

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

ANNUAL REVIEW

2018/19

Supported by the Coordinating Centre at

Palliative Care Institute

Liverpool

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1. FOREWORD FROM THE CHAIR OF THE INTERNATIONAL COLLABORATIVE

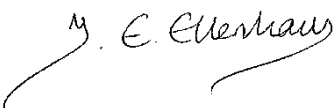
It is my great pleasure to introduce to you the Annual Review of the International Collaborative for Best Care for the Dying Person, to be presented at our Annual General Meeting. The AGM will take place as part of the Sixth Annual Symposium, kindly hosted in beautiful Bergen, Norway, by Professor Dagny Faksvåg Haugen and her team at the University of Bergen.

2018/19 has been a year of growth and development, and this report contains progress updates on a number of Collaborative projects, including:

- the completion of a Quality Improvement Framework to support Collaborative members in the implementation of the 10/40 Model;
- the conclusion of the EraNET-LAC International CODE project, with successful achievement of all deliverables and milestones;
- achievement of the Year 1 milestones for the EU Horizon 2020-funded “Living Well, Dying Well: A research programme to support living until the end” (iLIVE) project;

I am sure you will join me in congratulating all those involved in these successes, which are discussed in more detail in Section 4 of this report.

I would like to express my personal thanks to all the Project Group Leads for their hard work and commitment, and to the Executive Committee for all they have contributed during the year. Thanks are also due to the staff at the Coordinating Centre who maintain the communication and drive between our annual meetings, and to all Collaborative members for their continued contributions of expertise, energy, and commitment to our important work. Together, we are the global focus for driving forward best care for the dying person, and, in the current pandemic circumstances, our work has never been more important.



Professor John Ellershaw

Chair of the International Collaborative for Best Care for the Dying Person
November 2019

2. ABOUT THE INTERNATIONAL COLLABORATIVE

2.1. Background

The International Collaborative for Best Care for the Dying Person (hereafter referred to as 'the Collaborative') was formed in January 2014 by a group of leading thinkers, practitioners and researchers from 12 countries who had previously worked together on a EU FP7 Co-ordination and Support Action Grant to optimise research for the care of cancer patients in the last days of life, known as OPCARE9.

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.

2.2. Objectives

The Constitution of the International Collaborative was ratified in 2014 and sets out the following core objectives.

The Collaborative will:

- 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
- Drive forward an international 'care for the dying' research agenda and undertake collaborative international research
- Encourage international learning and teaching collaborations to improve the care for the dying
- Set, articulate and nurture care for the dying related values, quality indicators, obligations and strategic aims across the international clinical community
- Provide an international platform for health professionals to communicate with each other to improve the care for the dying
- Support the development 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
- 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
- Develop and take part in societal debate about care for the dying person and the wider issues of death and dying in society
- Hold an Annual General Meeting
- Hold an Annual Symposium

2.3. Governance

The Collaborative is overseen by an Executive Committee currently comprising 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 Institute, University of Liverpool, UK.

3. EXECUTIVE COMMITTEE UPDATE

During 2018/19, the Executive Committee has continued to meet via teleconference every two months to maintain oversight of the Collaborative's operation and development.

3.1. Collaborative Membership

At the end of its fifth full year of operation, the Collaborative represents 22 countries, encompassing 92 members and 20 organisations. We are pleased to say that this is the widest global reach that has been achieved by the Collaborative in the five years since its inception.

Membership continues to be made available to both individuals and organisations, with fees based upon countries' income levels as reported by the World Bank. Organisational membership entitles an institute or organisation to register to register three people as members of the Collaborative.

All Collaborative members, whether individual or organisational, are entitled to receive:

The quarterly newsletter of the International Collaborative for Best Care for the Dying Person

- A reduction in registration fees for the annual conference and workshops held by the International Collaborative
- Secure online access to the members' section of the International Collaborative website
- Access to the International Collaborative Documents and Quality Assurance Tools

Further information on joining the Collaborative can be found on the website at <https://bestcareforthedying.org/member-benefits/>.

3.2. Dissemination

The Collaborative's increasing international reach is largely due to the efforts made by its members in disseminating and sharing news about its work. 2019 saw Collaborative abstracts accepted for poster and oral presentations at major international meetings, and the first Open

Meeting of the International Collaborative held at the 16th World Congress of the European Association for Palliative Care in Berlin on 24th May.

While our dissemination activity is undoubtedly increasing there remains great scope for further development, and the Executive Committee requests that any member planning to attend a national or international conference kindly considers 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 to ensure that central records 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 of active Project Groups is included as Appendix 1, 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 ERANet-LAC CODE project is a three-year project (2017-2020, reference ELAC2015/T07-0545) involving partners in Argentina, Brazil, Uruguay, Germany, Poland, the UK and Norway. The project has the following aims:

- develop the CODE™ questionnaire into an international tool to assess the quality of care for dying patients and support for their relatives (iCODE)
- use the iCODE in an international survey of bereaved relatives after cancer deaths in hospitals, and obtain a report on the current level of care provided
- demonstrate that care may be improved on the basis of iCODE results, by conducting quality improvement projects in one country in Europe and one in South America.

When the International Collaborative met in Buenos Aires in November 2018, the CODE international survey was almost complete. We ended up with 914 completed questionnaires, well above our goal of 600, and no country had less than 100 responses. During the 2018 Symposium, the results of the survey were discussed and presented for the first time, and the

last project phase planned. Before the meeting, project co-workers in the seven countries had conducted focus group interviews with bereaved relatives. These interviews had given us plenty of ideas for quality improvement based on the weakest areas identified by the survey in each country. During the meeting we planned the interventions for Argentina and Poland, the two improvement initiatives to be carried out as part of the project. However, every country volunteered to do a limited quality improvement project based on the survey results.

In 2019, interventions were conducted at two sites in Argentina and one in Poland. The projects employed acknowledged quality improvement methodology, with assessments via participatory action research. A report has been completed, and results will be discussed and presented in Bergen in November 2019. In addition to the quality improvement work, participants have been working on project publications and presentations, and we are pleased to say that the project has met its scheduled deliverables and milestones.

The iCODE website is regularly updated (www.icode7.org), and the project was presented at several important conferences the last year. A number of abstracts have been published or submitted for forthcoming conferences, and a scientific paper from the first part of the project has been published. An open meeting was recently arranged in Bergen to present results from the project to the public. We are very pleased that the final project conference could be incorporated into the 6th Annual Research Conference of the International Collaborative, "A Good Ending – Good for All", with support from the Norwegian Research Council.

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

How we care for the dying is perhaps the most pressing personal, social and public health issue of the 21st century. Every year around 4 million people die in the EU as a result of chronic disease and illness. Many will die in pain or distress, die alone, and die without appropriate health or social care for the patient and/or the family.

The iLIVE project was developed to address this problem by demonstrating the effectiveness and cost-effectiveness of two innovative interventions in end-of-life care:

- a digital clinical tool to optimize medication management
- an international volunteer programme to support patients dying in the hospital and their families.

iLIVE will also provide in-depth understanding of the concerns, expectations and preferences of dying patients and their caregivers, and deliver the first Core Outcome Set (COS) for care of the dying. Finally, iLIVE will enhance the awareness and engagement of the community at large with the reality of death and dying.

To realise this, we will perform an 11-country prospective cohort study of 2200 patients with a

life expectancy of six months or less, across different settings, diagnoses, ages (18+), genders, socio-economic and religious groups. The evaluation of both interventions and the development of the COS are embedded in this cohort study.

After extensive preparation, the iLIVE project officially started on January 1st 2019, celebrated with a kickoff meeting in Rotterdam, NL. These and other consortium meetings were characterized by great enthusiasm and fruitful discussions. In the months since, the study protocol has been developed and fine-tuned, and is currently awaiting approval by ethics committees in the participating countries.

We developed an overall protocol for the cohort study, and specific protocols for both the medication study and the volunteer study, with careful consideration given to determine which questions to ask at which moments of a patient's illness trajectory, resulting in solid questionnaires. These questionnaires will be complemented with qualitative interviews, for which an interview guide has been developed. In addition, the volunteer work package has performed a Delphi study to gain consensus on core concepts to be included in the hospital volunteer training programme, and the medication work package has developed rules for a digital clinical tool to optimize medication management in the last phase of life, based on literature and expert consultation. All study materials are currently being translated into the languages of the participating countries, after which pre-testing of the study procedures and data collection will take place.

While activity in 2019 focused mainly on preparing the study, 2020 will see the start of our fieldwork. The medication tool will be implemented in three countries in a stepped wedge cluster design, and the volunteer program will provide a train-the-trainer course for volunteer coordinators from all five participating countries. We are looking forward to obtaining the first results, and more information can be found at the study website: www.iliveproject.eu.

4.3. Quality Improvement Framework

The International Collaborative's Facilitator Network was established in 2017 to drive forward the implementation of the 10/40 Model for Best Care for the Dying Person. Its members are healthcare professionals who have been nominated by their institution, state, or country to coordinate work centred on the development, implementation, and dissemination of the 10/40 Model.

At the Summer School event in May 2018, the Facilitator Network agreed to share their knowledge and lessons learnt in order to develop a Quality Improvement Framework (QIF) to support the 10/40 Model's 4-phase, 10-step implementation process. Work on the QIF

continued in November 2018 at the Facilitator Network Meeting held during the Fifth Annual International Collaborative Symposium in Buenos Aires, Argentina, and was finally presented to participants at the 2019 Summer School in Spain.

The QIF, which will shortly be available on the Collaborative website, provides a robust source of information for new or existing members of the Collaborative planning to initiate the implementation of the 10/40 Model in their own place of work. It contains a wide range of resources to support each step of the process, including documents, leaflets, toolkits, checklists, and focus group questionnaires, alongside training programmes with learning outcomes, an audit tool, and research questionnaires such as iCODE. Also included in the framework is information on becoming a country/state-wide Reference Centre to disseminate the work of the International Collaborative.

The resources contained in the QIF were provided by the members of the Facilitator Network based on their own experience of implementing the 10/40 Model, and each was initially submitted in the facilitators' native language. All documents have subsequently been translated to English, and versions in both languages will be available on the website for members to access.

We are pleased to say that a poster abstract on the QIF was accepted for the Sixth Annual International Collaborative Symposium in Bergen, Norway, where members of the Facilitator Network will be on hand to discuss the project in more detail and answer any questions.

As well as the QIF, the Facilitator Network is also working on recommendations for optimal oral care for the dying person and the development of syllabus content and learning outcomes for a training programme to meet the 10 Key Principles for Best Care for the Dying Person. For further information on the work or membership of the Network, please contact Susie Wilkinson at drsusie@btinternet.com or Grethe Skorpen Iversen at grethe.skorpen.iversen@helse-bergen.no.

4.4. The Annual International Collaborative Summer School

The Annual International Collaborative Summer School aims to engage professionals working in end of life care worldwide by providing an international forum for interdisciplinary knowledge sharing, where experiences, current topics and new perspectives on key issues regarding end of life care will be debated, compared and discussed.

Since its first event in 2017 the annual Summer School has welcomed an average of 29 participants each year, representing between six and eight countries, and satisfaction rates have averaged 4.7/5 for both session content and organisation. The 2019 event, held in

Benalmádena, Spain, was equally well-received with participants attending a range of sessions around the 10/40 Model, Quality Improvement Framework, and the Collaborative's EU-funded research projects, as well as an action planning workshop to determine how to apply the learning points in their own workplaces.

Since Summer School first began, changes have been made each year to ensure that the format meets the expectations of its participants as well as the objectives of the International Collaborative. The 2020 event will see the most stimulating and attractive programme yet, focusing on the provision of dedicated time and space for Project Group members to meet and develop their project work within the Collaborative. For the first time, Summer School 2020 will also see a call for abstracts to share research and best practice in end of life care.

The 2020 programme will focus on the following projects:

- The International Collaborative 10/40 Model: Facilitators Forum
- The iLIVE Research Study: WP3 Volunteer Study
- The Serious Illness Communication Programme
- The Spanish Cui-DAR End of Life Care Plan

As always, the success of Summer School will depend not only on the scientific programme or the venue and organisation, but also its participants. Attracting participants from both inside and outside of the International Collaborative is one of the main opportunities of this event, and we hope that the new format for Summer School 2020 will appeal to more delegates as we aim to bring together many voices to develop our shared vision of excellence in end of life care.

5. LOOKING FORWARD

As 2019 draws to a close, we look forward with excitement to the ground-breaking work that the Collaborative's project groups will continue to undertake in 2020 and beyond.

In order to potentiate our global impact, the Executive Committee have developed a series of in-year strategic objectives for 2020 based upon the core Collaborative objectives as set out in the Constitution. These will be presented in draft form for discussion at the Annual General Meeting in Bergen and the final version circulated with the Members' Update email at the end of the year. We look forward to reporting on progress at the 2020 AGM.

Planning is also well underway for future events that will further consolidate the work of the Collaborative and provide an inspiring platform upon which the invaluable fellowship of its members can continue to flourish. 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 2020

Taking place in Málaga, Spain, from 7th to 9th May 2020, the 4th Annual International Collaborative Summer School will for the first time include a number of Project Group meetings, as described in Section 4.4 above. This new initiative is intended to accelerate each group's progress by providing dedicated time for colleagues to come together and concentrate collectively on the development of their collaborative work.

5.2. Seventh Annual Symposium, 16-19 November 2020

We are pleased to announce that the Annual International Collaborative Symposium will return to Liverpool in 2020. Taking place from 16th to 19th November, the seventh occurrence of our 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.

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

APPENDIX 1: THE PROJECT GROUP PORTFOLIO

PROJECT GROUP 1 - 10/40 MODEL		
1.1	10/40 Model Documentation, Congruence and Implementation	Carl Johan Fürst John Ellershaw Susie Wilkinson
1.2	International Collaborative Reference Centres	Susie Wilkinson Grethe Skorpen Iversen Marisa Martin-Rosello
1.3	Project India	Stan Macaden Susie Wilkinson
1.4	Project Spain	Marisa Martin-Rosello
PROJECT GROUP 2 - QUALITY ASSURANCE		
2.1	Clinical Document Audit Toolkit	Tamsin McGlinchey Jo Davies Vilma Tripodoro
2.2	CODE	Catriona Mayland
2.3	An international collaborative review of 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		
3.1	ERA Net LAC iCODE	Dagny Faksvåg Haugen
3.2	iLIVE - EU Horizon 2020	Agnes van der Heide
3.3	Serious Illness Care Programme	Susie Wilkinson
PROJECT GROUP 4 - EDUCATION		
4.1	Summer School	Marisa Martin-Rosello
4.2	Collaborative Visiting Fellow Programme	Executive Committee
PROJECT GROUP 5 - COORDINATION		
5.1	International Collaborative Coordination	John Ellershaw
5.2	2019 Annual Symposium: Bergen, Norway 4 th -7 th November 2019 "A good ending – good for all"	Dagny Faksvåg Haugen Grethe Skorpen Iversen
5.3	2020 Annual Symposium: 16-19 November, Liverpool, UK	John Ellershaw
5.4	2021 Annual Symposium: 2-5 November, Cologne, DE	Raymond Voltz
5.5	2022 Annual Symposium: Malaga, Spain	Marisa Martin-Rosello

*“Specialist expertise and general challenge meet here
in the dimension of our common humanity.”*

Dame Cicely Saunders