

International
Collaborative
for Best Care
for the Dying Person

ANNUAL REVIEW

2019/20

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Contents

1. Foreword from the Chair of the International Collaborative	2
2. About the International Collaborative	3
3. Executive Committee Update	3
3.1. 2019/20 Strategic Objectives	3
3.2. Membership	6
3.3. Education & Training Endorsement Framework	7
3.4. Website development strategy	7
3.5. Dissemination	8
4. Project Group Developments	8
4.1. ERANet-LAC CODE: International Care Of the Dying Evaluation (CODE): quality of care for cancer patients as perceived by bereaved relatives	9
4.2. Living Well, Dying Well: A research programme to support living until the end (iLIVE)	9
4.3. Quality Improvement Framework	10
4.4. Facilitator Network	11
5. Looking Forward	12
5.1. Fourth Annual Summer School, 7-9 May 2021	12
5.2. Seventh Annual Symposium, 15-19 November 2021	13
Appendix 1: Terms of Membership	14
Appendix 2: Project Groups	15

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 2019/20.

It is fair to say that 2020 has been a year of challenges that none of us could have anticipated. The coronavirus pandemic has had an enormous impact on daily life, leaving us all learning to cope with constantly-changing priorities and new ways of working. Nowhere is this more true than in the healthcare sector, where the complex and competing demands of the past ten months could easily have led to a loss of momentum amongst the Collaborative's membership. Instead, though, we have seen a renewed vitality and commitment to furthering our work.

I am pleased to say that we have made excellent progress towards achieving the strategic objectives set by the Executive Committee at the end of 2019 to support the Collaborative's constitutional aims, with work continuing throughout the year on our two major international research projects. ERANET LAC CODE, under the leadership of Prof Dagny Faksvåg Haugen, is now in the writing-up stage, and the iLIVE project led by Professor Agnes van der Heide is moving into its second year of preparation and implementation.

2020 also saw the opening of our second International Collaborative Reference Centre, this time in Argentina, and two more organisations have had their clinical documentation assessed for congruence with the 10/40 Model. The 10/40 Model itself is now underpinned by a comprehensive Quality Improvement Framework containing a wide range of guidance documents and templates, together with a framework for endorsement of external education and training courses to support its implementation, and all this is now available for members on the Collaborative's new state-of-the-art website at bestcareforthedying.org.

Each of these achievements is described in more detail later in this document, and I am immensely proud to be able to report such remarkable progress in spite of the adversities presented by the health crisis. 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. I would like to express sincere thanks 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, in the midst of the current pandemic, our efforts have never been more important.

Yours,



Professor John Ellershaw

Chair of the International Collaborative for Best Care for the Dying Person
November 2020

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, 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 2019/20, 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. 2019/20 Strategic Objectives

At last year's Annual Symposium event in Bergen, the Executive Committee approved a set of strategic objectives for the 2019/20 year in support of the Collaborative's core aims as set out in its Constitution. Despite the impact of the coronavirus pandemic on capacity and services, excellent progress has been made against the objectives, as described below.

AIM 1: Build on, extend and foster the collaborative working relationship established during the OPCARE9 EU 7th Framework Project, guided by the principles of the Collaborative for Best Care for the Dying Person.		
2020 Strategic Objectives		Progress update
1(a)	Increase membership by 50%	See Section 3.2
1(b)	Develop a robust financial model to underpin the Collaborative	Group membership has been introduced alongside organisational and individual membership

AIM 2: Drive forward an international 'care for the dying' research agenda and undertake collaborative international research		
2020 Strategic Objectives		Progress update
2(a)	Complete the ERANet LAC CODE project according to agreed milestones	See Section 4.1
2(b)	Achieve all of Year 2 milestones for EU Horizon 2020 iLIVE project	See Section 4.2
2(c)	Develop a strategy for further collaborative research	Three new Collaborative research projects developed: <ul style="list-style-type: none"> • 10/40 Model Delphi • Co-LIVE • Serious Illness Conversations Programme Development of formal strategy will now take place in 2020/21.
AIM 3: Encourage international learning and teaching collaborations to improve the care for the dying		
2020 Strategic Objectives		Progress update
3(a)	Promote project development at Summer School	Summer School 2020 was cancelled due to the coronavirus pandemic; however, projects scheduled for discussion (in particular the Serious Illness Conversations Programme and the Facilitator Network) have since been progressed in a series of Zoom meetings.
3(b)	Develop a framework for education delivery endorsed by the Collaborative	See Section 3.3
AIM 4: Set, articulate and nurture care for the dying related values, quality indicators, obligations and strategic aims across the international clinical community		
2020 Strategic Objectives		Progress update
4(a)	Arrange an open meeting/workshop at the next EAPC World Congress, to be held in Helsinki in 2021	Request submitted to EAPC but was declined by the organising committee. Individual abstracts will be submitted to EAPC 2021.
4(b)	Dissemination of the 10/40 Model	Successful dissemination has continued, with a total of 13 organisations having received approval of their clinical documentation following a robust congruence assessment process.

AIM 5: Provide an international platform for health professionals to communicate with each other to improve the care for the dying		
2020 Strategic Objectives		Progress update
5(a)	Produce a strategy for ongoing development of the Collaborative website	See Section 3.4
5(b)	Develop a sustainable model for Summer School to increase and sustain attendance levels	Development plans for Summer School continue subject to the limitations of the Covid-19 pandemic
AIM 6: Support the development of the “International Collaborative 10/40 Model for Best Care for the Dying Person” and associated materials and processes within a five year Quality Assurance Cycle		
2020 Strategic Objectives		Progress update
6(a)	Establish new International Collaborative Reference Centres	Congratulations to Dr Vilma Tripodoro and her team at Pallium Latinoamerica, who have successfully established a new Reference Centre in Buenos Aires, Argentina.
6(b)	Launch the Quality Improvement Framework	See Section 3.4
6(c)	Conduct a Delphi survey among members on the Collaborative’s 40 core outcomes for care for the dying	Project currently in development; objective to be carried forward to 2021.
AIM 7: Develop an effective communication strategy across international partners to enable innovative growth in support of dynamic international care for the dying work streams, acknowledging, disseminating and celebrating success		
2020 Strategic Objectives		Progress update
7(a)	Promote the work of the Collaborative at the following: <ul style="list-style-type: none"> Latin American Congress of Palliative Care International Congress on Palliative Care, Montreal Other relevant national and international meetings 	See section 3.5
7(b)	Distribute a minimum of four Members’ Update emails	Achieved.

AIM 8: Develop and take part in societal debate about care for the dying person and the wider issues of death and dying in society		
2020 Strategic Objectives		Progress update
8(a)	Deliver a dedicated session on societal debate at the 2020 Annual Symposium	Deferred due to pandemic; now scheduled to take place in 2021.
AIM 9: Hold an Annual General Meeting		
2020 Strategic Objectives		Progress update
9(a)	To hold an Annual General Meeting at the Annual Symposium in November 2020	Meeting scheduled to take place online on 16 th November 2020.
AIM 10: Hold an Annual Symposium		
2020 Strategic Objectives		Progress update
10(a)	Deliver the 7th Annual Symposium in Liverpool, UK (16 th -18 th November 2020)	Deferred due to pandemic; now scheduled to take place in 2021.
10(b)	Develop the programme for 8th Annual Symposium in Cologne, Germany (2021)	The 8 th Annual Symposium will now take place in Rotterdam in 2022.

3.2. Membership

In recognition of the unprecedented challenges faced by the healthcare community in 2020, the Collaborative's Coordinating Centre has continued to provide support throughout the year to members and organisations whose fees have remained unpaid, on the understanding that these will be brought up to date at the earliest opportunity. At the time of writing, the number of paid subscriptions stands at 89 members from 12 countries, but it should be noted that these figures do not represent the total numbers for 2019/20, and an update will be issued at the end of the calendar year by which time we expect that all outstanding payments will have been made.

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 1 on page 14.

3.3. Education & Training Endorsement Framework

An important development in 2020 was the Executive Committee's introduction of the new Education & Training Endorsement Framework, part of the Collaborative's commitment to providing its members with opportunities for education, training and development that supports the delivery of best care for the dying person and the implementation of the 10/40 Model.

The Endorsement Framework provides an opportunity for member organisations to promote their own education and training courses to a much wider audience than they might otherwise reach, through inclusion on the regular Collaborative Update newsletters and a dedicated listing on the public-facing element of the new bestcareforthedying.org website. Approval also allows organisations to use an exclusive "endorsed by the International Collaborative" logo on their course marketing materials.

In turn, Collaborative members attending these endorsed courses will benefit from a discount of at least 10% on the registration fee, as well as the assurance that the course has been assessed by the Executive Committee and is in line with the Collaborative constitutional aims.

A Course Endorsement Proposal form is available from the International Collaborative website, together with associated guidance.

3.4. Website development strategy

The Coordinating Centre has produced a comprehensive strategy for the bestcareforthedying.org website, identifying specific aims to better meet the needs and expectations of its users, both within and outside of the Collaborative:

Website Aims	
Aim 1	To be a valuable resource for members, containing accurate and timely information on relevant topics related directly or indirectly to the Collaborative's core business.
Aim 2	To disseminate the Collaborative's research, quality improvement and educational work to its membership and the wider healthcare community.
Aim 3	To be a platform for communication between members to facilitate peer support, networking, and the sharing of thoughts and ideas.
Aim 4	To raise awareness of the Collaborative within the healthcare community and attract new members.
Aim 5	To advertise and promote International Collaborative events.

Underpinning these aims is a series of objectives intended to ensure that the website becomes a valuable resource for Collaborative members. Foremost in 2020 was the the development of a new website, designed and built with our members in mind and offering a clearer understanding of the Collaborative's structure and function. The new site contains transparent information for non-members, as well as a dedicated interactive space for members only, where they can communicate, share ideas, and access the full suite of Quality Improvement Framework tools (see Section 4.3).

We are delighted to be able to launch the new site at our Annual General Meeting on 18th November 2020, and hope that you will find it to be a useful resource.

3.5. Dissemination

The 2020 pandemic resulted in the widespread cancellation of academic conferences, including our own Summer School and Annual Symposium, and severely limited our plans to disseminate the work of the Collaborative to national and international audiences. However, the world is now adjusting to the 'new normal' and a number of major conferences have already announced online programmes for 2021. This brings a great opportunity for the Collaborative to increase its international profile as events open up to more members than ever before.

With this in mind, the Executive Committee requests members planning to attend a conference in the coming year to kindly consider submitting an abstract on the work of the Collaborative. In this way, we hope to further enhance the Collaborative's visibility and membership, thereby increasing its potency as a force for developing research and quality improvement in care for dying patients on a global scale.

Members participating in dissemination activity on behalf of the Collaborative are requested to advise the Coordinating Centre so that a record of activity can be maintained. The Centre can also provide approved poster and PowerPoint templates should they be required.

4. PROJECT GROUP DEVELOPMENTS

A great deal of progress has been made across all Collaborative project groups in the past twelve months. The full list groups is included as Appendix 2 (page 15), and detailed updates on key projects are set out overleaf.

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, and final reports have been submitted to the ERANet-LAC Secretariat and the various national funding agencies.

The project team are continuing to disseminate their findings and, thus far, articles have been published in Palliative Medicine¹ and BMC Palliative Care². Another paper has been submitted and is currently under review, and a further five manuscripts are in preparation. The project team continues to work on the dissemination of results, and hopes to submit at least two more papers this year.

Three posters and a free oral communication from the project were presented at the online EAPC World Research Congress 2020. A poster has been accepted for virtual presentation at the Latin American Palliative Care Congress in March 2021, and abstracts have also been submitted to various national conferences. Data from the project are being used in one Master and three PhD theses, by the Brazilian, German and Norwegian partners. Data will also be used for further psychometric testing of the i-CODE questionnaire.

The project website www.icode7.org is being kept updated and gives an overview of dissemination activities. The booklet "Innovations Umbrella – Improving the care for dying patients and support for the relatives. A collection of ideas and experiences from the ERANet-LAC CODE project" may be downloaded from the website or by this link: <https://tjinfo.uib.no/Vedlegg?id=f6a7088ae4cec596f566c8c7b1004145>

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.

¹ [Assessing quality of care for the dying from the bereaved relatives' perspective: Using pre-testing survey methods across seven countries to develop an international outcome measure.](#)

Mayland CR, Gerlach C, Sigurdardottir K, Hansen MIT, Leppert W, Stachowiak A, Krajewska M, Garcia-Yanneo E, Tripodoro VA, Goldraij G, Weber M, Zambon L, Passarini JN, Saad IB, Ellershaw J, Haugen DF. *Palliat Med.* 2019 Mar;33(3):357-368. doi: 10.1177/0269216318818299. Epub 2019 Jan 10.

² [Factors affecting quality of end-of-life hospital care - a qualitative analysis of free text comments from the i-CODE survey in Norway.](#)

Hansen MIT, Haugen DF, Sigurdardottir KR, Kvikstad A, Mayland CR, Schaufel MA; ERANet-LAC CODE project group. *BMC Palliat Care.* 2020 Jul 7;19(1):98. doi: 10.1186/s12904-020-00609-x

This year, the project team has developed and completed a protocol for an international cohort study of patients in the last phase of life. Instruments and procedures have been developed for patient recruitment and data collection at baseline and follow-up, and the protocol has been approved by research ethics committees in almost all participating countries. Although the start of the study was delayed due to the COVID-19 pandemic, in November 2020 three countries were able to include their first patients. A protocol has been developed for complementary qualitative interviews with patients, family members and attending health care professionals, and these interviews will also commence around November 2020.

For the study on medication management, we developed 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 as part of the cohort study.

The volunteer work package involves a phase 2 complex intervention study to evaluate a hospital palliative and end of life care volunteer programme. The study will be conducted in five countries as part of the cohort study. 2020 has seen the development of an international Core Curriculum for Volunteers, 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.

Despite the major impact of the pandemic, we have been able to further work on the project and set important steps, and we are hopeful that patient recruitment and data collection can be fully launched in 2021.

4.3. Quality Improvement Framework

We are delighted to announce the launch of the International Collaborative Quality Improvement Framework, now available to members via the bestcareforthedying.org website. Developed by the Facilitator Network (see Section 4.4), the QIF has been designed to support organisations in the implementation of the 10/40 Model.

The 10/40 Model is based on the ten key principles for best care for the dying person³, and addresses 40 outcomes of care that can be integrated into a clinical document to support individualised care for the dying person at the bedside. It is underpinned by a four-phase,

³ [Best care for the dying patient](#)

Ellershaw John E, Lakhani Mayur. *BMJ* 2013; 347 :f4428 doi: <https://doi.org/10.1136/bmj.f4428> (Published 12 July 2013)

ten-step implementation and dissemination structure, designed by the Facilitator Network, to embed the model into clinical practice.

Having worked with the 10/40 Model for a number of years, individual members of the Facilitator Network had each built up a range of resources in their own language to support its implementation and dissemination. For the first time, these resources have been brought together, translated, and organised into a Quality Improvement Framework (QIF) to assist organisations using the 10/40 Model to develop their own tools and resources more easily.

The resources within the QIF include leaflets, flyers, check lists, audit tools, reflection proforma, focus group questions, and evaluation questionnaires, and each is available in English as well as in its original language. It provides all members of the Collaborative with tools that can be used at each of the four phases or ten steps of the implementation and dissemination process.

To support the QIF the facilitator network is also Developing an outline training programme which includes curriculum content, learning outcomes and teaching methods, and we look forward to reporting progress on this in 2021.

4.4. 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. 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.

Network Facilitators usually have very productive workshops at the Summer School and at the Annual Symposium week, but of course, given the restrictions on international travel this has not been possible in 2020. However, the members have continued to meet via Zoom to discuss 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
- Development of a proposal regarding an educational programme on the implementation of the 10/40 model
- Several Reference Centres in progress
- QIF update and review before launching on the new webpage
- Mouth Care project for optimal oral care for the dying person, from 2020 in collaboration with a dentist

In addition to the work noted above, several facilitators are also involved in the iLIVE research project and others in the Serious Illness Conversations Project.

At the time of writing (November 2020), the Facilitator Network has grown to include 25 facilitators from 12 countries within the International Collaborative. In 2020 alone, facilitators from four new countries have joined the network and taken part in the quarterly meetings with the wider group. Indeed, the network now spans such a large geographical area that, since June 2020, it has been necessary to hold two asynchronous but identical meetings to cater for members from different time zones.

If you would like to join the Facilitator Network, or to enquire further about its work, please contact Susie Wilkinson drsusie@btinternet.com or Grethe Skorpen Iversen grethe.skorpen.iversen@helse-bergen.no.

5. LOOKING FORWARD

To build upon the successes of 2020, 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 2021 Annual General Meeting.

Planning is also well underway for future events that will further consolidate the work of the Collaborative, and we remain hopeful that we will be able to meet in person in 2021. We encourage you to save the following dates in your diary now to ensure that you can share in what is sure to be a series of dynamic and enriching events.

5.1. Fourth Annual Summer School, 7-9 May 2021

Scheduled to take place in Málaga, Spain, from 7th to 9th May 2021, the 4th Annual International Collaborative Summer School will follow the same innovative programme that was proposed for the cancelled 2020 event. This includes 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.

As the trajectory of the pandemic is still unclear, we are also preparing a back-up plan whereby Summer School can be delivered via Zoom in case international travel is not permitted.

5.2. Seventh Annual Symposium, 15-19 November 2021

Pandemic-permitting, we hope to welcome our members to Liverpool next year for the Seventh Annual International Collaborative Symposium, scheduled to take place from 15th to 19th November 2021. This flagship annual event will incorporate the national UK conference “Global Research and New Innovations in Best Care for the Dying Person”, endorsed by the Association for Palliative Medicine of Great Britain & Ireland. Again, alternative plans will be developed to ensure that the event can be delivered virtually, if necessary, but we remain hopeful that we will be able to welcome you to Liverpool in person once again.

Further details and registration information for both of these events will be communicated to members via the regular email newsletter. We hope that as many members as possible will join us to share learning and drive forward the development our exciting research, development and education project portfolio.

APPENDIX 1: 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:

- **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

APPENDIX 2: PROJECT GROUPS

PROJECT GROUP 1 - 10/40 MODEL		
Project		Led by
1.1	10/40 Model Documentation, Congruence and Implementation	Carl Johan Fürst John Ellershaw Susie Wilkinson
1.2	Reference Centres	Susie Wilkinson Grethe Skorpen Iversen Marisa Martin-Rosello
1.3	Project India	Naveen Salins Susie Wilkinson
1.4	Project Spain	Marisa Martin-Rosello
1.5	Project Portugal	Rui Carneiro
1.6	10/40 Model Delphi Study	Carl Johan Fürst John Ellershaw
1.7	Co-LIVE	Agnes van der Heide
PROJECT GROUP 2 - QUALITY ASSURANCE		
Project		Led by
2.1	Clinical Document Audit Toolkit	Vilma Tripodoro/Jo Davies
2.2	CODE	Catriona Mayland
2.3	Optimal oral care practice for the dying person	Grethe Skorpen Iversen
2.4	Development of a Quality Improvement Framework	Susie Wilkinson
PROJECT GROUP 3 - RESEARCH		
Project		Led by
3.1	ERA Net LAC iCODE	Dagny Faksvåg Haugen
3.2	iLIVE - EU Horizon 2020	Agnes van der Heide
3.3	Serious Illness Conversations Programme	Susie Wilkinson
3.4	Co-LIVE [Project proforma awaited]	Agnes van der Heide
PROJECT GROUP 4 - EDUCATION		
Project		Led by
4.1	Summer School	Marisa Martin-Rosello
4.2	Collaborative Visiting Fellow Programme	Executive Committee
4.3	Education Framework	Susie Wilkinson
PROJECT GROUP 5 - COORDINATION		
Project		Led by
5.1	International Collaborative Coordination	John Ellershaw
5.2	2020 Virtual Symposium: 16-19 November, via Zoom	John Ellershaw
5.3	2021 Annual Symposium: 15-19 November, Liverpool, UK	John Ellershaw
5.4	2022 Annual Symposium: Rotterdam, Netherlands	Agnes van der Heide