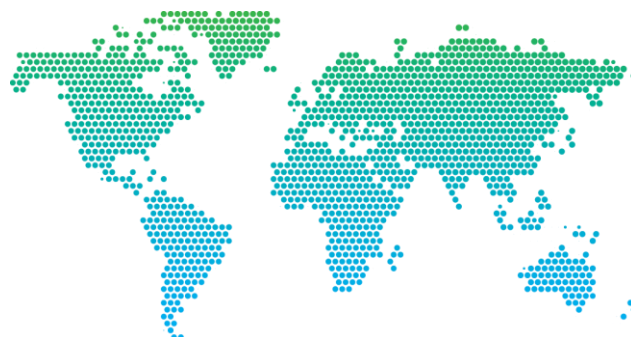


Reference Centre

Annual

2023/24



ORGANISATION DETAILS

Organisation name	Institute Pallium Latinoamérica (non-profit organisation) www.pallium.com.ar
Number and type of centres supported	<ol style="list-style-type: none"> 1. Pallium Latinoamérica Institute (home-based care) 2. Instituto de Investigaciones Médicas A. Lanari (University of Buenos Aires) (hospital care) 3. Hospital de Gastroenterología CB. Udaondo (Government of Buenos Aires City) (PCU) 4. Hospital Universitario Privado de Córdoba (Córdoba City) (home-based care and hospital) 5. CCP Baires (Private hospice Buenos Aires City)(hospice care) 6. Hospital do Buen amor (Barretos, Brasil)(PCU)(Hospital care) 7. Hospital Privado de Comunidad (Mar del Plata. Buenos Aires, Argentina) (hospital care) (Hospital care) 8. Hospital das Clínicas Samuel Libânio, Regional hospital of Pouso Alegre, Minas Gerais, Brazil. (Hospital care)

PROGRESS SINCE LAST REPORT

Progress against Reference Centre's action plan	<p>Pallium LA, during this forth year as Reference Centre, aimed to continue providing six main functions as International Collaborative Reference Centre:</p> <p>Primary function 1: Maintain and enhance the clinical documentation</p> <p>The PAMPA program (version 2.0/2016) is available to Argentina and Latin-American Spanish-speaking countries. It is currently in use in 8 sites in different phases of development, and its implementation is congruent with the 10/40 Model statements. No changes have been made to the care plan document itself in the past year.</p> <p>The CCP Baires designed an implementation research protocol to evaluate the effectiveness of the PAMPA program. The staff is still working on the preparation phase.</p> <p>The Hospital Privado de Comunidad de Mar del Plata, joined the Program in 2022 (https://www.hpc.org.ar/hospital/la-historia/). We conducted the post-implementation audit with the first 100 patients. The PC team is working on analysing the results and a SWOT analysis of the implementation process.</p> <p>The Hospital Do Amor (https://hospitaldeamor.com.br / Barretos, Brazil) has finished the first implementation phases of the 10/40 Model. We assessed 600 case records using the pre-implementation clinical toolkit. The draft manuscript for publication is still in progress, led by Dr. Michelle Uchida (Brazil) and Dr. Vilma Tripodoro (Argentina).</p>
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The Hospital das Clínicas Samuel Libânio, Regional hospital of Pouso Alegre, Minas Gerais, Brazil joined the Collaborative recently and we are working with Dr Tatiane Crepaldi and planning the first steps of implementation of the 10/40 Model. The PAMPA will be translated and adapted to the Brazilian Portuguese and culture. https://www.hcsl.edu.br/index_hcsl_1.asp

The Buen Samaritano Hospice unfortunately discontinued the Program due to changes in the Direction of the hospice and the retirement of coordinator nurses. They agreed with the commitment of a publication focused on these 7 years of experience with the Program. Data analysis is still in progress.

Primary function 2: Provide support and guidance.

Dr. Vilma Tripodoro (VT) has led the PAMPA program since 2009, and she has participated in the Collaborative as an Executive Committee member since its foundation in 2014. In addition, she has been involved in international initiatives promoting the 10/40 Model of Improvement. This year after the distribution of the Annual questionnaire we conducted a discussion group about the results and we proposed to explore barriers and facilitators of how to spread the PAMPA Program beyond the PC team in general hospitals.

The results of this process of exploration will be presented at the Annual Conference in Porto in November.

A synthesis of the main barriers to dissemination is: The implementation of the PAMPA programme faces several barriers, including a lack of awareness and motivation among health professionals outside the palliative care teams, excessive workloads and inadequate training in palliative care. Institutional challenges such as insufficient support from authorities, lack of clear procedures and poor communication policies further complicate the situation. In addition, the lack of dedicated palliative care units and high staff turnover affect the continuity and quality of care.

These problems are compounded by wider contextual factors, such as the current economic crisis and precarious working conditions, which contribute to a general lack of interest in and dehumanisation of care. Addressing these barriers requires a comprehensive approach that includes better training, improved communication and stronger institutional support to ensure effective implementation of PAMPA.

On the other hand, key facilitators include the commitment of clinical staff to participate in the PAMPA, empowerment of families regarding their right to palliative care, and institutional recognition of the palliative care team. Feedback from research on family experiences, promotional materials to raise awareness among healthcare teams, and the interest of medical leaders and residents in involving palliative care for non-oncological end-of-life patients also play crucial roles. These factors collectively enable open conversations, consideration of non-physical aspects, timely end-of-life care, and a structured approach that prioritises relevant aspects, including family involvement and patient preferences. The PAMPA programme also facilitates quantitative and qualitative data measurement, ensuring comprehensive care and continuous improvement.

Primary function 3: Provide coordination and support

Education, training, and support delivered in short training focused on "The last days of life: diagnosing dying and quality of care based on the ten principles". The principles were updated after the DELPHI consensus was published (McGlinchey et al 2023). We have a complete registry of all user sites.

Function 4: Contribute and participate in the International Collaborative

Pallium LA has continued working on a Quality Improvement Framework within the Facilitators network. VT participated in all meetings and discussions. VT reviewed the Learning outcome Document (10/40 Model) with the Facilitators Group.

In addition, VT submitted in 2023 a proposal to the [MSCA Doctoral Networks 2023 | Marie Skłodowska-Curie Actions \(europa.eu\)](#). The proposal submission, postponed to 2024, aims to design, implement and evaluate the effectiveness of an EoL care programme (PAMPA®) for dying patients in Argentina. It is a Qualitative mixed-methods, multicentre, quasi-experimental (pre-post) design implementation study. This research focuses on the need for innovative approaches to ensure the effectiveness of implemented interventions. Proposed methodologies and clinical benchmarking toolkits align with the standards of the Collaborative. This proposal is also part of the Project Group about effectiveness of the 10/40 Model.

Function 5: Annual reporting

We have registered all activities to support organisations in developing a quality assurance programme aligned with existing health services.

The main results of the Annual survey highlighted that the PAMPA Care Plan offers multiple advantages for patient care. First, it organises and systematises practice, allowing for a structured and comprehensive approach. Second, it prioritises patient needs, prevents suffering, and optimises resource utilisation. Third, PAMPA humanises care, facilitates farewells, and unifies criteria and practices among the healthcare team. In summary, it enhances the quality of interventions, patient follow-up, and communication between the team and the family.

PAMPA offers several benefits for patient care, including the organisation and systematisation of practice, prioritisation of needs, prevention of suffering, and optimisation of resources. However, it also presents challenges such as team overload, risk of stigmatisation and automation, and difficulties in home implementation. Additionally, the clinical record may lack clarity in certain aspects and requires extra time for record keeping.

To address these challenges, the following strategies are proposed:

Training and Communication: Provide adequate training on completing the PAMPA clinical record and its importance.

1. Adaptation to the Context: Make the clinical record more user-friendly and applicable in various settings, including home care.
2. Multidisciplinary Teamwork: Distribute the workload among team members and ensure availability during nights and holidays.
3. Continuous Reflection: Encourage reflection on the care process to avoid mechanisation and improve care quality.
4. Optimisation of Records: Use technology to facilitate data recording, reducing time and improving accuracy.
5. Periodic Evaluation: Conduct regular evaluations to identify obstacles and adjust implementation as needed.

Each context is unique, so these strategies should be tailored to the specific needs of the team, institutions, and patients.

Function 6: Reference group and national developmental work

Pallium Latinoamérica has an interdisciplinary staff of co-workers in Buenos Aires City with public health, the National Cancer Institute and the University of Buenos Aires and El Salvador influences. It is also responsible for physicians, nurses, psychologists and social workers in many hospitals and community health care services across Argentina. In addition, we contributed to PAMPA implementation and training on the International 10/40 Model.

OTHER ACTIVITY

Research and Development

Pallium Research Network (RED-In-PAL) has been involved in National and International Research Projects related to "The Collaborative".

1. The CODE questionnaire is now validated in Portuguese from Brazil, led by Juliana Passarini. The manuscript is still in submitting process. The validation into Spanish is also in progress but delayed for local reasons of lack of funding.
2. We participated in the design of the Work Group project "Staff Perception Questionnaire for Care Plan Implementation." (From the Facilitators Group).
3. We submitted 2 abstracts to the SECPAL Annual Congress (Malaga Spain October 2024) and 2 abstracts to the Annual Conference Porto in November 2024
4. We are still working on the RESEARCH GRANTS 2023 from the National Cancer Institute: iLIVE Project, focused on **Costs of informal care at the end of life**. We received a fellowship for a one-year grantee finishing at the end of 2024 Fellow Dr María Coller. Director Dr Vilma Tripodoro.

Indexed international publications related to the Collaborative and the best care for the dying from our group (2023-2024)

1. Joshi M, Ásgeirsdóttir GH, Bakan M, Kodba Čeh H, Haugen DRF, Lunder U, Víbora Martín E, Morris B, Rasmussen BH, Romarheim E, Tripodoro V, van der Heide A, Veloso V, Yildiz B, Zambrano S, Strupp J, Voltz R; iLIVE Consortium. Dealing With Temporality in Patients With Life-Limiting Disease: An International Qualitative Study. *Qual Health Res.* 2024 Aug 26;10497323241263751. doi: 10.1177/10497323241263751. Epub ahead of print. PMID: 39186945.
2. Tripodoro VA, Veloso VI, Víbora Martín E, Kodba-Čeh H, Bakan M, Rasmussen BH, Zambrano SC, Joshi M, Háldánardóttir SÍ, Ásgeirsdóttir GH, Romarheim E, Haugen DF, McGlinchey T, Yildiz B, Barnestein-Fonseca P, Goossensen A, Lunder U, van der Heide A. 'Someone must do it': multiple views on family's role in end-of-life care - an international qualitative study. *Palliat Care Soc Pract.* 2024 Aug 1;18:26323524241260425. doi: 10.1177/26323524241260425. PMID: 39099623; PMCID: PMC11295216.
3. Di Gennaro S, Fila J, Veloso V, Lasmarías C, Tripodoro VA; GRUPO PCA-ARGENTINA Y RED-IN-PAL (PALLIUM LATINOAMÉRICA). Escala autoeficacia percibida sobre planificación compartida de la atención (ACP-SEs) Argentina [Perceived self-efficacy scale on shared care planning (ACP-SEs) Argentina]. *Medicina (B Aires).* 2024;84(4):619-628. Spanish. PMID: 39172560.
4. Lamfre LS, Hasdeu S, Coller MAG, Tripodoro VA. Economic impact of informal care of cancer patients at the end of life. *Ann Palliat Med.* 2024 Jan;13(1):73-85. doi: 10.21037/apm-23-240. PMID: 38316399.
5. Lamfre LS, Hasdeu S, Coller MAG, Tripodoro VA. Economic impact of informal care of cancer patients at the end of life. *Ann Palliat Med.* 2024 Jan;13(1):73-85. doi: 10.21037/apm-23-240. PMID: 38316399.

CO-LIVE Study (Non-indexed paper published)

Iturri, A., Veloso, V., De las Heras, J. I., Steren, Z., Tripodoro, V. A. (2024). Cuidados al final de la vida y despedidas durante la pandemia: relatos sobre experiencias de familiares en duelo. *Revista M. Estudios Sobre a Morte, Os Mortos E O Morrer*, 9(17). <https://doi.org/10.9789/2525-3050.2024.v9n17.e12649>

Two other manuscripts of CO-LIVE study were submitted and they are under revision.

National and International Congress accepted free communications (posters or oral) and parallel session

1. SECPAL Congress October 2023 (**Salamanca, Spain**) Poster presentation. Multidisciplinary Perceived Self-Efficacy for Shared Care Planning What should we teach-learn in Argentina?
2. SECPAL Congress October 2023 (**Salamanca, Spain**) Poster presentation. Dying with dignity during the COVID-19 pandemic in Latin America: Perspectives of bereaved family members in five countries (CO-LIVE Study)

	<ol style="list-style-type: none"> 3. SECPAL Congress October 2023 (Salamanca, Spain) Oral presentation. iLIVE: live well, die well. A project to support life to the end. (iLIVE Project) 4. Rotterdam Annual Conference 2023(The Netherlands) Poster presentation: Experience and Evaluation of the 10/40 Model of Private Community Hospital, Mar del Plata, Argentina: PAMPA@ Programme and oral presentation 5. ALCP Latin American Association of PC (Colombia 2024) Use of the pre-implementation tool of the 10/40 model in a brazilian palliative care hospital: a descriptive study. Uchida M, Tripodoro V. 6. Summer School Malaga, 2024 Awarded Poster presentation: CO-LIVE Latin America qualitative study. The role of rituals in humanising the dying process: tensions between politics and culture during the Pandemic in five Latin American countries. On behalf of CO-LIVE Latinoamérica Group Tripodoro V, Veloso VI, Acero A, Castro S, Carballo MB, Montilla S, León MX, Ferreras B, Soto-Guerrero S, Perez-Cruz PE, Uchida M, López Saca M, Rodriguez M, Orellana S, Las Heras JI, Ida Korfage and Agnes van der Heide.
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Learning and Teaching	<p>Topics related to 'Best Care for the Dying Person' have been presented at relevant regional and national courses, Latin American conferences, and undergraduate and post-graduate training programs for healthcare professionals. The workshop "The last days of life: 10 principles of care" is a short training course replicated at any palliative and primary care level. It is part of our Master in Palliative Care curriculum, advanced courses, the undergraduate level at the Institute Lanari-University of Buenos Aires and other teaching activities. Every year, more than 250 students attend these workshops.</p> <p>By the end of 2024 (date to be confirmed) we are planning to perform a PAMPA seminar focusing on the 10/40 Model and based on the learning outcomes. We will invite all partners in the PAMPA program but also open to others professionals from different backgrounds.</p>
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Quality Assurance	We conducted the post-implementation audit based on 100 clinical records from the HPC Mar del Plata in Argentina. We will published the results of this implementation in a national journal.
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DOCUMENTATION OF COMPLAINTS/CONCERNS RAISED

From within user sites	We have not received any reports on complaints or concerns regarding using the PAMPA from user sites.
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From relatives, families or carers:	We have not received any reports on complaints or concerns regarding using the PAMPA from families or carers.
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OBJECTIVES FOR THE YEAR AHEAD

1.	To focus on areas of improvement identified with the clinical benchmarking toolkit setting by setting and team by team
2.	To spread and consolidate the 10/40 Model-PAMPA in Argentina and beyond (Brazil).
3.	To work on implementation research on PAMPA effectiveness
4.	To join other initiatives from the Collaborative (research, education and quality improvement).
5.	To apply to The MSCA Doctoral Networks 2024 Marie Skłodowska-Curie Actions (europa.eu).

Any other business.

1. The PAMPA team of Mar del Plata, Private Community Hospital participated in the Latin American Forum on Quality and Safety in Health, promoting the PAMPA Program in a lecture. <https://www.lacapitalmdp.com/con-foco-en-el-paciente-se-debatio-en-el-hpc-sobre-la-calidad-y-seguridad-en-salud/>



2. Pallium and the Cudeca Foundation announce the 3rd short story writing competition 'Historias Llenas de Vida' ('Stories Full of Life'). We received until now 75 short tales!! <https://www.pallium.com.ar/certamen-relato-2024/>
3. Pictures of Poster and oral presentation in Rotterdam Annual Conference (2023), ALCP International Congress (Colombia) March 2024 and SECPAL oral presentation (Salamanca, Spain)

