INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: HR/DP-24/25-46809

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of project

Exploring the experience and needs of patients and their family members / informal caregivers when living with cancer-related pain.

Invitation Paragraph

I would like to invite you to participate in this research project which forms part of my **Doctoral** research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

The purpose of the project is **to understand the experience of patients living with cancer-related pain and family members / informal caregivers who care for a loved one with cancer-related pain.**

We know that cancer-related pain is complex and can have a significant impact on the individual living with it and those around them. This project aims to understand the experience of cancer-related pain and understand what support is available for people affected by it.

Why have I been invited to take part?

You are being invited to participate in this project because **you are:**

- **A person with lived experience of cancer-related pain and has experienced pain in the last 12 months.**
- **Are a family member / informal caregiver of someone with lived experience of cancer-related pain.**
- **Over the age of 18 years old.**
- **Based within the UK.**

What will happen if I take part?

If you choose to take part in the project you will be asked to **complete a short online survey that contains screening questions and the consent form. This is to ensure that you meet the criteria to take part in the interviews and have given consent prior to taking part. The screening questions will be used to make sure you meet the inclusion criteria. An example of the screening question would be:**

- **Are you a person who has experienced cancer-related pain?**

- **Have you experienced pain in the last 12 months?**

Once you have completed the screening and consent stage, you will be interviewed by the researcher, Martin Galligan. Participation will take place **using Microsoft Teams. The interview will last approximately 60 minutes and will take place at a time that is convenient for you.**

As part of participation, you will be asked to provide **your experience of living with or caring for someone with cancer-related pain. The researcher will ask you open questions that will focus on your experience of cancer-related pain, the impact it has had on you and how you have accessed support from healthcare professionals.**

The interviews will be audio and video recorded, but only the audio data will be used to collect information. No personal, identifiable information will be collected during the interviews as part of the research data.

Example questions that could be asked during the interview include:

- **Can you tell me about your experience of cancer-related pain?**
- **Can you tell me about the type of support you have been given regarding the management of your cancer-related pain?**
- **Did you feel involved in the decisions regarding the management of your cancer-related pain?**
- **Have you felt able to discuss any questions regarding your or your loved ones cancer-related pain?**

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign an **electronic** consent form.

Incentives

If you agree to take part in the interviews, you will be given a £25 voucher as a thank you for your time.

What are the possible risks of taking part?

The risks of taking part in this study are very low. However, the focus of the interviews will be on your experiences of living with or caring for loved ones with cancer-related pain. This will require you to share your experiences, and this may cause some distress or upset depending on the experience that you are sharing. If at any point during the interview, you feel uncomfortable or do not wish to answer a question, please let the researcher know. At the end of the interview, the researcher will give you a list of options to access any additional support if needed.

The interviews will focus on your experiences. This may result in your sharing examples of healthcare professionals who have practiced in an unsafe way. If this occurs, the researcher will support you in discussing this and addressing any safety

concerns. It is the responsibility of all healthcare professionals to act within their professional code of conduct; this includes raising concerns regarding unsafe practices.

What are the possible benefits of taking part?

There will be no immediate benefits to you for taking part in this study although some people find it helpful to share their experiences. The findings from this study will be used to help us explore the overall experience of cancer-related from different perspectives. The overall aim of this doctoral work is to develop an intervention that will support healthcare professionals in the assessment and management of cancer-related pain. This intervention will help improve healthcare professionals' knowledge, skills and confidence to help them deliver improved cancer care.

Data handling and confidentiality

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018).

- **Personal identifiable information - we will ask that during the interview you try not to use any names of people or hospitals where treatment is being received.**
- **Audio recordings will be used for transcription purposes only and will be deleted on 1st January 2026.**
- **Any video recordings will have the audio removed and be immediately deleted to protect anonymity and confidentiality.**
- **Data will only be shared within the research team and not with a third party.**
- **Data will be anonymised during the analysis using unique codes for each interview.**
- **A transcription service will be used to transcribe the audio recordings of the interviews into written text. Video recordings will not be shared with transcription service, only audio recordings.**

King's College London has a responsibility to keep information collected about you safe and secure, and to ensure the integrity of research data. Specialist teams within King's College London continually assess and ensure that data is held in the most appropriate and secure way.

Data Protection Statement

If you would like more information about how your data will be processed under the terms of UK data protection laws please visit the link below:

https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research

What if I change my mind about taking part?

You are free withdraw at any point of the project, without having to give a reason. Withdrawing from the project will not affect you in any way. You are able to withdraw your data from the project up until **1st January 2026**, after which withdrawal of your data will no longer be possible due to **the data will have been anonymised and added to the wider data for analysis.** If you choose to withdraw from the project we will not retain the information you have given thus far.

How is the project being funded?

The **National Institute for Health Research (NIHR) is funding this project as part of an individual Doctoral Research Fellowship.**

What will happen to the results of the project?

The results of the project will be summarised in **in the researcher's doctoral thesis (PhD). The findings will also be shared in conference abstracts and publication in healthcare journal. If you would like to see a copy of any publications, please contact the researcher via email (Martin.1.galligan@kcl.ac.uk).**

The researcher will have to adhere to their professional code of conduct and practice throughout the project. This may involve them raising an anonymous concern with the relevant professional regulatory body such as the Nursing & Midwifery Council or the Health & Care Professionals Council if any unsafe practice is reported by the participants and not voluntarily reported by them.

Who should I contact for further information?

If you have any questions or require more information about this project, please contact me using the following contact details:

Martin.1.galligan@kcl.ac.uk

What if I have further questions, or if something goes wrong?

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project you can contact King's College London using the details below for further advice and information:

Dr Emma Briggs
Senior Lecturer
Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care
King's College London
Room 1.14, James Clerk Maxwell Building

57 Waterloo Road
LONDON SE1 8WA
Emma.briggs@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Additional Support

If, at any point during the interview, you feel upset or distressed by the experiences you share, the researcher will pause the conversation and provide support. If you disclose any unsafe practices, the researcher will assist you in raising these concerns.

You may want to seek additional support after the interview is completed, or if you wish to raise a concern regarding the care you have received. This may include:

Support

- **Contacting friends and/or family**
- **Contact your named cancer key worker or oncology team.**
- **Contacting GP or local psychological support services.**
- **Macmillan support line 0808 808 0000**
- **Local Maggies Centre https://www.maggies.org/cancer-support/**
- **Tenovus Cancer Care Free support line 0808 808 1010**
- **Blood Cancer UK support line 0808 2080 888**
- **Breast Cancer Now support line 0808 800 6000**
- **Pancreatic Cancer UK support line 0808 801 0707**
- **Prostate Cancer UK support line 0800 074 8383**
- **Jo's Cervical Cancer Trust support line 0808 802 8000**
- **The Swallows Head & Neck cancer support line 07504 725 059**
- **Pain Concern help line 0300 123 0789**
- **Carers UK support line 0808 808 7777**
- **Pain Tool Kit resources https://www.paintoolkit.org/resources**

Raising Concerns

- **Contacting Patient Advice and Liaison Service (PALS) at your local hospital.**
- **Contacting complaint team at your local hospital**
- **Contact Care Quality Commission (CQC) via their website https://www.cqc.org.uk/give-feedback-on-care?referer=contactus**
- **Contacting local Freedom to Speak Up Guardian at your local hospital**
- **Contacting National Guardian via their website https://nationalguardian.org.uk**