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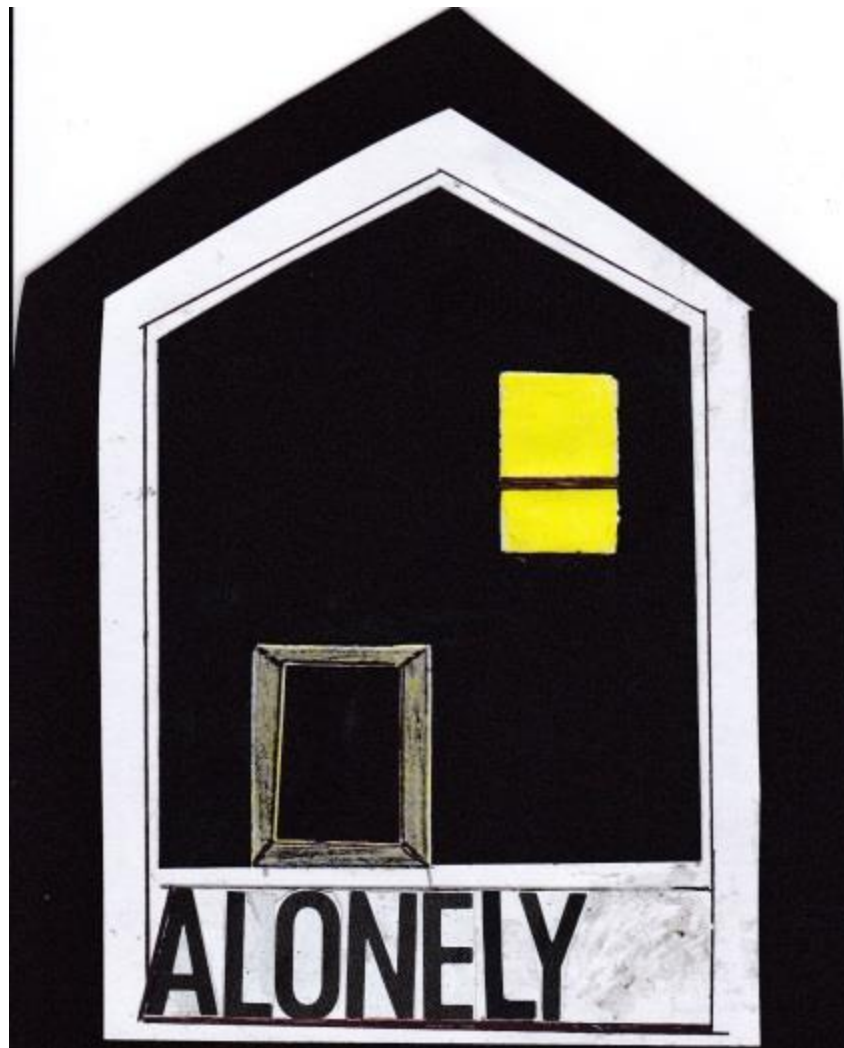
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## Isolation and loneliness of older people: Coproducing research with community researchers

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Arts & Humanities  
Research Council



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While I have written this final report, it is important to stress that this research was undertaken collaboratively with the Alonely Community Researchers, the isolation and loneliness of older people working group as well as the Productive Margins collective.

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Cover image by Chloe Scholefield 2016

## **1 Introduction and background to the project**

Over the last year a group of volunteer community researchers have been working with academics from the University of Bristol and professionals from the Southville Community Development Association exploring the isolation and loneliness of older people in their community and considering ways of addressing the concerns and challenges uncovered.

The project was carried out as part of the Productive Margins: Regulating *for* Engagement research programme which aims to coproduce new ways of envisioning and engaging regulation. The project proposes that; *“Communities are tired of endless ‘consultations’, desiring instead bottom-up mechanisms arising out of the everyday lives of those who are caught up in regulatory regimes. Our claim is these regimes can be redesigned and harnessed for engagement, ensuring communities at the margins are engaged in regulatory processes and practices.”* ([www.productivemargins.ac.uk](http://www.productivemargins.ac.uk)). Grounded in a localised perspective the research aimed to innovate through working with older people and community organisations to identify interventions and strategies that start from the premise of recognising and celebrating the skills, experience, knowledge, interests and expertise of the older community, resulting in ‘community’ services, research outputs and innovative approaches for provider organisations to work in a coproduced way with older people.

The project was conceived through activity and discussions between members of the Productive Margins forum. The Southville Community Development Association (SCDA) had been involved in a number of previous projects focused on aspects of isolation and loneliness of older people in Greater Bedminster and so put forward, and then supported, the development of the project as one of the community-based coproduced projects within Productive Margins as a way to build on the work already undertaken.

The project was overseen by a working group comprised of community development professionals in Merthyr Tydfil and Greater Bedminster and academics from the Universities of Bristol and Cardiff. Two community researchers were appointed to work on projects in (a) Merthyr Tydfil, Wales and (b) Greater Bedminster in Bristol, England. This report focuses on the project based in Greater Bedminster. The Bristol based community research associate, Dr Jenny Barke (JB), was managed by Dr Simon Hankins (SDH), CEO of the SCDA with academic line management from the academic lead on the project Dr Helen Manchester (HM, University of Bristol) as well as the working group more generally. During the course of the project, bi-weekly meetings were held between JB and HM and monthly meetings were held between JB and SDH. The full working group met monthly for a full day.

The aim of this report is to describe the formation and development of the project in Bristol which became the Alonely group. The report will outline the work we have undertaken, discuss our findings and recommendations and reflect on the research process and methods employed.

### **Defining isolation and loneliness**

The terms isolation and loneliness are often used almost interchangeably but it is important to note that social isolation refers to the objective circumstance of having little contact with other people; while loneliness refers to the subjective state of negative feelings related to perceived social isolation (Wenger et al, 1996). Although isolation and loneliness are separate constructs, there is a great deal of overlap and separating the two is a challenge (Findlay, 2003). For instance, there is

evidence to suggest that people without meaningful social connections are at risk for loneliness (Masi et al, 2011). There is also evidence to suggest that when people feel lonely their social interactions are likely to change; they think and act differently and their perceptions of the social environment alter (Cacioppo & Hawkley, 2009).

Most of us will experience loneliness at some point in our lives and loneliness can be seen as an adaptive mechanism. Cacioppo et al (2006, 2015) describe loneliness as a signal that has evolved to warn an individual of a social threat. As a member of a social species we need to be connected to others in order to survive, prosper, and reproduce. Essentially the uncomfortable feelings associated with loneliness motivate us to reconnect with others. However, for some individuals this experience is prolonged and becomes maladaptive leading to negative physical and psychological health and wellbeing (Qualter et al, 2015).

It is generally well accepted that social connections are important to our psychological and emotional well-being. Evidence also consistently suggests that loneliness has a significant influence on aspects of our physical and psychiatric well-being including depressive symptomatology (Cacioppo et al., 2006; 2010; VanderWeele et al., 2011; Victor & Yang 2012), suicidal thoughts (Rudatsikira, Muula, Siziya, & Twa-Twa, 2007), cognitive decline (Wilson et al., 2007), recurrent stroke (Cacioppo, Capitanio, & Cacioppo, 2014), obesity (Lauder, Mummery, Jones, & Caperchione, 2006), increased vascular resistance and elevated blood pressure (J. T. Cacioppo, Hawkley, Crawford, et al., 2002), poor sleep quality (J. T. Cacioppo, Hawkley, Berntson, et al., 2002; Pressman et al., 2005) and lowered immunity (Pressman et al., 2005). Furthermore, a recent meta-analysis (Holt-Lunstad et al 2015), reporting on 70 studies with 3,407,134 participants, found that social isolation, loneliness and living alone all had a significant impact on mortality.

Particular risk factors that contribute to isolation and loneliness include; small social networks and infrequent/poor quality contact with friends and family (Bondevik & Skogstad, 1998; Hawkley et al., 2005; 2008; Routasalo et al., 2006); physical health symptoms including stress (Hawkley et al., 2008); living alone, lack of a significant confidant, marital or family conflict (Routasalo, Savikko, Tilvis, Strandberg, & Pitkala, 2006, Hawkley et al., 2008); divorce and widowhood has previously been identified (Dugan & Kivett, 1994; Samuelsson, Andersson, & Hagberg, 1998) and age; self-reported loneliness is highest during adolescence and older age (Qualter et al, 2015), there is also some evidence to suggest that loneliness may be a genetic trait (Goossens et al, 2015).

Loneliness is a complex and multifaceted concept. It relates to interpersonal social relationships (both in terms of quality and quantity), specific life events (including moving home or retiring), social structures (such as the perception of age or expectations regarding friendships during adolescence) as well as an individual's social environment (where they live, local infrastructure) (Jopling 2015). How individuals respond to and experience these factors is informed by individual differences, such as personality type and cognitive variables (Qualter, 2015). The determinants of loneliness are a combination of, and interplay between, internal and external factors. An individual's subjective experience and perception of their social world is, therefore, key to how they experience loneliness.

Both globally and in the UK there appears to be a growing awareness and increasing concern regarding loneliness within society; the issue has been widely reported within the media. National campaigns in the UK have been developed to raise awareness of loneliness

([www.campaigntoendloneliness.org](http://www.campaigntoendloneliness.org)). Campaigns such as these are important in raising awareness of the issue and addressing stigma; both at policy level and across the general public.

### **Older people and loneliness**

Roughly 20% of the UK population is aged over 60 and this is expected to rise in the near future (United Nations, World Population Ageing, 2007, & Office for National Statistics, age structure of the UK). Evidence suggests that older age is a time of increased loneliness (Qualter et al, 2015); it is estimated that about 10% of the UK population over 65 are lonely all or most of the time (Victor 2011). Therefore, a significant number of older people in the UK are at risk of loneliness. This is recognised by organisations working with older people who are seeking to address this issue and explore the evidence ([www.ageuk.org.uk](http://www.ageuk.org.uk)).

It is important to note that in older age, a number of specific risk factors for loneliness emerge or become more likely. These include losing a partner, retiring from work, reduced social activities due to impaired health either of self or partner, as well as geography, for instance evidence suggests that older people are more likely to be lonely in deprived urban areas (Dykstra et al, 2005, Victor et al, 2005, Middling 2011). There are also particular groups of older people who may be at increased risk of loneliness including those on a low income, ethnic minority groups, LGBT men and women, and those over the age of 80. (Victor et al, 2005, 2012, Age UK 2011, Stonewall 2011). Loneliness has been found to increase with age (Bolton 2012), with older women more likely to say they feel lonely than older men (Beaumont 2013) and older people in residential care report greater loneliness than those in the community (Kneale 2012). In addition to the increase of risk factors in older age, there is also some evidence to suggest that different factors protect against loneliness at different stages of life. During early adulthood it is the quantity of social engagement that protects against loneliness whereas in mid and later life, the quality of social engagement is protective against loneliness (Victor & Yang, 2012).

While there are specific risk factors with regards to loneliness during older age it is important not to stigmatise this stage of life. Research in this area needs to reflect on social attitudes about age and older people and consider how these may impact upon how older people experience loneliness, as well as how this life stage is conceptualised. Schirmer & Michailakis (2015) propose that research tends to focus on the psychological and medical causes or consequences of loneliness. They suggest that it is important to explore the way in which the loneliness of older people is framed and understood across society.

While social conceptions of age and the role of older people differ between cultures and over time, across our lives we are defined by our age. Social and legal regulations govern the 'right' age to do many things including vote, have sex, have children, marry and retire. Reporting on findings from their survey which explored attitudes to age in Britain, Sweiry and Willitts (2012) describe a complex picture. The mean age at which respondents thought people stopped being described as young was 41 years while the age that people started to be described as old was 59 years. People aged over 70 were viewed as more friendly, more competent and as having higher moral standards than those in their 20s. However, people over 70 were also given the lowest status ratings. A third of respondents reported experiencing age discrimination in the past year. However, people aged under 25 were

twice as likely to have experienced age prejudice than all other age groups. The authors conclude that *"age-related discrimination and stereotypes are rooted in British society."*

Much of the discourse in recent years around our ageing society has related to its financial cost, particularly in terms of health and social care. Maybe as a consequence, or cause, of this research indicates that ageist attitudes are common among health and social care professionals (Clarke 2009). The WRVS commissioned report 'Gold Age Pensioners' (2011) puts forward an argument to challenge the current narrative about age. The researchers demonstrate that in 2010, people aged over 65 made a net contribution to the British economy of £40 billion and they calculate that by 2030 this is likely to grow to £77 billion. Not only do older people make a positive financial contribution to society but they also have hidden value through their spending power, social caring, and volunteering.

Negative attitudes towards older people, and ageist stereotypes, are likely to isolate older people and excluded them from engaging in society (Abrams et al, 2009). They may also make researchers less likely to include them. Nash (2015) suggests that the marginalisation of older people has highly negative consequences. Older people may internalise ageism leading to lowered physical and emotional wellbeing, this in turn can lead to withdrawal from community engagement. Therefore, research into loneliness in older age needs to come from a neutral space of exploration, looking for both positive and negative experiences.

### **Researching with older people**

One way to carve out a neutral space of exploration may be to coproduce research (and solutions) with older people themselves. Durose et al (2012) explain in their review that coproduction is a way of meaningfully including communities in the research process. In coproduced research the role of the researcher, their relationship with the community and the way in which all parties contribute and engage is reconceptualised. Not only are communities and individuals empowered, but research is also likely to have enhanced ecological validity. Adopting this approach and coproducing research on loneliness with older people recognises the value of older people themselves. Furthermore it may be that there is a socialisation effect in gathering of a research group in and of itself that produces positive change (Masi 2011, Minkler et al, 2006).

While there are definitely examples of older people's involvement in research and both academic papers (e.g. Gutman et al, 2014, Ottmann et al, 2011) and 'how to' guides (e.g., [www.ndti.org.uk](http://www.ndti.org.uk) and [www.scie.org.uk](http://www.scie.org.uk)) are available; it does seem to be under-developed (Beresford & Croft, 2012). It needs to be acknowledged that how to coproduce research is highly context dependent (Martin 2010) and there is no one clear definitive way of approaching coproduction. Walker (2007) writes that older people's involvement in research is generally found on a continuum between consumerism and empowerment. Consumerism consists of researchers consulting with older people while the other end of the continuum involves older people as active researchers. Walker suggests that most research with older people tends to be at the consumerist end of the spectrum. Burholt et al (2010) agree that few studies have involved the full participation of older people. They define full participation as involvement in three aspects of the research process: (1) Research design (2) Conducting research and (3) Dissemination. In their review of published studies Burholt et al identify 11 projects which met at least two of these criteria and just five which met all three. In order to



ensure that older people can access and engage fully and meaningfully with all stages of the research process, it is essential to consider and address underlying social assumptions about ageing as well as practical concerns such as identifying, engaging and training older people. Through addressing these issues older people can be empowered rather than consulted because they are both valued and able to access all aspects of the research process.

A particular barrier to older people's engagement in research may be a perception that there is a need to be qualified to take part; research can seem daunting and off-putting. It is essential that training older people in research methods and supporting them to become researchers is considered. A particular criticism of the literature in this area is that few studies adequately describe exactly how they prepared and trained older people (Beresford 2002). Coproduction methods are rarely described in any kind of detail. Reports of how coproduction works in practice are infrequent (Bovaird & Loeffler, 2007). Yet, as Burholt et al (2010) explain "*It is only by subjecting participatory research training programmes to the scrutiny of the scientific community that we will be able to identify the essential elements of the art and science of andragogy that should be employed in training older adults.*"

Burholt et al (2010) detail a training program undertaken with Age Concern in North Wales. The training aimed to increase the knowledge and skills of older people in order to enable them to participate actively in a research project. The researchers hoped that following this training the participants would be able to pass on their skills and knowledge to others, encouraging long-term change within the community. The training delivered to older people was based on the principles of andragogy (Knowles 1986). This assumes that older learners have life experience which can be drawn on during training, they take responsibility for their own learning and are likely to approach learning in a practical way, meaning that they learn in order to do a particular thing (Knowles 1986, 1996). It is important to note that the learning styles of older people tend to be different to younger learners. Nine training sessions were delivered over two months. Sessions were loosely based on masters level social science research methods training and were delivered informally. The authors note that involvement was positive across the research project except for the literature review which co-researchers did not really engage with. When considering the value of including older people as researchers the authors conclude that: "*The involvement of older people in this research has contributed to lower refusal rates of interviewees, an increased understanding of the topic under study and innovative approaches to research such as the formulation of unusual hypotheses.*" It is important to note that for older people personal interest in the topic was an important motivator whilst accreditation was of little interest.

Leamy and Clough (2006) describe a project which trained older people in research methods in order for them to take part in a research study on housing decisions. In their project the research training (Certificate in social research methods) was accredited by Lancaster University and details of the training were published online. Older people attended a series of workshops and lectures. In terms of the research itself the authors state that the way in which older researchers and interviewees interacted was different from the way that interviewees would have interacted with younger researchers. They suggest this is because they are a similar age and likely to have more similar experiences as well as sharing an interest in the topic area. The researchers feel that this led to more in-depth disclosures than would normally occur in a research interviews. Participants reported that the reason for becoming involved in the project came from an interest in the topic, as well as general

educational curiosity. Participants reported that they valued becoming involved in something they saw as beneficial to others.

The Joseph Rowntree Foundation neighbourhood programme is another example of a research project in which older people were empowered throughout the project. The research ran over three years in four areas of the UK. The Joseph Rowntree Housing Trust (JRHT) runs retirement villages and older people's housing schemes. It was observed that few older people requested the support that the Trust offered when transitioning into extra care and the staff wondered if this related to the environment being supportive. In response to this, JRHT and the Joseph Rowntree Foundation (JRF), wanted to understand more about the importance of environment and community in relation to isolation and loneliness at a neighbourhood level. The programme adopted a participatory action research approach in which community researchers worked alongside academics and community groups. The programme aimed to '*...explore how a neighbourhood approach could engage and contribute to the wellbeing of people at risk of or experiencing loneliness*'. Community researchers (including, but not exclusively, older people) were recruited and trained in participatory research methods. Data was gathered in a range of different ways and analysed by the community researchers. This led to further data collection, analysis and implementation of ideas.

A particular strength of the programme is that it was independently evaluated. In their evaluation of the JRF programme Collins and Wrigley's (2014) note that volunteers generally became involved after previous community volunteering experience or due to personal experience of loneliness. Those involved in the programme gained confidence, self-worth and emotional intelligence; they suggest these skills boost resilience and may be protective against loneliness. At a community level the programmes contributed to changes across the community in terms of making new connections, and increasing the number of activities available. The report highlights the importance of a key person or organisation to bring people together and move a project forward. The authors also highlight the importance of projects unfolding organically rather than keeping to a predetermined rigid timeframe.

### **Using arts based approaches with older people**

A central question within the Productive Margins project asks: "*What happens when diverse communities and academics come together to re-shape engagement and work creatively with ideas that run through society, law, history and art?*"

With this question in mind, central to the Alonely research project was the desire to explore the creative repertoires of older people. There are a myriad of creative and arts based methods and defining what is meant by this phrase can be problematic. Arts and creativity can themselves be seen as research practice. While arts based research has grown considerably in the last decades, earlier origins can be found from the 1920's (Prosser 1998). Since then diverse disciplines have repeatedly used and reported arts based methods and techniques in research (Boyden and Ennew, 1997; Prosser 1998; Pink 2001; Broadhead 2004). According to Blackstone et al (2008) "*The attraction of this mode of research derives in part from its widely regarded capacity to directly engage broad sections of the public.*" (P2).

The value of creativity and arts participation in positive ageing and in challenging social assumptions and stereotypes of age is well evidenced and has been explored in a number of contexts (Bernard et

al, 2015). The benefits appear to be considerable, both physically and psychologically (Cohen 2006). For instance Cohen (2009) reports a significant reduction in doctor visits, medication use and loneliness for older people involved in arts groups. He also suggests that engaging older people in the arts can challenge a deficit model of later life. Furthermore, arts participation by older people has been found to support the development of stronger communities (Cooper and Thomas, 2002). In their evaluation of Bealtaine (an arts festival for older people in the Republic of Ireland) Léime & O'Shea (2008) report that 98% of those surveyed said that attending the festival increased their social networking and 94% said that it increased their engagement in the local community. In the UK a series of initiatives and reports have concluded that arts participation encourages positive engagement and improved health of older people and more cohesive communities (e.g. Bernard et al, 2015, Cutler 2009, newdynamics.group.shef.ac.uk, Mental Health Foundation 2011).

The arts can be utilised in community engagement and research in many different ways. In using these methods the researcher must be clear about which stage/s the arts based research techniques will be used. They can be employed as warm-up exercises, fill-in activities, or as the main data collection (Kirby 1999). For instance, arts projects can engage older people, can be used to disseminate findings or can be part of knowledge translation (Eakin & Endicott, 2006). Participatory arts can also be research in themselves in terms of collecting or analysing data (Rossiter et al, 2008) and writing a theatrical piece can be used as a reflexive exercise in 'collectively voicing' (Passila et al, 2015). Research and performance can be explored iteratively, as a process for creating new meanings and understandings (Finley 2005; Denzin 2003).

In coproducing and creating arts projects older people can create and share narratives. An example of this is the 'Ages and Stages' project (Keele University) which created a theatre piece and exhibition with an intergenerational group of actors. The project considered perceptions of ageing and what involvement in the process means for 'ageing well' and for promoting intergenerational understanding. The findings (Bernard 2015) highlight the need to challenge cultural stereotypes of ageing and highlight the positive role that theatre can play in this, and in social inclusion and community cohesion.

## 2 The research project

This section details the research carried out by the community research group. As highlighted in the literature review a common criticism of coproduced research is the lack of detail in describing the research processes. In order to address this, this section describes in detail how the research group was formed, the training received, the research process, analysis and dissemination activities.

### Stage 1: Forming a group and defining the research

The central aim of this project was to coproduce research exploring if and how loneliness impacted on older people in Greater Bedminster with local older people. Therefore, the first task was to bring together a group of older people to coproduce research with. In order to do this, the research associate; JB, contacted and met with local groups and individuals including people who worked in statutory and voluntary services, as well as those who worked specifically with older people. Being based in a community organisation and line managed by SDH, CEO of the Southville Community Development Association (SCDA) the researcher was able to draw on the connections and expertise of those working for and with the SCDA.

In addition to exploring existing links, JB attended local and city wide events and meetings related to older people and/or loneliness in order to promote the project and meet with people who may be interested in collaborating. The research was also advertised on relevant websites, social media, newsletters and magazines. E-flyers were sent to individuals identified by SDH and paper flyers were available at the Southville Centre (the local community centre managed by the SCDA). Once a few people had expressed an interest in the project, an initial meeting was held. At this meeting four of us discussed the aims of the research and how to expand the group. We planned a follow-up meeting and information event and decided to meet every two weeks at first, for about two hours. It was agreed that JB would design and share an e-flyer and printed flyers and all group members would promote the research project to friends, contacts and organisations we knew. Over the next few meetings the group expanded gradually and a core group of eight was formed as detailed below.

### *Alonely researchers: why and how they became involved*

Alex: Steve on our team, suggested I might be interested in the project. I heard the group were going to look into Loneliness and Isolation in Older People in Southville and thought I would like to help with it. I was living alone at the time and liked to fill my time up with constructive activities. This seemed a good opportunity.

Carol: I was already involved with a group thinking about loneliness in old age in the area and I became interested in the research being carried out by this project and wanted to join in. One way I thought I could contribute was via the dramatic interpretation of that research.

Catherine: I have always been keen to highlight the existence of isolation and loneliness in care homes, since having seen so much of it myself, after regularly visited my Mother in one. This project, I felt, might be a good place to explore the subject a little further.

Chloe: Having worked with older people in the social care sector and hearing stories of loneliness and witnessing the effects of it on a regular basis, I wanted to get involved in a project that would enable these experiences to be shared on a wider scale and voiced in a creative yet practical way that would allow loneliness to be discussed more openly hopefully reducing the stigma whilst

possibly offering up some ongoing solutions

Chris: Since June 2014 I have been in recovery from a stroke, hence my involvement in a project local to me, which challenged this condition on a number of levels. I have lived in BS3 since 1983, working in the theatre and then teaching the practice of radio. I went on to become a lecturer in broadcasting at university - before my early retirement

Judith: I had recently separated from my husband & moved into area also I have a background in social work & interest in research attracted me to project.

Steve: The subject of loneliness is so important in this day and age. As someone who has experienced such moments, I was drawn to the topic. As an artist performer, I felt capable of contributing the theatrical bits which reached out to a wider audience and received such positive feedback on raising awareness of loneliness in old age. The whole experience has been enlightening and was woven beautifully together through cooperation and great teamwork. Now for the further work to make a difference

Teri: I'd been part of a small and most stimulating meeting at the Southville Centre where we were looking at some of the issues around isolation and loneliness and how to encourage new ways to engage...something along those lines! I wanted to continue with this discussion of ideas so joining the group made sense. But I was going through long-term health issues and found the challenges of continuing to be in the group too stressful, as I found (or felt) myself to be in conflict, primarily personal, partly group-wise, too much of the time ... so I thought it best to leave. I'm glad that I gave myself a chance to be part of something valuable.

The project started with a broad remit in terms of the research question and the methods of investigation. There was a desire to explore loneliness, the methods of coproduction and to consider regulation and engagement. In order for the research to be meaningful, it was particularly important to SDH and the SCDA that we explored both experiences of loneliness and how to coproduce solutions. In our first research group meetings we discussed what had drawn us to the project and why we were interested in the topic of loneliness, we shared some of our own experiences; both personal and from our professional backgrounds.

From very early on the community research group were keen to define the research question and methods we would use. There was a tension between plans being able to emerge from the group in a coproduced way and people being able to understand the project and what was being asked of them. In response to this, and in order to define the research in a coproduced way, JB facilitated a series of exercises with the group over several sessions.

In the first exercise we discussed what we understood 'research' to be and why people might do it. We then used three questions as a framework to consider what to explore in the project:

1. What do we want to understand better?
2. How can we do that?
3. How do we tell people what we found out?

Each question was written on a large flip chart and we added post it notes in response. We then read through all the responses, gathered them into themes and discussed them. In a further session

we carried out an asset mapping exercise (for further information see [www.abcdinstitute.org](http://www.abcdinstitute.org)) and explored physical resources, personal/professional contacts, local groups and personal skills.

Bringing these exercises together enabled us to collectively explore and understand what we wanted to do; how we could do it, as well as what resources we had to work with. This 'scaffolded' our thinking, providing us with the beginnings of a research plan that drew on the assets of the group members and gave us a shared vision. Through these exercises we were able to prioritise and broadly define our research question and plans. Within the group people wanted to explore and understand the experiences of loneliness. Others were interested in looking explicitly for solutions. There was also a strong desire to draw on creative methods and think about creative ways of analysing and disseminating our research. In order to accommodate these different interests, we came up with the following research question and plan:

**Research question:** How do older people experience loneliness in the Greater Bedminster area and what activities and/or services do they use and/or require in order to reduce feelings of loneliness?

**Methods:**

- Postcard exercise: we planned to go to venues across Greater Bedminster and meet with older people and ask them to complete a postcard with a question on the front about loneliness. We wanted this to be visually interesting and asked Chloe Scholefield (CS), a member of the group who is an artist/curator, to explore ideas around this.
- Focus group with service providers/professionals who work with older people in Greater Bedminster: we wanted to explore professional perceptions of the issue and ask people to identify possible solutions/changes.
- Interviews with older people: we wanted to ask people about their own experiences as well as their ideas about what could/should be done (if anything).

**Dissemination:** A project report, academic papers, presentations and a theatre piece, written by the group based on interviews, aiming to make older people's experiences of loneliness more visible

**Stage 2: Preparation for fieldwork**

Having defined our broad research questions and plans, the next step was to prepare for the fieldwork and establish exactly how we would carry out the research. We decided at this point to meet more regularly and for a little longer (every week for three hours). JB used notes from exercises such as asset mapping as a starting point to design sessions that would draw-on, and build-on, the group members existing knowledge and skills and prepare everyone for the research fieldwork. JB then developed and delivered a series of sessions as detailed below.

Session	Details
1	<p><b>Research ethics and general principles of research</b></p> <p>The aim of this first session was to consider the general theoretical principles of qualitative research and reach a clear common understanding of the ethical principles we were working within. This was delivered in seminar style with JB talking through a series of Powerpoint slides which considered: why we do research, different approaches to</p>

	<p>research, the principles of qualitative research, subjectivity &amp; reflexivity, ethics (principles and processes), informed consent, confidentiality and anonymity. These topics were discussed both theoretically and specifically in terms of our project.</p>
2	<p><b><i>What is data?</i></b></p> <p>In advance of the session JB emailed a list of possible questions for postcards, interviews and a focus group, taken from on our early conversations and exercises. The aim of the session was to consider the different types of data that can be accessed and the importance of question style and format in its collection. During the session we developed a shortlist of questions we wanted to ask using postcards, interviews and a draft topic guide for the focus group. We also drew-up a long list of venues to visit for our postcard exercise and discussed dates we were available. After the session, the venue list, potential dates and postcard questions were shared with the group as an online survey using 'Survey Monkey' and through this we reached a consensus regarding the final postcard questions, venues to visit and dates to do this.</p>
3	<p><b><i>What are interviews?</i></b></p> <p>Helen Thomas-Hughes, a senior research associate with responsibility for training across the wider Productive Margins programme came and delivered the first part of the session concentrating on interviewing theory and practical skills. She discussed a range of different possibilities and ways of carrying out research. The group were able to ask questions and explore different ways we might approach the research activity. Having an external person talk to the group at this juncture was valuable in terms of providing the group with space to take a step back and examine our plans from a different perspective.</p> <p>Following this JB shared example interview schedules which we discussed looking at the types of questions used, the flow of the interview, follow-up questions and prompts.</p>
4	<p><b><i>Practical interview skills</i></b></p> <p>This session was a practical workshop. Most of the session was spent in pairs interviewing one another using our draft interview schedule. We then discussed the schedule and made some changes. Several group members had experience of interviewing; within a counselling context as well as within social work and broadcasting. This allowed us to consider different ideas and come to a shared understanding of how we, as a group, wanted to carry out interviews.</p>
5	<p><b><i>Troubleshooting and review</i></b></p> <p>The aim of this session was to have some time to look through all our plans and ensure that we were all happy with the questions, plans, dates and ethical principles and processes involved. We came to a final agreement regarding the semi-structured interview schedule, topic guide and postcard questions. We also discussed different strategies for managing situations that could occur. CS presented designs of a tea trolley that we could take to venues when collecting postcards in order to attract people, and we confirmed the dates we would do this and how it would work in practical terms.</p>

Following the final training session HM (the project academic lead) met with the research group (without the research associate-JB) and facilitated a focus group to explore members' experiences of the project to date. Questions explored how and why people had become involved in the project, their experiences generally as well as their thoughts on the training they had received.

The research group members explained that they became involved in the project for a variety of reasons including an interest in research, wanting to do something pragmatic about loneliness, some saw the project as a chance to explore artistic and creative methods and several people identified as having experienced loneliness themselves.

The research topic was the main incentive for becoming involved for many; *"I think the main thing is, for me, the topic. If the topic didn't interest me, I wouldn't be here."*

Within this, a particular interest for many was raising awareness of the topic of loneliness:

*"And I think, from my point of view, it is an awareness-raising exercise..... I would like it to be awareness-raising and I would like to see us produce something creative that everyone can come to, or have access to, or see and go, 'Oh, actually I hadn't thought about how people feel,' and things like that."*

The importance of the research being meaningful and action-oriented was highlighted by several members of the group, as one person explained:

*"So, if we do research and it brings out some sort of answers, well good; then we get some answers to it..... I like to do things."*

There was a strong desire for the research to promote change and action and also for the process itself to be interesting and creative:

*"I think the essential thing is we are working towards a goal. That is important..... I know going to so many meetings which are a 'talking shop' and nothing gets done. I understand the value of meetings, but... sometimes, but, at the end of the day, you think it is brainstorming and ideas thrashing around, sometimes which can be stimulating, but often meetings are about this clause, that clause. I get bored, personally. I like some action to come out of it."*

When discussing their involvement in the project people felt engaged in the process and believed that the research was meaningful. Within this people highlighted the importance of having a paid worker, or someone who had responsibility for 'driving the project forward'.

*"..... it has felt very equal, despite the fact that we know that she (JB) is a paid worker and she is going away and doing more work than we are in between times. But I felt that our contribution has been real. It has not just been, 'Oh, I want to know what you think but then I am going to go away and do it anyway.' It has felt very real, I think."*

It was important to people that there was a facilitator who had certain responsibilities. One person described JB as having *".... been in the driving seat and taken a back seat"*. This idea was expanded on:



*"The outcome of the research, I think, is determined by us, but the actual process of research is driven by JB, and quite right..... because I think we are on a relatively limited time that we're available, and, personally, it is how to get things done. I think, if we'd had rotating Chairs and all that, I don't think it would have added a blind bit of difference really."*

In terms of feeling prepared for the fieldwork, people described some anxiety but felt overall that the training has been pitched at the right level. They particularly valued having had a chance to practice interviews and increase their confidence:

*"I think if you are taking anything on and you are thinking about it, you know you are never totally prepared. I mean, I am not just being glib saying that; everything I go into, I suppose, for me there is always worry; there is always the unknown. So, if we are awake, we can't be totally prepared and, if we were trying to get totally prepared, we would never get the damn thing done."*

*"I think the training has definitely taken me from here to there. So I am not totally prepared, like you say, but it has moved me from one place to another. So there was a point in having it. And things like talking about ethics and some of the theory was interesting"*

**Stage 3: Fieldwork**

Fieldwork was carried out between October 2015 and January 2016. Group members took part in activities to varying extents; all took part in at least some of the events. During this time we had few whole group meetings as time was taken up with the fieldwork.

**Tea Trolley**

We took our yellow tea trolley to a series of venues and events across the Greater Bedminster area. The aim of this exercise was to engage the local community in conversations about loneliness. As a group we felt strongly that traditional methods of 'recruiting' participants can be off-putting. We wanted our research to be fun, interesting and easy to participate in. Engaging directly with people in different settings and having a prop that generated interest and conversation was important to us. Generally, between three and five group members went to each venue and offered tea and cupcakes to the people we met. We talked about our project and asked people if they would be interested in completing a postcard. We decided to offer people the choice of the three cards below.



If you ever feel lonely, what makes things better?

Loneliness is.....

What would make life better for older people in our community?

The focus of the three questions differed so that people could choose to share their own, individual experiences or consider community level ideas for other people. The postcard 'loneliness is....' was included in order to explore what words and phrases people associated with loneliness; additionally we also felt that it was a card people could feel confident completing regardless of whether they felt they had personal experience or advice to offer.

We took the tea trolley to six venues which were chosen for geographical diversity as well as aiming to meet those who could fall in to risk categories for loneliness. We collected 68 postcards in total.

#### **Venues**

- Flu Vaccination Clinic (open to all patients aged over 65 from GP practices in Greater Bedminster)
- Retirement village
- Social group/coffee morning
- Pensioner preferred tower block residents meeting
- A club for older people in a community centre
- An older people's forum meeting

#### **Interviews**

The study was advertised widely on websites, social media, in paper and electronic newsletters and via individuals and networks who shared the information with their contacts. In addition, information about the interviews was given to people while collecting postcards at tea trolley events. Those who were interested in taking part were given information sheets and consent forms to read and a convenient time was arranged to be interviewed. Before all interviews a discussion took place about the nature of the research and informed consent was obtained. Participants were reminded that interviews could be stopped or paused at any time and that they did not have to answer any questions if they were uncomfortable doing so, or were uncertain of their answer. In total we interviewed 14 people (seven men and seven women) aged between 52 and 88 (mean age = 72 years), see table below.

<b>Name (pseudonym)</b>	<b>Age</b>
Barbara	72
Fred	74
Andrea	52
Charles	70
David	70
Eve	65
Harry	88
George	82
Julia	79
Issac	86
Karen	62
Lauren	68
Mark	67
Margaret	69

#### **Participants**

All interviews were audio recorded and transcribed. Members of the research group conducted at least one interview each, either one-to-one or in tandem with the Research Associate-JB. Additionally, another member of the project working group RS (Rosamund Sutherland, Professor of Education, University of Bristol) conducted an interview. Members of the research group who carried out interviews alone followed an agreed lone working protocol and JB was on-hand for support if needed. Interviews were conducted in interviewees' homes or at one of two community centres (in a private space) at the participants' choosing. Interviews lasted between about 30 and 90 minutes.

### ***Focus Group***

We invited a wide range of people working in the local community in both the voluntary and statutory sectors to attend a focus group exploring the isolation and loneliness of older people with an emphasis on exploring solutions. The focus group was comprised of seven individuals who worked for local and city-wide organisations, or were engaged in local voluntary/community development activity. We decided in advance that two research group members would co-chair the session with others asking follow-up questions using the topic guide that had been developed by the group.

All participants were sent information in advance and informed consent was obtained. The session lasted just under two hours and was audio recorded and transcribed.

### **Stage 4: Data analysis and findings**

Once data had been transcribed and anonymised, the group met and discussed how best to proceed. We discussed the subjective nature of qualitative analysis and what that meant in terms of rigor.

We then went back to our research questions and decided to go through the postcards, interview and focus group data looking to answer the different aspects of the questions. Firstly, we wanted to explore the data in order to understand more about the experience of loneliness and make our own suggestions about possible support and solutions. Secondly, we wanted to explore the specific services and support that participants had highlighted as either useful or needed. We then wanted to use our data to write a theatre piece to further explore and highlight our findings.

In order to achieve these objectives, we devised a system that we worked with over seven sessions. We divided into pairs and each pair read an interview transcript, making notes throughout and underlining salient points as well as any particular recommendations for services and/or support. After reading the transcript, each pair discussed their thoughts and identified three or four emergent themes (and highlighted specific suggestions for services). Once all the pairs had completed this process we came back together and in turns reported back to the group about the transcript we had read and presented the themes we had found in the data. A list of themes was kept by JB and through constant comparison techniques we found common themes emerging across the data set. The feedback sessions were audio recorded and transcribed. Once the final transcript had been analysed in this way, the group discussed how best to bring this all together. It was decided that JB would read the transcriptions of our discussions of the transcripts and go back to the list of themes we had detailed and produce a document that refined and described the themes. This was then

shared with the group by email in advance of a meeting and formed the basis of a discussion. At the end of this discussion we refined the list of themes and wrote a list of specific recommendations.

We took a similar approach to analysing the focus group transcript. This was shared and read by all group members. JB then came up with a list of 'initial thoughts' which were shared with the group and refined through a group discussion. We also read through the postcards and discussed the cards people had chosen to answer, the way that questions had been answered as well as the content of responses.

### Postcards

Of the 68 postcards we collected at tea trolley events, 21 were in response to: *If you ever feel lonely, what makes things better?* The same number completed: *What would make life better for older people in our community?* The greatest response (26) was to: *'Loneliness is....'*

In response to the question, *'If you ever feel lonely, what makes things better?'* respondents described social activities *"being in groups of people-clubs etc,"* and getting out and about *"going for a walk and saying hello to someone."* Others described keeping busy at home through individual activity such as *"I do the gardening and keep busy doing housework"* or watching TV, listening to the radio or reading a book. A few people wrote about their pets, either walking them or talking to them; *"Debate the world talk to the cat"*. While most responses were quite pragmatic, a few people described how they psychologically managed feeling lonely with comments such as *"Remembering people love you although you can't see them often."* A few people told us they did not feel lonely.

In response to the question *'What would make life better for older people in our community?'* the majority of responses related to social events including local clubs, activities and trips *"Maybe a social afternoon with someone entertaining someone of interest coming to talk, trips which we used to have."* A few responses directly related to specific council services and transport, in particular wanting buses to go to specific places and affordable community transport. Several people wrote that older people should get involved with local charities and community activities. There was some suggestion that people needed to make a choice to be connected with their community and that people did not have to be lonely. For instance; *"Getting people involved in their community. Loneliness is people's choice not to be involved"* and *"You must come out.... and mix with the people."*

The third postcard *'Loneliness is...'* garnered a wide range of responses. As with the first question, some people explicitly answered they were not lonely; *"not me"*. Again, as with previous questions, many people wrote about pragmatic concerns and causes of loneliness such as health issues, caring responsibilities and transport. However, this question seemed to generate more emotional responses than the previous questions. Feeling disconnected from others was highlighted as an important factor, as demonstrated by the following responses: *"Not being connected to people (friends, family or people around you)"; "Feeling that no-one is interested in me" and "Not having anyone who cares"*.

Depression was specifically mentioned by several people, for instance *"Feeling on your own thing there is noone you can turn too makes me feel depressed"*. And again, (Loneliness is)... *"Empty space. It's something that is black and old (music helps) having a good friend is great."* Another wrote that:

*'Loneliness is like a dark cloak enveloping you, depression sets in and you are lost in the depth, sometimes tears set in and I am lost in self misery. No-one can help you, I eventually drag myself out of the depth, difficult but necessary. Because I wish I was dead and I know I am on the depth.'*

Similarly to responses to previous postcards the individual responsibility for not being lonely was highlighted: *"Not necessary-get together more"* and *"Relying on other people"* and one person explicitly stated that loneliness was an individuals' fault and choice.

## **Interviews**

Across interviews people discussed how loneliness had impacted on their own life and the lives of those around them. Some reflected on their own concerns for the future and the plans they might put in place so they were not lonely. Others discussed reconceptualising 'older' for themselves and talked of a desire to challenge what 'older' means. Our analysis of the interview transcripts revealed three key themes; (1) Connecting and disconnecting, (2) Points of vulnerability, (3) Older identity and Individual differences.

### ***Connecting and disconnecting***

Loneliness was described as a sense of disconnection from the world and across interviews people highlighted the importance of meaningful social connections. As expressed by Charles:

*"If you are lonely and you have got no contact with people, I think that is probably one of the worst things that a human being could encounter, isn't it?"* (Charles)

In line with the literature on loneliness the importance of having good friends, rather than lots of casual connections as you get older, was discussed by several interviewees; *"Friendship is so very important; good, true friendships are very important. That is the greatest antidote to loneliness."* (Fred)

The absence or loss of friends was a source of sadness and loneliness for many;

*"Then I realised I had lost another friend. I think I have got one more friend to lose, and all my immediate friends have known me since I was 18 or 20..... that will be it..... then you think, well, gosh, who am I going to talk to? ..... as you get older and older and your means of contact with fellow thinking, males or females, are gone."* (Isaac)

While some people felt that making new friends was unlikely, others discussed expressly looking for, and trying to make, new friends. In order to do this people looked for activities and groups in libraries, online, in newspapers, local newsletters and through friends. Some people were happy to go along and try new things:

*"... I always went to all the dance classes on my own. Yes, I would join anything on my own; that doesn't bother me. If you wait for a friend to go with you, usually they keep letting you down, or decide not to come that week. So I gave up on that a long, long time ago. I decided just to go on my own, wherever I wanted to go."* (Barbara)

For others going alone to events was more challenging. Margaret described how having a friend to go out with would be valuable:

*“There are times when I have got things to do and I think, ‘I really don’t want to do this, I just want to stay at home,’ which is fine for me, but I suspect that, even when people who are alone, you lose confidence, you feel safe in your home, even if there are things you can go to, unless you have got a friend to go with who is going to jolly you up to go, it might just feel, especially at this time of year, safer.”(Margaret)*

While some lived near to, and described good relationships with, their family, others had family who lived far away and a lack of connection was described. Often people ascribed this to societal change;

*“Family connections might be the odd telephone call. It is something to do with British society as well. We are more isolated, our marriages break-up, our relationships break-up, we live longer, working grandparents. The traditional stereotypes have and it is difficult to know what has replaced them; what is making them all up as we go along?” (Eve)*

The value of technology as a tool to connect with others, particularly family who lived far away, was highlighted by several people:

*“Skype is a wonderful invention. Have you ever Skyped at all? We Skype our daughter. We have got two daughters, one with us and one living in America and she has got a daughter, so there is one grandchild. We see them every week on Skype. I know a lot of older people see their grandchildren and their children; that is a marvellous invention.” (Fred)*

However, while several people discussed the value of Skype and the internet generally, as a tool for connecting, others had never used computers and several did not want to learn. While most of those who used the internet found it a useful tool, the downside of social media, in particular the way in which it can make a person feel excluded or disconnected, was also discussed:

*“... When you go on Facebook, you see ‘Went out for a meal with 10 other people,’ and I am left down here..... I looked at Facebook the other night and a friend of mine for 30 years, he is on his own now, and he put a Facebook thing, ‘Just landed at Singapore airport,’ and I am thinking, ‘Why not me?’” (Charles)*

### **Points of vulnerability**

This theme relates to the different times and transitions periods in a person’s life where they may be at particular risk of loneliness. Across interviews people talked of times when they felt loneliness more acutely, or looking ahead people identified times when they may feel lonely as they got older. Retirement was a central issue across the interviews. In its simplest sense, for many people retirement led to less contact with other people. Several people talked of a double retirement which entailed retiring from their career or paid full-time job, then working part-time or voluntarily and then again retiring from that later:

*“That hit me hard then, my working retirement. My eventual retirement, of course, came in easy stages; but my first retirement hard. Mentally I went downhill quite seriously at the time. The reason why? Because you realise that you are on your own. Up until then I had all sorts of people I could go and have advice for or go and chat to. It was a very communicative job, so you were always talking on the phone or somebody or ring up so-and-so, ‘I’ve got a problem.’ All that goes overnight.” (Isaac)*

People managed retirement in different ways, many went on to work voluntarily, as Isaac described, or joined local organisations and clubs. While retirement was described as challenging by some, others highlighted the joys it can bring. Karen described how she decided to make retirement a time of complete change and moved house as a way of managing that particular transition:

*“So I retired about eight years ago now, hugely early, at the same time as the kids were getting to sort of teenage/leaving home type thing, and my mum died, so, actually, that was a huge crisis for me..... Of course, when you finish work, you lose a lot of your networks, your friendship networks and things. It just becomes different really and everybody is preoccupied with different things. So that was difficult..... I celebrate every day I moved here. I really do, because, having been through really quite a difficult time, to come through that and out the other side and, actually, really enjoy doing lots and lots of things.”* (Karen)

Losing a partner was described by several interviewees as a particularly challenging time of increased loneliness. This was both in terms of grieving being a lonely process and also more long-term, being alone after having lived with another person was described as lonely.

*“I lost my husband six years ago, and that is when this loneliness....it is walking into the house and you know there is nobody there. Because (my husband) is not in the house anymore. That is still strange. So I keep myself busy. I have had to, because otherwise I think I would have gone to bits..... Yes, you have got to get on. Life goes on, doesn't it? The only thing is I haven't said nights. At night, even now, I still feel it at night, but I have got a reason. I have a clock radio by the side of me, so, if I wake at one o'clock in the morning, I just pop the radio on. That definitely helps a lot. You feel you are not on your own. I know it is only a radio and it is only talking, but you feel you are not on your own. Yes, and I have listened to it long enough now, night time listening, that you feel you know the person who is talking.”* (Lauren)

The point that Lauren made regarding nights resonated across interviews; for some people certain days of the week or times of the day were particularly difficult. Weekends and evenings were described as particularly lonely times. Julia's comment below is typical of many;

*“But, when you think about it, we are all sat in our little boxes here, watching television on our own at night..... Sundays seem to be the worst day, always the worst day. If I have a bout of 'down in the dumps', it is a Sunday always. Don't ask me why, but I think you have got a lot going on during the week, but Sunday is dead.”* (Julia)

### **Older identity and Individual differences**

This theme is concerned with age both as a social construct and how people conceptualise their own older age. Interviewees discussed what being older meant to them. For some there were clear ideas about the changes that occurred as one got older. For instance George described being older as a distinct stage of life; *“Old people are not young people with wrinkles. They are old people, aren't they?”* (George)

Others however wanted to challenge the idea of 'older people':

*“I do not identify with being an older person. I think that can be a problem at times. I do admit to people that I am about to be 70, just to get used to the idea, really. So I don't find that sense, but I*

*don't want to be in this old company of older people. Now, that makes me feel dreadful just saying that, because the people that I have met have been perfectly OK people and nice people and have interesting things to say, but I still don't want to do that."* (Margaret)

Eve described how other people's concepts of age and ideas of what older people want had stopped her from engaging with many of the activities advertised as being for her age group. Like many interviewees she also felt the bracket of 'older' was too wide. Many people felt there should be categories within this group. As one person pointed out, numerically (and maybe socially) there is as much difference between 50 and 85 and there is between 50 and 15.

*"There are various older people activities, but one of the problems about the older people demographic is that you have got what is called the 'young old' and the 'old old'. From some research I have done, there seems to be some problems the young old find very difficult to integrate with the old old. So you need to join a group that is not going, 'Let's sing Vera Lynn songs.'* (Eve)

Some people talked of a process of reconceptualising their own ideas of their older age:

*"Well, I got aware of the facts a few years ago that I was imagining myself as this elderly woman with flowers in the garden, and I thought, 'Actually, I'm not going to do that anymore. I'm going to live to 150 and I'm going to write several novels. I'm going to do this, I'm going to do that.'* (Andrea)

For many, their concerns, plans and concept of older age related to how they had interpreted their parents' experiences. While Karen felt her parents were positive role models and had demonstrated how to retire well, others had concerns after having seen parents struggle with loneliness.

*"My mum and dad, I think, were good role models, because there were times when they did something ahead of the game. They could see what was going to happen, they could see they were going to get older. They needed to move into a smaller place or they needed to move closer to us. So it was quite brave to take the bull by the horns and actually make those sorts of decisions."* (Karen)

*"My mother was very much the same, at home, and she actually got quite agoraphobic. I didn't want the same situation to happen to me."* (Andrea)

Aside from their own concept of ageing, the way in which society generally categorises older people was discussed, in relation to the general invisibility of older people as well as negative representations and stereotypes.

*"The sense of being invisible, particularly older, people just walk past you; you are not actually seen. I can be fairly extrovert, I have gone back to being fairly extrovert and I can talk to people, but it sometimes comes as a sense of surprise that I have got a sense of humour and things like that, or the clichéd stereotypes when people expect you to be the traditional stereotype of fairly stupid and, 'Oh dear, do you want a cake, dear?'"* (Eve)

In addition to the cognitive process of understanding and conceptualising ageing people also highlighted physical process and the individual psychological processes related to 'ageing well'. A strong theme running through the interviews related to an individual's experience of ageing and an idea that loneliness is a personal responsibility, and how people deal with it relates to their



personality. While some people felt that the process of ageing was positive and freeing, other people expressed the view that the process could be difficult:

*“The ageing thing, that is depressing. I find that depressing at times. The body gives you some aches and pains, etc. Sometimes that gets me a bit down. I will look in the mirror and think, ‘Oh!’ It depresses myself, looking in the mirror, sometimes, and not being able to do the things one wants to do because your body just can’t do it anymore – that is depressing.”* (Barbara)

A few people felt that loneliness was almost an accepted part of ageing, and not always negative:

*“But, where loneliness is concerned, you just have to get used to it, don’t you? You get used to it and sometimes you feel happy that you are on your own, sometimes, because you haven’t always got the stamina. I can’t bounce around like I used to.”* (George)

Some people felt quite strongly that all individuals have a responsibility to get out into the world and engage in order to manage feelings of loneliness. Several interviewees felt that people have an individual responsibility not to be lonely, as expressed by Harry:

*“I mean, it is no good shutting yourself away and not having time for other people and not helping where you can. I try to be as helpful as I can with shopping for neighbours and one thing and another. I heard an old saying once: ‘If you meet a person without a smile, give them yours’. That is what I live by and I think I am pleasant to everybody and I find it is reciprocated; people are pleasant to me. You have got to make your own life and get on with it. It is no good thinking, ‘I am lonely, poor little me.’ You have got to pull yourself together and say, ‘This is what life has dealt me and I have got to get on with it.’”* (Harry)

Others considered how personal experience and expectations could impact on how people experience loneliness in older age:

*“I don’t think it is just personality. I think it is what their life has been. I don’t know if I can explain this... In my case, my husband and I, we are to blame again, we never liked going out to other people’s homes; we were much happier with people coming to us. Our flat was always an open house – Boxing Day, New Year’s Eve and that type of thing. Alright, he was 20 years older than me, so that probably is a bit Victorian, but I think we were brought up where your family comes first and you concentrate on that.”* (Julia)

The complexity of managing loneliness and the challenges of supporting people who were chronically lonely was discussed across interviews. There was a strong sense that loneliness did not just happen in older age but rather it related to an individual’s whole life experience. There was also an acknowledgement that helping the loneliest is difficult. Several people pointed out that any number of clubs and activities will not help someone who is in a place of chronic loneliness.

*“If you are a person that does get lonely and then you go down, you get more depressed, so you don’t want to go out, you haven’t got the motivation to go and be with people, I don’t quite know how you would get over that, if you haven’t got that inner strength that allows you to get out of it. It is no good people saying to you, ‘Pull yourself out of it,’ because, if you are right down there, you can’t. You need something a bit more constructive than that to make people think about what they might be able to do or how they could move themselves in that situation”.* (Barbara)

## **Focus group**

The aim of the focus group analysis was more pragmatic in nature, rather than exploring individual experiences, as we had with the interviews, the aim was to understand the main issues that those working with older people felt were particularly salient in identifying and supporting isolated and lonely older people. We identified three key themes. The first related to defining what was meant by 'older', the second theme was concerned with how to engage with older people and the third related to the use of technology. In this section we have decided not to use names or identify where people worked as we felt it made them easily identifiable.

### ***Defining 'Older'***

Similar to the older people we interviewed, the focus group attendees highlighted that 'older people' are not a homogenous group and need to be viewed as individuals.

*"I was thinking earlier that over 50s or over 60s are classified in a certain way. I think we, at whatever age we are, we have got to look at other groups and say they are not all tarred with the same brush..... So I think it is really important that we are open to the individual."*

People felt that there are different needs at different ages and that our expectations of being older are changing.

*"I think we have got to start to change our idea about older people, because I am the 60s generation and we are certainly not interested in a lot of the stuff that people think older people want to do. So I think there is going to be a whole generation like me coming along soon who have the same sort of emotional needs, but their interests are different."*

People felt that older people generally did not want to be compartmentalised and spend time just with other older people. Intergenerational activity was seen as important;

*"When I retired seven years ago, I had been working for the previous 20 years with a really mixed age group, but mostly young people..... Suddenly I retired and I wasn't mixing with anybody under the age of 50, 60. I really miss that..... all the things that are open to you, all the groups and the clubs and whatever, are just for 60 year olds. I wouldn't want that."*

Several people expressed the view that others saw you as old once you had retired; they felt that for many, once you had retired your value and contribution to society appeared to be less:

*"I remember someone where I worked who was head of public relations, really, really amazing woman, really high-functioning and I remember her coming back after she had retired and said, 'The amount of people that just treat me like a little old lady.'*

### ***Engaging older people***

Participants discussed the challenges of finding and engaging older people in projects and groups. The importance of both money and time to carry out engagement exercises were highlighted.

People felt that leaflets, adverts in newsletters and posts on social media reached a small section of people and that meeting people in person was more engaging:

*"I found it much more successful once you meet people face-to-face and you can get their trust. Even putting something through their doors isn't necessarily going to get them to come to something."*

Several people also said that coming to groups alone can be quite intimidating and that many people tended to attend if a friend came with them:

*"I find that quite a lot of people, they want somebody to come with them or be with them or they have come with a friend."*

Transport concerns and accessibility around getting to events were pointed out, particularly in terms of those who have mobility issues.

Within the discussion of engagement there was a strong focus on the differences between genders. People felt very strongly that women engage more in social activity as they get older whereas men are less likely to attend social events although they may talk alongside doing an activity.

*"I think, if you want to get older men along to activities, you have to talk to men and find out what they actually want, because I would quite happily go somewhere and have a chat, my husband would not even considerate it."*

## **Technology**

Technology was discussed as both a support and challenge. Some people felt that there was an age divide in the ability and confidence to engage with technology:

*"I was just thinking that, when I am at work, certain people say, 'Can I take your email?' and they are normally about 70, and I say, 'Yes, fine.' And after 70 there is a bit of a cut off. It is like, 'What's that?' or, 'No, I don't use technology,' or something like that. So it is changing, definitely."*

Others disagreed and felt that different levels of engagement with technology related more to individuals' life experiences and maybe the type of profession they had been a part of.

*"One thing I have noticed recently, my father is 81 and he has taken to computing very well, and he uses that to keep in touch with people. I know he is often isolated, but he has joined, a couple of his buddies have started up this email system so that people can keep in touch."*

Several people discussed the role that specific types of technology can play in keeping people connected and highlighted the usability of many modern apps:

*"The thing is, with mobile technology as well, because, for one, it is an intuitive design, which, actually, crosses all age ranges and abilities..... So, if the technology is increasing and its accessibility, more people are more likely to be able to access it and go, 'Actually, I can use this'."*

However, many of the group were unsure how they could use new technology with older people and felt it was an underused resource.

*"So I completely understand, the role of technology is becoming more and more and more imbedded in what we do, but it is almost like how do we tap into that?"*

### Stage 5: Developing recommendations

The previous section outlined our exploration and discussion of themes across the data in answer to the first part of our research question; *“How do older people in Greater Bedminster experience loneliness?”* We also wanted to consider and develop a series of practical recommendations from comments made by research participants directly on postcards, in interviews and by focus group members as well as those recommendations that could be drawn out of the data analysis. Specifically, we wanted to address the second part of our research question: *“What activities and/or services do older people use and/or require in order to reduce feelings of loneliness?”* Therefore, following discussion and analysis of all the postcard, interview and focus group data JB circulated the transcripts of our discussions. These were read and we came together with the specific purpose of developing a list of recommendations.

As a group we felt that it was important to recognise that loneliness is structural, physical, spiritual and emotional. It is not always negative: positive things can come out of feeling lonely. While not everyone who experiences feelings of loneliness wants this ‘solved’, for many, there is a desire for change; loneliness can have a highly detrimental impact on an individual’s psychological and physical well-being. A particular concern for some of the group was the challenge of reaching the loneliest and whether we had reached those people who were most at risk of chronic loneliness. We felt that overall we had spoken mainly to people who were lonely but were finding ways of managing loneliness; the ‘functioning lonely’ as one of the group commented. Therefore, we felt it was important to highlight the need for a variety of different approaches and ideas to support older people with chronic loneliness but also wanted to highlight the need for preventative measures designed to reduce the number of people becoming lonely. We also felt that it was important to highlight the stigma of loneliness and ageing and to address this by giving people the space and opportunity to talk about loneliness.

In order to support people (those who feel lonely and those who want to engage in order not to feel lonely later) we identified the following recommendations:

<b>Ideas to improve existing services</b>
<p><b>Where to find information:</b> Our findings suggest that people do not always know where to look for existing services, advice and activities-as one of the group commented; ‘you need to know what you want to know before you look for it’. We therefore suggest regular advice sessions both in local cafes and taken around to older peoples groups. Taking information and advice to older people in their local communities seems a more engaging exercise than asking older people to contact centralised services.</p>
<p><b>Increasing evening and weekend activities:</b> While there are a range of activities for older people in Greater Bedminster, we feel there is a need for evening and weekend activities. Sundays and evenings were specifically highlighted as times of increased loneliness and a time when few events or activities took place. Several people questioned what they saw as the assumption that older people do not go out in the dark.</p>
<p><b>Volunteer support and co-ordination:</b> We think that people need support in order to initially engage in volunteering and also to continue engaging. Especially as older people retire there may be an</p>

interest in local volunteering but it is not always easy to find out where there are openings. Furthermore, those already actively volunteering wanted the opportunity to be part of informal and formal networks with access to support and advice. We suggest having local volunteering forums and fairs held in local venues and publicised specifically for older people.

**Supporting providers:** We felt there may be a need for a forum of some kind for people in both the statutory/voluntary sector to share best practise, again on a local level. This could be a series of physical events such as meetings or more virtual such as email groups or a newsletter etc. This suggestion arose directly from the focus group. Participants reflected that the session had been valuable for them in learning more about what was happening locally through other providers.

#### Preventative measures

**Retirement course:** We see this as a way of supporting people as they transition from work. It seems that at this point in their careers/lives people need to know more about their local area and meet others who are retiring. An individuals' local community becomes more relevant at this time. When we have explored retirement courses they tend to be in the work place or sometimes residential. We feel this could be a real opportunity to bring a group of people together in their local community to meet others locally who are retiring at a similar time and to find out more about things that are happening in their community, on a hyper-local level.

**Tech support:** We feel that many older people would benefit from support trying out new technology. We therefore suggest drop-in sessions, maybe in a local café, to help people setting up Facetime/Skype, or trying out devices. Maybe a sort of 'internet café' for over 50's, we also suggest that this should be run with local young people, maybe Sixth Form students. This seems like an ideal opportunity to explore and forge intergenerational links. Additionally, the focus group felt strongly that technology was an important area for all older people and that events with a purpose may be more interesting to men.

**Older people's café:** We discussed the idea of having a co-operative space for skills exchange which could include young people. We felt that this could start with a pop-up that is evaluated to give a case for support/funding. This could become a community hub and a space from which retirement courses could run as well as tech sessions, support groups etc. This could be a way of making older people more visible in the community.

#### Specialist and professional support for those who are experiencing loneliness

**Emotional support:** This should be available locally for those experiencing chronic loneliness; we recognise that loneliness is often associated with other psychological and emotional challenges such as depression and grief. Support could include small informal self-supporting groups up to intensive one-to-one psychological support with qualified therapists. We feel it is important to recognise that there is a genuine need for professional social and psychological support around loneliness and that addressing loneliness cannot simply just be the responsibility of communities or volunteers.

**Vulnerable groups:** We want to highlight the importance of developing support for those most at risk of loneliness. This needs to be specialist provision. We feel there is a need for further research exploring the impact of loneliness on different groups of older people.

<b>Making older people more visible and destigmatising loneliness</b>
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<p>We feel that at a wider societal level there is a need to address issues of stigma around loneliness as well as challenge dominant perceptions of older people. We feel that the first step in doing this should be to make the experiences of older people and loneliness more visible within communities. We strongly feel that people need the opportunity to discuss loneliness and this should reach across age groups. Our first step in exploring this is to use our research to write and perform a theatre piece on loneliness and use this as a way to understand more about loneliness as well as disseminate our findings.</p>
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### **Stage 6: Alonely**

Central to this project was the desire to use arts methods to explore our findings, it was important to many of the group that we produced a creative outcome and this was a key objective of this project from the start. We felt that this could be a powerful way of further exploring our data and starting a conversation about older people and loneliness, thus starting to address issues around stigma.

As we were completing data collection in December 2015, the opportunity arose to bid for funding to develop and share our work at a festival in London in June 2016. The working group and the research group were excited by this idea and with HM we developed and submitted a funding bid to take part in the Connected Communities Festival at Somerset House as part of the Utopias Festival. The process of writing this bid together meant making decisions about the format of our contribution which led to a series of decisions being made at working group and research group level. At the same time, we decided that it was important that anything creative was also shared locally. With this in mind JB met with the Artistic Director at the Tobacco Factory Theatre-an arts venue in Greater Bedminster, and organised a date in July 2016 to share our work. In developing the bid, we decided to commit to producing a theatre piece and installation. In order to achieve this, we asked Adam Peck (AP), a dramaturg, to work on the project. AP has a background working in devised theatre and a great deal of experience working with community groups. He also came to mind as he had previously written and performed a show about loneliness. We asked Chloe Scholefield (CS), who had been working as part of the group since the start of the project to curate the project and start putting together ideas for the installation. We also asked Stand + Stare to be a part of the project and realise CS's ideas and plans, Stand + Stare are an artistic collective who create interactive exhibitions and installations with a narrative focus and have worked in a range of settings. Barney Heywood and Lucy Telling at Stand + Stare had worked with HM on a previous project, also with older people and they brought with them experience and expertise in project management and design.

Once funding was secured in February 2016 we had clear goals to work towards-dates were booked for the London Festival and the Tobacco Factory performance. At this point we had completed the initial analysis of our data and were moving on to start to think about next steps. As a starting point the research group met with AP and CS in March 2016. We introduced ourselves and discussed what had attracted us to the project and what we wanted to achieve from the festival and Tobacco Factory activities. There was a great deal of interest in writing and performing monologues based on

the data we had collected. AP explained the role of a dramaturg is to absorb what people are saying and doing and co-author a script that relates to this.

A question that was important to us all was whether we were representing ourselves, our data or both? We wondered if it was possible to even untangle it all at this point and whether that mattered. We also reflected that within the group there were differences of opinion about loneliness and the meaning of different aspects of the data; writing a series of monologues would allow us to express a variety of ideas. We agreed that while whole monologues would not be verbatim accounts of data some sections would be direct quotes. We wanted to represent the different themes we had explored in our analysis and decided that JB would go back to data and organise quotes from the interviews into the themes we defined during analysis and share with AP. We then arranged to meet with AP to start process of writing a series of monologues that could sit alone for the Festival but with a thread/through line for the Tobacco Factory Theatre. When we met with AP we also discussed the importance of space; initial discussions with the team organising the festival suggested the setting may be structured to look like a village green or fete and we were concerned that this may be incongruous with a series of monologues about isolation and loneliness. We felt that we might need to create space within a space either physically or using technology (maybe mobiles or headphones). We wondered if we could have a booth with a small audience. We asked CS to explore this idea and she came up with a series of mood boards and we settled on the idea of a small house like structure with a chalkboard wall for collecting further data. Over the next month we started to explore and refine our ideas. We confirmed who would be performing (four group members) and devised a rough timeline for the coming months:

**Timeline:**

- May: Writing back and forth between group members and AP. CS to work with Stand + Stare to develop the installation through an iterative process with feedback and input from the research group
- June: Weekly rehearsals and portable installation to be built
- June 24-26: Festival at Somerset House
- First week of July: Intensive rehearsal period to rework monologues
- July 8: Tobacco Factory Theatre Performance

The monologues were developed collaboratively between individual group members and AP. Initial ideas and thoughts were explored collectively in meetings and AP then worked one to one with people who had particular ideas they wanted to work on. He also worked with the data to explore the themes we had identified and the final monologues reflect and describe our data (see appendix).

The final installation was developed to be both a stand-alone exhibit as well as a performance space. CS worked with Stand + Stare and the group as a whole to interpret and make sense of our needs and ideas and present them in a visually interesting but also useable way.

**Alonely at the Utopia Fair June 2016**

The research group, members of the working group, CS, AP and friends and family made the trip to the Utopia Fair held at Somerset House for 3 days in June. Stand + Stare with support from CS installed the set. Over the weekend visitors were invited into our installation to watch the

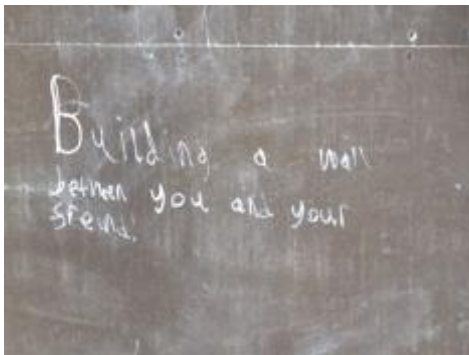
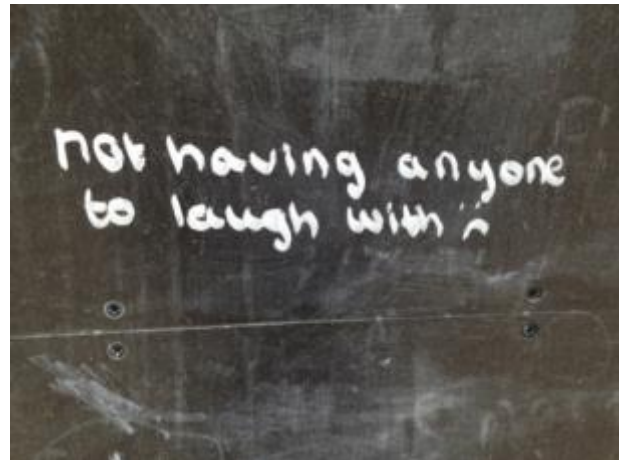
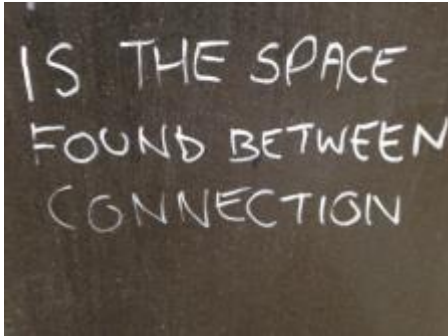
monologues being performed. These monologues were also available to listen to through headphones on the exterior of the installation, along with iPads that displayed some of the research material collected during the project. On one wall was a space for visitors' feedback, asking people to finish the sentence 'Loneliness is...'



During the festival, monologues were performed on a rota by two performers in each slot. After each performance we found that audiences tended to stay and as the weekend went on these became Q & A or discussion sessions. The conversations we had were very positive, and we were happy with the responses to the monologues. We felt that people wanted, and valued, the opportunity to reflect on the topic of loneliness. Many people said that there should be more awareness of the topic and more space to discuss related issues. In addition to this we felt that the festival gave people an opportunity to practise their monologues and get used to performing. The chalk board also gave us a chance to ask people for their thoughts on loneliness. A selection of these are provided below:







### **Alonely at the Tobacco Factory Theatre**

Following the weekend in London the group had a week before starting rehearsals to change the 22 monologues we had written with AP into one piece for the Tobacco Factory performance. During the writing process we had decided that we needed to ask someone to come in and direct the piece for the Tobacco Factory Theatre. This was quite a change for the group, until this point decisions had been collective and work had been highly collaborative. With a week to turn a series of monologues into a coherent theatre piece we decided the pace and structure needed to change. JB suggested a director to work with the group-Lucy Tuck (LT) an experienced actor and deviser who was known socially to a number of the group and had worked with AP previously on several projects and, as such, they were familiar with one another's ways of working. Prior to the intensive week LT met with JB and with AP separately and discussed the project overall, the performers and the material. She then spent time going through the monologues and thinking about how they could be performed. She came up with the idea of the performers working as an ensemble, using seemingly simple techniques and theatrical devices. Coming into rehearsal LT had a clear idea of the structure of the piece and how it would fit together. While this was not set in stone and some aspects changed (we used fewer monologues than originally planned) it was crucial to have a framework ready to go.

Alonely was performed at the Tobacco Factory Theatre on 8<sup>th</sup> July 2016 to a sold out audience of 200 people and the performance was followed by a Q & A between the group and the audience. We received a great deal of feedback and people commented that the show could go into care homes,

schools and other local venues. Below are some of the comments received on feedback forms we handed out after the show:

**Alonely Feedback:**

Brilliant!

I think you should present at the Edinburgh Fringe.

It would make a really powerful radio play/documentary which might reach those very isolated.

Take project to schools.

Get more funding for Bristol wide project especially culturally diverse communities.

Great performance thank you.

It would be good to take the show to schools and old peoples homes, clubs etc.

Great and thought provoking show. More!

Moving, honest, thoughtful all under the lovely umbrella together.

What a fantastic performance. Powerful and terrifying older people, really reflective on research process.

This is a good idea to perform the research in this way because makes many people to be involved.

I thought the show was very powerful and emotional having a background of working with older people and being a loner and having a loss of parents I have heard every scenario that you played out.

It was a wonderful show which made some very realistic comments on society and an ageing society today. I would like to see a society where through positive use of social network media people were able to build an inclusive society.

**Reflections from the community research group**

After the research activity and performances of Alonely at the Utopias Festival and in Bristol at the Tobacco Factory Theatre HM (again without JB present) facilitated a second focus group with the community researcher group to reflect on their experiences overall and consider future plans.

In terms of the research overall, as in the previous focus group, it was clearly important to group members that there had been a purpose to the project and that they were “..... *actually doing something pragmatic, rather than discussing.*”

In terms of the process some felt the research meetings were a little long initially and there were concerns about whether it would be a 'talking shop'. However, people generally understood the need for meetings and training and understood that in addition to the practical aspects meetings allowed the group to become a collective:

*"I think it was quite important. I mean the business of each meeting you could think, well it could have been shorter, but actually the process of having so many is probably what's held the group together I think."*

*"And the other thing we grew as a homogenous group, you know, it wasn't ... I don't like meetings, you know, discussions a lot but bringing the group together it was just fun to be there so ..."*

*"I think the process of the group, you know the life of the group has been interesting and worked. You know the getting to know each other and starting to trust each other and we all come from very very different backgrounds really...."*

The group felt that facilitation was important, and explained that having one individual with a clearly defined role in holding and organising the group (JB) was crucial. Within this, practical aspects were highlighted including having a budget, buying drinks and food, and being first to meetings:

*".....her job {JB} was very clearly defined. You know she knew what she was doing, why she was doing it and what she was there for and she gave us that really. It felt like a gift."*

*"You know like this is what we're all here for and we're all in it together. So that was the equality thing, we're all in it together, but she was also very clear that she had a different role from us."*

In discussing the analysis of data a few people felt there was occasionally a jump in analysis sometime and wondered *"where did that come from?"*

Another reflected that: *"actually I think people's minds were changed in the process of discussion and that was also very ... made you feel sort of open including Jenny's."*

One of the group described this process in the following way:

*"JB picks out as a result of what people had said, she manages to focus on the crucial things or aspects of and even if in some cases we didn't all together put emphasis on them. Once she had done that and put it, you know in a bit when she brought it out, I felt she'd done it right, but yet she clarified it."*

In reflecting on the analysis and the project overall one person explained that decisions:

*".....were made collectively but under guidance. Not very obviously guidance, but you know. In the end I suppose JB put down what it was that we'd been discussion and she interpreted it and put it down and I think it was all pretty fair."*

This process was underpinned by having become a collective and through respecting one another's views. Respect and equality were discussed throughout the focus group, it was emphasised that facilitating and engaging in coproduced work needs to involve respect:

*"Not a sort of a patronising respect. So I think she (JB) genuinely respects and feels that people have an equal value."*

In discussing the monologues and final events some people worried that the energy given to the performances meant that other outcomes were not given the same attention. It is important to note that members differed in terms of how much they had wanted to be involved in performances, for some it was of little interest:

*"...I think for me I really enjoyed the actual research and the learning about it, doing the interviewing, analysing the interviews, all that sort of stuff, thinking about it and I didn't really get involved in the performance element"*

However, for others the performance was central:

*"So yeah and so that's why I stayed involved and because of the creative ... knowing that the research would be somehow presented in a creative way. That's really close to my heart because I think well-being and creativity go hand in hand, so yeah."*

*"I think for me certainly it exceeded expectations. It was fantastic. In fact, it was the most important thing I've ever done I think in terms of getting on that stage up there and putting it over...."*

*".... I've done research and stuff as well in the past and it was just so notice to actually be able to make it accessible to the public in a way that actually had a huge emotional impact as well as to get people chatting and things because research is normally a document, but it's amazing that there's been the budget and there's this whole programme of actually putting research into a way that people go "Oh I can understand that" and then it just leads on to even more conversations and outcomes."*

In addition to the value of research and their engagement in the process overall group members were also personally affected by the research topic and as one person stated:

*"By doing this project I....you know everybody gets lonely at times. I've recognised in me, whereas before I didn't and I'm quite upfront about it. Now it took the shame away about the whole topic."*

### 3 Thoughts on coproduction and engagement

The community research group came together to explore the isolation and loneliness of older people in Greater Bedminster and the previous section described how the group was formed, our methods of investigation and our findings regarding loneliness. This research project also set out to explore methods of coproduction and asked if and how this method could support the engagement of local older people in the research itself and in project outcomes. As highlighted in the literature review, it would not be possible to suggest that there is any one correct way to approach coproduction; in fact the flexibility of those working on coproduced projects may be one of the most essential criteria for the success of a project. However, looking back across this project there are a series of points that are useful to reflect on in terms of methods of coproduction and in particular methods that facilitated engagement with the research process.

While it may seem an obvious point, it is important to recognise that coproduced research is coproduced with those who are interested in working on a project. Whatever preconceived ideas there are about a project, those who come to work on it are those who influence it. As a researcher it is therefore essential to get to know those you are working with, to understand their skills, interests, needs and abilities as well as their motivation for involvement so that you can work to support these. This can happen through formal asset mapping processes and other engagement activities or less formally over lunches and conversations. One of the joys of this project has been the number of pre-meeting meetings with different group members as well as coffees on North Street, fish finger sandwiches in the Hen & Chicken, tapas at the Tobacco Factory bar and Papa Deli sandwiches and fruit platters during rehearsals. The conversations that take place during the informal times over food and drink are often the most insightful and valuable. It was during these moments that I really got to know the individuals I was working with. Any coproduced project has to recognise that people come with a plethora of skills, experience and expertise and working with these is likely to lead to people wanting to be a part of the project and feeling more committed and engaged as they feel valued and appreciated.

While it is important to draw on the expertise and lived experiences of individuals within a group it is also essential to become a group. This again often happens over lunches and coffees; however, beyond this there needs to be a clear shared purpose, something that all group members can invest in and feel that they have something to contribute towards. This is not to suggest that everyone has to have the same motivations and goals; I would suggest that valuing and allowing for differences is a key part of coproducing research. However, it is important to have a common and shared understanding of the research aims, processes and project goals.

Within the group we came together around the idea of wanting to understand more about loneliness. The first months of working towards a research question and then a period of training allowed the group to form and become a collective with shared ideas and a shared vision. On reflection it was useful to start the project with a small number of people and build a larger group together. While there were some links and existing relationships between the research group members, most did not know one another when we started which meant that we were a new group. We took a pragmatic approach to research training, rather than an abstract or theoretical approach and learning took place through exploring scenarios together, sharing examples of practice and embodied roleplaying rather than learning the theory. This meant that the group built shared

languages around ethics and research processes and allowed different voices and ideas to be explored. Furthermore, in voicing opinions and thoughts people were able to get to know one-another and we became a group.

Our discussions and decisions during the research training stage were rooted in individuals' skills and motivations and these provided a skeleton for the research activity and approach. This idea of a skeleton is really important to me. If something is too open it's hard to understand and see how you can engage with it. On the other hand, if something is very clearly structured and defined it is hard to feel ownership or influence. For me this tension and how it is managed, is possibly the most critical aspect of coproducing research. A great deal of this skeleton is also formed by external factors such as particular deadlines that have to be met, the motivations of others involved in the project (in this instance the working group as well as the wider Productive Margins Forum), holidays, participant availability and funding. Having a basic skeleton gave the group a starting point and something to come together around. As the Research Associate on the project I think an important aspect of my role was ensuring there was a skeleton, but that all involved could 'flesh this out'.

The role of the community researcher within a coproduced project can be challenging. A particular challenge is that coproduced research needs to have input from structures that sometimes appear to talk in different languages. The Research Associate therefore needs to talk to and about both structures, finding a way to work that both structures are happy with is not always simple. Sometimes however it is simply about explaining why and how something is done in the way it is. We all know what we know, and do what we do, based on previous experience. Coproduction is challenging to this and means having to take on a different perspective. This means finding a new place to position yourself that is different from where you started. As a community researcher there are specific challenges and tensions and negotiating these is an ongoing aspect of the project.

In a practical sense I feel that a key part of the researcher role is to ensure that project targets are met whilst allowing for as much fluidity as possible. I was often aware of a discrepancy in being the only paid worker within the community research group and felt a responsibility to do the 'boring bits'; organising meetings and taking minutes etc. Whilst I suggested a rotating Chair and different minute takers this was not something that group members wanted. On reflection I have learnt that the things which look like engagement are not necessarily the things that make a project coproduced. I felt that while people wanted to get involved they did not necessarily want the final responsibility. As the 'paid worker' I felt this final responsibility was mine. For me it was important to provide the skeleton for the project and scaffold its development, building a space where the community researchers felt it was their project, but for me to be there to 'drive it', as the group suggested in the focus group. It is essential working on a project like Alonely to understand when to scaffold, when to take a step back, how to bring a group together and when people need time on an individual level.

Whilst, as noted earlier, it is important to develop the project around the different skills and interests of group members, it is also important to remember and try to address the different motivations those involved in the research had for becoming involved in the project. This relates to both the community research group and the working group. At working group level there are academic commitments to the wider Productive Margins project as well as individual interests and

individual career motivations. Community partners also have motivations for involvement in the project, which need to be recognised. In this context it was important to SDH and the SCDA that we explored loneliness and identified outcomes that could be realised by the local community. SDH was particularly interested in methods of coproduction and the learning this project could provide in terms of community engagement. The community researchers had a range of motivations for being involved in the project both personal and topic related. Some of these were met by being a part of the group and by carrying out the research itself. However, many motivations were also related to project outcomes which are ongoing and will need continued support (probably by the SCDA) beyond the life of this project.

Without a doubt the biggest challenge during this project has been time, in terms of the number of researcher days allocated to the project, the time members of the working group have allocated to work on the project, the availability and time that community researchers can commit to, as well as the overall timeline of the project. Coproducing research needs time, to meet, to become a group as well as time to come to collective decisions and often different people are available at different times.

Having a creative outcome and expression of the research was important to many of the group. This related to some people's individual interests and motivations but also went beyond this. As a group we wanted to engage the local community in a dialogue about loneliness, I think it is important to highlight that we see Alonely as more than a dissemination event, the hope is that it is the start of a conversation that engages people in the issues it touches upon. One of our aims was to address the invisibility of older people and provide a space and opportunity to discuss loneliness. We feel that as an engagement exercise Alonely is likely to reach a group of people who may not read a research report or attend an academic presentation. The Tobacco Factory Theatre audience was comprised of academics, people working with older people in the statutory and voluntary sector, members of the local community and many who had taken part in and/or supported the research over the course of the project. Going forward we hope that Alonely continues to provide a space for community engagement.

As my role on the project concludes there are particular challenges around organising the next steps and future projects. As I have highlighted, while people were highly committed to the project, it seemed that they did not want to have the final responsibility for organising meetings or sending around emails. I do recognise that it may well be that as long as I have been in position and have adopted that organising role others may not have felt the need to step forward to undertake those tasks. However previous researchers such as Collins and Wrigley's (2014) have also highlighted the importance of a key person or organisation in managing coproduced research. Therefore, to support and encourage continued engagement on any coproduced project I would suggest that there is a need for a central person (probably in a paid position) to have the time and responsibility to take on a facilitating or development role. This role needs financial support to enable venue hire, transport costs and the essential lunches and coffees. While coproduction is about working together in a collaborative way, it becomes much simpler, and may be more likely to succeed, if there is someone who can start the conversation and do the 'boring bits' as well as understand, utilise and support both individual motivations/skills and group development.

#### 4 Conclusion

Over the course of this research project and through a range of research activities within the local community we have learnt a great deal about the isolation and loneliness of older people in Greater Bedminster. We found that when the topic of loneliness is first discussed people generally talk about the inevitability of loneliness as one gets older and suggested solutions are pragmatic, for instance better transport and more clubs and activities. Although these issues are important ones to address, once discussion goes beyond the pragmatic much more complex social and psychological causes and possible solutions are identified.

Connecting to and building a local community as one gets older appears to be crucial to preventing loneliness. Thinking about this and being aware of it earlier in life may be a protective or preventative measure in itself. Certainty talking about and addressing stigma around ageing was important to many of those involved in this research project. Within this, defining what is meant by older and what older might mean to us as individuals is crucial. Making older age generally, and loneliness specifically, more visible and finding a space to talk about concerns seems essential. It appears that preventative measures designed to support people as they approach particular transitions such as retirement may be highly beneficial. If being 'old' held less stigma, if older people were more visible and if loneliness was discussed throughout our lives then we might start to make changes that celebrate and support older people.

As this research project ends there are a range of different outcomes being explored based on the findings presented in this report. The community research group members have formed a collective called ILOP (Improving Life for Older People) which is being supported by SDH and the SCDA and are currently exploring four of the outcomes identified previously:

(1) Technology pop-up sessions in local cafes aimed at older people but also working with local young people. JB, in conjunction with the SCDA, has written and secured funding from the Big Lottery Fund awards for all in order to support the development of this initiative. This funding has enabled the group to employ a development worker one day a week to manage the project which will soon be up and running. JB and HM will be supporting the group in evaluation activities.

(2) There is also interested in taking forward the retirement course idea and this is being explored by SDH and members of the working group.

(3) The idea of adopting a local venue and using it as an older people's café is currently being actively explored by staff at the SCDA it seems there may be a few options for this going forward.

(4) Some of the group are interested in taking the Alonely show on further. The show performed at a festival in Bristol in September, at a University of Bristol Event in October and at a Productive Margins engagement event in the centre of Bristol's shopping centre 'Cabot Circus' in November. We have also discussed taking the show on tour. A particular challenge lies in who organises this and how. We are exploring different options, in conjunction with the SCDA, at the moment.

Throughout this project a concern, as highlighted previously, has been whether we should concentrate on reaching the most isolated and lonely and whether we should make a concerted effort to be representative and include those older people who are categorised as at an increased risk of loneliness. While we may not have reached the most isolated and lonely within this project, I



would argue that working in a coproduced way with a group of older people in the community has supported a different way of researching that has gone beyond usual ideas and recruitment methods.

Older people appeared more likely to talk to other older people about loneliness. Many of those who took part in our research had never taken part in a research project before. It may be that to reach those who are the most isolated and lonely, research needs a greater amount of time to access those groups of people who, as they are isolated, may be particularly challenging to reach. However, it is also important to explore and understand normative experiences of loneliness. The research reviewed in this report clearly demonstrates that large numbers of the population, in particular the older population, are likely to experience loneliness. In a community setting it may be that we cannot reach the most vulnerable and isolated, these people may need more intensive and multidisciplinary support than a community project can provide. However, if the statistics in the literature review are correct, then there is a clear need to work on resilience and preventative measures as well as highlight this topic more generally and this is where we place this project.

We feel that further research is needed to explore loneliness from a longitudinal perspective and a life-course approach to loneliness would be particularly valuable. In order to develop and evaluate any preventative measures, longer-term research projects with follow-ups over many years would be the ideal way to assess their impact on loneliness.

We also feel that activism addressing ageism and the perceived invisibility of older people is needed. As a group we also feel that more intergenerational opportunities should be developed so that both younger and older people have the opportunity to meet one another as equals. This should provide an opportunity for people to learn more about the joys and challenges of being older as well as take time to learn more about what it means to be a young person today.

This project and the outcomes the group are developing are rooted in the local community. The research questions, activities and outcomes are 'applied' in nature and the focus of this project has consistently related to building a sense of community. This sense of community has developed through engagement in a meaningful project which has real life application; it relates to a cause that group members believe in, but is also real, and outcomes are tangible. We suggest that 'Regulating *for* Engagement' means demonstrating to people that their opinions are listened to, their motivations are understood, their skills are valued and their actions are supported. For coproduced research projects to be successful particular consideration needs to be given to researchers' skills and time, overall project timeframes, methods of recruiting and engaging with older people, training and finally how project outcomes can be supported in a sustainable manner.

**Appendix: Alonely monologues****Written by the Alonely research group and Adam Peck**

- 1. Being alone** (*Loneliness*) F (or M)
- 2. Aching** (*Old age*) F
- 3. The Bus Ride** (*Old Age / Death*) M (or F)
- 4. Old?** (*Old age*) F (or M)
- 5. New friends?** (*Friendship*) F (or M)
- 6. Daily Bread** (*Mobility*) M (or F)
- 7. “Retiring”** (*Retirement*) F
- 8. Losing your love** (*Loneliness – losing a companion*) M
- 9. The Home** (*Care Homes*) F (or M)
- 10. Packed In** (*Loneliness – losing a companion*) M
- 11. Walking** (*Loneliness*) F (or M)
- 12. All I need** *Loneliness* F (or M)
- 13. In an ideal world** (*Utopia*) M and/or F
- 14. Close** (*Loneliness / Depression*) M
- 15. Retreating** (*Loneliness*) M (or F)
- 16. The Radio** *Loneliness* F (or M)
- 17. On My Own** (*Loneliness*) F (or M)
- 18. Always there** (*Loneliness / Isolation*) M (or F)
- 19. Wonderful Skype** (*Loneliness / Technology*) F (or M)
- 20. Help** (*Loneliness / Depression*) W (or M)
- 21. The Dog and the Garden** (*Loneliness*) M (or F)

**1. Being alone** (*Loneliness*) F (or M)

'It's all down to you', they say, 'your personality'. And I think that's probably right. Some people just seem to be better at dealing with being on their own than others. I wish I was better.

I suppose I've never been the biggest socialiser, but then at work I was always around other people. You don't have to make an effort – other people are just there. But when work goes, well the socialising goes too. And if you haven't made friends outside of that... you don't really have anyone.

There's family I suppose – for some people. But for me it was always just me and my mum and dad – I don't have any brother or sisters. And obviously my mum and dad passed away quite a while ago now.

I suppose really good friends stay in touch. But I never seemed to make any of them. Maybe it's my own fault. Maybe I didn't make enough of an effort – because I was liked – at work – I got on with people, it's just... well.... You lose contact when you stop working and then it's hard to bridge those gaps again.

You lose contact with people. You don't mean to – it just happens. People drift don't they...? You have the best of intentions to stay in contact. You take phone numbers, but then you never call. And neither do they.

When you get older you feel that more. When no one calls. I don't say that to make you feel sorry for me. It's just one of those things – people just don't stay in touch. Perhaps they never did. It's just, like I say, you feel it more when you're older.

## **2. Aching** (*Old age*) F

I ache. I ache all over sometimes. Makes me feel old.

I am old. But feeling it is the worst.

We're not young people with wrinkles are we...? We're older. We've had lives and experiences. We've done things.

Maybe it's all just in the mind. Maybe if I decide that I'm not going to be ~~an old lady~~ I won't. I don't want to be ~~an old lady~~. But then I look in the mirror and think 'Oh, who's that!?' It depresses me.

Because of course when you get to my age it's your body that decides what you do, not your brain. Like Bette Davis said, 'Old age is not for sissies'. And I'm not a sissy. But not being able to do what you want because your body says 'no' is hard. And it's only going to get worse.

There is one thing to be said for getting older though – you care less about what other people think of you. It doesn't matter. I wish I'd known that when I was younger. Yes, I think if I'd worried less I'd have done more. Too late for that now...

Still, I don't spend my time regretting. I've made a point of that. Don't live in the past. Don't dwell. That's important. And I'll always have my sense of humour. That's important too. And what's to say there isn't still plenty left to do with my life. It's not over is it... far from it – it's just different to what it used to be...

**3. The Bus Ride** (*Old Age / Death*) M (or F)

As you get older your friendship group gets smaller... it diminishes. It's as though one-by-one they get off the bus. And over time there's hardly anyone left – and at the end there's just the driver... whoever he is.

And the smaller the group the closer to the inevitability of it you get... We're all heading in the same direction aren't we...? And it makes you think... every time someone gets off... will I be next? Will I be the next one to ring the bell?

**4. Old?** (*Old age*) F (or M)

What is old? Am I old? Do you look at me and see an old person. I hope not. I don't feel old. And that's what they say isn't it – you're only as old as you feel. Well I may have my wrinkles... and I might not be able to walk as well I used to, but I'm not old. Old is nearly dead. And I'm not nearly dead. I've got plenty of life left in me yet. Look at me. Do I look nearly dead to you?

**5. New friends?** (*Friendship*) F (or M)

I don't want to go to the community room. I'm happy on my own. I don't want to spend my time with strangers. And I know what you're thinking, you're thinking they wouldn't be strangers if I spent time with them. But I haven't got time for that.

And besides I don't want to make new friends. Where would be the point? Relationships take time to develop, friendships take years. You have to invest in them. I haven't got time for that anymore. There wouldn't be any depth – we wouldn't know each other, not properly. So I'll just sit here. I'm happy on my own. Sometimes I look out of the window. Other times I watch the TV or read. It's alright being on your own...

**6. Daily Bread** (*Mobility*) M (or F)

It's as though getting older means you lose things. And I don't mean misplacing your door keys. I mean things get taken away from you. It's a slow process, but it's like your life is slowly eroded. And you can feel it coming, creeping up on you. And you think... how have I ended up here, like this, without the things I had before. It's hard.

I used to drive – that was what got me out of the house when I started having trouble with my legs. I drove to the bakery every day to get my bread. And even if that was all I did in a day that was alright – because I'd been out and done something – seen some people. But then they took away my driving licence. I can still drive, of course. But I'm not allowed to. They took a lot more than my licence. They took my independence.

I can't walk far you see... without the stick. So the bakery's out of the question now. Alison has offered to take me there, but that's not the same is it... I don't want to rely on her... be a burden... she's got her own things to be getting on with. So she just drops in a loaf from the supermarket when she remembers... You know... a Hovis or Warburtons.

I do miss the bakery. I liked the people there – we knew each other, we chatted. Not about much, but we talked. It's important. More important than I realised. It's those simple things that keep you going. The little interactions... they make you feel human. And the bread well... it was really good.

They say I should get out more. Go to events. 'There's plenty for you to involve yourself in', they say. But any number of events isn't going to help if I can't get there is it...?



## 7. "Retiring" (Retirement) F

'You need to look after yourself Janice', that's what they said. So that's what I do. I look after myself. Here I am, looking after myself.

Years ago when people retired they moved to the countryside didn't they? They just up-ed and off-ed to the sticks. It seemed to be the thing to do – getting away from the city. I don't think it's like that anymore. I think that's the worst thing I could possibly do.

I didn't want to stop work. But I didn't have a choice. 'You're unfit to work', they said. 'It wouldn't be good for you to go back into a work environment'. What do they know?

I used to talk to people. You don't think twice about it do you – on the phone, in the office, people in the post office – you're talking all the time. But then... well... if you don't have any reason to leave the house – which when you retire you often don't... you don't talk to anyone. Work gave me a sense of purpose – somewhere to go.

I thought to begin with I'd be going back some time. But I never did. So I retired without ever actually making the decision. It's a massive thing retirement. And no one prepares you for it. A bit like having a baby, no one can really tell you what it's like until it's happened. And then there's no going back. Some people take part-time jobs don't they... volunteer and such. I can see why... it keeps you busy. It keeps you connected. It's important that. But I don't think they'd even let me do that.

It's hard to remember sometimes what it was like – the daily routine, getting up, going to work. It just slipped away really. Of course, things might get better. I just need to think about the future. Reconfigure... adjust... you know.

*(She sits for a moment, lost in thought or showing us how she sometimes gets lost in thought.)*

I'm not sure this is what they meant when they said I should look after myself? Too much time to think. Still...

**8. Losing your love** (*Loneliness – losing a companion*) F

He died on a Friday. I'd been looking after him for a while by that point – you know caring for him through his illness. And then he went. And I hadn't had any time to think about what life might be like without him. We'd just got on with it. When he was diagnosed, we just... coped. It was a full-time job looking after him, but I wouldn't have had it any other way of course. I loved him. He would have done the same for me I know he would, but I suppose what I'm getting at is... it took up a lot of my time caring for him.

And then when he finally went I found it hard to cope. He'd tried to talk to me about it, but I hadn't wanted to. He was the most important thing – that's what I kept telling myself, but really I just didn't want to think about a life without him. I knew he was going to die. I knew that. I'd come to terms with that. But I hadn't given any thought whatsoever to being here on my own...

Whenever I came back to the house I'd go in the bedroom and say hello to him – even though he wasn't there anymore. I had to. I couldn't get used to him not being there. He was part of my life for so long – and that bedroom, all those hours... I suppose I was in shock – my whole life had changed.

I went about my day-to-day life in a sort of dream. I wasn't coping. I knew I wasn't, but I didn't know what to do about it. And I suppose I didn't want to admit it to myself. I'd go in a shop and then I'd have to come out again because I wasn't shopping for him as well. I couldn't go anywhere new – I had to stick to familiar streets and routes. I don't know why. Nothing seemed real, nothing seemed right. It was just unbelievably odd and I couldn't see a life beyond that.

I'm better now. Although I quite often find myself with nothing very much to do. Life doesn't... fill me up like it used to. I don't know what to do about that really. I suppose I should do something – get out of the house at least... But to be honest, I can't really be bothered doing anything anymore – I know it sounds a bit morose, but it's like the purpose has gone. And I don't mean Richard. I mean I just don't feel the same as I used to. A friend said she thinks I'm depressed, that I should see a doctor, get some tablets. But I don't want to do that. I don't think it will help, not really. That's not what this is about.

Time will tell. Isn't that what they say? Maybe that's all I need. Some more time.

### **9. The Home** (*Care Homes*) F (or M)

The doors are numbered from one to twenty-five and each room has the photograph of the person whose room it is. On a temporary basis of course. I don't think anyone comes here thinking they'll be here long. I certainly didn't.

So this is room number four and on the door is a rather fetching photograph of my seventy-sixth birthday. That was quite some time ago now. You can still tell it's me mind – I haven't aged that much, thank you.

I've been here for about eight months. And I've seen a fair few come and go even in that short space of time. The photographs change more often than you'd like to think, but the numbers always stay the same. That's something I suppose. A constant.

So there are only twenty-three of us living here at the moment. Two have not long since departed. Their photographs are still on their doors – numbers eighteen and nineteen funnily enough. I'm glad I'm not in room twenty. Ernest must be shaking in his boots. It wouldn't be the first time there's been a run of numbers.

I do like looking at the photographs. You can tell a lot about a person by looking at their face – what sort of life they've had, whether they're cheerful and open, if they're optimistic or not. I think a face tells you how a person's lived – like experience is written in the lines.

There's a lady I hear shouting out for help. It happens any time of day or night. Sometimes I think I should go and check if she's alright. But then that's not my job to do that. Someone's paid to care for her. That's why we live here. But it's... well, shocking. It makes me feel scared. It doesn't get any easier either – the longer I live here – it still feels the same as the day I arrived.

Countless others have lived in here before me of course. And left...

We come here to die don't we, that's the truth of it... might as well say it. We get older than old and then we disappear. Perhaps we disappear before then. Only two of out of the twenty-three people that live here have friends or family who come to visit. It'll be that way until we die I should imagine. So maybe we really do disappear before our time.

**10. Packed In** (*Loneliness – losing a companion*) M

My wife died fifteen years ago. We'd been married 43 years. Quite unexpected, her dying – burst aorta. I wasn't there. It was all over by the time I got home. From the allotment, which was only up the road. Packed in the allotment after that.

More unexpected was what do I do now she's gone. I hadn't thought about it at all... There's not a day goes by when I don't miss her. Fifteen years now.

Don't get me wrong, I've got plenty to do, I'm not bored, sitting at home and moping all the time. I go out, I do the garden, I see my old friends from work – we have a lunch together every month or so and the three or four of us meet up sometimes in the evening to go out. I see my son, of course, and my grandchildren sometimes too.

We lived here in this house for 40 years, see. Only the second owners. So we know our way around. Well, I do...

I don't go to the football any more though. I don't like coming home to an empty house. I hate it. You see we used to have a lovely routine. I wasn't a fan of the football club when we first got here - it was her. She was the one who'd always supported them. She'd been a fan since she was young. But she stopped going once she had the kids like many other young mums at the time – priorities change don't they...? I don't know whether we bought the place because the ground was within earshot - we never talked about it – but looking back we probably did... Anyway she marched me off there in the early days and pretty soon I got the bug.

So, on a match day, she'd be busy round the house, with the radio set to the local station. You could hear the cheering of the fans from the garden, that's how close we are to the ground. Quite loud it was when there was a goal.

And I'd be off to watch the match, see. Oh they were great times on a Saturday afternoon, win or lose. More often losing I seem to remember. Just me and my boy... when he was around. And then, when the match was over, we'd come back home and she'd have the tea ready and she'd tell me all about the game - because she'd heard it all on the radio, with all the commentators view on it and everything. Who played best, what players they were missing, how the ref had missed this or that foul or given it to the wrong team... We'd have a good old chin wag about it. She knew her stuff.

But now, since she passed away, I found I couldn't face it any more. I couldn't face coming home to an empty house, you see - not having her to chat to about it... So I stopped going. Just like that. Twenty-two years I went to the home games and then never again after she died. It wasn't the same. I still hear the goals go in mind – on a Saturday afternoon – and I do miss it – but I could never go back. It's hard still being here when so much has changed around me. But I wouldn't leave the house of course – it means too much.

**11. Walking**     (*Loneliness*) F (or M)

Walking

Walking walking walking

Walking morning, noon and night.

Walking as distraction.

Walking denying loneliness

Walking as escape

Walking walking walking walking

Walking morning, noon and night

Walking away from love

Walking away from abandonment

Walking away from lonely evenings

Walking walking walking walking

Walking morning, noon and night

Walking away from weekends alone

Walking away from guilt

Walking anywhere to keep on the move

Walking walking walking walking

Walking away from suicidal thoughts

Walking away from sleepless nights

Walking towards a better future

Walking morning, noon and night

Walking walking walking walking

Walking walking walking walking

Walking walking walking walking

Walking walking walking

**12. All I need** *Loneliness* F (or M)

All I need is someone to talk to.

All I need is someone to visit.

All I need is to get out of here.

All I need is to talk.

All I need is a visit.

All I need is to get out.

All I need is someone.

Talking.

Visiting.

Here.

That's all I need.

Someone.

**13. In an ideal world** (*Utopia*) M and/or F

In an ideal world I'd never feel lonely.

In an ideal world there'd always be someone to talk to, when you want.

In an ideal world everyone would feel loved.

In an ideal world someone would come into my room every half an hour to make sure I'm still alive.

In an ideal world it would be alright to be alone.

In an ideal world I wouldn't sit inside wishing I was out.

In an ideal world I'd live much closer to my grandchildren.

In an ideal world loneliness wouldn't exist.

In ideal world I'd always feel somebody cared for me.

In an ideal world I wouldn't feel worse in Winter.

In an ideal world I'd never be on my own for very long.

In an ideal world my friends and neighbours would keep an eye on me in case of need.

In an ideal world the word 'loneliness' wouldn't be in the dictionary.

In an ideal world everyone would remain as valuable at the end of their life as they were at the beginning.

In an ideal world I'd feel useful to someone.

In an ideal world I'd feel needed by someone.

In an ideal world...

I suppose... in an ideal world...

**14. Close** (*Loneliness / Depression*) M

My name is Harry. I'm seventy-five years old. And I lost my wife recently. (*Beat*) One year ago actually. She died of cancer. We were close... She was my wife.

Now I live alone. The house is empty. Or that's the way it feels. In many ways it's still full – full of our things, memories. But... it's difficult. I find it difficult... adjusting... being able to get on... being able to say these things.

I feel like crying.

To begin with I just shut the front curtains and didn't answer the door. I wanted to shut out the world. I still do sometimes. I hear a knock at the door and ignore it.

The phone doesn't ring – not like it used to. There were always people calling for Linda. Life felt busier then. Even if it wasn't me who was busy, it was just nice to have stuff going on. Life.

I feel like this a lot actually. I just feel overcome... with sadness. There's no other way to describe it. I don't know where it comes from. I don't even feel it happening sometimes. It just comes... like a fog. I can feel it... a heaviness descending... pulling me into myself. And I don't want to do anything when that happens. I just want to sit here... like this.

(*Pause*)

Time passes. I lose track of how much time sometimes. It's hard. I feel like crying.



**15. Retreating** (*Loneliness*) M (or F)

I spend a lot of time – too much time probably – at home on my own, thinking about the past. It's hard not to. That's where most of my life is. The things I've done, the people I've known. Memories. I think it's important to remember.

But at the same time you can't spend all your time looking back. One has to be positive. You have to reach out, join a club, do things. That's what people do isn't it. They get out and do things.

It's hard though when you know loneliness is always just around the corner. Sometimes it feels as though I'm waiting for it, and when it comes I can feel very depressed. It's like a dark cloak enveloping you. And you get lost in it. In the depths of it. And it can be very hard to come back from that place. No one can help you. Only yourself. And sometimes you don't want to help yourself – sometimes you can't see the point. Then you draw back and get on with things.

I try to keep myself busy. You have to don't you. Otherwise you spend too much time thinking. And that's not good for anyone.

**16. The Radio** *Loneliness* F (orM)

I have a radio clock beside my bed. It's like a friend. I pop it on when I'm feeling lonely. Usually in the middle of the night, but other times too. So if I wake up at one in the morning I switch on the radio. It definitely helps. I don't feel so alone. The talking stations are the best. And you get used to the presenter. You feel like you know the person who's talking – their voice. Sometimes I can guess what they're going to say next, how they're going to respond to a news article or song. It's a comfort. I can see why people write in to radio stations. It's personal, intimate. You feel like you know the person even though you've never met.

**17. On My Own** (*Loneliness*) F (or M)

When I was young I used to go off on my own, on my bike, into the woods, foraging for food. I'd be gone for hours.

I was never one to spend much time with other people. I just liked being on my own... always did.

Then I suddenly realised I had no one to talk to. All that time I'd spent alone and then I just couldn't get it out of my head how... alone I was. You hear about people who die and no one finds them for weeks. And I thought... that could be me. And I couldn't stop thinking about it. But could I do? I don't really have anyone I'd call a friend.

I have a sister, but I've not seen her since mum died. And I think that was for the best. And as far as I know there is no other family, so...

I'm not outgoing. I don't go out. I wouldn't know where to start making friends. Like I say I've been happy on my own. But suddenly I feel differently. I was always so determined to feel like a whole person without anyone else around.

It's less acceptable when you're older to spend time on your own isn't it. There's a stigma. People assume things... that you must be lonely. All that time I've spent without a care for other people and now I'm starting to think differently. But where do you start, where do you make friends. It sounds ridiculous doesn't it at my age, wanting to make friends... but... well... I do. So where do I go? Can anybody tell me?

**18. Always there** (*Loneliness / Isolation*) M (or F)

I have been a Roman Catholic for 61 years and it helps me constantly. I have had terrible things happen in my life but God has got me through. I pray and connect with the Holy Spirit. I find it so amazingly powerful – prayer I mean.

It is easy to forget sometimes that He is always with you... when things are going wrong in particular – but you are loved by God all of the time. You are never really lonely when you have God and you have to try and remember that.

When I was caring for my Mum in her care home, that place became a real community and actually, when she died, I really missed it and the feeling of family there. I became more lonely when I was not involved with her care, but that was also because my husband and I had to move to a new city because of his work and I found it really hard. Now we're older it's different... Being retired and not needing to get up for work... and no-one needing me – my children or elderly parents – it can start to feel... well I can feel a bit sorry for myself sometimes. But if I wake up feeling a bit low I just ask the Holy Spirit to come down on me and you would be amazed at the peace and calm that comes from that prayer time. My faith really helps me. God can pick you up from the depths of loneliness.

And He brings people together of course. We all meet at Church and it is just wonderful knowing that the people there are all searching for a closer relationship with God and knowledge of his teachings. It upsets me when you tell people you're a Christian, and they look at you like you're from outer space! I'm just a normal person who believes in God – what's wrong with that? There's nothing wrong with believing and having faith.

I do think when you are older, you lose a lot – your work, your children, your parents. And your friends – you know they die or move away. And you can be very lonely. So I think when you get older, you have more time to be sad and that is when people tend to go to God. Try Him, I challenge you, you will never look back!

**19. Wonderful Skype** (*Loneliness / Technology*) F (or M)

Skype is a wonderful invention. Have you ever Skyped at all? It's wonderful. You see I was one of those people who said, 'I don't understand computers, I can't get along with them. I don't want to stare at a screen'. But it's not like that really. You feel connected. It really works.

We Skype our daughter in Australia. We've got two daughters – one with us and one living down under and she's got a son. And we see them nearly every day on Skype. I know a lot of older people don't see their grandchildren and their children, and without Skype neither would we. It's a marvellous invention. That, for a person stuck at home, if they've got a computer or even an iPad... it's wonderful technology.

I think anyone who doesn't have a computer but is able to get one, they should. Because there are courses to teach you computing and to get on the internet – Silversurfers – and, if they can get Skype, then you can stay in contact with your family, even though they may be in other countries or miles away. I know a lot of grandparents do that. That can really help a person.

**20. Help** (*Loneliness / Depression*) W (or M)

I know people who've just shut themselves away. More people do that than I think you realise. They just don't go out, don't answer the door. Because once you're in that state it's very hard to get out. It's all very well people saying 'Pull yourself out of it', but if you're right down there, you can't. And some people don't want to be helped. And if somebody doesn't want to be helped, they won't be.

**21. The Dog and the Garden** (*Loneliness*) M (or F)

Sometimes I feel invisible. People seem to just walk past me and not even notice I'm there. I don't know why that is really. It hasn't always been like that. I think, 'I'm still here. I'm still the person I always was'. But then I wonder whether that's true. It's hard to know who you are when there's no one around to talk to.

But there's Max. He's not much of a talker, but he's always there. He's my best friend. My only friend I suppose. I feed him and in return he keeps me company. If only other relationships in life were so simple.

I've got a garden which is nice, and I take good care of that. So whether I'm inside looking out into the garden or actually outside in the garden, Max is there bounding about. Or sitting with his tongue hanging out mainly.

He's a Labrador cross. Not entirely sure what he's crossed with come to think of it. Sue got him from a lady she knew when he was just a puppy. Been with us ever since. I don't know what I do without him now. Hopefully it won't come to that.

I spend a lot of time in the house on my own with Max. It feels like weeks go by sometimes. He's a good dog. Not much of a talker like I say. But he's a good listener.

## References

- Abrams, D., Eilola, T., & Swift, H. (2009). *Attitudes to age in Britain*. Corporate Document Services.
- Age UK (2011). A Snapshot of Ageism in the UK and across Europe.
- Beresford, P. (2002). User involvement in research and evaluation: liberation or regulation?. *Social policy and society*, 1(02), 95-105.
- Beresford, P., & Croft, S. (2012). *User Controlled Research: Scoping Review*.
- Bernard, M., Rickett, M., Amigoni, D., Munro, L., Murray, M., and Rezzano, J., (2014) Ages and Stages : the place of theatre in the lives of older people . *Ageing and Society*, Available on CJO 2014 doi:10.1017/ S0144686X14000038
- Blackstone et al and the Working Committee (SSHWC): A Working Committee of The Interagency Advisory Panel on Research Ethics (PRE) (2008) Research Involving Creative Practices Social Sciences and Humanities Research Ethics Special (unpublished)
- Bolton, M., Bowling, A., Burholt, V., Cattan, M., Cacioppo, J., Holt-lunstad, J., ... Walker, A. (2012). Loneliness--the state we're in: A report of evidence compiled for the Campaign to End Loneliness. Retrieved from [www.ageuk.org.uk/brandpartnerglobal/oxfordshirevpp/ documents/loneliness the state we are in - report 2013.pdf](http://www.ageuk.org.uk/brandpartnerglobal/oxfordshirevpp/documents/loneliness%20the%20state%20we%20are%20in%20-%20report%202013.pdf)
- Bondevik, M., & Skogstad, A. (1998). The oldest old, ADL, social network, and loneliness. *Western Journal of Nursing Research*, 20(3), 325-343
- Bovaird, T., & Loeffler, E. (2007). Assessing the quality of local governance: a case study of public services. *Public Money and Management*, 27(4), 293-300.
- Bowers, H., Lockwood, S., Eley, A., Catley, A., Runnicles, D., Mordey, M., Barker, S., Thomas, N., Jones, C. and Dalziel, S. (2013) Widening choices for older people with high support needs. Joseph Rowntree Foundation
- Boyden, J., & Ennew, J. (1997). *Children in focus: a manual for participatory research with children*. Rädda Barnen.
- Burholt, V., Nash, P., Naylor, D., & Windle, G. (2010). Training older volunteers in gerontological research in the united kingdom: Moving towards an andragogical and emancipatory agenda. *Educational Gerontology*, 36(9), 753-780.
- Cacioppo, J. T., & Hawkley, L. C. (2009). Perceived social isolation and cognition. *Trends in cognitive sciences*, 13(10), 447-454.
- Cacioppo, J. T., Cacioppo, S., Cole, S. W., Capitanio, J. P., Goossens, L., & Boomsma, D. I. (2015). Loneliness Across Phylogeny and a Call for Comparative Studies and Animal Models. *Perspectives on Psychological Science*, 10(2), 202–212. <http://doi.org/10.1177/1745691614564876>



Cacioppo, J. T., Hawkley, L. C., & Thisted, R. A. (2010). Perceived social isolation makes me sad: 5-year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago Health, Aging, and Social Relations Study. *Psychology and aging, 25*(2), 453. Cacioppo, Capitanio, & Cacioppo, 2014),

Cacioppo, J. T., Hawkley, L. C., Crawford, L. E., Ernst, J. M., Burleson, M. H., Kowalewski, R. B., ... & Berntson, G. G. (2002). Loneliness and health: Potential mechanisms. *Psychosomatic Medicine, 64*(3), 407-417.

Cacioppo, J. T., Hughes, M. E., Waite, L. J., Hawkley, L. C., & Thisted, R. A. (2006). Loneliness as a specific risk factor for depressive symptoms: cross-sectional and longitudinal analyses. *Psychology and aging, 21*(1), 140.

Cacioppo, S., Grippo, A. J., London, S., Goossens, L., & Cacioppo, J. T. (2015). Loneliness: Clinical Import and Interventions. *Perspectives on Psychological Science, 10*(2), 238–249. <http://doi.org/10.1177/1745691615570616>

Cattan, M., & White, M. (1998). Developing evidence-based health promotion for older people: a systematic review and survey of health promotion interventions targeting social isolation and loneliness among older people. *Internet Journal of Health Promotion, 13*, 1-9.

Cattan, M., White, M., Bond, J., & Learmouth, A. (2005). Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions. *Ageing and Society, 25*(1), 41–67. <http://doi.org/10.1017/S0144686X04002594>

Clark, A. (2009). Ageism and Age Discrimination in Social Care in the United Kingdom: A Review from the Literature. *London: Centre for Policy on Ageing*.

Cohen G (2009) New theories and research findings on the positive influence of music and art on health with ageing, *Arts & Health, 1:1*, 48-62, DOI: 10.1080/17533010802528033

Collins, A. B., & Wrigley, J. (n.d.). CAN A NEIGHBOURHOOD APPROACH TO LONELINESS CONTRIBUTE TO PEOPLE ' S WELL- BEING ?, (July 2014).

Cooper, L., & Thomas, H., (2002), 'Growing old gracefully: social dance in the third age', *Ageing & Society, 22*(6), pp.689-708

Coyle, C. E., & Dugan, E. (2012). Social isolation, loneliness and health among older adults. *Journal of aging and health, 24*(8), 1346-1363.

Cutler, D., (2009) *Ageing Artfully: Older People and Professional Participatory Arts in the UK*, The Baring Foundation

De Jong-Gierveld, J., & Kamphuls, F. (1985). The development of a Rasch-type loneliness scale. *Applied psychological measurement, 9*(3), 289-299.

Denzin, Norman K. (2003) *Performance Ethnography: Critical Pedagogy and the Politics of Culture*. Thousand Oaks, CA: Sage.

- Dickens, A. P., Richards, S. H., Greaves, C. J., & Campbell, J. L. (2011). Interventions targeting social isolation in older people: a systematic review. *BMC Public Health, 11*(1), 647. <http://doi.org/10.1186/1471-2458-11-647>
- Dugan, E., & Kivett, V. R. (1994). The importance of emotional and social isolation to loneliness among very old rural adults. *The Gerontologist, 34*(3), 340-346.
- Durose, C., Beebeejaun, Y., Rees, J., Richardson, J., & Richardson, L. (2012). Towards Co-Production in Research with Communities, 1–15.
- Dykstra, P. A., Van Tilburg, T. G., & de Jong Gierveld, J. (2005). Changes in older adult loneliness results from a seven-year longitudinal study. *Research on aging, 27*(6), 725-747.
- Eakin, J. M., & Endicott, M. (2006). Knowledge Translation through Research-Based Theatre. *Healthcare Policy, 2*(2), 54–59.
- Findlay, R. a. (2003). Interventions to reduce social isolation amongst older people: where is the evidence? *Ageing and Society, 23*(5), 647–658. <http://doi.org/10.1017/S0144686X03001296>
- Finley, S. (2005). Arts-based inquiry: Performing revolutionary pedagogy. *The Sage handbook of qualitative research, 3*, 681-694.
- Goll. (2014). A qualitative study of barriers to social participation among lonely older adults : the influence of social fears and identity Johanna C Goll D . Clin . Psy . Thesis ( Volume 1 ) University College London UCL Doctorate in Clinical Psychology Thesis declar, 1(Volume 1).
- Goossens, L., Verhagen, M., van Roekel, E., Cacioppo, J. T., Cacioppo, S., & Boomsma, D. I. (2015). The genetics of loneliness: The quest for underlying mechanisms and developmental processes. *Perspectives on Psychological Science, 10*, 213–226.
- Griffin, J. (2010). *The lonely society?* Mental Health Foundation.
- Gutman, C., Hantman, S., Ben-Oz, M., Criden, W., Anghel, R., & Ramon, S. (2014). Involving Older Adults as Co-researchers in Social Work Education. *Educational Gerontology, 40*(3), 186-197.
- Hawkley, L. C., Hughes, M. E., Waite, L. J., Masi, C. M., Thisted, R. A., & Cacioppo, J. T. (2008). From social structural factors to perceptions of relationship quality and loneliness: the Chicago health, aging, and social relations study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 63*(6), S375-S384.
- Holt-Lunstad, J., Smith, T. B., Baker, M., Harris, T., & Stephenson, D. (2015). Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review. *Perspectives on Psychological Science, 10*(2), 227–237. <http://doi.org/10.1177/1745691614568352>
- Hughes, M. E., Waite, L. J., Hawkley, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys results from two population-based studies. *Research on aging, 26*(6), 655-672.

Joping, K., (2015) Promising Approaches to reducing Isolation and Loneliness in Later Life, Age UK & Campaign to End Loneliness

Kirby, P. (1999) Involving Young Researchers: How to enable young people to design and conduct research, York: JRF / Youth Work Press.

Klee, D., Mordey, M., Phuar, S., Russell, C., Klee, D., Mordey, M., ... Russell, C. (2014). Asset based community development – enriching the lives of older citizens. <http://doi.org/10.1108/WWOP-06-2014-0017>

Kneale, D. (2012). Is social exclusion still important for older people?. *The International Longevity Centre–UK Report*.

Knowles, M. (1996). Adult learning. . *The ASTD Training and Development Handbook*.

Knowles, M. S. (1986). *Using learning contracts: Practical approaches to individualizing and structuring learning*. Jossey-Bass.

Lauder, W., Mummery, K., Jones, M., & Caperchione, C. (2006). A comparison of health behaviours in lonely and non-lonely populations. *Psychology, Health & Medicine*, 11(2), 233-245.

Leamy, M., & Clough, R. (2006). How older people became researchers. York: Joseph Rowntree Foundation. Available online at [www.jrf.org.uk/bookshop](http://www.jrf.org.uk/bookshop).

Martin, S. (2010). Co-production of social research: strategies for engaged scholarship. *Public Money & Management*, 30(4), 211-218.

Masi, C. M., Chen, H.-Y., Hawkey, L. C., & Cacioppo, J. T. (2011). A meta-analysis of interventions to reduce loneliness. *Personality and Social Psychology Review: An Official Journal of the Society for Personality and Social Psychology, Inc*, 15(3), 219–266. <http://doi.org/10.1177/1088868310377394>

Michalak, E. E., Livingston, J. D., Maxwell, V., Hole, R., Hawke, L. D., & Parikh, S. V. (2014). Using theatre to address mental illness stigma: a knowledge translation study in bipolar disorder. *International Journal of Bipolar Disorders*, 2, 1. <http://doi.org/10.1186/2194-7511-2-1>

Middling, S., Bailey, J., Maslin-Prothero, S., & Scharf, T. (2011). Gardening and the social engagement of older people. *Working with Older People*, 15(3), 112-122.

Minkler, M., Vasquez, V. B., & Shepard, P. (2006). Promoting environmental health policy through community based participatory research: a case study from Harlem, New York. *Journal of Urban Health*, 83(1), 101-110.

Nash, P., (2014) <https://ageingissues.wordpress.com/2014/07/18/the-last-accepted-ism/online> blog accessed September 2015

[newdynamics.group.shef.ac.uk](http://newdynamics.group.shef.ac.uk),

Ni Leime, A., O’Shea, E. (2009) An Evaluation of the Bealtaine Festival, Age and Opportunity, Dublin.

Office for National Statistics, (2013) Age structure of the UK; Statistical Bulletin [http://www.ons.gov.uk/ons/dcp171778\\_334975.pdf](http://www.ons.gov.uk/ons/dcp171778_334975.pdf)

Ogilvie, A. (2014) <http://www.themj.co.uk/Let-neighbourhood-networks-take-the-strain/196897>  
Accessed September 2015

Ottman, R., Lipton, R. B., Ettinger, A. B., Cramer, J. A., Reed, M. L., Morrison, A., & Wan, G. J. (2011). Comorbidities of epilepsy: results from the Epilepsy Comorbidities and Health (EPIC) survey. *Epilepsia*, 52(2), 308-315.

Pässilä, A. H., Oikarinen, T., & Harmaakorpi, V. (2015). Collective voicing as a reflexive practice. *Management Learning*, 46(1), 67-86.

Perissinotto, C. M., & Covinsky, K. E. (2014). Living alone, socially isolated or lonely—What are we measuring?. *Journal of general internal medicine*, 29(11), 1429-1431.

Pink, S. (2001). Doing ethnography: Images, media and representation in research. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 3 (1).

Pressman, S. D., Cohen, S., Miller, G. E., Barkin, A., Rabin, B. S., & Treanor, J. J. (2005). Loneliness, social network size, and immune response to influenza vaccination in college freshmen. *Health Psychology*, 24(3), 297.

Pressman, S. D., Cohen, S., Miller, G. E., Barkin, A., Rabin, B. S., & Treanor, J. J. (2005). Loneliness, social network size, and immune response to influenza vaccination in college freshmen. *Health Psychology*, 24(3), 297.

Prosser, J. (1998). *Image-based research: A sourcebook for qualitative researchers*. Psychology Press.

Qualter, P., Vanhalst, J., Harris, R., Van Roekel, E., Lodder, G., Bangee, M., ... Verhagen, M. (2015). Loneliness Across the Life Span. *Perspectives on Psychological Science*, 10(2), 250–264. <http://doi.org/10.1177/1745691615568999>

Rossiter, K., Kontos, P., Colantonio, A., Gilbert, J., Gray, J., & Keightley, M. (2008). Staging data: Theatre as a tool for analysis and knowledge transfer in health research. *Social science & medicine*, 66(1), 130-146.

Routasalo, P. E., Savikko, N., Tilvis, R. S., Strandberg, T. E., & Pitkälä, K. H. (2006). Social contacts and their relationship to loneliness among aged people—a population-based study. *Gerontology*, 52(3), 181-187.

Rudatsikira, E., Muula, A. S., Siziya, S., & Twa-Twa, J. (2007). Suicidal ideation and associated factors among school-going adolescents in rural Uganda. *BMC psychiatry*, 7(1), 67.

Russell, D., Peplau, L. A., & Ferguson, M. L. (1978). Developing a measure of loneliness. *Journal of personality assessment*, 42(3), 290-294.

Samuelsson, G., Andersson, L., & Hagberg, B. (1998). Loneliness in relation to social, psychological and medical variables over a 13-year period: A study of the elderly in a Swedish rural district. *Journal of Mental Health and Aging*, 4(3), 361-378.

Schirmer, W., & Michailakis, D. (2015). The Luhmannian approach to exclusion/inclusion and its relevance to Social Work. *Journal of Social Work*, 15(1), 45-64.

Sheiham, A. (2005). Oral health, general health and quality of life. *Bulletin of the World Health Organization*, 83(9), 644-644.

Stonewall (2011) Lesbian gay and bisexual people in later life ([https://www.stonewall.org.uk/sites/default/files/LGB\\_people\\_in\\_Later\\_Life\\_\\_2011\\_.pdf](https://www.stonewall.org.uk/sites/default/files/LGB_people_in_Later_Life__2011_.pdf))

Sweiry, D., & Willitts, M. (2012). Attitudes to age in Britain.

United Nations, (2007) World Population Ageing, <http://www.un.org/esa/population/publications/WPA2007/WORLD%20POPULATION%20AGEING%202007.pdf>

VanderWeele, T. J. (2011). Sensitivity analysis for contagion effects in social networks. *Sociological Methods & Research*, 40(2), 240-255.

Victor, C. (2011). Loneliness in old age: the UK perspective. *Age UK Oxfordshire (2011) Safeguarding the Convoy: a call to action from the Campaign to End Loneliness*.

Victor, C. R., & Yang, K. (2012). The prevalence of loneliness among adults: a case study of the United Kingdom. *The Journal of psychology*, 146(1-2), 85-104.

Victor, C. R., Scambler, S. J., Bowling, A. N. N., & Bond, J. (2005). The prevalence of, and risk factors for, loneliness in later life: a survey of older people in Great Britain. *Ageing and Society*, 25(06), 357-375.

Walker, A. (2007). Why involve older people in research?. *Age and Ageing*, 36(5), 481-483.

Wenger, G. C., Davies, R., Shahtahmasebi, S., & Scott, A. (1996). Social isolation and loneliness in old age: Review and model refinement. *Ageing and Society*, 16(03), 333-358.

Wilkins J 2007/2008 reports accessed via <https://www.dorsetforyou.com/article/376802/Evaluation-of-Dorset-POPP>

Wilson, R. S., Scherr, P. A., Schneider, J. A., Tang, Y., & Bennett, D. A. (2007). Relation of cognitive activity to risk of developing Alzheimer disease. *Neurology*, 69(20), 1911-1920.

WRVS (2011) Gold Age Pensioners: Valuing the Socio-Economic Contribution of Older People in the UK March 201