

ANNUAL REVIEW

2024/25

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1. FOREWORD FROM THE CHAIR OF THE INTERNATIONAL COLLABORATIVE

Dear Collaborative Member.

I am pleased to present to you the International Collaborative's Annual Review for 2024/25.

Over the past year, the International Collaborative for Best Care for the Dying Person has continued to make steady progress towards its vision: a world where all people experience a good death as an integral part of their individual life, supported by the very best personalised care.

Since its formation in 2013, the Collaborative has brought together clinicians, researchers, and educators from around the world to improve standards and strengthen the evidence base for end-of-life care, and I am both pleased and proud to report that our membership now encompasses over 1,000 individuals from 77 countries.

In terms of this year's activity, progress has been made towards achieving charitable status under UK law, which will enhance the Collaborative's sustainability and ability to attract funding. The relaunch of Project Groups has encouraged members to collaborate on focused topics such as bereavement, biobanking, and benchmarking, while our new Research, Quality Improvement, and Education Programmes have helped to coordinate and strengthen our activities.

The 10/40 Model for Best Care for the Dying Person continues to expand internationally, supported by the Facilitator Network and our growing number of Reference Centres. Education remains central to our mission, with the Summer School and webinar programme providing valuable opportunities for shared learning and engagement.

On behalf of the Executive Committee, I thank all members for their continued dedication and collaboration. Together, we are improving care for people at the end of life and supporting healthcare professionals worldwide to deliver compassionate, high-quality care.

Yours,

Professor John Ellershaw

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Chair of the International Collaborative for Best Care for the Dying Person November 2025

2. ABOUT THE INTERNATIONAL COLLABORATIVE

The International Collaborative for Best Care for the Dying Person was formed in January 2013 by a group of leading thinkers, practitioners and researchers from 12 countries who shared the common aim of improving standards and increasing the evidence base in end-of-life care.

The International Collaborative has developed a series of core aims, the pursuit of which is overseen by an Executive Committee of seven Executive Officers elected by the membership. Administrative support is provided by the International Collaborative Coordinating Centre, which is based at the Palliative Care Unit, University of Liverpool, UK.

The vision of the Collaborative is a world where all people experience a good death as an integral part of their individual life, supported by the very best personalised care.

3. EXECUTIVE COMMITTEE UPDATE

During 2024/25, the Executive Committee has continued to meet every two months to maintain oversight of the Collaborative's operation and development and is pleased to provide the following updates.

3.1. 2024/25 Strategic Objectives

Following last year's Annual General Meeting, the Executive Committee approved a set of strategic objectives for the 2024/25 year in support of the Collaborative's core aims. Good progress has been made against the objectives, as demonstrated in the Red-Amber-Green rated table in Appendix 1 on page 13.

3.2. Joint EAPC Task Force on Care for the Dying

In November 2023 the Collaborative partnered with the European Association for Palliative Care (EAPC) to establish a joint Task Force on Care for the Dying. This initiative aims to improve end-of-life care across Europe and beyond, focusing on the last days and hours of life. The Task Force drives research, quality improvement, and education through activities such as webinars, newsletters, and collaborative meetings.

A central goal is the creation of an EAPC White Paper on Care for the Dying, which will raise awareness among healthcare professionals, policymakers, and the public about the importance of holistic, patient-centred care at the end of life. The paper will cover physical, psychological, social, and spiritual aspects of dying, as well as cultural, societal, and political



considerations. It will serve as a reference for clinicians, offering guidance on symptom management, communication, cultural sensitivity, and ethical issues.

Chaired by Professor John Ellershaw (University of Liverpool, UK) and co-chaired by Professor Agnes van der Heide (Erasmus University, The Netherlands), the Task Force will advocate for policy changes, interdisciplinary collaboration, and improved care practices. This collective effort aims to ensure a compassionate and dignified experience for dying individuals and their families across Europe and beyond.

In 2025 the Collaborative was pleased to host an open meeting of the Task Force at the EAPC World Congress in Helsinki, Finland, which attracted approximately 50 delegates.

If you would like to join the Task Force, please contact admin@bestcareforthedying.org.

3.3. Project Groups

In 2024 the Executive Committee relaunched project groups within the Collaborative, enabling colleagues from around the world to work together on topics of shared interest that will contribute to the development of 'best care for the dying person'. Project groups have a maximum term of three years and must be led by a Full Member of the Collaborative, who sets annual objectives for the group and reports against their progress to the Executive Committee on a yearly basis. Participation in these groups is open to all members of the Collaborative.

To date, the Executive Committee has approved the creation of nine project groups as outlined in the table below, and several additional groups are in development.

Project Group	Led by
Engagement with bereaved relatives, including	
Care of the Dying Evaluation (CODETM)	Dr Catriona Mayland
10/40 Model staff perception questionnaire	Dr Susie Wilkinson
International benchmarking in care for the dying	Prof John Ellershaw
Project MiMI - Imminent death in internal medicine	Dr Rui Carneiro
Biobank in palliative medicine	Prof Lia van Zuylen
Serious Illness Care Programme	Dr Anna Sandgren
The EU iLIVE Legacy	Prof Agnes van der Heide
Training for facilitators of the 10/40 Model	Anette Duarte/Drofn Birgisdottir
	Prof John Ellershaw/Prof Agnes van
EAPC White Paper Development	der Heide



If you are a Full Member of the Collaborative and have an idea for a project group, please submit the proforma available from the project groups webpage here: https://www.bestcareforthedying.org/project-groups.

3.4. Charitable Status

With the aim of ensuring the sustainability and future development of the Collaborative, the Executive Committee is pleased to share that it has taken further steps towards establishing the Collaborative as a registered charity under UK law.

Members of the Executive Committee were appointed as Trustees in the summer of 2025, paving the way for a formal application to become a registered charity. This application was submitted in August and is currently under review by the UK Charities Commission.

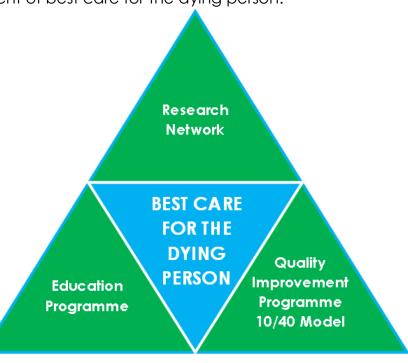
Achieving charitable status will cement the Collaborative's position as an organisation established for the public benefit and will present opportunities to raise funds through applications to a wider range of grant-awarding bodies.

4. WORK PROGRAMMES

A key development in 2025 was the formalisation of three work programmes within the Collaborative to support the development of best care for the dying person:

- Research Network, coordinated by Professor Agnes van der Heide
- Quality Improvement
 Programme, coordinated by
 Dr Susie Wilkinson
- Education Programme, coordinated by Professor Carl Johan Fürst

The work of each of these work programmes is detailed overleaf.





4.1. Research Network

The Collaborative is committed to driving forward an international research agenda in care for the dying and to date has secured funding for two major international projects. The International Care of the Dying Evaluation (iCODE) project saw seven countries use the CODETM bereavement questionnaire to research bereaved relatives' perceptions of quality of care for cancer patients. The project, which received funding of €0.818 million from the Network of the European Union, Latin America and the Caribbean Countries on Joint Innovation and Research Activities (ERANet-LAC), is now complete and continues to publish its findings.

The "Live Well, Die Well: A research programme to support living until the end (iLIVE)" project is also now in the analysis and reporting phase. Further information about the project's progress in 2025 is described below.

4.1.1. Living Well, Dying Well: A research programme to support living until the end (iLIVE)

The iLIVE project was a 13-country research project funded under the EU Horizon 2020 programme, which aimed to contribute to high-quality personalised care at the end of life and to increase community engagement with the reality of death and dying.

Eleven countries participated in the project's cohort study, which sought to gain insight into the aims, concerns and care needs of people with an advanced illness and their families. Cohort study participants filled in questionnaires at baseline and four weeks later. If patients died within six months, bereaved family and attending healthcare staff were asked to complete post-mortem questionnaires and patients' medical files were analysed to collect information about care in the last week of life. Complementary qualitative interviews with patients, family members, and attending healthcare professionals added in-depth insights.

Embedded in the cohort study was the medication study, where three countries evaluated a so-called Clinical Decision Support System (CDSS) that includes a specific set of rules on medication management for patients in the last phase of life.

A second study embedded in the cohort study was the evaluation of a hospital palliative and end of life care volunteer programme, which saw five participating countries implement infrastructures for hospital volunteer services, an international 'Train-the-Trainer' course, and a Learning Lab where volunteer service coordinators could exchange experiences.

Over 1400 patients and 600 relatives were included in the cohort study, with a subset of these also participating in the medication or volunteer studies. The data have provided much insight into the experience of dying in the 21st century in different countries and cultures.



Alongside these empirical studies, a Core Outcome Set (COS) is also in development to assess quality of end-of-life care as experienced by patients and relatives. To progress the COS, a literature review was conducted, followed by an international Delphi study and a final consensus meeting.

Throughout the project, a continuous effort focused on engagement of the wider community with the iLIVE project and its aims, through newsletters, presentations at conferences, and social media activities.

The project and its funding were successfully completed by the end of 2023. A final report summarising the results was approved by the EU, and ten articles on findings of different parts of the study have been published in peer-reviewed scientific journals thus far. A large number of additional scientific papers are currently being developed to further disseminate the findings.

4.2. Quality Improvement Programme – 10/40 Model

The 10/40 Model for Best Care for the Dying Person comprises ten key principles and 40 outcomes of care that can be integrated into a clinical document to support individualised care for the dying person at the bedside. These principles and outcomes have been evaluated and validated by a three round Delphi study, the results of which were published in *Palliative Medicine* in February 2023¹.

The 10/40 Model is supported by a four-phase, ten-step implementation and dissemination framework, which enables clinical sites to develop their own care plans in line with the standards set in the model. To date, 21 care plans from 13 countries have been approved as congruent with the 10/40 Model, and these have been implemented in over 1,000 clinical sites.

Our Reference Centres continue to play a vital role in the international development and implementation of the 10/40 Model. In 2024, Arohanui Hospice Service Trust in New Zealand was the latest organisation to be recognised as a Reference Centre, joining the Regional Centre of the Excellence for Palliative Care (Western Norway), Instituto Pallium Latinoamerica (Argentina), Kasturba Hospital Manipal (India) and The Institute for Palliative Care (Sweden) in providing knowledge and advice to 10/40 Model user sites based on direct experience of

¹ McGlinchey T, Early R, Mason S, et al. Updating international consensus on best practice in care of the dying: A Delphi study. Palliative Medicine. 2023;37(3):329-342. doi:10.1177/02692163231152523



implementing the model within the cultural norms, national policies, and healthcare economies of their respective countries.

4.2.1. The 10/40 Model Facilitator Network

The 10/40 Model Facilitator Network was established in 2017 to drive forward the work of the Collaborative, and there are currently 34 facilitators representing 13 countries. Members of the network are healthcare professionals who have been nominated by their institution, state or country to coordinate work centred around the development, implementation and dissemination of the 10/40 Model. If you are engaged in work with the 10/40 Model and would like join the network, or to enquire further about its functions, please email the Coordinating Centre admin@bestcareforthedying.org.

The Facilitator Network meets virtually quarterly to progress its work, supplemented by faceto-face workshops at Summer School and the Annual International Conference. developments from 2024/25 are described below.

4.2.1.1. The 10/40 Model User Site Survey

In the summer of 2024, a survey was undertaken that invited the owners of twenty 10/40 Model-congruent care plans to give their views on the use of those plans in their clinical settings. There was an 85% response rate, with results indicating that most of the care plans are used in the hospital inpatient or hospice setting. Minimal disadvantages for using the care plans were cited, with most respondents instead describing the benefits. Specific comments included: "it provides structure for staff"; "promotes better patient and family care and empowers the interdisciplinary team"; and "the plan is holistic and helps to guide the clinician to cover every important aspect required to provide good care of the dying person".

During 2025 the User Site questionnaire has been revised to align with the annual Reference Centre questionnaire. It is anticipated this revised survey will be distributed electronically to all 1,000+ 10/40 Model user sites in January 2026 as part of the Collaborative's Quality Improvement Framework.

The 10/40 Model Staff Perception Questionnaire 4.2.1.2.

The Facilitator Network has also developed a 'Staff Perception Questionnaire' to assess the knowledge, skills, and experience of clinical staff who are using 10/40 Model-congruent care plans to support patients in the last hours or days of life. The questionnaire was piloted in five English-speaking countries in the summer of 2024 to determine the acceptability of the



questions, and minimal amendments were required. Phase two of the project will be a validation study of the questionnaire to ensure it is a rigorous instrument that can be used by all members of the Collaborative to thoroughly examine the use of the 10/40 Model. The validation study will commence in November 2025.

4.2.1.3. Training the 10/40 Model Implementation Leaders

The implementation of a new care plan into a clinical area requires education and a systematic process of implementation. To this end, members of the Facilitator Network, led by Sweden with participation from Spain, Argentina, Norway and the Netherlands, are designing a course programme relevant to those leaders who want to train other healthcare professionals on how to implement a care plan into their clinical area. A focus group interview guide has been developed to assess the needs of implementation leaders the results will inform the development of the course programme, which will be piloted in 2026

4.2.2. Quality Improvement Framework

Over many years, members of the Facilitator Network have developed a wide range of resources in multiple languages to support the 10/40 Model's implementation and dissemination, including leaflets, flyers, check lists, pre- and post-implementation audit tools, reflection proformas, focus group questions, and evaluation questionnaires. With the aim of supporting other organisations to implement the 10/40 Model and develop tools and documentation appropriate to their own care settings, network members have translated their resources into English and organised them into a 'Quality Improvement Framework' (QIF) aligned with the 10/40 Model's four-phase ten-step implementation plan. Full Members of the Collaborative can access the QIF resources in both English and the documents' original language via the 'Tools and Resources' section of the www.bestcareforthedying.org website.

During 2024/25, the Quality Improvement Programme and the 10/40 Model have been presented to many countries, including Finland, Canada, Spain, Russia, Eastern Europe, Australia, and China.

4.3. Education Programme

4.3.1. Seventh Annual Summer School, 12-13 May, Málaga, Spain

In May 2025, the seventh International Collaborative Summer School took place at the headquarters of the Cudeca Institute, the Yusuf Hamied Centre for Training and Research, in Málaga, Spain. The programme covered two intense days in which researchers and clinicians



from different countries had the opportunity to debate and present cutting-edge research in end-of-life care, addressing diverse issues from the perspective of the most recent scientific advances in the field. The following topics were included in the programme:

- Care for the Dying: The 10/40 Model for Best Care for the Dying Person
- Research in the International Collaborative
- Quality Improvement and international Benchmarking in Care for the Dying
- Education and Training, including communication in serious illness and the serious illness care program

4.3.2. Webinar Programme

Established in 2021 in response to the COVID-19 pandemic and the subsequent loss of faceto-face education and training opportunities, the Collaborative's webinar programme is now in its fifth year. Operating on the virtual Zoom platform, the webinar programme has enabled the Collaborative to raise the profile and awareness of its work, as well as informing health and social care professionals and the public of issues related to the improvement of care for dying people and their families.

The 2024/25 programme covered the following topics

- Don't forget the children when a parent is dying of cancer
- Can dying with scleroderma be dignified? A look at the evidence for palliative care for people with scleroderma
- Medication Management at the End of Life: Implications for clinical practice from the EU Horizon 2020 iLIVE Project
- Developing an international biobank for research in palliative care

Webinars are recorded and made freely available on the Collaborative website for a period of three months, following which they are archived for access by Full Members of the Collaborative only. We encourage our members to use these recordings for education and training purposes within their clinical settings.

A new webinar programme for 2026 is currently in development and details will be shared in the regular Collaborative newsletter, distributed via email on a bi-monthly basis.

Further information about registration for webinars and other Collaborative events is available in the Courses and Events section of the www.bestcareforthedying.org website.



5. LOOKING AHEAD

To build upon the successes of 2025, the Executive Committee are already working on objectives for the coming year. Once ratified, these objectives will be shared with members in the December newsletter, and we look forward to reporting on progress at the 2025 Annual General Meeting.

Planning is also well underway for future events that will further consolidate the work of the Collaborative. We encourage you to save the following dates in your diary to ensure that you can share in what is sure to be a series of dynamic and enriching events. Information about registration will be published on the www.bestcareforthedying.org website in due course.

5.1. Research Thinktank, 12 February 2026

The next Research Thinktank will take place on 13 February 2025. This coming event will focus on the research aspects of several of our active project groups, with a programme designed to encourage the sharing of experiences, discussion of challenges, and promotion of collaboration in the conduct of end-of-life care research. All members of the Collaborative are welcome to attend and contribute to the discussions, which will help to inform the development of our project groups and future research strategy.

5.2. Eighth Annual Summer School, 11-12 May 2026

On 11 and 12 May 2025, Collaborative members will come together once more at the Cudeca Institute's Yusuf Hamied Centre for Training and Research in Málaga, Spain, for an intense two-day programme of workshops aimed at promoting and developing the work of the Collaborative, providing networking opportunities for 10/40 Model facilitators, and encouraging collaborative working within established project groups.

The 2026 Summer School programme will offer the opportunity for delegates to attend a mix of workshops on themes. In addition to the main workstreams, a number of themed sessions will run specifically for project groups, intended to accelerate each group's progress by providing dedicated time for colleagues to come together and concentrate collectively on the development of their collaborative work.



5.3. 11th International Conference on Best Care for the Dying Person, 18-19 November 2026

The Collaborative's flagship Annual International Conference on Best Care for the Dying Person will return to Lund, Sweden, in 2026. Taking place on 18 and 19 November, the programme will include plenaries from world-leading clinicians and academics, as well as parallel workshops and oral presentations from submitted abstracts.

6. CONCLUSION

In conclusion, the 2024/25 year has been one of continued progress and growth for the Collaborative. Significant strides have been made towards achieving the strategic objectives, particularly through the establishment of the new Work Programmes, and the further development of resources to support the implementation of the 10/40 Model. The growth in membership has further strengthened the Collaborative's global reach, ensuring more clinicians and researchers can contribute to the advancement of end-of-life care.

Looking ahead, the Collaborative is well-positioned to build on its accomplishments with exciting events planned for 2026, including the Eighth Annual Summer School and the Eleventh Annual International Conference on Best Care for the Dying Person. With the upcoming research initiatives and continued focus on quality improvement, the Collaborative remains dedicated to its vision of a world where all individuals experience a dignified and compassionate death, supported by the highest standards of personalised care. commitment of its members and partners will be vital as the Collaborative continues to drive efforts to improve care for dying individuals and their families on a global basis.

APPENDIX 1: AIMS & OBJECTIVES RAG REPORT

AIM	1: Undertake international research in care for the dying	RAG	
1(a)	Validate the CODE questionnaire in at least three further languages (Spanish, Portuguese and Kannada (Indian language)		
1(b)	To establish the EU Horizon 2020 iLIVE Legacy Project Group		
1(c)	Progress research ideas from Summer School into project groups: International benchmarking of 100 case notes 24hr practice review of an aspect of care for the dying 		
AIM 2: Drive forward an international 'care for the dying' research strategy			
2(a)	To revise and resubmit the international research project on the Serious Illness Care Programme (COMCARE) to the EU Research Programme		
2(b)	To develop an EU Marie Curie PhD Programme linked to the International Collaborative		
2(c)	To deliver the annual Research Thinktank meeting		
2(d)	Submit the 40 core outcomes for publication on the COMET database		
2(e)	Undertake an Implementation Research study on the 10/40 Model strategies and effectiveness in Spain		
2(f)	To facilitate a PhD study on the 10/40 Model in India		
AIM		D.4.C	
	are for the dying	RAG	
3(a)	Advertise five locally-run courses on the bestcareforthedying.org website	RAG	
		RAG	
3(a)	Advertise five locally-run courses on the bestcareforthedying.org website Consider EU COST Action and Erasmus bids for the development of a European network to advance practice in care for the dying across Europe, to include a	KAG	
3(a) 3(b)	Advertise five locally-run courses on the bestcareforthedying.org website Consider EU COST Action and Erasmus bids for the development of a European network to advance practice in care for the dying across Europe, to include a training course for the 10/40 Model Deliver education opportunities to the wider healthcare community by preparing and delivering a series of four online webinars	RAG	
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5(b)	Link health services bereavement practices with the Quality Improvement Framework, including CODE.		
5(c)	Encourage take-up of the 10/40 Model and provide support to the 21 organisations with congruence-approved documentation, underpinned by the Facilitator Network		
5(d)	Maintain five established International Collaborative Reference Centres and support the further development of three others in Portugal, Spain, and the UK		
5(e)	Promote the Quality Improvement Framework		
5(f)	Achieve the objectives set by the Facilitator Network: To pilot an education package for training the trainers in Sweden To develop and implement the Staff Perception Questionnaire		
AIM 6: Develop an effective communication strategy within the International Collaborative			
6(a)	Implement an 18-month strategic content development plan for the new bestcareforthedying.org website		
6(b)	To utilise linkages with iLIVE WP8 and, when iLIVE finishes, merge relevant content into the Collaborative website		
6(c)	Maintain bi-monthly mailshot communications via the bestcareforthedying.org website		
6(d)	Establish a subgroup, including representation from the CM team in iLIVE, to oversee the development of the Collaborative's online presence		
AIM 7: Globally disseminate the work of the International Collaborative			
	Promote the work of the Collaborative at the following:		
	 Latin American Congress of Palliative Care Symposium, March 2025, Sao Paulo 		
	EAPC World Congress, May 2025, Helsinki		
7(a)	5150 B		
/ (0)	EAPC Research Congress May 2026, Prague		
7(a)	 EAPC Research Congress May 2026, Prague PAL 2026, Montreal 		
/(u)	, ,		
7 (u)	PAL 2026, Montreal		
/(u)	 PAL 2026, Montreal Oceanic conference, Brisbane 2025 		
AIM	 PAL 2026, Montreal Oceanic conference, Brisbane 2025 Asia Pacific Hospice Network, Malaysia Indian Association of Palliative Care conference 2026 	RAG	
AIM	 PAL 2026, Montreal Oceanic conference, Brisbane 2025 Asia Pacific Hospice Network, Malaysia Indian Association of Palliative Care conference 2026 8: Organise and promote international meetings to advocate best care for the	RAG	
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AIM	9: Ensure the sustainability and growth of the International Collaborative	RAG
9(a)	Increase membership income by £2,000	
9(b)	Generate at least £1,000 income from Summer School	
9(c)	Generate at least £2000 income from the 9 th Annual Symposium in Porto	
9(d)	Develop a robust financial model to underpin the Collaborative	
9(e)	Achieve "registered charity" status	
9(f)	Review mission statement	
9(g)	Develop a five-year strategy	