INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

Cicely Saunders International
Better care at the end of life

KING'S College LONDON

Integrated short-term palliative rehabilitation (INSPIRE)
From Concept to Clinical Trial

Dr Jo Bayly

31st May 2024

Funded by the European Union

Clinical career

My Background-
Hospice Rehabilitation

1987 Leeds School of Physiotherapy
1996-2015 Specialist physiotherapist in palliative care, Liverpool

"Why didn't I get all this support months ago"?
Peter, Stage IV lung cancer

Conception of the research question

Clinical research career pathway

- 2008-2011 HEE/NIHR Masters of Research in Health Sciences (Now pre-doctoral fellowships
- Research practitioner on Respiratory Symptom Intervention Feasibility Trial
- 2013-2014 National Cancer Research Institute Scholarship
- 2015 submitted Clinical Doctoral Fellowship Application
- 2016 started fellowship

Disability and cancer

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

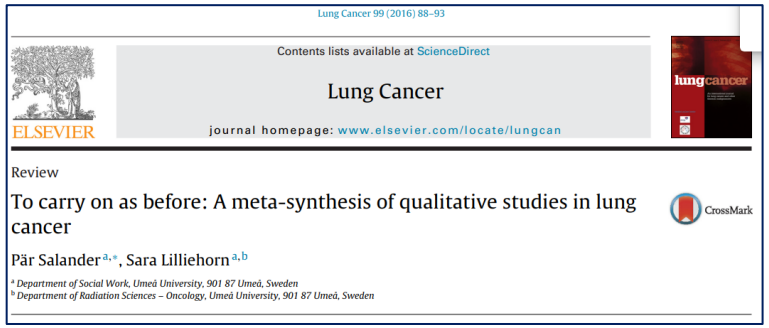
- Cancer is a main cause of illness burden, loss of function, disability and death
- > 1 million Europeans affected by disability related to incurable cancer[1]
- Globally, 250 million DALYs due to cancer: second only to cardiovascular disease[2]
- 1 in 3 adults with cancer require help with personal activities
- 1 in 2 need help with activities like shopping and getting around
- Disability reduces quality of life and leads to unplanned admissions to hospital[3]

Loss of function is rated as one of most common unmet needs – people want to live as normally as possible[4,5]

People want to live as normally as possible

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

- Continuing with usual routines & important roles
- No longer feeling 'who I once was'
- Being able to perform daily activities
- Adequate symptom control
- A sense of control
- Strengthen relationships with loved ones
- Maintaining dignity
- Maintaining a sense of humour
- Sharing time with friends and family
- Not being a burden


Lung Cancer 99 (2016) 88–93

Contents lists available at ScienceDirect

Lung Cancer

journal homepage: www.elsevier.com/locate/lungcan

Review

To carry on as before: A meta-synthesis of qualitative studies in lung cancer

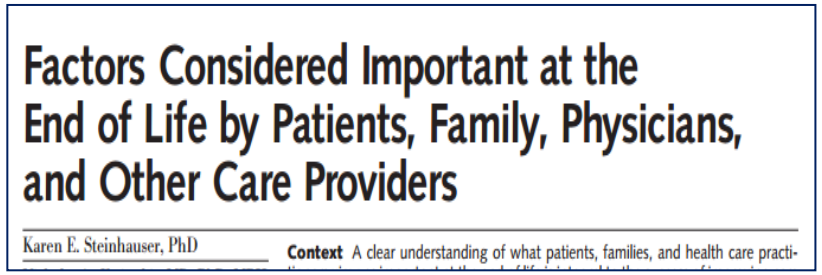
Pär Salander[a,*], Sara Lilliehorn[a,b]

[a] Department of Social Work, Umeå University, 901 87 Umeå, Sweden
[b] Department of Radiation Sciences – Oncology, Umeå University, 901 87 Umeå, Sweden


Original Article

The Landscape of Distress in the Terminally Ill

Harvey Max Chochinov, MD, PhD, Thomas Hassard, PhD, Susan McClement, PhD, Thomas Hack, PhD, CPsych, Linda J. Kristjanson, PhD, Mike Harlos, MD,


Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

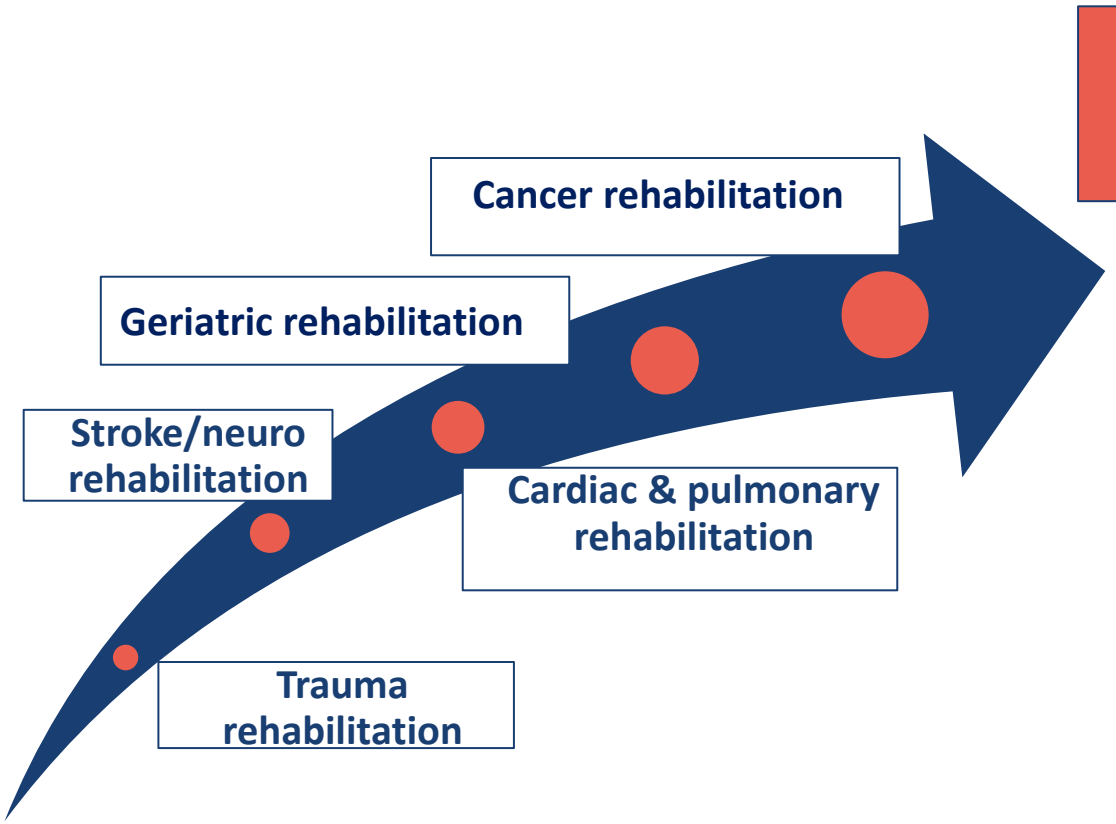
Karen E. Steinhauser, PhD

Context A clear understanding of what patients, families, and health care practi-

[Salander 2016, Lung Cancer];[Chochinov et al JPSM 2009]; [Steinhauser et al. JAMA 2000]

Rehabilitation in palliative care

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer



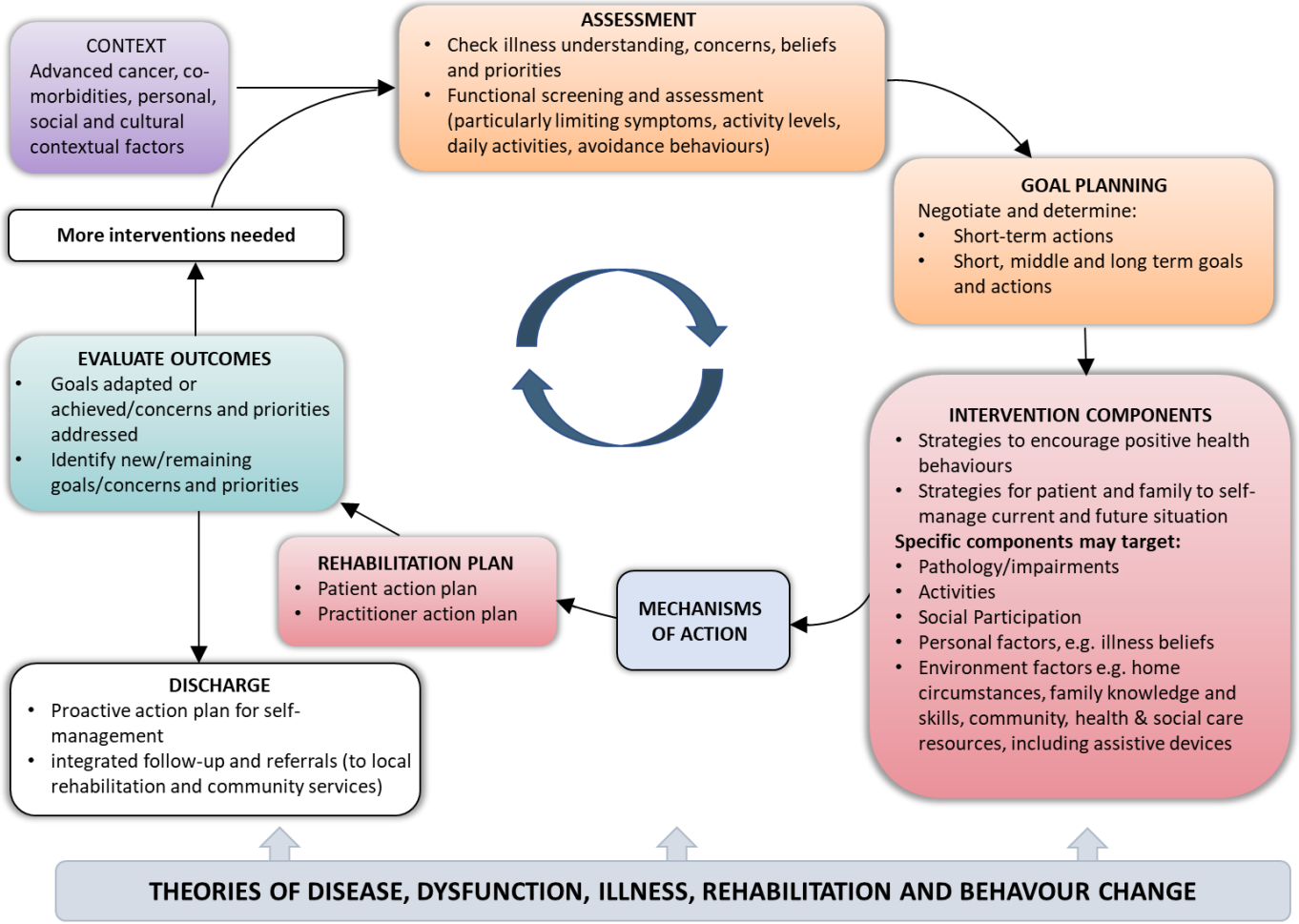
Palliative rehabilitation?

- Access to palliative care services has increased
- **Rehabilitation remains under-resourced and variable within palliative care[9]**

My PhD: Conceptualising and developing a palliative rehabilitation intervention

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

- Theoretically informed model of rehabilitation
- Developed with patients, family members and clinicians
- Intervention Manual to support high fidelity
- **3 manualised sessions** delivered by an expert rehabilitation practitioner
- **Core components:** self-management of symptoms, physical activities and fitness, social participation



My PhD: Testing a palliative rehabilitation intervention

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

Bayly et al. Pilot and Feasibility Studies (2018) 4:160
https://doi.org/10.1186/s40814-018-0350-0

Pilot and Feasibility Studies

RESEARCH Open Access

Developing an integrated rehabilitation model for thoracic cancer services: views of patients, informal carers and clinicians

Joanne Bayly[1*], Bethany M Edwards[1], Nicola Peat[2], Geoffrey Warwick[3], Ivo M Hennig[4], Arvind Arora[4,5], Andrew Wilcock[4,5], Irene J Higginson[1] and Matthew Maddocks[1]

Abstract

Background: Access to rehabilitation to prevent disability and optimise function is recommended for patients with cancer, including following cancer diagnosis. Models to integrate rehabilitation within oncology services as cancer treatment commences are required, but must be informed by those they are intended to support. We aimed to identify views of patients, carers and clinicians to develop and refine a rehabilitation model to be tested in a feasibility trial for people newly diagnosed with lung cancer or mesothelioma.

Methods: We conducted a focus group study with people affected by lung cancer or mesothelioma, their carers and clinicians providing their care to identify priorities for rehabilitation in this period. We sought views on core intervention components, processes and outcomes and integration with oncology services. Data were analysed using thematic analysis.

Results: Fifteen clinicians (oncologists, nurse specialists, physiotherapists and occupational therapists), nine patients and five carers participated. A proposed outline rehabilitation model was perceived as highly relevant for this population. Participants recommended prompt and brief rehabilitation input, delivered whilst people attend for hospital appointments or at home to maximise accessibility and acceptability. Participants recognised variation in need and all prioritised tailored support for symptom self-management, daily activities and the involvement of carers. Clinicians also prioritised achieving fitness for oncology treatment. Patients and carers prioritised a sensitive manner of approach, positivity and giving hope for the future. Participant's recommendations for outcome measurement related to confidence in usual daily activities, symptom control and oncology treatment completion rates over objective measures of cardiorespiratory fitness.

Conclusion: The importance of providing tailored rehabilitation around the time of diagnosis for people with lung cancer or mesothelioma was affirmed by all participants. The refined model of rehabilitation recommended for testing in a feasibility trial is flexible, tailored and short-term. It aims to support people to self-manage symptoms, tolerate cancer treatments and to remain active and independent in daily life. It is delivered alongside scheduled hospital appointments or at home by an expert practitioner sensitive to the psycho-social sequelae that follow a diagnosis of thoracic cancer.

Keywords: Lung cancer, Mesothelioma, Focus groups, Rehabilitation, Qualitative, Intervention development, Feasibility trial

* Correspondence: joanne.bayly@kcl.ac.uk
[1]Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, Kings College London, Bessemer Road, Denmark Hill, London SE5 9PJ, UK
Full list of author information is available at the end of the article

Original Article

CLINICAL REHABILITATION

Clinical Rehabilitation
1–15

DOI: 10.1177/0269215519888794
journals.sagepub.com/home/cre
SAGE

Short-term integrated rehabilitation for people with newly diagnosed thoracic cancer: a multi-centre randomized controlled feasibility trial

Joanne Bayly[1], Lucy Fettes[1], Eleanor Douglas[2], Maria J Teixiera[1], Nicola Peat[3], India Tunnard[1], Vishit Patel[1], Wei Gao[1], Andrew Wilcock[2], Irene J Higginson[1] and Matthew Maddocks[1]

Abstract

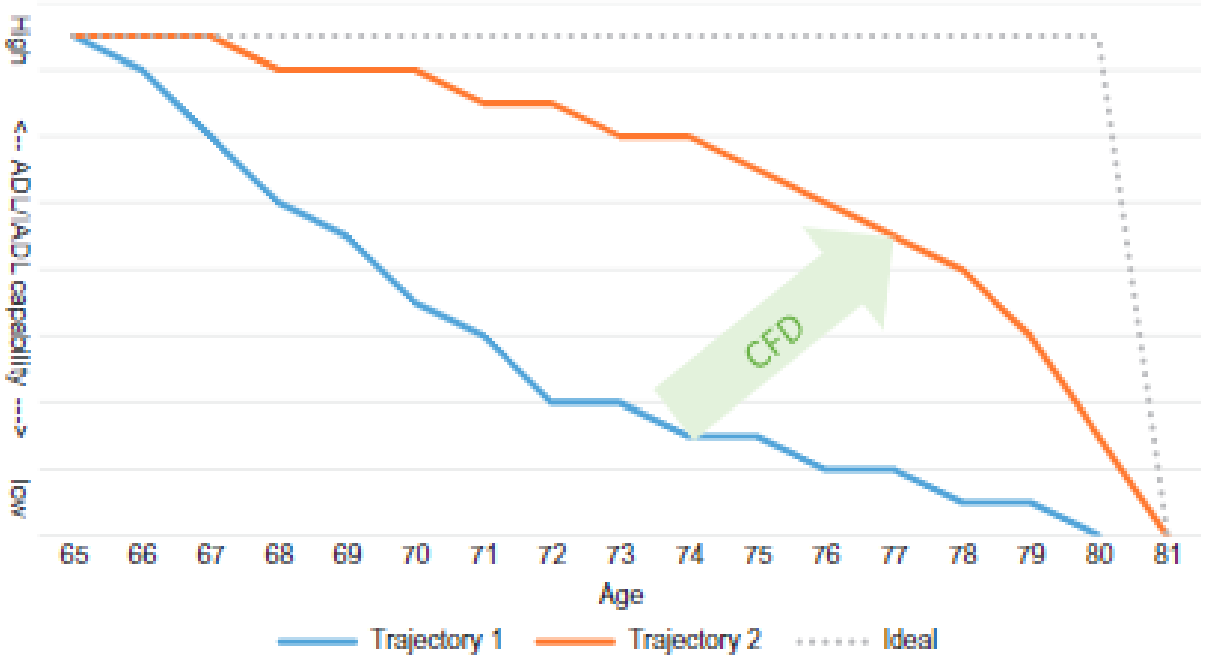
Objectives: The main objective of this study is to determine the feasibility of recruiting and retaining patients recently diagnosed with thoracic cancer to a trial of short-term integrated rehabilitation; evaluate uptake of theoretically informed components targeting physical function, symptom self-management and participation; estimate sample size requirements for an efficacy trial.
Design: Parallel group randomized controlled feasibility trial.
Setting: Three U.K. hospitals.
Participants: Patients ≤eight weeks of thoracic cancer diagnosis, Eastern Cooperative Oncology Group Performance Status 0–3, any cancer stage and treatment plan.
Interventions: Participants randomly allocated (1:1) to short-term integrated rehabilitation and standard care or standard care alone over 30 days.
Main measures: Primary: participant recruitment and retention, targeting ≥30% of eligible patients enrolling and ≥50% of participants reporting outcomes at 30 days. Secondary: intervention fidelity; missing data and performance of outcome measures for self-efficacy, symptoms, physical activity and health-related quality of life.
Results: Of 159 eligible patients approached, 54 (34%) were recruited. A total of 44 (82%) and 39 (72%) participants reported outcomes at 30 and 60 days, respectively. Intervention fidelity was high. Rehabilitation was delivered across 3 (1–3) sessions over 32 (22–45) days (median (range)). Changes in clinical outcomes were modest but most apparent at 60 days for health-related quality of life: Functional Assessment of Cancer Therapy Lung Cancer score median (interquartile range) change 9.7 (−12.0 to 16.0) rehabilitation versus 2.3 (−15.0 to 14.5) standard care.

[1]King's College London, London, UK
[2]University of Nottingham, Nottingham, UK
[3]Guy's and St Thomas' NHS Foundation Trust, London, UK

Corresponding author:
Joanne Bayly, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, Bessemer Road, London, SE5 9PJ UK.
Email: joanne.bayly@kcl.ac.uk

Palliative rehabilitation aims to:
1. compress functional decline

- Maintain/improve participation in roles and activities
- Minimise deconditioning
- Reduce symptom burden
- Reduce emotional distress
- Minimise social isolation
- Reduce threats to self identity & self worth[1]
- Reduce health economic costs?
- Improve survival[2]?



[Gore 2018]

[1][Granger CL 2016]; [2][Higginson IJ et al 2014]

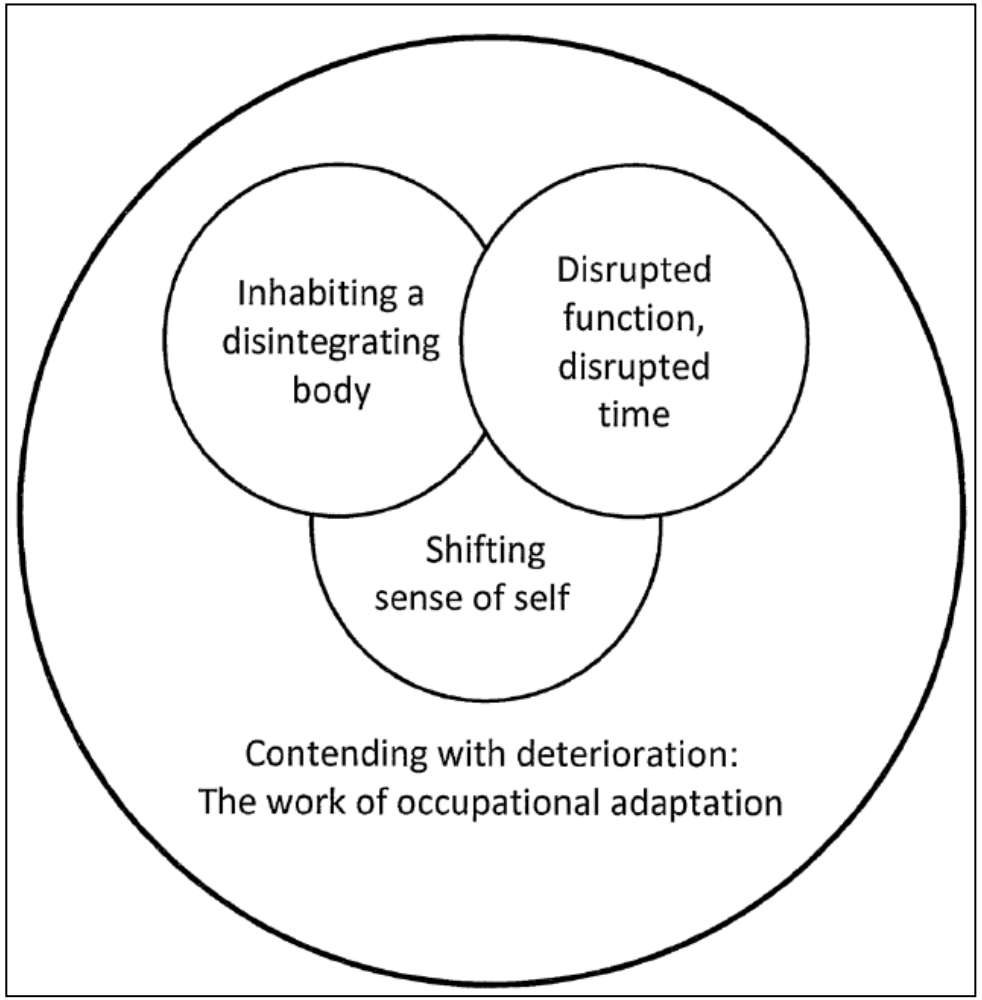
Palliative rehabilitation aims to:
2. support during periods of recovery AND decline

KING'S College LONDON

Living actively in the face of impending death: constantly adjusting to bodily decline at the end-of-life

Deidre D Morgan,[1,2] David C Currow,[3] Linda Denehy,[2] Sanchia A Aranda[2,4]

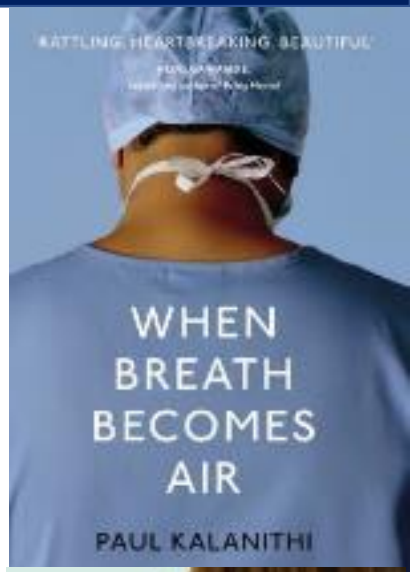
…"we must challenge nihilistic attitudes that view functional decline as inevitable and ignore opportunities to optimise function at the end-of-life"



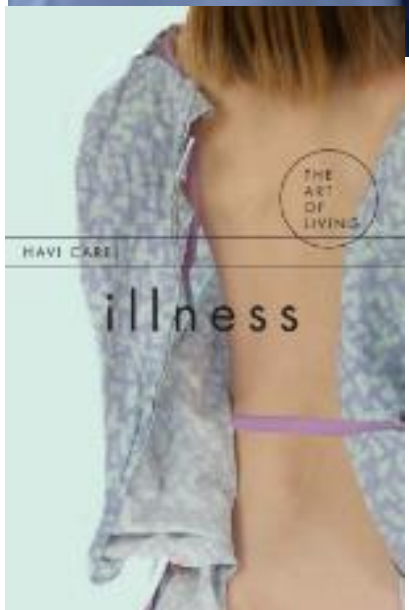
[Morgan 2018 BMC Palliative Care]

Palliative rehabilitation aims to:
3. support people who are living while dying

"Severe illness wasn't life-altering, it was life-shattering… someone had just fire-bombed the path forward"



""No-one asked me how I feel about my illness…when doctors ask 'how are you?' they mean 'How is your body? ... They will not want to know how my life has changed because of my illness, how they could make it easier for me"

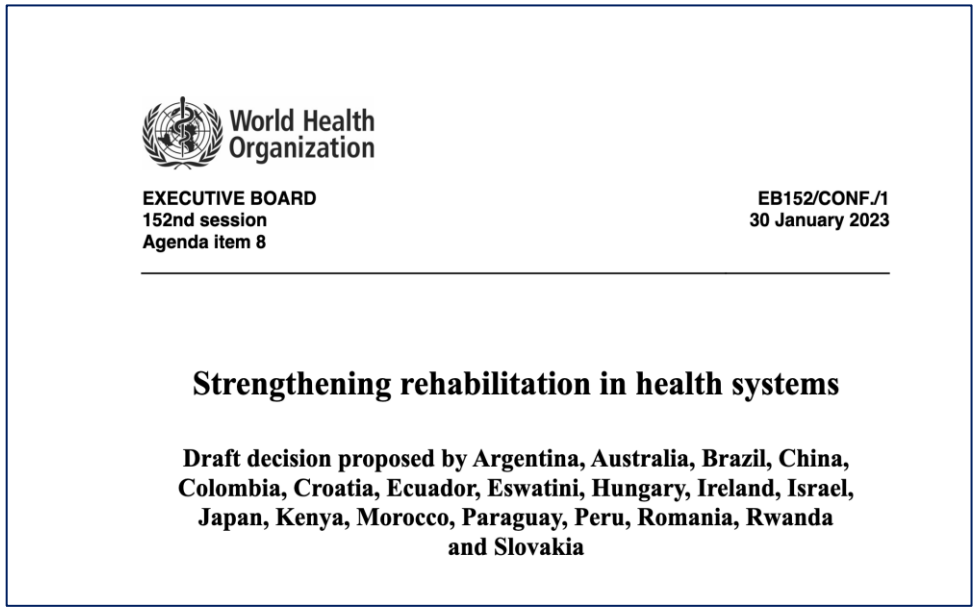


Rehabilitation – an essential service

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

First World Health Assembly resolution on rehabilitation passed May 2023

World Health Organisation Policy on Universal Health Coverage (UHC)
Rehabilitation and palliative care both essential services in quality health systems



World Health Organization

EXECUTIVE BOARD
152nd session
Agenda item 8

EB152/CONF./1
30 January 2023

Strengthening rehabilitation in health systems

Draft decision proposed by Argentina, Australia, Brazil, China, Colombia, Croatia, Ecuador, Eswatini, Hungary, Ireland, Israel, Japan, Kenya, Morocco, Paraguay, Peru, Romania, Rwanda and Slovakia

- Both should be **integrated** within **primary, secondary, and tertiary health systems** using a **multi-professional workforce**

https://apps.who.int/gb/ebwha/pdf_files/EB152/B152_CONF1-en.pdf

Rehabilitation – a definition


Point of View/Directions for Research

Rehabilitation Definition for Research Purposes. A Global Stakeholders' Initiative by Cochrane Rehabilitation

Neurorehabilitation and Neural Repair 2022, Vol. 36(7) 405–414
© The Author(s) 2022
Article reuse guidelines: sagepub.com/journals-permissions
DOI: 10.1177/15459683221093587
journals.sagepub.com/home/nnr
SAGE

Stefano Negrini, MD[1,2], Melissa Selb, MSc[3,4], Carlotte Kiekens, MD[5], Alex Todhunter-Brown, PhD, BSc[6], Chiara Arienti, MSc, PhD, DO[7], Gerold Stucki, MD, MS[3,4,8], Thorsten Meyer, PhD[9], and 3rd Cochrane Rehabilitation Methodology Meeting participants[†]

"In a health care context," rehabilitation is defined as a **"multimodal, person-centered, collaborative process" (Intervention-general),** including interventions **targeting a person's "capacity** (by addressing body structures, functions, and activities/participation) **and/or contextual factors related to performance**" **(Intervention-specific)** with **the goal of "optimizing" the "functioning" (Outcome)** of **"persons with health conditions currently experiencing disability or likely to experience disability, or persons with disability" (Population).**

Rehabilitation requires that all the items of the definition are satisfied.

Integrating rehabilitation into palliative care

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

UHC brings rehabilitation and palliative care together as core components in the care continuum[1,2]

Rehabilitation and palliative care services traditionally organise around differing but complementary goals for care[3]:

- **Optimising functioning**
- **Minimising suffering**

Burden of disease is related to time lived with disability not just premature death

[1][WHO, 2017]; [2][WHO 2014][3][Timm 2017, Wellcome Open Res]

INSPIRE consortium

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

- Cicely Saunders Institute, King's College London
- University of Edinburgh
- European Association of Palliative Care
- Hospices Civils de Lyon
- Lyon Ingénierie Projets
- Istituto Nazionale dei Tumori|Fondazione IRCCS
- AUSL Reggio Emilia
- University of Southern Denmark
- University of Bergen
- European Cancer Patient Coalition
- Region of Southern Denmark
- Charles University Prague

INSPIRE objectives and ambition

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

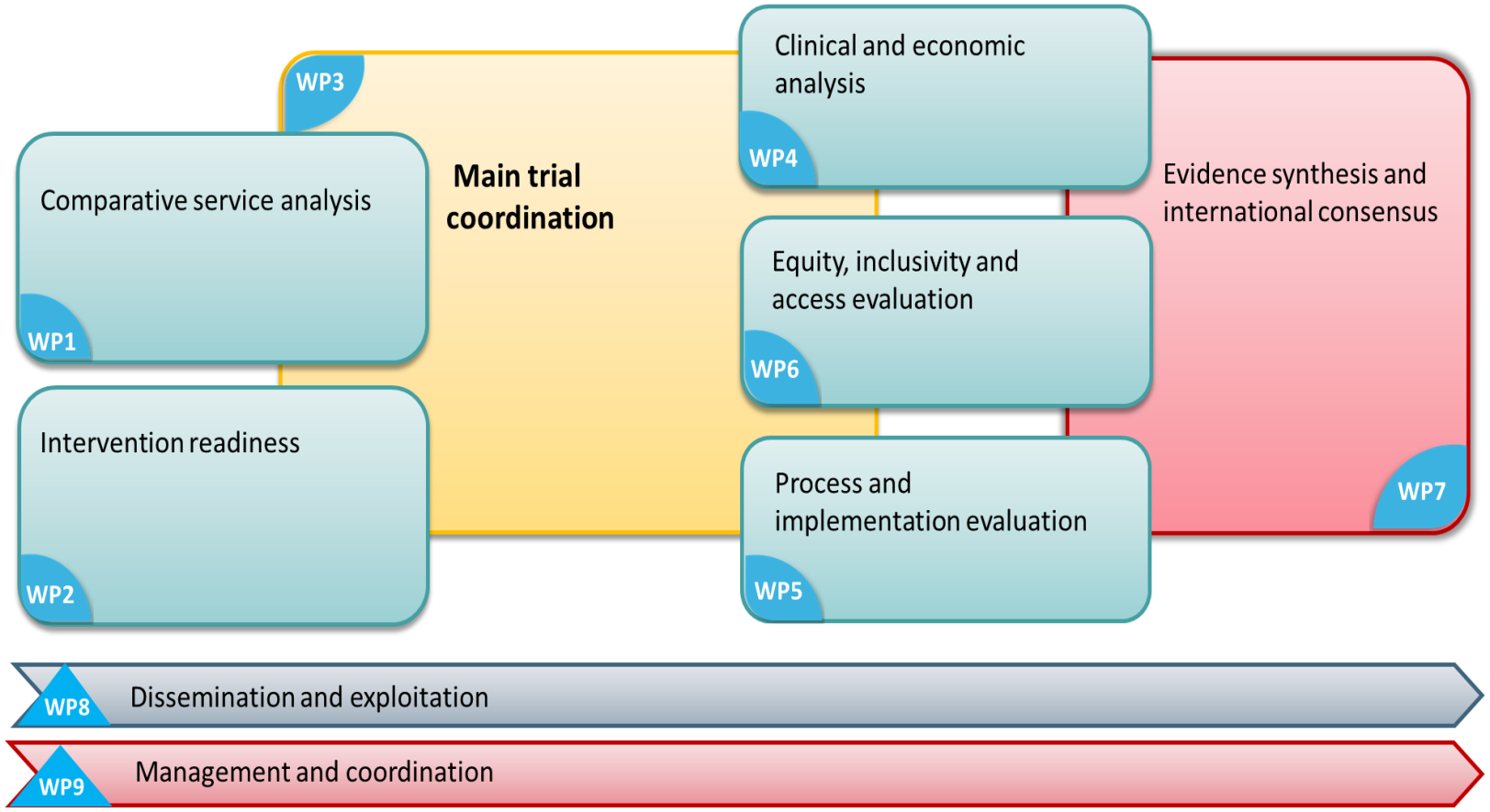
- **Test the clinical and cost effectiveness** of integrated short-term palliative rehabilitation intervention for people with incurable cancer
- Evaluate if person-centred, tailored and equitable rehabilitation intervention **reduces symptom burden and disability, increases social participation**, leading to **better quality of life**
- Test if the intervention will **reduce the burden of care** for families
- Identify an effective model of rehabilitation that can be **delivered as part of routine care** for people with incurable cancer

INSPIRE Methodology

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

Incorporates:

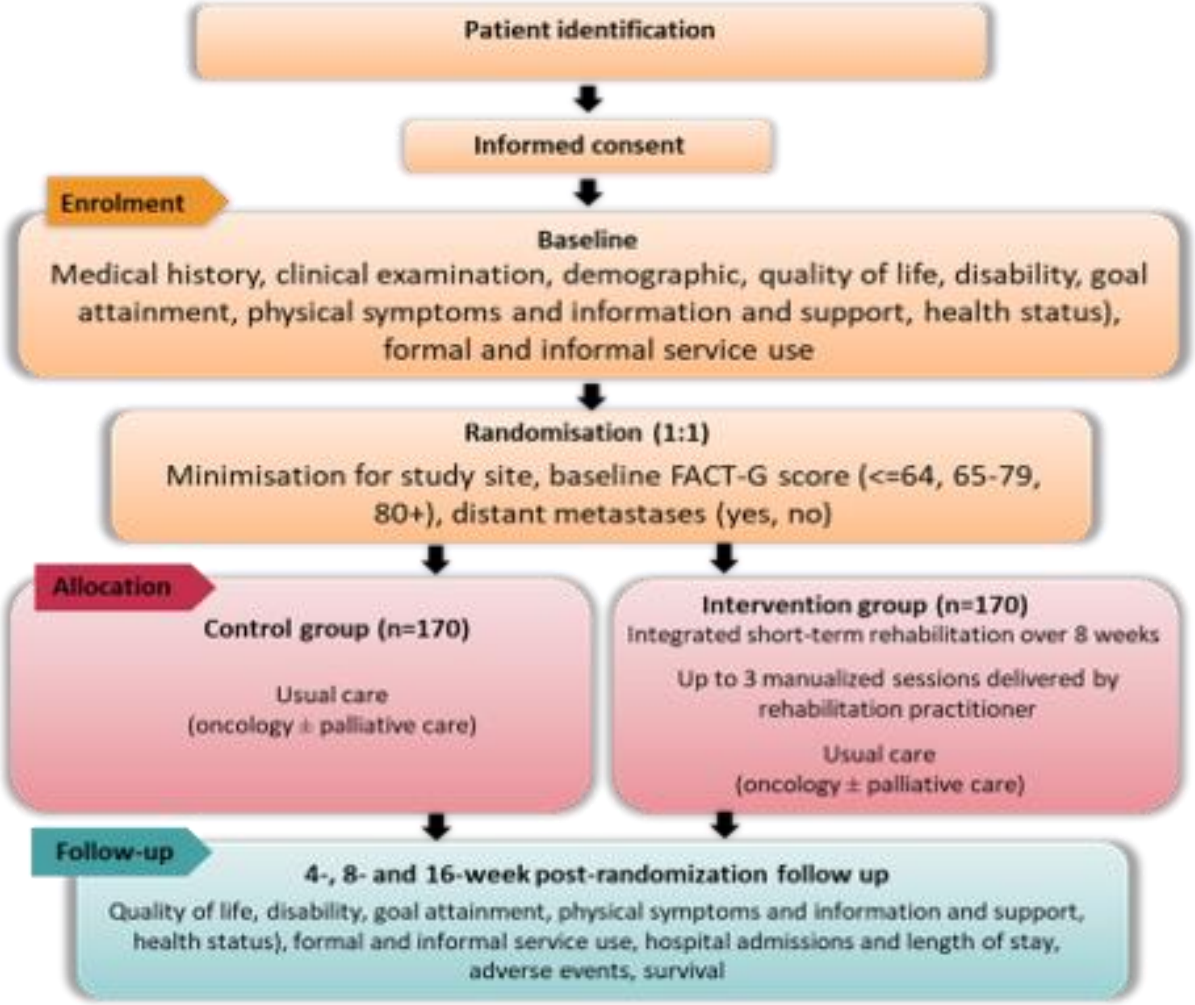
- Comparative analysis of health services
- Randomised controlled trial
- Evaluations of equity and inclusivity, processes and implementation
- Evidence synthesis and Delphi consensus study



INSPIRE Randomised Controlled Trial

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

- Multinational, multisite, randomised, assessor-blind, controlled trial
- Six European countries (France, Denmark, Norway, Italy, UK, Czech) 10-12 sites
- Broad eligibility criteria
- Usual care ± palliative rehabilitation over 8 weeks
- Primary endpoint quality of life (FACT-G) at 8 weeks



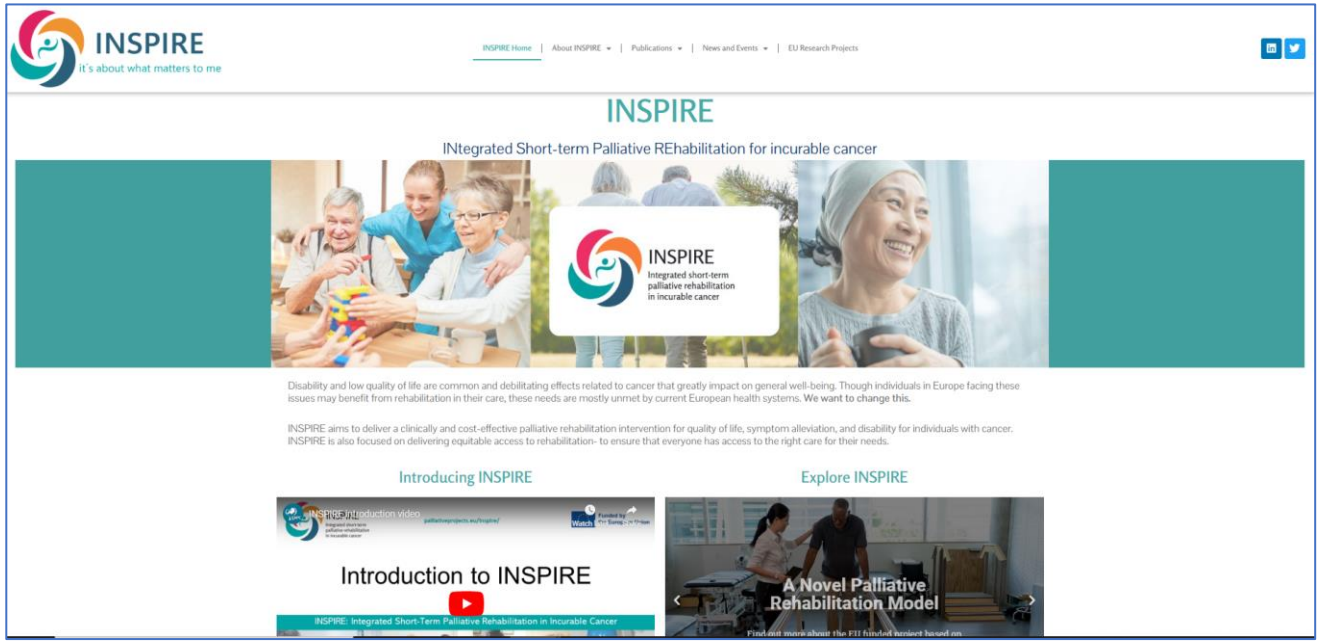
Where to find out more?

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

Integrated Short-term Palliative Rehabilitation to improve quality of life and equitable care access in incurable cancer (INSPIRE): a multinational European research project

Palliative Care & Social Practice
2023, Vol. 17: 1–14
DOI: 10.1177/26323524231179979

Joanne Bayly, Hilde Hjelmeland Ahmedzai, Maria Grazia Blandini, Barbara Bressi, Augusto Tommaso Caraceni, Joana Carvalho Vasconcelos, Stefania Costi, Stefania Fugazzaro, Monica Guberti, Mai-Britt Guldin, May Hauken, Irene Higginson, Barry J.A. Laird, Julie Ling, Charles Normand, Lise Nottelmann, Line Oldervoll, Cathy Payne, A. Toby Prevost, Guro B. Stene, Elisa Vanzulli, Eduardo Veber, Guillaume Economos and Matthew Maddocks; on behalf of the INSPIRE consortium



[INSPIRE - Integrated short-term palliative rehabilitation (palliativeprojects.eu)]

Any questions?

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

Comparative analysis of health services

INSPIRE
Integrated short-term palliative rehabilitation in incurable cancer

- 23 documents: palliative rehabilitation concept described in half (Italy > Denmark, Norway > UK, France) though care delivered in parallel or separate pathways.
- 225 survey respondents:
  - 54% replied that rehabilitation was a component of the cancer pathway
  - 56% shared records in hospital (12% between care settings)
  - 67% had joint educational activities
  - 44% routinely screened for rehabilitation needs
- 22 interviews stakeholders:
  - common understanding of the main concept but unclarity about the distinction with palliative care.
  - access described as a postcode-lottery with lack of priority, funding, pathways and education.