

**Research Study:**

**Setting the Agenda for Patient and Public Involvement in Cancer Survivorship Research in Older Adulthood**

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You are being invited to take part in a research study led by Dr Amanda Drury who is a nurse researcher from University College Dublin. This information sheet is to help you decide if you would like to take part in a research study to share your views on research topics which should be prioritised in cancer care for older adults.

Before you decide whether or not you wish to take part, please read this information leaflet carefully. This study is funded by the Irish Research Council, grant number: HPF.2014.715.

**What is this research about?**

We would like to identify the most important cancer and cancer care research topics that people over the age of 65 who are living with and after cancer believe should be addressed by research studies. This study aims to understand:

1. What older adults living with and after cancer think about cancer research?
2. What older adults living with and after cancer believe are the most important topics for research about cancer survivorship in older adulthood?
3. What helps or prevents older adults living with and after cancer from being involved in cancer research?

### **Why are we doing this research?**

This study will help to ensure that future research projects on cancer and cancer care in older adulthood are focused on the issues that are most important to people who are living with and after cancer. This project will also support the development of strategies to support people living with and after cancer to be involved in the development, design, conduct and dissemination (publication) of research studies and the results of these studies.

### **Why have I been invited to take part?**

You can take part in this study if 1) you are over the age of 65 years of age, and 2) you have ever been diagnosed with any form of cancer.

### **What will happen if I decide to take part in this research study?**

We wish to hear your views, opinions and listen to your experiences. If you choose to participate in this study, you will be asked to participate in:

- 1) One 30-40 minute telephone interview between May and July 2021,
- 2) Three questionnaires between August and October 2021.

We will ask for your written consent before we conduct the initial interview. The consent form is included with this information sheet.

#### *Interviews*

If you agree to be interviewed, we will arrange to speak with you over the phone. You will be asked about:

- 1) your understanding of research and your experiences of cancer research,
- 2) your perceptions of research priorities for cancer survivorship in older adulthood, and
- 3) the resources you believe could support older adult cancer survivors' to be involved as partners in the development, design, conduct and dissemination of research.

The interview will last between 30-40 minutes. We would like to tape record the interview so that we can listen to it afterwards. After the interview, we will use the tape recording to transcribe the interview word by word by an external company. If you would like to read a typed copy of the interview, please let us know and we will send it to you when it is ready.

#### *Questionnaires*

If you agree to participate in the questionnaires, you will be sent three questionnaires by email or post every 2-4 weeks between August and October 2021. The reason for having three rounds is to build agreement on the research topics which should be prioritised in cancer care for older adults. Each survey will take a maximum of 10-15 minutes to complete. By returning a completed questionnaire in each round of the questionnaire study implies your consent to continue participating in the questionnaire study. To protect your identity, you will be asked to self-select an identifier. This identifier will be used to ensure your responses remain confidential (we will not be able to identify you) and to enable us to link each round of the survey throughout the duration of the project.

### **Will I be asked to do anything else if I take part?**

At the end of this study, everyone who takes part will be invited to an online conference where the results of this study will be shared. Each person will have the opportunity to comment on the results and provide feedback to the researchers.

### **Do I have to take part?**

You do not have to take part in this study. It is entirely voluntary. If you decide not to take part, you do not have to give us a reason. The research team will not divulge the information you provide, or the fact of your participation, to any person.

### **Can I change my mind at any stage and withdraw from the study?**

If you decide to take part and then change your mind, you can leave the study at any time. You do not have to give us a reason. Should you wish to withdraw from the study, we will destroy any personal data which could be used to identify you. If you withdraw from the study, we will keep interview and survey data that we have already collected, as we need to manage your information in specific ways to ensure the research is reliable and accurate. You may withdraw from the study by contacting Dr Amanda Drury via email at [amanda.drury@ucd.ie](mailto:amanda.drury@ucd.ie).

### **What are the benefits of taking part in this research study?**

There are no direct benefits to you from participating in this study. We hope that the information we gain from you and other participants of the study will provide an understanding of the research topics which should be prioritised in cancer care for older adults and the strategies which could best support older adults living with and after cancer to be involved as partners in future research projects.

### **What are the risks of taking part in this research study?**

Sometimes people might get upset when talking about their experiences of cancer or with healthcare services. You do not have to take part in this study if you think that talking about your experiences will upset you or if you feel too unwell to take part. Should you decline to take part in any aspect of the study, or decline to answer particular questions, your decision will be respected, and you will not be asked to provide an explanation for your decision. If you do become upset during the interview, the researchers will listen and provide you with an opportunity to express your concerns. If appropriate, the researchers will also advise you to avail of additional supports such as the Irish Cancer Society support line helpline (1800 200 700). A list of cancer support groups and services is also available via the Irish Cancer Society website (<https://www.cancer.ie/cancer-information-and-support/cancer-support/find-support/local-cancer-support-affiliates>).

### **How will I find out what happens with this project?**

At the end of this study, you will be invited to an online conference where the results of this study will be shared with everyone who wishes to attend. If you wish, we will send you a written copy of the study results.

### **How will my data be used?**

We will be using your name, telephone number and address or email address to contact you about the research study, and to support data collection procedures. We will not keep your name or contact information once the study is completed.

You will be asked some demographic questions prior to the interview and prior to the survey to provide background information for the study, including your age, gender, diagnosis and region of residence.

### **How will my privacy be protected?**

To ensure that your privacy is protected:

1. Made-up names (pseudonyms) will be used to protect your identity on all the information we collect.
2. Any information that might identify you will be removed from notes and files.
3. All materials will be stored securely.
4. Only those researchers directly involved in the study will be allowed access to the information we collect.

Your name and contact information will be stored in a password protected database on a secure, encrypted folder to which only Dr Amanda Drury will have access. We will not keep your name or contact information once the study ends, including the recording of your interview. After this time, your personal information will be removed from the participant database.

Your consent form will be retained for seven years after completion of the study. After that time, Dr Amanda Drury will destroy all data relating to the study.

### **Will my personal data be used in future studies?**

The data collected for the purpose of this study will not be used in future studies.

### **What is the lawful basis to use my personal data?**

We are carrying out this research in the public interest and will process personal data for scientific research purposes under Articles 6(1)(a)(e) and 9(2)(j) of the General Data Protection Regulations (2018). This means that we will only use your data in the ways needed to conduct the research study.

### **What are my rights?**

As a participant of this research study, you have a number of rights under data protection (GDPR) regulations:

1. You have the right to access all personal information held about you by the researchers.
2. You have the right to change or request deletion of personally-identifiable information held about you for the purpose of this research, including your name, address or contact information.
3. You have the right to data portability; this means you may request the research team move, copy or transfer your personal information to other organisations or services in a readable format.
4. You have the right to restrict or object to the processing of personally-identifiable information.

Should you wish to withdraw from the study, we will destroy any personal data which could be used to identify you. If you withdraw from the study, we will keep interview data that we have already collected, as we need to manage your information in specific ways to ensure the research is reliable and accurate. You may withdraw from the study by contacting Dr Amanda Drury via email at [amanda.drury@ucd.ie](mailto:amanda.drury@ucd.ie).

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact

- Data Protection Officer, University College Dublin. Email: [gdpr@ucd.ie](mailto:gdpr@ucd.ie). Website: <https://www.ucd.ie/gdpr>

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: [www.dataprotection.ie](http://www.dataprotection.ie).

**Ethical Permission:**

This study has received ethical approval from the University College Dublin Human Research Ethics Committee.

**Indemnity:**

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

**Contact details for further information:**

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Dublin 4  
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Thank you for taking the time to read this information sheet. If you still have questions, please do not hesitate to contact the researchers who are conducting this study using the details provided.

**Next Steps:**

If you agree to participate in this study, we would ask you to complete the consent statement available here:

[https://healthandagriscience.fra1.qualtrics.com/jfe/form/SV\\_3DEquuxNZUKI9LE](https://healthandagriscience.fra1.qualtrics.com/jfe/form/SV_3DEquuxNZUKI9LE)