Participant Information Leaflet – Website information

Co-designing and piloting educational materials with patients and healthcare providers following a postpartum haemorrhage - follow up

INTRODUCTION

You are being invited to give feedback regarding the material you received following a postpartum haemorrhage. Before you decide whether to take part it is important for you to understand why we are doing this research and what is involved. Please take time to read this leaflet, and if you want to, discuss it with your colleagues, family, or friends. Please feel free to ask us if anything is not clear, or if you would like more information. Thank you for taking the time to read this.

ABOUT THE STUDY

We invite you to participate in this project to assist us evaluate the educational materials provided to a patient following a postpartum haemorrhage (PPH). This study is part of a larger project, which has the overall aim of standardising the management of PPH in maternity units in Ireland. As part of this process, we are interested in ensuring women are informed about PPH before, during and after the event.

DO I HAVE TO TAKE PART?

No, participation is completely voluntary. You are free to refrain from participation in this study or to withdraw from the study at any time.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

We are asking you to complete a short survey relating to the material you received. You will not be asked to give any personal information. Your responses will be digitally recorded using software survey tool REDCap. The data from this study will be stored on a password-encrypted computer connected to the UCC server. The responses from the survey will be analysed by the study investigators to make updates to the material produced.

BENEFITS, RISKS and SAFETY

The findings from this study will allow us to evaluate standardised patient information to ensure it is user friendly and easily accessible. If any of the questions or any of your answers cause you concern or worry please don't hesitate to contact the research team either Joye McKernan or Professor Richard Greene at 021 420 5053 or email joye.mckernan@ucc.ie and r.greene@ucc.ie in confidence. Also please don't hesitate to view supports on https://www.patientadvocacyservice.ie/

WHAT HAPPENS TO THE INFORMATION COLLECTED?

The study data will solely be accessible to the study research team. All information collected from you will be kept private and confidential and will be stored on the UCC server in a password-encrypted file. The information collected is anonymous. You are not asked to submit any identifiable information.

WHAT HAPPENS TO THE INFORMATION FROM THE STUDY?

Data which you provide to us will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation.

The General Data Protection Regulation allows us to process your data because you have provided your consent. Your personal information will be stored securely at Cork University Maternity Hospital.

INSURANCE

This study is covered by the Clinical Indemnity Scheme, which is operated by the State Claims Agency for staff working in the health services.

WHAT WILL HAPPEN TO THE RESULTS OF THIS RESEARCH?

Results of this research will be used to update patient information following a post-partum haemorrhage and may inform future projects.

FOR HOW LONG WILL THIS DATA BE KEPT?

As per research procedures we store your anonymous de-identified data for future related research for a period of 25 years. Further research analyses may be performed but this will be subject to further ethics approval if applicable. If you have any complaints in connection with our processing of data, you can contact UCC's Information Compliance Manager:
Office of Corporate & Legal Affairs
University College Cork
Western Road, Cork

E: foi@ucc.ie Tel: +353 21 4903949

You also have the right to lodge a complaint with the Data Protection Commission. Details of how to lodge a complaint can be found on the Data Protection Commission's website (www.dataprotection.ie), or by telephoning 1890 252 231.

WHO HAS REVIEWED THIS STUDY?

All research in Ireland is carefully reviewed by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing, and dignity. This study has been approved by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC).

WHAT WILL HAPPEN IF I DO NOT WISH TO CARRY ON IN THIS STUDY?

You are free to withdraw at any time, for any reason and without giving a reason.

WHERE CAN I GET MORE INFORMATION?

If you have any further questions regarding this study, please contact the Study Investigator: Dr Joye McKernan, telephone: 021 4920503, email: pphqii@ucc.ie
https://www.ucc.ie/en/npec/researchprojects/postpartumhaemorrhagequalityimprovementinitiative/