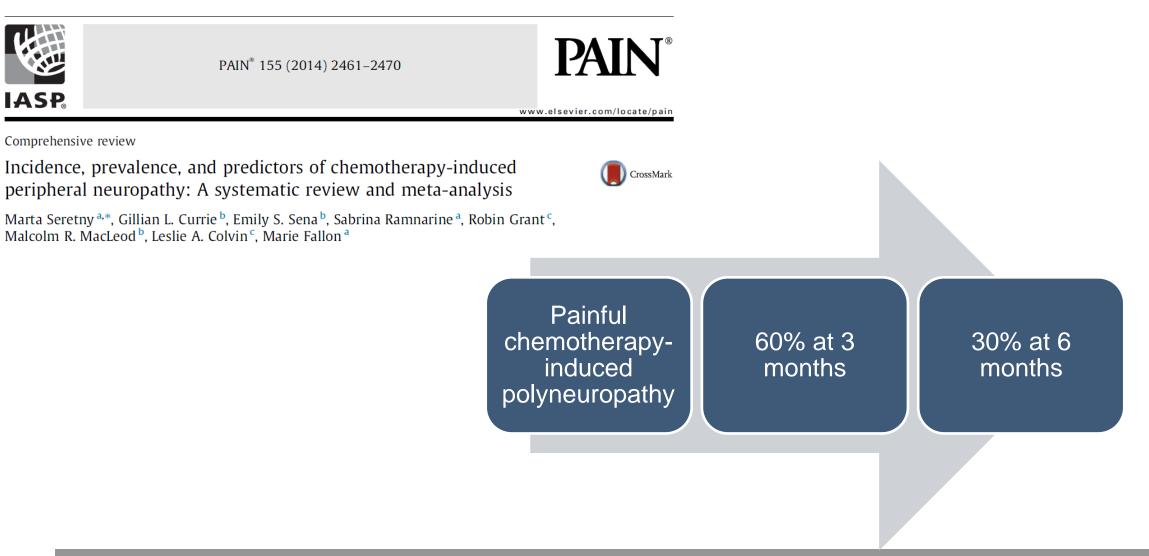
# 40% have pain within first year following treatment

- chemotherapy, surgery, radiotherapy

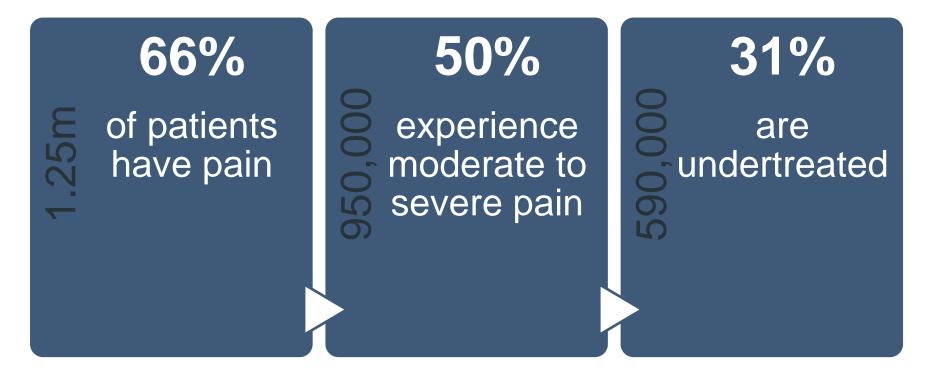
But <10% have pain after 5 years following treatment wide variation in prevalence though



## 1. INCREASED CANCER SURVIVAL Pain from cancer treatment



SIP



1.9m deaths from cancer each year in Europe



Greco 2014, van den Beuken-van Everdingen 2016

## 2. PATIENT EXPERIENCE Influences on pain control





## 2. PATIENT EXPERIENCE Daily trade-offs

# **Concept of trading-off**

#### ORIGINAL ARTICLE

Exploring interference from analgesia in patients with cancer pain: a longitudinal qualitative study

Ana Manzano, Lucy Ziegler and Mike Bennett

Review Article

Patient and caregiver perspectives on managing pain in advanced cancer: A qualitative longitudinal study

Julia Hackett<sup>1</sup>, Mary Godfrey<sup>2</sup> and Michael I Bennett<sup>1</sup>



Palliative Medicine I-9 © The Author(s) 2016 Reprints and permissions: sagepub.co.uk/journals/Permissions.nav DOI: 10.1177/0269216316628407 pmisagepub.com © SAGE

Journal of

**Clinical Nursing** 

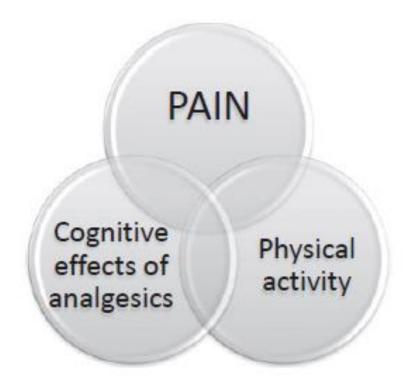


Figure 2 Triad of elements balanced in cancer pain.



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## 2. PATIENT EXPEREINCE Identifying the correct pain management context



End of life care Clinician led management Accepts side effects in order to have pain relief



Chronic tumour related pain Supported self-management Tolerates only modest side effects for pain control



Cancer survivor Self-managing Prefers to be free of analgesia



## 3. ASSESSMENT AND OUTCOME STANDARDS ICD-11 Classification

**Narrative Review** 

# PAIN

ICD-11

# The IASP classification of chronic pain for *ICD-11*: chronic cancer-related pain

Michael I. Bennett<sup>a</sup>, Stein Kaasa<sup>b,c,d</sup>, Antonia Barke<sup>e</sup>, Beatrice Korwisi<sup>e</sup>, Winfried Rief<sup>e</sup>, Rolf-Detlef Treede<sup>f,\*</sup>, The IASP Taskforce for the Classification of Chronic Pain

Correctly identifying the nature and cause of pain in a cancer patient or cancer survivor is important to achieve optimal pain control



## **3. ASSESSMENT AND OUTCOME STANDARDS** European standards on cancer pain management

DOI: 10.1002/ejp.1346

#### REVIEW ARTICLE

WILEY **EJP** 

Standards for the management of cancer-related pain across Europe—A position paper from the EFIC Task Force on Cancer Pain

Michael I. Bennett<sup>1\*</sup> | Elon Eisenberg<sup>2\*</sup> | Sam H. Ahmedzai<sup>3</sup> | Arun Bhaskar<sup>4</sup> | Tony O'Brien<sup>5,6,7</sup> | Sebastiano Mercadante<sup>8</sup> | Nevenka Krčevski Škvarč<sup>9</sup> | Kris Vissers<sup>10</sup> | Stefan Wirz<sup>11</sup> | Chris Wells<sup>12</sup> | Bart Morlion<sup>13</sup>

Eur J Pain. 2019;23:660-668.

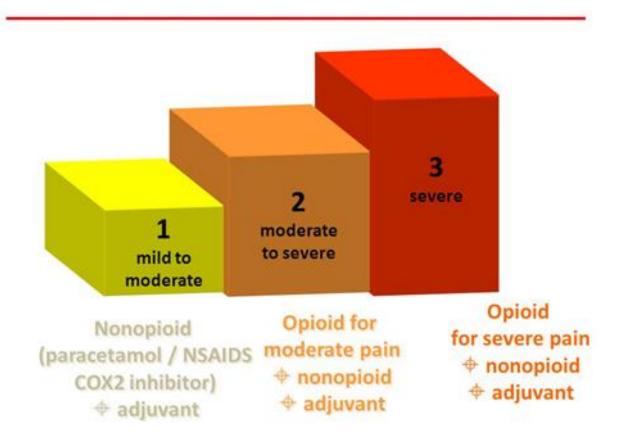
Importance of:

- Pain screening
- Pain assessment
- Management plan
- Tailored treatment
- Regular review



## **4. OPIOID ANALGESIA**

## The WHO analgesic ladder





## 4. OPIOID ANALGESIA Opioid access before death is still difficult

#### n=6080 patients

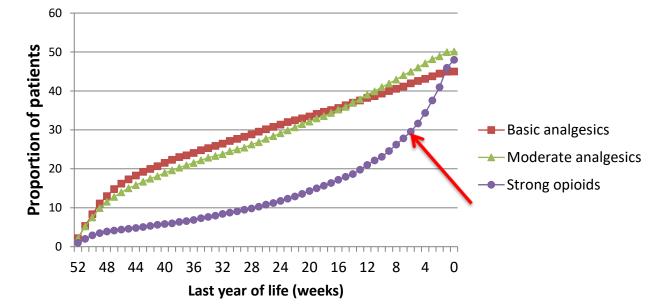
#### **Research Paper**

### PAIN

#### Opioid prescribing for patients with cancer in the last year of life: a longitudinal population cohort study

Lucy Ziegler<sup>a,\*</sup>, Matthew Mulvey<sup>a</sup>, Alison Blenkinsopp<sup>b</sup>, Duncan Petty<sup>b</sup>, Michael I. Bennett<sup>a</sup>

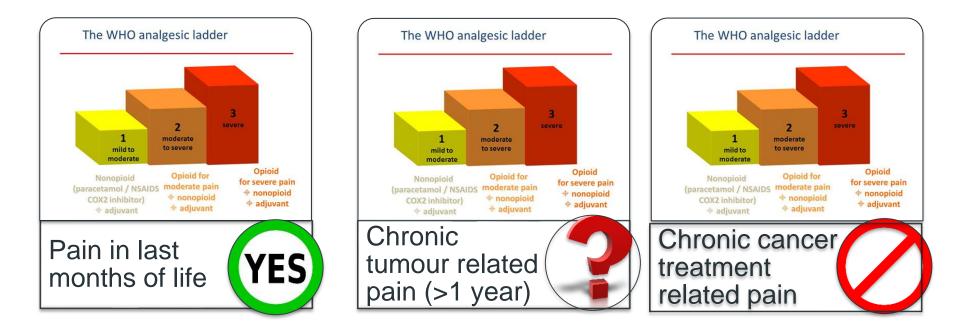
November 2016 • Volume 157 • Number 11



6 weeks before death, only 30% of cancer patients had been treated with a strong opioid



## 4. OPIOID ANALGESIA Opioids not appropriate for longer term pain



'Longer term pain' poorly defined; chronic pain > 3 months

- A small proportion of people may obtain good pain relief with opioids in the long-term if the dose can be kept low and especially if their use is intermittent
- Risk of harm increases substantially at doses above 120mg/day of morphine, but often no increased benefit



## SUMMARY

Cancer-related pain represents a wide spectrum of patients and mechanisms

• and must be assessed in context of any underlying disease

Opioids remain cornerstone of analgesic management in those with active disease

- if used alongside supported self-management and tailored prescribing
- but opioids for longer term pain need careful review to minimise long term consequences



# ICD-11 classification and EFIC management standards have been developed and agreed

- Potentially important steps forward for improving patient outcomes
- BUT:
- Need incorporation into Beating Cancer Plan as we move to the implementation phase if patient care is to improve across Europe



# Thank you

m.i.bennett@leeds.ac.uk



# Joop van Griensven President, Pain Alliance Europe (PAE)



14h20-14h30: Cancer pain patient story

**MEP Dolors Montserrat** (Spain, EPP), Member of ENVI, Co-chair, ENVI Health Working Group, Member of BECA & Member of MEPs against cancer

MEP Sirpa Pietikäinen (Finland, EPP), Member of MEPs Against Cancer

**MEP Sara Cerdas** (Portugal, S&D), Vice-Chair of BECA, Member of ENVI & Cochair, Health Working Group, Member of MEPs against cancer (*video message*)

**MEP Alessandra Moretti** (Italy, S&D), BECA Member and Coordinator for S&D, Co-Chair of the European Parliament Intergroup Challenge Cancer (*video message*)



Stefan Schreck, Adviser for Stakeholder Relations, DG SANTE

**Ortwin Schulte**, Head of the Health Unit at the Permanent Representation of Germany to the EU

**Eduardo Netto**, Deputy Director of Oncological Diseases National Programme, Directorate-General of Health, Portugal

**Tit Albreht**, Head of the Centre for Health Care, National Institute of Public Health, Slovenia





# Pain as an element of NCCPs and survivorship care plans

Ass. Prof. Tit Albreht, MD, PhD, National Inst. of Public Health E-mail: <u>tit.albreht@nijz.si</u>





Cancer is a disease closely related to the problems of pain management:

- Pain as a symptom of disease
- Pain as a consequence of treatment (e.g. surgery)
- Pain as a side effect of treatment
- Pain as a chronic phenomenon in remission
- Pain as a symptom in terminal disease





- Usually, the issue and problem of pain is addressed as a part of palliative care services
- This creates a stigma for those patients who need only pain management for a condition, which is not related to an active disease
- It would be much more adequate to place pain management in the segment covering survivorship



Co-funded by the Health Programme of the European Union

# Definitions of survivorship



- Definition of the JA CanCon (<u>www.cancercontrol.eu</u>): A cancer survivor is defined as anyone with a diagnosis of cancer and who is still alive. This includes patients having completed primary therapy and who are free of disease as well as those patients living with recurrent and/or advanced disease.
- Definition according to WHO: Rehabilitation (though not cancer specific) is defined as "a process aimed at enabling them [people with disabilities] to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels." In fact, cancer may be seen as a chronic illness with patients enduring physical and psychological symptoms years after treatment.



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# Pain management in survivorship care plans



- Placement of pain management among survivorship care and services as a change of paradygm
- Development of personalised Survivorship care plans, which among other topics – include also pain management of any origin but related to the management of cancer
- Comprehensive follow-up care guidelines need to include also pain management for all patient needs



Co-funded by the Health Programme of the European Union





- As cancer is a chronic disease and many cancer patients need to live with the disease, it is important to recognise and manage:
  - Identification of the cause for pain
  - Anticipate pain when it may appear as a side- or late-effect of treatment
  - Provide adequate service for cancer patients needing comprehensive and personalised pain management



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## **RESPONSES FROM THE AUDIENCE / Q&A**





15h25-15h40: Responses from the audience / Q&A

1. Quality of life – Andrew Davies, Co-Chair of the European Cancer Organisation's Network on Survivorship and Quality of Life

 Survivorship – Charis Girvalaki, EU Affairs Manager, & Grazia Scocca, Legal Expert, European Cancer Patients Coalition (ECPC)

**3.** Palliative care – Mike Bennett, Cancer Pain Task Force Co-Chair, EFIC



# Patrice Forget Chair of SIP



16h20-16h40: Synopsis and recommendations

# HIGH-LEVEL SUMMARY FOR BREAKOUT SESSION 1 - CANCER PAIN AND QUALITY OF LIFE

One positive aspect from the Beating Cancer Plan related to cancer pain and quality of life

The EBCP is patient-centric end addresses important issues such as quality of life and inequalities

One key area for improvement of the EBCP related to cancer pain and quality of life

 The EBCP should focus more on <u>how</u> patients and their families live rather than on <u>how</u> <u>long</u>

Concrete recommendations for implementing the EBCP related to cancer pain and quality of life..

• Civil society and patient representatives should play a more central role in proposing a way forward for pain management solutions



## HIGH-LEVEL SUMMARY FOR BREAKOUT SESSION 1 - CANCER PAIN AND SURVIVORSHIP

One positive aspect from the Beating Cancer Plan related to cancer pain and survivorship

Comorbidities and complications are addressed in the cancer plan

One key area for improvement of the EBCP related to cancer pain and survivorship

• There is room for improvement in the Flagship initiatives

Concrete recommendations for implementing the EBCP related to cancer pain and survivorship..

- Recognition of pain as one of the cancer-related complications
- Ensuring the patient is at the forefront of the system, and incorporating patient specificities
- Ensuring collaboration at national level together with the SIP national platforms to implement the plan



# HIGH-LEVEL SUMMARY FOR BREAKOUT SESSION 1 - CANCER PAIN AND PALLIATIVE CARE

One positive aspect from the Beating Cancer Plan related to cancer pain and palliative care

• N/A

One key area for improvement of the EBCP related to cancer pain and palliative care

- Greater prominence and recognition of cancer pain and palliative care within EBCP
- Incorporate ICD-11 classification and EFIC cancer pain standards into EBCP

Concrete recommendations for implementing the EBCP related to cancer pain and palliative care..

• Work with national representatives to lobby governments on importance of cancer pain management and palliative care as part of comprehensive cancer care.



# Paul Cameron Chair of the Advocacy Committee, EFIC



Paul Cameron, Chair of the Advocacy Committee at EFIC, summarised recommendations from the panel and breakout sessions:

- Patients should have access to high quality cancer pain management across Europe, throughout the cancer patient journey (from diagnosis to palliative care, and in survivorship)
- Civil society and patient associations should play a central role in the implementation of Europe's Beating Cancer Plan (for example, via the Commission's Stakeholder Contact Group and via opportunities arising from the new EU for Health Program 2021-2027)
- The ICD-11 classification of cancer-related pain, and exchange of best practices, such as the EFIC Standards for the management of cancerrelated pain across Europe, should be considered during the implementation of Europe's Beating Cancer Plan (for example, via Flagship 1 and the Knowledge Centre on Cancer)
- Pain, and in particular, cancer pain, should be adopted as a quality indicator in European health systems performance and assessment processes (for example, via Flagship 5 and the EU Network linking National Comprehensive Cancer Centres, and Flagship 9 and the Cancer Inequalities Registry)
- Cancer pain should be recognised as a cancer-related complication (for example, via Flagship 5 and the creation of new European Reference Networks looking at challenging cancer conditions)
- Specialised education and training for healthcare professionals in the field of pain management should be encouraged across Europe (for example, via Flagship 5 and the EU Inter-speciality Cancer Training Programme)
- In the immediate future, continued engagement with governments across Europe via national representatives is critical for effective implementation of Europe's Beating Cancer Plan (for example via SIP National Platforms and SIP partner organisations' national representatives)





# Joop van Griensven President, PAE



16h40-16h45: Closure



# Thank you!

Contact details: jamie.wilkinson@efic.org



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