



Participant Information Sheet

Title of study: Exploring the Supportive Care Needs of Families Affected by Pancreatic Cancer: A Mixed-Methods Study

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

1. What is the purpose of the study?

We are undertaking a project to understand how pancreatic cancer affects the wellbeing of families dealing with a diagnosis. This study involves a survey to collect information on the supportive care needs of family members of those who have been diagnosed with pancreatic cancer, and the emotional impacts they may experience as a result of their loved one's diagnosis.

2. Why have I been chosen?

We are inviting anyone, over the age of 18, with a family member who has been diagnosed with pancreatic cancer to take part.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. If you choose to take part, you can change your mind at any time and withdraw from the study without giving a reason. Should you choose to withdraw from this study, you may do so by exiting the online survey or stopping your completion of a paper survey. In the event of withdrawal, we will not use any of your data for our data analysis. If you withdraw after this time, the data will have been de-identified and won't be able to be withdrawn.

4. What will happen to me if I take part?

After you have read this information and provided your consent to participate, you will be asked to **complete a survey** regarding your supportive care needs and wellbeing. This survey takes an average of 12-minutes to complete.

5. What are the possible risks or disadvantages of taking part?

It is unlikely that there will be any direct risks to you from taking part in the study. However, it is possible that asking questions related to these topics may be sensitive. In the event that you become distressed, you may stop participation at any time. A list of supportive organisations will also be provided at the end of the survey.

6. What are the possible benefits of taking part?

Your participation will provide insight into the experiences of families affected by pancreatic cancer and help us to better understand how families may be supported during this time.

7. What if something goes wrong?

If you have any concerns about the research study, please get in touch with the chief investigator, Dr Gary Mitchell. Contact details are provided at the end of this information sheet. They will be able to answer your questions. *Should you remain unhappy and wish to make a formal complaint, you can contact the Research Governance Team at Queen's University Belfast (Telephone: 028 9097 2529; Email: researchgovernance@qub.ac.uk).*

8. Will my taking part in this study be kept confidential?

Your participation in the survey is completely confidential. Data will be stored as a password protected file on a password protected computer at Queen's University Belfast.

Because the data we collect from you may be of interest to other researchers, we will publish it on a publicly accessible online data repository. At that point, anyone can access the fully anonymised data which cannot identify you. We only do this with your permission (please confirm this on the consent form).

9. What will happen to the results of the research?

The research team may disseminate the findings via conference proceedings or publication in peer reviewed scientific journals. An internal report of the findings will also be developed which we can share with participants who wish to receive a copy.

10. Who is organising and funding the research?

This research is being conducted as part of a Department for the Economy (DfE) funded PhD studentship. The research team consists of Tara Anderson (PhD student, QUB, School of Nursing and Midwifery), Dr Gary Mitchell (Reader, QUB, School of Nursing and Midwifery), Dr Gillian Prue (Reader, QUB, School of Nursing and Midwifery), and Dr Lisa Graham-Wisener (Reader, QUB, School of Psychology).

11. Who has reviewed the study?

The study has been reviewed and given favourable opinion by Queen's University Belfast, Medical Health & Life Sciences Ethics Committee (Ref: MHLS 24_137).

12. Contact for Further Information

If you would like to talk in more details about any aspects of this research, please contact:

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Chief Investigator: Dr Gary Mitchell

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*Reader, School of Nursing & Midwifery, Queen's
University Belfast*

This research will be conducted in compliance with data protection legislation. For more information about how we look after your information, how to access your rights and who to contact if you have any queries or concerns about data protection please visit the Queen's University Belfast website - www.qub.ac.uk/privacynotice/Research/ListofResearchPrivacyNotices/PrivacyNoticeforResearchParticipants

Thank you for your interest in this study and for taking the time to read through this information sheet.