

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

ANNUAL REVIEW

2022/23

CONTACT DETAILS

International Collaborative for Best Care for the Dying Person Coordinating Centre

Palliative Care Unit
University of Liverpool
North West Cancer Research Centre
200 London Road, Liverpool, L3 9TA
United Kingdom

Tel: +44 (0) 151 794 8886

Email: admin@bestcareforthedying.org

Website: www.bestcareforthedying.org

EXECUTIVE OFFICERS

Chair

Professor John Ellershaw
Professor of Palliative Medicine, University of Liverpool, UK

Vice Chair

Professor Carl Johan Fürst
Professor of Palliative Medicine, Lund University, Sweden

International Liaison Lead

Dr Susie Wilkinson
Palliative Care Unit, University of Liverpool, UK

Coordinating Centre Administrator

Jo Davies
Palliative Care Unit, University of Liverpool, UK

Contents

1. Foreword from the Chair of the International Collaborative	2
2. About the International Collaborative	3
3. Executive Committee Update	3
3.1. 2021/22 Strategic Objectives.....	3
3.2. Membership.....	3
4. Research	4
4.1. ERANet-LAC CODE: International Care Of the Dying Evaluation (CODE): quality of care for cancer patients as perceived by bereaved relatives	4
4.2. Living Well, Dying Well: A research programme to support living until the end (iLIVE) ..	4
5. Education	5
5.1. Fourth Annual Summer School, Benalmádena, Spain.....	5
5.2. Webinar Programme.....	5
6. Quality improvement	6
6.1. The 10/40 Model	6
6.2. Quality Improvement Framework	6
6.3. Facilitator Network.....	7
7. Conclusion	8
7.1. Research Thinktank, 15 February 2024	8
7.2. Sixth Annual Summer School, 13-14 May 2024.....	8
7.3. Ninth Annual Conference, November 2024.....	8
Appendix 1: Aims & Objectives RAG Report	10
Appendix 2: Terms of Membership	12
Appendix 3: Project Groups	13

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 2022/23.

Throughout the past year, the Executive Committee, supported by the Collaborative members, has continued to work hard to deliver the ambitious objectives set in November 2022, and the detail of this report is testament to our significant achievements.

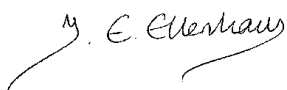
The Collaborative continues to potentiate and develop its research portfolio and position itself as the world leader in care for the dying research, with work continuing on our two major international research projects. The ERANet-LAC CODE group, under the leadership of Prof Dagny Faksvåg Haugen, continues to publish its important findings, while the international EU Horizon 2020-funded iLIVE project led by Professor Agnes van der Heide is also nearing completion. Its cohort study is the most ambitious study ever undertaken on care for the dying, and we are pleased and proud to be engaged in its work.

We were delighted in May to visit the beautiful Yusuf Hamied Centre for Studies & Research in Palliative Care for our annual Summer School, about which you can read more below. We're also very much looking forward to welcoming members from around the world to Rotterdam on 15 and 16 November 2023 for the Eighth Annual Symposium. Alongside these face to face events, we have also maintained our programme of online webinars, which continue to be well attended.

Work on the 10/40 Model for Best Care for the Dying Person continues, and we have now established International Collaborative Reference Centres in Norway, Argentina, India and Sweden, with more under development in Spain and Portugal. Overall, 20 organisations have had their clinical documentation assessed for congruence with the 10/40 Model. The 10/40 Model itself is underpinned by a comprehensive Quality Improvement Framework containing a wide range of guidance documents and templates, which is available on the Collaborative's website at www.bestcareforthedying.org.

As always, our success is down to the hard work of our Project Group Leads and the sustained input of energy and expertise from our Executive Committee and Facilitator Network. My sincere thanks go to each of these 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 working with you all.

Yours,



Professor John Ellershaw

Chair of the International Collaborative for Best Care for the Dying Person
November 2023

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.

Ratified in 2014, 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 with a three-year term of office. 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 2022/23, 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 on its key workstreams.

3.1. 2021/22 Strategic Objectives

Following last year's online Annual General Meeting, the Executive Committee approved a set of strategic objectives for the 2022/23 year in support of the Collaborative's core aims as set out in its Constitution. Very good progress has been made against the objectives, as demonstrated in the Red-Amber-Green rated table in Appendix 1 on page 10.

3.2. Membership

Membership continues to be made available to individuals, organisations, and groups, with fees based upon countries' income levels as reported by the World Bank. Membership terms and entitlements are set out in Appendix 2 on page 12.

In the 2022/23 year the Collaborative achieved 196 members from 18 countries.

4. RESEARCH

A great deal of progress has been made across all Collaborative project groups in the past twelve months. The full list of project groups is included as Appendix 3 (page 13), and detailed updates on key projects are set out below.

4.1. ERANet-LAC CODE: International Care Of the Dying Evaluation (CODE): quality of care for cancer patients as perceived by bereaved relatives

The project period ended in January 2020, but dissemination of project results has continued further over the last year. The following paper has been published since the last annual review: Gerlach C, Baus M, Gianicolo E, Bayer O, Haugen DF, Weber M, Mayland CR, on behalf of the ERANet-LAC CODE scientific group. What do bereaved relatives of cancer patients dying in hospital want to tell us? Analysis of the free-text comments from the International Care of the Dying Evaluation (i-CODE) survey: a mixed methods approach. *Support Care Cancer* 2022; 31(1):81.

A paper about the validation of the i-CODE questionnaire in Brazil has been submitted for publication.

For further information, please consult <https://clinicaltrials.gov/study/NCT03566732>.

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

The iLIVE project is a 13-country research project funded under the EU Horizon 2020 programme, that aims 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 participate in the cohort study that is aimed at getting insight into the aims, concerns and care needs of people with an advanced illness and their family. Participants in the cohort study fill in questionnaires at baseline and four weeks later. Complementary qualitative interviews with patients, family members and attending health care professionals will add in-depth insights.

Embedded in the cohort study is the medication study, where three countries will evaluate the added value of 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. The study has a pre-post intervention design.

A second study that is embedded in the cohort study is the evaluation of a hospital palliative

and end of life care volunteer programme. Five countries participating in this volunteer study have implemented infrastructures for hospital volunteer services in the participating sites, an international 'Train-the-Trainer' course, and a Learning Lab where volunteer service coordinators can exchange experiences.

Nearly 1400 patients and 800 relatives were included in the cohort study; a subset of these patients and relatives also participate in the medication or volunteer studies. The data collection has now been completed and results are currently being analysed.

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. The results are currently being analysed for international publication.

A continuous effort in the project focuses on engagement of the wider community with the project and its aims, through newsletters, presentations at conferences, and social media activities.

The iLIVE project will be formally completed by the end of 2023.

5. EDUCATION

5.1. Fourth Annual Summer School, Benalmádena, Spain

May 2023 saw the International Collaborative Summer School take place at the new headquarters of the Cudeca Institute, the Yusuf Hamied Center, in Benalmádena, Spain. The programme covered three intense days in which researchers and clinicians from different countries had the opportunity to debate and present cutting-edge research on Palliative Care, addressing diverse issues from the perspective of the most recent scientific advances in the field. The following topics were included in the programme:

- The 10/40 Model for Best Care for the Dying Person
- The Serious Illness Care Programme
- The Marie Skłodowska Curie Action Doctoral Network programme
- Facilitator workshops
- Cui-DAR, the Spanish care plan currently in development at Cudeca.

5.2. Webinar Programme

In 2021 as a result of the COVID-19 pandemic, with the imposed social distancing and loss of

education and training opportunities, the International Collaborative initiated a programme of training sessions via Zoom. These events proved so popular that they are now in their third year, despite the return to normal following the end of the pandemic. Operating on this virtual platform has enabled the International 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 improving the clinical care of people who are dying. Four webinars were held in 2022/23, and the topics were as follows:

- Global challenges for opioid use in care for the dying person
- Families' perceptions of how we care for their dying relatives
- How to assess palliative care needs: should we be taking a more creative approach?
- Is a good death achievable?

There have been between 40 and 60 attendees at each event from both within and outside of the Collaborative. A new programme for 2024 is currently being planned.

6. QUALITY IMPROVEMENT

6.1. The 10/40 Model

The 10/40 Model is comprised of ten key principles for best care for the dying person and 40 outcomes of care that can be integrated into a clinical document to support individualised care for the dying person at the bedside. In 2021/22 the 10/40 Model was 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.

¹McGlinchey 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)

6.2. Quality Improvement Framework

The International Collaborative Quality Improvement Framework (QIF) has been developed by the Facilitator Network (see Section 6.3). It has been designed to support organisations and individuals in the implementation of the 10/40 Model and is available to members via the www.bestcareforthedying.org website.

Over a number of years of working with the 10/40 Model, members of the Facilitator Network have developed a range of resources in their own languages to support the model's implementation and dissemination. These resources have been translated and organised into a QIF to assist organisations implement the 10/40 Model and help them in developing their own tools and resources to meet their own clinical needs.

The resources within the QIF include leaflets, flyers, check lists, pre- and post-implementation audit tools, reflection proforma, focus group questions, and evaluation questionnaires, and each is available in English as well as in its original language.

6.3. Facilitator Network

The Facilitator Network was established in 2017 to drive forward the work of the International Collaborative for Best Care for the Dying Person. There are currently 33 facilitators representing 14 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 Collaborative's 10/40 Model of Care.

The Network Facilitators were engaged in a very productive workshop at the annual Summer School in Malaga in May 2023. The members have also continued to meet four times a year via Zoom to carry on their discussions and progress their work on the following topics:

- A review and update of the Foundation course training programme which includes curriculum content, learning outcomes and teaching methods.
- The Development of a questionnaire to evaluate the knowledge, skills and experience of clinical staff of using a 10/40 care plan to support patients in the last days of life.
- The Development of an education package to 'train the trainers' for the person who guides and is responsible for the implementation of the 10/40 Model in their clinical setting
- The development of new Reference Centres
- A review and update of the QIF
- The preparation of a paper for publication on the optimal oral care for the dying person

Courses submitted by the Facilitator Network have also been endorsed by the Collaborative and are available at discounted prices to all members through the website.

In addition to the work noted above, several facilitators have been involved in the iLIVE research project.

If you would like to join the Facilitator Network, or to enquire further about its work, please contact Susie Wilkinson drsusie@btinternet.com

7. CONCLUSION

To build upon the successes of 2023, the Executive Committee are already working on objectives for the coming year. Once ratified, these objectives will be shared with members in the next update email and we look forward to reporting on progress at the 2024 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.

7.1. Research Thinktank, 15 February 2024

The next Research Thinktank will take place on 15 February 2024. The Thinktank gives members an opportunity to present ideas for new international research projects and join in discussions that will help to inform our future research strategy, and we hope that as many as possible will attend.

7.2. Sixth Annual Summer School, 13-14 May 2024

On 13 and 14 May 2024, Collaborative members will come together once more at the Cudeca Institute's Yusuf Hamied Centre in Benalmádena, Spain, for an intense two-day programme of workshops aimed at promoting and developing the 10/40 Model of Best Care for the Dying Person, providing networking opportunities for facilitators, and encouraging collaborative working within established project groups. The main theme of the programme will be 'Best Care for the Dying Person'; also included are a number of Project Group meetings 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.

7.3. Ninth Annual Conference, November 2024

The 2024 Annual Conference of the International Collaborative on Best Care for the Dying Person will be hosted by Escola Superior de Saúde Santa Maria (Porto, Portugal), together with Sociedade Portuguesa de Medicina Interna. The most likely date is the week of 12-15 November 2024. This symposium will include presentations on the results of MIMI ((Imminent Death in Internal Medicine) Project Portugal, under the main topic: Communication and Integration – improving care for the dying people and their families.

We look forward to the year ahead, to seeing and meeting as many members as possible at our planned events. We also welcome new members and hope to extend the reach of the Collaborative to continue our impact on care for the dying 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	
AIM 2: Drive forward an international 'care for the dying research strategy		RAG Rating
2(a)	To 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)	Prepare a paper for publication on optimal oral care practice for the dying person	
2(e)	Publish and disseminate the results of the Delphi survey on the Collaborative's 40 core outcomes for care for the dying	
2(f)	Submit the 40 core outcomes for publication on the COMET database	
2(g)	Undertake an Implementation Research study on the 10/40 Model strategies and effectiveness in Latin America and Spain	
2(h)	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)	Develop a funding bid to EU COST Action 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: 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
4(a)	Develop a structure for the strategic development of the 10/40 Model	
4(b)	Link health services bereavement practices with the Quality Improvement Framework, including CODE.	
4(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	

4(d)	To disseminate findings of the 10/40 Delphi Study to those organisations that have congruent documents.	
4(e)	To hold to an online meeting with all organisations that have achieved congruence, to present results of Delphi	
4(f)	Maintain four established International Collaborative Reference Centres and support the further development of two others	
4(g)	Promote the Quality Improvement Framework	
AIM 5: Develop an effective communication strategy within the International Collaborative		RAG Rating
5(a)	Implement an 18-month strategic content development plan for the new bestcareforthedying.org website	
5(b)	To link to the iLIVE website, and when iLIVE finishes, to merge relevant content into the Collaborative website	
5(c)	Maintain bi-monthly mailshot communications via the bestcareforthedying.org website	
5(d)	Establish a subgroup, including representation from the CM team in iLIVE, to oversee the development of the Collaborative's online presence	
5(e)	Build and utilise linkages with WP8 of iLIVE to disseminate the Collaborative's work	
AIM 6: Globally disseminate the work of the International Collaborative		RAG Rating
6(a)	Promote the work of the Collaborative at the following:	
	<ul style="list-style-type: none"> Latin American Congress of Palliative Care Symposium, November 2022 Costa Rica 	
	<ul style="list-style-type: none"> EAPC World Congress, June 2023 	
	<ul style="list-style-type: none"> PAL 2024, Montreal 	
	<ul style="list-style-type: none"> Asia Pacific Hospice Network, October 2023 	
<ul style="list-style-type: none"> Indian Association of Palliative Care conference February 2023 		
AIM 7: Organise and promote international meetings to advocate best care for the dying person		RAG Rating
7(a)	To hold an Annual General Meeting at the 8 th Annual Symposium in November 2023 in Rotterdam	
7(b)	Deliver the 8th Annual Symposium in Rotterdam, November 2023	
7(c)	Develop the programme for 9th Annual Symposium in Porto (2024)	
7(d)	Agree and announce the date and location of the 2025 Annual Symposium	
7(e)	Deliver the Summer School event in 2023	
7(f)	Develop a sustainable model for Summer School to increase attendance levels	
AIM 8: Ensure the sustainability and growth of the International Collaborative		RAG Rating
8(a)	Increase membership income by £3,500	
8(b)	Generate £1,000 income from Summer School	

8(c)	Generate £2000 income from the 7 th Annual Symposium	
8(d)	Develop a robust financial model to underpin the Collaborative	
8(e)	Develop a strategy for sustainability of the Collaborative <ul style="list-style-type: none"> • Explore charitable status • Explore linkage with the EAPC 	

APPENDIX 2: TERMS OF MEMBERSHIP



Terms of Membership

All members shall be entitled to:

- Receive the quarterly e-newsletter of the International Collaborative for Best Care for the Dying Person
- A reduction in registration fees for the Annual Symposium and other events held by the International Collaborative
- Secure online access to the members' area of the International Collaborative website
- Vote on international Collaborative business
- Stand for election to office in the governing Executive Committee

Who can join?

Membership is available to those who have paid the annual subscription as set by the Executive Committee, and:

- hold a recognised formal qualification in medicine, psychology, social sciences or nursing, or have relevant professional equivalence
- are or have been actively engaged in research or clinical work with people with palliative and/or end of life care needs.

Membership categories

The Collaborative has three membership categories. The named individuals within each category are permitted to access the Collaborative's tools and resources; wider dissemination is not permitted.

- **Individual** - one person
- **Organisation** - up to three people from one single organisation or institution
- **Group** - up to twenty people from a maximum of three organisations and/or institutions

Membership fees

Membership fees are set on a sliding scale according to [World Bank country income classifications](#) and are payable annually (by 31st January) as set out in the table below.

Country income category	Individual One person	Organisation Up to 3 people from one organisation or academic institution		Group Up to 20 people from a maximum of 3 organisations and/or institutions
		• <100 beds • home care teams	• >100 beds • academic institutions	
High	£60	£120	£240	£1000
Upper Middle	£40	£90	£180	£750
Lower Middle	£20	£60	£120	£500
Low	£10	£30	£60	£250

For further information visit www.bestcareforthedying.org

APPENDIX 3: PROJECT GROUPS

PROJECT GROUP 1 - RESEARCH		
Project		Led by
1.1	ERANet-LAC iCODE	Dagny Faksvåg Haugen
1.2	iLIVE - EU Horizon 2020	Agnes van der Heide
1.3	Serious Illness Conversations Programme	Susie Wilkinson
1.4	Optimal oral care practice for the dying person	Grethe Skorpen Iversen
1.5	10/40 Model Delphi Study	Carl Johan Fürst John Ellershaw
1.6	10/40 Model strategies and effectiveness in Latin America	Vilma Tripodoro
1.7	Collaborative Research Strategy	John Ellershaw Agnes van der Heide
1.8	The White Rose Project (CODE)	Catrina Mayland
PROJECT GROUP 2 – EDUCATION		
Project		Led by
2.1	Summer School	Marisa Martin-Rosello
2.2	Webinar development	Susie Wilkinson Mark Boughey
PROJECT GROUP 3 – 10/40 MODEL		
Project		Led by
3.1	10/40 Model Documentation, Congruence and Implementation	Carl Johan Fürst John Ellershaw Susie Wilkinson
3.2	Reference Centres	Susie Wilkinson Grethe Skorpen Iversen Vilma Tripodoro Naveen Salins
3.4	Project Spain	Marisa Martin-Rosello
3.5	Project Portugal	Catarina Simões
PROJECT GROUP 4 – QUALITY ASSURANCE		
Project		Led by
4.1	Promote the Quality Improvement Framework	Susie Wilkinson
4.2	10/40 Model Staff Perception Questionnaire	Susie Wilkinson
PROJECT GROUP 5 – COORDINATION		
Project		Led by
5.1	International Collaborative Coordination	John Ellershaw
5.2	Website content development plan	John Ellershaw
5.3	Communication strategy	John Ellershaw
5.4	Financial model development	John Ellershaw Mark Boughey
5.5	2022 Annual Symposium: Liverpool, UK	John Ellershaw

5.6	2023 Annual Symposium: Rotterdam, Netherlands	Agnes van der Heide
-----	---	---------------------