



1st International Knowledge Translation Symposium Edmonton Classification System for Cancer Pain (ECS-CP)



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EXECUTIVE SUMMARY

The 1st International Knowledge Translation Symposium – Edmonton Classification System for Cancer Pain took place in Edmonton, AB Canada on October 23-24, 2010. The Edmonton Classification System for Cancer Pain (ECS-CP) Research Team in collaboration with the European Palliative Care Research Centre (PRC) and EAPC Research Network (EAPC RN) were pleased to welcome 47 participants from Australia, Canada, Israel, New Zealand, Norway, Japan and the United States, to the two-day symposium. The event was jointly sponsored through funding from the Canadian Institutes for Health Research (CIHR) Meetings, Planning and Dissemination Grant, the CIHR Pain NET Grant, the Division of Palliative Care Medicine at the University of Alberta and the PRC.

The core objectives of the symposium were to discuss:

1. Continuing to advance cancer pain classification through research;
2. The use of evidence based approaches to patient assessment;
3. Knowledge Translation (KT) to promote evidence based patient assessment.

Discussions for the two days were to be framed with the following three questions that were posed to the participants:

1. What is your appraisal of what has been developed so far? Should we continue our work and evolve the ECS-CP or is it so flawed we need to re-think the whole approach?
2. How do we as a community of researchers and clinicians align with the work of the PRC and the EAPC RN and that vision for a classification system for Cancer Pain?
3. Assuming we develop a clear answer to 1 and 2 above what direction would you recommend this initiative moves with further research, clinical application and KT strategies?

The first day consisted of educational presentations. Stein Kaasa provided a comprehensive overview of the reasons we need a classification system for cancer pain based on the progress of the EAPC RN. Cheryl Nikolaichuk presented an overview of the development of the ECS-CP over more than 20 years. Viki Muller provided an overview of some of the history and organization of the TNM Classification of Malignant Tumors (TNM) classification system for cancer and the Diagnostic and Statistical Manual of Mental Disorders (DSM) as examples of how we can learn from other supervisory organizations. Eduardo Bruera presented on the strengths and weaknesses of the ECS-CP and emphasized that the future success of the ECS-CP is linked to the ability to remain short and simple. Peter Lawlor discussed the strengths and weaknesses of the ECS-CP administration manual. Donna Zhukovsky provided an overview of the unique issues relevant to pediatric care that would be important considerations in developing a pediatric version of the ECS-CP. Representatives of the ten core members of the research team provided an overview of the use of the ECS-CP in routine clinical practice at each of their sites.

During the second day the participants had the opportunity to learn more, discuss and came to a consensus developing a Knowledge Translation (KT) Plan and advancing the ECS-CP Research Agenda. Discussions focused on answering the following questions (1) How can we introduce cancer pain classification into routine clinical care (2) How could we advance the KT dissemination plan (e.g. administration manual revisions, case scenario development, publications, conferences)? (3) Should we develop an international supervisory group for the ECS-CP? (4) How should we proceed with ongoing collaboration/merge with the work of the EAPC RN cancer pain assessment and classification proposal? (5) A research agenda for the ECS-CP - do we need 2 versions, a clinical and research pain classification system?

The meeting proved to be a highly interactive forum, which assisted in garnering leadership commitment and expertise to inform the further development and uptake of the ECS-CP. Moreover, it helped to determine how widely used the ECS-CP has become and inform barriers to further implementation into clinical practice and research. **The group came to five Main Conclusions:**

1. The ECS-CP is ready to move to the next phase of its growth. It has a carefully reasoned design and research to date attests to its validity and predictive value.
2. Do we need one tool or two? Do we need a single, multipurpose tool, or a research tool plus a shorter, simpler to use clinical version? Consensus is that we should go forward with one tool as the ECS-CP has been studied and is ready to use; to introduce a second version could be confusing and could substantially interfere with progress.
3. There is strong interest in establishing an International Steering Committee to oversee further development of the tool. The primary purpose would be to serve as the oversight body to approve any changes in the tool. The International Steering Committee should not be under the umbrella of an established International Society but rather, should (for now) be free standing. However, we should be open to establishing a relationship with one or more International Societies, with particular attention paid to the relationship being low maintenance and being unlikely to result in bureaucracy.
4. There is strong interest in promoting further research with the ECS-CP. This could be accomplished through establishing some kind of blog or web presence to support an informal research network.
5. There should be attention paid to developing and implementing a Knowledge Translation strategy.

Next Steps

The Symposium members strongly recommended:

1. To organize a follow-up meeting of the Symposium one to two years from now.
2. To establish working groups:
 - a. Clinical user's group
 - b. Administrative manual / user's manual group
 - c. Research network (see point 4 above).
 - d. Pediatric working group
 - e. Language translations group - One of several functions would be to facilitate discussions between individuals who want to use or develop or validate translations of the ECS-CP.
 - f. Knowledge translation group
 - g. Other groups as the opportunity arises



**International development and validation of the
Edmonton Classification System for Cancer Pain - where do we go from here?
October 23-24, 2010**

<p>Day 1. Saturday, 23 October 2010</p> <p>1. Introductory session (Chairs – Robin Fainsinger and Eduardo Bruera)</p> <p>PRESENTATIONS:</p> <p>A. Developing a classification system for cancer pain – the progress of the European Palliative Care Research Collaborative - Stein Kaasa</p> <p>B. Developing a classification system for cancer pain - 20 years of progress in Edmonton - Cheryl Nekolaichuk</p> <p>C. International Supervising organizations as a model for a classification system – what can we learn from others? - Viki Muller</p> <p>2. Developing a new agenda (Chairs – Cheryl Nekolaichuk and Stein Kaasa)</p> <p>PRESENTATIONS:</p> <p>A. Strengths and weaknesses of the ECS-CP: the view from Houston – Eduardo Bruera</p> <p>B. Strengths and weaknesses of the ECS-CP administration manual – Peter Lawlor</p> <p>C. Challenges and Opportunities in developing a classification system for cancer pain in pediatrics – Donna Zhukovsky</p> <p>D. Rapid fire commentary – the views of our collaborating centers in using the ECS- CP in routine clinical practice (10 min each)</p> <ol style="list-style-type: none"> i. Peter Lawlor ii. Michaela Bercovitch iii. Lyle Galloway/Neil Hagen iv. Donna Zhukovsky v. Gina Kaye vi. Odette Spruyt <p>3. Highlights of afternoon Meeting – Neil Hagen</p>	<p>Day 2. Sunday, 24 October 2010:</p> <p><i>Developing a Knowledge Translation Plan and Advancing the ECS-CP Research Agenda</i></p> <p>1. Developing a Knowledge Translation Plan Introduction to morning discussion and Question period Chairs: Robin Fainsinger, Cheryl Nekolaichuk</p> <p>A. How can we introduce cancer pain classification into routine clinical care? Chair: Robin Fainsinger Rapporteur: Jose Pereira</p> <p>B. How could we advance the KT dissemination plan (e.g. administration manual revisions, case scenario development, publications, conferences)? Chair: Peter Lawlor Contributor: Neil Hagen Rapporteur: Michael Downing</p> <p>C. Should we develop an international supervisory group for the ECS-CP? Chair: Cheryl Nekolaichuk Rapporteur: Russell Goldman</p> <p>2. Setting a research agenda</p> <p>A. How should we proceed with ongoing collaboration/merge with the work of the EAPC RN cancer pain assessment and classification proposal? Chair: Stein Kaasa Rapporteur: Deb Dudgeon</p> <p>B. A research agenda for the ECS-CP - do we need 2 versions, a clinical and research pain classification system? Chair: Eduardo Bruera Rapporteur: Sharon Watanabe</p> <p>3. Identification of Next Steps and Closing Remarks Robin Fainsinger Neil Hagen Stein Kaasa Cheryl Nekolaichuk</p>
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PARTICIPANTS

Mills, Elaine	Australia	Melbourne	Young, Shari	Canada	Edmonton
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			ADMINISTRATION:		
			Muller, Viki	Canada	Edmonton

1. DAY 1: 23 OCTOBER 2010

1.1 Introduction – Robin Fainsinger [click on title to view slides]:

The symposium was an excellent opportunity for a face to face meeting with the 10 core research team members (Appendix 1) involved in the recently completed ECS-CP International Multicentre Validation study¹ along with the invited experts. Dr. Fainsinger summarized the objectives that the group hoped to accomplish at the symposium into the following themes:

1. Continuing to advance cancer pain classification through research:
 - Garner leadership commitment and expertise to inform the further development and uptake of the ECS-CP
 - Agreement to form an expert panel on the development of the ECS-CP
 - Agreement to hold a follow-up meeting (in person or via teleconference or videoconference)
 - Agreement to incorporate the ECS-CP in cancer pain related research
 - Identification of future research priorities
 - Identification of barriers to further research

2. Use of evidence based approaches to patient assessment:
 - Identification of the strengths and weaknesses of the clinical application of the ECS-CP
 - Agreement to incorporate the ECS-CP into clinical work
 - Discussion on how to promote incorporation of the ECS-CP into clinical work
 - Identification of barriers to the implementation of ECS-CP into clinical practice
 - Review and revision of the ECS-CP administration manual

3. Knowledge Translation to promote evidence based patient assessment:-
 - Establishment of a working group to develop a teaching tutorial to assist with further uptake, teaching and implementation of the ECS-CP
 - Development of a web presence to promote Knowledge Translation (KT)
 - Development of an outline for a manuscript to focus on the clinical application of the ECS-CP based on an education tutorial
 - Development of plans for an annual / biennial KT symposium on pain classification and assessment

1.2 Discussion

Discussions for the two days were to be framed with the following three questions that were posed to the participants:

1. What is your appraisal of what has been developed so far? Should we continue our work and evolve the ECS-CP or is it so flawed we need to re-think the whole approach?



¹ Fainsinger RL, Nekolaichuk C, Lawlor P, Hagen N, Bercovitch M, Fisch M, Galloway L, Kaye G, Landman W, Spruyt O, Zhukovsky D, Bruera E, Hanson J. An international multicentre validation study of a pain classification system for cancer patients. *Eur J Cancer*. 2010 Nov;46(16):2896-904. Epub 2010 May 17. PubMed PMID: 20483589.

2. How do we as a community of researchers and clinicians align with the work of the EAPC RN and that vision for a classification system for Cancer Pain?
3. Assuming we develop a clear answer to 1 and 2 above what direction would you recommend this initiative moves with further research, clinical application and KT strategies?

1.3 Presentations: See Appendix 2 For Copy Of Slides

[1.3.1. Developing a classification system for cancer pain – the progress of the European Palliative Care Research Collaborative - Stein Kaasa](#)

Stein Kaasa provided a comprehensive overview of the reasons we need a classification system for cancer pain. This was the motivation for the European Palliative Care Research Collaborative (EAPC RN) including pain classification as a central theme of their research program. A comprehensive literature review concluded that the best validated system at this point is the Edmonton Classification System for Cancer Pain (ECS-CP). This has resulted in an ongoing collaboration between the EAPC RN and the Edmonton group to further the vision of developing an internationally recognized classification system for cancer pain.

[1.3.2. Developing a classification system for cancer pain - 20 years of progress in Edmonton - Cheryl Nekolaichuk](#)

Cheryl Nekolaichuk presented an overview of the development of the ECS-CP over more than 20 years. This started with the vision and idea of one man (Eduardo Bruera) and has evolved through a number of validation studies including a recently completed multicentre international study that has provided further information on reproducibility, and predictive and inter-rater validity².

[1.3.3. International Supervising organizations as a model for a classification system – what can we learn from others? - Viki Muller](#)

Viki Muller provided an overview of some of the history and organization of the TNM classification system for cancer. The TNM has evolved from changes based on expert opinion to a formal process of continuous monitoring and evaluation of evidence. The *Diagnostic and Statistical Manual of Mental Disorders (DSM)* is used to classify psychiatric disorders and has also evolved to improve the process for modifications. In summary, an ideal supervisory organization would have multicentre and global representation, have terms of reference, avoid conflicts of interest, have an informed process for evaluation and modification, and have sufficient infrastructure and funding.

1.4. Developing a new agenda (Chairs – Cheryl Nekolaichuk and Stein Kaasa)

PRESENTATIONS:

[1.4.1. Strengths and weaknesses of the ECS-CP: the view from Houston – Eduardo Bruera](#)

Eduardo Bruera emphasized that the future success of the ECS-CP is linked to the ability to remain short and simple. Although we need to reduce variability in use across settings, we need to avoid increasing complexity. This will help adoption and ideally also be useful as an outcome measure to demonstrate acuity and use of resources. Major concerns are to ensure that addiction and “chemical coping” are not missed as a risk factor and the rising prevalence in the literature of incident pain driven by the increased availability of new and expensive pharmacological options. It will be important to retain the inclusion of a balance of physiological and psychological factors.

² Nekolaichuk C., Fainsinger RL., Lawlor P. A validation study of a pain classification system for advanced cancer patients using content experts: the Edmonton Classification System for Cancer Pain. *Palliat Med* September 2005 vol. 19 no. 6 466-476

[1.4.2. Strengths and weaknesses of the ECS-CP administration manual – Peter Lawlor](#)

Peter Lawlor described the ease of access to the online manual. However a number of areas of improvement to consider would include a contact number for feedback from users, the present order of information that creates navigational issues for users, and ways in which the present case examples and “frequently asked question” sections could be revised.

[1.4.3. Challenges and Opportunities in developing a classification system for cancer pain in pediatrics – Donna Zhukovsky](#)

Donna Zhukovsky provided an overview of the unique issues relevant to pediatric care that would be important considerations in developing a pediatric version of the ECS-CP. Issues of communication in children and the involvement of parents are major concerns.

1.4.4. Rapid fire commentary – the views of our collaborating centers in using the ECS- CP in routine clinical practice (10 min each)

i. [Peter Lawlor \(Ireland\)](#)

Peter Lawlor reviewed some of the international study variation of ECS-CP assessments and outcomes across the different sites and the potential reasons for this variability.

ii. [Michaela Bercovitch \(Israel\)](#)

Michaela Bercovitch used a complex case example to demonstrate some of the problems unique to their setting and made suggestions for increasing the uptake of international use of the ECS-CP.

iii. *Lyle Galloway/Neil Hagen (Calgary)*

Lyle Galloway and Neil Hagen described the local circumstances in Calgary that could account for some of the most visible outliers in outcomes in their results. Understanding the ECS-CP’s clinical utility and value appears to be a limitation to routine use.

iv. [Donna Zhukovsky \(Houston\)](#)

Donna Zhukovsky indicated that initial use of the ECS-CP in the study was enhanced by the support of the research nurse. Achieving stable pain control was limited by the speed of discharge of patients in their setting. Introduction of the ECS-CP into daily practice remains a work in progress and could be enhanced by considering some changes in the abbreviations and increased understanding of the value in daily clinical practice.

v. [Gina Kaye \(Auckland\)](#)

Gina Kaye indicated that they found use of the ECS-CP relatively easy to introduce and it did change practice. Consideration of encouraging use by Family Physicians as well as Oncologists may have some benefit to improve management of pain in cancer patients. The ECS-CP could be adapted to encourage earlier referral of difficult cancer pain patients.

vi. [Odette Spruyt \(Melbourne\)](#)

Odette Spruyt indicated her group uses the ECS-CP in routine clinical care and as a quality outcome measure. The value increases with the understanding that comes with familiarity of routine clinical use.

1.5. Highlights of the Afternoon Meeting – Neil Hagen

Neil Hagen summarized the afternoon presentations with the following points:-

1. Based on the experience of other specialty classification groups we can expect this work to take many years.
2. Symptom expression is a complex construct.
3. Do we need a clinical or a research classification system or both?
4. We need a “quick users guide” to supplement the ECS-CP manual.
5. There will be unique issues to address for a Pediatric ECS-CP.
6. For whom would the ECS-CP be most useful – clinicians, researchers, or administrators?



2. DAY 2: 24 OCTOBER 2010

2.1 Developing a Knowledge Translation Plan

2.1.1. How can we introduce cancer pain classification into routine clinical care?

Chair: Robin Fainsinger

Rapporteur: Jose Pereira

Robin Fainsinger started off the session by making the following points:

- Assessment use is widespread.
- All specialists use some kind of common assessment language.
- The TNM and DSM are just two examples of standardized expert-derived classification systems.
- The need for a classification of cancer pain is widely endorsed.
- We need a cancer pain classification system and we need to use it.
- Variance in ECS-CP features across settings may be due to true differences and misinterpretation in intended use (i.e. emphasizing need for education).
- This is a Specialist tool. It is not intended for Oncologists or Family MDs.
- The concept of cancer pain classification will never gain traction without increasing adoption and ongoing evaluation and adaptation.
- What would it take to get you and your program to use a clinical classification for cancer pain?

There was strong agreement during the discussion that assessment tools must be utilized. Currently many centers and clinicians are under-using assessments as a standard of care. There was agreement that it is inappropriate that symptoms go unassessed. Unfortunately, there are often limited resources invested in the clinical or administrative areas in the health care system to assist in assessment. As a result implementation at many locations is slow. The variances in pain classification that may exist are due not only to differences within programs but also due to the interpretation of the tool (ECS-CP) itself. The latter issue is a testament to the importance of education.

The management of cancer pain is different than managing *other* types of non-cancer pain. The ECS-CP is a clinical tool to help specialists treat their patients. As such, one must understand the intricacy and complexity of the tool. Taxonomy must be *right* and needs to be developed, standardized and relevant to cancer pain and palliative care. Many spoke to the challenge of measuring pain intensity routinely in clinical practice due to the lack of a common standard that is simple and reproducible. This would be useful not only for clinical care, but also benchmarking and research. It was emphasized that a pain intensity number is subjective, and when reviewed in isolation one can lose sight of additional dimensions of pain experienced by the patient that could be a composite of physiological and psychosocial factors. This speaks to the complexity of treating palliative patients and cancer pain.

The tool may also be utilized on an administrative level, assisting in the identification of workload and to advocate for resources and different settings of care due to the intensity of patient needs.

Challenges experienced in the adoption of this tool include cultural issues. There is often resistance to change and as a result a lot of work must be put into “buy-in”.

“if [the ECS-CP] is not used, [we] cannot mentor others, we can’t model good practice in this area therefore [we] need to start reflecting how we are using [it]”.

Some spoke to the clear vision they share for the value of the ECS-CP as a clinical tool. This could be enhanced by prognostic staging triggers that would suggest a multi-modal over an opioid centered approach may be required for a particular patient.

Suggestions to increase adoption included that the tool should be:

- 1) *Simple*: There is a potential need to (a) simplify the method for collecting and capturing information; (b) reformat how it is currently being completed; (c) develop a meaningful score similar to what has been used in intensive care settings.
- 2) *Clinically relevant*: It needs to answer the question: “What is the product from the assessment and what does it mean?”
- 3) *Valuable*: It needs to be seen to be useful at the bedside and in daily clinical practice. The person who is using it has to see some benefit to the patients.
- 4) *Validated*: It needs to be available in other languages and the acronyms must have meaning.
- 5) *Transferable*: It needs to be adaptable to varying settings: Intensive vs. hospice vs. specialized clinics.
- 6) *Monitored*: There could be a method to hold people accountable to complete the tool.

By increasing adoption of the tool, evaluation and adaptation will be possible. Future areas of research include:

- (1) Further clarification of the role of the tool: Is it a screening vs. assessment vs. clinical vs. research tool. An education strategy is required.
- (2) Validate the tool for other areas outside of cancer pain. Cardiovascular, neurology and nephrology patients were given as examples. Funding support may be brought in from these areas.
- (3) Language: Should be translated and validated. Acronym must be meaningful in other languages. Eg. Cognitive Function: CI, CU does not have meaning in French or other languages. “*When we present clinical experiences, we must use a common language.*” A validated French translation would be critical for use with Francophone Canadian patients and communities in Canada.

[2.1.2. How could we advance the KT dissemination plan \(e.g. administration manual revisions, case scenario development, publications, conferences\)?](#) [click on title to view slides]

Chair: Peter Lawlor

Contributor: Neil Hagen

Rapporteur: Michael Downing

*“How are we going to disseminate what knowledge we have already?
[It is] not enough to generate tools and practice guidelines and to outline best practices,
there has to be some kind of process to support the system in their uptake”*

Neil Hagen began by providing an overview of Knowledge Translation (KT) and Management. He provided the following definition from the World Health Organization: *Knowledge management is a set of principles, tools, and practices that enable people to create knowledge, and to share, translate and apply what they know to create value and improve effectiveness.* (WHO)

He went on to summarize the bibliometric analysis of the Edmonton Symptom Assessment System (ESAS)³, which was completed to learn about the KT attributes that has encouraged the adoption of the ESAS within the global palliative care community.

Neil offered some ideas for a framework for how to construct a KT strategy to promote uptake of the ECS-CP.

Models of KT Strategy (Creation of framework through):

- 1) Identification of early adopter (innovators in local areas);
- 2) Determining how to apply best practice so it is inherently obvious to the users on how it can help their patients and their programs;
- 3) Encouraging research to expand on earlier studies;
- 4) Use of Multiple languages which adds interest by advertising collaborations to translate tools to other languages;
- 5) Targeting specific groups:
 - a. End-users
 - b. Societies, organizations, pain e.g. IASP
 - c. Researchers – clinical and health services
 - d. Advertising – journals, place within well known websites, Blast emails
 - e. 10 Targets (each target requires its own targeted leaflet or 1-pager to gain buy-in
 - i. Clinicians – providing them with “quick cards” as well as “instructional manuals”
 - ii. Program Directors
 - iii. Regional Administrators
 - iv. IT staff
 - v. Financial Staff
 - vi. National Organizations – e.g. CIHI
 - vii. Researchers
 - viii. Public – to increase awareness of palliative growth and pain management
 - ix. Patient – to show how the ECS-CP will impact and improve their pain management
 - x. Culture and language sensitivity and applicability

Potential Tactics to promote uptake of the ECS-CP:

- 1) Advertising
- 2) Promote editorials in Society Publications
- 3) Linking ECS-CP website to other well established websites to help with uptake
- 4) Email announcements through list servers – linking with other societies.
- 5) Identification of simple promotional tools – a) download ECS-CP, (b) simple case tutorials. (c)Translations readily available. (d) List of current research studies.
- 6) Blog for researchers and other users.

³ Cummings G, Biondo PD, Campbell D, Fainsinger R, Stiles C, Muise M, Hagen N. Can the global uptake of palliative care innovations be improved? Insights from a bibliometric analysis of the Edmonton Symptom Assessment System. *Palliat Med.* 2011; 25: 71-82

Development of the ECS-CP KT Strategy:

The discussion surrounding the advancement of the ECS-CP KT strategy was initially centered on the “Stick vs. Carrot” analogy (i.e. an old analogy for positive vs. negative reinforcement). The attendees agreed that the methods to promote use of the tool would likely involve both the carrot and the stick.

The discussion then focused on uptake of the ECS-CP and the quality of use. As an example, while the ESAS has been taken up by many countries, there is uncertainty about the quality of the uptake of that tool. An ESAS survey was completed in Norway which indicated that there are numerous translations most of which were incorrect and not intuitively comparable with the original English version. The Edmonton team was challenged to focus on one standardized version of the ECS-CP.

It was suggested that the group also disseminate the tool further than within the Palliative care community by encouraging oncologists to use the ECS-CP as a referral tool. The ECS-CP can also be used by an organization to help administrators determine utilization of services. Many institutions, however, do not have the ability to impose the use of tools at this point.

An important point was brought forward positing the allowance of academic freedom and open access vs. control around quality. It was agreed that both are required. We need to determine how to maintain control yet encourage freedom?

The creators of the ECS-CP made a collective decision not to copyright the tool with the purpose to empower. It was stated that if the initial process involved a central depository that required authorization, many of the grass roots efforts would have had difficulty being established. The uptake of a tool is strongly linked to feeling free to use as [the user’s] needs dictate. The purpose of the tool was to empower people to treat their patients.

Suggestions to promote use of the tool included:

- The concept of Open Sourcing: If someone wants to use the tool, one must register the use to ensure standardization. There will not a be a charge for use (example: Pallium Leap)
- Wiki Concept Blog: Allows easy access and monitors changes

The issue of managing different versions was highlighted. If anyone can make changes, how will the tool remain meaningful? Quality control will then become a big concern.

There was consensus that there may be greater uptake of the ECS-CP clinically if there is flexibility to its use. A research tool must however be standardized. Many echoed that standardization is crucial. If people make their own changes, then a standardized system no longer exists. Any agreements and formal changes should be made by an international body preferably based on further validation studies.

2.1.3. Should we develop an international supervisory group for the ECS-CP?

Chair: Cheryl Nekolaichuk

Rapporteur: Russell Goldman

Examples of tools that the group could draw from to create a supervisory group for the ECS-CP included: the TNM, DSM, The International Statistical Classification of Diseases and Related Health Problems 10th Revision (**ICD-10**), and EAPC RN systematic classification for cachexia.

Lessons we can learn from other supervisory organizations if we decide to establish our own group could include:

- 1) *Multidisciplinary panel*: to avoid bias and provide added credibility;
- 2) *Global representation*: for rapid dissemination and language translation;
- 3) *Terms of Reference*: to clarify goals, aims, vision and mission;
- 4) *Transparent and open process*: for a non-biased, credible approach and avoid conflict of interest;
- 5) *Not biased by particular health care system*: to ensure a transferable tool;
- 6) *Informed decision making*: based on a systematic review of empirical data;
- 7) *Coordination between working groups if applicable*: to create a cohesive team;
- 8) *Consistent terminology and approach*;
- 9) *Evidence Based*: decisions based on literature and research;
- 10) *Infrastructure and Funding*: to support continuation of work.

It was suggested that it might be too early to think of an international group considering the limited uptake of the ECS-CP, but considering the need to use the tool correctly and the specialist nature of the tool, it will be necessary at some point. It may be appropriate to use the power of journal editors in the future to impose standards in terms of reporting especially with regard to aiding reproducibility of research results.

Participants were more comfortable with very open free ranging use, with a reference point that people can turn to for assistance. It was stated that the group needs to find a balance between monitoring/control and open access. Restrictions on use such as the need to register can delay implementation and make some institutions reluctant e.g. the need to register to use the Liverpool End of Life Care Pathway. While early adopters can often be trusted to honor the integrity of a tool, the balance can change depending on where the tool is in terms of uptake, particularly as use becomes more widespread e.g. the “viral” use of the ESAS with multiple adapted variations. Changes need to be relatively infrequent as demonstrated by the DSM, as frequent changes can cause confusion in users. However the time between modifications can be well used to do further consensus work and validation research.

It was pointed out that the “Open Source Approach” is currently being used with the ECS-CP – it is available on the palliative.org website along with the administration manual. Creation of an International group may require more momentum and time and, may come from increasing adoption and interest from people using it who want to create a supervisory group. It can be a complex and expensive endeavor. Language translation is another complex area that will need to be considered. The concept of a Wikipedia approach was endorsed as a very useful concept to allow users to provide ongoing feedback. The European Organization for Research and the Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) was used as an example where open access and translation is used extensively. Standardization here is ensured through copyright and is available on their website with copyright used as a measure to ensure appropriate use, not for financial gain.

The two questions posed to the group with regard to the need for and structure of an international supervisory group was not answered by the discussion and more time will be required to sort through these concepts.

The two questions posed to the group were:

- 1) Should we develop an international supervisory group?
- 2) If so, what would that group look like?

2.2. Setting a research agenda

2.2.1 A. How should we proceed with ongoing collaboration/merger with the work of the EAPC RN cancer pain assessment and classification proposal?

Chair: Stein Kaasa Rapporteur: Deb Dudgeon

Stein Kaasa began the discussion by summarizing the following challenges and provided ideas on how the collaboration can move forward.

Challenges that must be addressed:

Confusion between terminologies exists. There are numerous needs that must first be met:

- a) Need to provide training in future on the different concepts (measures/assessments and outcomes).
- b) Need to agree on how to apply or use the outcomes.
- c) Need to be clear when discussing use in clinical work, quality assurance/ benchmarking or research capacities. There are different ways to use the ECS-CP tool in clinical practice. It can be used as a screening tool, as a diagnostic tool or to assess follow up when treating patients. In clinical practice the outcomes are on an individual level; in quality assurance, on a group level and in research, it is a combination of both.
- d) Need to be clear on aims.

In order to bring collaboration forward:

The Group needs to be somewhat more official to collaborate. The suggestion was put forth that there be a “loose network” with a mandate that is open minded, accessible for participation and transparent with an open invitation to others. Representatives of the EAPC and EAPC RN could contribute to the establishment of a supervisory group and a mandate. The group not only needs to combine willingness and time, but minimum resources must be in place in order for the group to be sustainable. These resources could be in the form of administrative and part/ full time research support. Better use of resources can be accomplished by using Post Doctoral Fellows and PhD candidates.

The issue of the name of the ECS-CP as a benefit or liability was explored and has pros and cons. A lot of work has been completed already and the Edmonton tools (i.e. ESAS, ECS-CP) are widely recognized and easily available. There was some consensus that, in future, consideration be given to calling the tool the “International Classification System for Cancer Pain.” However the name is less important than concern with content and user friendliness. A non emotional and scientific approach should be utilized. There was agreement that this is not a tool that should ever be used for financial advantage, but the issue of copyright for standardization purposes received some support.



Collaboration with the EAPC RN, has resulted in the incorporation of the ECS-CP into international studies of the EAPC RN group, with confirmation of domains to include in a classification system providing a solid foundation.⁴ This collaboration has been very successful and of mutual benefit..

⁴ Knudsen AK, Aass N, Fainsinger R, et al. Classification of pain in cancer patients – a systematic literature review. Palliative Medicine 2009; 23(4):295-308.

As everyone agreed we should move forward and there already is a successful collaboration on which to build, the main issue identified was: - How do we build on what is already successful and what are the next steps?

Partnerships with other organizations such as the International Association for the Study of Pain (IASP) were considered. The group was cautioned in this regard: the terms of reference with other larger organizations are usually quite loose, outcomes are strongly dependent on the limited number of people completing the tasks, and the added bureaucracy may hinder progress. Progress can be very slow and may be more efficient with informal work. Umbrella organizations may not be of benefit at this point, as political complexities ensue. However despite these reservations endorsements from some organizations can be helpful and a combined approach might be the way to proceed in this matter e.g. the IASP Palliative Care group.

There is a need to keep building momentum. This can be done with a follow up publication to the recent international ECS-CP study and also by completing validated translations.

“If we have learned something – it is a good time to take it to the next step. [The group] must now focus on what needs to be done to improve the current version”

It was agreed that there was consensus that the present participants working on the ECS-CP should continue to move forward and widen participation. The issue of a name change such as the “International Classification System for Cancer Pain” would mature at a future time. At this stage it was decided that we should avoid the umbrella of an established organization, but obtaining endorsements in the future would be beneficial. An important initial step in moving forward internationally is to begin with translations to French and other languages.

2.2.2. A research agenda for the ECS-CP - do we need 2 versions, a clinical and research pain classification system?

Chair: Eduardo Bruera

Rapporteur: Sharon Watanabe

Eduardo Bruera made some introductory remarks as a preamble to the discussion:

1. The challenge is to define the usefulness of a research vs. a clinical approach to classification of cancer pain.
2. We have to consider the advantages of more sophisticated assessments of some of the concepts such as substance abuse, somatisation and incident pain vs. a pragmatic approach which would favor a more simple assessment that would be more likely to encourage use by clinicians.
3. How much can we get away with increasing the complexity of assessment of the included dimensions or adding new dimensions such as pain intensity or opioid dose escalation?

The discussion highlighted a number of important issues and questions that could be considered for further research:

1) Should pain intensity be included as a feature of the ECS-CP? Pain intensity and the inclusion of this dimension in the pain classification system has pros and cons. It was a strong predictor of complexity of care in the research done to date, but on the other hand it is dynamic and more likely to change rapidly than the other dimensions. There were different opinions on the value of including this dimension.

2) What is the role of opioid dose/escalation index in the ECS-CP? Opioid dose/escalation index is a complicated construct and it remains unclear what role if any this should have in the pain classification system.

3) What are the benefits and challenges of developing a weighting system? Weighting of the dimensions and assigning a number value to provide a composite of the risk factors for complexity of care could enhance clinical relevance. This may have more value for benchmarking or quality assurance. However the creation of this kind of “staging” needs to recognize that patients are complex and change over time requiring consideration of a “time expiry” requiring repeat classification at undetermined intervals.

4) What additional features might be contributing to poor pain management outcomes? There is a large variance in the outcome that may not be explained by the current model.

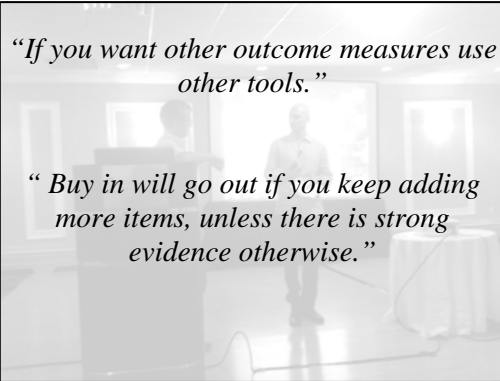
5) What is the role of cognitive function and psychological distress? Clinically relevant features of the ECS-CP that require judgment, such as cognitive function and psychological distress, need further evaluation.

6) How can we better demonstrate the clinical utility of the ECS-CP? The clinical application in everyday use needs more work to demonstrate how the ECS-CP can change management and improve patient care while at the same time having a limited burden: The ECS-CP provides a systematic documentation system for assessments that we are already doing in clinical practice. Demonstrating we will save time by documenting the information in a systematic fashion and improving communication with other health care professionals who will be involved in the care of the patient was endorsed as an important concept.

7) How can we develop a more user-friendly manual? Creating a more user-friendly manual was highlighted as a key next step. We must ensure that it is simple, short and the value is readily apparent without requiring the extensive reading of the present manual. Ideally, the assessment form for the ECS-CP should be self-explanatory, as a user manual is not always read even if it is short. The manual could include tips on why this might be useful for you and include modules or links that provide more information where necessary. Using experts in education would enhance the content and evaluation of manual development.

8) How could we develop a parallel classification system for cachexia and pain to assist with uptake? It was suggested we could consider developing a parallel framework for assessment and classification for cachexia and pain, as it might be easier to promote the whole concept to clinicians.

There was a strong consensus that developing a research ECS-CP would not be helpful or beneficial at this time because: (1) the ECS-CP still requires increased uptake into routine clinical practice; (2) the time and energy to develop a second tool would be a distraction and dilute our present efforts.



“If you want other outcome measures use other tools.”

“Buy in will go out if you keep adding more items, unless there is strong evidence otherwise.”

2.3. Identification of Next Steps and Closing Remarks

Neil Hagen summarized the discussion with some conclusions and suggestions for next steps:

Five Main Conclusions:

1. The ECS-CP is ready to move to the next phase of its growth. It has a carefully reasoned design and research to date attests to its validity and predictive value.
2. Do we need one tool or two? Do we need a single, multipurpose tool, or a research tool plus a shorter, simpler to use clinical version? Consensus is that we should go forward with one tool as the ECS-CP has been studied and is ready to use; to introduce a second version could be confusing and could substantially interfere with progress.
3. There is strong interest in establishing an International Steering Committee to oversee further development of the tool. The primary purpose would be to serve as the oversight body to approve any changes in the tool. The International Steering Committee should not be under the umbrella of an established International Society but rather, should (for now) be free standing. However, we should be open to establishing a relationship with one or more International Societies, with particular attention paid to the relationship being low maintenance and being unlikely to result in bureaucracy.
4. There is strong interest in promoting further research with the ECS-CP. This could be accomplished through establishing some kind of blog or web presence to support an informal research network.
5. There should be attention paid to developing and implementing a Knowledge Translation strategy.

Next Steps

The Symposium members strongly recommended:

1. To organize a follow-up meeting of the Symposium one to two years from now.
2. To establish working groups:
 - a. Clinical user's group
 - b. Administrative manual / user's manual group
 - c. Research network (see point 4 above). Pediatric working group
 - d. Language translations group - One of several functions would be to facilitate discussions between individuals who want to use or develop or validate translations of the ECS-CP.
 - e. Knowledge translation group
 - f. Other groups as the opportunity arises

APPENDIX 1. Research Team, Expertise and Role⁵

The research team consists of a comprehensive international panel of experts in the field of palliative care, pain management and psychometrics

Investigator	Site	Expertise	Role
Principal Applicants			
Dr. R. Fainsinger	Edmonton, AB	palliative care pain; previous involvement with ESS and rESS development	<ul style="list-style-type: none"> To oversee research project To provide intellectual direction for study design, data analysis, review of findings and dissemination of findings To classify consecutive cancer patients in clinical practice and collect relevant clinical data
Dr. C. Nekolaichuk	Edmonton, AB	psychosocial oncology; research methodology; measurement and evaluation; previous involvement with rESS development	<ul style="list-style-type: none"> To provide intellectual direction for study design, data analysis, review of findings and dissemination of findings To conduct data analysis
Collaborators			
Dr. M. Bercovitch	Tel Aviv, Israel	palliative care pain	<ul style="list-style-type: none"> To classify consecutive cancer patients in clinical practice and collect relevant clinical data as required To participate in review of analyzed data To provide input into the preparation of manuscripts for publication
Dr. E. Bruera	Houston, TX	palliative care	
Dr. M. Fisch	Houston, TX	oncology, palliative care pain	
Dr. L. Galloway	Calgary, AB	palliative care pain	
Dr. G. Kaye	Auckland, NZ	palliative care pain	
Dr. W. Landman	Auckland, NZ	palliative care pain	
Dr. P. Lawlor	Dublin, Ireland		
Dr. O. Spruyt	Melbourne, Australia	palliative care pain	
Dr. D. Zhukovsky	Houston, TX	palliative care pain	
Research Staff			
Mr. Hue Quan	Edmonton, AB	Data Manager	<ul style="list-style-type: none"> To assist the research coordinator with updating any required changes and maintaining the database.
Mr. John Hanson	Edmonton, AB	Statistician	<ul style="list-style-type: none"> To complete statistical analysis.
Ms. Viki Muller	Edmonton, AB	Research Coordinator	<ul style="list-style-type: none"> To coordinate the study, assist with the preparation & dissemination of study findings.

⁵ Fainsinger RL, Nekolaichuk C, Lawlor P, Hagen N, Bercovitch M, Fisch M, Galloway L, Kaye G, Landman W, Spruyt O, Zhukovsky D, Bruera E, Hanson J. An international multicentre validation study of a pain classification system for cancer patients. *Eur J Cancer*. 2010 Nov;46(16):2896-904. Epub 2010 May 17. PubMed PMID: 20483589.

APPENDIX 2. PRESENTER BIOGRAPHIES

DR. MICHAELA BERCOVITCH

Dr. Michaela Bercovitch lives in Israel, near Tel Aviv where she is active in Tel HaShomer's Oncological Hospice, Beit Friedman, part of Sheba Medical Center as a senior medical doctor and Research and Informational Coordinator. Dr. Bercovitch is also a member of the academic staff, functioning as a lecturer, at Tel Aviv University Sackler School of Medicine. Dr. Bercovitch was born in Romania, Bucharest where she finished her schooling and received her MD in Pediatrics. In 1987 she emigrated in Israel and after two years training in Internal Medicine and Geriatrics she decided to continue her medical activity in the Oncological Hospice.

Her research activity includes studies and publications about pain control, the use of high doses of opioids for pain relief and their impact on the patients' survival. Moreover she has developed various clinical auditing tools and a unique (in Israel) hospice oriented clinical database. During the last three years she has been involved in a number of international pain research projects. Recently she wrote for the latest edition of the Oxford Textbook of Palliative Medicine a chapter about treatment of pain with TENS, and some chapters in other medical books about Euthanasia, other non medical treatments for chronic pain, about the role of the physician near death, and the effect of setting on the work of the team (chapter of an Oxford Ed book that will be published)

DR. EDUARDO BRUERA

Dr. Bruera earned his medical degree at the University of Rosario (Argentina) in 1979. He completed his training in Medical Oncology and joined the University of Alberta and the Cross Cancer Institute in Edmonton (Canada) in 1984. Dr. Bruera became Professor of Oncology and The Alberta Cancer Foundation Chair in Palliative Care. In 1999 he became Professor of Medicine and the F.T. McGraw Chair in the Treatment of Cancer at The University of Texas M. D. Anderson Cancer Center (USA). Dr. Bruera has had a strong interest in the development of palliative care around the world. He has mostly worked on education, clinical program development, and research in Latin America and the Caribbean. He collaborated for many years with the World Health Organization and the Pan American Health Organization as regional point for palliative care and as leader of a number of specific projects. Dr. Bruera has published more than 600 papers, abstracts, and book chapters. He has trained hundreds of physicians over the years who are currently practicing palliative care around the world.

DR. LYLE GALLOWAY

Dr. Galloway went to medical school and completed a family medicine residency at the University of Alberta. After 7 years of family practice, he went 'back to school' to complete the palliative care fellowship program at the University of Calgary. He has worked in the Calgary palliative care system since, mostly as one of the attending physicians and medical director of the IPCU (Intensive Palliative Care Unit) at Foothills Hospital. Dr. Galloway is a clinical associate professor with the Departments of Oncology and Family Practice, he is married with 2 kids, and when not being a doctor or a dad spends his time playing music and cycling.

DR. NEIL HAGEN

Dr. Neil Hagen completed his undergraduate medical education at the University of Alberta followed by two years of internal medicine at McGill University, Adult Neurology residency training at the Mayo Clinic, and a fellowship in Neuro-oncology and Cancer Pain at Memorial Sloan Kettering Cancer Centre in New York.

He is currently Professor in the Departments of Oncology, Medicine and Clinical Neurosciences at the University of Calgary, where he is the Head of the Division of Palliative Medicine.

His major research interests are related to the assessment and management of cancer pain, including opioid pharmacokinetics, breakthrough pain and most recently, the analgesic effects of tetrodotoxin in cancer pain. He also is interested in cancer control, particularly population-based standards of cancer treatment, evidence-based decision making, knowledge management, and in organizational ethics.

DR. ROBIN L. FAINSINGER

Dr. Fainsinger graduated from the University of Cape Town in South Africa in 1981. In 1991, he completed the first fellowship in Palliative Care medicine at the University of Alberta in Edmonton, Canada. He continues to reside in Edmonton where he was Director of the Palliative Care Program at the Royal Alexandra Hospital from October 1994 – April 2006. He is the Clinical Director of the Tertiary Palliative Care Unit at the Grey Nuns Hospital, Director of the Division of Palliative Care Medicine in the Dept of Oncology, and Medical Director for the Edmonton Zone Regional Palliative Care Program. He is a Professor in the Division of Palliative Care Medicine, Department of Oncology at the University of Alberta. He is active in education and research, and has published articles on a number of palliative care topics, with an interest in dehydration, delirium, sedation at the end of life, and a classification system for cancer pain. He has over 160 publications in journals and book chapters.

DR. STEIN KAASA

Stein Kaasa is Professor of Palliative Medicine at the Institute of Cancer Research and Molecular Medicine, Faculty of Medicine, Norwegian University of Science and Technology, Trondheim (NTNU), chair of “Pain and Palliation Research Group” and leader at the Palliative Medicine Unit at Trondheim University Hospital and Cancer Director, Norwegian Directorate for Health.

He also holds the position as chair of the European Association for Palliative Care Research Network (EAPC RN) and is a member of the Board of Directors of the International Association for Hospice and Palliative Care (IAHPC).

Since 2006 he has been the principal investigator and director of the “The European Palliative Care Research Collaborative (EPCRC)”. A 6th Framework EU funded project under the call “Combating Major Disease – Combating Cancer” 2006-2010.

Professor Kaasa is also the leader of Workpackage (WP) 3 in “Reflecting the Positive diversities of European priorities for research and measurement in end of life care” (PRISMA); a 7th Framework EU funded project under the call “Optimising research on end of life care of cancer patients” 2008-2011.

In 2009, he established the “The European Palliative Care Research Centre (PRC)” through an initiative by the Palliative Care Research community and EAPC among others (www.ntnu.no/prc). The PRC will establish a formal collaboration with clinical and academic institutions and individual researchers across Europe and from other parts of the world. The EAPC RN will be an important contributor and facilitator of this work.

DR. GINA KAYE

Dr. Gina Kaye is originally from the UK. She came to Medicine later than usual having already done a degree in Psychology and rather a large amount of traveling. She trained in Bristol in the UK and spent her first 6 years post qualifying working there. She initially trained as a hospital physician with a specialist interest in Palliative Care. Dr. Kaye moved to New Zealand in 2004 and worked at South Auckland Hospice for 4 years and recently made the move into GP territory taking her Primex exam at the end of 2008.

DR. PETER LAWLOR

Dr. Peter Lawlor is a Clinical Scientist in Palliative Care at the Élisabeth Bruyère Research Institute. He holds an appointment with the University of Alberta as adjunct Associate Professor in the Division of Palliative Care Medicine. Dr. Lawlor began his appointment as Medical Director of the Élisabeth Bruyère Palliative Care Unit in January 2010. Dr. Lawlor obtained his basic medical degree in 1983 and an M.Med Sc. degree in pathology in 1985 from University College Dublin. He underwent four years of general professional training in Dublin teaching hospitals, and a year of general practice training in the UK. He then immigrated to Canada to work as a family physician. He commenced a Palliative Medicine Fellowship at the University of Alberta in 1996. He has subsequently worked in all parts of the Edmonton Palliative Care Program over a period of eight years. Prior to returning to Dublin, he was Director of the University Hospital Palliative Care Program in Edmonton. He returned to Dublin in April 2004 as a consultant in palliative medicine at Our Lady’s Hospice and St James’s Hospital. Dr. Lawlor completed his Palliative Care clinical research fellowship under the mentorship of Dr. Eduardo Bruera in Edmonton in the mid ‘90s. He worked with Dr. José Pereira as Palliative Care Community Consultants in the Edmonton regional program for a number of years, seeing patients in their homes and in the community. He has published some of the seminal studies in Palliative Care in Delirium and is

also a keen educator who is very well liked by learners. His research interests include pain assessment and opioid side-effects.

Ms. VIKI MULLER

Ms. Muller is the Research Manager for the Division of Palliative Care Medicine. She manages research projects in the division and assists with grant applications, ethical approvals and administrative and financial aspects of various studies. She holds a Masters of Public Health, specializing in Health Policy and Management.

DR. CHERYL NEKOLAICHUK

Cheryl Nekolaichuk, PhD, RPsych, is a registered psychologist with a special interest in psycho-oncology and palliative care. She obtained her undergraduate and graduate training at the University of Alberta (U of A), graduating with a B.Sc. (Pharmacy) in 1979; a M.Ed. (Counselling Psychology) in 1990; and a PhD (Counselling Psychology) in 1995. Her postgraduate training included a NCIC Terry Fox Fellowship in the Division of Palliative Care Medicine, U of A, with a focus on measurement and evaluation in palliative care. She is a psychologist on the Tertiary Palliative Care Unit at the Grey Nuns Hospital and an Associate Professor in the Division of Palliative Care Medicine, Department of Oncology, U of A. Her clinical and research interests revolve around supporting patients and families through end of life transitions, including psychosocial aspects of pain and pain classification; symptom assessment; and understanding the experience of hope in palliative and end of life care.

DR. ODETTE SPRUYT

Dr Spruyt has been at the Peter MacCallum Cancer Centre in Melbourne, Australia since 1998, leading a consultative team with academic interests and responsibilities as Head of the Department of Pain and Palliative Care. She has participated in a number of national and international studies in palliative care. Her special areas of interest include integrating palliative care into cancer care, symptom management particularly pain control, and the development of palliative care in resource poor settings.

DR. DONNA ZHUKOVSKY

Dr. Zhukovsky directs the Pediatric Palliative Care program at MD Anderson Cancer Center and maintains a strong focus on clinical care and research while promoting education in the field of Palliative Medicine. She obtained her undergraduate and medical education at McGill University in Montreal where she graduated with a B.Sc. and First Class Honors in Biology (Human Genetics) in 1978 and a M.D., C.M. in 1982. Subsequent postgraduate training included an Internal Medicine Residency at McGill (1982-1987) and a Cancer Pain Fellowship in the Department of Neurology at Memorial Sloan Kettering Cancer Center (1987-1989). She is board certified in Internal Medicine (1985), Medical Oncology (1987), and by the American Board of Hospice and Palliative Medicine (1997, recertification 2004).