**ABC4Nurses: Quality of care improvement in advanced breast cancer**

**Participant Information Leaflet - Delphi Study**

| **Principal Investigator:** | Dr Amanda Drury, Assistant Professor of Nursing  
School of Nursing, Midwifery and Health Systems,  
University College Dublin  
Belfield  
Dublin 4  
Ph: 01 716 6481. E-mail: amanda.drury@ucd.ie. |
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| **Research Team Members**   | Professor Theresa Wiseman, The Royal Marsden NHS Foundation Trust & University of Southampton, United Kingdom.  
Ms Celia Diez de Los Rios, Researcher, European Oncology Nursing Society, Brussels, Belgium.  
Dr Gulcan Bagcivan, Koc University, Istanbul, Turkey.  
Dr Grigorios Kotronoulas, University of Glasgow, Glasgow, United Kingdom.  
Dr Maura Dowling, National University of Ireland Galway, Galway, Ireland.  
Ms Sema Erdem, Europa Donna, Turkey.  
Ms Violet Aroyo, Europa Donna, Turkey. |

You are being invited to take part in a research study lead 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 what content an educational programme for cancer nurses about advanced breast cancer (ABC) care should include. Before you decide whether or not you wish to take part, please read this information leaflet carefully.

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

This study is funded by Pfizer. This study will be conducted independently by the research team, and the funding body will not have any impact on the conduct of this study or dissemination of the study results. Only Dr Amanda Drury will have access to personal information, such as your name and email address which will be used to contact you to invite you to take part in each questionnaire.

**What is this research about?**
We would like to identify the topics that cancer nurses should be educated about in order to provide high-quality care to people living with advanced breast cancer.

**Why are we doing this research?**
This study will help to ensure that education programmes on advanced breast cancer are focused on issues that are most important to people who are living with and caring for people who are living with advanced breast cancer. The project will support the design of an education programme for cancer nurses who care for people with breast cancer in Europe.
Why have I been invited to take part?
You can take part in this study if you are: a) A person who is living with advanced or metastatic breast cancer; b) a health professional with experience looking after people living with advanced or metastatic breast cancer, c) a researcher with experience and interests in advanced or metastatic breast cancer; d) an advocacy professional with experience supporting women living with advanced or metastatic breast cancer; d) a family member or caregiver of a person who is living with advanced or metastatic breast 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 three rounds of an online Delphi survey, between October and November 2021.

If you agree to participate in the questionnaires, you will be sent three questionnaires by email every 2-4 weeks. The reason for having three rounds is to build agreement on the topics that should be included in an education programme about advanced breast cancer for cancer nurses.

We will ask for your electronic consent before you participate in the first questionnaire. A link to the consent form is included at the end of this information sheet. By completing any subsequent questionnaires associated with this study, it will imply your continued consent. To protect your identity, you will be asked to generate an identifier code from questions in the consent form. The same questions will be used to generate your unique identifier in each of the three questionnaires. This identifier will be used to ensure your responses remain confidential and to enable us to link each round of the survey throughout the duration of the project.

Do I have to take part?
No. It is up to you to decide whether or not to take part.

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 any 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.

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 can help us to design an education programme for cancer nurses which can help to improve the quality of care available to people living with advanced breast cancer.

What are the potential risks of taking part in this research study?
There are no anticipated risks in taking part in these three questionnaires. However, some people might find taking part in surveys time-consuming or upsetting. If you think that talking about your experiences will upset you, you do not have 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 while completing this questionnaire and require further support, the healthcare professionals who manage your cancer treatment can provide you with advice on additional supports which are available to you in your country. If you are upset by any of the questions raised in this questionnaire...
and would like to speak with the research team, please contact Dr Amanda Drury via email at amanda.drury@ucd.ie.

**How will I find out what happens with this project?**
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 and 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 delphi study is completed in March 2022.
You will be asked some demographic questions in the survey to provide background information for the study, including your background as a patient, caregiver, healthcare professional, researcher or advocate.

**How will my privacy be protected?**
All information that is collected about you, or responses that you provide, during this study will be kept strictly confidential. You will be identified by a unique identification number, and any information that you share will have your name and email address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to.
Your name and contact information will be stored in a password protected database on a secure, encrypted folder which will only be accessible by Dr Amanda Drury. We will not keep your name or contact information once the study ends in March 2022. 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 based on your consent to participate and in the public interest under Articles 6(1)(a) & (e) and will process any special category personal data for scientific research purposes under Article 9(2)(j) of the General Data Protection Regulations. 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 contact information held about you, including your name and email address.
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 responses that we have already collected from you, 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.

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. 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.

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 or questions:
Dr Amanda Drury, Assistant Professor of Nursing
School of Nursing, Midwifery and Health Systems,
University College Dublin
Belfield
Dublin 4
Ph: 01 716 6481. E-mail: amanda.drury@ucd.ie.

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 wish to take part in this study, please complete the consent form at the following link: https://healthandagriscience.fra1.qualtrics.com/jfe/form/SV_bQHSLH0o8VVsbCC