

Study Title: Exploring Arts Practices in Palliative and End of Life Care

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Jenny Baxley Lee (PhD Researcher)



Dear Arts in Health Professional,

I'd like to invite you to participate in this survey. Before deciding to participate, it is essential that you understand the intent of the study and what you will be asked to do. Please read the information below and feel free to ask any questions you may have before you begin. Thanks in advance for your time and consideration.

What is the purpose of this study?

The purpose of the study is to better understand arts practices and engagement in palliative and end of life care. A second aim is to distinguish the professional work of artists from the work of creative arts therapists and other healthcare professionals who may engage the arts.

Why have I been invited to participate?

You have been invited to participate due to affiliation with professional work in arts in health. Perhaps you were invited by a colleague or through an arts in health professional network or membership such as the National Organization for Arts in Health, Arts and Health Australia, or the Culture, Health and Wellbeing Alliance.

Do I have to take part?

Participation in the survey is voluntary. You do not have to take part in the survey and you may stop participation at any time with no need to explain your decision.

What can I expect if I decide to participate?

If you decide to participate, you will click on the link to the online survey and you will be asked to respond to a series of questions related to providing the arts in palliative or end of life care settings. The survey will take 10-15 minutes to complete. If you would like to stay in touch regarding study findings, you will be asked to provide your email address at the end of the survey. Also, if you would be willing to share the survey link, you will be asked to provide the consented email addresses of artists, health professionals and/or program coordinators who may be willing to participate in the study.

Are there any risks to participation in this survey?

There is no known risk to participation. No information will be used for marketing or commercial interests. If you feel distressed by the survey, please contact any of the support organizations listed at the end of the Participant Information Sheet. You may also contact the Researchers at any time with any question or concern you may have.

Are there any benefits to participation in this study?

While no direct benefits are anticipated, the aim of the study is to better understand the potential impact or value of the arts for individuals receiving palliative or end of life care.

What if something goes wrong?

While it is very unlikely that something will go wrong, any concerns will be taken seriously. Ulster University has procedures for investigating and handling adverse effects that will be following during the research. The University will provide an indemnity statement for research that has been approved through the appropriate governance and ethical review processes. Any complaints will be taken seriously and should be made to the Chief Investigator or the University.

Here is a link to Ulster University Research Governance website:

https://www.ulster.ac.uk/data/assets/pdf_file/0011/75638/Complaints.pdf

Will my responses be kept confidential?

The study responses will be anonymous, and the results will be kept confidential. The IP address of the participants will be disabled to ensure anonymity.

How will my responses (and data) be stored?

Ulster University is the sponsor or managing organization for this study and we will use information gathered from you and/or your records in order to carry it out. We will act as the data controller, which means that we are responsible for looking after your information and using it properly, as stipulated in GDPR and the Data Protection Act 2018. Ulster University keeps study-related information for 10 years after the study has finished/until 2029. You can find out more about how we look after your information at: <https://www.ulster.ac.uk/about/governance/compliance/gdpr>

Because we need to manage your survey response in specific ways after you complete the survey, in order for the research to be reliable and accurate, your rights to access, change or move your information are limited. Please note that if you withdraw from the study, we will keep the information that we have already obtained. To protect your rights, the survey is anonymous with the exception of your decision to share your email address, which will not be linked to the survey responses in any way.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your survey response in a way that is not lawful, please contact the Information Commissioner's Office (ICO). Our Data Protection Officer is Eamon Mullan and he can be contacted at e.mullan@ulster.ac.uk

What will happen with the results of this survey?

The results of this study will be shared with the participants who have requested contact via email. The results will also be written in partial fulfillment of the PhD qualification and may be submitted for publication in an academic journal or presented at professional conferences.

Who is organizing and funding the research?

The study is being organized by Ulster University and no funding is associated with the research. This study has been approved by Ulster University Institute of Nursing and Health Sciences Research Governance Filter Committee in January 2018.

Further Information

If you have any questions or concerns about this research, please do not hesitate to contact Jenny Baxley Lee by email at jlee@arts.ufl.edu.

If you have additional concerns about this research, you may contact the Chief Investigator at Ulster University, Professor Sonja McIlpatrick, at s.mcilpatrick@ulster.ac.uk; +44 28 9036 8066.

Thank sincerely you for your input, which is so valuable.

Jenny Baxley Lee
Ulster University PhD Researcher

Support Organizations

NHS Moodzone - <https://www.nhs.uk/Conditions/stress-anxiety-depression/>
RCN, Counselling service 0345 772 6100 - <https://www.rcn.org.uk/get-help/member-support-services/counselling-service>
BMA wellbeing and support group - 0330 123 1245 - <https://www.bma.org.uk/advice/work-life-support/your-wellbeing/counselling-and-peer-support>
RCPCH - <https://www.rcpch.ac.uk/resources/where-go-help-support-doctors-wellbeing>