# Pain assessment a standardised computer based tool in the near future?

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## The EPCRC research collaborative

- A pan-European translational research programme
  - Basic scientists, clinicians from various disciplines, computer scientists, clinical researchers
- Financed through the 6th framework of the European Commission (EU) "Combating Cancer"







# Overall objectives

- The overall objectives are to
  - identify genes and genetic variation relevant for inter-individual variation in opioid responses
  - improve classification and assessment of pain, depression and cachexia by computer assisted approaches
- This also includes
  - The development of European evidence-based guidelines for assessment and treatment





### The work

- Is organised in WPs (work packages)
- WP 2.1 Assessment and classification
- Objective:
  - To develop a computer based symptom assessment and classification tool for pain, cachexia and depression for use in palliative care
    - Clinical work
    - Research







# Background

- Approximately 70% of advanced cancer patients experience pain at some point during their disease
- IASP Task Force on Cancer Pain survey:
  - 2/3 of patients scored max. pain intensity as 7 on an 11-point Numerical Rating Scale (NRS)
- Inadequate symptom assessment
  - reported as the single most important barrier for adequate symptom management







# Unfortunately

- There is little consensus on how to
  - Assess pain and other prevalent symptoms in advanced cancer
  - Classify pain and other prevalent symptoms in advanced cancer
- A review revealed 80 tools for self-reported pain in palliative care
  - Still development of new ones!

Hølen et al, 2006, Hjermstad et al, subm.







## Recommendations exist

#### **EAPC Expert working group, JPSM 2002**

- NRS for simple assessment of pain intensity
  - NRS-11; Numerical rating scale (0 10)
- BPI Short Form for <u>multidimensional</u> pain assessment
  - In adult patients without cognitive impairment
  - BPI-SF 3 dimensions
    - severity: 4 items
    - interference with activity: 3 items
    - interference with mood: 4 items
- Short Form McGill Pain Questionnaire
  - In studies that specifically assess pain quality
- But, still development of new tools
  - ??? content, focus, use, population







## So, there is a need for consensus

- Systematic use of existing body of knowledge
  - Literature
- Expert involvement
  - At various stages of the development process
- Patient involvement
  - Quantitative and qualitative approaches
- Clinical testing
  - At various stages of the development process
- Cross-cultural testing
  - Including translation
- Perceived as relevant for those experiencing pain
- Feasible for use in clinical work
- Buy-in, a crucial factor







# The strenghts of the EPCRC

- Research collaborative
  - International
  - Translational
    - Clinical work
    - Basic sciences
  - Multi-disciplinary
  - Members from WHO task force, EAPC, IASP
- Systematic work in a long-lasting researching collaborative







# The EPCRC stepwise approach

Step 1	Determine the content of the measure based upon					
	<ul> <li>the existing body of literature</li> </ul>					
	<ul><li>the content of widely used forms</li><li>clinical expert experience</li></ul>					
	<ul> <li>advice from an expert panel.</li> </ul>					
	Generate an item pool for pain assessment, primarily based upon					
	<ul><li>existing pain assessment tool</li></ul>					
	<ul> <li>that reflects the recommended dimensions</li> </ul>					
Step 2	Data collection I					
Step 3	Analyses of data and functional specification of a computerized pain tool					
Step 4	International expert evaluation II					
Step 5	Patient involvement, qualitative interviews and focus groups					
	<ul> <li>to document qualitative evidence of content and face validity</li> </ul>					
Step 6	Development of a computerised model					
	<ul> <li>software based upon collected data</li> </ul>					
Step 7	International data collection II					
Step 8	Data analyses					
Step 9	Programming of first version of the computer based pain assessment tool					







# Step 7, the upcoming data collection

- An international multi-centre computer based data collection
  - Symptom assessment by computers
- Objectives:
  - to answer the following two research questions:
    - What are the optimal domains and items for assessment and classification of pain, depression, physical function and cachexia in palliative care cancer patients?
    - How may these domains/items be presented to place the least possible burden on the patients, by use of a computerised tool?







## More specifically, the study will:

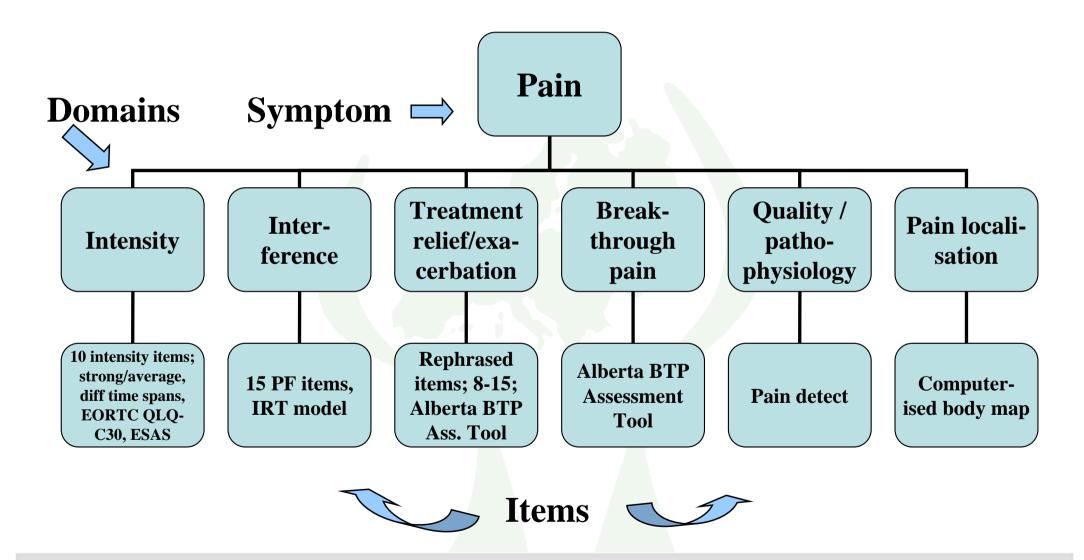
- Determine the feasibility of applying a computer based system for symptom assessment and classification in palliative cancer care
  - examine differences across groups related to acceptance of computers (age, culture, stage of disease, cognitive / physical function etc)
  - examine the user-friendliness of the tool
- Test and validate the performance of selected domains and items for classification and assessment of pain and cachexia
- Explore the validity of domains and items for depression
- Test an IRT model for mobility as a part of the physical function domain







## The concepts









## The stepwise approach once more

- Advantages are
  - It calls for collaboration
  - It is systematic
  - It is iterative
  - It may be confirmative

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## Step 1, literature reviews

#### - Pain tools / Pain assessment

- Update of a previous review
- New expert survey on content and dimensions for pain assessment in PC

#### Pain assessment

Numerical rating scales vs. Verbal rating scales

## Breakthrough pain

- Great variations in the definitions and no consensus on classification.
- Agreement that BTP needs a separate, thorough assessment
- Seven assessment tools identified, none of them independently validated

## Pain Body Maps

• Existing versions of pain body maps, content, use, validation have been explored

#### - Pain Classification

 Three formal classification systems identified; the IASP classification system, the Edmonton Classification System for Cancer Pain (ECS-CP), and the Cancer Pain Prognostic Scale







# The review on pain tools, 1

- Need to update the previous literature review, including the expert survey on the content of pain assessment tools in PC (Hølen et al, JPSM 2006)
- An EAPC pain expert group previously identified the 5 most relevant dimensions for pain assessment in PC:
  - Intensity
  - Temporal pattern
  - Treatment (exacerbating/relieving factors)
  - Location
  - Interference
- 230 publications were identified (2003 March 2008)
- Nine met the inclusion criteria, included 11 tools







# The review on pain tools, 2

- Most tools were multidimensional; with 8 to 10 dimensions
- Three of the 5 highest ranked dimensions from the previous review: intensity, treatment (relief/exacerbation), location were included in 7, 6 and 5 tools respectively
- Pain intensity was assessed by various NRS / VRS
- Three publications gave a reason for developing a new tool
- The selection procedures for items/dimensions were lacking in 6 of the tools
- Patient / expert groups were involved in 5 tools
- SO,
- The development rarely followed recommended methodology
- Often driven by specific research interests
- Does not add to a consensus base







### Seven of the 11 identified tools

Author Year and country	Identified pain tool	Pain dimensions in tool	Pain items	Other domains in the identified pain tool	Study aim and type
Bercovitch 2002 Israel	Multidimensional Continuous Pain Assessment Chart – MCPAC	Int	1	Medication, sleep, mobility, QOL	Examine use of chart in clinical practice over time Clinical observational study
Bostrom 2004 Sweden	Pain Control in Palliative Care Questionnaire - PC- PCQ	Treat, Bel, Hist	6 (3 with before and after format)	Pain control, contact with Dr, support of relatives, feeling of security, who/what do you do call when pain not controlled	Compare pain experience before and after referral to PC Clinical observational study
Chen 2003 Taiwan	Pain assessment form – PAF The Perceived Meanings Of Cancer Pain Inventory – PMCPI	Int, Treat, Loc, Dur Beliefs	5	Degree of pain relief in last week  Loss, threat, challenges	Examine levels of hope and associations with pain Clinical observational study
Choi 2006 Korea	Korean Pain Assessment Tool – KCPAT  Patient Satisfaction Questionnaire	Int, Loc, Qual, Aff  Treat, Inf	3	Compliance with medications, response to stress, spiritual, control, support of relatives + symptom registration checklist  Satisfaction	Evaluate the use of KCPAT in clinical setting Tool validation study
Gutsgell 2003 USA	No name – designed by author	Int, Temp, Treat, Loc, Inf, Qual, Dur, Breakthrough pain	14		Evaluate characteristics of pain and adequacy of treatment Clinical observational study

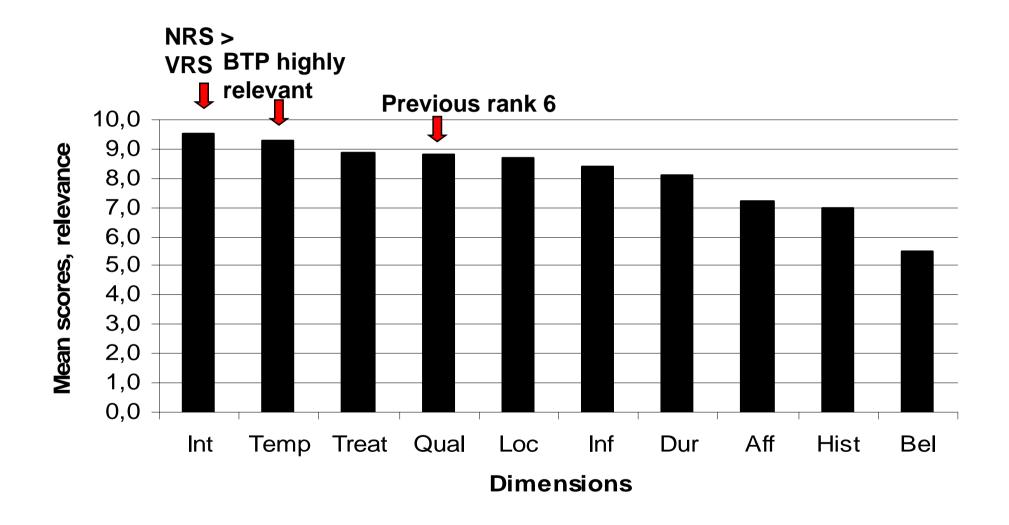
Pain dimensions: *Int*: Intensity, *Temp:* Temporal pattern, *Treat*: Treatment effect incl. relief/exacerbating factors, *Loc:* Location, *Inf:* Interference, *Qual:* Pain quality, *Aff:* Affect, *Dur:* Duration, *Bel:* beliefs incl. attitudes, coping, beliefs about causes and consequences, *Hist:* Pain history







# Expert survey, 72% response rate









## Step 2, 1st data collection,1

- Based on the first literature review (2006), clinicians' and patients' input, a pilot study and expert evaluations
- A Norwegian national study 2006 2007, 10 centres
  - by use of a software prototype
  - primarily assessing pain intensity, pain interference and physical function
  - a computerised pain body map was included
  - first version of a computerised pain body map
  - 732 pain assessments were collected
    - M / F: 210 (53%) / 188
    - Mean age 73
    - Mean performance status 70







# Step 2, 1st data collection, 2

- 95% of the patients reported an average pain score for the last 24 hrs of ≤ 5 (NRS-11, BPI)
- A single NRS-11 item contains adequate information on pain intensity for clinical purposes
- For patients with pain scores of up to 8 (NRS-11) there is little to be gained by using multiple items
  - Consistent with Step 1 results

Two reviews

Expert survey

- Feasibility
  - The vast majority (76%) did not require any assistance when completing the questions directly on the computers





## The answer is YES

It is possible to develop a consensus-based tool

### Through

- Collaborative work
- A systematic approach
- Adherence to accepted methodology
- Lots of energy
- An international perspective





