Participant Information Sheet

Title of the Study: Patient and Public Involvement in the Design, Implementation, and Delivery of Post-ICU Healthcare Services in Eastern India

Department:
Department of Anaesthesiology and Critical Care
All India Institute of Medical Sciences (AIIMS), Bhubaneswar

Introduction

You are 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.

What is the purpose of the study?

The purpose of this study is to explore how patients and the public—especially ICU survivors, their caregivers, and community members—can contribute to designing and delivering better post-ICU healthcare services. We aim to set up a Patient and Public Involvement and Engagement (PPIE) group that will help us adapt, evaluate, and improve post-discharge interventions such as follow-up clinics, patient information materials, and rehabilitation programmes.

Why have I been invited?

You have been invited because:

- You are a recent ICU survivor, a caregiver, or someone with relevant experience.
- Your insights and experiences can help us understand how to improve care for people after an ICU stay.

Do I have to take part?

No. Participation is entirely voluntary. If you decide not to take part, it will not affect the care you receive in any way. If you decide to participate, you can withdraw from the study at any time without giving a reason.

What will happen if I take part?

If you choose to take part, you may:

- Join the PPI group and attend group meetings or workshops.
- Review and provide feedback on patient information materials or mobile app content.
- Participate in surveys, interviews, or group discussions.
- Help shape future follow-up services for ICU survivors.

Your participation may range from a one-time session to regular involvement depending on your interest and availability.

What are the possible benefits?

- Your feedback can help make post-ICU care more patient-friendly and culturally appropriate.
- You may feel empowered by contributing to meaningful healthcare changes.
- You will have the opportunity to learn from and share experiences with others.

What are the possible risks or inconveniences?

- Some discussions may bring up emotional memories related to your or your loved one's ICU experience.
- You are free to skip any question or stop participating at any time if you feel uncomfortable.

Will my information be kept confidential?

Yes. All information collected will be kept strictly confidential. Any personal data will be anonymised and stored securely. You will not be identified in any publications or reports.

What will happen to the results of the research?

The results of the study may be published in journals and shared at conferences. Summaries will also be made available in lay language. You can request a copy if you wish. The feedback from the PPIE group will directly inform improvements in patient care and communication.

Who is organising and funding the research?

This study is being conducted as part of a PhD project by Mr. Subhasish Nayak, under the guidance of Dr. Swagata Tripathy, Professor from the Department of Anaesthesiology and Critical Care, AIIMS Bhubaneswar.

Contact for further information:

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Participant's Consent Form

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Please read the following statements carefully and sign below if you agree to participate.

1. I confirm that I have read and understood the Participant Information Sheet provided to me, or it has been read to me in a language I understand.
2. I have had the opportunity to ask questions and have received satisfactory answers to all my questions.
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason, without any consequences to my care or legal rights.
4. I understand what my participation will involve, including attending group meetings, providing feedback, participating in interviews or surveys, and helping shape post-ICU services.
5. I am aware of the possible benefits, risks, and inconveniences related to participation, including the possibility of discussing emotional topics.
6. I understand that any information I provide will be kept confidential, anonymised, and stored securely. I understand that my identity will not be revealed in any reports or publications.
7. I understand that the results of the study may be published or presented but will be anonymised and that I can request a summary of the findings.
8. I agree to take part in this research study.

Participant's Name: _____

Participant's Signature: _____

Date: _____

Address: _____

Contact Number: _____

Researcher's Name: _____

Researcher's Signature: _____

Date:_____