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# Independent Living Functions for the Elderly (IN-LIFE)

## Supporting communication in dementia

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**Abstract.** Independent Living Functions for the Elderly (IN-LIFE) is a 3 year multidisciplinary, multisite European project that aims to prolong and support independent living for people with cognitive impairments, through (ICT) services. Sheffield is one of six research sites and is focused on enhancing communication and conversations using touch screen computers.

**Keywords.** Dementia, psychosocial, communication, ICT

### 1. Introduction

Dementia is an umbrella term applied to a collection of progressive neurological disorders that at present cannot be prevented or reversed. Age is the biggest risk factor for developing dementia [1] and as life expectancy continues to grow, the number of people in the world with dementia is predicted to rise from 46.8 million in 2015 to 74.7 million by 2030 and to 131.5 million by 2050 [1]. There is no single cause of dementia and no single pattern to the way it affects people. Alzheimer's disease (AD) is the most common cause of dementia, accounting for 42% of cases [2] although vascular dementia (VaD; 23.7%) and mixed AD and VaD (21.6%) are also common [2].

A notable early symptom of AD is problems with working memory, such as difficulties recalling and discussing recent events, although people's memories for events from earlier in their lives, particularly childhood and early adulthood, are typically unaffected [3]. As dementia progresses, all aspects of cognitive function are implicated which in turn affects people's social, emotional and everyday behaviours. The progressive debilitation these changes cause makes people with dementia increasingly reliant on family or professional caregivers for meeting all their needs [4].

Among the many challenges faced by people with dementia and those who care for them communication is particularly problematic. This in part arises from the working memory problems which, among other things, make it difficult for people to hold conversations [5]. In addition, they can frequently repeat phrases [6] and their responses can give the appearance of not listening to what their conversation partner is

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saying. This can be frustrating and disempowering for people with dementia and distressing for the family and care staff they are trying to communicate with [7]. Developing interventions to support communication and maintain relationships between people with dementia and those who care for them is a growing social and healthcare priority. As highlighted in the Prime Minister's Challenge on Dementia 2020; "we wish to encourage greater personalisation in the provision of post-diagnostic services...incorporating new ideas including technology solutions into everyday practice [8].

## **2. Information and Communication Technologies (ICTs)**

People with dementia have been increasingly exposed to technologies to assist and enable in a number of life domains [9] and utilising technological interventions in dementia care is now common practice. Nevertheless, these technologies have generally been appropriated to address issues of safety and security and carer reassurance applying interventions and research conducted to examine this. Many of the prevailing technological interventions have also addressed the declining cognition that characterises dementia as well as those memories that have been compromised. Although these aspects remain important, this continuing focus neglects what is retained and done well in addition to the persons capacity to continue communicating effectively and continue participating in activities important to them [10]. Nevertheless, the potential of contemporary ICT's is beginning to be recognised in the dementia literature and there has been an exciting influx of research evidence that has utilised new forms of ICT in order to engage effectively with the person with dementia in activities considered important to them [11]. This additional focus is essential when questioning whether the person with dementia may gain from contemporary ICT usage in line with the rest of the population [4].

### **2.1. Computer Interactive Reminiscence and Conversation Aid (CIRCA)**

CIRCA is a multimedia computer system developed to support and promote communication between people with dementia and caregivers [5]. CIRCA is based on reminiscing: the process of recollecting memories from one's life, for example about work or hobbies, and speaking about these with one or more other people. The process of recollecting personal memories can be prompted by various stimuli including photographs and artefacts. Engaging in reminiscing is considered to contribute to well-being and provide a positive activity for people with a diagnosis of dementia [12].

CIRCA is an innovatively designed interactive software application comprising a broad range of stimuli to prompt reminiscing with people with dementia [4]. The CIRCA system was developed with a user centered design approach to address the expressed need for supported conversations with their loved ones reported by those in a caring role. Consultations involved people living with the condition and those in supporting roles, both formal and informal regarding the potential need for the CIRCA system. The development of the prototype was then carried out iteratively and consistently involving the intended users' perspectives and opinions throughout [4].

For the person with dementia, CIRCA provides the opportunity to make independent choices and engage as an equal partner during conversations with others [5]. Furthermore, caregivers re-evaluated their expectations of the person with

dementia and viewed them ‘in a new light’ whilst formal caregivers reported feelings of increased competence within their caring role [5]. Although early development of CIRCA involved groups of participants as well as one-to-one sessions, no systematic study of CIRCA as a stimulus for a group activity has been previously undertaken. However, there is growing evidence that participation in group-based activities can be beneficial for people with dementia. For example, [13] demonstrated improvement in cognitive function and quality of life of people living with dementia participating in Cognitive Stimulation Therapy (CST).

### **3. Methods**

#### **3.1 Design**

This paper describes a quasi-experimental pre-post design where all participants will receive the intervention. The formal assessments will also be repeated at three months to explore possible maintenance of any positive effects of the intervention. The project comprises two parts: part (i) 8-session CIRCA-based group activity; and part (ii) two-week home use of CIRCA.

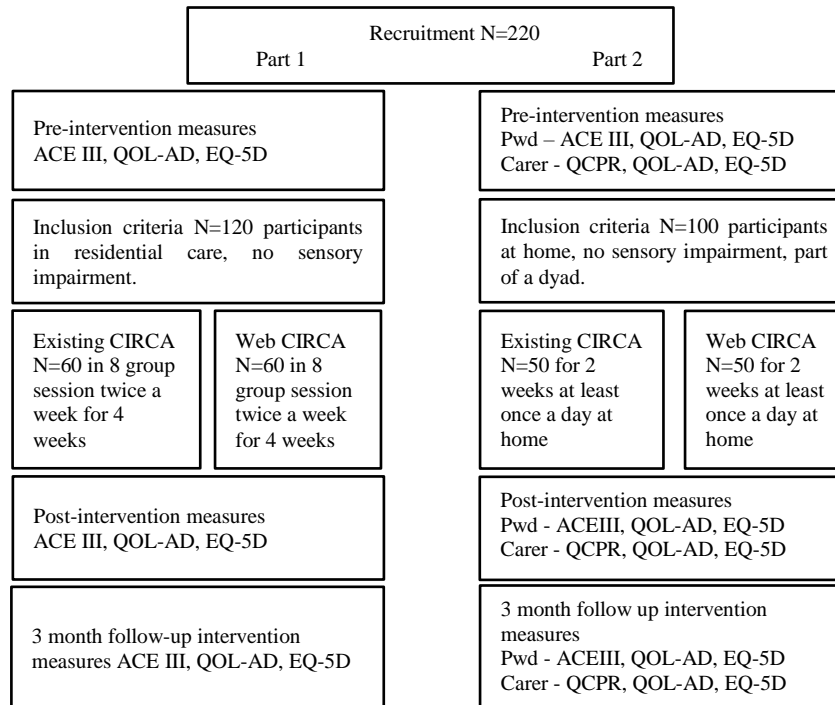
#### **3.2 Sample size**

The primary outcome will be the impact of CIRCA on cognitive function. The Addenbrookes Cognitive Examination – third edition (ACE-III) will be used to assess cognition at three time points: baseline, at the end of the intervention and three- months post intervention. To detect a standardised mean change or effect size of 0.25 on the ACE-III outcome with 90% power and 5% (two-sided) significance level, and assuming 15% attrition, a minimum sample size of 200 people with dementia will need to be recruited.

#### **3.3 Participant and recruitment**

A total of 220 older adults living with cognitive impairment will be recruited from partner organisations in and around Sheffield, UK. These partners are Sheffcare Ltd. (a provider of residential care, day care and support at home), Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Health & Social Care and Alzheimer’s Society Sheffield. The recruitment process and inclusion criteria flow chart are described in Figure 1.

**Figure 1.** Recruitment of participants and intervention applied



Part (i) 120 participants will be recruited; half will participate in 8-session group activities using the existing CIRCA app and half will use web-based CIRCA (CIRCA-WB). Part (ii) 100 participants living at home will participate with a partner, half of whom will use the existing CIRCA app and half will use CIRCA-WB for two weeks, at least once a day.

3.4 Ethics - HRA approval was received and a favorable opinion from the Sheffield REC, reference 16/YH/0354.

### 3.5 Materials

#### 3.5.1 Assessment measures

**Cognition** - The primary outcome measure is the Addenbrookes Cognitive Examination-III (ACE-III) [14]. The ACE-III is scored out of 100 within 5 domains; attention, memory, fluency, language and visuospatial skills. The ACE-III cognitive domains have been found to correlate significantly with standardised neuropsychological tests illustrating high levels of sensitivity and validity [14].

**Quality of Life** - The Quality of Life in Alzheimer’s disease (QOL-AD; [15] is the secondary outcome measure. The QOL-AD has 13 items measuring physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. QOL-AD can be completed by people with a range of dementia

severity. QOL-AD has good internal consistency, validity and reliability [13] and is recommended by the European consensus on outcome measures for psychosocial interventions in dementia [16].

Health status - The EQ-5D [17], a self-reported health and quality of life measure will be used as another secondary measure. EQ-5D has been widely used with a range of study populations producing a simple value of health status.

Caregiving relationship - The Quality of the carer-patient relationship (QCPR) is a measure appropriate for both the carer and the person with dementia. The QCPR is a measure of relationship quality, comprising 14 items to assess warmth, levels of conflict and criticism in the caregiving relationship [18]. The QCPR will be used to examine the impact of using CIRCA with family caregivers in part (ii) of the study.

### 3.6 Procedure

Part (i) –CIRCA group activity - One hundred and twenty participants with dementia will be recruited from Sheffcare and the local Alzheimer’s Society. Within Sheffcare, half will be participants from the day care programme and half from residential care. The Alzheimer’s Society participants will be people living at home in the community. The group intervention will run twice a week for 60 minutes per session over 4 weeks and consist of each group and one researcher interacting with CIRCA. Ten groups will use the original CIRCA and ten groups will use CIRCA-WB.

Part (ii) – CIRCA at home - Fifty participants with dementia will be recruited from Sheffield Teaching Hospitals (STH) and Sheffield Health & Social Care (SHSC). Each participant will be required to have a spouse, family member or friend willing to participate with them (the dyad). All participants in part (ii) will take part in their own homes and the intervention will run for two weeks and participants will be asked to engage with CIRCA at least once per day. A further 50 dyads will be recruited and use the CIRCA-WB. Internet enabled devices will be provided to the participants with a Wi-Fi package to enable participants to access the web-based CIRCA.

### 3.7 Analysis

All data will be entered into SPSS for Windows (version 20) for analysis and two 2 x 3 mixed analyses of variance (ANOVA) will be performed with the between participant factor of group (CIRCA or CIRCA-WB) and the within participant factor of time (pre-intervention, post-intervention and at three month follow-up) for scores from the formal measures (ACE-III (QCPR), QOL-AD, EQ-5D). The video recordings of the 160 group sessions (20 groups x 8 sessions each) will be examined using the Observer video analysis software to look at group interactions and participation. The audio from the video files will be transcribed and analysed using Nvivo.

## 4. Results

The study will be completed by January 2018. The first 54 participants have completed the 8 session programme using CIRCA as a standalone device. They are aged between 70 and 100 years, with ACE-III scores between 6-84 (mean 45.37) and QOL-AD scores between 21-41 (mean 30.73). Post-intervention assessment to date (n=37) shows

maintenance of cognitive function (ACE-II mean 45.162) and slightly higher QOL-AD (mean 32). Sample recordings illustrate the efficacy of CIRCA in facilitating group sessions.

## **5. Discussion**

This paper has addressed issues relating to broadening the use of existing ICT's and applications for people with dementia across Europe. Using CIRCA as an example, we will provide data on the accessibility and acceptability of tailored web-based applications for people with dementia. This study will also provide data on delivering instructions for using web-based applications and setting up technology for people with dementia to use at home. The study will also provide data on the potential of CIRCA to support a group activity for people with dementia. If successful, the group-based programme could add to the growing range of interventions available for dementia care settings to support social interaction, conversation and engagement. This study will also provide data on the potential of CIRCA as an activity for people living with the early stages of dementia at home. Specifically, we will learn about the strengths and limitations of CIRCA for supporting social interaction at home. We will also add knowledge about creating web-based applications tailored to the needs and requirements of people living with dementia. The present study is part of a larger European trial that is developing a cloud-based platform for people with dementia across Europe to access. The IN-LIFE platform will offer CIRCA-WB along with 18 other web-based services to support people to live well with dementia. These alternate services are being investigated in parallel in five other European countries and if successful, the results will contribute to existing research and practice regarding the 'best' ways to engage people with dementia using contemporary ICT's.

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