



International End-of-Life Doula Symposium 2022

Summary Report

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We would also like to acknowledge valuable contributions from speakers **Jennifer Owens** founder of [From Butterflies to Angels](#), and **Valoria Walker**, founder of [Doula by Destiny](#). Finally, we would like to thank **Merilynne Rush**, founder of [The Dying Year](#) for her consultancy role in developing the symposium.

The End-of-Life Doula Symposium was funded by an Impact Acceleration Account, through the UKRI and the ESRC.

To cite this report: Krawczyk, M., Clare, E., Collins, E., Johnson, E., Mallmes, J., Mallon, A., Farr, S., Oberle, K. and Rigal, J. (2022). The International End-of-Life Doula Symposium Report. Dumfries: The University of Glasgow.

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Background

End-of-Life Doulas (EOLDs) hold the potential to reconfigure the culture and care practices of dying, death, and bereavement. Over the last few years public and health care interest in the role and services has developed exponentially within specific countries, particularly within the global North. To date, there have been few opportunities for practitioners to collectively discuss their work and interests within an international context. The International End-of-Life Doula (EOLD2022) Symposium was designed as a facilitated virtual space for discussions about these issues within an international context. It was the first international symposium or conference of its kind.

This report summarizes the events of the symposium, held over three days on April 25-27th 2022, and highlights our next steps in developing an international research working group. The symposium was a co-produced effort, emphasizing collaboration and direct engagement with practitioners in creating a shared space to: 1) understand better individual practices and local priorities; 2) explore overlap and differences in regional/national practices and concerns; and 3) to map future interests across an international landscape. Project collaborators were solicited from the four countries where EOLD are most active: Australia; Canada; the United States; and the UK. Symposium participants were drawn from collaborators' professional networks. Countries represented during the sessions included Canada, the UK, the US, Australia, Spain, Sweden, and Columbia.

The EOLD2022 Symposium was part of a project funded by an Impact Acceleration Grant from the UKRI/Economic and Social Science Research Council User Engagement Fund, led by Dr Marian Krawczyk at the University of Glasgow. The funding has been established in recognition of the idea that high levels of engagement across different stakeholders can lead to more productive collaboration and effective, sustainable outcomes for academic and non-academic partners. Collectively, this invitation-only symposium is part of a larger project which is designed to generate international cooperation and collaboration, facilitate peer learning and skills sharing, and support policy development for end-of-life care both nationally and internationally.

Symposium Format

The symposium was held over three days and in a variety of formats. We chose timings and formats so that we could build on the conversations from each day, thereby ensuring that the symposium was responsive to participants' contexts and interests. To address the differences in time zones, the sessions from Day 1 and 2 were run twice to ensure that as many people as possible could attend from different time zones.

Day 1 consisted of four pre-recorded talks by collaborators, with live Q&A discussion in specific time zones.

Day 2 consisted of unstructured 'drop in' sessions, facilitated by symposium collaborators and volunteers. This provided the opportunity to connect with other symposium attendees and to discuss the previous day's presentations and conversations.

Day 3 brought all the symposium attendees together at the same time. Participants were first organized into small one-hour facilitated group discussions, with discussion points based on the

symposium themes and conversations. This small-group discussion was then followed a closing panel with all the symposium collaborators reflecting on the main themes, ideas, and issues that arose during the conference.

We also produced a [symposium website](#) which, along with details of the meeting, hosts a range of practical and conceptual resources which were referenced by participants. The website also hosts recordings of the four main symposium presentations delivered by the project collaborators. The recorded presentations can also be viewed on YouTube [here](#). Since its development, the website has had visitors from Canada, the UK, the US, Australia, Spain, Sweden, Malaysia, New Zealand, Columbia, Viet Nam, and South Africa.

Symposium Participants

A key goal of this event was to develop collaborative relationships with EOLD practitioners and organizations across different countries. This required the project collaborators be involved in developing the symposium, including multiple meetings to discuss format and themes.

The symposium was an 'invitation-only' event to ensure that it was primarily focused on experienced practitioners. Potential participants were identified by the symposium collaborators and volunteers, and these individuals were sent personal invitations to attend. Over each day of the symposium there were varying numbers of participants, with an overall average of 30 participants per session. Countries represented during the sessions include Canada, the UK, the US, Australia, Spain, Sweden, and Columbia.

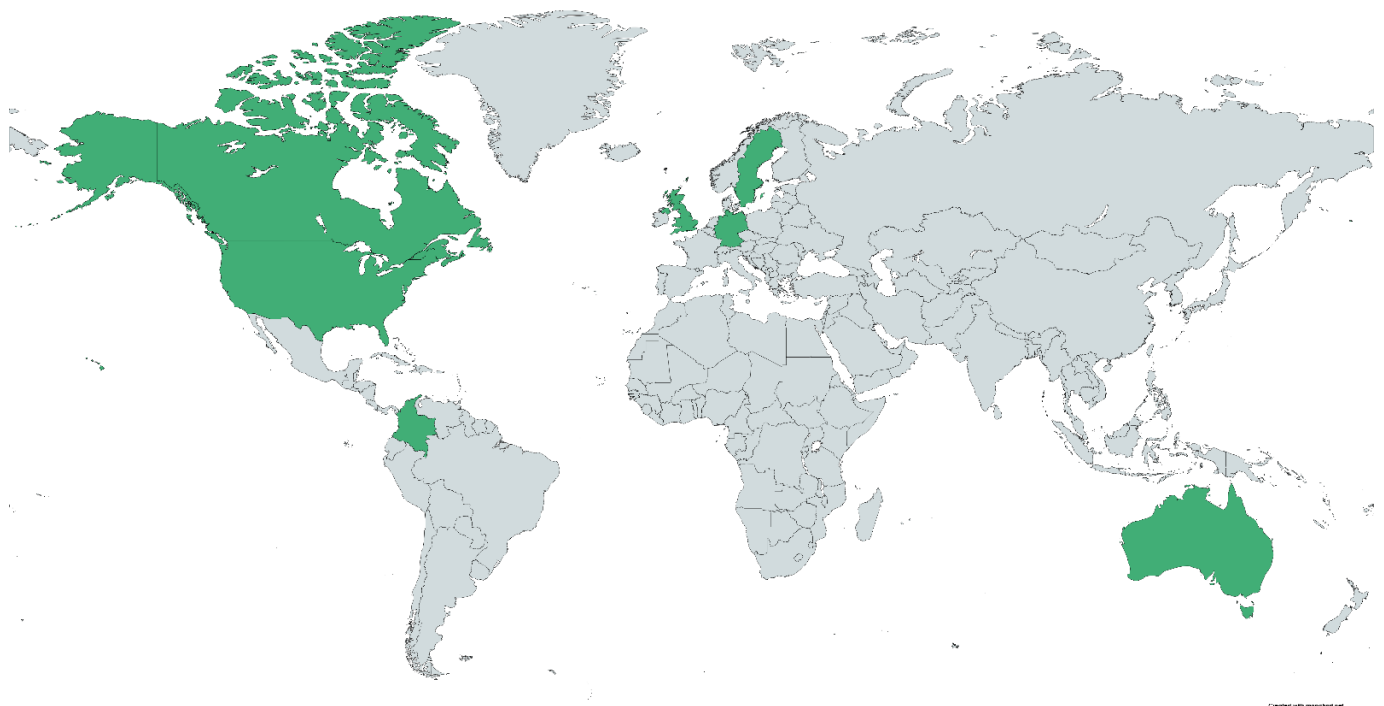


Figure 1: Countries of Symposium Representation

Symposium Discussions

The EOLD2022 symposium offered a range of opportunities for both structured and unstructured conversations. The symposium collaborators and volunteers took de-identified handwritten notes across the three days of discussion, as well as reflexive notes about their own thoughts and perspectives on the topics discussed. We also took note of comments within the Zoom chat function. We then collated all our notes and focused on topics that generated significant conversation and/or came up repeatedly. These 'hot topics' relevant across international boundaries is summarized in Figure 2. All participants were aware of the note-taking and provided consent.

The EOLD2022 symposium was also structured around four themes: developments; disruptions; dilemmas; and directions. These themes were offered as provocations, based on previous research and practitioner consultation. The intent was to explore these ideas and concerns from multiple positions, thereby strengthening practitioners' capacity to think critically and act flexibly. A summary of the symposium themes is offered in Figure 3.

We also analysed and organized symposium participants' discussions and debates through the themes of developments, disruptions, dilemmas, and directions. A summary of these is offered in Figure 5.



Figure 2: Hot topics of symposium conversations

Symposium Themes



Developments

This theme attends to developmental roots of the field of practice. What can we learn from the emergence of the contemporary EOLD role? How might knowledge of this history illuminate current practice, radical ideals, contemporary dilemmas, and future pathways?



Dilemmas

This theme relates to the many challenges and dilemmas facing current practitioners as the field expands, including but not limited to standardization and professionalization.



Disruptions

This theme considers EOLD as cultural 'change agents' with the capacity to engender disruptive innovations in end-of-life care. How are EOLD reconfiguring relations of care in ways that enable individual and collective shifts in dying, death, and bereavement?



Directions

This theme relates to the possible future directions for EOLDS, both as individuals, and collectively. How might EOLD meet the changing landscape of dying, death, and bereavement in the 21st century?

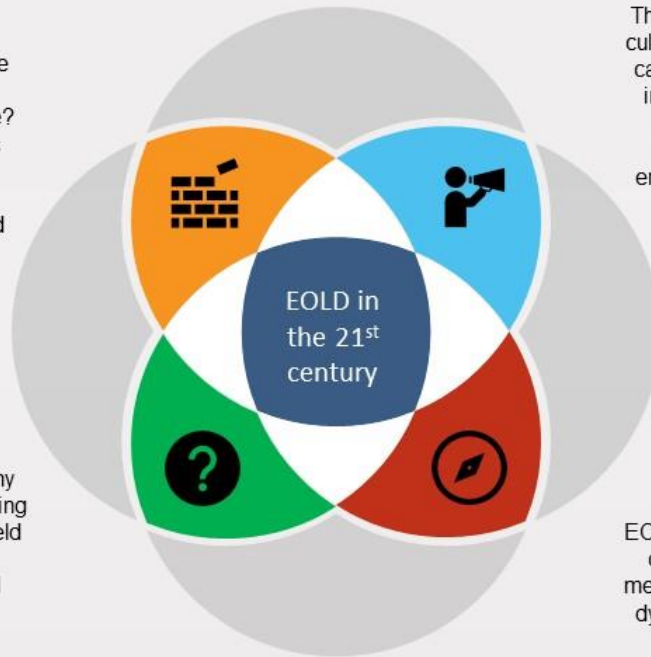


Figure 3: Summary of key discussions within symposium themes

Developments

The 'developments' theme focused on the developmental roots of the field of practice and what we can learn from the emergence of the contemporary EOLD role. Symposium participants highlighted four main aspects when discussing the development of EOLDS: 1) the historic loss of experiential knowledge and community supports in dying and death; 2) the close relationship between pregnancy/birth and dying/death; 3) how caregiving historically has been seen as 'women's work'; and 4) the intended and unintended consequences of mainstreaming hospice and palliative care.

Disruptions

The 'disruptions' theme considered EOLDS as cultural 'change agents' with the capacity of engender disruptive innovations in end-of-life care. Symposium participants highlighted multiple (often overlapping) pathways to positive disruption, including: 1) providing a unique philosophy of care blended with specialist knowledge and skills; 2) engaging in public advocacy about the benefits of EOLDS; 3) offering practices for enhancing death literacy; 4) participating in or leading Compassionate Community initiatives, 5) practicing cultural humility¹ across all cultural contexts, including one's own; 6) addressing structural inequalities in end-of-life care; and 7) championing inclusionary practices and practitioners.

¹ The three tenets of cultural humility are life-long learning and critical self-reflection; mitigating power imbalances; and advocating for institutional accountability in relation to end-of-life issues and care.

Dilemmas

The 'dilemmas' theme encompasses the many challenges facing current practitioners as the field expands. The main issues discussed were: 1) concerns for standardizing certification, regulation, and/or professionalization; 2) the relationship between 'lay' experiential knowledge and 'codified' professionalized knowledge; 3) the consequences of naming the role and associated practices; 4) payment as empowerment and as problem; 5) integration with formal health care systems; 6) the relationship to hospice and palliative care; and 7) lack of current practitioner diversity.

Overall, and perhaps unsurprisingly, one of the main points of discussion regarding the future of EOLDs was how best to negotiate these issues. As the term 'balancing' was often invoked by participants, these tensions are represented below as an intersecting spectrum (rather than merely as opposites) across five domains which must be balanced and negotiated in thinking about future developmental pathways.

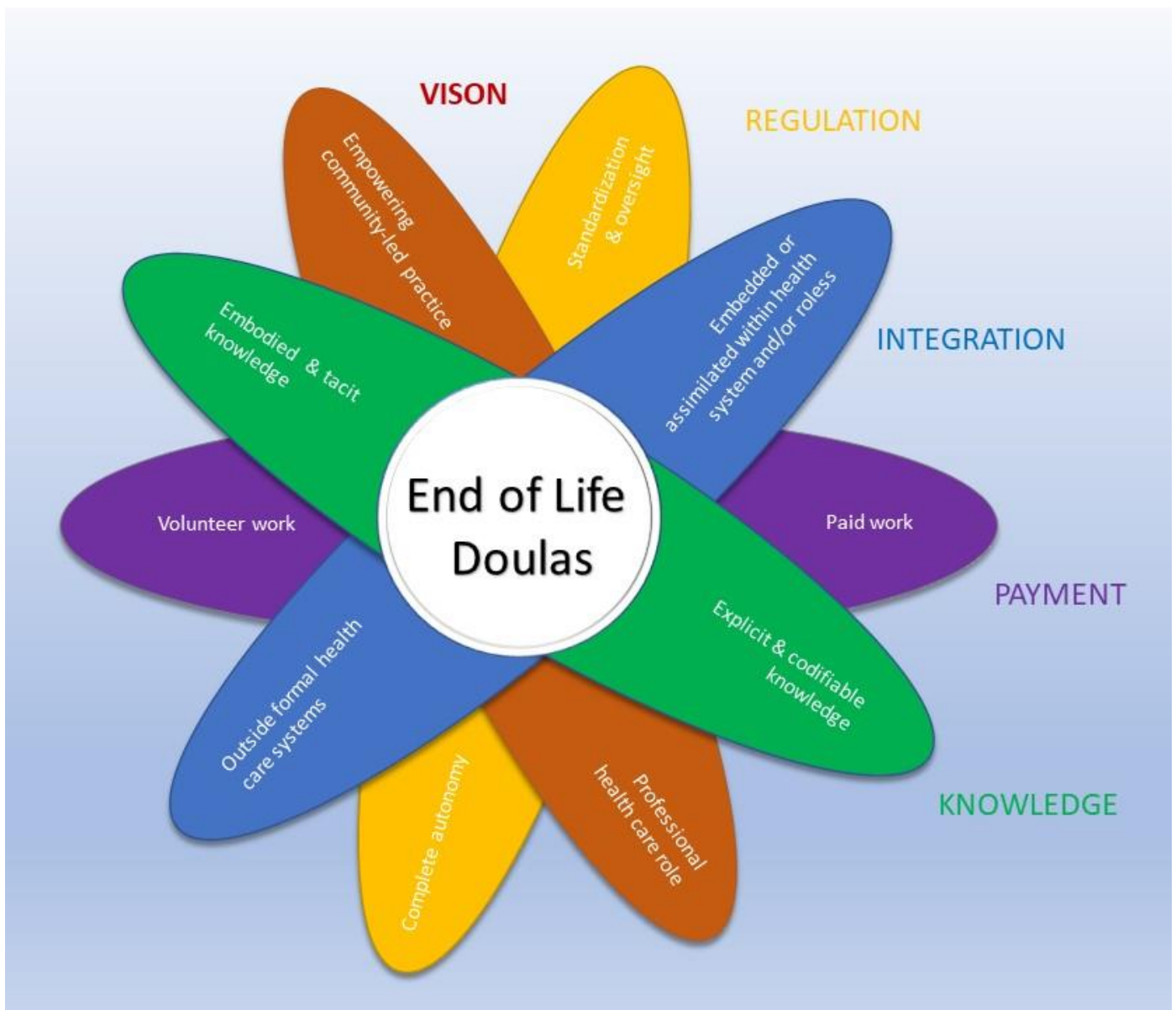


Figure 4: Key intersecting tensions in the development of the EOLD role

Directions

The 'directions' theme related to the possible future directions for EOLDs, both as individuals and collectively. Participant topics of discussion included: 1) addressing changes in contemporary dying, such as assisted dying; 2) ensuring a meaningful vanguard role as cultural change agents; 3) differing potential integration pathways; 4) long-term thinking and models of change; 5) balancing/negotiating developmental tensions, and 5) the need for research and international discussions.

Symposium participants identified that supporting robust developmental pathways will require further 'neutral' opportunities to gather, and within a collaborative international context. This was exemplified within the symposium evaluation, where participants identified the importance of hearing different perspectives and experiences from different countries. and led by a diverse group of stakeholders.

Benefits of developing an international forum also included establishing an international presence for what is becoming a transnational movement; knowing more about integration initiatives within regions at the forefront of this work; learning about different health and social care structures and regulations; making the movement more inclusive beyond predominantly visible English-speaking white middle-class women from the global North; and to link individual EOLD care across international boundaries. The desire for international collaboration was also discussed in relation to developing a research base for the field.

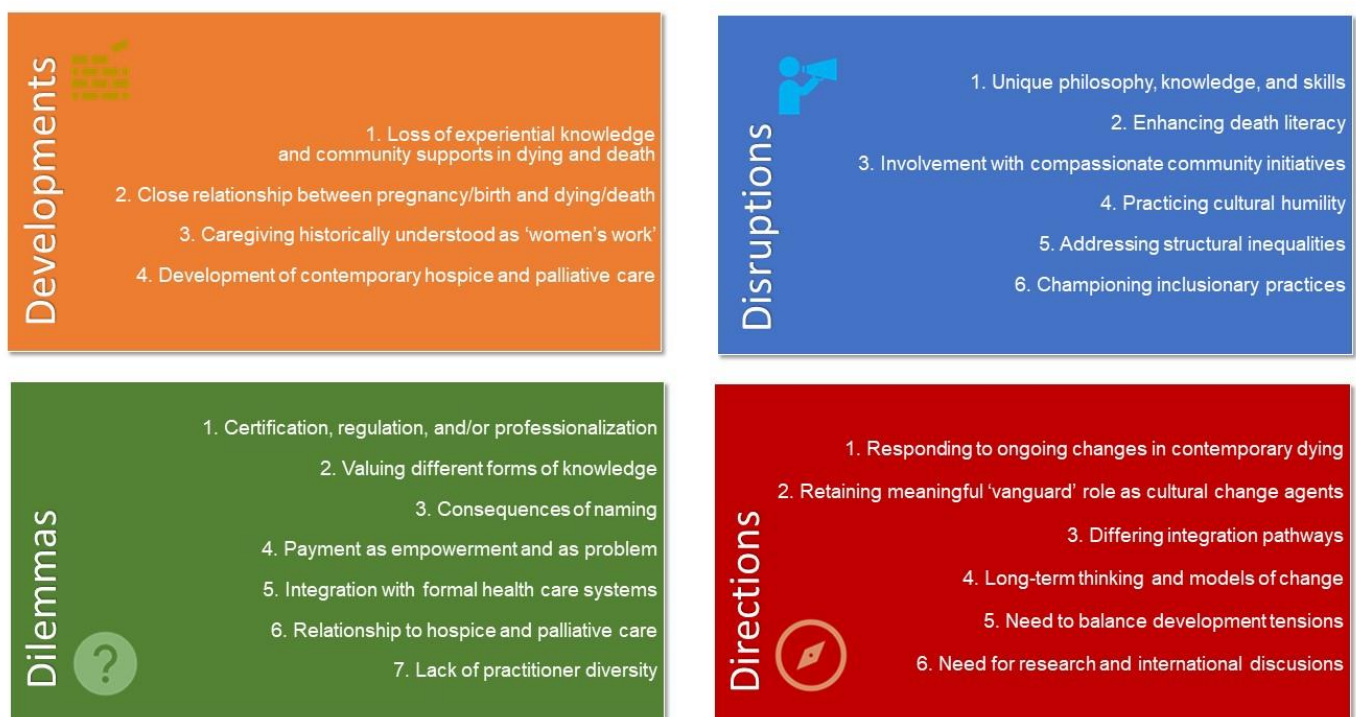


Figure 4: Summary of key discussion points within symposium themes

Feedback

One hundred percent of the symposium feedback rated the event as “very interesting”, as well as “very or somewhat useful”. Participants highlighted numerous beneficial outcomes from symposium attendance, including: an increased awareness of global issues; a sense of inclusion; the sharing of resources; exposure to a wider community of practice and diverse perspectives; and enhanced future sustainability of the field, as well as personal invigoration.

Next steps

Our first step, after distribution of this report, is to follow up with symposium participants who have expressed interest in developing an international research working group.² Initially, participants will be drawn from symposium participants who have expressed a wish to be involved and have provided their contact information specifically for this. We will also be publishing more detailed symposium findings in an open-access journal article.

Over the next year, the goals of the proposed working group are to organize initial meetings to solidify membership and potential board members, establish a taxonomy of international research possibilities and priorities, and develop a ‘second annual’ symposium event for 2023. As part of these meetings, we will continue developing a sharable database with key resources that will enhance members’ ability to influence research and policy development at the international level. Our overall goal is to create a collaborative (rather than competitive) international research group that enables EOLDs to influence policy and be agents of change at the international level.

If you would like more information or have any inquiries, please contact:

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² It is important to note although the future research this group conducts may be useful to those who wish to develop international standards and scope of practice, the direct development of these frameworks is outside the goals of this project.