PhD Project Proposal - Exploring the use of video calls to help prevent loneliness and reduce the risk or impact of dementia

1.Background to the study

Social isolation, loneliness, and dementia

Social isolation and loneliness have the potential to contribute to increasing the risk of cognitive decline [1-3] and can increase an older person's chances of premature death by 14% [4]. Recent reviews on interventions [1, 2, 5] to reduce social isolation revealed that those interventions that targeted 'maladaptive social cognition', were participatory, and theory driven, were more effective. Dickens et al (PMS Exeter) revealed only one study that focused on the use of social networking by computer [6]. Our recent rapid search revealed a current UK study of telephone befriending [7] and several new studies ranging from a feasibility study [8] to trials on the effects of video calls on isolation [9, 10] but none of the latter were in the UK. Reviews highlighted the need for further research on IT based interventions to reduce loneliness or social isolation among older people, especially those isolated in nursing homes with a high risk for cognitive decline.

Social isolation is the lack of 'structural' and 'functional' social support. Structural social support is normally assessed through the size of networks and frequency of contacts. Functional social support is a subjective judgment of the quality or perceived value of emotional, instrumental and informational support provided by others. Loneliness is a subjective concept resulting from a perceived absence or loss of companionship. The need for companionship and to feel related to others is a core human need within Self-Determination Theory [11]. There are a number of validated tools to assess social support and loneliness, though concepts of social isolation and loneliness may not always be clear and the tools used to measure it may not be sufficiently sensitive to pick up important changes e.g. in the quality of contact [1].

Victor and Bowling [12] in a longitudinal study of 287 people over 8 years found that prevalence of loneliness at both time points was very similar, with 9% reporting severe loneliness; 30% reporting that they were sometimes lonely, and 61% reporting that they were never lonely. A quarter (25%) demonstrated decreased and 15% worsened loneliness. Improvements in physical health and improved social relationships were linked to reduced levels of loneliness. Victor's prevalence figures are mirrored by a recent community study of 1255 people aged 65 and over found that 8% were very lonely and a further 38% moderately lonely [13]..

Family caregivers, or sometimes 'secondary' caregivers (e.g. brothers or sisters of the 'local' caregiver), may live some distance from the older person but could contribute to contact and social stimulation for the older person through technology [14]. On the other hand both older people and their family may be concerned that video calls may replace face-to-face visits [15]. Improving the quality and quantity of social contacts may help in maintaining quality of life both of people with dementia and their families[16, 17] but it is not clear if the capability for video calls improves overall quantity and quality of contact.

People at-risk or with early stages of dementia and video calls

The main 'digital divide' is by age. Age is the biggest predictor of non-internet-use; in the United Kingdom (UK) in 2011, only 33% of those aged 65+ used the internet compared to 99% of those aged 14-17. However, various initiatives, including in Plymouth, have attempted to address this age-divide in use of the Internet. In the Plymouth SeniorNet (PSN) project (2012-2014) 144 people aged 65+ were helped to 'go online' (Jones et al, in preparation). We assessed impact on contacts with others, loneliness, mental health and how beneficiaries valued going online. Contacts with others (Lubben scale [18]) were significantly increased, beneficiaries showed reduced loneliness scores (Gierveld scale [19]) from baseline to follow-up, and improved mental wellbeing (WEMWBS [20]). Better communication with family and friends clearly gave the most value to beneficiaries among different Internet

uses. Having the Internet was valued less than having TV but more than (e.g.) having a weekly visit from a cleaner. The main analysis did not differentiate between using email or Skype for family contacts but anecdotally we know that video calls were used by many. Many of those who bought new computers favoured the use of tablet computers (Figure 1). There was no control group in this study so reduced loneliness may have been partly the result of contact with the project volunteers rather than family. Cognitive impairment was not assessed in these participants, but as people living in their own homes – albeit often with considerable social care input – they were relatively independent and, at most, likely to have mild cognitive impairment.
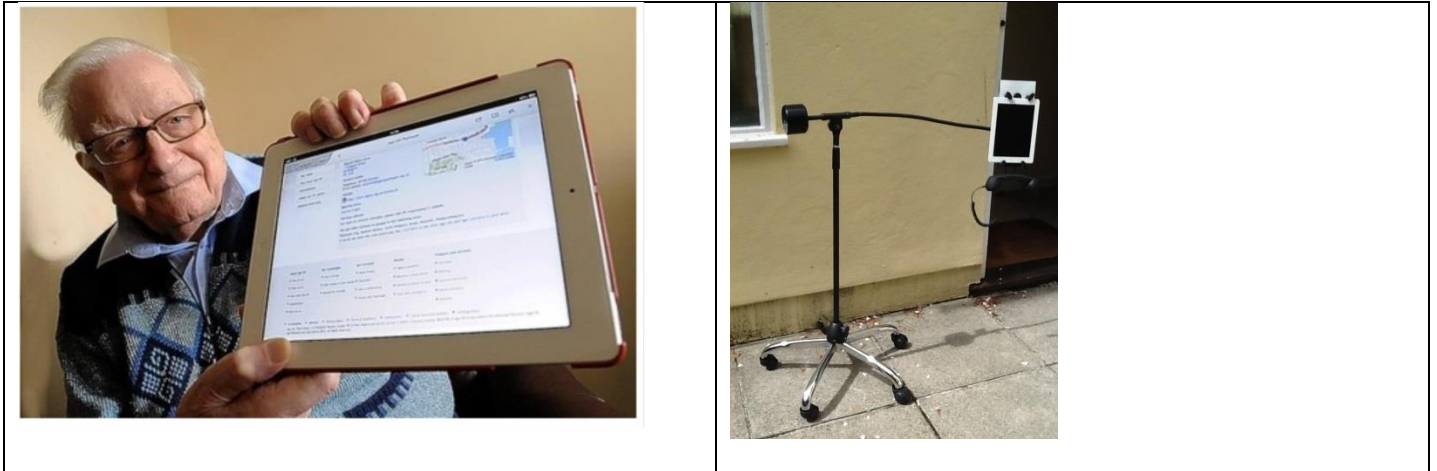

Figure 1 (left). Participant from PSN with tablet computer.

Figure 2 (right). Skype on Wheels prototype (showing retro handset)

Another project underway (Jones, in progress) is a proof of concept study of 'Skype on Wheels' in care homes and community hospitals. The main focus of this study has been the design of a 'chassis' (Figure 2) suitable to allow a carer or nurse take a video call then wheel it round to a resident. The older person, perhaps with dementia, may see it as a telephone call ('retro' handset) in which you can see the other person (rather than describing it as 'Internet use'). The first care home to trial this was Waypoints, Plymouth, a new purpose-built care home specialising in dementia. Waypoints opened in 2013. Skype on Wheels was introduced to the home in January 2014 when there were relatively few residents. From January 2014 onwards two residents made use of Skype with their families. Both had early onset dementia but were able to use Skype. Since March however both residents have left Waypoints and over the course of the year the home managers decided to concentrate on more severe cases of dementia. Staff felt that none of these residents were capable of using Skype. It was felt that, as a minimum, residents needed to be able to engage with, and understand, television. Only two of the current residents are able to do so but their understanding of television is still very limited. We have therefore withdrawn Skype on Wheels.

In conclusion, video calls are likely to be feasible (given appropriate technology to assist) with older people with no noticeable or mild cognitive impairment, perhaps moderate levels of dementia but not with more advanced dementia (typified by not being able to engage with television and not able to follow and understand simple instructions). A study in care homes with a 'mixed' population with varying degrees,from at-risk to early stages, of cognitive impairment/dementia would allow clarification of for whom video calls might be useful and lead to a definitive RCT of its impact on loneliness and mental wellbeing. In the longer term, others are starting to explore impact of video calls on cognitive functioning [21] and this willpart of our research trajectory.

Opportunities for this PhD study to explore use of video calls in different settings

In order to assess the feasibility and acceptability of both an intervention involving the use of IT to reduce loneliness among people at risk of dementia, and trial methods, the PhD student will have access to the following data:

1. <u>Dataset and cohort from PSN</u>: The main analysis of the PSN dataset (140 older people living in their own homes) did not focus specifically on video calls and their relationship to improvements in contacts, loneliness, or mental health. Age UK Plymouth is the holder of the contact details and (with ethical permission) a subset could be recruited for further study. We plan to conduct interviews with 10-20 to provide the basis of a pilot study to further explore appropriate outcome measures and the use of Internet for video calls and email at the more 'independent end' of the spectrum.

2. <u>Alfi Connect project</u>. RJ is a co-investigator on this new BT funded project. We have just obtained ethical permission. The aim of Alfi is to recruit 60 people living in their own homes in Cornwall thought to be isolated and not using the Internet, but able to consent. They will trial 'Skype via TV' which is thought to be simpler to use than using Skype as part of Internet use. BT will lead the research for the first 12 months starting in September 2014. We have included in the project design (and ethical approval) an additional follow-up interview (18 months, March 2016) with a Plymouth University researcher in anticipation of this PhD study. There will be variable use of Skype according to their families' willingness and abilities to do so. There is likely to be considerable drop out from Alfi but we estimate that 20-30 people may be available for interview at 18 months. Qualitative interviews with 10-20 will explore contacts and loneliness and if used, video calls (thematic analysis). We can apply for minor amendment to the ethics approval depending on the needs of the PhD.

3. <u>Skype on Wheels</u>. RJ has ethical approval for proof of concept/usage study and is in the process of installing 4 Skype on Wheels devices in care homes in Devon. The focus will be on care home residents at risk or early signs of cognitive decline and not on advanced dementia. At the moment ethical approval is simply for usage data but the PhD student will extend that to a trial comparing before/after in 4 care homes with/waiting for Skype on Wheels. Interviews with residents will focus on social contact, loneliness, and dementia assessment. The PhD student, through review of this proof of concept study, will gain an understanding of the importance of stakeholder involvement in technology design and implementation before attempting to assess impact.

4. <u>Survey of care homes in Plymouth</u>. RJ has been collaborating with NEW Devon CCG (MacLennan, Davey) in a survey of all care homes in Devon, their current use of the Internet, and their willingness to participate in use of Skype on Wheels. This will provide the PhD student with a sampling frame and information about 'resident-mix', wifi, and willingness of care homes.

2. **Problem or issue to be investigated**

Cotton's work [22] and our own PSN project suggest that video calls can be useful and can help improve contacts and reduce loneliness (at least for independent older people). But we don't know if this is the case for people, with likely more cognitive impairment in care homes. The impact of social contact on quality of life both of resident and family may be substantial. On the other hand video calls may serve to remind residents even more vividly that they are in a care home and physically separated from their family. Therefore we need to know which groups of people it works best for, to have a more focused definition of the study group, and a better qualitative understanding of the impact on contacts and quality of life.

We need to be able to assess loneliness, quantity and quality of contacts, but we are not sure that the tools we are using work 'properly' for video calls (as part of overall contact). Therefore more qualitative exploration of these issues, comparing interview data with quantitative data is needed to know that methods for a subsequent trial are correct.

3. Hypothesis, aims and objectives

Aims: The proposed study would assess the acceptability of video calls between family and residents in care homes, would develop and test feasibility of data collection methods and reduce uncertainty about required sample size needed for a full trial. A definitive trial would assess impact on quality of contacts, loneliness, and mental wellbeing for care home residents with, at most, mild levels of cognitive impairment. This study will explore evidence for our hypotheses1-4 below (i.e. to show reduced feelings of loneliness). It will also explore the perceptions of barriers and benefits of video calls for the main family contact. In preparing for the main pilot study it will explore use of video calls by people currently living independently in their own homes and check the suitability of outcome measures.

Objectives:

1. To identify which older people (in which settings, with which family support, and with which technology) are able to make use of video calls
2. To identify barriers, facilitators, and benefits to using video calls as perceived by older people with varying degrees of cognitive impairment, and their main family contact and so map out a model for how video calls will operate in care homes.
3. To select outcome measures
4. To assess the feasibility of collecting outcome data
5. To make a preliminary assessment of changes in social contacts, loneliness, and mental wellbeing in care homes to recommend whether or not a cluster RCT in care homes is feasible and needed and if so what methods are required.
6. To recommend whether or not a cluster RCT in care homes is feasible and needed and if so what methods are required.

Hypothesis:

Our hypothesis is that:

1. There is a group (size as yet unknown) of older people, who are as yet functioning well or may have mild cognitive impairment, who are able, perhaps with some assistance and/or good technology design, to start using video calls in addition to, or instead of, audio calls or face-face contacts, with family and friends, particularly those who live at some distance.

With this group of older people and their family callers, use of video calls

2. Improves the quality and perhaps frequency of contact for the older person.
3. Empowers the main video call family contact and reduces negative feelings for that person.
4. Reduces feelings of loneliness and improves mental wellbeing for the older person

Research Trajectory

After the PhD, this study should lead to a definitive RCT of video calls in care homes. Further, we might explore whether video calls help reduce risk of deterioration in cognitive functioning and dementia for the older person.

4. Proposed methodology

1. Select outcomes
   (a) Literature review. The student will review the literature on (i) key concepts and tools available for measuring the main outcome, and (ii) related interventions. For example, the Lubben social network scale [18] was used alongside the Gierveld Loneliness scale [19] and the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) [20] in the PSN project. The Alfi Connect project will use the latter
   (b) Further exploration of PSN dataset. . Most would assume that video calls (e.g. Skype) would improve the 'connectivity' between participants compared to a normal telephone call [23], especially for older people with hearing difficulties. Such improvement in contact quality will not be identified by Lubben but may impact in Gierveld and possibly WEMWBS but video calls may also increase connections (Lubben). Further exploration of the relationship between Lubben, Gierveld, use of the Internet in the PSN dataset alongside the literature review could help clarify use of different tools.
   (c) Use evidence from literature and existing data sets to identify which sub groups in care homes might be suitable for video calls and what outcomes should be used.
2. Recruitment and follow-up interviews with 10-20 participants in the three ongoing studies including the early adopter care home sites; interviews with care home staff and families. A purposive sample of those who may have used video calls and with a range of changes to social networks and loneliness will be recruited. Mixed quantitative/qualitative interviews will examine the impact of video on the perceptions of connectivity and loneliness of older people. Interviews would include further use of assessment tools to explore their agreement with qualitative data. We would identify those who continue to use the Internet and what, if any, role video calls have in this use. We would seek to recruit and interview the main video call contact for those participants who used it. Interviews with family members and care home staff would focus on the family carer's perception of the benefit or otherwise of video calls. Analysis will allow conclusions to be drawn about how to put video calls into operation in the care homes at individual and care home level. Prototype logic model will be developed
3. Pilot cluster trial over one year in 8 care homes with four care homes randomized to immediate intervention and four to 6 month ('waiting list') delayed intervention of Skype on Wheels available for use by residents (approx. 10-20 per home) with families. Eight care homes in Devon will be recruited from those identified by a Clinical Commissioning Group survey (McLennan, Davey, Jones) nearing completion. Skype on Wheels devices will have been proof of concept tested in other care homes and will be available for this PhD study. (Eight devices will be available from other funding). This study will:
   a. Test feasibility of recruiting homes and randomizing;
   b. Pilot selection of individuals within homes for involvement and use of video calls, number and quality of contact,
   c. Pilot collection of pre and post data on loneliness, and mental wellbeing, as well as demographics, level of dementia and other comorbidities. Data will also be collected from relatives and usage data.
   d. Study qualitatively how Skype on Wheels works in the care home environment
   e. Analyse quantitative data to identify which participants engaged and any changes in outcomes.
4. Synthesis including changes to the logic model of how Skype on wheels works and an outline of the key issues for the next steps in the evaluation.

5. Relevance/significance

Benefits for older people, their families, and care homes: The participants in this research will have the opportunity for better family contact, and to contribute to an understanding of the role of video calls in reducing loneliness. Care homes will be made aware of the potential role that video calls may have in the service they offer.

Benefits for PenCLAHRC and Plymouth University: This new collaborative research project developing the growing portfolio in e-health for older people, linking with VOYAGE, and the PenCLAHRC HSR team in Plymouth. The work would also provide evidence for bids for EU Structural Funds in Cornwall; ehealth is one of the areas for investment from 2015, and use of video calls in a number of settings to support older people is a likely investment area. This research therefore is intended to pave the way for application to that and other external funds.

Project timeline

2015												2016												2017											
J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D
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		2	2	2	2	2						4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4					

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