

PARTICIPANT INFORMATION SHEET

A survey of psychological services in UK hospices: what exists, what works and what may not?

UCL Research Ethics Committee Number: 15281/001

You are invited to take part in a research study. Before deciding whether to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read this information carefully and ask us if there is anything that is not clear or you would like more information.

What is the purpose of this study?

Psychological distress is common for people living with terminal illness, and for their family carers. But evidence suggests that for some people receiving palliative care, including those in hospices, access to psychological support is limited. We are running this national survey to explore how psychological services are provided in hospices across the UK to help us understand more about current delivery of and access to these services. This could potentially inform future efforts to develop best practice. This study is being conducted as part of a student project in partial fulfilment of a PhD. The online survey will be open from Tuesday 12th November 2019 until Tuesday 24th December 2019.

Why have I been invited to take part?

You have been invited to take part because you or your colleagues have advised us that you are involved in the organisation and/or delivery of psychological services at the hospice where you work. If you think somebody else at your hospice would be better placed to complete this survey, we would be very grateful if you could pass the survey invitation email onto them instead. Please let us know if you choose to do this, so that we can make sure to contact the right person through the rest of the study. Please note, **we are only asking for one response** from each of the 200 hospices providing care to adult patients in the UK.

All participants should be aged 18 or over, able to speak English well enough to be able to fully understand the information in this document and in the consent form, and be in a position to comment on the delivery of psychological services at the hospice where they are employed.

Do I have to take part?

No, it is up to you to decide whether or not you take part in this study. If you agree to take part, you will be asked to sign a consent form as part of the questionnaire, indicating you are happy to take part based on the information we have told you about the study. You are free to ask any questions to the research team at any time using the contact details at the end of this document. You can withdraw at any time without giving a reason and without it affecting you personally or professionally in any way by emailing daisy.mcinnerney.18@ucl.ac.uk

What happens if I agree to take part?

If you agree to take part, you should follow the link to the online questionnaire provided to you in the invitation email. You can access the questionnaire at any time that is convenient for you. We will ask you to provide your email address, so you are able to log in and out of the questionnaire, and can therefore save your progress and complete it in more than one sitting if needed.

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You will be asked 23 questions, most of which are multiple choice, that have been organised into the following sections:

- **Basic information** about yourself and your professional role
- **Organisation of psychological support services** at your hospice
- **Types of psychological support** being offered to patients and family carers by your hospice
- **Access to psychological support** for patients and family carers at your hospice

At the end of the survey, you will also be given the option to register your interest to:

- Receive a copy of the results of the survey, and/or
- Hear about opportunities to get involved in further related studies conducted by the research team running the study and/or
- Enter the prize draw to win one of two £30 vouchers and/or
- Receive a personalised certificate of survey completion.

We will delete your email address at the end of the study and will not contact you again, unless you state you would like us to keep your details for any of the reasons listed above. In this case, we will store your email address until it is no longer needed for the purpose you have specified and for no longer than 24 months from the close of the survey. Your information will only be held for this long if you indicate you would like to receive a copy of the results of the survey or would like to hear about opportunities to get involved in further related studies. You may also contact us at any time and request that we securely delete your email address from our system (there is no need to give a reason) and we will do so immediately.

We have tested the questionnaire in a pilot study and participants reported that the questionnaire was clear and easy to fill out, and took on average 15-20 minutes to complete. We will also send three emails reminding you of the survey closing date. If you would like us to stop sending the reminder emails, please send an email to researcher, daisy.mcinnerney.18@ucl.ac.uk, who will make a note that you do not wish to receive any further reminders.

What happens if I don't want to take part or change my mind about taking part?

Taking part is voluntary. You do not have to participate and you can withdraw at any time without consequence or pressure, personally or professionally.

Are there any benefits to taking part?

There are not likely to be any direct benefits to you for taking part in the survey. However, in recognition of your time, you will have the opportunity to be entered into a prize draw to win one of two £30 vouchers. You can also tell us if you would like to receive a personalised certificate recognising your participation to demonstrate your engagement in research (you can sign up for this at the end of the survey).

Are there any disadvantages or risks to taking part?

Participation in this online study is low-risk. We recognise that taking the time to complete this survey may be an inconvenience to you. We have tried to minimise this inconvenience by keeping the questionnaire as short and clear as possible. You can also complete it on any device with an internet connection – whether at home or at work. We recommend you complete the survey in one sitting where possible, but you will also have the option of logging out and returning to the survey in a second sitting.

We also ask that you please refrain from naming or identifying any individuals in your survey responses, to protect their identity (although if you do mention any names or identifying details, they will be deleted from the study during analysis).

What if something goes wrong?

In the first instance, if you wish to discuss a complaint, you should contact researcher Daisy McInnerney (daisy.mcinnerney.18@ucl.ac.uk) to resolve the matter. However, should you feel that your complaint has not been handled satisfactorily you can contact the Chief Investigator, Patrick Stone (p.stone@ucl.ac.uk). You also have the

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right to contact the Information Commissioners Office (ICO) if you have any complaints or concerns about how your data is being handled (<https://ico.org.uk/make-a-complaint/>).

Will my taking part in this study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

- **Your personal data:** You do not have to provide your name as part of the questionnaire unless you choose to do so for use on a personalised certificate. We will store your email address in a secure, password-protected database on a server hosted by University College London (UCL). Only members of the research team will be able to access this database. We will retain your personal identifying information until they are no longer needed for recruitment or for the purpose you have specified, which will be no longer than 24 months from the close of the survey, at which point they will be securely destroyed. Your information will only be held for this long if you indicate you would like to receive a copy of the results of the survey or would like to hear about opportunities to get involved in further related studies. If you do not indicate that you would like us to contact you again for any of the reasons listed above, your email address and any other personal identifiers will be securely destroyed at the end of project.
- **Your survey responses:** Before the research team analyse the questionnaire responses, each participant will be assigned a 3 digit code. Any personally identifiable information you provide will be stored in a separate database, and will not be linked to your responses to the questionnaire. Your de-identified data will be collected, stored, handled, and processed by the research team at UCL, in accordance with the General Data Protection Regulations (GDPR) 2018. In the interests of academic transparency, anonymised data collected for this research may also be shared with other research groups or used for other research purposes after the completion of this study.
- **Online survey software:** Data will be initially collected by the online software, Opinio, which will securely transfer the data to the department running the study, where it will be stored in a secure, password protected, confidential file on the UCL S: drive. The data will also be stored by UCL Information Services for six months and will then be permanently deleted from the Opinio system

Data Protection Privacy Notice

- UCL is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you until they are no longer needed for recruitment or for the purpose you have specified, which will be no longer than 24 months from the close of the survey, at which point they will be securely destroyed. Your information will only be held for this long if you indicate you would like to receive a copy of the results of the survey or would like to hear about opportunities to get involved in further related studies. Your personal data will be processed for the purposes outlined in this notice. The legal basis that will be used to process your personal data will be the conduct of a “public task”. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights we will use the minimum personally-identifiable information possible. Whenever possible we will pseudo-anonymise your personal data.
- The data processor for this project will be UCL. The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data. You can find out more about how we use your information at <https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice> or by contacting data-protection@ucl.ac.uk.
- If you are concerned about how your personal data will be 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/>

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What will happen to the results of the study?

Study findings will be submitted for publication to relevant peer-reviewed journals and academic or clinical conferences. Research outputs may include anonymised quotes from participants' survey responses. Personal identifiable information will not be used for the analysis or reporting of any findings from this study. Participants' individual contact details will not be divulged to anyone outside this project. You will be able to indicate in the questionnaire if you would like us to contact you with the results of the study. You can also email daisy.mcinnerney.18@ucl.ac.uk at any point who will be able to help you access a copy of the results once they are available.

Who is running this study?

This study is conducted by a group of researchers from the Marie Curie Palliative Care Research Department at UCL. The survey is being run as part of an Economic and Social Research Council (ESRC) and Marie Curie co-funded PhD studentship awarded to Daisy McInnerney. The overall aim of the project is to tailor and evaluate a psychotherapeutic intervention for patients receiving palliative care, and their family carers. Professor Patrick Stone is the Chief Investigator. UCL is the Sponsor of the study. Individuals from UCL (the sponsor organisation) and regulatory organisations may look at your research records to check the accuracy of the research study.

Who should I contact?

If you would like further information about this study or wish to discuss the project further contact Ms Daisy McInnerney (daisy.mcinnerney.18@ucl.ac.uk) in the first instance. In the event you are not satisfied with the response, please contact Chief Investigator Professor Patrick Stone (p.stone@ucl.ac.uk).

Thank you for taking the time to read this.

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