Participant Information Sheet – Health Care Professional

LIO (Let it out): developing and evaluating an emotional disclosure-based intervention in UK hospices

We would like to invite you to take part in our research study, which will involve taking part in a focus group where you work, led by a researcher from UCL; or taking part in an interview with the researcher. This information sheet explains the aim of the study, and what it would involve for you. Before you make a decision, it is important for you to understand why the study is being carried out, and what it will involve. Please take your time to read the following information carefully and discuss it with your family or friends if you wish. Please feel free to email us if there is anything that is not clear or if you would like more information.

Why is the study being done?

Providing emotional and psychological support to people living with terminal illness is a core part of the holistic care provided by hospices. It has been suggested that simple, low-cost interventions could be valuable in helping hospices to support their patients' emotional and psychological needs. Research suggests that writing or talking about your feelings can have both physical and psychological benefits for some people. Our research team are evaluating an intervention called LIO (Let It Out) that is based on this principle. LIO is specifically tailored for people receiving palliative care from hospices. It provides self-guided instructions for people living with a terminal illness to express their feelings in a way that may help to bring them comfort.

We are asking people receiving care from your hospice to try out LIO and tell us about their experience with it. We are going to use their views and experiences to further refine its design so it is as easy to use and as beneficial as possible. It is also crucial that LIO is easy and practical for hospice staff and volunteers to implement and deliver. That is why we are inviting staff and volunteers involved in delivering or organising psychological and emotional support to take part in focus groups and/or interviews with the research team.

In these focus groups and/or interviews, we will present the design of LIO to you, and ask you to think about the practicality of implementing LIO at your hospice. You will be asked to consider the features of its design and if and how they may need to be adapted to suit both the staff and patients at your hospice. You will also be asked to think about where LIO might fit into your current pathways of care, who may be involved in delivering it on a day-to-day basis, and what resources or support may needed to support its successful implementation. We would also like to discuss with you any risks or benefit you may have observed patients' experiencing, or may expect to see, when trialling the intervention. We want to use your insights, together with those of the people with terminal illness trialling LIO, to inform and refine its design to make sure it suits the specific needs of people receiving hospice care, as well as those who deliver it.

We will also separately be exploring the views of family carers regarding their views and experiences of caring for a person who is testing or using LIO.

Why have I been chosen?

You have been identified as a health and social care professional or volunteer who is involved in delivering, organising or referring people to psychological and emotional support services at a UK hospice. You may have been involved in helping to deliver LIO to people living with a terminal illness receiving care from this hospice.

Do I have to take part?

No, your participation in this study is completely voluntary. If you do not want to answer the questions, please make the researcher aware. You can withdraw from the study at any time without giving a reason. If you withdraw from the study all the data that has been collected as part of the interview or focus group can be destroyed if you wish for up to three months after your participation in the study is complete. After this point all data will be anonymised and we will no longer be able to withdraw your data.

Taking part in the study

If you decide to take part, please download a copy of this information sheet to keep and fill out the online consent form by following the link at the end of this sheet. Directly after the informed consent form, there will be a short demographics questionnaire asking for basic details about your background and position at the hospice where you work. If you do decide to take part you are free to withdraw from the study at any time and without giving a reason.

What do I have to do?

If you agree to participate in the study, you will be invited to take part in a focus group with other members of staff and/or volunteers at the hospice where you work, led by a researcher from UCL. The focus group will take place over a video call (using the platform Microsoft Teams) or, if face-to-face meetings are viable, in a private room at the hospice where you work, at and time that is convenience for all members of the focus group. We expect the group discussion to last between 60-90 minutes. If you are not able to attend at the time of the focus group, we would still like to hear your thoughts; therefore we may invite you to take part in an interview with the researcher. The interview will be a discussion with a researcher again either by video call or if feasible, in a quiet location of your choice and at a date and time convenient for you. We expect the discussion to last 45-60 minutes. The discussions (in the interviews and focus groups) will all be voice-recorded, and we will also take notes by hand, to help us check the recordings.

You will also be sent a PDF version of the intervention guide in advance of the focus group, along with a link to a 'practice' version of the study platform, which you can look at in advance of the meeting if you have time.

During the focus group or interview discussion, you will be asked to think about the practicality of implementing LIO at your hospice. You will be asked to consider the features of its design and if and how they may need to be adapted to suit both the staff and patients at your hospice. You will also be asked to think about where LIO might fit into your current pathways of care, who may be involved in delivering it on a day-to-day basis, and what resources or support may needed to support its successful implementation. We would also like to discuss with you any risks or benefit you may have observed patients' experiencing, or may expect to see, when trying the intervention. We want to use your insights, together with those of the people with terminal illness trying LIO, to inform and refine its design to make sure it suits the specific needs of people receiving hospice care, as well as those who deliver it.

What will happen to the information that I give?

We will combine the insights from the focus groups and/or interviews, with our insights from our research with people with terminal illnesses who have tested the intervention, and their informal carers (both at the hospice where you work, and from other hospices) to inform the tailoring and refinement of the LIO intervention. We hope by incorporating these views into the design of the intervention, we can help make the tool as beneficial and practical to implement in the hospice environment as possible. We will also use your insights to inform the design of any future research studies (for example, randomised controlled trials) that we may run to test the efficacy of the intervention developed as a result of this research project.

How long will I be in the study?

You will be asked to participate in a focus group discussion expected to last approximately 60-90 minutes, or an interview lasting approximately 45-60 minutes.

Benefits of taking part

There will be no direct benefit to you for taking part in this study. However, by taking part you will help to inform the design of the LIO intervention and any future research evaluating its feasibility and efficacy. This is important because people living with terminal illness often experience significant psychological and emotional distress, and we hope that in the future, hospice teams may be able to use LIO to help alleviate some of this distress for some of their patients.

Risks/harm of taking part

We do not anticipate any risks or harm to you as a result of taking part in this study, although it is possible that these discussions may touch on some difficult subjects. If you should wish further advice or support we will signpost you to relevant resources.

What if there is a problem?

If you are concerned about any aspect of this study, please speak to the researchers who will do their best to answer your questions. Please contact Ms Daisy McInnerney at liostudy@ucl.ac.uk or +44(0) 7810 590441. If you remain unhappy, or wish to make a complaint about the conduct of the study, you can contact the supervisor of this project: Dr Nuriye Kupeli, Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, 6th Floor, Maple House, 149 Tottenham Court Road, London W1T 7NF, email: N.Kupeli@ucl.ac.uk; 020 7679 9724 (x09724).

If you are not satisfied with the way your complaint is handled, please contact the UCL Research Ethics Committee (REC) Chair at: ethics@ucl.ac.uk

Confidentiality

All information that is collected about you during the course of the research will be kept strictly confidential by the research team. The only exception to this will be if you disclose any information which suggests possible risk to the safety of patients or staff. If this arises, you will be informed that confidentiality cannot be maintained by the research team in that particular regard, and the appropriate personnel will be informed. In all other cases, any personal information will have your name and address removed so that you cannot be identified from it. Only the research team will have access to the notes from the meetings. An additional external transcriber may listen to the voice recordings and type these up as written scripts, but this person will have signed a confidentiality agreement with UCL. All data will be handled, processed, stored and destroyed in accordance with the Data Protection Act 2018 (DPA 2018) and General Data Protection Regulations (GDPR 2018). Voice

recordings will be downloaded from the portable recorder onto a secure computer server, and the original recording deleted.

However, please note that whilst we will ask all participants **not** to disclose any information discussed during the focus group, we cannot guarantee confidentiality on behalf of other members of the focus group.

Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

Your personal data will be processed for the purposes outlined in this notice.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

The personal data (including your name and the answers you provide to generate your unique identifier) will be processed for no longer than 3 months following data collection (i.e. from the date you finish the study). Your email address will also be stored for no longer than 3 months from the date you finish the study, unless you specifically indicate on the consent form that you would like us to keep it in order to send a summary of study results to your and/or to hear about future opportunities to be involved in related research. In those instances, your email address will be stored for no longer than 18 months following data collection. We will pseudo-anonymise (key-code) the personal data you provide, and we will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Results of the research study

We will present the findings of this study to people living with terminal illnesses, their family carers, health and social care professionals and researchers. We will produce accessible and informative updates through social media and by writing blogs for relevant organisations. We will present the findings to health and social care professionals and researchers at academic meetings. We will also seek to publish papers in scientific journals. All information collected during the study will be combined to form the results, so no individual will be identified in any report or publication. If you take part in the study you will be asked if you wish to receive a written summary of the results.

Funding and review of the research study

This research has been reviewed and funded by Marie Curie and by the Economic and Social Research Council, and is being conducted by researchers in the Marie Curie Palliative Care Research Department at UCL. It has been reviewed and approved by the UCL Research Ethics Committee [project 15281/002, 19 May 2020].

Contact for further information

For further information please contact Ms Daisy McInnerney via email: liostudy@ucl.ac.uk or phone +44(0) 7810 590441

Thank you for taking the time to read this information sheet.
Your help makes our research possible.

Follow this link to go to the online informed consent form.
It is vital that you complete this form before taking part in the focus group or interview.