

## **APPENDIX IV: Expert Consent Letter for Phase 1 Participation**

### **Introduction**

You are invited to participate as an expert in Phase 1 of a research study that aims to develop and validate an AI-powered, personalized education module for dementia and palliative care. Your expertise is essential to ensure the clinical relevance, safety, and appropriateness of the educational content generated by the system.

### **Purpose of the Study**

The goal of this study is to create a trustworthy, adaptive educational module for people living with dementia, their caregivers, and healthcare professionals. In Phase 1, we seek your expert input to evaluate and improve the quality of AI-generated responses, curate reliable sources, and ensure the system meets high standards of accuracy, empathy, and ethical compliance.

### **What Does Participation Involve?**

As an expert participant, you will:

- Review and rate AI-generated responses to dementia and palliative care queries for relevance, clarity, empathy, and actionability.
- Assess the trustworthiness of cited sources.
- Identify any misinformation or demographic bias in the responses.
- Provide feedback on the usability of the educational module through a standardized questionnaire (System Usability Scale).
- Complete a brief demographic questionnaire at the start of your participation

Your participation will involve evaluating approximately 15–20 queries, with each response independently reviewed by at least three experts. The estimated time commitment is 1–2 hours.

### **Confidentiality and Data Protection**

Your privacy and the protection of your personal data are of utmost importance in this study. The research team is committed to handling all information you provide in accordance with the highest ethical and legal standards, including the General Data Protection Regulation (GDPR). The data is protected according to the internal policies of University of Maribor, as published on: <https://www.um.si/en/o-univerzi-en/document-center/protection-of-personal-data/>

**Types of Data Collected:** We will collect information relevant to your participation, including your demographic data and your evaluations of AI-generated responses. No unnecessary personal data will be collected

**Purpose of Data Use:** All data will be used exclusively for research purposes, specifically for evaluating and improving the AI-powered dementia and palliative care education module.

**Data Processing:** Your data will be processed in a secure environment of University of Maribor, and only authorized members of the research team will have access to it. Data will be anonymized or pseudonymized to protect your identity. No directly identifiable information is collected.

### **Data Storage and Security**

**Secure Storage:** All digital data will be stored on encrypted servers, within the secure infrastructure of University of Maribor, with strict access controls. Physical documents, if any, will be kept in locked cabinets within secure facilities.

**Access Controls:** Access to data is restricted to authorized research personnel only. Role-based access controls are implemented to ensure only those who need to process your data can do so

**Data Backup and Recovery:** Regular backups are performed, and robust disaster recovery procedures are in place to prevent data loss.

**Retention Period:** Data will be stored only for as long as necessary to fulfill the research purposes and legal obligations, but at most for 5 years after the study ends.

### **Data Sharing and Future Use**

**Data Sharing:** Data will not be shared with third parties except as required by law or for scientific publication, in which case only anonymized or aggregated data will be used.

**Future Research:** If data may be used for future research projects, explicit consent will be sought, and you will have the option to decline such use.

### **Contact Information**

For any questions regarding confidentiality or data protection, please contact the principal investigator, dr. Izidor Mlakar, [izidor.mlakar@um.si](mailto:izidor.mlakar@um.si) or the institutional privacy officer, assoc. prof. dr. Miha Dvojmoč, [dpo@um.si](mailto:dpo@um.si).

### **Consent Statement**

By participating, you acknowledge that you have read and understood the confidentiality and data protection measures described above and agree to the secure handling of your data in line with current regulations and best practices.

Please tick or ask someone to help you tick each box:

- ☐ I have read or had this letter read to me, and I understand it
- ☐ I agree to take part in this study

**Thank you for considering being part of our study. Your help is very important to us.**