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**The Pandemic, Dementia and the Arts (PDA) Study**

**Participant Information Sheet**

**Dear potential participant,**

My name is Valeria Lembo and I am a PhD Student at the School of Health in Social Science of the University of Edinburgh, where I work with the ECRED Centre (Edinburgh Centre for Research on Dementia).

The Covid19 pandemic has hugely affected the daily lives of people affected by dementia in the UK and had a great impact on dementia-inclusive community activities.

Research shows that art and leisure activities can have a positive impact on the lives of people with dementia, family members and carers. For my research, I want to know more about the role of arts, crafts and leisure in the lives of people affected by dementia, especially in these times of restrictions and social isolation.

I am also interested in how organisations and groups delivering dementia-inclusive activities have adjusted through the pandemic and what challenges they are facing.

For these reasons I would like to invite you to take part in this research project.

**Who can take part in the research?**

You can join the project if you are a person affected by dementia living in the UK.

Either you are a person with dementia / memory problems with capacity to consent, or a family member, friend or carer of someone with dementia. You enjoy the arts and crafts and/or you join dementia-inclusive group activities.

You can also join if you are an organiser, artist or volunteer based in the UK and involved in dementia-inclusive activities related to arts, crafts and leisure.

Research will be online only to guarantee safety for everyone. You will need a good Internet connection, a phone, or tablet or a computer to access email and the video call platform Zoom.

**If you are a person with dementia, you can join the research activities with the help of a family member, a friend or carer, if you wish.**

Please, take time to decide whether you wish to take part – if you don’t want to take part, you don’t have to!

After a first phone-call or video call, I will invite you to take part in different activities. The research is divided into 3 stages.

**You don’t have to join all 3 stages and activities to be a research participant:**

 **1) Taking part in online activities together:**

I would love to join online leisure, arts and crafts activities with you!

If you are a person affected by dementia, an organiser or someone leading an online activity you can invite me to join.

I will ask permission to take part and join as a participant.

After the session I will take some notes. These notes will describe the things that we did during the activities and your actions, or quote some of what you said during them. Notes will only be about those who consent to take part in the study.

**2) A Creative Exchange:**

This will consist of sharing with me pictures of your creations, stories or poems, videos or recordings of your home performances, anything creative.

In exchange, I will also share with you a creative work realised by me (pictures, songs, texts etc.). After the first exchange you can decide if you wish to carry on and start a correspondence with me. This will be led by you. You can share creative materials at your pace and for a maximum of 10 times.

You can send me your videos, pictures, texts or recordings via Whatsapp or email.

You will still be the copyright owner of your creations and I will ask your permission for publishing or sharing anything you send me.

**3) Online Interviews:**

I want to invite you to one-on-one interviews for a max. number of three interviews (but one-off interview will be also okay).

These will be held by videocall on Zoom and last no more than 50 minutes. Interviews will be about your engagement with arts, crafts and leisure activities during the pandemic. All interviews will be video-recorded with your permission and not shared with anyone.

**Consent**

Before joining a research stage we will check and record formal consent together through a one-on-one videocall, that we will schedule in advance via phone call or email.

I will read aloud the points listed in the consent form for each stage and how I will treat your data. You can confirm each point by saying yes or no.

I will also send the consent forms by email in advance so that you can read them carefully. If you prefer, you can fill in the consent form from your computer, type in your name and send it back to me by email.

I will ask formal consent:

* Before the first observation of online activities.
* Before starting the creative exchange.
* Before the first interview.

However, I will regularly check with you for consent during the whole course of the research and will ask to record informal consent before each research activity.

**How will my information be kept safe?**

The material produced during the study will include:

* Video/audio recordings and transcripts of the interviews.
* Notes taken after the online dementia-inclusive activities.
* Recordings, pictures, photos, texts etc. that you will send to me through the ‘creative exchange’.
* Video/audio recordings and transcripts of the art-based focus group activity.

Everything will be stored safely and analysed by me only (including if you stop taking part in the research).

You will have the copyright of your creations and I will ask permission for sharing the pictures and recordings you send me. This will only be for research purposes such as papers, presentations and my thesis.

I will treat everything you say or share with absolute respect. I will not use your real name, unless you agree otherwise: you will be given a fake name that you can choose yourself if you want. I will also change the name of groups, organisations and activities unless they would like to be identified. Your personal details such as name, email and telephone number won’t be accessed by anyone.

Protecting your confidentiality is really important for the project. But if you reveal that you or someone you know are at risk of harm, then we’ll talk about it to see together how best to handle the situation.

All your personal information and details will be stored safely at the University of Edinburgh for 5 years.

**Do I have to participate?**

If you do not want to be included **it is fine to say no. This will have no impact on the services you receive and the activities you attend.**

**You don’t have to join all 3 research stages and activities to be a research participant.**

You can stop taking part in the research at any time without having to tell me why.

**Benefits and risks**

Participation in this study involves minimal risk. If you allow me to share your photos or videos, you could be identifiable even though I will use a fake name. I can blur your face if you prefer.

Talking about your experience of living with dementia can make you feel sad or upset but it is also an opportunity to share your views and get involved in dementia research. We can stop the activity whenever you want.

Taking part in the research activities, however, could be also fun and enjoyable, an opportunity to share your hobbies, passions and experiences and get involved in dementia research.

In the longer term, I hope that this research will help to better understand the role of arts, crafts and group activities in the lives of people affected by dementia, especially during the Covid19 pandemic.

**Contact and further information**

If you have questions or would like to be involved please get in touch with me.

 

Valeria Lembo

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**My research supervisors are:**

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If you wish to contact someone independent of the research or you wish to make a complaint about this study, please contact the Head of School Matthias Schwannauer at the School of Health in Social Science, University of Edinburgh (Tel: +44 (0)1316513954).

If you are a person with dementia or a carer/family member and wish to talk about your situation, local support is available by contacting:

**Alzheimer Scotland Freephone Helpline: 0808 808 3000**

**Thank you very much for reading this important information.**