

Actual Projects in Palliative Care and Pulmonology

Ivan Guerreiro MD
Division of Pulmonology

Lisa Hentsch MD MSc
Division of Palliative Medicine



Original articles

How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)?
A comparison of palliative care and quality of life
in COPD and lung cancer

J M Gore, C J Brophy, M A Greenstone

American Thoracic Society Documents

An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses

Paul N. Lanken, Peter B. Terry, Horace M. DeLisser, Bonnie F. Fahy, John Hansen-Flaschen, John E. Heffner, Mitchell Levy, Richard A. Mularski, Molly L. Osborne, Thomas J. Prendergast, Graeme Rocker, William J. Sibbald[†], Benjamin Wilfond, and James R. Yankaskas, on behalf of the ATS End-of-Life Care Task Force

THIS OFFICIAL STATEMENT OF THE AMERICAN THORACIC SOCIETY (ATS) WAS ADOPTED BY THE ATS BOARD OF DIRECTORS, MARCH 2007

American Thoracic Society Documents

An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses

Paul N. Lanken, Peter B. Terry, Horace M. DeLisser Mitchell Levy, Richard A. Mularski, Molly L. Osborn Benjamin Wilfond, and James R. Yankaskas, on behalf of the American Thoracic Society



EDITORIAL
COPD

THIS OFFICIAL STATEMENT OF THE AMERICAN THORACIC SOCIETY
MARCH 2007



CrossMark

Palliative care for people with COPD: effective but underused

David M.G. Halpin

Affiliation: Dept of Respiratory Medicine, Royal Devon and Exeter Hospital, Exeter, UK.

Correspondence: David M.G. Halpin, Dept of Respiratory Medicine, Royal Devon and Exeter Hospital, Barrack Road, Exeter, EX2 5DW, UK. E-mail: d.halpin@nhs.net



@ERSpublications


Despite its effectiveness palliative care is underused in the majority of patients with COPD
<http://ow.ly/d0YH30hPKeu>

Cite this article as: Halpin DMG. Palliative care for people with COPD: effective but underused. *Eur Respir J* 2018; 51: 1702645 [https://doi.org/10.1183/13993003.02645-2017].



EUROPEAN RESPIRATORY JOURNAL
ERS OFFICIAL DOCUMENTS
D.J.A. JANSSEN ET AL.

European Respiratory Society clinical practice guideline: palliative care for people with COPD or interstitial lung disease

Daisy J.A. Janssen ^{1,2}, Sabrina Bajwah ³, Michele Hilton Boon⁴, Courtney Coleman⁵, David C. Currow⁶, Albert Devillers⁷, Chantal Vandendungen⁷, Magnus Ekström ⁸, Ron Flewett⁹, Sarah Greenley¹⁰, Mai-Britt Guldin¹¹, Cristina Jácome ¹², Miriam J. Johnson¹³, Geana Paula Kurita^{14,15}, Matthew Maddocks³, Alda Marques¹⁶, Hilary Pinnock ¹⁷, Steffen T. Simon¹⁸, Thomy Tonia¹⁹ and Kristoffer Marsaa ²⁰



Hôpitaux
Universitaires
Genève



Hôpitaux
Universitaires
Genève



Palliative Care Provision for Patients with Advanced Chronic Obstructive Pulmonary Disease: A Systematic Integrative Literature Review

Tanja Fusi-Schmidhauser^a, Alessia Riglietti^b, Katherine Froggatt^c, and Nancy Preston^c

^aPalliative and Supportive Care Clinic, Oncology Institute of Southern Switzerland and Ente Ospedaliero Cantonale, Lugano, Switzerland;

^bRespiratory Care Department, Ospedale Regionale di Lugano, Ente Ospedaliero Cantonale, Lugano, Switzerland; ^cInternational Observatory on End of Life Care, Faculty of Health and Medicine, Lancaster University, Lancaster, UK

COPD: JOURNAL OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE
2020, VOL. 17, NO. 4, 410–418
<https://doi.org/10.1080/15412555.2020.1782867>



Living with Advanced Chronic Obstructive Pulmonary Disease: A Qualitative Interview Study with Patients and Informal Carers

Tanja Fusi-Schmidhauser^{a,b}, Katherine Froggatt^c, and Nancy Preston^c

^aPalliative and Supportive Care Clinic, Institute of Oncology of Southern Switzerland and Ente Ospedaliero Cantonale, Lugano, Switzerland;

^bInternal Medicine Department, Ospedale Regionale di Lugano, Ente Ospedaliero Cantonale, Lugano, Switzerland; ^cInternational Observatory on End of Life Care, Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster, UK



Impact Factor: **3.6** / 5-Year Impact Factor: **4.4**




[Journal Homepage](#)

[Submission Guidelines](#)



Restricted access | Research article | First published online October 26, 2021

Palliative care integration for patients with advanced chronic obstructive pulmonary disease (COPD): Identifying essential components using participatory action research

[Tanja Fusi-Schmidhauser](#)  , [Katherine Froggatt](#), and [Nancy Preston](#)  [View all authors and affiliations](#)

[Volume 35, Issue 10](#) | <https://doi.org/10.1177/02692163211028972>

Fusi-Schmidhauser et al. *COPD* 2018

Fusi-Schmidhauser et al. *COPD* 2020

Fusi-Schmidhauser et al. *Palliative Medicine* 2021

Palliative care for patients with severe chronic lung disease – a Swiss position paper

Sabina Anna Guler, Tanja Fusi-Schmidhauser, Filipa-Alexandra Baptista Peixoto Befecadu, Markus Hofer, Garance Kopp, Andreas Ebnetter, Steffen Eychmüller, Katrin Esther Hostettler.

In press (Respiration)

- Recommendations pratiques completes et utiles
- En collaboration avec Palliative.ch



Volume 97, Issue 5

May 2019



RESEARCH ARTICLES | JANUARY 16 2019

Can Early Introduction of Palliative Care Limit Intensive Care, Emergency and Hospital Admissions in Patients with Severe Chronic Obstructive Pulmonary Disease? A Pilot Randomized Study

Subject Area: Pharmacology, Pneumology.

[Jean-Paul Janssens](#) ; [Catherine Weber](#); [François R. Herrmann](#); [Chloé Cantero](#); [Aline Pessina](#); [Caroline Matis](#); [Roselyne Merlet Viollet](#); [Ludivine Boiche-Brouillard](#); [Jerôme Stirnemann](#); [Sophie Pautex](#)

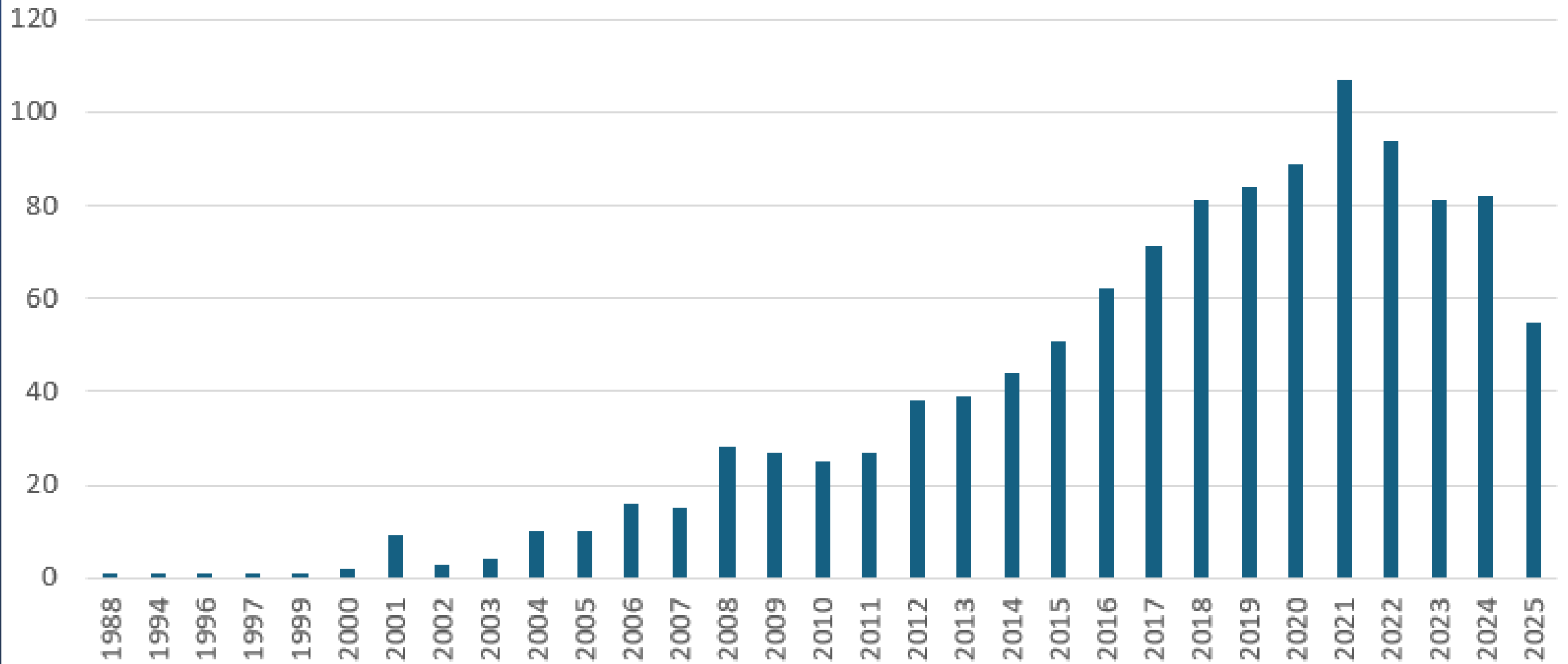
RESEARCH ARTICLE

Recollection of participating in a trial: A qualitative study of patients with severe and very severe chronic obstructive pulmonary disease

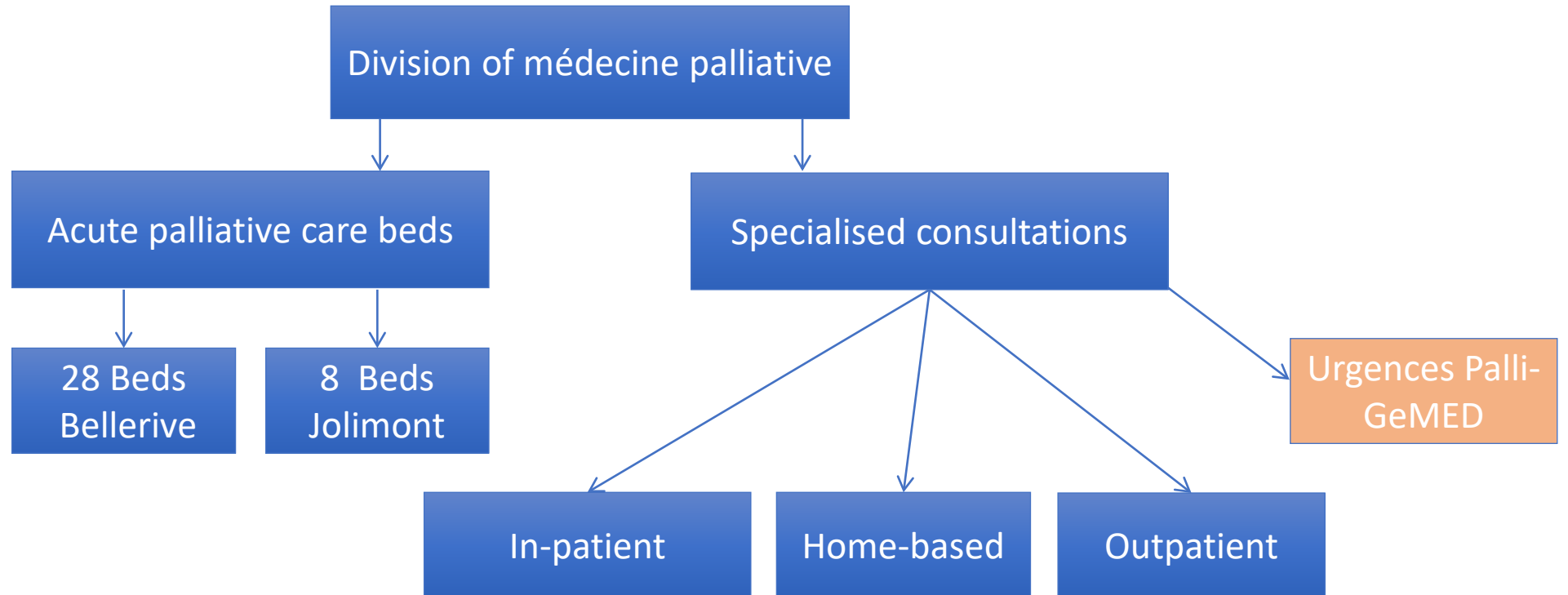
Claudia Véron ¹ ² ³ ⁴ ^{*}, Sophie Pautex ¹ ^e, Catherine Weber ¹ ^e, Jean-Paul Janssens ² ^e, Christine Cedraschi ^{3,4} ^{*}

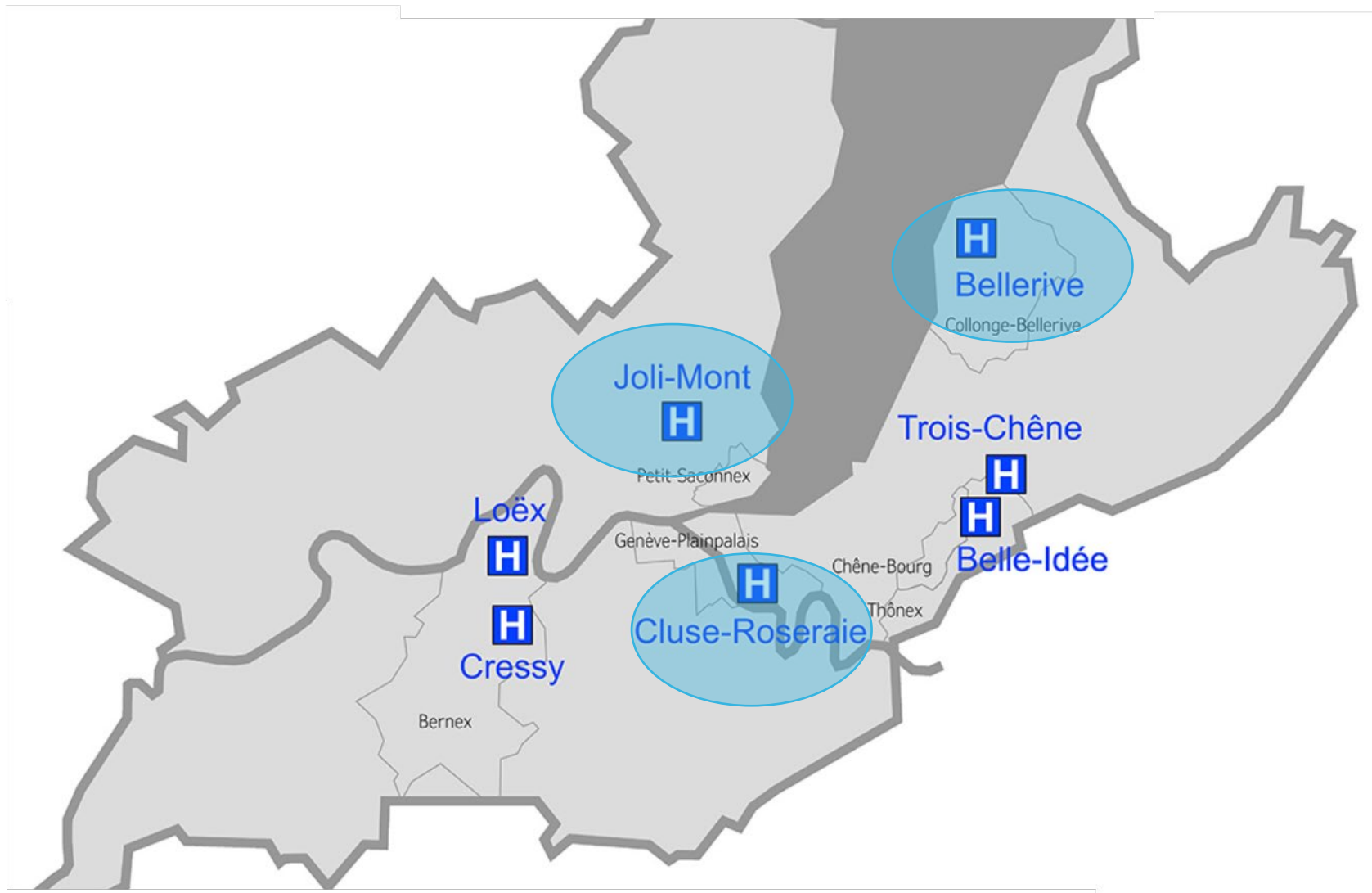
Véron et al. *Plos One* 2018
Janssens et al. *Respiration* 2019

Publications since 1988 evaluating palliative care in respiratory diseases



Division of Palliative Medicine





Collaboration palliative care- pulmonology



Dre Lisa Hentsch
Médecin adjointe service de
médecine palliative
Responsable de la COSPA AMB



Dr Ivan Guerreiro
Médecin adjoint service de
pneumologie



Pre Sophie Pautex
Cheffe du service de médecine
palliative



Pre Anne Bergeron
Cheffe du service de pneumologie

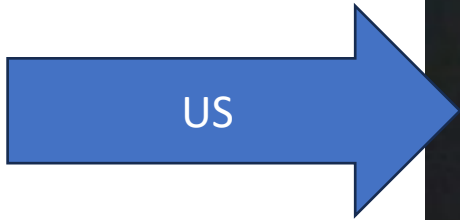


Dr Grégory Berra
Médecin adjoint service
pneumologie



Dre Aileen Kharat
Médecin adjointe service de
pneumologie





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Universitaires
Genève



LIGUE **PULMONAIRE** GENEVOISE

Study n°1

THERAPEUTIC ADVANCES in
Respiratory Disease

Original Research

Healthcare professionals' representation toward optimal palliative care provision for COPD patients: a cross-sectional survey

Filipa Alexandra Baptista Peixoto Befecadu , Paola Gasche, Dan Adler, Ivan Guerreiro , Sophie Pautex  and Lisa Hentsch 

Ther Adv Respir Dis

2025, Vol. 19: 1–13

DOI: 10.1177/
17534666251341748

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- Questionnaire
- Pneumologists, nurses, assistant nurses, physiotherapists
- Inpatient and outpatient setting



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Baptista Peixoto Befecadu et al. *Ther Adv Respir Dis* 2025

Healthcare professionals' representation toward optimal palliative care provision for COPD patients: a cross-sectional survey

Filipa Alexandra Baptista Peixoto Befecadu , Paola Gasche, Dan Adler, Ivan Guerreiro , Sophie Pautex  and Lisa Hentsch 

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Table 2. Participants' perceptions of the benefits of palliative care.

In your opinion, palliative care can help:	N = 56	Percent
Alleviate physical, psychological, and spiritual symptoms	53	94.6
Improve quality of life and have a positive influence on the trajectory of the disease	42	75
Initiate discussions on the advance care plan	31	55.4
Provide support to caregivers (respite/education)	31	55.4
Managing the end-of-life phase	26	46.4
Discuss prognosis	9	16.1
Improve patients' understanding of the disease	9	16.1

Table 4. Referral practices for COPD patients to specialized palliative care services.

When do you refer COPD patients to specialized palliative care (outpatient/hospital/home)? N = 44	When do you refer COPD patients to specialized palliative care (outpatient/hospital/home)? N = 44				
	Never	Rarely (<25%)	Often (25%–50%)	Most of the time (50%–75%)	Almost always (>75%)
At the time of diagnosis	29 (65.9%)	14 (31.8%)	1 (2.3%)	0 (0%)	0 (0%)
After the first acute exacerbation	25 (56.8%)	17 (38.6%)	2 (4.5%)	0 (0%)	0 (0%)
After several acute exacerbations	13 (29.5%)	9 (20.5%)	10 (22.7%)	10 (22.7%)	2 (4.5%)
At the end-of-life	7 (15.9%)	2 (4.5%)	7 (15.9%)	12 (27.3%)	16 (36.4%)
Other	33 (75%)	2 (4.6%)	4 (9.1%)	2 (4.5%)	3 (6.8%)

COPD, Chronic obstructive pulmonary disease.

Healthcare professionals' representation toward optimal palliative care provision for COPD patients: a cross-sectional survey

Filipa Alexandra Baptista Peixoto Befecadu , Paola Gasche, Dan Adler, Ivan Guerreiro , Sophie Pautex  and Lisa Hentsch 

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Timing ?

No
network
knowledge

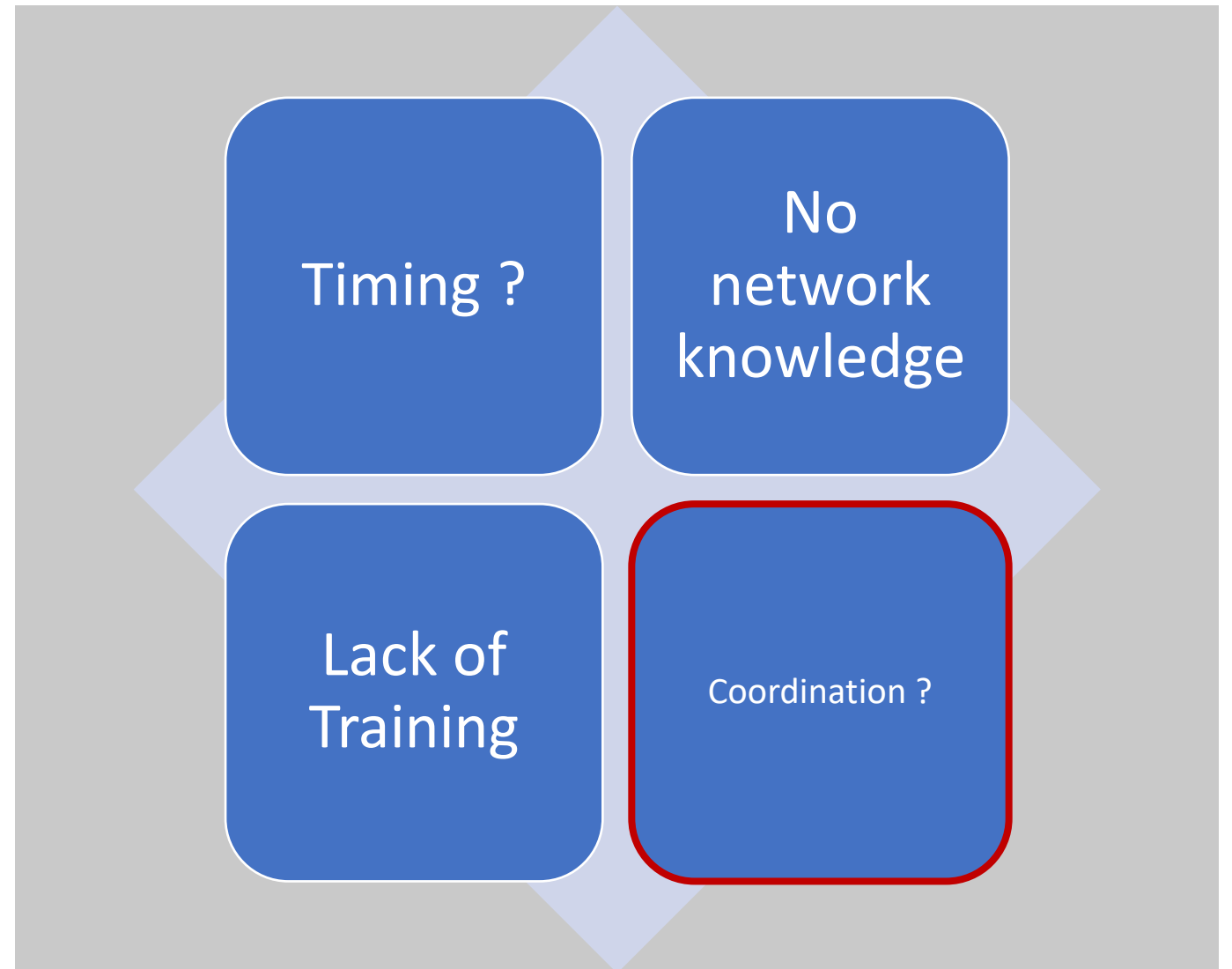
Lack of
Training

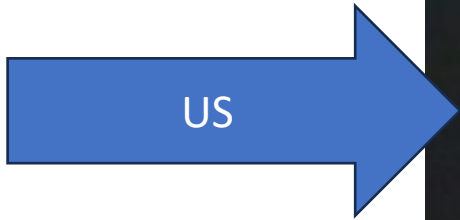
Coordination ?

Healthcare professionals' representation toward optimal palliative care provision for COPD patients: a cross-sectional survey

Filipa Alexandra Baptista Peixoto Befecadu , Paola Gasche, Dan Adler, Ivan Guerreiro , Sophie Pautex  and Lisa Hentsch 

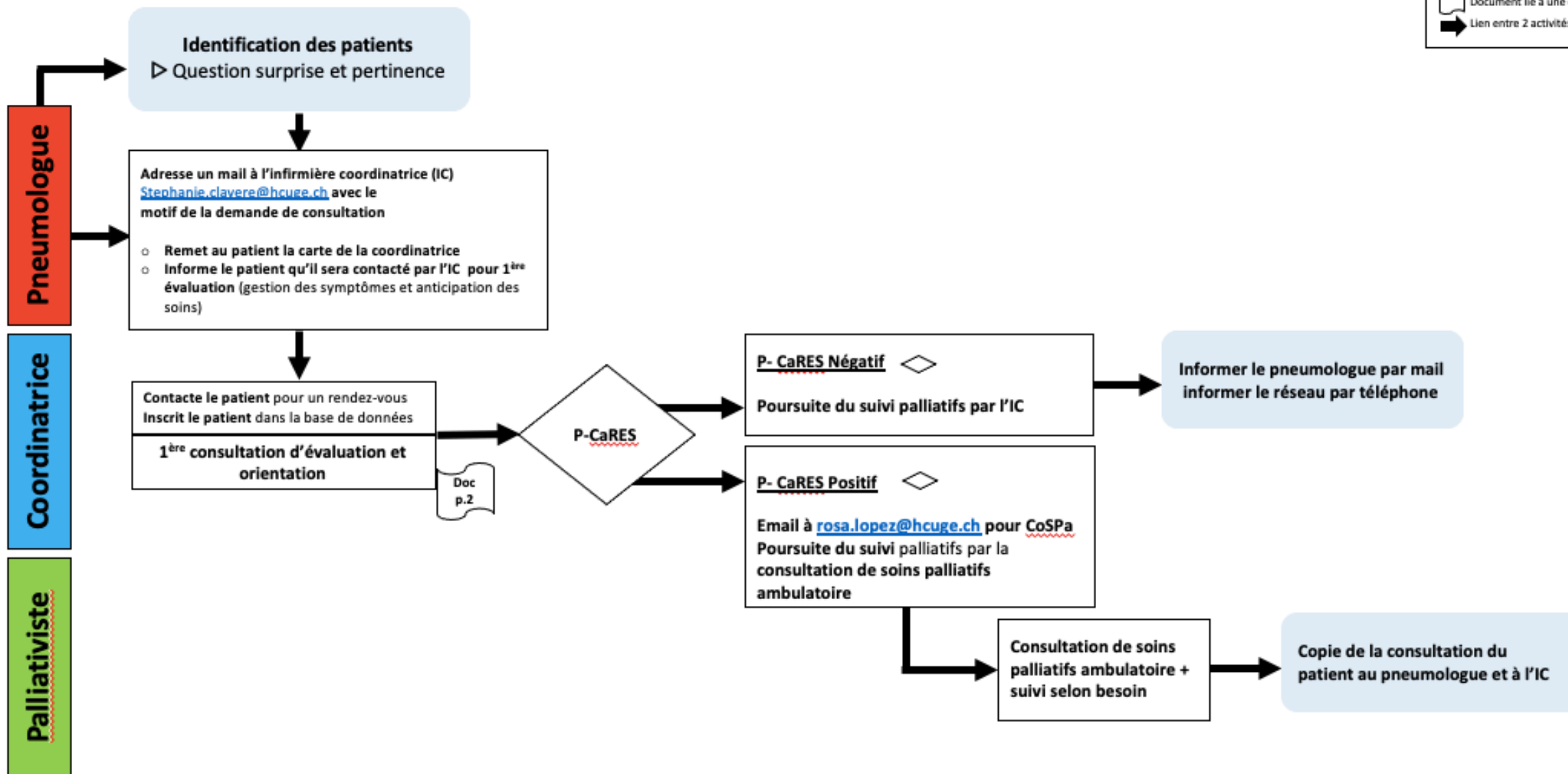
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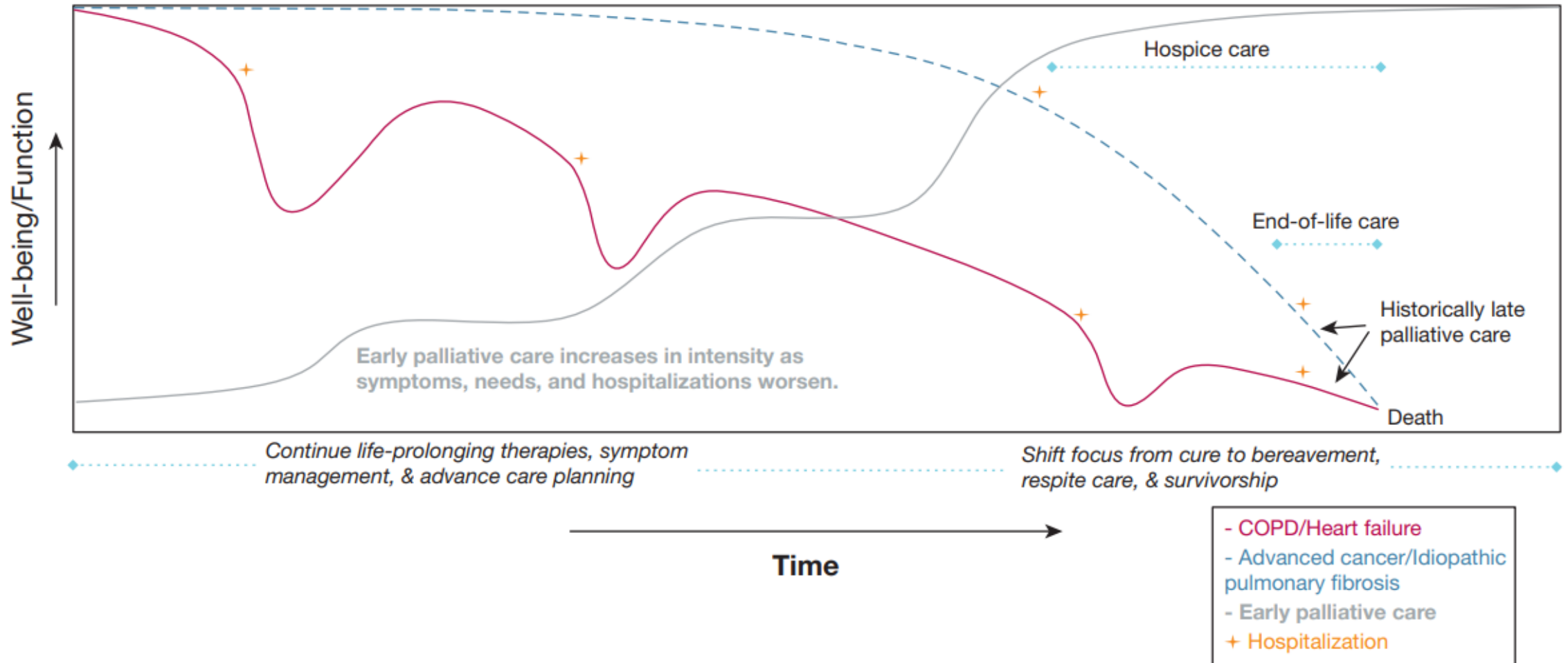
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Parcours du patient pneumo-soins palliatifs ambulatoire





Early Palliative Care and Trajectories of Decline in Serious Illness



Collaboration

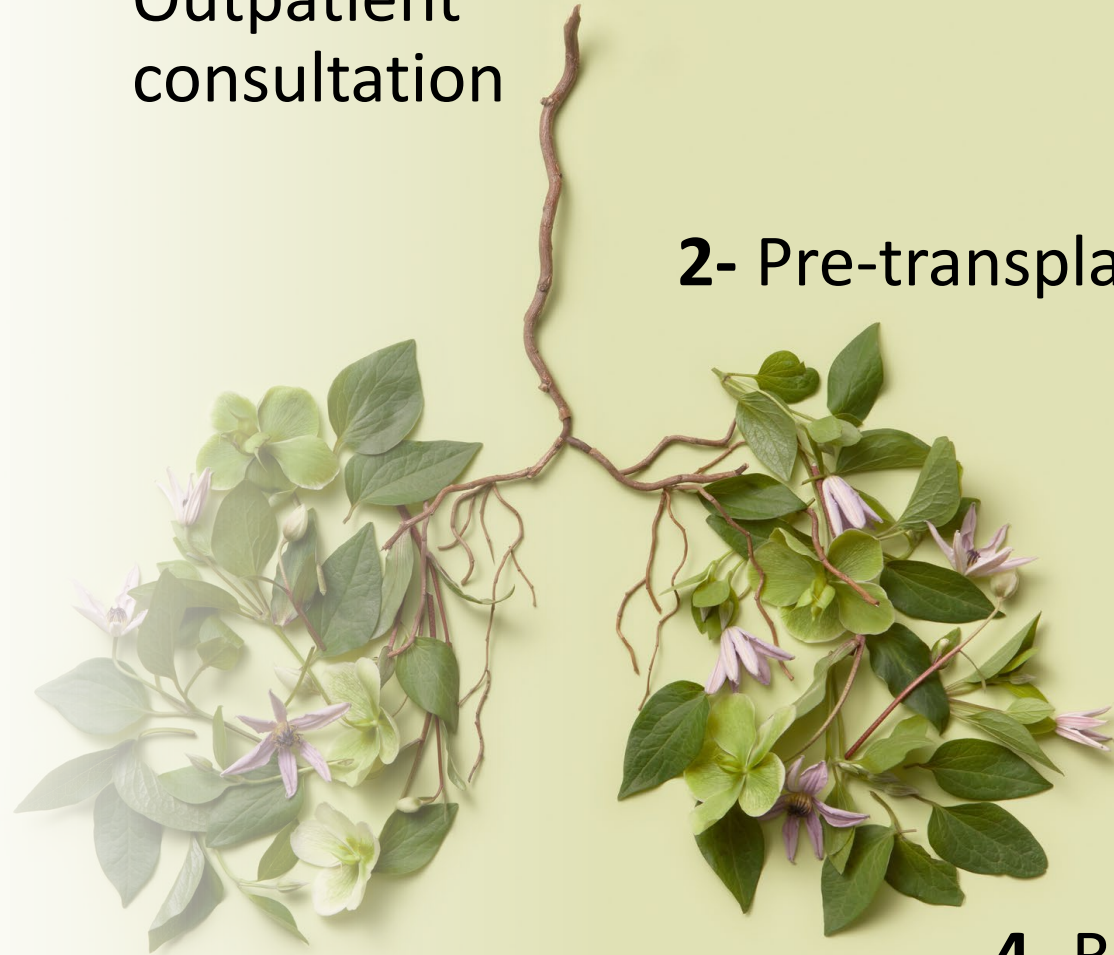
◆ 4 axes

1-
Outpatient
consultation

2- Pre-transplant workup

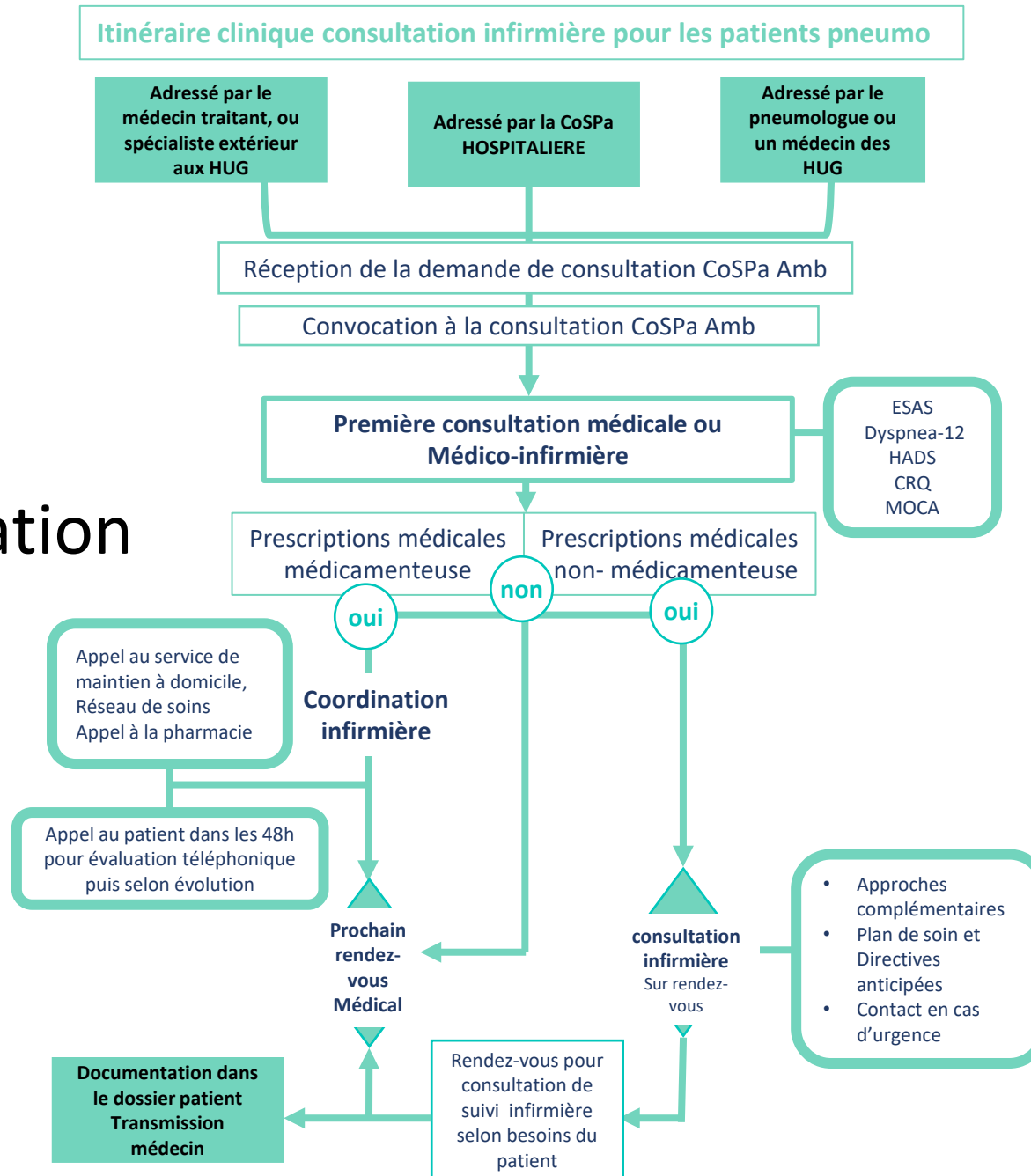
3- Pulmonary
rehabilitation

4- Research

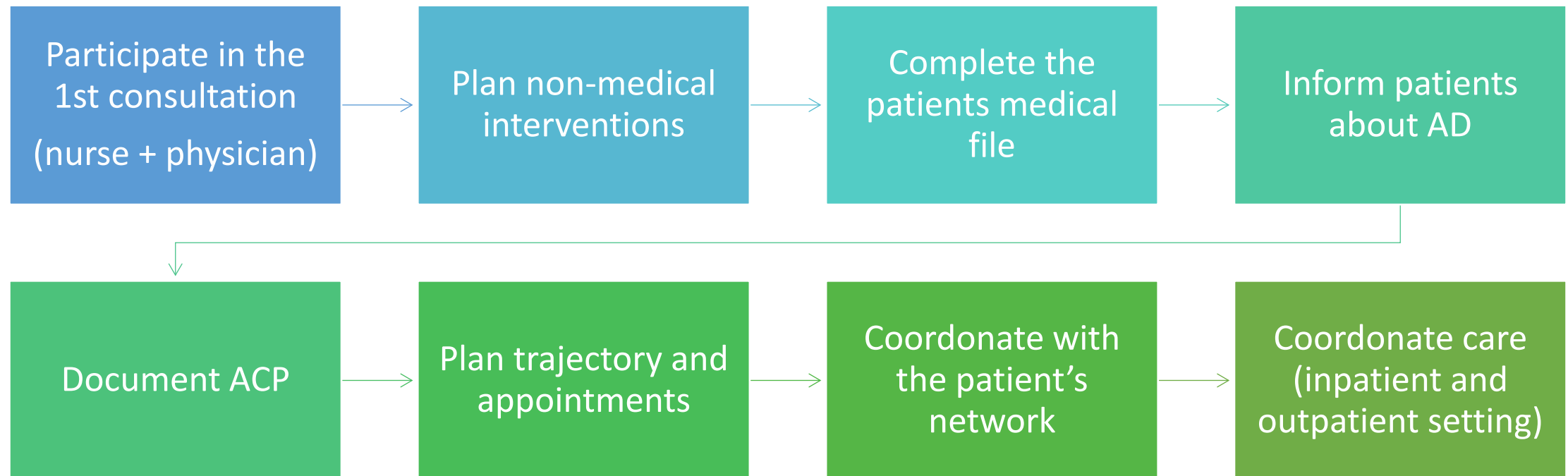


1. Nurse-led consultation

Adapted from Caroline Matis



Palliative care and pneumology nurse coordinator



1. Nurse-led consultation

2024 Summary

	N= 22
Age (years)	68 (45-88)
Sex	
Men	12 (55 %)
Women	10 (45 %)
Diagnosis	
COPD	13 (59 %)
ILD	8 (36 %)
Other	1 (5%)
Main symptoms at baseline	
Dyspnea	10 (45 %)
Anxiety	5 (23 %)
Drowsiness	2 (9 %)
Depression	1 (5%)
Fatigue	1 (5%)
Nausea	1 (5%)
Not documented	2 (9 %)
Interprofessional palliative care consultation <i>(physician and nurse)</i>	17
Nurse-led consultations	36
Visits per patient (mean)	4 (1-9)
Non-pharmacological interventions	
Reflexology	4
Clinical hypnosis	11
Light-touch massage	6
Completed an advance care plan	9 (41%)
Already had advanced directives	3 (14%)
Completed advanced directives	8 (36%)

Table 1. Consultation data for the year 2024

Data are absolute numbers or mean (range) unless otherwise stated.
COPD= Chronic Obstructive Pulmonary Disease. ILD= interstitial lung disease.

1. Nurse-led consultation

2024 Summary

93% alive at the end of the year!

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COPD= Chronic Obstructive Pulmonary Disease. ILD= interstitial lung disease.

2. Pre-transplantation



2. Pre-transplantation

14 patients seen
0 refusal

Consultations (* uniquement pour les patients CF)

- Nutrition (Dre Laurence Genton)
- Métabolisme phospho-calcique (Dr Ivan Padlina)
- Psychiatrie (Dr. Galani Vasiliki)
- Dermatologie (Dr Emmanuel LAFFITTE)
- Maladies infectieuses (Pr VAN DELDEN/Dr NEOFYTOS)
- Médecine dentaire
- Gynécologie (pour les femmes)
- O.R.L (Pr Basile LANDIS)
- Gastroenterologie*
- Diabetologie*
- Orthopédie septique (seulement si ATCD bursite, arthrite et ostéite)
- Consultation de vaccinologie + consultation médecine tropicale et rappels vaccinal selon proposition (Attention le patient doit être convoqué avec son carnet de vaccination si disponible)
- Consultation soins palliatifs (Lisa Hentsch)

3. Round Tables Pulmonary Rehabilitation

Anticipation and palliative care



4. Research



HUG Palliative care and pneumology publications

- Baptista Peixoto Befecadu FA, Gasche P, Adler D, **Guerreiro I**, Pautex S, **Hentsch L**. Healthcare professionals' representation toward optimal palliative care provision for COPD patients: a cross-sectional survey. *Ther Adv Respir Dis*. 2025;19:17534666251341748.
- **Guerreiro I**, Pautex SM, Bergeron A, Baptista Peixoto Befecadu F, **Hentsch L**. Soins palliatifs précoces dans les maladies respiratoires chroniques. October 2023 [Revue internationale de soins palliatifs](#) Vol. 38(2):76-89 DOI: [10.3917/inka.242.0076](#)
- **Guerreiro I**, Pautex S, Bergeron A, Baptista Peixoto Befecadu F, **Hentsch L**. [Early palliative care for the management of breathlessness in pulmonary diseases]. *Rev Med Suisse*. 2023 Dec 20;19(855):2390-2394.
- Baptista Peixoto Befecadu F, Stirnemann J, **Guerreiro I**, Fusi-Schmidhauser T, Jaksic C, Larkin PJ, da Rocha Rodrigues G, Pautex S. PANDORA dyadic project: hope, spiritual well-being and quality of life of dyads of patients with chronic obstructive pulmonary disease in Switzerland - a multicentre longitudinal mixed-methods protocol study. *BMJ Open*. 2023 May 12;13(5):e068340. doi: 10.1136/bmjopen-2022-068340. Erratum in: *BMJ Open*. 2024 Jun 19;14(6):e068340corr1. doi: 10.1136/bmjopen-2022-068340corr1. PMID: 37173103; PMCID: PMC10186441.
- **Hentsch L**, Carballo S, Janssens JP, Ossmann L, Pautex S. [A palliative care approach of patients with chronic obstructive pulmonary disease]. *Rev Med Suisse*. 2017 Oct 18;13(579):1792–6.

Palliative care-pulmonology - Ongoing project

Recruiting ⓘ

Integrating Palliative Care Education in Pulmonary Rehabilitation

ClinicalTrials.gov ID ⓘ NCT06046547

Sponsor ⓘ Aveiro University

Information provided by ⓘ Alda Sofia Pires de Dias Marques, Aveiro University (Responsible Party)

Last Update Posted ⓘ 2024-01-30

Recruiting ⓘ

Telepalliation - Digital Platform for Patients in Palliation and Their Relatives

ClinicalTrials.gov ID ⓘ NCT04995848

Sponsor ⓘ Aalborg University

Information provided by ⓘ Birthe Dinesen, Aalborg University (Responsible Party)

Last Update Posted ⓘ 2023-07-19

Not yet recruiting ⓘ

GRACE - Graduated Response for Advanced COPD With Enhanced Support (GRACE)

ClinicalTrials.gov ID ⓘ NCT06967324

Sponsor ⓘ Copenhagen University Hospital, Hvidovre

Information provided by ⓘ Kirstine Skov Benthien, Copenhagen University Hospital, Hvidovre (Responsible Party)

Last Update Posted ⓘ 2025-05-15

Recruiting ⓘ

"Turkish Validation of the Respiratory Distress Observation Scale in Palliative Care"

ClinicalTrials.gov ID ⓘ NCT06922292

Sponsor ⓘ Istinye University

Information provided by ⓘ Elif Kabasakal, Istinye University (Responsible Party)

Last Update Posted ⓘ 2025-04-16

Not yet recruiting ⓘ

Palliative Care Health Literacy Education and QOL Compared to Usual Care (PACED)

ClinicalTrials.gov ID ⓘ NCT06089499

Sponsor ⓘ University of Missouri, Kansas City

Information provided by ⓘ Kelly Counts, University of Missouri, Kansas City (Responsible Party)

Last Update Posted ⓘ 2023-10-18

HUG Palliative care and pulmonology research

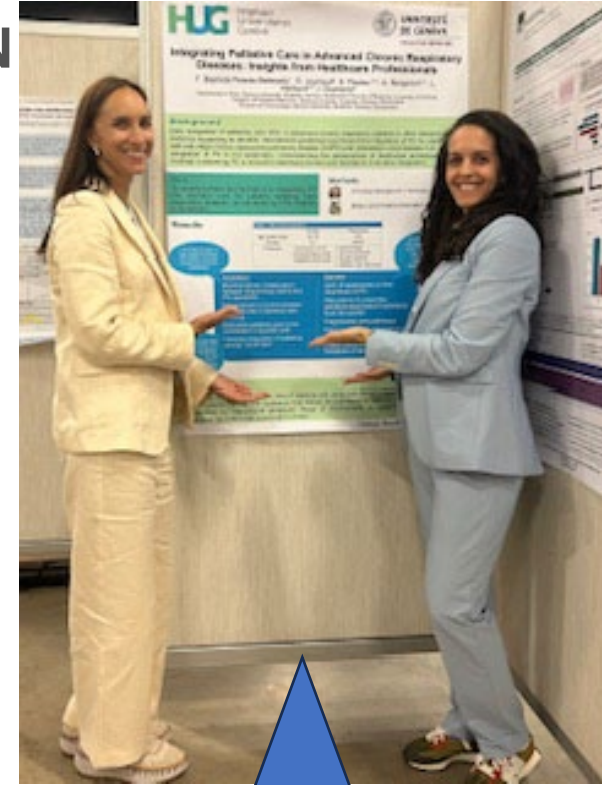
INTEGRA-1 : Barriers and facilitators to the integration of palliative care in standard care for patients with respiratory diseases: perspective of healthcare professionals

INTEGRA-2 : Barriers and facilitators to the integration of palliative care in standard care for patients with respiratory diseases: perspective of patients and carers

HYPNEA : Effectiveness of hypnosis on breathlessness mastery in patients with refractory dyspnea: a randomised controlled trial

BREACH-fMRI : Breathlessness patterns in Patients with Cancer, COPD and Heart failure: an fMRI feasibility study

INTEGRA-1 AND INTEGRA-2 PC AND PNEUMO NURSE-LED CONSULTATION





EFFECTIVENESS OF HYPNOSIS ON BREATHLESSNESS MASTERY IN PATIENTS WITH PERSISTANT DYSPNEA: A RANDOMISED CONTROLLED TRIAL (HYPNEA)



Primary outcome:
Breathlessness Mastery

Secondary:
Dyspnea, anxiety, depression,
Qol, ...

PI: Lisa Hentsch

Design: RCT

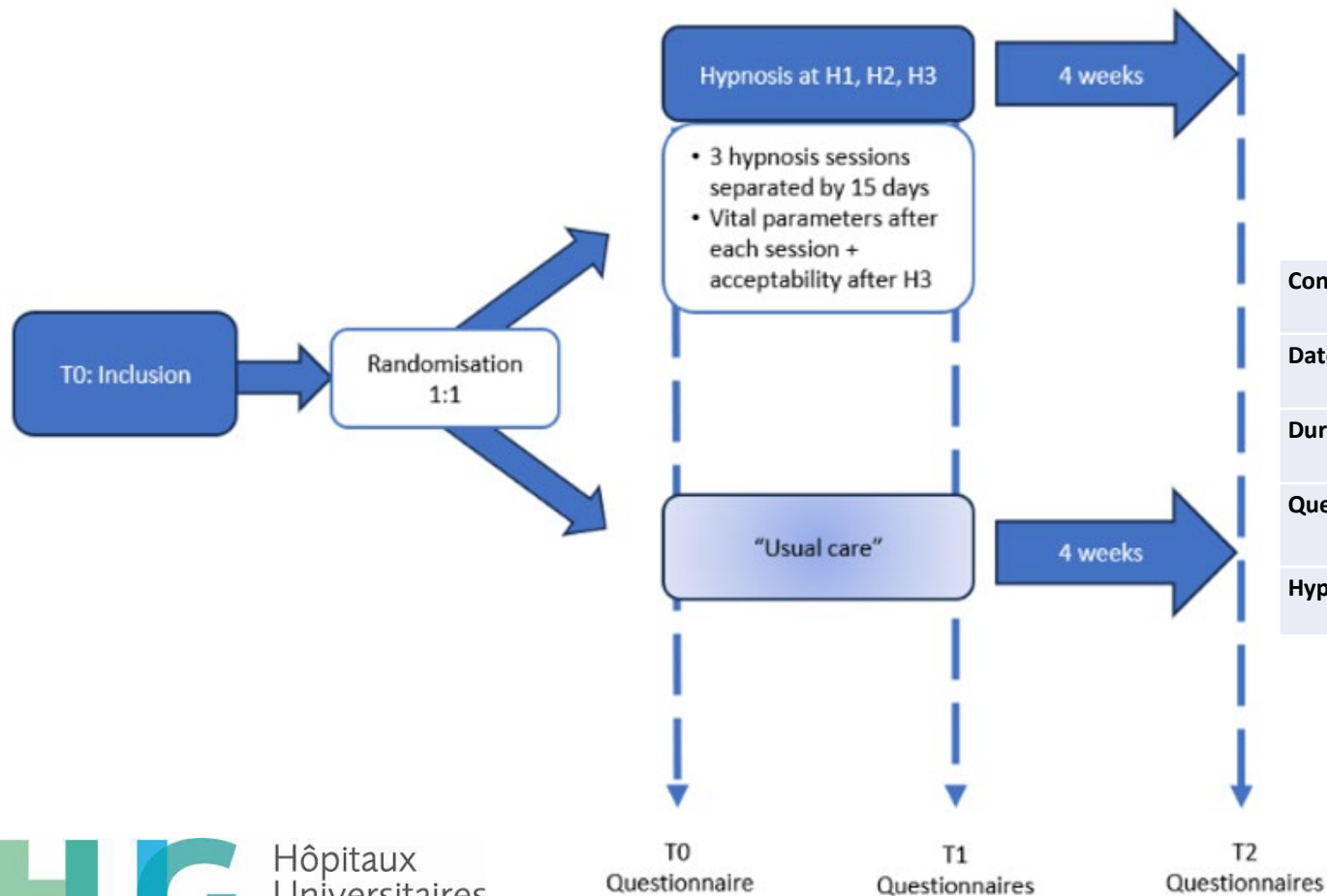
Financing: Fond Lancardis

Stage: revision CER

Start: september 2025

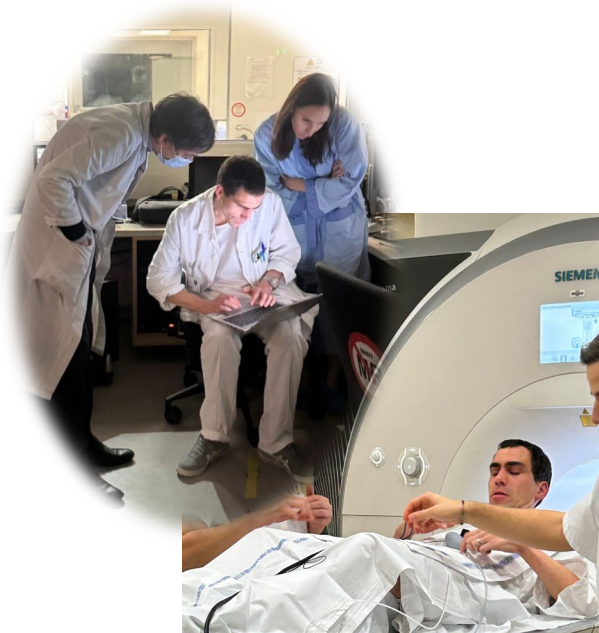
Nb de patients: 82 patients (41 per groupe)

EFFECTIVENESS OF HYPNOSIS ON BREATHLESSNESS MASTERY IN PATIENTS WITH PERSISTANT DYSPNEA: A RANDOMISED CONTROLLED TRIAL (HYPNEA)



Consultations	0	H1	H2	H3	4
Date	0	Week 2	Week 4	Week 6	Week 10
Duration (minutes)	30-45	30	30	30-45	30
Questionnaires	X			X	X
Hypnosis sessions		X	X	X	

BREATHLESSNESS PATTERNS IN PATIENTS WITH CANCER, COPD AND HEART FAILURE: AN FMRI FEASIBILITY STUDY (BREACH-FMRI)



Objectif Principal:

Etudier la faisabilité

Secondaires:

Différence de patterns entre pathologies

Symptômes, effets secondaires

PI: Lisa Hentsch

Design: faisabilité

Financement: Fond départemental HUG

Stade: révision CER

Début: juillet 2025

Nb patients: 4 HF, 4 COPD, 4 cancers, 4 sains

Collaboration entre SP, pneumo, cardio, onco, neuro, neuro-radiologie

Genève + Bâle + Tessin

BREATHLESSNESS PATTERNS IN PATIENTS WITH CANCER, COPD AND HEART FAILURE: AN FMRI FEASIBILITY STUDY (BREACH-FMRI)

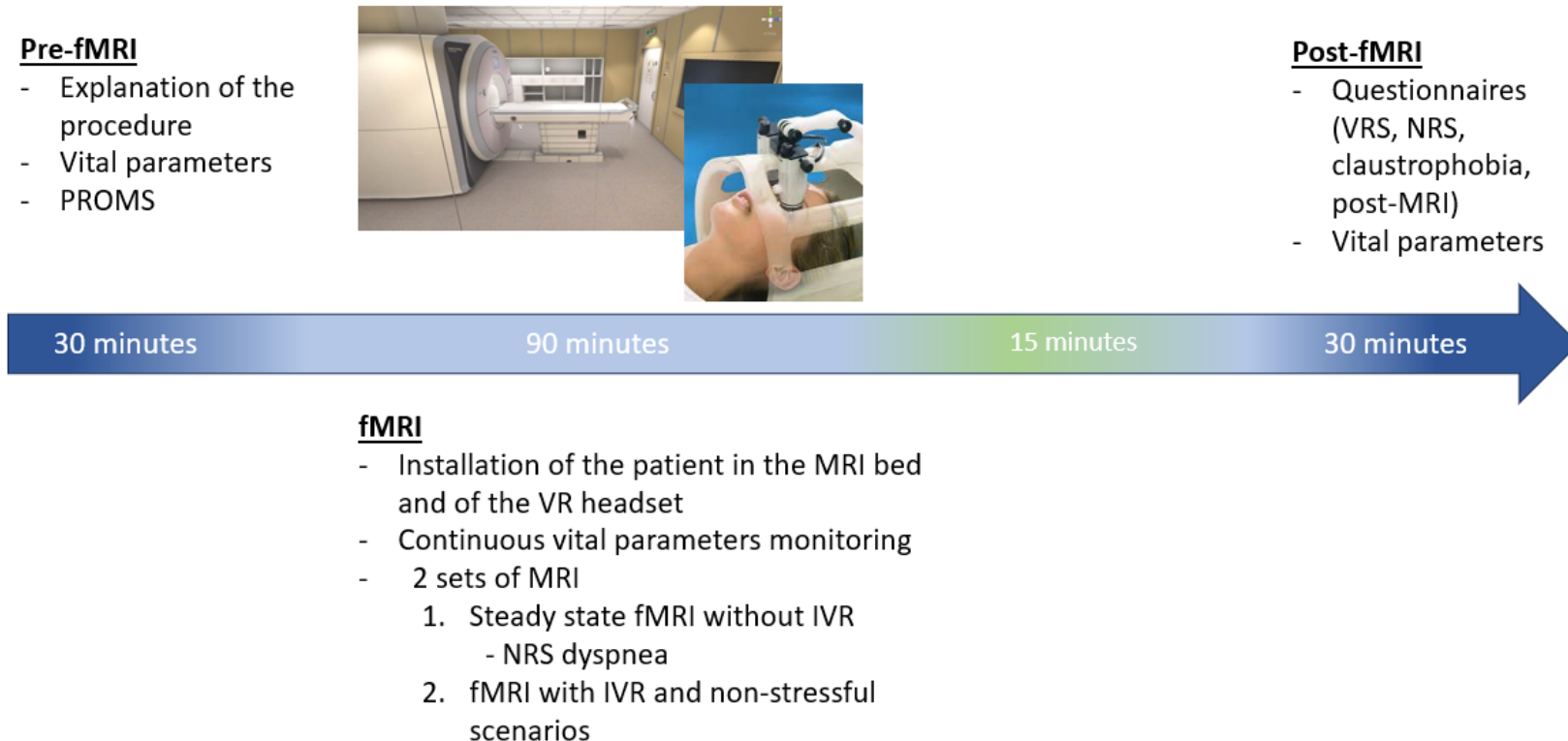
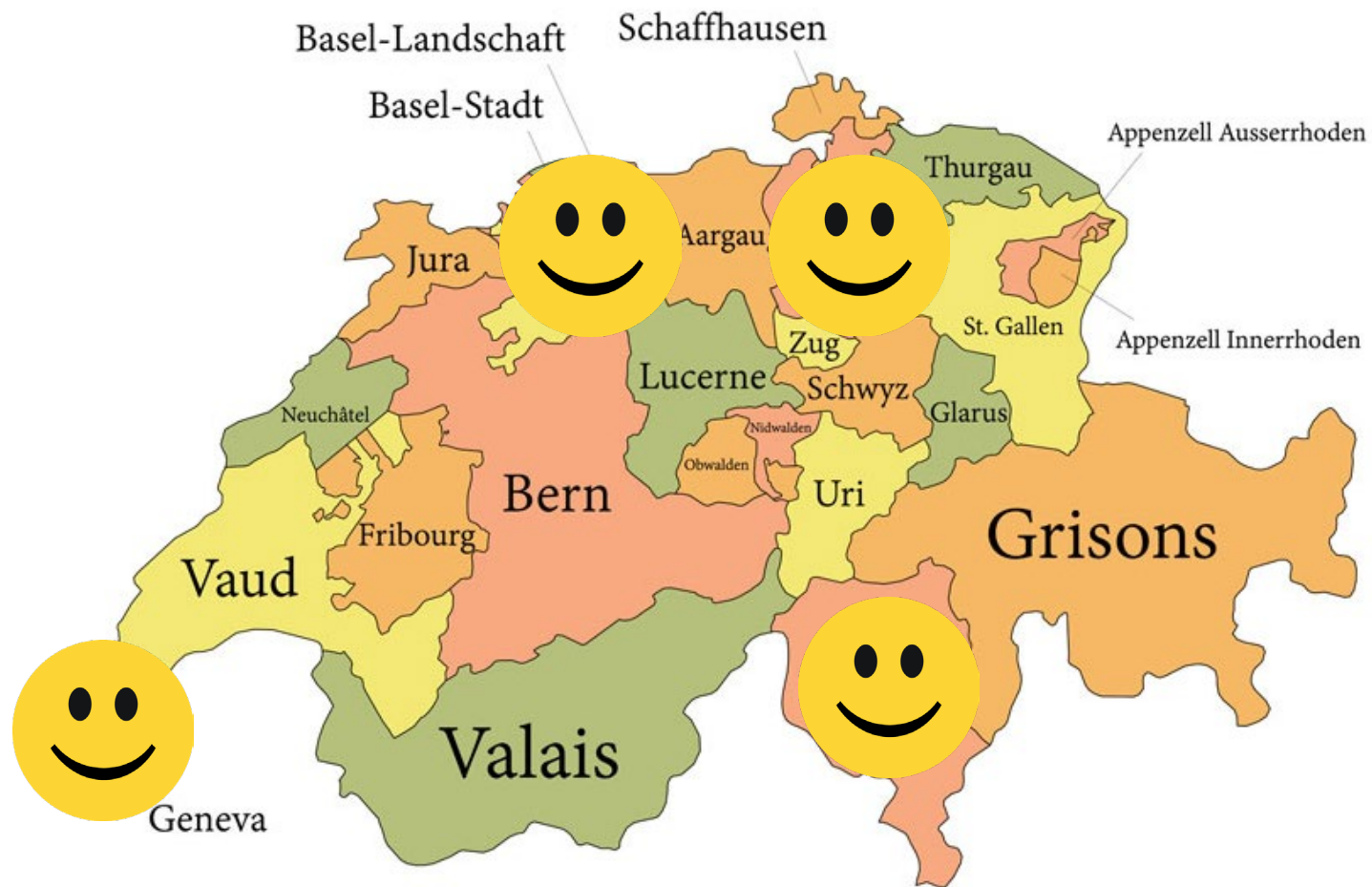


Figure 1

Vital Parameters: saturation of oxygen, respiratory rate, transcutaneous CO₂ (not during MRI)

VRS: verbal rating scale, NRS: numeric rating scale, IVR: Immersive Virtual Reality

PROMS (patient-reported outcome measures): D12: Dyspnea-12; ESAS: Edmonton Symptom Assessment Scale, HADS: Hospital Anxiety and Depression Scale; CRQ: Chronic Respiratory Questionnaire



Caroline Hertler, Valentina González Jaramillo, Sandra Eckstein, Tania Fusi-Schmidhauser and Lisa Hentsch



Caroline He




ckstein, Tania Fusi-Schmidhauser and Lisa Hentsch



Perspectives


RESEARCH ARTICLES | MARCH 26 2025

Impact of an Interdisciplinary Approach to the Management of Refractory Dyspnoea on Patient Quality of Life by a Non-Palliative Respiratory Care Team: A Pilot Study

Subject Area:  [Pneumology](#).

[Gregory Clark](#) ; [Noemie Vuilleumier](#); [Leo Vanini](#); [Marc Marechal](#); [Jean-Marc Fellrath](#)

Respiration (2025)

<https://doi.org/10.1159/000545313>  [Article history](#).

PubMed:40139182

 Karger

Conclusion

The implementation of palliative care for patients living with respiratory diseases:

- Is possible
- Requires coordination to improve access
- Requires a motivated multidisciplinary team
- Can be very gratifying
- Needs to be evaluated

Conclusion

The implementation of palliative care for patients living with respiratory diseases:

- Is possible
- Requires coordination to improve access
- Requires a motivated multidisciplinary team
- Can be very gratifying
- Needs to be evaluated



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Critères d'inclusion /exclusions HYPNEA

- Patients will be eligible for inclusion if they fulfil all following criteria:
 - Patients aged ≥ 18 years and
 - Primary diagnosis of metastatic cancer, **COPD stage at least 3B or E, ILD**, or CHF and
 - Dyspnea stage NYHA III-IV or **mMRC 3-4**
- Patients will be excluded if they:
 - Have had hypnosis treatment in the last 12 months
 - Have an estimated life expectancy of less than 6 months
 - Have participated in pulmonary rehabilitation in the last 6 months
 - Have been hospitalised in the last month (30 days)
 - Are unable to come to the hospital for 3 outpatient consultations (1 every two weeks)
 - Have a condition that would interfere with their ability to respond to the questionnaires (i.e. cognitive impairment, hearing impairment, etc.)
 - Are not eligible for a hypnosis session due to a psychiatric disorder

Critères d'inclusion /exclusions BREACH-fMRI

- Inclusion criteria:
 - Age \geq 18 years and
 - Followed by the **outpatient palliative care clinic** of the Geneva University Hospitals, Switzerland (HUG) and
 - **Breathlessness at rest > 2 on the NRS (numeric rating scale 0 to 10)**(Appendix 2) and
 - Persistent breathlessness (persistent dyspnea for > 3 weeks despite adequate and maximal medication according to the pathology) and
 - In a stable clinical condition, i.e. without an episode of acute cardiac, respiratory and/or neurological failure leading to hospitalization in the previous 4 weeks and
 - Have a diagnosis of either HF stage NYHA III-IV or **COPD with dyspnea on modified MRC scale grade 3-4** or oncological disease with either primary or secondary pulmonary location
- The presence of any one of the following exclusion criteria will lead to exclusion of the participant, for example:
 - Breathlessness at rest \geq 8 on the NRS (numeric rating scale 0 to 10) (Appendix 2)
 - Contra-indication to fMRI (Appendix 3)
 - Inability to lie down flat (supine position)
 - Diagnosed psychiatric illness (severe depression, severe anxiety, psychosis, other) or receiving antipsychotic treatment that is deemed to be a contraindication for fMRI based on physician judgement
 - Neurological disorders according to a neurological assessment, diagnosed dementia (frontotemporal dementia, Alzheimer's disease, etc.), brain pathology (tumor, stroke, Parkinson's disease, etc.), epileptic disease
 - Presence of claustrophobia, acrophobia, photophobia, severe hearing loss and/or severe visual deficit
 - Contraindication to IVR (migraines, photosensitive epilepsy, vertigo)