

## **INTenSE –**

“Improving dementia care through self-experience”

### **Information for participants**

We invite you to participate in a group discussion within the European research project INTenSE. Please take the time to read this information sheet carefully in order to decide whether or not to participate in our project. Please feel free to ask us if something is incomprehensible to you or if you need further information.

We thank you in advance for your interest in our project!

### **The INTenSE research project**

As the prevalence of people with dementia increases, it becomes crucial to better understand the needs of people living with dementia and to create environments where they can get the best care. The CE has concerns about the increasing shortage of healthcare professionals in dementia care. Although specialized education programmes in dementia have begun to appear in recent years, there remains a lack of consistency across Europe. Moreover, they often fail to equip students with an adequate level of dementia knowledge to anticipate the required care. This results in a professional workforce that requires additional professional training in order to work successfully with people with dementia. Even then, professional development programmes can fail to provide insight into many of the needs of people with dementia.

The project Improving dementia care Through Self-Experience (INTenSE) will educate, equip and train health and social care professionals to better support people with dementia, using innovative learning approaches and ICT tools that explore the lived experience of the person with dementia. INTenSE will support the creation of up-skilling pathways for professionals across Europe that incorporate and promote successful self-experience methodologies and practices to increase knowledge and understanding of the lived experience of dementia. As a form of experiential learning, simulation practices integrate different ways of knowing (e.g., thinking, feeling and doing) to improve care services. Examples are Virtual Dementia Tours (VDT), role-plays and Theater Laboratories practices. INTenSE will make integrated self-experience practices widely available via a training program for the current and next generations of dementia professionals.

All project activities have been designed to successfully achieve the following project objectives:

1. Detailed scoping review of the state-of-the-art of self-experience practices and focus groups to identify best practices of VDT, role-plays and Theater Laboratories, and to collect transnational experience to be included in the INTenSE e-booklet.
2. Co-design and development, at European level, of the INTenSE Dementia Simulation toolkit (DST) to simulate dementia symptoms and create empathy and real understanding as a means to change dementia care practice and to improve the quality of care.
3. Co-design of an ICT web platform as a tool for creating mutual learning through the exchange of experiences, thus fostering the digital competences of professionals.

### **What are the aims of the focus group discussion?**

In small groups, representatives of health care, culture, education and IT development will discuss their experiences with self-awareness practices in the context of dementia. We want to find out which self-awareness practices can be used to approach the experience of people with dementia in order to improve dementia care and support by means of increased knowledge and empathy. We also want to find out which aspects are significant for the development, implementation and evaluation. It is important that the participants discuss with each other and share their experiences.

### **Why are we inviting you?**

We are inviting you because you have experience in developing, implementing, applying or evaluating self-awareness practices in dementia or are confronted with the issue of dementia personally or with your relatives. We know from other studies that self-awareness practices such as virtual reality applications, role plays or theater scenes are successfully used in dementia-related education, training and further education. What has been your experience? In your opinion, what would be important aspects for the development of an intervention integrating different practices or techniques of self-awareness in dementia? We would like to talk to you about that.

### **What does participation mean for you?**

You will take part in a small group discussion with 5 to 8 people. Taking into account the COVID-19 pandemic situation, the discussion will take place online. This ensures that discussions can take place in a safe environment. A member of our working group will moderate the discussion. A second team member will take notes on the course of the conversation. The group discussion will last a maximum of 2 hours and will be recorded.

Participation is voluntary and can be revoked or cancelled at any time without giving reasons. Termination is not associated with any disadvantage for you. If you are interested

in participating, you will receive this information sheet and be asked for your written consent.

### **What are the advantages of participating?**

We hope that you will find our project interesting and that you can benefit from the experiences and views of others. You will also contribute to the development of a new intervention of dementia-related self-awareness.

### **How is the data evaluated and what happens to the results?**

A transcript of the tape recording will be made to evaluate the content. Names, places and other personal details are replaced so that it is no longer possible to draw conclusions about individual persons. The results will be used for the development of an intervention within the INTenSE project and will be published. The results will also be presented to the public at a meeting in Germany.

### **How is your data handled? (Information on data protection law)**

The data from the focus group discussions is needed for the purpose of the study objective named above. All information and statements will be collected anonymously. The evaluation will be carried out on the basis of the anonymised data exclusively for scientific purposes within the study. The results of the study will be used in anonymised form, i.e. a reference to the person is no longer possible. We assure you that all persons involved will comply with the provisions of the data protection laws. The anonymised data will no longer allow any conclusion to be drawn about your identity. This means that it is not possible to subsequently change this anonymised data.

In order to be able to coordinate the dates for the small group discussions with you, the study team of the Martin Luther University Halle-Wittenberg will collect your contact details (name, address, telephone number) as part of the enclosed consent form. Access to your contact details is restricted to the following persons at the Institute of Health and Nursing Science at Martin Luther University: Prof. Dr. Gabriele Meyer, Dr. Anja Bieber und Juliane Stubner. This personal data will be kept separate from all other data and will not be linked to your statements at any time and will be deleted immediately after the end of the study.

Responsible for data processing is Prof. Dr. Gabriele Meyer, the head of the Institute for Health and Nursing Science, Magdeburger Straße 8, 06112 Halle (Saale), Telefon: 0345-557 4498, E-Mail: [gabriele.meyer@medizin.uni-halle.de](mailto:gabriele.meyer@medizin.uni-halle.de).

The legal basis for data processing is Art. 6 para. 1 DS-GVO/ EU General Data Protection Regulation.

You have the right to request information about the personal data collected from you, to receive a copy and, if necessary, to demand that it be corrected or deleted. You also have the right to restrict the processing of your data and its portability.

The responsible data protection officer at Martin Luther University Halle-Wittenberg is Ms. Wera Kiesel (Universitätsring 19/20, 06108 Halle (Saale), Telefon: 0345-552 1018, E-Mail: [wera.kiesel@verwaltung.uni-halle.de](mailto:wera.kiesel@verwaltung.uni-halle.de)). If you suspect that your rights may have been violated during the collection, processing or use of your personal data, you can contact the Saxony-Anhalt State Commissioner for Data Protection, Dr. Harald von Bose (Leiterstr. 9, 39104 Magdeburg, Telefon: 0391-81803-0, E-Mail: [poststelle@lfd.sachsen-anhalt.de](mailto:poststelle@lfd.sachsen-anhalt.de)).

Participation in this study is voluntary. You can terminate your participation in the study at any time without giving reasons and without negative consequences.

### **Who can be contacted in the case of questions?**

We will be happy to answer your questions at any time. Please contact:

Dr. Anja Bieber, Tel. 0345-557 4427, [anja.bieber@medizin.uni-halle.de](mailto:anja.bieber@medizin.uni-halle.de) or

Juliane Stubner, Tel. 0345-557 4130, [juliane.stubner@medizin.uni-halle.de](mailto:juliane.stubner@medizin.uni-halle.de)

If you agree to participate, please confirm your consent on the enclosed sheet (consent form) by signing it.

**Please support this study by participating.**