

APPENDIX V: Patient Consent Letter for Phase 2 Participation

(to be translated into AI4HOPE pilot languages)

About This Study

You are invited to take part in a research study about dementia and palliative care education. The goal is to make information and support better for people living with dementia and their families.

What Will Happen If You Join

You will be asked questions about you and use a new education tool. You can ask for help from a family member, friend, or staff at any time. You can stop participating whenever you want, for any reason

Your Privacy

Your personal information will be kept private and safe. Your name and details will not be collected. We will only collect your search patterns, i.e. words you use to search and how you rate the answers. The results may be shared for scientific publications, but for all participants together, thus no one will know what you wrote or rated.

Your Choice

You do not have to take part if you do not want to. You can change your mind at any time, and this will not affect your care. You can ask questions at any time.

Contact Information

If you have questions or want to know more, you can contact the main researcher, dr. Izidor Mlakar, izidor.mlakar@um.si, tel. +386 2 220 7267 or ask someone you trust to help you.

If you have concerns about your data, you may contact the principal investigator (dr. Izidor Mlakar, izidor.mlakar@um.si, tel. +386 2 220 7267) or the designated data protection officer (assoc. prof. dr. Miha Dvojmoč, dpo@um.si). You also have the right to file a complaint with the relevant data protection authority.

Consent Statement

Please tick each box or ask someone to help you:

- ☐ I have read or had this letter read to me, and I understand it
- ☐ I had a chance to ask questions and got answers I understand
- ☐ I know I can stop at any time and do not have to give a reason
- ☐ I agree to take part in this study

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

APPENDIX VI: Family Caregiver Consent Letter for Phase 2 Participation

(to be translated into AI4HOPE pilot languages)

Introduction

You are invited to participate in a research study focused on dementia and palliative care education. The study aims to improve support and information for people living with dementia and their family caregivers like you

Purpose of the Study

The purpose of this study is to develop and test an educational tool that provides helpful information for caregivers and people with dementia. Your feedback and experiences will help us make this tool better for families in similar situations

What Participation Involves

- Complete a brief demographic questionnaire at the start of your participation
- We will only collect your search patterns; i.e. words you use to search and how you rate the answers
- Ask the AI assistant about dementia and palliative care and review and rate AI-generated responses to queries
- Provide feedback on the usability of the educational module through a standardized questionnaire (System Usability Scale).

You can stop participating at any time, for any reason, without affecting your care or support

Confidentiality and Data Protection

- Your personal information will be kept private and secure
- We will not collect any directly identifiable information such as name, address, and other details
- Study results may be published or presented, but no one will know it was you
- We will only collect your search patterns; i.e. words you use to search and how you rate the answers

All digital consent records will be stored securely and managed according to data protection regulations and internal privacy policy of the University of Maribor (see <https://www.um.si/en/o-univerzi-en/document-center/protection-of-personal-data/> for more details)

Voluntary Participation

Participation is completely voluntary. You can change your mind and withdraw at any time, with no impact on your or your loved one's care. You may also ask us questions at any time.

Risks and Benefits

- There are no anticipated risks from participating in this study
- Your input will help improve educational resources for dementia care and support for the families

Contact Information

If you have questions or want to know more, you can contact the main researcher, dr. Izidor Mlakar, izidor.mlakar@um.si, tel. +386 2 220 7267 or ask someone you trust to help you.

If you have concerns about your data, you may contact the principal investigator (dr. Izidor Mlakar, izidor.mlakar@um.si, tel. +386 2 220 7267) or the designated data protection officer (assoc. prof. dr. Miha Dvojmoč, dpo@um.si). You also have the right to file a complaint with the relevant data protection authority.

Consent Statement

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