**PARTICIPANT INFORMATION SHEET**
**Welfare Attorney/Welfare Guardian/Nearest Relative**

**Kinections Project**

**You are being invited to consider giving your permission for your ward/relative/person you are consenting for 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.**

**We would then ask that you put your own views about the research aside and to consider and take into account, the past and present wishes and feelings of your ward/relative/person you are consenting for, had they been able to consent for themselves.**

**Please take time to read the following information carefully and discuss it with others if you wish.**

**Please ask me if there is anything that is not clear or if you would like more information. Thank you for reading this.**
**Name of Researcher: Dr Edel Roddy**
**Contact Details: Email- edel.roddy@uws.ac.uk Mob.No. 07720897717**

**What is the purpose of the study?**
This study, Kinections, aims to explore the idea of 'community' for people in care homes living with dementia or a cognitive impairment. The research team are looking to find out more about the ways in which people with a dementia or cognitive impairment are supported to be part of the care home community; with a particular focus on their everyday experiences and interactions in the care home.

**Why has the patient been chosen?**
Your ward/relative/person you are consenting for has been asked to take part as they have: been deemed to be an adult with incapacity due to a dementia or cognitive impairment.

However, they currently lack the capacity to make an informed decision about whether they can take place in a research study. We are therefore asking you as their Welfare Attorney/Welfare Guardian/Nearest Relative, if you will give consent on their behalf to join this study. This is permissible under the Adults with Incapacity (Scotland) Act 2000.

**Do they have to take part?**
No. It is up to you to decide whether they take part in the research or not. If you decide that they should take part you are free to change your mind at any time and without giving a reason and this will not alter their care in any way, now or at any stage in the future.

**What will happen to your ward/relative/person you are consenting for if they take part in the research?**

The researcher will be observing your relative/ friend/ person you are consenting on behalf of as they spend time in communal spaces, for example in the care home lounge, dining room, public spaces. The researcher will also be observing your relative/ friend/ person you are consenting on behalf of during their interactions with others.. The observation will only go ahead if the other person/ people, for example staff member, involved have given their consent to being observed. The periods of observation will last on average 5-15 minutes.

After the period of observation the researcher will then go to a private area to write up notes on what they saw. It is these notes that may then be shared as part of the research study. The focus of the observation is to report on practices which appear to enhance engagement and interaction between your relative/friend/person you are consenting on behalf of and others.

**What are the possible benefits of taking part?**
Your ward/relative/person you are consenting for may not get a direct benefit from taking part in this study.

It is hoped that through these observations there may be new learning generated about what helps to create positive outcomes for your relative/ friend. It is also planned that the findings of this research will inform future practices in care homes.

**What are the possible disadvantages and risks of taking part?**
It is not anticipated that involvement in the study will pose any disadvantage or risk to your relative.

**What if there is a problem?**
It is not anticipated that any problem will arise for you during the study. However, if you wish to make a complaint or have any concerns over any aspect of the study, at any time, please contact the researcher – Edel, or the Principal Researcher – Dr Anna Jack-Waugh - whose contact details are available at the end of this information sheet. Alternatively if you wish to contact someone independent of the study you can contact Professor Debbie Tolson, whose details are also available at the end of this sheet.

**What happens when the study is finished?**
The findings of the study will be shared to inform further development of practices in care homes. Findings will be shared in informal and formal ways including learning events, online resources, written reports, journal publications and conference presentations. These findings will take the form of stories and examples of engagement and interactions between your relative/ friend and others.

**Will taking part in the study be kept confidential?**
All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard the privacy of the patient at every stage.

The study is confidential. However, in the unlikely event that the researcher witnesses aspect of care and practices that raise concern, this will be immediately discussed with the care home manager and/or social services.

The care homes involved in this study is information in the public domain. Crossgate Care Home will not be named in association with the data collected about your relative/friend/person for whom you are providing consent.

Prior to data (stories, examples) that has been generated being shared publicly any unique characteristics or details that may potentially identify your relative/ friend will be removed. In place of your relative's/friends/person you are providing consent for actual name, the stories and examples linked to your relative/friend will be shared using a fictitious name.

The University of the West of Scotland is registered under the Data protection Act and has an Information Security Policy to safeguard the collection, processing and storage of confidential information.

**What will happen to the results of the study?**
You will be given the opportunity to, if you wish, view the data which has been collected following the observation of your friend/relative/person you are providing consent for, prior to it being shared more widely. If for any reason you do not wish this data to be included in the study, it will be removed; you will not have to provide a reason for wanting it to be removed.

Findings of the study will be shared through informal and formal means as described above; with your relative/friend/ person for whom you are giving consent for being identified using a fictitious name.

**Who is organising the research and why?**
This study has been organised/sponsored by University of the West of Scotland and funded by Life Changes Trust.

**Who has reviewed the study?**
The study proposal has been reviewed by the School of Health and Life Sciences Ethics Committee, University of the West of Scotland. All research involving adults without capacity is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from Scotland A REC. Crossgate Care Home management approval has also been obtained.

**If you have any further questions about the study please contact Dr Anna Jack-Waugh on: 013873 45800 or email: anna.jack-waugh@uws.ac.uk**

**If you would like to discuss this study with someone independent of the study please contact:**

**Prof. Debbie Tolson**
**Director of the Alzheimer Scotland Centre for Policy and Practice**
**University of the West of Scotland**
**Lanarkshire Campus**

**Email: Debbie.tolson@uws.ac.uk**
**Tel.: 01698 283 100 ext. 8669**

**Thank you for taking the time to read this information sheet**