

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

ANNUAL REVIEW

2021/22

CONTACT DETAILS

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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 2021/22.

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 2021, and the detail of this report is testament to our significant achievements.

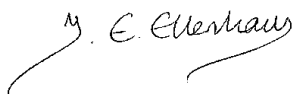
The Collaborative continues to potentiate and develop its research portfolio and position itself as the world leader in care for the dying research, with work continuing on our two major international research projects. The ERANet-LAC CODE group, under the leadership of Prof Dagny Faksvåg Haugen, is now publishing its important findings, while the international iLIVE project led by Professor Agnes van der Heide is nearing the end of its data collection period. 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.

2022 has also seen an abatement of the pandemic, meaning for the Collaborative a return to face to face events. We were delighted in May to visit the beautiful new Yusuf Hamied Centre for Studies & Research in Palliative Care for our first Summer School in three years, about which you can read more below. We're also very much looking forward to welcoming members from around the world to Liverpool on 12th and 13th October for the Seventh 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, 17 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
October 2022

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 2021/22, 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 2021/22 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 2021/22 year the Collaborative achieved its highest level of membership ever, with 204 members from 17 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 over the last year. Two more papers have been published since the last annual review. One is a paper presenting results on the advance care planning items included in the questionnaire in Argentina and Norway¹. This paper was included in the PhD thesis of Dr. Nina Elisabeth Hjorth at the University of Bergen. The second article presents further validation of the CODE questionnaire based on project data.² These results were also presented in a free communication session at the digital EAPC World Research Congress this spring.

A third paper on qualitative results has been submitted for publication and is currently under review.

¹Hjorth NE, Huffhammer KO, Sigurdardottir K, Tripodoro VA, Goldraij G, Kvikstad A, Haugen DF, on behalf of the ERANet-LAC CODE project group. Hospital care for the dying patient with cancer: does an advance care planning invitation influence bereaved relatives' experiences? A two country survey. *BMJ Support Palliat Care* 2021; online ahead of print. doi: 10.1136/bmjspcare-2021-003116

²Mayland DR, Keetharuth AD, Mukuria C, Haugen DF. Validation of 'Care Of the Dying Evaluation' (CODE™) within an international study exploring bereaved relatives' perceptions about quality of care in the last days of life. *J Pain Symptom Manage* 2022; 64:e23-e33.

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 and are currently involved in patient recruitment and data collection. The cohort study 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 CDSS will be evaluated in three countries in a study with a pre-post 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.

Alongside these empirical studies we have also been further working on the development of a Core Outcome Set to assess quality of end of life care as experienced by patients and relatives. We further focused on engagement of the wider community with the project and its aims, through newsletters, presentations at conferences, and social media activities.

Despite the major impact of the pandemic that continued in 2022, we have been able to further work on the project and set important steps. In 2023, patient recruitment and data collection be completed. We plan to analyse the results of different work packages in 2023.

4.3. The CO-LIVE study on quality of palliative care: experiences of health care professionals and relatives from 14 countries during the COVID-19 pandemic

During the COVID-19 pandemic, measures imposed by governments and healthcare institutions to limit spreading of the disease may have negatively impacted the quality of care for dying patients.

Aiming to provide insight into similarities and differences between countries, we studied the experiences of healthcare workers caring for patients in their last days of life during the COVID-19 pandemic as well as of those of relatives of people who died during the COVID-19 pandemic.

An open online survey study, consisting of purposively designed measures of perceived quality of care for dying patients, was conducted among healthcare workers and relatives from April 2020 to June 2021 in Belgium, Czech Republic, Norway, Slovenia, the Netherlands, United Kingdom, Argentina, Brazil, Chile, Colombia, El Salvador, Uruguay, Indonesia and Japan. We collected questionnaires from over 3,000 healthcare workers and bereaved relatives.

Preliminary results show important differences between countries in the impact of the COVID-19 pandemic and related measures on end-of-life care. Although in all countries the majority

of healthcare workers reported sufficient quality of medical and nursing care, there were large differences in perceived limitations in treatment and care due to the pandemic. Results of relatives' experiences will be synthesized and analysed in due course. In addition to scientific papers on national data, we plan to publish at least two scientific papers on this international comparative study.

5. EDUCATION

5.1. Fourth Annual Summer School, Benalmádena, Spain

After a COVID-enforced absence of three years, May 2022 saw the International Collaborative Summer School take place at the new headquarters of the Cudeca Institute, the Yusuf Hamied Center, in Benalmadena, 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:

- iLIVE Work Package 3 – the volunteer study
- The Serious Illness Care Programme
- Facilitator workshops
- Cui-DAR, the Spanish care plan currently in development at Cudeca.

For the first time, the Collaborative invited scientific abstracts for oral and poster presentation at Summer School. Twenty-two were received, with three being selected for oral presentation and the remainder presented as posters. The poster prize was awarded to Anna Sandgren of Linnaeus University, Sweden, for her poster 'Patient Identification for Serious Illness Conversations: A Scoping Review'.

5.2. Webinar Programme

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 virtual training sessions via the Zoom platform. 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. Following a successful first year of webinars in 2021, four webinars were planned for 2022. The topics included:

- Is Advanced Care Planning worth advancing?
- Why would we assist in someone's dying?

- Dying in the digital age: are you prepared?
- Global challenges for opioid use in care for the dying person

There has been between 40 and 60 attendees at each event from both within and outside of the Collaborative. A new programme for 2023 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. During 2021/22 the 10/40 Model has been evaluated and validated by a three round Delphi study.

The 10/40 Model is supported by a four-phase, ten-step implementation and dissemination framework.

6.2. Quality Improvement Framework

The International Collaborative Quality Improvement Framework (QIF) has been developed by the Facilitator Network (see [Section 4.5](#)). 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 up a range of resources in their own languages to support its 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. More recently the Facilitator Network has developed a Foundation course training programme which includes curriculum content, learning outcomes and teaching methods.

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 32 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 very productive workshop at the annual Summer School in Malaga in May 2022. 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:

- Experience of implementing and disseminating the 10/40 Model, including projects and also new developments due to the pandemic
- The development of new Reference Centres
- To update the QIF
- Mouth Care project for optimal oral care for the dying person
- The development of an EU COST proposal to assist in funding the work of the Facilitator Network
- 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 are also involved in the iLIVE research project and others in the COMCARE submission which focuses on the serious illness conversation guide and an advanced communication skills core curriculum for nurses.

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

7. CONCLUSION

To build upon the successes of 2022, 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 2023 Annual General Meeting.

Planning is also well underway for future events that will further consolidate the work of the Collaborative. With the return to in-person meetings firmly established, 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, February 2023

The next Research Thinktank will take place in February 2023. 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. Fifth Annual Summer School, 18-20 May 2023

From 18th to 20th May 2023, Collaborative members will come together once more at the Cudeca Institute's Yusuf Hamied Centre in Benalmadena, Spain, for an intense three-day programme of meetings 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. Eighth Annual Symposium, November 2023

The 2023 Annual Symposium of the International Collaborative on Best Care for the Dying Person will be hosted by Erasmus MC, University Medical Center Rotterdam, the Netherlands, together with Amsterdam University Medical Center and Netherlands Comprehensive Cancer Organisation. The most likely date is the week of 13 November 2023. This symposium will include presentations on the results of the international EU funded iLIVE project. It will also launch the new national guideline on Best care for the dying person.

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 and Portuguese)	
1(c)	Devise an adapted delivery programme for the EU Horizon 2020 iLIVE project in light of the coronavirus pandemic	
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)	Finalise a three-year strategy document for further collaborative research, to include: <ul style="list-style-type: none"> • Serious Illness Care Programme • 10/40 Model 	
2(b)	Undertake an Implementation Research study on the 10/40 Model strategies and effectiveness in Latin America	
2(c)	To facilitate International collaborative research for the Serious Illness Care Programme - COMCARE	
2(d)	Prepare a paper for publication on optimal oral care practice for the dying person	
2(e)	To deliver the annual Research Thinktank meeting	
2(f)	Publish and disseminate the results of the Delphi survey on the Collaborative's 40 core outcomes for care for the dying	
2(g)	Submit the 40 core outcomes for publication on the COMET database	
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)	Encourage take-up of the 10/40 Model and provide support to the 17 organisations with congruence-approved documentation, underpinned by the Facilitator Network	
4(b)	To disseminate findings of the 10/40 Delphi Study to those organisations that have congruent documents.	

4(c)	Maintain two established International Collaborative Reference Centres and support the further development of three others	
4(d)	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)	Maintain bi-monthly mailshot communications via the bestcareforthedying.org website	
5(c)	Establish a subgroup to oversee the development of the Collaborative's online presence	
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 Virtual Symposium, November 2022 Costa Rica EAPC World Congress, 18-20 May 2022 	
	<ul style="list-style-type: none"> PAL 2022, Montreal, 18-21 October 2022 	
	<ul style="list-style-type: none"> Asia Pacific Hospice Network, 2023 	
	<ul style="list-style-type: none"> Indian Association of Palliative Care conference 2023 	
	6(b)	Build and utilize linkages with WP8 of iLIVE to disseminate the Collaborative's work
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 7 th Annual Symposium in October 2022	
7(b)	Deliver the 7th Annual Symposium in Liverpool, 10-14 October 2022	
7(c)	Develop the programme for 8th Annual Symposium in Rotterdam (2023)	
7(d)	Agree and announce the date and location of the 2024 Annual Symposium	
7(e)	Deliver the Summer School event in 2022	
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	

APPENDIX 2: TERMS OF MEMBERSHIP

International Collaborative
for Best Care
for the Dying Person



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	Co-LIVE	Agnes van der Heide
1.5	Optimal oral care practice for the dying person	Grethe Skorpen Iversen
1.6	10/40 Model Delphi Study	Carl Johan Fürst John Ellershaw
1.7	10/40 Model strategies and effectiveness in Latin America	Vilma Tripodoro
1.8	Collaborative Research Strategy	John Ellershaw Agnes van der Heide
1.9	The White Rose Project (CODE)	Catriona 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
4.2	Promote the Quality Improvement Framework	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