



**Educational intervention related to nursing care of Haemophilia patients/clients**

**PARTICIPANT INFORMATION SHEET**

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| **Title** | Educational intervention related to nursing care of Haemophilia patients |
| **Coordinating Principal Investigator/ Principal Investigator** | Mr. Miles Kenny |
| **Location** | Royal Prince Alfred Hospital, Sydney Local Health District (SLHD) |

**1. Introduction**

You are invited to take part in a research study looking at the impact of an educational intervention on nursing confidence and competence when caring for patients/clients with Haemophilia. The aim of the study is to compare the effectiveness of education as opposed to no educational intervention.

The study is being conducted within Sydney Local Health District by Miles Kenny, Clinical Research Coordinator, Cell & Molecular Therapies, Royal Prince Alfred Hospital. The study will be completed under the supervision of Associate Professor Mark Elkins as part of a requirement for the Graduate Certificate in Health Research course.

This Participant Information Sheet (PIS) will tell you what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask.

**2. Study Procedures**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form in REDCap.

All study participants will be required to complete a brief Eligibility Criteria Survey to confirm eligibility via REDCap after signing the eConsent form. If eligible, participants will be required to complete a brief Baseline Characteristics Survey via REDCap. These questionnaires should take 5 mins to complete in total. All study participants will also be required to complete a confidence scale survey and a multiple-choice competency questionnaire.

You will be given 3 weeks to complete these initial outcome assessments. After 3 weeks, you will receive an email to inform you which group you have been randomised to.

You will then be randomised into an intervention or control group using a computer generated random number system. There is a 50% chance of being randomised to either group and you will be notified of your group via email.

The educational intervention will be delivered as a 30-60 minute PowerPoint presentation. A link to the presentation recording will be emailed to participants. The presentation will contain information, graphics, and visual aids relevant to Haemophilia and best-practice nursing care for patients/clients with this condition. If you are randomised into the intervention group, you will be required to review the educational presentation within 2 weeks. Access to the educational intervention will be monitored and participants will be followed up via email to review the intervention if necessary. Additionally, an automated reminder email will be sent at the end of the 1st and 2nd weeks of access, to remind you to review the educational presentation.

The control group will not receive the educational intervention. The control group will be emailed the educational presentation upon study completion.

Approximately two months later, after the educational intervention has been delivered to the intervention group, all study participants will also be required to repeat the confidence scale survey and the multiple-choice competency questionnaire.

The confidence scale survey and competency questionnaire will assess your confidence and competence when providing care for patients/clients with Haemophilia. These assessments will take approximately 10-20 minutes to complete.

**3. Risks**

No foreseeable risks for participants of this study have been identified by the investigator.

**4. Benefits**

The educational intervention will contribute towards staff Continuing Professional Development (CPD) hours. The educational outcome may result in improved patient/client outcomes by facilitating quality nursing evidence-based care of patients/clients with haemophilia.

**5. Costs**

There is no cost for participation in this study, nor will you receive payment.

**6. Voluntary Participation**

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason by contacting the Principal Investigator, Miles Kenny on [Miles.Kenny@health.nsw.gov.au](mailto:Miles.Kenny@health.nsw.gov.au).Please be advised that your participation or non-participation will be kept confidential.

If you decide to withdraw from the study, we will not collect any more study-related information from you. If you want to withdraw please let us know and tell us what you would like us to do with the information we have collected from you up till then. If you wish, your information will be removed from our study records. It will not be included in the study results, unless we have analysed and published the results.

**7. Confidentiality**

All the information collected from you for the study will be treated confidentially and will be stored on a SLHD REDCap database.Only the Principal Investigator,Miles Kennywill have access to it. The data will be analysed at Royal Prince Alfred Hospital. All data for use in journal publications and presentations will be de-identified (de-identified data means that you/your information will not be identifiable). All participants will be assigned a unique study identifier upon study enrolment. The files will be retained for 7years from the day the study is completed. Once the retention period expires the files will be disposed of.

**8. Storage of Data**

The SLHD software licence for REDCap will be used for research data collection and storage. REDCap is a secure, web-based, non-commercial, data management tool designed for research purposes. Data collected by REDCap is stored on servers in the SLHD data centre. Stored data is secured, private, and confidential.

**9. Future use of Data**

The data collected in this project may also be used in future research studies. The results of this study and de-identified data may be shared in the future with national and international collaborators, any stored data that is used for related or future research, will first be reviewed and approved and approved by an appropriately constituted Ethics Committee. You can indicate your agreement to this on the REDCap Participant eConsent Form. You will be made aware of the results upon study completion via the email address you provided during enrolment

**10. Further Information**

When you have read this information, the Principal Investigator, Miles Kenny is available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact them on (02) 9515 8453 or via email [Miles.Kenny@health.nsw.gov.au](mailto:Miles.Kenny@health.nsw.gov.au). This information sheet is for you to keep.

**11. Ethics Approval and Complaints**

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X23-0325.