



## Participant Information Leaflet

### EOLAS Pilot ONLINE information and support programme

<b>Research Team:</b>	Professor Agnes Higgins, School of Nursing and Midwifery, Trinity College Dublin
	Dr. Mark Monahan, Dr Jean Morrissey, Dr Gobnait Byrne, Carmel Downes and Dr Karin O’Sullivan, School of Nursing & Midwifery, Trinity College Dublin
<b>Study Sponsor:</b>	Partly funded by the Public Service Innovation Fund
<b>Data Controller:</b>	Trinity College Dublin
<b>Data Protection Officer</b>	Data Protection Officer, Secretary’s Office, Trinity College Dublin, Dublin 2. Email: <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a>

Dear EOLAS Attendees,

We would like to invite you to take part in this research study to learn more about your experience of the EOLAS online information and support programme

This study will involve two parts: an anonymous survey and audio-recorded interviews.

This study is being conducted by Professor Agnes Higgins together with a research team from the School of Nursing and Midwifery, Trinity College Dublin. The study is partly funded by the Public Service Innovation Fund.

Before you decide whether to participate, you need to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. If there is anything that is not clear, or you would like more information about the study, please contact Prof Agnes Higgins (Phone: 353 (0) 860 456826; Email: [ahiggins@tcd.ie](mailto:ahiggins@tcd.ie)) or Dr Karin O’Sullivan (Email: [kosulli7@tcd.ie](mailto:kosulli7@tcd.ie)).

**Part 1: The Study**

### *Why is this study being done?*

The purpose of this study is to evaluate the feasibility, acceptability, and usefulness of the EOLAS online information and support programme. Gaining knowledge about your experience has the potential to improve the online programme.

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

You are being asked to take part in this study as you have partaken in the EOLAS Online programme, as either an attendee or a facilitator. Your experience means you may have important insights about how to improve the online programme.

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

Your participation in this study is entirely voluntary. If you decide not to take part, you do not have to give a reason and your decision will not have any adverse consequences.

### *How will the study be carried out?*

This study will use two methods to hear about your experience: an online anonymous survey and an interview.

The survey will consist of a series of questions about your experience, and you will be able to complete it online. If you decide to take part in the interview part of the study, the interview will be conducted over the phone or on the online platform Microsoft Teams hosted by School of Nursing & Midwifery at Trinity College University of Dublin. The interview will be for a duration of about 30 minutes. We will audio record the interview.

### *What will happen to me if I decide to take part?*

You will receive a link to the anonymous survey from an EOLAS facilitator near the end of the programme but are under no obligation to fill it out. If you do complete the survey, returning the survey means you are consenting to us using the information.

To take part in the interview, you will be required to complete an opt-in form. You will find the opt-in form at the end of the survey. If you want to take part in an interview, and do not want to do the survey, you can decline to consent to the survey and you will be re-directed to the interview opt-in form. Once you submit an opt-in form, a researcher will contact you to discuss the process, answer any questions you might have, and arrange a suitable time for the interview. During the interview, the researcher will ask questions about your experience of the EOLAS programme. You can refuse to answer any of the questions or stop the interview at any time.

Prior to taking part in the interview, you will be asked to fill in an online consent form. Submission of your consent form will be understood as signed consent. Your signed consent form will be downloaded, securely retained for a period of 7 years, and then destroyed. You will be given a copy of your signed consent, signed also by the researcher.

As it is only possible to interview 18-20 participants, should we get more people expressing interest, we will randomly select who we will interview. We will contact you to let you know the outcome of this process.

#### *What will happen to my Data?*

The survey data will be collated with everyone else's survey, so there is no way anyone will know how you responded to the survey questions. If you take part in the interview, we will use the audio recording from the interview to transcribe the discussion. The audio itself will be deleted as soon as the transcription is complete. Should any identifying personal information be included in the interview the transcript will be irrevocably anonymised during the transcription stage and your interview will be given a pseudonym. 14 days after the interview has been completed any information linking you to the interview transcript will be destroyed. You will be given a copy of your transcript if requested. If you would like a copy of your transcript, please contact Agnes Higgins and she will send it to you when it is ready.

The audio recording of consent, interviews and transcript will be stored in a password protected file on a secure, encrypted server in the School of Nursing and Midwifery, Trinity College Dublin to which only Prof Agnes Higgins will have access.

After completing the study, the researchers may decide to present the findings to forums such as fellow healthcare practitioners, service user groups, or publish in peer-reviewed journals or on the EOLAS project website (<https://eolasproject.ie/>). No information which reveals your identity will be disclosed.

#### *What happens if I change my mind?*

As the survey is anonymous, we will not be able to identify your survey once you have submitted it. However, if you decide to take part in the interview and then change your mind, you can leave the study at any time up to data being fully anonymised and the commencement of data analysis. Due to anonymization of the transcripts this request has to be made within 14 days after the interview was carried out, after that there will be no way of identifying which transcript is yours.

Should you withdraw from the interview part of the study, your interview transcript will be deleted and not used. You may withdraw from the study by contacting Agnes Higgins (Phone: 353 (0) 860 456826; Email: [ahiggins@tcd.ie](mailto:ahiggins@tcd.ie)) or Karin O'Sullivan (Email: [kosulli7@tcd.ie](mailto:kosulli7@tcd.ie))

#### *Are there any benefits to taking part in this research?*

There are no direct benefits to you from participating in this study. We hope that the information we gain from you will provide an understanding of the benefits of the EOLAS online programme, as well identify areas that need improvement.

*Are there any risks to me or others if I take part?*

There are no apparent risks to your participation, however participating in the interview has the potential to provoke difficult emotions and memories. If that occurs the researcher will be sensitive to your needs and stop the interview if that is what you would like and guide you to further support.

*Will I be told the outcome of the study?*

The results of the study will be reported in medical/scientific journals and disclosed at medical/scientific conferences, copies of which will be sent to the EOLAS steering group and published on EOLAS website. No information which reveals your identity will be disclosed.

## **Part 2: Data Protection**

*What information about me (personal data) will be used as part of this study?*

We will be using your name, phone number and/or email address that you provide us with to contact you about the interview part of the study. We will not keep your name or contact information once your interview has been transcribed and anonymised 14 days after your interview.

*What will happen to my personal data?*

Your name and contact information will be stored in a password protected sharepoint on a secure, encrypted server in the School of Nursing and Midwifery, Trinity College Dublin to which only the research team will have access. We will not keep your name or contact information once your interview has been transcribed. After this time, your personal information will be removed from the participant database.

Your written consent form will be retained until after the interview has been anonymised. After that time, Prof Agnes Higgins will destroy all data relating to the study.

*Who will access and use my personal data as part of this study?*

Only the researchers will access the personal data that you provide as part of this study. The interviews will be transcribed by an external company, Audiotrans Ltd. The company has an agreement with the university and subject to follow the legislation regarding confidentiality. They will only get access to the audio recording.

*Will my personal data be kept confidential?*

Your privacy is important to us. Your participation in this study will be kept strictly confidential, and we will not be informing anyone that you took part in this study. We take many steps to make sure that we protect your confidentiality and keep your data safe. A

data protection impact assessment has been undertaken and identified that the risk of a data breach where your personal data could be accessed by a third party was low.

All members of the research team and transcription team who will have access to your data have received data protection training and are under obligations of confidentiality as part of their employment.

Only the researcher interviewer and the transcriber (Audiotrans Ltd.) will have access to the audio recording of the interviews. Once the transcript has been completed and returned to the interviewer, the audio files will be erased by Audiotrans Ltd. The interview transcript will be coded and anonymised 14 days after your interview.

Electronic data from survey will be stored in password protected files, on a secure, encrypted server in the School of Nursing and Midwifery, Trinity College Dublin to which only researchers will have access to this data.

Your identity will be protected by assigning you a unique identifying code in interview transcripts. The identifying code will not be associated with your name or contact information. Information that might identify you will not be used in any presentation or publication arising from this study.

#### *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)(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.
  1. By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the

research. You can exercise any of these rights by contacting Agnes Higgins School of Nursing and Midwifery, TCD, 24 D'Olier St., Dublin 2. Email: [ahiggins@tcd.ie](mailto:ahiggins@tcd.ie)

2. Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).
3. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you have the right to lodge a complaint with the Data Protection Commissioner at: <https://www.dataprotection.ie/>.

### Part 3: Costs, Funding and Approval

*Has this study been approved by a research ethics committee?*

This study has received ethical approval from the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin on 12<sup>th</sup> October, 2021. Reports on this project will be submitted to the Research Ethics Committee on an annual basis until the project is completed.

Ethical approval has also been received from the Ethics Committee in Naas General Hospital, and Letterkenny University Hospital Research Ethics Committee.

This study is being conducted by Professor Agnes Higgins with a research team. The study is partly funded by the Public Service Innovation Fund.

*Is there any payment for taking part? Will it cost me anything if I agree to take part?*

No, you will not receive payment for taking part in this study.

### Part 4: Future Research

*Will my personal data and/or biological material be used in future studies?*

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

### Part 5: Further Information

*Who should I contact for information or complaints?*

If you have any concerns or questions, you can contact:

1. Principal Investigator: Prof Agnes Higgins [ahiggins@tcd.ie](mailto:ahiggins@tcd.ie) School of Nursing and Midwifery, TCD, 24 D'Olier st., Dublin 2.
2. Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).

*Will I be contacted again?*

If you complete the survey and opt in for an interview, you will be contacted again to arrange this.

### **Next Steps**

If you decide to participate in the survey, please complete by accessing the online link that you will receive from the EOLAS facilitators near the end of the programme.