



**RESEARCH
COLLABORATION
S AND
BREAKTHROUGH
IN PALLIATIVE
CARE**

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AGENDA

- Background and literature review
- Examples
 - Palliative Care collaborations
 - Interdisciplinary Collaborations
 - International and Australian examples

BACKGROUND

- The development of palliative care in most countries in 60's and 70's happened largely outside mainstream healthcare systems and outside academic institutions
- Primary focus on service development
- Focus on patients and families/caregivers in real-world settings
- Strongest driving force was development of clinical programmes
- E.g. home care, hospices, nursing homes and multidisciplinary teams
- Historically, conduct of research in palliative care populations impeded by multiple barriers

STUDY POPULATIONS

- Frail, vulnerable
- Perception of inappropriateness
- Ethical concerns
- Small
- Heterogenous
- Described/defined differently

STUDY DESIGN/METHODOLOGY

- Variable outcomes measured
- Lack of consensus on how to measure outcomes
- Lack necessary quality to give input into evidence-based medicine

HEALTHCARE SYSTEMS

- Researchers, clinicians, administrators with different priorities
- Fragmentation of healthcare systems
 - small numbers
 - loss to follow up
 - non standardized procedures
 - data heterogeneity

PROGRESS

- Late 90's, early 2000's large research groups established in some countries in order to improve palliative care research
 - National
 - International
- Requirement of groups to be of sufficient size and output
- Train sufficient clinician-scientists within palliative care research
 - permanent academic posts
 - provide responsibility and incentives
- FUNDING: predictable and sustainable



**EXAMPLES:
PALLIATIVE
CARE
COLLABORATIONS**

EAPC RESEARCH NETWORK

- The European Association for Palliative Care Research Network (EAPC RN) was established in 1996
- Development of clinical guidelines
- Organise research meetings and conferences
- Aim to conduct Pan-European Prospective Studies

The EAPC RN:

- Provides an established structure for collaborative research
- Has an infrastructure for data handling and organisation of research studies
- Acts as a focal point for discussion and exchange of knowledge
- Hosts the biennial EAPC World Research Congress which includes the biennial Vittorio Ventafridda Lecture
- Provides a Junior Forum for PhD students and other less experienced researchers

The EAPC RN offers an open invitation to all healthcare professionals who see the potential and value of conducting collaborative European multicentre research



Members
Area



EU-Funded Palliative Care Research

The European Association for Palliative Care (EAPC) is a core partner of many large European Union funded studies, with knowledge transfer and stakeholder engagement as a primary focus.

Horizon Europe

Horizon 2020

Erasmus+

EU4 Health

Horizon Mission

Horizon Europe



<https://palliativeprojects.eu/>

WHAT IS “PAINLESS” ?



- PAINLESS is a Horizon Europe Initiative
 - HORIZON-HLTH-2021-DISEASE-04 (2022-2027)
 - Project ID: 101057367
- Pain relief in palliative care of cancer using home-based neuromodulation and predictive biomarkers

PAINLESS

- PAINLESS consortium comprises institutions from Belgium, Czechia, Denmark, France, Germany, Israel, Portugal, Romania, Spain, and Switzerland
- Including academic and research bodies, healthcare services and institutions, software companies, dissemination and communication organisations, and targeting patient engagement and
- Funded by the European Union
- <https://palliativeprojects.eu/p>

Carrillo-de-la-Peña *et al.* *BMC Cancer* (2024) 24:705
<https://doi.org/10.1186/s12885-024-12455-8>

BMC Cancer

STUDY PROTOCOL

Open Access

Validity of central pain processing biomarkers for predicting the occurrence of oncological chronic pain: a study protocol

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PACCSC

- Palliative Care Clinical Studies Collaborative (PaCCSC) was established in 2006
 - in response to a request from the Department of Health and Ageing for the research needed to support the continued development of evidence-based trials in palliative care
- Australian-based research network located at the University of Technology Sydney (UTS)
- Partnership with Cancer Symptoms Trials (CST), and with support from the expert IMPACCT (Improving Palliative, Aged and Chronic Care through Clinical Research and Translation)
Trials Coordination Centre

PACCSC STRATEGIC PLAN



Interdisciplinary collaboration

Support and grow an interdisciplinary network of clinicians, researchers, consumers and stakeholders who collaborate to conduct high-quality clinical trials in palliative care.



Governance

Provide sustainable, independent governance to support members and collaborators to facilitate the conduct of high-quality clinical research in palliative care.



Capacity building

Build clinical trial capacity through training and mentorship that results in sustained growth of clinical trials in the palliative population.



High-quality investigator-led clinical trials

Sponsor and conduct clinical trials that are strategically focused on palliative care research priorities that will attract and secure competitive funding



Research translation

Contribute to the translation of clinical trial results into clinical practice and health policy to positively influence the care and outcomes of people affected by life-limiting illness

<https://www.uts.edu.au/research/impacct/palliative-care-clinical-studies-collaborative/paccsc-strategic-plan>

PROJECTS

Open clinical trials

- ✓ BETTER-B (AUS)
- ✓ Ketamine for depression
- ✓ Life-space assessment-palliative care (LSA-PC)
- ✓ Lorazepam for anxiety and palliative care
- ✓ The Up study

Closed clinical trials

- ✓ Breathlessness Exertion and Morphine Sulphate Study (BEAMS)
- ✓ Management of constipation in palliative care
- ✓ Morphine or Placebo (MOP)
- ✓ Pyridostigmine for constipation
- ✓ Risperidone and haloperidol in delirium
- ✓ Sertraline for breathlessness
- ✓ SKIPMDD study

**This Issue**Views **32,771** | Citations **28** | Altmetric **403**

PDF



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Cite



Permissions

Original Investigation

FREE

November 22/29, 2022

Effect of Regular, Low-Dose, Extended-release Morphine on Chronic Breathlessness in Chronic Obstructive Pulmonary Disease

The BEAMS Randomized Clinical Trial

Magnus Ekström, MD, PhD^{1,2}; Diana Ferreira, MD, PhD³; Sungwon Chang, PhD²; [et al](#)[» Author Affiliations](#) | [Article Information](#)

JAMA. 2022;328(20):2022-2032. doi:10.1001/jama.2022.20206

BEAMS

- To determine the effect of different doses of extended-release morphine on worst breathlessness in people with COPD after 1 week of treatment
- Multicenter, double-blind, placebo-controlled randomized clinical trial including people with COPD and chronic breathlessness. 20 centers across Australia; Sept 2016 to Nov 2019
- Randomized 1:1:1 to 8 mg/d or 16 mg/d of oral morphine ER or placebo during week 1; weeks 2 and 3, randomized 1:1 to 8 mg/d of morphine ER (added to the prior week's dose), or placebo.
- Primary outcome: change in the intensity of worst breathlessness on NRS to mean score after week 1 of treatment in 8 mg/d and 16 mg/d of morphine ER groups vs placebo group
 - Secondary outcomes included change in daily step count from baseline to mean step count from week 3

BEAMS RESULTS

- Results: 160 people randomized, 156 included in the primary analyses; median age, 72 years
- 138 (88%) completed treatment at week 1: 48 8 mg/d morphine, 43 16 mg/d morphine, 47 placebo
- Change in intensity of worst breathlessness at week 1 not significantly different between
 - 8 mg/d of morphine group and placebo group
 - 16 mg/d of morphine group and the placebo group
- At week 3, secondary outcome of change in mean daily step count was not significantly different between 8 mg/d; 16 mg/d; 24 mg/d; 32 mg/d of morphine group, and placebo group
- Conclusions: Among people with COPD and severe chronic breathlessness, daily low-dose, extended-release morphine did not significantly reduce the intensity of worst breathlessness after 1 week of treatment
 - These findings do not support the use of these doses of extended-release morphine to relieve breathlessness

PCOC

- PCOC (Palliative Care Outcomes Collaboration) (founded 2005) operates from the Australasian Health Outcomes Consortium (AHOC) at the University of Wollongong (UOW)
- Collaboration between UOW, Queensland University of Technology (QUT), and the University of Western Australia (UWA)
- Funded by the Australian Government Department of Health and Aged Care




PCOC PALLIATIVE CARE OUTCOMES PROGRAM

- PCOC framework and protocol for routine clinical assessment and response
- Developed in the specialist palliative care sector. Used extensively with tens of thousands of patients and families.
- Used in palliative care units, by consult teams and in the community; embedded into routine clinical practice
- Data collected used to:
 - Provide consistent information to plan and deliver care. Can be accessed immediately at the point of care
 - PCOC produces reports (6-monthly) for each participating health service
 - Drives internal quality improvement and national benchmarking

PCOC FOR RESEARCH

- PCOC collaborates with researchers on studies, programs, and grants
- There are three ways to complete research with PCOC:
 - Request a dataset from PCOC and complete research independent of PCOC involvement
 - Consult with PCOC on aspects of the research project
 - Invite PCOC to be part of the research team

Palliative Assessment and Clinical Response		(Please complete or affix Label here)											
[Insert Service Name Here]				UPI: Surname			First name:			DOB:			
Assess on admission, daily, at phase change and on discharge													
Year 20		Date											
		Time											
Patient Rated Score	Symptom Assessment Scale (0-10) Rate experience of symptom distress over a 24hr period 0 = absent 10 = worst possible												
	0 = Continue care 1-3 = Monitor and record 4-7 = Review/change plan of care; referral, intervention as required 8-10 = Urgent action												
	Distress from difficulty sleeping												
	Distress from Appetite												
	Distress from Nausea												
	Distress from Bowels												
	Distress from Breathing												
	Distress from Fatigue												
	Distress from Pain												
	Other												
Rated by Patient, Fam/Carer or Clinician Use codes = Pt, FC, Cl													
Clinician Rated Score	Problem Severity Score Actions (0-3) Refer to complete definition and rate each domain												
	0 = Continue care 1 = Monitor and record 2 = Review/change plan of care; referral, intervention as required 3 = Urgent action												
	Pain												
	Other Symptoms												
	Psychological / Spiritual												
	Family / Carer												
	Australia-modified Karnofsky Performance Status Scale (10-100) Refer to complete definition Consider MDT review at score of 50 or below												
	AKPS												
	RUG-ADL Refer to complete definition 4-5 = Monitor 6-10 = assist x 1 10+ = assist x 1, consider equipment, staff requirements, falls risk, referral 15+ = as above, pressure area risk, consider carer burden and MDT review 18 = as above, full care assistance x 2												
	Bed mobility												
Toileting													
Transfers													
Eating													
Total RUG-ADL (4-18):													
Palliative Care Phase (1-4 Died or D/C) Refer to complete definition Stable = Monitor Unstable = Urgent action required Deteriorating = Review plan of care Terminal = Provide EOL care Died = record date, no further assessment required Discharge (D/C) = assess at discharge													
Palliative Care Phase													
Staff Initials													

SAS SCORES

PCPSS SCORES

AKPS SCORES

RUG-ADL SCORES

PHASE

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Sage Journals

Medical Manuscript

Impact of Visitor Restrictions on the Pain and Psychological Wellbeing of Palliative Care Patients: A Cohort Study

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IMPACT OF VISITOR RESTRICTIONS

- To explore the impact of VR on patients' levels of physical pain and psychological distress
- Retrospective cohort study comparing two cohorts of patients admitted to a palliative care unit in a major metropolitan hospital in Australia; the first cohort from 1 April to 30 June 2019 (pre-pandemic; n = 96), and the second from 1 April to 30 June 2020 (during pandemic; n = 95)
- Patient-rated pain scores (using the Symptom Assessment Scale; SAS) and clinician-rated pain and psychological/spiritual severity scores (using the Palliative Care Problem Severity Score; PCPSS) on admission and on discharge or death were compared between pre-pandemic and pandemic cohorts. Discharge pain scores and change in scores from admission to discharge were also assessed via multivariable analyses.

Table 3. SAS Pain, PCPSS Pain, and PCPSS Psychological Score Categories at Admission and at Discharge/Death.

	SAS Pain at Admission			SAS Pain at Discharge/ Death			PCPSS Pain on Admission			PCPSS Pain on Discharge/ Death			PCPSS Psych Admin			PCPSS Psych Discharge/ Death		
	2019	2020	p-value	2019	2020	p-value	2019	2020	p-value	2019	2020	p-value	2019	2020	p-value	2019	2020	p-value
Total (n = 191)			0.548			0.028			0.331			0.791			0.178			1.000
Continue care	62 (64.6)	54 (56.8)		63 (65.6)	60 (63.2)		57 (59.4)	51 (53.7)		55 (57.3)	55 (57.9)		66 (68.8)	68 (71.6)		70 (72.9)	69 (72.6)	
Monitor and record	16 (16.7)	15 (15.8)		19 (19.8)	8(8.4)		21 (21.9)	31 (32.6)		26 (27.1)	21 (22.1)		23 (24.0)	26 (27.4)		19 (19.8)	18 (18.9)	
Review/change plan of care; referral, intervention as req	16 (16.7)	22 (23.2)		11 (11.5)	23 (24.2)		14 (14.6)	9 (9.5)		10 (10.4)	12 (12.6)		6 (6.3)	1 (1.1)		4 (4.2)	4 (4.2)	
Urgent	2 (2.1)	4 (4.2)		3 (3.1)	4 (4.2)		4 (4.2)	4 (4.2)		5 (5.2)	7 (7.4)		1 (1.0)	0 (.0)		3 (3.1)	4 (4.2)	
Alive sub-group (n = 45)			0.730			0.010			0.689			0.557			0.176			0.349
Continue care	13 (72.2)	16 (59.3)		12 (66.7)	24 (88.9)		11 (61.1)	15 (55.6)		13 (72.2)	22 (81.5)		14 (77.8)	20 (74.1)		16 (88.9)	26 (96.3)	
Monitor and record	3 (16.7)	4 (14.8)		5 (27.8)	0 (0)		3 (16.7)	8 (29.6)		5 (27.8)	4 (14.8)		2 (11.1)	7 (25.9)		0 (0)	1 (3.7)	
Review/change plan of care; referral, intervention as req	2 (11.1)	5 (18.5)		1 (5.6)	3 (11.1)		3 (16.7)	2 (7.4)		0 (0)	1 (3.7)		2 (11.1)	0 (0)		1 (5.6)	0 (0)	
Urgent	0 (0)	2 (7.4)		0 (0)	0 (0)		1 (5.6)	2 (7.4)		0 (0)	0 (0)		0 (0)	0 (0)		1 (5.6)	0 (0)	
Deceased sub-group (n = 146)			0.741			0.068			0.522			0.756			0.563			0.692
Continue care	49 (62.8)	38 (55.9)		51 (65.4)	36 (52.9)		46 (59.0)	36 (52.9)		42 (53.8)	33 (48.5)		52 (66.7)	48 (70.6)		54 (69.2)	43 (63.2)	
Monitor and record	13 (16.7)	11 (16.2)		14 (17.9)	8 (11.8)		18 (23.1)	23 (33.8)		21 (26.9)	17 (25.0)		21 (26.9)	19 (27.9)		19 (24.4)	17 (25.0)	
Review/change plan of care;	14 (17.9)	17 (25.0)		10 (12.8)	20 (29.4)		11 (14.1)	7 (10.3)		10 (12.8)	11 (16.2)		4 (5.1)	1 (1.5)		3 (3.8)	4 (5.9)	

IMPACT OF VISITOR RESTRICTIONS

- Pain scores in the pandemic cohort were higher for patients deceased on discharge, compared to the pre-pandemic cohort (SAS: coefficient = 0.86, 95%CI: 0.09 to 1.64, P = 0.029; PCPSS: coefficient = 0.24, 95%CI: -0.07 to 0.86, P = 0.131, respectively).
- Differences in SAS and PCPSS pain and psychological/spiritual scores for those discharged alive were not statistically significant.
- Conclusion: Among palliative care inpatients affected by VR, we observed higher pain scores for patients discharged deceased; suggesting that VR may have impacted the physical wellbeing (pain) of these patients.



EXAMPLES:
INTERDISCIPLINARY
COLLABORATIONS

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

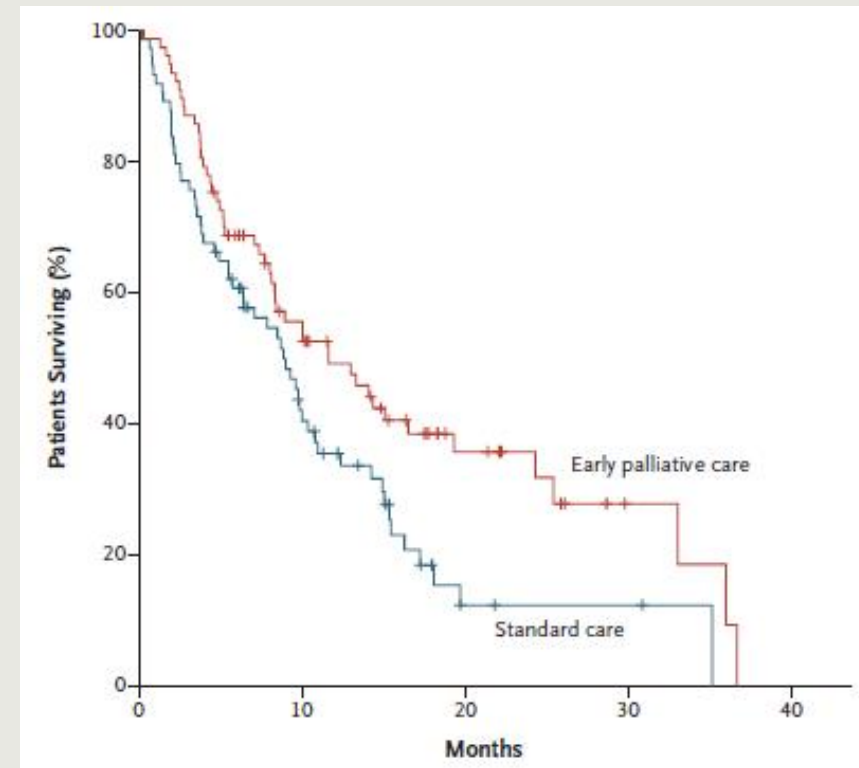
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EARLY PALLIATIVE CARE IN LUNG CANCER

- Massachusetts General Hospital, Boston
- Collaborators: Oncology, Palliative Care, Psychology and Psychiatry
- Landmark RCT that showed that among patients with metastatic non-small-cell lung cancer, early palliative care (routine, ambulatory) led to significant improvements in both quality of life and mood.
- As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but [possibly] longer survival.

EARLY PALLIATIVE CARE IN LUNG CANCER

- 151 patients randomized
- Patients assigned to early palliative care had a better quality of life than did patients assigned to standard care (mean score on the FACT-L scale [in which scores range from 0 to 136, with higher scores indicating better quality of life], 98.0 vs. 91.5; $P = 0.03$)
- Fewer patients in the palliative care group than in the standard care group had depressive symptoms (16% vs. 38%, $P = 0.01$)
- Fewer patients in early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, $P = 0.05$)
- Median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, $P = 0.02$).



FURTHER COLLABORATION: "INTEGRATE PC"

Journal of Clinical Oncology[®]
An American Society of Clinical Oncology Journal

[J Clin Oncol.](#) 2017 Mar 10; 35(8): 834–841.

Published online 2016 Dec 27. doi: [10.1200/JCO.2016.70.5046](https://doi.org/10.1200/JCO.2016.70.5046)

PMCID: PMC5455686

PMID: [28029308](https://pubmed.ncbi.nlm.nih.gov/28029308/)

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A
Randomized Clinical Trial

INTEGRATE PC

- 350 newly diagnosed patients, single site
- Collaboration with oncologists from 2 tumor streams
- Same design: intervention group met with a palliative care clinician at least once per month until death
- Primary endpoint: QOL at 12 weeks
- Secondary: QOL at week 24, mood and differences in EOL communication

INTEGRATE PC

- Intervention patients reported greater improvement in QOL from baseline to week 24 ($P = .010$) but not week 12 ($P = .339$).
- Intervention patients also reported lower depression at week 24
- Intervention effects varied by cancer type
 - intervention patients with lung cancer reported improvements in QOL and depression at 12 and 24 weeks, whereas usual care patients with lung cancer reported deterioration.
 - Patients with GI cancers in both study groups reported improvements in QOL and mood by week 12.
- Intervention patients were more likely to discuss their wishes with their oncologist if they were dying ($P = .004$).

FURTHER EXPANSION: "ALLIANCE"



[J Palliat Med.](#) July 2020; 23(7): 922–929.

Published online 2020 Jun 9. doi: [10.1089/jpm.2019.0377](https://doi.org/10.1089/jpm.2019.0377)

PMCID: PMC7307668

PMID: [32031887](https://pubmed.ncbi.nlm.nih.gov/32031887/)

Multisite, Randomized Trial of Early Integrated Palliative and Oncology Care in Patients with Advanced Lung and Gastrointestinal Cancer: Alliance A221303

ALLIANCE

- 405 newly diagnosed patients, multisite
- Collaboration with oncologists from 2 tumor streams. 18 sites: 9 academic and 9 community sites
- intervention group met with a palliative care clinician at least once per month until death
- Primary endpoint: QOL at 12 weeks

Standardization of procedures: Participating sites were required to have PC clinics with at least 6m experience providing care in the outpatient oncology setting, be led by a board-certified PC physician or advanced practice nurse (APN), and have the capacity to perform PC visits at the cancer practice on the same day as patients' oncology visits. At least one member of the PC team was required to complete a web-based training on the early integrated PC model, review the intervention manual, and train other clinicians at their site.

ALLIANCE

- Rate of missing data was high. Anticipated: 70% of patients would complete the FACT-G at baseline and week 12, but only 49.3% completed the measure.
- Delivery of intervention was suboptimal. 14.9% of intervention patients had no palliative care visits by week 12
- Intervention patients reported a mean 3.35 (standard deviation [SD]=14.7) increase in FACT-G scores from baseline to week 12 compared with usual care patients who reported a 0.12 (SD=12.7) increase from baseline (n=0.10): suggestive of improvement in quality of life for intervention patients

Conclusion: This study highlights the difficulties of conducting multicenter trials of supportive care interventions in patients with advanced cancer.

Comparative Effectiveness Trial of Early Palliative Care Delivered via Telehealth versus In Person among Patients with Advanced Lung Cancer: The REACH PC Trial

Joseph A. Greer PhD & Jennifer S. Temel MD on behalf of:


Chardria Trotter MPH MBA, Vicki A. Jackson MD MPH, Simone Rinaldi APN-BC, Mihir Kamdar MD, Areej El-Jawahri MD, Nora Horick MS, Kedie Pinto MS, Dustin Rabideau PhD, Josephine Feliciano MD, Isaac Chua MD MPH, Konstantinos Leventakos MD, Stacy Fischer MD, Toby C. Campbell MD, Michael W. Rabow MD, Finly Zachariah MD, Laura C. Hanson MD, Sara F. Martin MD, Maria Silveira MD, and the REACH PC Investigators

REACH PC

- June 2018 - May 2023
- 22 sites, 18 states
- ***1250 patients and their caregivers randomized***
- Within 12 weeks of diagnosis of advanced non-small cell lung cancer.
- Monthly visits in person or by video (initial visits all in person)
- ~ 5 visits both arms

REACH PC

- Primary aim: to evaluate the equivalence of effect of delivering early palliative care using video vs in-person visits in patient reported QOL.
- Secondary aims: to evaluate satisfaction with care, caregiver attendance, mood
- CONCLUSIONS: equivalence of effect of delivering early palliative care using video vs in-person visits on patient reported QOL [No significant difference in FACT-L, $p=.04$ for equivalence]
- Caregiver attendance greater for in person visits, no difference in satisfaction with care or mood symptoms



**PEARL :
PALLIATIVE
CARE EARLY
IN ADVANCED
LUNG CANCERS**

PEARL

- Palliative Care Early in Advanced Lung Cancers
- A collaboration between the Australasian Lung cancer Trials Group (ALTG)/ PaCCSC/ NHMRC Clinical Trials Centre (CTC)
- AIM: To determine whether early referral to palliative care improves health-related quality of life (HRQL), overall survival (OS) and use of health care resources in patients with recently diagnosed, advanced thoracic malignancies in the Australian healthcare setting

PEARL

- 113 pts and 78 carers; 15 sites Australia wide
- OVERALL: The proportion of patients that showed a sustained, substantial improvement in HRQL (FACTL-TOI) did not differ between arms, $X^2 (1, N = 113) = 0.02, p > 0.89$; AT 24 WEEKS: The proportion of patients that showed a sustained, substantial improvement in HRQL (FACTL-TOI) also did not differ between arms, $X^2 (1, N = 113) = 0.02, p > 0.88$
- Median overall survival of the cohort approximately 16.2 months; OS no significant difference between arms ($p=0.11$)
- Conclusion: Our study suggests that the palliative care needs of patients were addressed equally well by discretionary referral when clinically indicated
 - Appears to be no detriment to patients/carers from a model of timely referral to tertiary palliative care services, while receiving early and ongoing, primary or secondary palliative care from primary providers

ESMO DESIGNATED CENTRES

- Initiative of the European Society of Medical Oncology (founded 2003); objectives:
- Promoting integration of palliative care (PC) services into existing national cancer care guidelines
- Encouraging PC education/training for oncologists, and other healthcare professionals
- Expanding cooperation between ESMO and other existing professional medical associations and organizations

ESMO DESIGNATED CENTRES

of integrated oncology and palliative care services



The ESMO Designated Centres (DC) Accreditation Programme, initiated in 2003, recognises cancer centres that provide highly integrated oncology and palliative care services, with the goal of improving research, education and clinical practice by setting standards for service development.

ESMO DESIGNATED CENTRES

- more than 250 institutes from 55 countries worldwide
 - Australia: NSW 2 (Calvary Mater and St George), Melbourne 1 (Monash Health)
 - Malaysia: Selangor 2 (Sunway and Beacon)
- **Activities and Responsibilities**
 - Defining minimum standards for the provision of supportive and palliative care by cancer centres
 - Improving the level of involvement and expertise of oncologists in the delivery of supportive and palliative care to patients
 - Promoting palliative care issues and initiatives worldwide

ESMO DC WORKING GROUP SURVEY

- How can DCWG help centres and how can centres contribute
- Improve EDUCATION: meetings/seminars; educational courses; fellowships/grants/exchanges; guidelines, curricula/programmes, online databases
- Improve PROGRAM DEVELOPMENT: define structures, programmes/ provide guidelines/ meetings/ lobbying/ resources/ improve quality and motivation/ mentoring
- Improve RESEARCH:
 - Multi-centre studies – facilitate relations between centres, build networks
 - Links, platforms, sharepoints for materials, joint standards
 - Improve resources
 - Promotion and collaboration by ESMO; e.g. with EAPC



LIMITATIONS/RISKS

- Individual goals overshadowing collaborative intentions
- Limited feasibility of multi-site approaches
- Lack of funding
- Only large research institutions will participate
 - generalizability
 - omitted perspectives
 - failure to build broader research capacity
- Need for strong leadership as well as broad based participation

CONCLUSIONS/TAKE AWAY POINTS

- Strong collaboration necessary to achieve high quality palliative care research that is clinically meaningful and scientifically rigorous
- Key tenets for successful research collaboration
 - Mutual trust and respect
 - commitment to research goals
 - active engagement
 - maintenance of transparency and clear communication
- In order to continue the rapid progress in palliative care in establishing scientific and clinical legitimacy

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THANK YOU

