End of Life Doula International Research Group

5TH ANNUAL INTERNATIONAL RESEARCH SYMPOSIUM

Producing Knowledge, Shaping Practice

6–7 November 2026 · Online



DAY 1 · FRIDAY 6 NOVEMBER

Research in Practice

8:00–11:20 pm UK time

International research presentations, recorded for registered participants.

DAY 2 · SATURDAY 7 NOVEMBER

Research is for Everyone: Getting Started

7:00–11:30 pm UK time

Hands-on methods workshops and the Research Connections Lab.

THIS YEAR'S THEME

Research about end-of-life doulas is growing quickly, but who produces that knowledge, whose experience counts as evidence, and how does it find its way back into practice? **Producing Knowledge, Shaping Practice** invites us to see research as something doulas, researchers, educators and communities make together. Day 1 brings presentations from Portugal, Puerto Rico, Brazil and Australia, showing how knowledge is being built across very different cultural, community, educational and care settings, and a Research Spotlight shares further work from the United States, Canada and Australia. Day 2 turns to the practical, with hands-on introductions to research methods anyone curious about their practice can begin using, and small-group connections to spark future collaboration.

Day 1 **Friday 6 November · 8:00–11:20 pm UK time**

Research in Practice

Day 1 showcases current end-of-life doula research from around the world, highlighting how knowledge is being developed across different cultural, community, educational and practice settings.

8:00–8:15	Welcome: Where Are We Now as a Research Group?	Dr Marian Krawczyk
8:15–8:45	End-of-Life Doula Training in the Portuguese Context	PORTUGAL · Dr Matilde Gonçalves & Ana Catarina Sanches Infante
8:45–9:15	Living Research: Community Outreach as a Methodology for Knowledge About Death and Grief in Puerto Rico	PUERTO RICO · Wilka Roig, Limari Colón & Dr Mariangelly Sierra
9:15–9:25	Break	
9:25–9:55	Building the Evidence Base for End-of-Life Doula Practice in Brazil	BRAZIL · Professor Glenda Agra
9:55–10:25	Sitting with Death & The Unexpected Classroom: Death Doulas, Medical Students, and Two-Way Learning in Australia	AUSTRALIA · Danni Petkovic
10:25–10:35	Break	
10:35–11:05	Inside, Outside, In-Between: Positioning End-of-Life Doulas in Relation to Formal Care Systems in Australia	AUSTRALIA · Dr Andrea Babon
11:05–11:20	Closing reflections	

- Each presentation is 20 minutes, followed by 10 minutes of Q&A. Day 1 presentations will be recorded and made available to registered participants who are unable to attend live. Further research from our community is shared in the Research Spotlight at the end of this programme.

8:15 PM · PORTUGAL

End-of-Life Doula Training in the Portuguese Context

Dr Matilde Gonçalves, Assistant Professor and researcher, NOVA University Lisbon, NOVA FCSH, EOLD
Ana Catarina Sanches Infante, RN, EOLD, Founder and Training Coordinator for EOLD

End-of-life doulas constitute a community of training and personal development that emerged in 2019 from the need to rethink death and the ways in which one can be present during processes of transformation and heightened vulnerability throughout life. Through end-of-life doula training, participants acquire knowledge and develop competencies related to palliative care and end-of-life processes, thereby contributing to their own training and personal development.

The aims of this presentation are therefore: (1) to introduce end-of-life doula training; (2) to understand the reasons why individuals seek this training; and (3) to analyse whether, over the course of the training process, a process of personal transformation takes place and, if so, in which dimensions it is manifested.

Drawing on a questionnaire administered between November 2022 and March 2026 to the 80 individuals who completed end-of-life doula training, the 48 responses obtained will be analysed both qualitatively and quantitatively in order to address the aims outlined above.

At the theoretical level, this proposal is grounded in the work of Mezirow (1997), particularly regarding transformative learning (Moura, 2000), as well as in approaches to lifelong personal development through symbolic practices and language (Bronckart, 1997; Vygotsky, 2001).

This presentation seeks to contribute to the recognition of end-of-life doulas and to a deeper reflection on their role, as well as to the development of their organisational structures, training criteria, and fields of practice. At the same time, it acknowledges the need for broader studies on this topic.

8:45 PM · PUERTO RICO

Living Research: Community Outreach as a Methodology for Knowledge About Death and Grief in Puerto Rico

Wilka Roig, Limari Colón & Dr Mariangelly Sierra, Consciencia de la Muerte Puerto Rico

What counts as knowledge in the end-of-life doula field? Consciencia de la Muerte proposes that community outreach is itself a research methodology that builds situated, culturally grounded knowledge about how communities live with death and grief.

Between February 2025 and April 2026, we held 99 events across 16 municipalities in Puerto Rico, reaching over 1,100 people, co-created with local organisations and free for participants. Through registration data, surveys, participant observation, and 24 direct end-of-life accompaniments, we built a community diagnosis of how Puerto Rico manages death and grief, and what is missing. Findings reveal an almost total absence of formal accompaniment infrastructure, grief managed largely in silence or within religious frameworks, and strong demand.

From a Participatory Action Research framework, we reflect on the ethics of researching from within a community we also serve, and on generating knowledge from ancestral, communal ways of knowing.

9:25 PM · BRAZIL

Building the Evidence Base for End-of-Life Doula Practice in Brazil

Professor Glenda Agra, Interprofessional Study Group on the Sensitive Dimensions of Healthcare (GISS)

The Interprofessional Study Group on the Sensitive Dimensions of Healthcare (GISS) aims to develop projects that explore these dimensions from diverse perspectives. One of its research strands, “Presence: end-of-life doulas, interfaces, knowledge and praxis”, brings together a range of research proposals and initiatives to develop educational resources.

Three undergraduate research projects are currently underway.

BRAZIL · CONTINUED

The first explores ancestral knowledge, rites and rituals in the experiences of Latin American doulas; the second proposes the development of a card deck offering comfort and support to people approaching the end of life; and the third examines the transition between birth and dying as a sphere of doula practice. At postgraduate level, a doctoral thesis explores the presence of end-of-life doulas in intensive care units (ICUs). These projects address the cultural and spiritual dimensions of dying, compassionate presence, symbolic resources for accompaniment, and the integration of doulas into healthcare services.

The research is coordinated by Glenda Agra, the group's deputy leader, who supervises the students and develops further initiatives in collaboration with academic colleagues. These include a book chapter on end-of-life doulas in Latin America, an e-book on this movement in the Global South, and the First International Forum on End-of-Life Doulas, which will take place in 2026. Plans for 2027 include a module entitled "Art and Sensitive Care" and a free online course offered through the public university.

Growing academic and public interest, alongside international collaboration, presents opportunities to expand these initiatives. Challenges include limited funding and the scarcity of Brazilian research on the subject.

9:55 PM · AUSTRALIA

Sitting with Death & The Unexpected Classroom: Death Doulas, Medical Students, and Two-Way Learning in Australia

Danni Petkovic

This presentation shares findings from Australia's first doula-led death literacy program embedded in the UNSW Medicine & Health undergraduate medical curriculum. Community-based end-of-life doulas facilitated small-group sessions with Year 1 and 2 medical students across Sydney and regional campuses. Faculty clinicians were present in a supportive role, not as the experts, which softened the hierarchy, with storytelling leading the way alongside evidence, statistics, and real practice cases.

The first notable finding: students showed statistically significant improvements across all measured domains ($p<.001$), including death literacy, confidence in conversations about dying, and reflective capacity, across 250 matched pre-post responses.

The second finding was one we didn't plan for. Teaching clinicians changed too: experienced doctors began to acknowledge that death is not a failure, and not something to fix, but an inevitability to accompany. This is a scalable, evidence-informed model for embedding death literacy into medical education, and proof that culture change is possible.

10:35 PM · AUSTRALIA

Inside, Outside, In-Between: Positioning End-of-Life Doulas in Relation to Formal Care Systems in Australia

Dr Andrea Babon, Vice Chair, Holistic End of Life & Death Care Australia (HELD)

End-of-life doulas (EOLDs) have (re)emerged in Australia, as in other Western countries, partly in response to the medicalisation of dying and the difficulty of providing consistent, unhurried, person-centred care in highly regulated and fragmented formal care systems. Although 70% of Australians say they want to die at home, 80–90% of older Australians die in hospital or aged care. For EOLDs to support people in formal care settings, this paper asks how the role can become legible to formal systems without being reshaped in ways that erode its distinctive value.

This presentation argues that EOLDs occupy important "grey areas" between community and institutional care, lay and professional knowledge, and the social and clinical dimensions of dying.

AUSTRALIA · CONTINUED

These boundary-spanning positions create a challenge for integration: credentialling frameworks can give formal systems a recognisable way to assess knowledge and capability but may privilege what is measurable over the relational presence and flexibility the EOLD role must preserve.

The presentation draws on original 2026 research by HELD, undertaken to develop national practice standards and a credentialling framework for EOLDs in Australia. Semi-structured interviews with thirteen educators, thought-leaders and experienced EOLDs highlight varied views on formalisation and professionalisation within the sector.

Across these differences, participants generally accepted the need for greater structure and clarity around the EOLD role and a focus on public confidence and safety, while preserving the flexibility and relational qualities that distinguish the role.

Drawing on boundary-spanning and legitimacy frameworks, the paper explores how EOLDs can be supported to operate both inside and outside formal care systems: legible enough to be trusted by institutions, yet flexible enough to respond to people at the end of life and their families. In doing so, the paper contributes to current debates about how emerging EOLDs can gain institutional trust without losing the community-based, relational qualities on which their value depends.

11:05–11:20 pm Closing reflections

JOIN US TOMORROW

Day 2 · Research is for Everyone: Getting Started
Saturday 7 November · 7:00–11:30 pm UK time

Day 2 **Saturday 7 November · 7:00–11:30 pm UK time**

Research is for Everyone: Getting Started

Research is for everyone, even if you have never thought of yourself as a researcher. It often begins with curiosity: noticing something in your practice or experience that feels important, asking questions about it, and finding ways to explore, collaborate and share what you learn.

Day 2 offers three accessible, 45-minute workshops led by EOLD-IRG members, introducing different ways of turning questions, experiences and practice into research. Come along to learn, experiment and see which approaches might work for you.

7:00–7:30	What Counts as Knowledge? **OPENING SESSION** · Dr Marian Krawczyk
7:30–8:15	One Story in Depth: Using Case Studies to Explore End-of-Life Doula Practice as Research **WORKSHOP · CASE STUDY** · Sarah Farr, MSc
8:15–8:25	Break
8:25–9:10	Your Experience as Research: Making Sense of Practice Through Reflection **WORKSHOP · AUTOETHNOGRAPHY** · Dr Annetta Mallon
9:10–9:20	Break
9:20–10:05	Finding Meaning in Words: Creating Poems as Research **WORKSHOP · POETIC INQUIRY** · Dr Marian Krawczyk
10:05–10:15	Break
10:15–11:15	Research Connections Lab: From Shared Interests to New Possibilities **BREAKOUT ROOMS** · Facilitated by EOLD-IRG founding members
11:15–11:30	Closing

No experience needed. No previous research experience is required for any session.

Pre-register for the Lab. Choose one Delphi domain when you register so we can allocate breakout rooms.

7:00 PM · OPENING SESSION

What Counts as Knowledge? · Dr Marian Krawczyk

Different research traditions, cultures and ways of knowing; what is recognised as legitimate or valuable knowledge; and research ethics within and beyond formal institutional review.

7:30 pm

CASE STUDY

One Story in Depth: Using Case Studies to Explore End-of-Life Doula Practice as Research

Facilitator: Sarah Farr, MSc

Using an in-depth case or bounded example to explore practice, experience and context.

Why try it: case studies are easy to pick up because they build on what doulas already do — paying close, careful attention to one person, family or situation — and they offer a structured way to turn a single accompaniment, service or community project into evidence others can learn from.

Break 8:15–8:25 pm

8:25 pm

AUTO ETHNOGRAPHY

Your Experience as Research: Making Sense of Practice Through Reflection

Facilitator: Dr Annetta Mallon

Using personal experience reflexively as a source of research insight and analysis. This is also known as autoethnography.

Why try it: reflective research grows out of the journalling, debriefing and supervision many doulas already practise, so the main tools are ones you already have — and it gives a rigorous way to share the insider knowledge of sitting with the dying that is often missing from formal studies.

Break 9:10–9:20 pm

9:20 pm

POETIC INQUIRY

Finding Meaning in Words: Creating Poems as Research

Facilitator: Dr Marian Krawczyk

Exploring poetry as a way of generating, analysing and communicating research knowledge.

Why try it: no poetic training is needed — you work with words people have already spoken or written, so the method is quick to learn — and it suits doula work by capturing the emotional, embodied and unspoken dimensions of dying that conventional reports can flatten.

Break 10:05–10:15 pm

10:15–11:15 PM · BREAKOUT ROOMS

Research Connections Lab

From Shared Interests to New Possibilities

An informal small-group session for people with shared research interests. Join a breakout room for one of the six domains below, each facilitated by a founding member of the EOLD-IRG, to exchange ideas and explore future research and collaboration. No research project or idea needed.

The six research domains

Drawn from the EOLD-IRG's international Delphi study, which ranked them into three tiers of research priority. Choose one when you register.

TIER 1 · FOUNDATIONAL

Training and communities of practice

How doulas learn, are mentored and are supported to practise safely and well.

Key topics: Practice competencies · scope of practice · training and certification models

TIER 1 · FOUNDATIONAL

People's perceptions of end-of-life doulas

How the role is experienced and understood by clients, the public and care providers.

Key topics: Experiences of people who have hired or worked with a doula · public awareness

TIER 1 · FOUNDATIONAL

Skills and practices

What doulas actually do, and the different kinds of knowledge they draw on.

Key topics: Types of practice · types of knowledge · diversity of practice

TIER 2 · SYSTEM-LEVEL

Integration and professionalisation

How doulas work with, and could fit within, health and social care systems.

Key topics: Working with health professionals · integration pathways · professional recognition

TIER 3 · EXPLORATORY

Historical research

Where today's role comes from, rooted in older community traditions of caring for the dying.

Key topics: Community traditions of death care · influence of hospice and palliative care

TIER 3 · EXPLORATORY

New and emerging areas

Emerging questions for the field, led by concerns for equity and culture.

Key topics: Structural inequalities · cultural approaches · ideas of a 'good death'

11:15–11:30 pm Closing Groups come back together to share highlights and next steps.

Research Spotlight

We received more strong submissions this year than we could fit into the live programme. Rather than leave this work out, we are delighted to share it here, so that the research of everyone who submitted can be seen and recognised. These abstracts are not presented during the symposium — we warmly encourage you to read them and to connect with the authors if their work resonates with yours.

USA

End-of-Life Doulas in Rural Oregon Communities: The Experiences of Graduates from a Nonprofit Training Program

P. Rubio, Pacific University

The Peaceful Presence Project (TPPP) is a nonprofit organisation dedicated to increasing equitable access to end-of-life support by providing free training to EOLDs in rural Oregon. TPPP aims to fill the gap in care in rural communities where access to palliative or hospice care may be limited and not easily or equitably attainable. TPPP's program follows a Compassionate Community model of care, enhancing community capacity in caring for individuals nearing the end of life and ensuring equitable access to end-of-life support.

In this qualitative study, participants were selected from TPPP's Rural Oregon EOLD trainings held between March 2023 and May 2024. Semi-structured interviews were conducted to understand the lived experiences of six EOLD participants since the completion of the program. An interpretative phenomenological analysis (IPA) was used to understand how the EOLDs have understood and interpreted their experiences within the context of their rural communities.

Themes identified include: client-directed services, compassionate witnessing, challenges and barriers, beliefs about death, education on death, and the TPPP training. EOLDs supported client autonomy in decision-making and shared information on options. They provided empathy and trauma-informed care while desensitising themselves to clients' experiences. EOLDs reflected upon their own ideas and perceptions of death. They educated others on treatment options and advance care planning.

TPPP EOLDs discussed challenges and resources within their rural Oregon communities, as well as their experiences with the TPPP trainings and organisation.

Rubio, P. (2025). *End-of-life doulas in rural Oregon communities: The experiences of graduates from a nonprofit training program* [Doctoral dissertation, Pacific University].

CANADA

Silence, Pause, and the Unspoken

Jennifer McCrae CT, Certified Thanatologist & End-of-Life Doula, Soul Transition

In end-of-life care, there are moments when words are no longer the most important form of communication. There are pauses, silence, changes in breathing, withdrawal, stillness, and moments when a person appears to move between connection and letting go. I began to understand these moments as part of the liminal space of dying — a space that can be difficult for families and caregivers to understand.

What became increasingly clear to me is that regulation is also part of the unspoken. The emotional and physical state of the people in the room matters. When support staff and doulas are calm, grounded, and able to tolerate uncertainty, families can feel that calm. When a caregiver is anxious, rushed, or uncomfortable with silence, that can also become part of the environment. Through co-regulation, our presence can help create a sense of safety that allows families to slow down and be with what is happening.

One outcome of this project was seeing how understanding the liminal space can change the experience for families. With greater knowledge and preparation, there can be less fear, less urgency to intervene, and more ability to simply be present with the person who is dying.

This work has changed how I practise and what I teach.

CANADA · CONTINUED

I want caregivers to understand that we support people not only through what we say or do, but through how we are. I will continue teaching families, doulas, support staff, and caregivers to become more comfortable with silence, more aware of regulation, and more trusting of the space between words.

Sometimes the most powerful support we offer is the calm silence we bring into the room.

AUSTRALIA

Evaluating a Standardised End-of-Life Planning Framework Within End-of-Life Doula Practice: Findings from an Australian Pilot Study

Catherine Ashton, Critical Info

In Australia, End-of-Life Doulas are a rapidly growing non-clinical workforce supporting individuals and families through serious illness, dying, death and bereavement. Yet no nationally recognised framework guides how end-of-life planning information is documented or facilitated within Doula practice, creating challenges for consistency, quality assurance and workforce scalability.

This pilot evaluated the feasibility, acceptability and early outcomes of integrating the Critical Info Platform, a structured end-of-life planning and navigation tool, into End-of-Life Doula practice. Participating Doulas completed their own Critical Info profile before facilitating the process with clients living with a diagnosed life-limiting illness. Evaluation used the Death Literacy Index (DLI-9) and the Coping With Death Scale–Short Version (CWDS-SV), together with a program-developed Critical Info Impact Survey informed by the Six Change Levers in the Good Death Impact Network's Action Playbook (Good Death Impact Network, 2023).

Of 21 Doulas who expressed interest, 11 enrolled, with six Doulas and five clients completing evaluation surveys. Results were strongly positive: 90% of respondents took practical action, 80% updated important documents and 70% had important end-of-life conversations. Participants reported reduced overwhelm, improved organisation and greater planning confidence, with outcomes spanning practical preparedness, experiential learning, communication confidence and emotional preparedness.

To our knowledge, this is among the first Australian pilots to examine a standardised digital planning framework within End-of-Life Doula practice. Early findings suggest pairing structured navigation infrastructure with relationship-centred Doula support can strengthen preparedness, improve consistency across the emerging Doula workforce, and build broader community capacity around death literacy. We welcome the opportunity to discuss this work with fellow Symposium attendees.



Thank you for joining us

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