

**International
Collaborative
for Best Care
for the Dying Person**

ANNUAL REVIEW

2023/24

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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 2023/24.

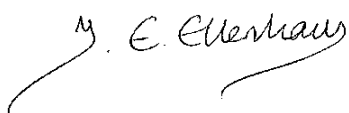
As the global landscape of healthcare continues to evolve, the importance of dignified, compassionate, and personalised care at the end of life remains paramount, and the work of the Collaborative is a testament to this profound need. Since its formation in 2014, the Collaborative has brought together practitioners and researchers from across the globe to improve care for those in their final days and hours, forging new pathways in research, quality improvement, and education.

Throughout the past year, Collaborative members have continued to work hard to deliver the ambitious objectives set in November 2023, and the content of this report is evidence of our significant achievements. The updates and initiatives detailed herein, from the relaunch of project groups to the formation of the EAPC Task Force on Care for the Dying, reflect the Collaborative's growing influence and ambition. Each step forward—whether it be the successful completion of the iLIVE Project, the expansion of the 10/40 Model, the growth of our membership, or the strides in securing charitable status—demonstrates the Collaborative's unwavering dedication to excellence in care for the dying.

As the challenges of end-of-life care continue to emerge, the Collaborative stands resilient, expanding its reach and impact through education, research, and international cooperation. It is the hope that this document not only informs but inspires continued involvement and innovation in achieving the shared goal of compassionate care for all those at the end of life. In this endeavour, every contribution, no matter how small, brings us closer to a world where every person can experience the best care as they die.

As always, our success is down to the sustained input of energy and expertise from our Executive Committee and Facilitator Network. My sincere thanks go to both groups for their invaluable contributions, and to the Coordinating Centre staff who maintain the communication and focus in between our annual meetings. Lastly, my thanks to you, the Collaborative members. Together, we are the global focus for improving care for dying people and I look forward to our continued collaboration.

Yours,



Professor John Ellershaw

Chair of the International Collaborative for Best Care for the Dying Person
November 2024

2. ABOUT THE INTERNATIONAL COLLABORATIVE

The International Collaborative for Best Care for the Dying Person was formed in January 2014 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 Constitution sets out 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 2023/24, 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. 2023/24 Strategic Objectives

Following last year's Annual General Meeting, the Executive Committee approved a set of strategic objectives for the 2023/24 year in support of the Collaborative's core aims as set out in its Constitution. Excellent progress has been made against the objectives, as demonstrated in the Red-Amber-Green rated table in Appendix 1 on page 12.

3.2. 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 new EAPC 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 will drive 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.

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 six new project groups as outlined in the table below, and several additional groups are in development.

Stream	Project Group	Project Group Lead
The 10/40 Model	10/40 Model Staff Perception Questionnaire	Dr Susie Wilkinson, UK
	International Benchmarking in Care for the Dying	Prof John Ellershaw, UK
	Project MiMI – Imminent Death in Internal Medicine	Dr Rui Carneiro, Portugal
Research Proposals	Biobank in Palliative Medicine	Prof Lia van Zuylen, The Netherlands
Quality Improvement	Care of the Dying Evaluation (CODE™)	Dr Catriona Mayland, UK
	Serious Illness Care Programme	Prof Anna Sandgren, Sweden

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 the first steps towards establishing the Collaborative as a registered charity under UK law. The committee is working on a formal application to the Charities Commission, which will be submitted in early 2025.

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.

3.5. Membership

The Collaborative continues to strive to make its benefits as accessible as possible to clinicians and researchers around the world, and a new development for 2024 was the introduction of free membership in addition to the standard paid options. Free Membership confers limited benefits; Full Membership incurs fees and confers the Collaborative's full range of benefits, including access to the 10/40 Model, discounted registration fees for conferences and events, and much more. A comparison of the different membership benefits can be found in the table below.

MEMBERSHIP BENEFITS	Membership (free of charge)	Full Membership (fees apply)
Regular Newsletter	✓	✓
Opportunity to participate in project groups	✓	✓
Opportunity to participate in major international research projects	✓	✓
Access to the Care of the Dying Evaluation (CODE) Tool	✓	✓
Access to the 10/40 Model for Best Care for the Dying Person	-	✓
Access to the Quality Improvement Framework	-	✓
Access to the Clinical Document Audit Toolkit	-	✓
Opportunities to develop and lead new research and quality assurance projects	-	✓
Discounted registration fees for Summer School	-	✓
Discounted registration fees for Annual Conference	-	✓
Guidance and support from the Coordinating Centre and Reference Centres	-	✓
Reduced-rate access to a range of additional events and training opportunities	-	✓

Full Membership continues to be made available to individuals, organisations, and groups, with fees based upon countries' income levels as reported by the World Bank.

At the time of writing, the Collaborative encompasses over 850 members from 64 countries.

4. THE 10/40 MODEL FOR BEST CARE FOR THE DYING PERSON

The 10/40 Model for Best Care for the Dying Person is at the heart of the Collaborative's work. It 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 implementing the model within the cultural norms, national policies, and healthcare economies of their respective countries.

5. RESEARCH AND DEVELOPMENT

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 CODE™ bereavement questionnaire to research bereaved relatives' perceptions of quality

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](https://doi.org/10.1177/02692163231152523)

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 “Living Well, Dying Well: A research programme to support living until the end (iLIVE)” project is also now in the analysis and reporting phase, and further information about the project’s progress in 2023/24 is detailed below.

5.1. 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, while 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 decision-making 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.

Nearly 1400 patients and 800 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 we have also been working on the development of a Core Outcome Set to assess quality of end-of-life care as experienced by patients and relatives. We conducted a literature review, an international Delphi study, and organised 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 was successfully completed by the end of 2023. A final report summarising the results was approved by the EU and currently we are working on a large number of scientific papers to further disseminate the findings.

6. LEARNING AND TEACHING

6.1. Sixth Annual Summer School, Málaga, Spain

May 2024 saw the International Collaborative Summer School take place once again 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
- National Benchmarking in Care for the Dying
- Education and Training

6.2. Webinar Programme

Established in 2021 in response to the COVID-19 pandemic and the subsequent loss of face-to-face education and training opportunities, the Collaborative's webinar programme is now in its fourth year and remains popular despite the return to normal following the end of the pandemic. Operating on the virtual Zoom platform, the webinar programme has enabled the Collaborative to raise its 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.

Four webinars were held in 2023/24 and topics were as follows:

- Facing Life's End: Understanding death anxiety and spiritual wellbeing
- The Role of Volunteers at the End of Life: Results from the EU Horizon 2020 iLIVE study
- Care for the Dying Person with Motor Neurone Disease
- Experiences and Preferences of People in the Last Phase of Life Across 11 Countries: Results from the international iLIVE Project

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 2025 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.

7. QUALITY IMPROVEMENT

7.1. The 10/40 Model Facilitator Network

The 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 health care 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 to join the network, or to enquire further about its functions, please email the Coordinating Centre admin@bestcareforthedying.org.

The Facilitator Network meets quarterly via Zoom to progress its work, supplemented by face-to-face workshops at Summer School and the Annual Conference. Key developments from 2023/24 are described below.

7.1.1. 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”*.

The survey will be repeated bi-annually as part of the Collaborative's Quality Improvement Framework.

7.1.2. The 10/40 Model Staff Perception Questionnaire

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 summer 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.

7.1.3. The Training the Trainers Course for 10/40 Model Facilitators

The implementation of a new care plan into a clinical area requires education and a systematic process of implementation. To this end, the Facilitator Network has designed a course programme relevant to those individuals who want to train other healthcare professionals on how to implement a care plan into their clinical area. The course programme will be piloted in 2025.

7.2. 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 their original language via the 'Tools and Resources' section of the www.bestcareforthedying.org website.

8. LOOKING AHEAD

To build upon the successes of 2024, 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.

8.1. Research Thinktank, 13 February 2025

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.

8.2. Seventh Annual Summer School, 12-13 May 2025

On 12 and 13 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 facilitators, and encouraging collaborative working within established project groups.

The 2025 Summer School programme will offer the opportunity for delegates to attend a mix of workshops on themes including the 10/40 Model for Best Care for the Dying Person, Research in End-of-Life Care, and Improving Clinical Care for Dying People. 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.

8.3. Tenth International Conference on Best Care for the Dying Person, 19-20 November 2025

The Collaborative's flagship Annual International Conference on Best Care for the Dying Person will return to Liverpool, UK, in 2025 to celebrate its tenth anniversary. Taking place at the Royal College of Physicians North on 19 and 20 November 2025, the programme will include plenaries from world-leading clinicians and academics, as well as parallel workshops and oral presentations from submitted abstracts.

9. CONCLUSION

In conclusion, the 2023/24 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 new project groups, the formation of the EAPC Task Force on Care for the Dying, and the further development of resources to support the implementation of the 10/40 Model. The growth in membership, alongside the introduction of free membership options, 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 2025, including the Seventh Annual Summer School and the Tenth 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. The 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 Rating
1(a)	Submit two further papers for publication to disseminate the findings of the ERANet LAC CODE project	
1(b)	Validate the CODE questionnaire in at least two further languages (Spanish, Portuguese, and Kannada)	
1(c)	EU Horizon 2020 iLIVE Project: <ul style="list-style-type: none"> To ensure deliverables are submitted in line with revised timelines. To publish and disseminate at least two papers 	
1(d)	To publish and disseminate at least two papers on the international Co-LIVE research project	
1(e)	Progress research ideas from Summer School: <ul style="list-style-type: none"> International benchmarking of 100 case notes 10/40 Model staff perception questionnaire 24hr practice review of an aspect of care for the dying 	
AIM 2: Drive forward an international 'care for the dying research strategy		RAG Rating
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 Latin America and Spain	
2(f)	To facilitate a PhD study on the 10/40 Model in India	
AIM 3: Encourage international learning and teaching collaborations to improve care for the dying		RAG Rating
3(a)	Advertise five locally-run courses on the bestcareforthedying.org website	
3(b)	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	
3(c)	Deliver education opportunities to the wider healthcare community by preparing and delivering a series of four online webinars	
AIM 4: Optimise the collaboration with the EAPC Task Force on Care for the Dying		RAG Rating
4(a)	Achieve the Year 1 objectives of the joint EAPC Task Force group	
4(b)	Develop a communication strategy with the EAPC Task Force group	
4(c)	Include Task Force development as a key agenda item at Executive Committee twice per year	

AIM 5: Support the development of the “International Collaborative 10/40 Model for Best Care for the Dying Person” and associated materials and processes within the Quality Improvement Framework		RAG Rating
5(a)	Develop a structure for the strategic development of the 10/40 Model	
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 20 organisations with congruence-approved documentation, underpinned by the Facilitator Network	
5(d)	To disseminate findings of the 10/40 Delphi Study to those organisations that have congruent documents	
5(e)	Maintain four established International Collaborative Reference Centres and support the further development of two others	
5(f)	Promote the Quality Improvement Framework	
5(g)	Achieve the objectives set by the Facilitator Network: <ul style="list-style-type: none"> • Submit paper for publication on mouth care for care for the dying person • To review our educational framework in light of developing the education package for training the trainers • To develop a consistent education package for training the trainers • To explore a mentorship network for the trained trainers 	
AIM 6: Develop an effective communication strategy within the International Collaborative		RAG Rating
6(a)	Implement an 18-month strategic content development plan for the new bestcareforthedying.org website	
6(b)	To link to the iLIVE website, and when iLIVE finishes, to 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	
6(e)	Build and utilise linkages with WP8 of iLIVE to disseminate the Collaborative's work	
AIM 7: Globally disseminate the work of the International Collaborative		RAG Rating
7(a)	Promote the work of the Collaborative at the following: <ul style="list-style-type: none"> • Latin American Congress of Palliative Care Symposium, March 2024, Colombia • EAPC Research Congress, May 2024, Barcelona • PAL 2024, Montreal • Asia Pacific Hospice Network, October 2023 • Indian Association of Palliative Care conference February 2024 	
AIM 8: Organise and promote international meetings to advocate best care for the dying person		RAG Rating
8(a)	To hold an Annual General Meeting at the 9 th Annual Symposium in November 2024 in Porto	

8(b)	Deliver the 9th Annual Symposium in Porto, November 2024	
8(c)	Develop the programme for 10th Annual Symposium in Liverpool, November 2025	
8(d)	Agree and announce the date and location of the 2026 Annual Symposium	
8(e)	Deliver the Summer School event in 2023	
8(f)	Develop a sustainable model for Summer School to increase attendance levels, aiming for 60 participants	
AIM 9: Ensure the sustainability and growth of the International Collaborative		RAG Rating
9(a)	Increase membership income by £3,500	
9(b)	Generate £1,000 income from Summer School	
9(c)	Generate £2000 income from the 8 th Annual Symposium in Rotterdam	
9(d)	Develop a robust financial model to underpin the Collaborative	
9(e)	Develop a strategy for sustainability of the Collaborative <ul style="list-style-type: none"> • Achieve charitable status 	
9(f)	Review the format and purpose of project groups	
9(g)	Develop a new strategic objective on public engagement, following work accomplished during iLIVE	
9(h)	Outsource membership administration	
9(i)	Develop a mission statement	
9(j)	Develop a five-year strategy	