



## TESA DRI

Technology enriched supported accommodation  
for people living with dementia, and their  
caregivers

Final report of work funded through the 2014 Commissioned  
Research Call – Dementia Care – 2<sup>nd</sup> Stage.

[Full Report](#)  
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## Executive Summary

The present study adopted a qualitative approach to gather a rich, in-depth understanding of the experiences of people living with dementia, their family caregiver and staff caregivers in technology enriched supported accommodation (TESA). A total of 243 tenants were living in nine TESA schemes at the time of data collection, which mapped to 91% of occupancy capacity. A total of 72% of the tenants were female with an age range between 51-97 years (mean 79). Fifty five point two percent (55.2%) of tenants were living on their own prior to moving into TESA. The tenants next of kin was generally an adult son or daughter for 65% of the sample, with siblings, spouse and other relatives/close friends making up the other descriptors of next of kin. Two percent (2%) of tenants did not have a next of kin. Only 2.5% of the sample had no other co-morbidities. Co-morbidities such as mental health, diabetes, heart/cardiovascular disease, diseases of the circulatory, respiratory and nervous system were identified within the sample. Interestingly 70% of tenants had not been hospitalised in the last twelve months, suggesting that a generally good health profile of each tenant was being maintained.

The environmental audit tool (EAT) is an assessment tool used to identify the quality of the environment for people living with dementia. The highest scoring item was 'be domestic' at an average of 90.34%, ranging from 62.5% -100% which indicated that the TESA schemes were as homelike as possible and had the ability to support the tenants to maintain their independence, aligned to the ethos of person-centred care. The data suggests that tenants had good opportunity for social interaction within the Scheme and local community. On

average the TESA facilities were designed to support wandering but not to encourage it. The Schemes highlighted the importance of stimuli to support independent navigation of the home space for example to get to bathroom. In some Schemes stimulation in the environment and safety were amongst lower scoring items. It is probable that schemes that foster independence, autonomy and control are associated with lower scores on safety items.

The technology audit demonstrated a wide range of technologies and devices operational within TESA. It could be suggested that the characteristics of person centred care were evident as primarily the provision of technologies was based on the individual tenants needs. It was evident that schemes operated different policies around the free movement of tenants, as some environments were locked while in others, tenants held the key to the front door. In all but one site, tenants received an immediate response from staff when they requested help from staff through an intercom. Routine and emergency methods of contacting staff were the same. Mobile phones were commonly used by tenants to keep in touch with their family. Data from the technology was not widely used within the schemes as only two facilities reported using this information for individual care planning.

Inclusive methods were adopted within the project to include tenants into the data collection phase of the project. Peer researchers, who were older people with an interest in working for a dementia related research project, were recruited trained and conducted research interviews with the tenants living in TESA, in collaboration with the project

research team. The peer researchers also supported the analysis of the data from the interviews. Collaborative relations between both informal and formal caregivers in conjunction with the tenants were viewed as key contributors for a good quality of life. The findings indicated that person-centred practice was at the core of care provision whereby tenants could thrive and flourish and maintain meaningful relationships with people and places. Not all tenants were aware of the technology provision within the housing schemes. However, those individuals who were aware of it, felt it gave them reassurance and feelings of security. Mobile phones emerged as a popular device to enable tenants to keep in touch with their families.

Art based focus groups were conducted in eight TESA facilities using materials like felt, clay and paint to create collage and other outputs that explored the lived experiences of tenants. Sixty-four participants at various stages of their dementia journey took part in the forty-eight art-based focus groups. The art could be considered an expression of their experiences without the need to formulate it into words. The findings supported the outcome of the one to one interviews. Autonomy, choice, independence, a sense of belonging, privacy, relationships and being content were strong features of this work

A total of twenty-five semi-structured interviews were conducted with informal caregivers (IC). The findings indicated that the transition into TESA had a positive outcome for both the formal and informal caregiver, and the tenant. A major theme was the shift of IC from a care provider modality to a care manager, one which appeared to be influenced by issues of burden and the perception of an inability to keep the person living with dementia (PLWD) safe. Assistive technologies in the facilities did not appear to impact on the decision-

making during transition however, they were valued once the PLWD resided in the TESA facilities. The findings provide an understanding of the caregiving responsibilities and how the transition alleviated the pressure of caregiving.

Twenty one semi structured interviews were conducted with formal caregivers of TESA. Four main themes were identified that were associated with some of the attributes of the Person-centred Practice Framework: promoting choice and autonomy, staffing model, using assistive technology and feeling that 'you're doing a good job'. The findings indicated that person centred practice was embodied in the ethos of the TESA facilities. Tenants' choice, autonomy and independence were central to the care provided by formal caregivers. Job satisfaction was high amongst the participants, and it was evident this increased when the facility was smaller in size. The technical provision in TESA was described as essential to the caregiving role. Additionally, the survey data exploring the attitudes of both formal and informal caregivers confirmed that technology was viewed as a way of increased quality of care, enhanced security and enabled independence. Both types of caregivers held relatively similar views around the benefits of technology, however their views on issues such as privacy and consent varied. Safety was considered more important than right to privacy by family caregivers. It would be interesting to explore if this is because of the training formal caregivers received around person-centred practice within the housing schemes.

This aims of TESA is to provide less physically intrusive support by care staff, whilst enabling risk management governance and promoting the concept of people retaining a sense of their own home. The findings suggest that TESA do in fact promote independence, dignity and support through person centred care delivery. The environment was found to be

supportive of the person-centred care model as 'be domestic' was the highest scoring item. Technology supported the formal caregiver to provide high quality, person centred care. Although technology was not a core feature for the tenants or informal caregivers, it was reported to provide reassurance and feelings of safety for both populations. In line with previous research, the technologies used within the schemes varied greatly across the nine facilities. These findings are relevant to policy makers, commissioners and providers of services to highlight the engagement of all stakeholders in the provision of care for PLWD and their families early from diagnosis in order to facilitate person-centred care (PCC) practices in community settings. A range of recommendations in terms of practice, policy and research are presented as a result of these findings.

## Chapter 1 Introduction

### Background

When living at home is no longer a viable option then alternatives should be available. Supported Housing is one such alternative, bringing together the best design of housing and care, offering a real home living scenario rather than residential or hospital care. With the global increase in the number of older people in society, there is a need for appropriate accommodation enabling people to grow older with support and dignity and not always in traditional institutional style care facilities. This is particularly true for people living with dementia (PLWD) as the progression of the disease erodes cognitive capacity and function. The increase in the number of people living with a diagnosis of dementia suggests that a significant need for alternative accommodation to home will emerge. Supported housing offers accommodation to help people live as independently as possible with additional physical support where necessary. Some supported housing schemes integrate technology such as digital alarms, sensors in the flats, sometimes with associated remote monitoring capability. This aims to provide less physically intrusive support by care staff, whilst enabling risk management governance and promoting the concept of people retaining a sense of their own home. Supported housing for PLWD is generally built with due regard to dementia specific environmental design principles (Pierce, Cahill, Grey, & Dyer, 2015).

In the context of Northern Ireland, the Regional Strategy 'Improving Dementia Services in Northern Ireland' (Department of Health Social Services and Public Safety, 2011) and

'Systems, Not structures-Changing Health and Social Care (Bengoa, Stout, Scott, McAlinden, & Taylor, 2016) are significant drivers in the planning of dementia services and developing care pathways. They place emphasis on the need to support people with dementia to live with dignity and independence. With over 850,000 people in the United Kingdom living with dementia adequate service provision is vitally important (Alzheimer's Society, 2014). Supported housing care models that provide technology as a core feature of the facility bring an added dimension to the care provision with the assumption that this may meaningfully enhance the quality of care. However, there is very little research evidence to demonstrate the impact technology can have in this setting.

### [Context of the study](#)

In Northern Ireland, technology enriched supported housing schemes for PLWD have been available for more than fifteen years. The care model within the housing schemes seeks to promote independence, dignity and support. The model is often a collaborative care initiative, made up of different partnerships, often between the healthcare trust, housing associations and housing executive. However, little is known about these models of care to inform practice and enhance future development. Often there is heterogeneity in design, technical specifications and environmental features. This interwoven ecosystem has at its core the need to deliver person-centred supported housing that will sustain those ageing with dementia and engage informal carers. This study presents an overview of nine technology enriched supported housing schemes in Northern Ireland for PLWD. As part of this each scheme, its environmental design and technology integrated into the facility was explored. The many stakeholders of each scheme were consulted, including the tenants, the family caregivers and the staff. Additionally, this work sought to understand how

people transition into and live in a technology enriched supported housing model. The acronym TESA-DRI was developed for every day communication about the project, standing for: *Technology Enriched Supported Accommodation - Dementia Research Initiative*. TESA (short working title) was approved for funding by the HSC R&D Office on behalf of Atlantic Philanthropies on 31st July 2014, with grant of £385,490.00 awarded. Start date: 13<sup>th</sup> January 2015 and end date 12<sup>th</sup> January 2018.

## Aim and Objectives

**Aim:** To explore the perspectives of PLWD who live in person-centred supported, technology enriched housing schemes, their family and paid employees at the facilities.

### Objectives:

- To describe the lived experience and perspectives of tenants
- To explore the use of creative methods as an inclusive approach of engaging PLWD in the research
- To understand family and informal carer views on transitioning to and living within the supported housing scheme
- To explore and understand the paid employee's knowledge, skill, and understanding towards working in a technology enriched supported housing model
- To capture the attitudes of informal and formal caregivers towards technology
- To create a picture of technology enriched supported housing schemes in terms of the tenant profile, lived environment and technology provision

- To evaluate the impact of technology on clinical decision making and care pathways of tenants
- To evaluate the experiences of older people as peer researchers in the TESA project
- To deliver best practice learning on findings from research in useful clinical format to transfer knowledge quickly into services for PLWD

## Research Design

Technology enriched supported housing is considered a complex ecosystem of housing, where technology and care are core to the nature of the provision. The study adopts a qualitative approach to get an in-depth understanding of all the stakeholders engaged in each scheme. A range of methods were incorporated into this study to gather rich information from tenants, their family and staff caregivers about their experiences and perspectives of technology enriched supported housing. Descriptive demographic information was obtained from each of the nine participating housing schemes, along with an environmental and technology audit. Table one sets out the participant inclusion criteria. One-to-one interviews were undertaken with all stakeholders (informal and formal). Included tenants were invited to participate in art-based focus groups to provide an inclusive medium to elicit and share experiences and perspectives. Finally, all caregivers were invited to complete a survey to gather attitudes towards technology. The data collection timeline is set out in Appendix 1. The triangulation of evidence across methods and researchers enhanced the reliability and validity of the data. The research was underpinned by the Person-centred Practice Framework (McCormack & McCance, 2017a). This framework has been adopted in this study to enable the analysis of a range of factors

that might support person-centredness such as values of respect, self-determination, autonomy, understanding and empowerment. The framework provides a lens through which to view the data as it is systematically analysed through thematic analysis.

*Table 1. The Inclusion criteria for participation in TESA-DRI*

<b>Tenants at each facility</b>	<b>Informal Carers</b>	<b>Formal Carers</b>
Must be permanently living in scheme	Over age 18	Over 18 years
Living and settled in the facility. Staff will guide on this.	Nominated by the tenant and/or staff at the facility	Working at the facility (permanent & contract staff will be included)
Consent obtained according to project protocol	Willing to give consent	Willing to give consent

### [The Project Consortium](#)

The project consortium brought together academia Ulster University (Ulster) and Queen Margaret University Edinburgh (QMU) and the non-government agency Engage with Age (EWA), who provide services to advocate for older people in the community. The research team consisted of a chief investigator (Professor Suzanne Martin; Ulster), three co-investigators (Professor Assumpta Ryan; Ulster, Professor Brendan McCormack; QMU and Mr Eamon Quinn; EWA), a full-time researcher based at Ulster (Ms Janeet Rondon-Sulbarhan and a part time researcher based in EWA (Mrs Jean Daly-Lynn). A steering group was set up and consulted with on three different occasions throughout the project as well as ad hoc contact by phone and email. The group included two individuals living with dementia, a family caregiver, individuals working in the voluntary sector providing support for PLWD, a director of a technology company, as well as representatives from the Northern

Ireland Housing Executive, Supporting People, Housing Associations and the Trust. An overview of the steering committee meetings are set out in Appendix 2. Additionally, there was an international team of three academics who were consulted during the project.

## [The Report](#)

To support the reader of this report we have set out the description of the following acronyms.

IC= informal caregiver, any informal caregiver such as family and friend

FC= formal caregiver, paid, formal or employed staff caregiver

TESA= technology enriched supported accommodation

The caregivers= both family and staff caregivers

PCC- person-centred care

PLWD= person living with dementia. While the use of abbreviations to describe individuals living with dementia runs contrary to the person-centred approach that underpinned this study, for pragmatic reasons and purely for the purpose of this report, the abbreviation PLWD will be used to refer to person(s) living with dementia.

An outline of each chapter is as follows:

**Chapter 1:** Background and context for the present study

**Chapter 2:** An overview of the literature and a systematic review of technology within supported living and residential settings

**Chapter 3:** Ethical issues

**Chapter 4:** Technology enriched supported housing in Northern Ireland

**Chapter 5:** Interviews with tenants

**Chapter 6:** Creatively engaging with tenants

**Chapter 7:** Family caregiving

**Chapter 8:** Formal caregiving

**Chapter 9:** Quantitative study on the attitudes of formal and informal caregivers towards technology

**Chapter 10:** Patient and public involvement

**Chapter 11:** Discussion and conclusion

**Chapter 12:** Dissemination summary

## Chapter 2 Overview of the literature and a systematic review of technology within supported living and residential settings.

### Introduction

To explore the perspectives of PLWD who live in technology enriched supported living environments and their caregivers, it is important to identify and review the relevant literature. The multi-layered approach in this study necessary to explore these complex living environments requires understanding of many different topics such as living with dementia, caregiving, person-centred practice, housing, supported living and technology. This chapter seeks to set out the current research in these domains and investigate its relevance to this study.

### Living with dementia

Dementia is an umbrella term for a cluster of symptoms that damage and destroy brain cells having a profound effect on a person's cognitive ability. This degenerative condition greatly exacerbates the normal aging process and can significantly impact on independence and quality of life. Each presentation of dementia is unique depending on the severity, progress of condition, type of dementia, and the subjective experience of the symptomology. Currently there is no cure for this chronic condition so long-term dependence on care provision is often inevitable. Cognitive impairment is the most common feature of these diseases affecting communication, language, understanding, mood, and impacting on everyday tasks. Neuropsychiatric symptoms such as depression, stress, irritability, agitation, anxiety and disinhibition can also manifest in a number of ways (Lyketsos et al, 2012).

As the demographic is changing and older people are living longer, the prevalence of dementia is increasing. Over 50 million people worldwide are reported to be living with dementia, and estimates predict that this figure could be at 150 million by 2050 (World Health Organization, 2018). Currently, in the United Kingdom (UK) there are 850,000 PLWD (Alzheimer's Society, 2014) with an estimated cost to the economy of £26 billion a year, a figure that is predicted to double in the next 30 years (Department of Health, 2015). Research in developed countries has indicated that dementia is associated with huge economic implications and this is expected to continue to rise (Wimo, Jönsson, Bond, Prince, & Winblad, 2013). Thus, within high-income countries dementia care has become a governmental priority (Prince et al., 2013).

Recent surveys have shown that 85% of people diagnosed with dementia would prefer to stay at home for as long as possible rather than go into a care facility (Department of Health, 2015). Two thirds of PLWD in the UK live in the community and most care is provided by approximately 670,000 family and friends, saving the state over £11 billion per year (Alzheimer's Society., 2015). The current challenge for governments is to develop health and social care services to cope with this growing need and in doing so support the quality of care for PLWD, their caregivers and their families. There have been policy initiatives promoting optimal care for this population, expanding to all care settings, whether home, hospital or care home (Department of Health, 2015). Many PLWD move into a type of care homes when it is no longer possible for them to live at home and often when informal caregivers are unable to manage their growing care needs (Livingston et al., 2017). However, research has shown that PLWD who live in care homes experience lower quality of life than those living at home (Hoe, Katona, Orrell, & Livingston, 2007).

## Caring for a person living with dementia

Informal or family caregivers (IC) are usually a family member, often a spouse or friend, generally female, who assume the overall caring responsibility for a person experiencing daily difficulties due to a debilitating condition, physical, cognitive or emotional, including dementia (Alzheimer's Society., 2015; Bertogg & Strauss, 2018; Brodaty & Donkin, 2009; Carers Trust Action Help Advice, 2015). Informal caregiving will generally have a relational dimension, and whilst often the elder spouse is the designated main carer, other family members often provide significant contributions. There are many stages to caring and indeed the nature and type of care varies depending on the needs of the person in need of care (São José, 2018). Many studies have reported the negative impact of caregiving, particularly on those who care for PLWD who may experience clinical depression or anxiety or other less severe psychological impacts (Cross, Garip, & Sheffield, 2018; Wang, Liu, Robinson, Shawler, & Zhou, 2019; Watson, Tatangelo, & McCabe, 2018).

Mainly, the caregiving model has been explained using the framework of stress-coping models whereby 'the onset and progression of chronic illness and physical disability are stressful for both the patient and the caregiver' (Schulz & Sherwood, 2008: 105). Other factors affecting caregivers are associated with the type of care provided. Archbold (1983) initially conceptualised caregiving into two types: care providers and care managers however this falls short of capturing the complexity of informal care/caring as described by São Jose (2018), who attempts to critique the empirical literature on this topic specifically for the fourth age (later life with care, associated with loss of agency and decay) highlighting the inherent complexity of caring.

Care providers identify the services the individual needs and put measures in place to meet these needs, while care managers identify the services and buy them. Care providers are proactive while care managers arrange for others to provide care (Brodaty & Donkin, 2009), therefore care providers tend to be an at-risk population (Archbold, 1983). When a loved one moves into a supported living environment the role of the informal caregiver can change to that of a care manager, while paid staff become the provider of the daily care required. The way in which a caregiver supports and cares for an individual living with dementia significantly impacts their quality of life. The negative impact of caregiving on the informal caregiver has been outlined, and this might also be an issue for paid caregivers. It is reported that paid staff can have low job satisfaction, staff burnout, high staff turnover, difficulty recruiting, low pay and inadequate training (Bird, Anderson, Macpherson, & Blair, 2016). However, person-centred care approaches are reported to reduce the negative impact of caregiving for paid staff (Barbosa, Sousa, Nolan, & Figueiredo, 2015). Within any care setting it is essential to recognize and meet the needs of all the stakeholders, particularly the staff, the tenants and families. The challenge in meeting these needs is that each stakeholder group is diverse and different.

## [Supported living Environments](#)

When aging in place is no longer possible, alternative housing solutions are required. Housing for older people has evolved over the years, in turn creating a range of care models and terminology within this field. Specialist housing comes in several forms from sheltered accommodation, to supported housing to residential care. The support provided to tenants or residents within the different housing setting varies greatly, from support available if

necessary to 24-hour care. The decision around the most appropriate housing for an older PLWD depends on their needs, particularly if it is health or social care needs. Individuals with greater healthcare needs might be more suitable for nursing care within a nursing home, while supported environments are more focused on maintaining independence as well as personal and social care needs. Identifying suitable housing is essential as it impacts physical, mental and emotional health (Rijnaard et al., 2016). The care home sector has a range of challenges on the horizon such as providing 'homes for life', reducing hospital admissions and being cost effective.

Policy guidance and indeed societal preference promotes home based care for PLWD (Department of Health, 2015). However, as dementia advances it may be necessary to move into accommodation with additional support (Garvelink et al., 2018; Livingston et al., 2017). In recent years, different models of long-term support have been introduced (Livingston et al., 2017), and with that emerged a range of different terms (Howe et al. 2013).

In the UK, the recognition of the link between housing and health has gained traction (Wild, Clelland, Whitelaw, Fraser, & Clark, 2018) and extra care housing has emerged as an alternative to sheltered housing or very sheltered housing, currently, referred to as housing with care; a model known in the United States (USA) as assisted living (Brooker et al., 2011). Similarly, there has been a growing interest in the development of small-scale, homelike residential care models with facilities specifically designed for PLWD such as the Eden Alternative (Livingston et al., 2017). These models of care provision aspire to preserve the rights of the tenants giving choice and control over their housing options with a greater focus on independent living (Department of Health, 2015).

Supported housing is defined as 'any housing scheme where housing is provided alongside care, support or supervision to help people live as independently as possible in the community' (DCLG and DWP, 2016: 9-10). Essentially, housing and care services are separate entities. Care services are provided by staff over a 24-hour period, but nursing services are not available. Housing is rented from a housing association and each tenant must sign a tenancy agreement upon moving into the housing scheme. Typically, tenants rent a self-contained apartment or flat and a care plan is developed with the support team after an individual needs assessment. Household tasks can be completed by the tenant independently or with support from a family caregiver, staff caregiver, or paid for from an alternative source. A range of social activities are available and are often integrated into the wider community. This model can be tailored according to specific need and by this very nature, the model is considered a person-centred approach. It enables tenants to maintain life skills, independence and have support where necessary.

Supported living strives to become an alternative to a person's own home when it is no longer possible for the individual to live on their own. Transitioning into a care environment is a significant life event (Gillsjö, Schwartz-Barcott, & von Post, 2011). Fostering a sense of home, place and belonging within any care environments is very important (van Hoof et al., 2016). Research indicates that multiple factors impact on the sense of home such as feeling secure, maintaining identity, independence, choice and nurturing memories (Rijnaard et al., 2016). Additionally, comfort, a sense of ease, as well as the ability to be one's self and establish relationships is important. Interrelating factors such as the social, environmental and psychological context have also been identified but further research is needed to

identify how they could enhance individuals' sense of home (Rijnaard et al., 2016). O'Malley and Croucher (2005) report that independence, privacy and security are essential features of extra care housing.

### Person-centred Practice

The model of care focuses on the way care is delivered to meet the demands of all the stakeholders (Patricia, Rn, & Med, 2006). Person-centred care (PCC) approaches have been recognised and accepted as the best way to provide quality care. In the UK, this approach has become an integral part of health, and health and social care policy and strategies (Department of Health, 2009, 2015, DHSSPSNI, 2011a, 2011b; Scottish Government, 2010; Welsh Government, 2017). PCC has permeated the long-term care (LTC) sector and has become the central tenet of 'culture change' targeted at the improvement of outcomes and the transformation of the facilities from medically driven institutions to individualised settings where care is provided according to the person's unique needs, choices, abilities and life history (Koren, 2010; McCormack & McCance, 2017a).

The theory of PCC in dementia first described by Kitwood (1997), postulates that the person is at the centre of their own care and the concept of personhood is central to PCC (Kitwood, 1997; Rogers, 2011; Sabat & Harré, 1992). While this term has become familiar in the field of dementia care, it has been challenging to agree on its components and meanings. For example, Brooker, (2004) used the VIPS framework to describe PCC as a concept comprising four elements: V – valuing all people regardless of age and cognitive ability; I – recognising people as individuals; P – understanding the world from the perspective of PLWD and their carers; and S – a positive social environment conducive to acceptable wellbeing.

Additionally, McCormack and McCance (McCormack et al., 2010; McCormack & McCance, 2017; McCormack & McCance, 2006) developed the person-centred practice framework (PCPF) as a holistic structure that focuses on the characteristics of a person-centred culture within which person-centred care can be provided. This framework has been adopted in this study, as its holistic nature enables the analysis of a range of factors that might support person-centredness, which is defined as 'an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development (McCormack & McCance, 2017b: 20). From this viewpoint, McCormack and McCance (2010, 2017) have operationalised the factors that might enable person-centredness into a macro-context and four constructs: pre-requisites, care environment, person-centred processes and person-centred outcomes. All constructs and their full set of attributes are shown in Table 2.

*Table 2. Person-centred practice framework constructs (McCormack and McCance, 2017)*

<p><b>Macro-context</b> includes major external factors related to health and social care policy, strategic frameworks, workforce developments and strategic leadership.</p>
<p>1. <b>Prerequisites</b> focus on the attributes of the care worker and include: being professionally competent; having developed interpersonal skills; being committed to the job; being able to demonstrate clarity of beliefs and values; and knowing self.</p>
<p>2. <b>The care environment</b> focuses on the context in which care is delivered and includes: appropriate skill mix; shared decision-making systems; effective staff relationships; supportive organizational systems; power sharing; potential for innovation and risk taking; and the physical environment.</p>
<p>3. <b>Person-centred processes</b> focus on delivering care through a range of activities and include: working with patient's beliefs and values; engaging authentically; being sympathetically present; sharing decision making; and providing holistic care.</p>
<p>4. <b>Person-centred outcomes</b>, are the results of effective person-centred practice and include: good care experiences; involvement in care; feeling of well-being; and fostering a healthful culture.</p>

There is an acknowledgement that the philosophy and principles of PCC should be at the heart of any existing and emerging models of dementia care (Koren, 2010; McCormack & McCance, 2017a). While there is evidence of the application of PCC approaches in long-term care settings, hospital wards and care homes (Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie, 2014; Williams, Hadjistavropoulos, Ghandehari, Yao, & Lix, 2013) such evidence has not yet been found in the supported accommodation model enriched with assistive technology. Some research has suggested the positive impact of staff training aimed at dealing with challenging behaviour in care homes, as staff reported reduced symptoms in residents and changes in their own attitudes by adopting an empathetic approach that fostered the development of relationships (Goyder, Orrell, Wenborn, & Spector, 2012). Other research suggests the need to redress the relations of power and change organisational cultures in dementia care in order to realise the potential of the contribution of direct-care staff in person-centred practice who feel disempowered and who receive

limited training, recognition or remuneration (Scales, Bailey, Middleton, & Schneider, 2017).

Similarly, other studies have highlighted the need to provide staff in LTC settings and extra care housing facilities with person-centred care training in order to enhance their acquired knowledge of the approach through their daily work experience and to support them in dealing with challenging behaviours (Evans, Fear, Means, & Vallely, 2007; Hunter, Hadjistavropoulos, & Kaasalainen, 2016).

### [Technology enriched supported living environments](#)

Electronic health solutions have been described as essential tools to providing cost effective, quality health care services to aging populations (Martínez-Alcalá, Pliego-Pastrana, Rosales-Lagarde, Lopez-Noguerola, & Molina-Trinidad, 2016). Technology and assistive devices have the potential to enhance the long-term care needs of PLWD and their caregivers. Additionally, technology can enhance knowledge exchange, education, and virtual environments, in turn, increasing the standards of the care environments (Martínez-Alcalá et al., 2016). Technology is considered useful in the lives of PLWD to promote independence, improve quality of life, manage risk and increase safety, support all users (PLWD, family, caregivers) and to personalise support (Cahill, Begley, Faulkner, & Hagen, 2007). The word 'technology' is in itself a very broad term, spanning a wide range of devices with different functionalities. It is a term that describes assistive devices that can support PLWD with prompts and reminders, alarm systems, automatic lights, domestic appliances that switch themselves off at a certain point, easy-to-use remote controls and phones, monitoring, and therapeutic interventions (Buckley, 2006). Pervasive telecare technologies include a range of sensors to detect motion, pressure, inactivity, falls and temperature

which automatically send a signal to a carer or monitoring centre to provide assistance when it is needed. Wearable devices such as electronic tracking chips and GPS locators can locate a person if they get lost and alarm pendants and bracelets can call for assistance in the event of an emergency. Additionally, assistive technologies such as touch screen devices can be used for entertainment and quality of life to support reminiscence through pictures, music and Apps, and as memory aids. Innovative devices are continually emerging into the marketplace and as research prototypes which means technology to support PLWD is a very fluid environment.

The advantages of using technology to enrich care and support include increasing the PLWD's freedom and independence (White & Montgomery, 2014); free up caregivers time for meaningful interaction and other duties (Robinson et al., 2007); peace of mind for the caregiver (Alwin, Persson, & Krevers, 2013; Mao, Chang, Yao, Chen, & Huang, 2015); and reduce unnecessary physical intrusion (Morgan, 2003). The challenges associated with such an environment include technology replacing care as opposed to complementing care provision (Landau, 2009), unreliability and failure of devices (Altendorf & Schreiber, 2015), a noisy living environment due to alarms (Bressler, Redfern, & Brown, 2011), and a violation of privacy (Niemeijer et al., 2010). The use of such assistive technologies has generated huge debate around safety, risk, privacy and autonomy (Landau, 2009; Niemeijer et al., 2011). Additionally, questions arise such as decision making around the use of technology (Alwin et al., 2013; White & Montgomery, 2014), establishing consent from the PLWD (Martínez-Alcalá et al., 2016), identification of who gets access to the data (Landau, Auslander, Werner, Shoval, & Heinik, 2010); and incorporating person-centred care into a technology enriched setting (Robinson et al., 2007).

According to Gibson *et al* (2014), there were 1.7 million telecare users, 171 technology products and 331 services for PLWD in the United Kingdom (UK). Despite this, assistive technology provision is fragmented, it can be difficult to access, and devices to support well-being and quality of life often fall outside the scope of provision (Gibson *et al.*, 2014). Many literature reviews have already been undertaken to explore the impact of assistive technology within the lives of PLWD. One review stated that more robust evidence is needed to explore the impact assistive technology can have on the care of PLWD (Fleming & Sum, 2014). Forty-one papers met the inclusion criteria in the review which concluded that the evidence for the effective use of assistive technology to improve the safety and security of PLWD is very weak. Common issues reported were difficulties using systems, lack of acceptance by the user and the reliability of the technology. Recommendations within the review included the need for careful assessment, early introduction of technology, personalised technology approaches and more robust evidence. Topo (2009), reported in her literature review, that many of the sixty-six studies included were undertaken in residential care or hospital settings primarily concerned with the needs of formal caregivers. The findings indicated that more robust research is needed, the cost effectiveness is currently unknown and personalisation of technology for users is important. Additional challenges include the wide variability of aims, technology design, outcome measures and the limited voice of PLWD in reported studies. Another significant literature review had a specific focus on surveillance technologies both for PLWD and intellectual disability within a residential care setting (Niemeijer *et al.*, 2010). A total of seventy-nine papers met the inclusion criteria from international sources. A wide range of themes emerged from the findings, including functional efficacy, duty of care versus autonomy, freedom and consent,

safety/ risks, substitution of care, dignity/ stigmas, staff burden, person-centred care and privacy. A major conflict emerged between the interests of the institution and the interests of the resident. Additionally, a lack of in-depth analysis was evident, no agreement on the ethical application of technology was reached and the residents' perspectives were not often included.

The use of technology within care at present and in the future has not been formulated into a clear plan (Sugihara, Fujinami, Phaal, & Ikawa, 2013). Little evidence indicates the changing technology requirements as a person's dementia progresses. Additionally, some technologies would not be as suitable for those at a more advanced stage of dementia or for those living within a residential or nursing home (Olsson, Engström, Skovdahl, & Lampic, 2012). A key role in the provision of technology enriched care is enabling a PLWD to live in their own home environment for longer (Leroi et al., 2013; Zwijsen, Niemeijer, & Hertogh, 2011). However, as housing options increase so too should the provision of technology enabled services to enhance care and increase quality of life. Although research suggests that telecare and other assistive technologies play a key role in the various housing models such as supported housing (Gibson et al., 2007), there is currently a gap in the literature on the impact of technology on the everyday lived experience of those living with established dementias in a supported living environment.

## A Systematic Review of Electronic Assistive Technology within Supported Living

### Environments for People Living with Dementia

A systematic review of the literature was undertaken to identify the types of technology used in supported living and residential care and to explore how individuals with dementia are included within the studies exploring technology interventions (Daly Lynn et al., 2017). Four major databases (Embase, Medline, PsychInfo and CINAHL) were systematically searched up until May 2016. The search terms were as follows: (Dement\$ OR Alzheimer\$ OR cognitive adj3 impairment\$) AND (nursing adj3 home\$ OR assisted adj3 living OR residential adj3 care OR support\$ adj3 living OR care adj3 home\$) AND (tech\$ OR assistive adj3 device\$ OR smart adj3 home\$ OR telecare OR alarm adj3 system\$ OR intercom\$ OR sensor\$ OR actuator\$ OR alarm adj3 bracelet\$ OR bed adj3 alarm\$ OR motion sensitive light\$ OR fall adj3 detector\$ OR activit\$ adj3 monitor\$ OR tracking adj3 device\$ OR monitor\$ OR wearable adj3 device\$ OR surveillance).

A total of N=3229 papers were retrieved in the initial search and N=61 met the inclusion criteria. The data was extracted using the following characteristics: purpose of the study, participants, setting, methodological design, data analysis, technology intervention, ethical considerations, the voice of the PLWD and the outcome of the study. The studies were then grouped together in terms of the technical intervention. Six categories of technical interventions were defined: Telecare; light therapy; robotic companion; well-being and leisure; simulated presence; and orientation.

Within telecare interventions, there was significant heterogeneity in the twenty-three studies retrieved. A wide range of screening tools, outcome measures and technologies were evident. The study aims included the ability of technology to support night time needs, usability testing, assessing specific telecare devices, and gathering perceptions of telecare devices. A variety of outcomes from the technological intervention studies included the potential to enhance privacy, increase safety, providing PLWD a sense of security, addition feedback for staff care givers and promote independence. A range of technical issues were reported including false alarms, low batteries, connectivity problems and staff reporting alarm fatigue when recurrent false alarms were occurring. Staff reported frustration with false alarms and a sense of fear and reluctance around the integration of technology into care (Niemeijer, Depla, Frederiks, Francke, & Hertogh, 2014). Technology interventions were highlighted as both enhancing and invading privacy. Cost was also viewed as a barrier. The need for more robust, user-centred research to develop personalised and individual systems and devices was recommended.

The data were extracted from two papers and one Cochrane review focusing on light therapy. Care professionals reported being happy using dynamic lighting systems if there were benefits to the individuals they are caring for, even if this is only a belief of the benefits. The Cochrane review findings do not recommend light therapy due to lack of evidence. The methodological weaknesses of light therapy studies were highlighted. Robotic companions were an unexpected finding within the literature review. Twelve studies were retrieved. Five different types of robotic companions were found within the twelve studies. The findings included the potential to reduce agitation, increase interaction, reduce depression, and have a therapeutic impact. Interestingly, not all participants

accepted the robotic companion. This area of research was found to be in its infancy and further user centred research is required.

Eight studies focusing on technology intervention for well-being and leisure were retrieved. The studies incorporated a huge variety of topics from physical activity to cognitive rehabilitation to usability touch screen devices. The findings indicated that technology could be used to improve health and well-being and were enjoyable. One example illustrated a monitoring watch that reduced disturbance during the night, saved staff time and health changes could be identified through the technical data. Simulated presence was when a loved one made a personal recording to play to the PLWD to bring comfort when they were not there. Nine studies were included in this review focusing on the ability for a stimulated presence intervention to reduce agitation. The findings indicated that stimulated presence work well for some individuals but not for others however more robust research is needed to use this intervention in long term care settings. Finally, five studies were retrieved in the orientation and activities of daily living intervention category. Primarily, these technology studies looked at the usability of different devices such as taking medication, prompts to wash hands and planning activities.

The purpose of this section is to give a brief overview of the findings in the systematic review. The findings indicate that there are numerous systems and devices being used in healthcare environments. Additionally, there are significant differences in the methodological approaches used to explore the impact of these technologies. The findings suggest a range of positive outcomes for the use of technology intervention in care settings such as complementing staff care (Chan, Campo, Laval, & Estève, 2002), promoting

independence (Mihailidis, Boger, Craig, & Hoey, 2008), enhancing social interaction (Šabanovic, Bennett, Chang, & Huber, 2009) and providing a sense of security (Margot-Cattin & Nygård, 2006). A range of challenges were also reported such as acceptance of the intervention by tenants (Moyle et al., 2016) and staff (Niemeijer et al., 2014), false alarms (Capezuti, Brush, Lane, Rabinowitz, & Secic, 2009), cost (Altus, Mathews, Xaverius, Engelman, & Nolan, 2000), reliability and alarm fatigue (Niemeijer et al., 2014) and no reduction in falls (Holmes et al., 2007). Technology interventions were viewed in the literature as both an invasion of privacy (Niemeijer, Depla, Frederiks, & Hertogh, 2015) and a way to prevent unnecessary intrusion on privacy (Yayama et al., 2013). One of the main challenges for supported living environments found within this review, is the selection of suitable technology interventions. There was a significant lack of compelling evidence to indicate the technology intervention that was most effective. However, it is imperative that technology solutions are individual, have customisable features and can complement person-centred care.

## Summary

This chapter presents two things, firstly an overview of the literature in the topic area of living with dementia, supported living, person-centred care and technology enriched supported environments. Following this, a systematic review of literature on technology interventions used in residential and supported living environments was undertaken and presented. The findings highlight a lack of synthesise in the approach and technical interventions used. Although research suggests that telecare and other assistive technologies play a key role in the various housing models such as supported housing, there

is currently a gap in the literature on the impact of technology on the everyday lived experience of those living with established dementias in a supported living environment. The findings from this literature review informed the development of the technology audit tool described in Chapter 4.

**Dissemination from this stream of work:**

Daly-Lynn, J, Rondon-Sulbaran, J, Quinn, E, Ryan, AA, McCormack, B & Martin, S 2017, 'A systematic review of electronic assistive technology within supporting living environments for people with dementia' *Dementia*, vol 0(0), pp. 1-65. DOI: 10.1177/1471301217733649

## Chapter 3 Ethical Issues

### Introduction

Adhering to ethical protocols and governance was central to all the work undertaken in the project. The first year of the project focused on establishing best practice and obtaining the necessary approvals to work ethically with all the stakeholders within the project. This section first sets out the process used to obtain ethical approval and governance. It then makes the case for the importance of ethically engaging with PLWD in research and focuses specifically on technology-based research. Finally, the ethical approach for obtaining consent in this project was outlined.

### Obtaining ethical approval and governance

This project adhered to the ethical governance procedures and protocols within Northern Ireland, specifically at Ulster University, Health and Social Care Trusts and the Office for Research Ethics Committees Northern Ireland. Ethical governance activity started at project initiation. The process of obtaining ethical approval and research governance took most of the first year of the project. In advance of submitting the proposal for Ulster University Research Governance peer review, significant documentation for the project needed to be developed such as information sheets, consent forms, as well as the required templates (Ulster University and ORECNI have different forms to complete). The process of obtaining ethical approval and research governance is set out in Figure 1.

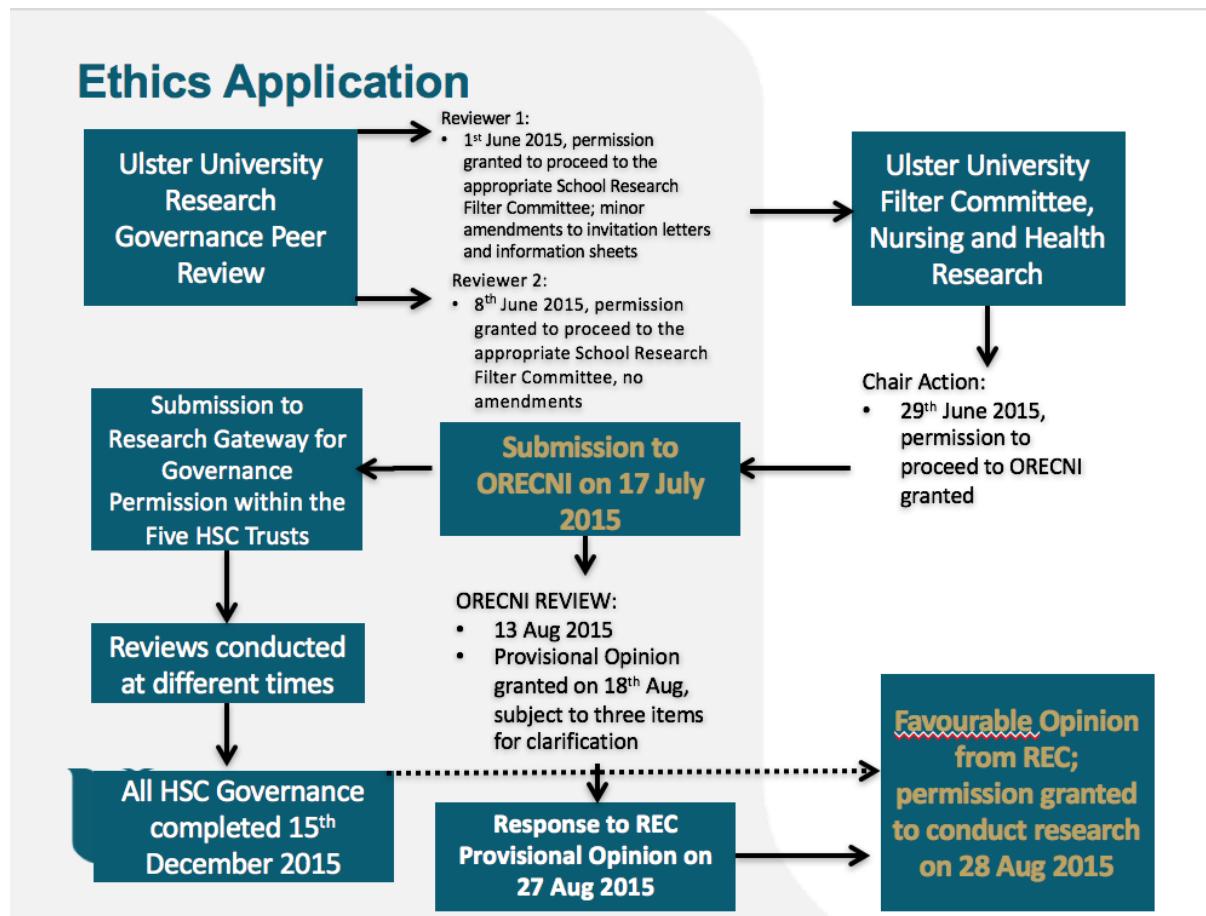


Figure 1. Ethical approval and research governance process

It was necessary to obtain research governance approval from the five Health and Social Care Trusts. Recent rationalisation of the system has enabled a single point of submission via a research ethics gateway, however this does not map to a single review point or process. Additional documentation such as good clinical practice certificates, Access NI and voluntary work placements were required by some of the Trusts. The first Trust approval was granted on the 14<sup>th</sup> of October and the final was granted on the 15<sup>th</sup> of December 2015. Through the lifetime of the project, three substantial amendments were submitted to ORECNI and subsequently sent to the Trusts for governance. The first substantial amendment was for changes to the scheme and paid staff information sheets, the second substantial amendment was to make necessary amendments to the information sheet and consent forms for participants living with dementia to participate in the creative focus groups and the final substantial amendment was to submit the informal and formal

caregiver survey on attitudes towards technology. Internal ethical reviews were undertaken on a regular basis throughout the project. The classification, storage and retention of project data was aligned to best practice of Ulster University guidelines. A risk register was developed and managed aligned to Department of Health Social Services and Public Safety (DHSSPS) guidance, to both monitor and manage risk (DHSSPS, 2002). This was reviewed and updated at monthly local management meetings. The lead for the risk register was the chief investigator who at one point identified the time delays in obtaining ethical approval as creating a risk to successful delivery of all activity within the project.

### Engaging People Living with Dementia in the Research

Within the United Kingdom, there are clear guidelines of ethical governance in place to support researchers and research participants. Indeed, Patient and Public Involvement in research is generally accepted as essential and a core pre-requisite to most of the major research funding agencies (Littlechild et al.,2014). The process of ethical engagement of participants in research may appear more challenging when the participants are perceived by ethical review panels to have decreased cognitive capacity. People who have a diagnosis of dementia, independent of where they are in terms of disease trajectory, will fall into this category. The Mental Capacity Act (2005) states that a person is assumed to have the competence to consent unless it is proven that they do not. This legal framework provides a backdrop to ensure a person has the capacity to make his or her own informed decision. First, it is vital that the person understands all the information and the decisions they are making; next the person must remember the information; the individual should consider all aspects of the information received; and finally disclose their decision. In the study by Perry & Beyer, (2012) where they explored the views of participants on telecare services, PLWD *“urged great caution when judging at what point a person is deemed to be unable to give informed consent”*.

The best way to understand the experiences of PLWD is to engage directly with them (Cahill et al., 2012). This requires researchers to develop a framework to maximise inclusion and participation within the chosen research methods and with a focus on the diverse range of skills a person may or may not have at the stage of their dementia. Numerous research studies in recent years have found that engaging in research gives PLWD a voice, an avenue to be listened to, to feel valued and to be recognized (Murphy, Jordan, Hunter, Cooney, & Casey, 2014). Hellstrøm, Nolan, Nordenfelt, and Lundh, (2007) recommend finding the best way to engage PLWD in the research process is to support their inclusion and safeguard against adverse risk. Developing policies and a framework to enhance participation is the best way to do this. Several studies have used methods to maximize the ability of participants with dementia to meaningfully engage in research interviews. For example, Nygard (2006) suggests building a relationship with participants to put them at ease, flexibility and developing familiarity with the interviewer. Additionally, research reported the interviewer receiving training to enhance skills to help build trust, recognise body language, particularly if the participant is experiencing distress or fatigue, and develop questioning strategies to ensure the participant is not put under any stress (Hubbard et al., 2006).

It is therefore important to consider the implications of introducing technologies to be evaluated within these research frameworks to maximise a person's ability to contribute and to enable meaningful inclusion. Building relationships with participants before interviews is a strategy used in research with PLWD which is known to maximise the meaningful involvement of participants (Murphy, 2014). Peer researchers were working alongside the research team in this project, collecting data and supporting the engagement of participants to encourage this aspect of building relationships. Family and informal carers could participate, independent of whether a relative tenant was participating. This ensures inclusivity of participation opportunity independent of each other.

Several ethical considerations have emerged within the literature when considering PLWD, technology provision and research, and the various stakeholders that can be involved. A

degree of complexity surrounds a person's capacity to consent and balancing this with any external forces that might impact the decision making process such as a positive response bias, lack of clear understanding of the technology, and caregivers' commitment to engage in research even though the PLWD may not want to (Kitwood, 1997). Additional issues include the type of technology and the debate around surveillance and GPS tagging to reduce caregiver worries and enable the PLWD security and independence can also have a profound impact on privacy (Cahill, 2003; Niemeijer et al., 2010). The ethical concepts of beneficence, autonomy, nonmaleficence and justice can undoubtedly collide from the perspective of various stakeholders involved in the research and later in the provision of such technology. It is important to maintain the perspectives, needs and requirements of the PLWD at the centre of the debate. Limited research explores ethical issues and assistive technology with PLWD. Godwin's, (2012) report specifically explored the views of participants with dementia on the ethical considerations and benefits of assistive technology. She found that participants not only commented on ethical issues, but showed logic, insight into their condition and empathy towards others. Perry and Beyer (2012) published an exploratory study with PLWD and participants with learning disability. They reported that although their sample size was small, participants had strong views on the ethical issues associated with assistive technology and telecare including the importance of privacy, consent, social isolation, assessment and review, motivation for telecare, and risk and safety.

It is essential that the methods used within the research design support the meaningful inclusion of PLWD. It is necessary to underpin ways of connecting and creating an understanding within the ethical framework. Appropriate communication is fundamental to robust ethical governance to ensure PLWD understand and consent to taking part in the research, they continue to consent to their involvement in research, and for the person to participate fully in the data collection. Hughes and Baldwin (2006) suggest that when considering ethical issues in relation to dementia care, rather than choose between a

theoretical approach it may be more appropriate to take a principle-based approach. The principles that should inform ethical practice in this subject area are stem from the 4 principles of medical ethics (Bjorneby, 2004);

\* Autonomy: People should be able to decide what they want to happen or be done to them.

\*Beneficence: We should try to do good to the people we care for.

\*Nonmaleficence: We should try to avoid doing people harm.

\* Justice: People should be treated fairly and equally.

## Research Consent for Persons Living with Dementia

Best practice in terms of research involving PLWD is to directly engage them as much as possible in the work. Our aim in the project was for PLWD dementia to consent to participate in the study rather than gaining assent from relatives. This was aligned to best practice in this research area (Higgins, 2013). After consultation with experts in this field (Prof Brendan McCormack and Jan Dewing), two approaches for consent were adopted and are set out, both underpinned by a 'process consent method' as described by Dewing (2008) to support engagement. The process consent method acknowledges that with any approach to consent with this population, it must be an on-going, fluid process that continues to checkin with the participant as necessary. It should be noted that process consent is an approach where 'permission' is sought to engage with PLWD and incorporates an understanding of how this person gives permission in their daily life. Technically, both approaches used within this project were process consent. Approach A was where the tenant provides consent for themselves and was only considered in conjunction with the

scheme manager after consultation with family members. It was aligned to the approach commonly used for the individual to consent. Consent was viewed as valid at that point in time (when consent form was signed) and therefore verbal consent was continually sought alongside observing for visual clues of withdrawal from the interview. Approach B, the process consent adopted within the project, created a paper trail of the consent given by the scheme manager and the next of kin. The tenant would not have been required to complete a consent form but verbal assent would have been taken in advance of the interview and monitored throughout.

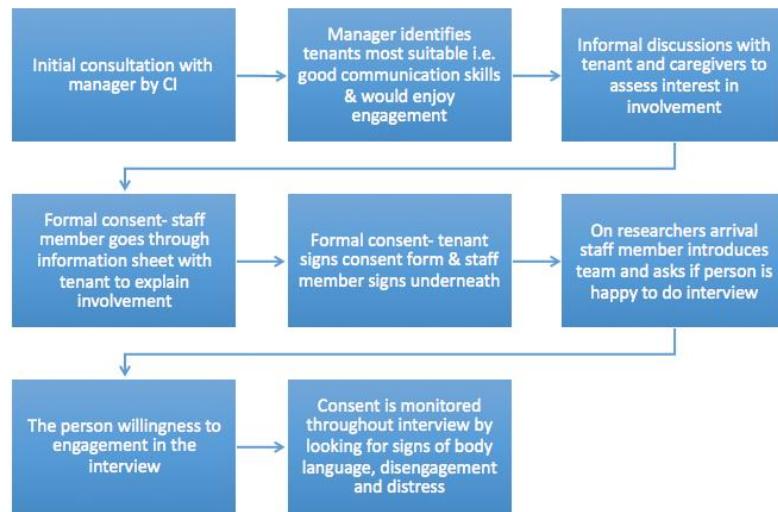
Collaboration between the scheme manager and the researcher was core to both approaches. The scheme manager first met with one of the researchers to discuss the project, the level of involvement from the scheme and the manager's role in the recruitment of all participants. During this conversation, the approaches for consenting tenants' involvement were outlined. Following this, the second researcher phoned the scheme manager to give further detail on recruitment and answer any questions. A timeline was set for the manager to identify participants and decide what type of consent approach would be the most appropriate. Managers were asked to inform PLWD about the project and to determine if they were interested in finding out more. Managers were also asked to consult with the family/next of kin as they considered the most appropriate type of consent. Up until this point both approaches to consent were the same. The approaches now diverge and are set out separately in the sections below.

#### Approach A Informed Consent

The first approach to consent is called informed consent and is set out in Figure 2. When the managers had identified tenants that were willing to hear about the project, a member of staff went through the information pack with the person (Project Leaflet, Information Sheet and Consent form Appendix 3, 4, and 5). The information sheet is explained and the person is told what would be involved if they said yes to the interview or focus group. At that point the PLWD decides whether or not to sign the consent form with the member of

staff. The staff member also signs the form to illustrate at that stage the individual was happy to be involved.

## Approach 1: Informed Consent



*Figure 2. Approach A - informed consent*

The manager then let the researcher know that a tenant had consented and they organised a time suitable for the interview. In the case of the focus group the dates were pre-arranged with the manager. The manager holds the consent forms until the researcher comes to the site. On the day of the interview, a member of staff goes to the PLWD in advance of the interview to remind them and identify if they are still happy to meet with the research team. The member of staff brings the research team to meet with the participant and introduces the researchers reminding the person about the project and asks them if they are still happy to take part in the interview. If the answer is yes- the person is told they can stop any time they wish and they are asked if agreeable for the interview to be recorded. The researcher monitored the person's consent throughout the interview by watching body language and looking for any signs of disengagement or distress. All interview participants consented using this first approach and a total of sixty-one participants consented in this way to participate in the focus groups.

## Approach B Process Consent

Approach B set out in Figure 3 is a formal process consent approach adopted within the project. It created a paper trail, checking first if the participant meets the criteria for the approach and then the consent given by the scheme manager and the consultee. A personal or nominated consultee was required to be selected by the manager. The tenant would not have been required to complete a consent form but verbal assent would have been taken in advance of the interview and monitored throughout.

## Approach 2: Process consent

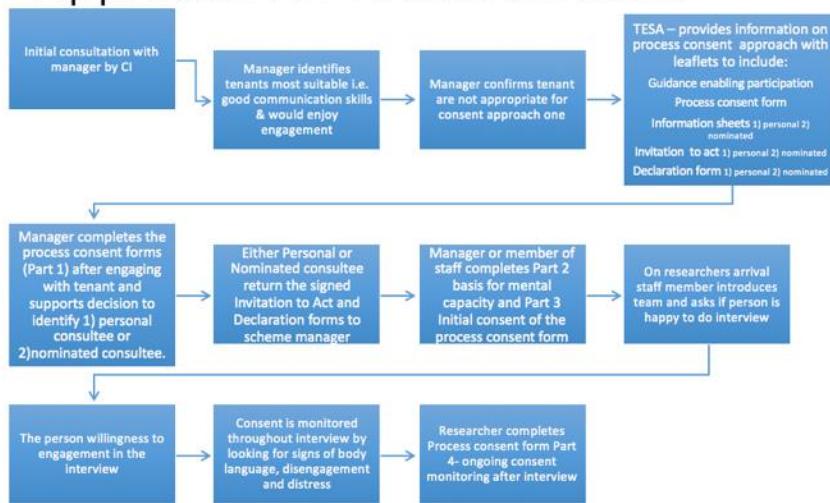


Figure 3. Approach B process consent

A 'personal consultee' is approached first if the PLWD is considered to lack capacity. They advise about the person's wishes and feelings about participation and are in a close personal relationship to the potential participant, e.g. spouse, partner, adult (son/daughter) other relative, close friend or past carer. Through the scheme manager, we sent out an invitation pack to the prospective personal consultee containing: a letter of invitation, a personal consultee information sheet, an invitation to act as a personal consultee and a personal consultee declaration form. The potential personal consultee was asked to respond to the invitation directly, returning a signed copy of the 'invitation to act as a

personal consultee' and the declaration form. Potential personal consultees had the opportunity to ask questions about the study on the phone, by e-mail or in person. If the invitation was accepted, the personal consultee remained in the project from the date they accepted the invitation until the PLWD ends with their participation in the project. Personal consultees were approached by the researchers at different stages in the research process to confirm whether the participant would wish to continue or withdraw their participation in the study.

A 'nominated' consultee is appointed by the researcher when a personal consultee is not able to take up the responsibility. They can be someone acting in a professional role (e.g. GP or a member of the care team). Before appointing a 'nominated consultee', the researchers will consult with the scheme manager and ask him/her to recommend individuals who would take up this role. It is likely that the manager would recommend a key worker because they are known to the potential participant and are aware of their feelings and wishes. For good practice, we ensured that when a key worker cannot assume this responsibility, the person acting as a 'nominated consultee' adopts an approach similar to that of an advocate, in which he/she meets the prospective participant, carers, family members and friends in order to gather relevant information on which to base their opinion about participation of the PLWD in the study. A nominated consultee was not required within the project.

Once the invitation to act and declaration form were returned to the research team, the researcher contacted the manager to collaborate on the process consent form (Appendix 6). Similar to approach A, on arrival the member of staff introduces the research team to the participant reminding the person about the project and asks them if they are still happy to take part in the interview. If the answer is yes, the person is told they can stop at any time and are asked if agreeable to record the interview. The researcher monitors the person's consent throughout the interview by watching body language and looking for any signs of disengagement or distress. The researcher carefully documents the indications that consent

is ongoing in Part 4 of the process consent form. No scheme manager felt that Approach B was required for the tenants that volunteered to take part in the interviews. The manager of one scheme felt three participants did not have capacity to give consent in this way for focus group participation. Process consent was adopted as a method to include these tenants.

### Ethical Issues that Emerged During the Project

Within the lifecycle of the project some ethical issues did emerge. For example, one particular housing scheme seemed to have a more paternalistic approach towards their tenants' involvement in the research. The research team were asked not to use the term dementia and it was requested that a formal caregiver was to be present during the interview. In advance of submitting the documentation to get ethical approval the Alzheimer's Society was consulted on the use of terminology and we were advised that it is good practice to acknowledge the term dementia. Novek and Wilkinson, (2017), describe the need to have situational sensitivity as opposed to universal approach when it comes to using terminology. It is important to note that although the participants with the formal caregiver present praised the formal caregivers during the interview this was not out of sequence with the other interviews. In addition, when discussing the project with formal and informal carers who were initially keen and relaxed, they showed more concern about participation when signing formal consent forms. Furthermore the process of gaining ethical approval for this project within Northern Ireland took significant man-hours in terms of paper work preparation and time invested in waiting on related approval to come through from all the bodies outlined above.

### Summary

Ethical issues often emerge in research and a thoughtful and vigilant approach is required when engaging PLWD in research. Ethical theories are helpful and encourage consideration of dilemmas from differing perspectives. Often there is no right or wrong rather a need for discussion and debate and the opportunity to percolate the issues into the arena where clinicians, policy makers, industry and academics can engage. It is essential that the methods used within the research design support the meaningful inclusion of PLWD. It is necessary to underpin ways of connecting and creating an understanding within the ethical framework. Appropriate communication is fundamental to robust ethical governance to ensure PLWD understand and consent to taking part in the research, they continue to consent to their involvement in research, and in order for the person to participate fully in the data collection. The current process is robust and autonomous, however, the time required to secure ethical approval puts many other aspects of the project at risk.

## Chapter 4 Technology Enriched Supported Housing in Northern Ireland

### Introduction

The purpose of this chapter is to provide an overview of the nine supported housing schemes participating in TESA-DRI. The main objectives are to illustrate the tenant profile, give an overview of the schemes environmental design and finally set out the technological provision within these settings. This aimed to create a picture of TESA within Northern Ireland at this current point in time.

### The Supported Housing Schemes

The study was conducted in all five Health and Social Care Trusts (HSCT) in a region of the UK where all facilities identified as providers of TESA for PLWD were invited to take part in the study. Access to the sample was obtained through the *Supporting People Programme*<sup>1</sup> – a government initiative created to provide a range of housing services for vulnerable adults . In most cases the primary funder for the facility was the HSCT with an approximate split of funding sixty percent Trust and forty per cent the *Supporting People Programme*. Care in the facilities is provided by a mix of HSCT staff and/or voluntary sector organisations; management is facilitated by housing associations. The dwellings in this type of accommodation consist of a range of housing options including, small units for up to 12 people with private en-suite bedrooms and communal living and kitchen areas, bigger units of the same type for up to 60 people and self-contained bungalows or apartments (25 or 30 per facility) within a defined/bounded complex that also offers communal recreational

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<sup>1</sup> See website

[https://touch.nihe.gov.uk/index/corporate/supporting\\_people\\_programme.htm](https://touch.nihe.gov.uk/index/corporate/supporting_people_programme.htm)

spaces and gardens. PLWD are tenants living within the care facilities and sign a tenancy agreement when they move into the scheme. It is at this point tenants are also asked to consent to the use of technology within the scheme. These facilities are regulated by the Regulation and Quality Improvement Authority (RQIA<sup>2</sup>). This is an independent body established in 2005 to regulate and inspect the quality and availability of health and social care services in this province of the UK. Managers of these facilities are required by the RQIA and in accordance with relevant legislation and DHSSPS standards, to deliver person-centred care (DHSSPSNI, 2011b). There are no specific measures for how person-centredness is operationalised across services.

#### **Inclusion criteria**

A total of 12 housing schemes met the inclusion criteria, offering housing with care and technology specifically to meet the needs of PLWD. These schemes were identified through Supporting People who were members of our steering committee. An invitation to participate was sent out to the manager of each housing scheme. The manager received an information sheet and consent form (Appendix 7 and 8).

- One responded to the invitation that they were not supporting PLWD.
- 11 facilities expressed an interest in participating in the project.
- Site J was excluded after a site visit confirmed this was a residential facility with single ensuite bedrooms and not supported housing. No data was included.
- Site K was not able to commit to participation in the project because of the time constraints on staff at the time.

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<sup>2</sup> See website <https://www.rqia.org.uk>

- Site H began the project and participated in aspects of the data collection however the decision was made by the project team to stop participation after the interview data collection. This facility had two accommodation types onsite. It was only during our interview phase it became clear that the supported housing was no longer allocated to PLWD.
- A total of eight sites completed all aspects of project data gathering.

More detail on this is provided in the Chapter 11, Table 28.

### Demographic Information

Demographic data was extracted from the nine facilities participating in the study from December 2015 until February 2017 (including site H). A form (Appendix 9) was used to extract the data. These facilities provided TESA for people aged 60 and over who had a diagnosis of dementia. Two hundred and forty-three records were collected. The data were entered by one of the researchers into SPSS 24 for analysis. The descriptive statistics of characteristics of the sample follow.

### Occupancy of the facilities

Table 3 shows that at the time of data extraction (2015-16) there were 243 tenants living in all the facilities. Overall, they were operating at 91% of their capacity. The number of places offered in each facility varied according to the size of the dwelling. Small facilities had a capacity of 12 to 15 places, medium-sized facilities of 23 to 35, and one of the two largest facilities had a capacity of 61 places. Some of the medium-sized facilities and the largest facility were operating at between 83% to 89% of their capacity. Both small facilities and two medium-sized facilities were at full capacity.

Table 3. Number of tenants residing in each facility across five HSC Trusts in Northern Ireland

Health & Social Care Trust	Facility	Capacity	Occupancy at time
Belfast	Site A	35	30 (86)
	Site B	30	29 (97)
	Site C	25	25 (100)
South Eastern	Site D	30	25 (83)
	Site E	23	23 (100)
Southern	Site F	12	12 (100)
Northern	Site G	61	54 (89)
Western	Site H	15	15 (100)
	Site I	35	30 (86)
	Total	266	243 (91)

#### *Age and Gender*

The 243 tenants living in the nine participating facilities belonged to the white ethnic group.

The age range of these tenants was between 51 and 97 years of age (mean 79) as shown in Table 4. Seventy-two per cent of the tenants were females and 28% males. The lowest proportion of tenants was in the age of 50-59 with 3.5% in total. The highest proportion of the sample was identified in the age ranges between 80-89 (44%) and 70-79 (32%). In both categories the proportion of females was higher than males – 22% in the 70-79 category and 34% in the 80-89 category. In the older old range, that is, 90-99, females outnumbered males by a fivefold – 1.7% and 8.5% respectively. The largest number of females reflect those of the general population in the 65 and older group in Northern Ireland where females are at 57% and males at 43%.<sup>3</sup>

<sup>3</sup> All references to comparisons with the general population in the 65 and over group correspond to the same source: Northern Ireland Research and Statistics Agency. Northern Ireland Neighbourhood Information Service, NINIS. (2014). Older people. Retrieved from Available online at:

<http://www.ninis2.nisra.gov.uk/public/census2011analysis/olderpeople/index.aspx>.

Accessed on 13th November 2017

*Table 4. Age and gender of tenants*

Age	Male	Female	Total (%)
50-59	2 (0.9)	6 (2.5)	8 (3.4)
60-69	13 (5.5)	11 (4.7)	24 (10.3)
70-79	23 (9.8)	51 (21.6)	74 (31.6)
80-89	24 (10.3)	79 (33.7)	10 (44.0)
90-99	4 (1.7)	21 (8.5)	25 (10.7)
Total (%)	66* (28.0)	168 (72.0)	234 (100)

Data missing N= 2 males/7 females

#### Marital Status

Widowhood was the most prevalent marital status of the sample as shown in Table 5. Fifty-five per cent of females were widowed, compared to 7.2% of males. The total of 62% of widowed individuals in our sample is higher than that of the 65 or over group in the general population with a proportion of 30%. Only 14.4% of our sample were married or living in partnership, compared to 54% of those aged 65 or over in the general population who are married or living in a same-sex civil partnership. The proportion of those who were single was similar to that of the 65s or over in the general population – 10% and 9.2%, respectively. The proportion of those divorced/separated in our sample more than doubled that of the general population, 14.4% compared to 6%.

*Table 5. Marital status of tenants*

Marital status							Total (%)
Single	Divorced	Married	In	Widow/er	Separated	Total (%)	
			partnership				

Male	9	12 (5.7)	14 (6.7)	3 (1.4)	15 (7.2)	3 (1.4)	
				(4.3)			56 (27)
Female	11	15 (7.2)	12 (5.7)	0 (0.0)	114	0 (0.0)	
				(5.2)		(54.8)	152 (73)
Total	20	27 (13)	26 (13)	3 (1.4)	129 (62)	3 (1.4)	208
(%)	(10)						(100)

Data missing N=35

#### Type of Accommodation

Prior to the transition into TESA, approximately one third of individuals (32.4%) were living in their own homes (Table 6), compared to nearly three-quarters (74%) of those aged 65 or over in the general population. There was a slight difference between individuals living in social rented housing (16.4%), compared to those 65 or over in the general population (13%). Nearly twice as many individuals used to live in private rented housing compared to the general 65s or over – 8% and 4.7%, respectively. Twenty per cent were living in communal establishments (11.1% in sheltered housing and 9% in a group home), compared to 4.5% of those aged 65 or over in the general population, of which, 76% live in care homes. Seventeen per cent of these were living in a hospital ward, compared to 2% in this sample of PLWD.

*Table 6. Accommodation prior entering the facility*

Accommodation type	Frequency (%)
Hospital ward	4 (1.9)
Flat	10 (4.1)
Group home	19 (9.2)

Private house (rented)	19 (7.8)
Sheltered housing	23 (11.1)
Other	31 (15.0)
Housing association	34 (16.4)
Private house (owned)	67 (32.4)
Total	207 (100)

Data missing N=36

#### Living Arrangements

Table 7 that the majority of individuals were living alone (55.2%) and the other half of individuals shared their accommodation in nearly equal proportions with a person who was not their relative (18%) or with a spouse/partner (17.5%). There was no data in this category to make comparisons with the 74% of those aged 65 or over described as living in owner occupied households.

*Table 7. Living arrangements of tenants prior to entering*

Living with	Frequency (%)
Other relative	5 (2.7)
With adult child	12 (6.6)
Spouse/partner	32 (17.5)
Sharing with other person	33 (18.0)
Alone	101 (55.2)
Total	183

Data missing N=60

### Nearest Relative

A large majority of individuals had a close relative as their next of kin. An adult child was the nearest relative for 66.5% of the sample. Brothers, sisters and other relatives accounted for 22.3% of the other relationships named as next of kin. Eight per cent of individuals were supported by their spouse/partner. See Table 8 below.

*Table 8. Kinship of tenant with next of kin*

Kinship	Frequency
None	2 (0.9)
Close friend	5 (3.0)
Brother	10 (4.3)
Sister	13 (5.6)
Spouse/partner	19 (8.2)
Son	29 (12.4)
Other relative	29 (12.4)
Daughter	35 (15.0)
Adult child (not specified)	91 (39.1)
Total	233 (100)

Data missing N=10

### Dementia Diagnosis

The majority of records in the facilities registered the diagnosis as “dementia” (29%) as shown in Table 9. In all the eleven categories of diagnosis obtained, the prevalence was

higher in females than males, except for “alcohol related dementia” where three out of the four cases were males. In total 72% of females had a diagnosis, compared to 28.1% of males. This gap between males and females is considerably higher to that of individuals in England and Wales where the prevalence of dementia in residential and nursing care homes for females has been reported at 59.2% and at 48.8% for males (Matthews & Dening, 2002)<sup>4</sup>.

*Table 9. Diagnosis of dementia*

Type of dementia	Male	Female	Frequency (%)
Dementia (type unspecified)	1 (0.5)	1 (0.5)	2 (1.0)
Early Dementia Onset	1 (0.5)	1 (0.5)	2 (1.0)
"Dementia" and other neurological condition	1 (0.5)	3 (1.4)	4 (1.9)
Alcohol Related	3 (1.4)	1 (0.5)	4 (1.9)
Dementia			
Other Neurological Condition	1 (0.5)	4 (1.9)	5 (2.4)
Type Unknown	1 (0.5)	4 (1.9)	5 (2.4)
Pre-senile/Senile	1 (0.5)	6 (2.9)	7 (3.3)
Dementia			

<sup>4</sup> All references related to prevalence comparisons correspond to the same source: Matthews, F. E., & Dening, T. (2002). Prevalence of dementia in institutional care. *Lancet*, 360(9328), 225-226.

Probable	Alzheimer's	2 (1.0)	6 (2.9)	8 (3.8)
Disease				
Cognitive Impairment		4 (1.9)	6 (2.9)	10 (4.8)
Korsakoff's Dementia		5 (2.4)	7 (3.3)	12 (5.7)
Other Dementia		6 (2.9)	11 (5.2)	17 (8.1)
Including Mixed Type				
Dementia				
Vascular Dementia		10 (4.8)	15 (7.1)	25 (11.9)
Alzheimer's Disease		8 (3.8)	40 (19.0)	48 (22.9)
"Dementia" as per file		15 (7.1)	46 (21.9)	61 (29.0)
Total		59 (28.1)	151	210 (100)
				(71.90)

Data missing N=33

The number of co-morbidities reported within the sample was 2.5% having no co-morbidities and an equal proportion of individuals with the highest number of eight co-morbidities. More than 25% of individuals experienced one co-morbidity, with cases of between two to four comorbidities accounting for 54% of the sample. The most common type of co-morbidity was mental health behaviour disorders at 11.4%, followed by diabetes at 10.4%. A small proportion of individuals (2.5%) had orthopaedic implants, reflecting the low proportion of those with falls (0.5%). Other serious conditions including, heart/cardiovascular disease, diseases of the circulatory, respiratory and nervous systems were more common.

Seventy per cent of individuals had not been hospitalised in the last twelve months. Less than a quarter had been in hospital once and the remaining 7% had been hospitalised between two to five times. Attendances to GPs in the last year ranged from zero (37.4%) to 20 (0.5%). Nearly 18% of individuals had attended their GP once, 14% had attended twice and nearly 12% had seen their GPs three times. The most common cognitive symptom reported was 'loss of memory' (88.4%). Two other common symptoms reported for more than 50% of the sample were 'disorientation' and 'poor judgement.' Table 10 shows that out of the seven symptoms listed on the extraction form, the least reported symptom was 'difficulties understanding spoken language' at 18%.

*Table 10. Classification of cognitive symptoms*

Symptom	Frequency (%)
Loss of memory	177 (88.4)
Disorientation	108 (54.0)
Poor judgement	107 (53.7)
Inability to reason	79 (39.3)
Wandering	71 (35.3)
Difficulties understanding written language	40 (20.0)
Difficulties understanding spoken language	36 (18.0)

Data missing N=42

#### [Summary of Demographic Data](#)

This section gives a snap shot of a point in time of the demographics of the population of people who have dementia and live in TESA. The purpose of gathering this data was to obtain quantified data on the tenant profile before moving to engage this sample in the

research. The housing schemes were operating at 91% of the occupancy at this time, with four out of the nine schemes at full capacity. This accounted for 243 tenants, with a mean age of 79 years of age and 28% male. Over half of this sample were living on their own before moving into TESA and adult children were most commonly reported as next of kin. The overall health profile of tenants indicated that co-morbidities were very common but 70% of tenants had not required a hospital visit in the last year. Loss of memory was the most common symptom reported at 88.4% of the tenants living in TESA.

## [Environmental Audit](#)

### [Introduction](#)

The environment in which a PLWD resides within can have a significant impact on their quality of life (Smith et al., 2012). The Environmental Audit Tool (EAT) (Fleming, 2011) provides a person-centred assessment tool for 'home like' care facilities. It is described as an observational tool that required the researcher to explore the environment alongside a member of staff (Fleming, 2011). The researcher within this project was a Professor of Occupational Therapy. An onsite environmental audit was completed at eight sites and three of those sites required two audits due to the differing facilities available for example bungalows and apartments.

### [Environmental Audit Tool](#)

The Environmental Audit Tool (EAT) (Fleming, 2011) was used to evaluate the facilities. This tool comprises 72 items selected to represent a set of design principles used in the development of facilities for older people experiencing difficulties. The items are grouped according to ten principles whereby the environment should:

1. Be safe and secure

2. Be small
3. Be simple with good visual access
4. Have unnecessary stimulation reduced
5. Have helpful stimuli highlighted
6. Provide for planned wandering
7. Be familiar
8. Provide opportunities for a range of social interactions from private to communal
9. Encourage links with the community
10. Be domestic in nature providing opportunities for engagement in the ordinary tasks of daily living.

The majority of questions are answered either 'yes' or 'no', some have a '*not applicable*' option and some provide for extra points in certain circumstances, for example, if the safety feature is unobtrusive. Each principle is considered to be a sub-scale with a score expressed as a percentage of the available score to ensure that all sub-scales have equal weight. The total score is the mean of the sub-scale scores(Fleming, 2010). The higher the percentage, the more adequate the facility is to accommodate people experiencing dementia.

### **Results**

Eight facilities completed the audit. Three of the sites completed two audits, one for each of the type of accommodation offered in the facilities (e.g. enclosed bungalows/flatlets and group facilities). The final scores in each of the domains were compared and the results are presented herewith.

### **Be safe and secure**

The principle of safety and security is measure with 14 statements that cover a wide range of safety measures across all living environments, including the garden, kitchen, front

entrance, bedrooms, etc. Safety is focused on keeping doors secure, keeping knives and/or appliances in the kitchen safe, ensuring the safety of the water temperature and providing adequate supervision to all tenants.

The majority of the facilities, as shown in Figure 4, had scores of over 50% in this principle, with the highest score being 63.64% and average 50.41%. The lowest score of 27.27% corresponds to independent accommodation offered in one of the sites (i.e. bungalows) in which every single tenant is responsible for their own safety measures, therefore staff completing the audit rated most of the answers as '*not applicable*', hence the low score.

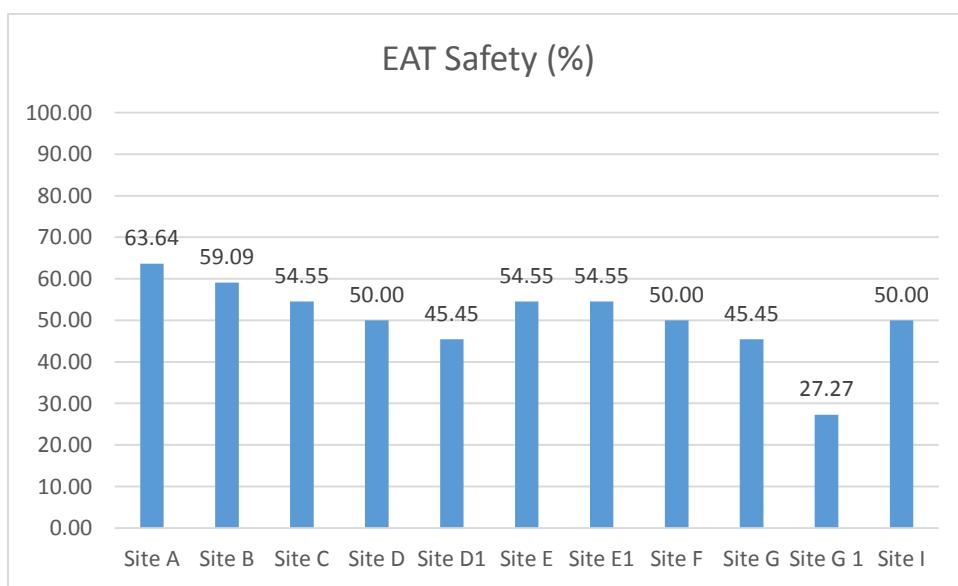


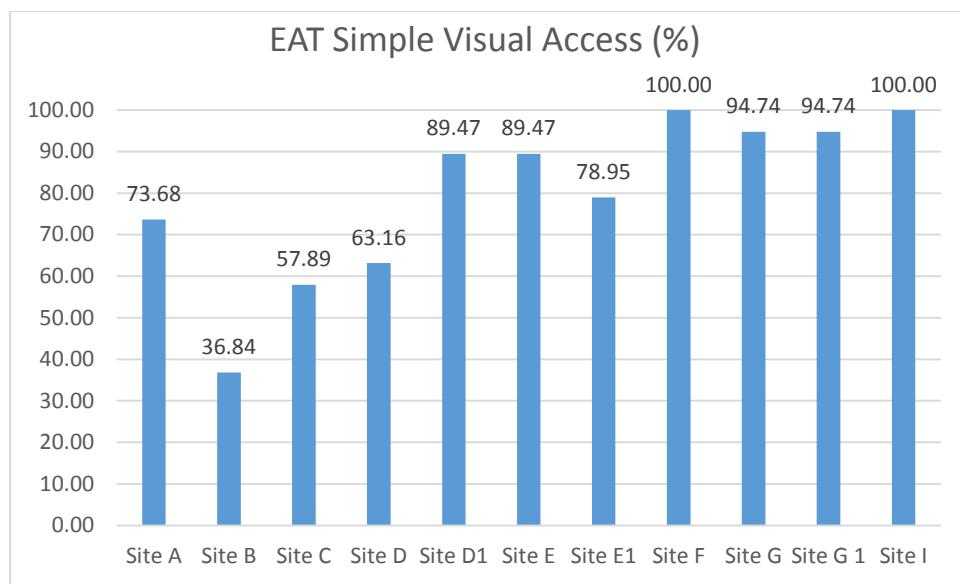
Figure 4. Safe and secure environment assessed with the EAT

### **Be small**

Data on the size of the facilities are incomplete (40%). The complete data indicate that nearly 30% of the facilities scored 100% in size, that is, they offered accommodation for ten or fewer people.

### **Be simple with good visual access**

The scores in this domain, as shown in Figure 5, range from 36.84% to 100% which reflect the principle of reducing confusion and providing an environment where tenants can see everywhere they want to go from wherever they are. The average score reported was 79.9%. The lowest score of 36.84% (Site B) corresponds to a facility for up to 30 people consisting of terraced houses with each house containing six en-suite single bedrooms. These houses incorporate a group living situation where a large kitchen with dining rooms are at the heart of the home, designed to enable people to participate in cooking, cleaning and other meaningful activities.

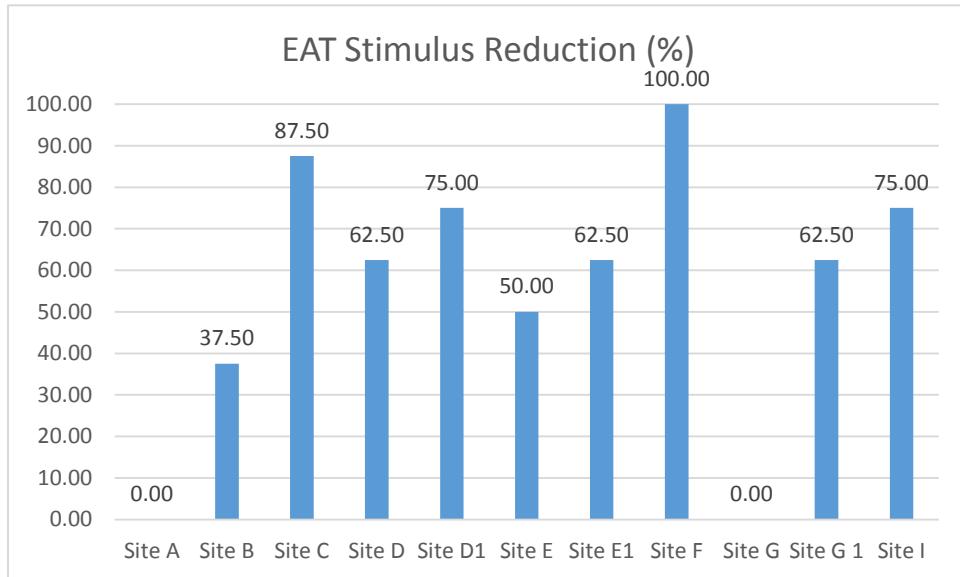


*Figure 5. Scores for visual access features assessed with the EAT*

#### **Have unnecessary stimulation reduced**

In this domain data are incomplete in two cases, thus, two of the facilities have a score of 0%. Again Site B, due to its special characteristics as explained above, has a low score of 37.5%. The rest of the scores vary from 50% to 100%, averaging 55.68% indicating that the

facilities are encouraging and achieving, in most cases, the reduction of unwanted stimulation as illustrated in Figure 6.



*Figure 6. Scores for stimulus reduction features assessed with the EAT*

#### **Have helpful stimuli highlighted**

Fifty per cent of the sites had a score of 100% in this domain, and an average score of 79.8% was reported, showing that the facilities provide tenants with the appropriate environment, so that they have access to all the areas with the minimum or no obstruction. The lowest score in this domain was 66.67%; there are data missing for one facility, therefore the score is shown as 0% (Figure 7).

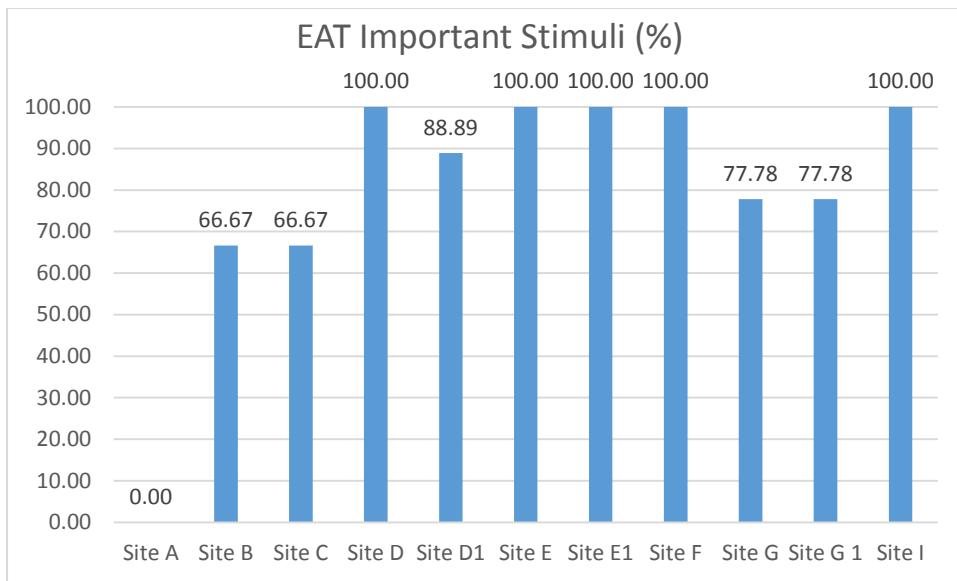


Figure 7. Scores for highlighting important stimuli assessed with the EAT

#### Provide for planned wandering

Data are complete for this principle. The results, which range from 33.33% to 100% and gave an average score of 78.79%, indicated that the facilities' design allows for safe wandering. The lowest score of 33.33% corresponds to a site where tenants live independently and enter and exit the facilities on volition (Figure 8).

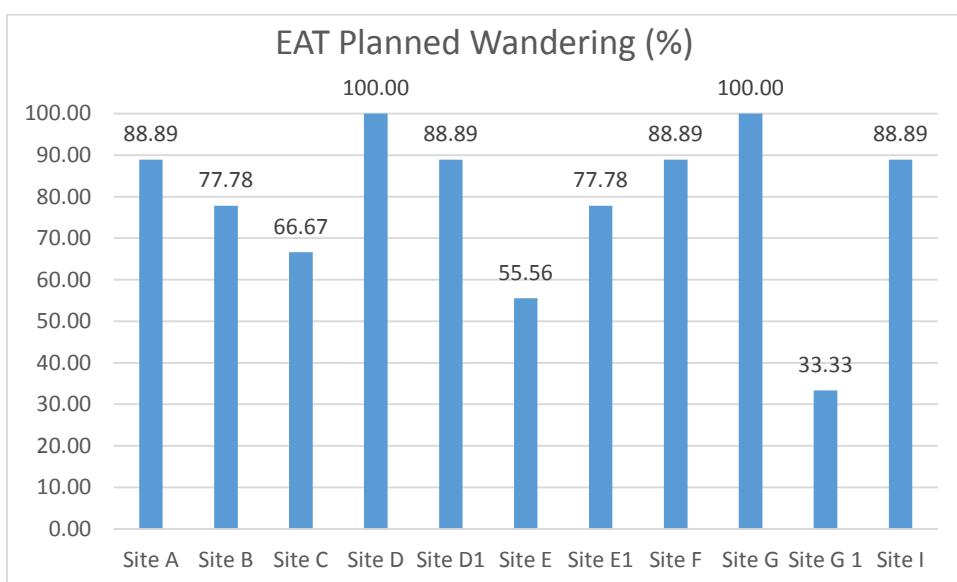


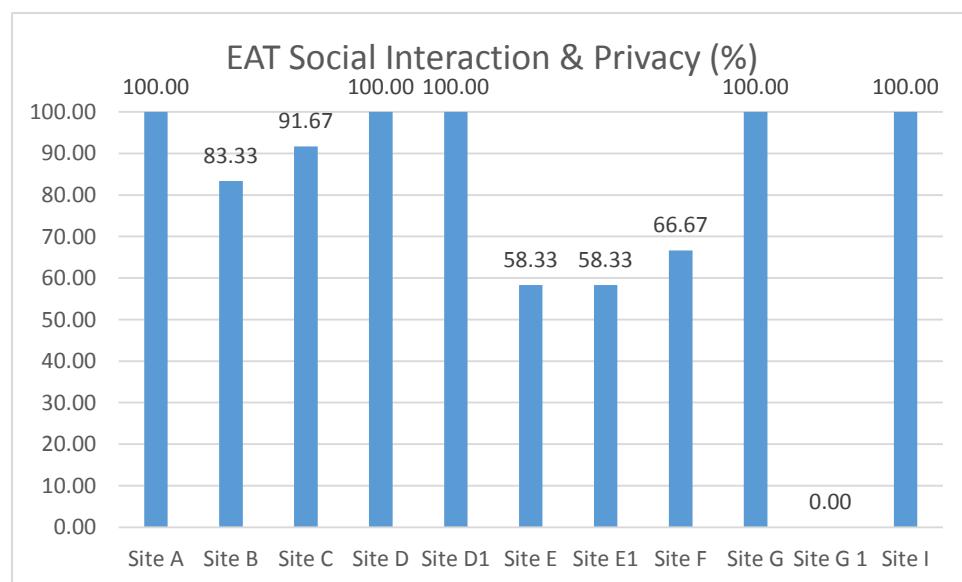
Figure 8. Scores for provision of planned wandering assessed with the EAT

### **Be familiar**

The principle of offering familiarity scored at 67% in all the facilities which is a good indicator that tenants are familiar with their surroundings and that most of the furniture items and décor are their own.

### **Provide opportunities for a range of social interactions from private to communal**

As shown in Figure 9, 4 of the facilities have a score of 100% in this principle and the remaining sites had scores ranging from 58.33% to 91.67%. The site scoring 0% corresponds to independent accommodation where tenants live in their own flatlets or bungalows, thus, the items used to measure this principle are '*not applicable*.' These results indicate that the facilities evaluated provide good opportunities for social interaction as well as private spaces to meet with friends or family.



*Figure 9. Scores for privacy and social interaction assessed with the EAT*

### **Encourage links with the community**

Eighty one point eight two per cent of the sites scored 100% in this principle, which demonstrates that the facilities provide tenants with opportunities to link with the community and encourage them to maintain and cultivate relationships with family and friends. **Be domestic in nature providing opportunities for engagement in the ordinary tasks of daily living**

Five of the facilities had a score of 100%, with the remaining scores ranging from 62.5% to 93.75%. These results demonstrate that the facilities are homelike environments that offer tenants opportunities to maintain their abilities for as long as possible and to live independently for longer in the community (Figure 10).

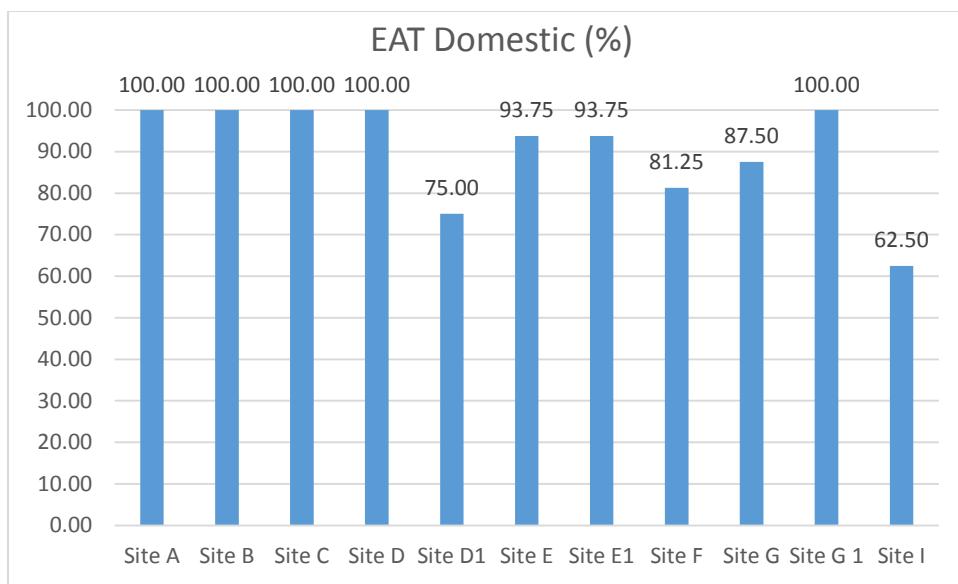


Figure 10. Scores for facilities being domestic assessed with the EAT

#### Summary of the results

The environments were poor in terms of safety and security which is possibly due to the nature of supported living enabling tenants to be as independent as possible (Table 11). The schemes were often larger than recommended which can lead to more confusion for the tenants. However, this item had missing data from four schemes. The data indicated

that the TESA schemes were simple and had good visual access to reduce confusion for tenants. A fair job was undertaken to reduce the unnecessary stimulation for tenants. The important stimuli were highlighted within the scheme which included good signage and aids to recognise familiar objects in their environments. The highest scoring item was 'be domestic' at 90.34% on average, ranging between 58.93%-100%, which indicated that the schemes within TESA were as homelike as possible. The total scores reported within the EAT ranged from 58.93%-77.68%, with an average of 71.19%. This descriptive data provides a reliable audit tool to assess if facilities are person-centred and assess the quality of the physical environment. The score indicated a moderate result and indicate improvements could be made.

*Table 11. Outcome from Environmental Audit Tool*

Principle	Score	Commentary
2. Be safe and secure	Range: 27.27%-63.64% Average: 50.41%	Poor in terms of safety and security.  Lowest score represents independent bungalows where each tenant was responsible for their own safety measures.
3. Be small	Range: 0%-100% Average: 45.45%	Poor in terms of size.  Three facilities scored 100% as they offered accommodation for ten people or less.  Data on the size of the facilities was incomplete (4 schemes).
4. Be simple with good visual access	Range: 36.84%-100% Average: 79.90%	Reducing confusion and visual access was a high score in most sites.  Lowest score reflects group living accommodation fostering a 'home based' design.
5. Have unnecessary stimulation reduced	Range: 0%-100% Average: 55.68%	Did a fair job of reducing the stimulation.  Majority of sites reducing unwanted stimulation.  Two sites 0% due to incomplete

			data.
6.	Have helpful stimuli highlighted	Range: 0%-100% Average: 79.80%	Lowest score reflects group living accommodation fostering a 'home based' design. The data indicated the schemes did a good job highlighting important stimuli. 5 sites achieved 100%. Data missing for one site.
7.	Provide for planned wandering	Range: 33.33%-100% Average: 78.79%	The data indicated schemes were designed to facilitate wandering but not encourage it. Low score indicates where tenants live independently.
8.	Be familiar	All scored the same Average: 66.67%	Moderately familiar surroundings and personalised tenants environment.
9.	Provide opportunities for a range of social interactions from private to communal	Range: 0%-100% Average: 78.03%	Indicates that tenants have good opportunities for social interaction and a choice of private spaces.
10.	Encourage links with the community	Range: 0%-100% Average: 81.82%	Suggests tenants have great opportunities to engage in community.
11.	Be domestic in nature providing opportunities for engagement in the ordinary tasks of daily living.	Range: 62.5%-100% Average: 90.34%	This high score reflects the home like environments found within TESA.

## Technology Audit

Whilst significant work has been completed globally on novel technologies to support PLWD there is limited research to explore or evaluate the impact of such technologies within supported living environments (Daly Lynn et al., 2017). A first step to enhance our understanding of the TESA facilities within Northern Ireland, was to gather data on the type and range of technologies used. The literature review in Chapter 2 identified how wearable devices, electronic tracking, companion robots, movement sensors and digital tools, for example, calendars, could all support PLWD in a care setting (Daly Lynn et al., 2017). The purpose of the audit is to set out the technologies used in TESA in Northern Ireland.

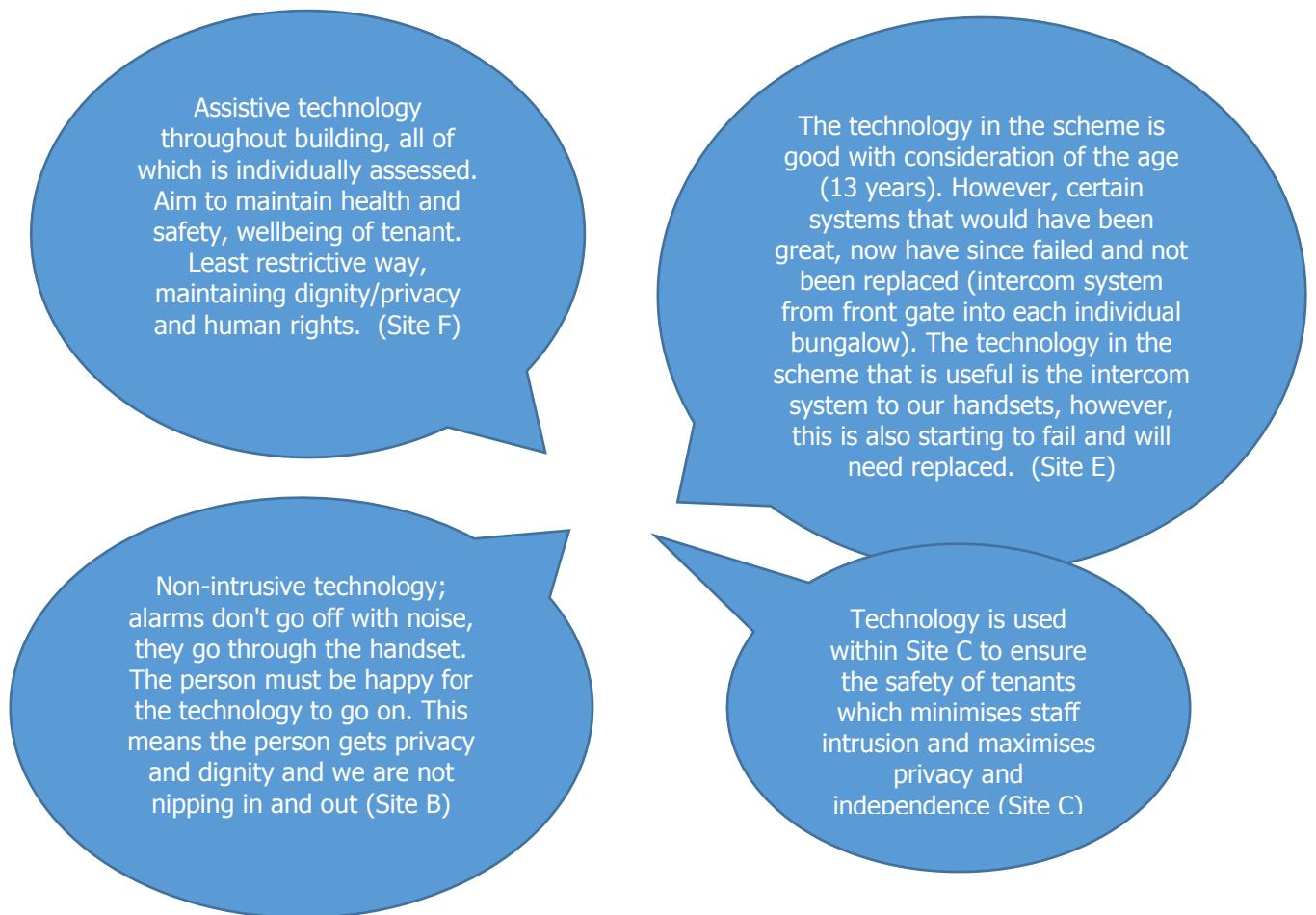
## Methodology

The Technology Audit Tool was developed as an outcome from the literature review undertaken in TESA-DRI (Daly Lynn et al., 2017). Due to the breadth of data to capture from the schemes and the complexity of terms for non-experts used in this field, it was decided to divide the audit into two parts. The first part was a template (Form A, Appendix 10) for completion by a designated person (scheme manager or senior member of staff) in each scheme to complete in their own time and email it back to the research team. A follow-up phone call was then made to the designated person to discuss the outcome of audit form A and complete part B (Appendix 11) over the phone. Audit form A contained 29 questions which consisted of multiple choice items, dichotomous variables ('yes' or 'no') with the option to expand on the answer given and three open-ended questions, two of which asked

participants to describe the technology used within the housing scheme and how a member of staff received alerts, and a final question giving participants the opportunity to make any other comments they felt were appropriate and were not included in the questions. The second part of the Audit (B) posed open ended questions as well as six multiple choice questions around policy, procedures and data management. The outcome from the Technology Audit is outlined for each scheme involved in the project. A total of eight schemes completed audit form A and four completed Audit form B. All data was included even if the second part of the audit was not completed. Numerous attempts were made to complete the audit B with the schemes where data were missing however the busy nature of the scheme meant it was not possible to fully complete all the audits. Only site H did not complete, as it was lost to attrition.

## Results

The opening question of the audit asked the scheme to describe the technology they use (Figure 11). Four of the schemes emphasised the advantages of the technology in terms of the independence and security it provided. The intercom system connected to handsets featured as a useful tool to provide alerts to staff while being non-intrusive. Two of the facilities emphasised the ethical use of technology prioritising privacy, dignity and human rights. Equally, technology in these facilities was used in non-restrictive ways, according to need and choice and with the main purpose of preserving the health, safety and wellbeing of the tenants. One facility pointed out the need to modernise the technology as it remained unchanged since its inception more than ten years ago. Three out of the four schemes that responded to Audit B stated that their technology systems were bespoke for their scheme.



*Figure 11. Housing schemes description of technology within facilities*

The earliest technology enriched scheme was opened in 2002, while the most recent was opened in 2014 (Table 12). This is an interesting observation in itself as the available technology would have changed significantly within those twelve years. CCTV was used at the entrance within four schemes, but no scheme used CCTV to monitor the entrance to individual tenant's flat or bungalow. Only one scheme (Site C) reported that there was no intercom or communication system in the tenants flat or bungalow. Two sites specified that tenants are able to use the intercom to see who is at their front door. Interestingly in

relation to the intercom, Site I stated '*there is but it's not used very often because it is confusing for tenants*'.

*Table 12. An Overview of Technologies within TESA Schemes*

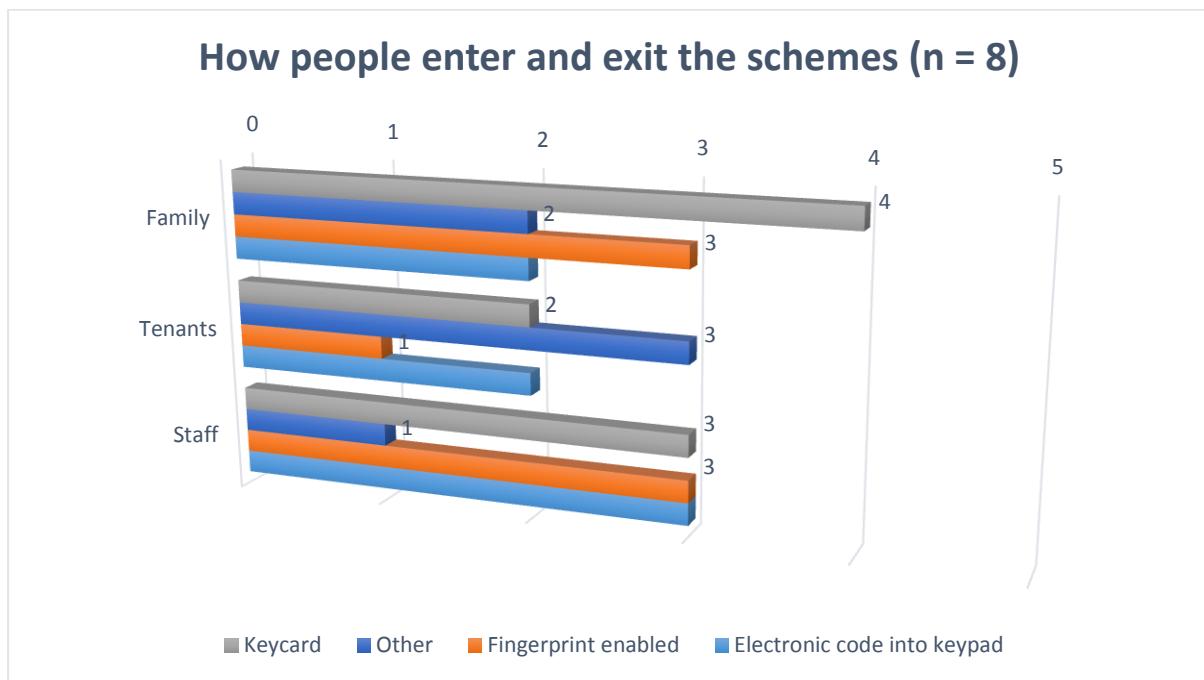
Name	Technology audit	Year Opened	CCTV entrance	CCTV in scheme	CCVT entrance to tenants flat	Intercom in Tenants flat	Staff alerts
Site A	A	2012	✓	✓	X	✓	Mobile phone
Site B	A	2005	X	X	X	✓	Mobile phone Monitoring station
Site C	A & B	2002	X	X	X	X	Mobile phone Monitoring station
Site D	A	2014	✓	X	X	✓	Staff pager
Site E	A & B	P1:2004 P2:2009	✓	✓	X	✓	Mobile phone
Site F	A	2008	✓	✓	X	✓	Staff pager
Site G	A & B	2005	X	X	X	✓	Mobile phone
Site H	-----	2011	-----	-----	-----	-	-----
Site I	A	2001	X	✓	X	✓	Mobile phone

\*P1= phase 1; P2= phase 2

#### *Sensors Used within the Scheme*

Entry in and out of the scheme are outlined in Figure 12 below. Two sites stated that tenants were not allowed to move freely. At five of the facilities audited, the first three modes of access (*electronic code into keypad, fingerprint enabled, key card*) were used by the three groups in diverse ways. The *electronic code into keypad* was used by all groups in the three facilities. One of these facilities also provided all users with a *key card*. At two facilities tenants were not provided with any assistive technology to enter or exit the scheme, instead, at one of them staff and families were *fingerprint enabled* and at the other

facility only staff were provided with an *electronic code into keypad* for direct access. The *other* method of entry and exit used by one of the schemes was a *key fob* (Figure 12). In two of the eight facilities evaluated, all three groups of users could ring a door bell or intercom to gain access (*other* category); this alarm goes to a handset which is generally held by a staff member. Tenants in these facilities were also free to go in and out using a key or key fob to their own front door. Family members and staff also had the option of ringing the intercom at the front of each property for access. Additionally, in one scheme tenants had their own key (*other* category) to enter and exit the scheme. Site F undertook a risk assessment with tenants to assess capacity for finger print access or the need for a locked environment.



*Figure 12 Assistive technology used by staff, tenants and families to enter and exit the schemes*

Additionally, data were collected on the sensors at various doors within the schemes: the main reception door, the doors to tenant's flats/ rooms and the side door, as illustrated in

Figure 13. Seven schemes reported sensors on the door of tenants flats or room to notify staff of the tenant entering or exiting the living space. Two schemes had no sensors on side doors and only two facilities had sensors to monitor traffic through the main reception door. One scheme had no main reception as tenants lived in bungalows.

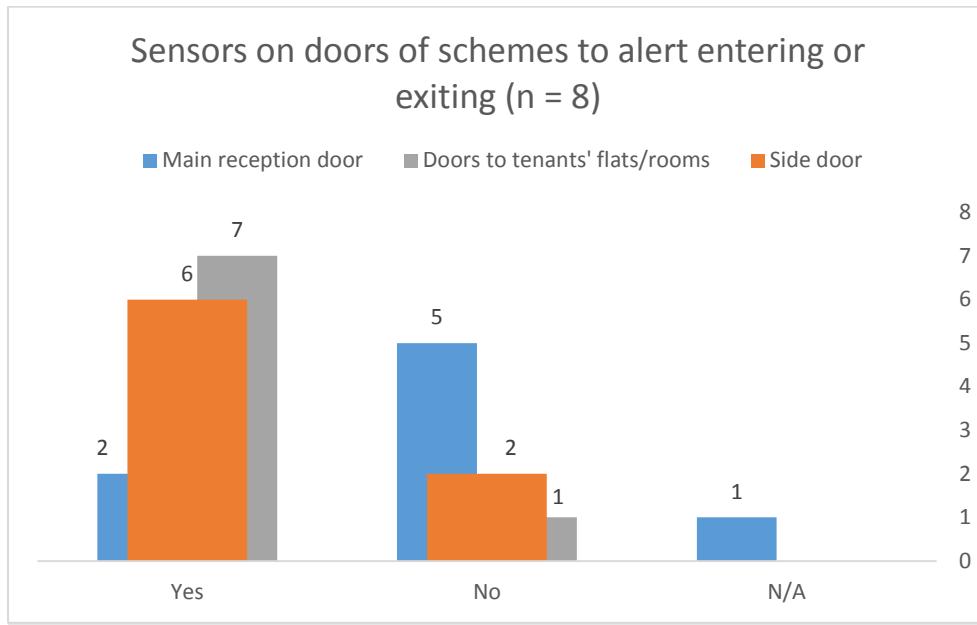
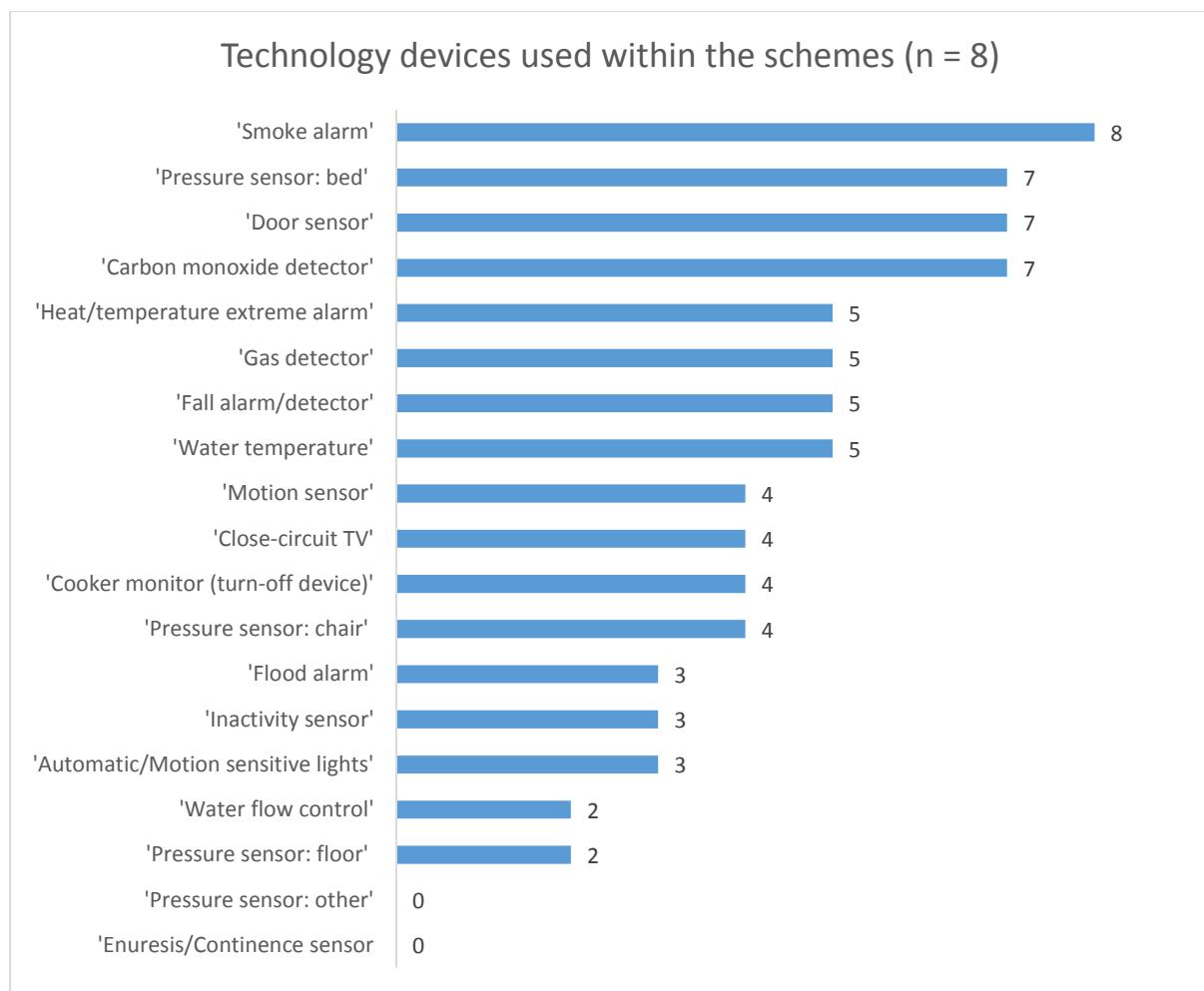


Figure 13. Sensor technology on doors within the scheme

#### Pervasive Technologies within the Scheme

Pervasive technologies used somewhere within the scheme whether it was the tenants home, common living environments and/ or customised areas were reported by schemes and illustrated in Figure 14. All schemes used smoke alarms and one site reported not using a carbon monoxide monitor (Site G). Devices such as fall detectors, bed sensors and chair sensors were widely used but primarily where there was a need as opposed to routinely adopted. No scheme reported using enuresis/continence sensors.



*Figure 14. Technology devices used within the scheme*

#### Devices Worn by Tenants

The findings from the audit indicated that wearable devices were only used with specific tenants if they indicated a need. Therefore, wearable devices were not part of routine provision but after a needs assessment. The sites that reported availability of wearable devices are outlined in Table 13 below.

*Table 13. Wearable Devices Worn by Specified Tenants*

	Site A	Site B	Site C	Site D	Site E	Site F	Site G	Site I
Electronic Tracking Device	✓	✓	✓				✓	
Alarm pendent			✓	✓	✓	✓	✓	✓
Alarm bracelet	✓		✓	✓	✓	✓		✓

## Devices Used within the Scheme

Figure 15 illustrates the wide ranges of devices available and used by tenants within the TESA schemes. The most frequently reported device used by tenants was a mobile phone. A music player, a TV and a computer were the electric devices most frequently made available to all tenants. No tenants had access to robotic companion devices. Site I had a Snoezelen room in situ with a water bed, water that changes colour, aromatherapy and fibre optics with colour changes. These rooms are considered a useful non-pharmacological intervention for PLWD (Sánchez et al., 2016).

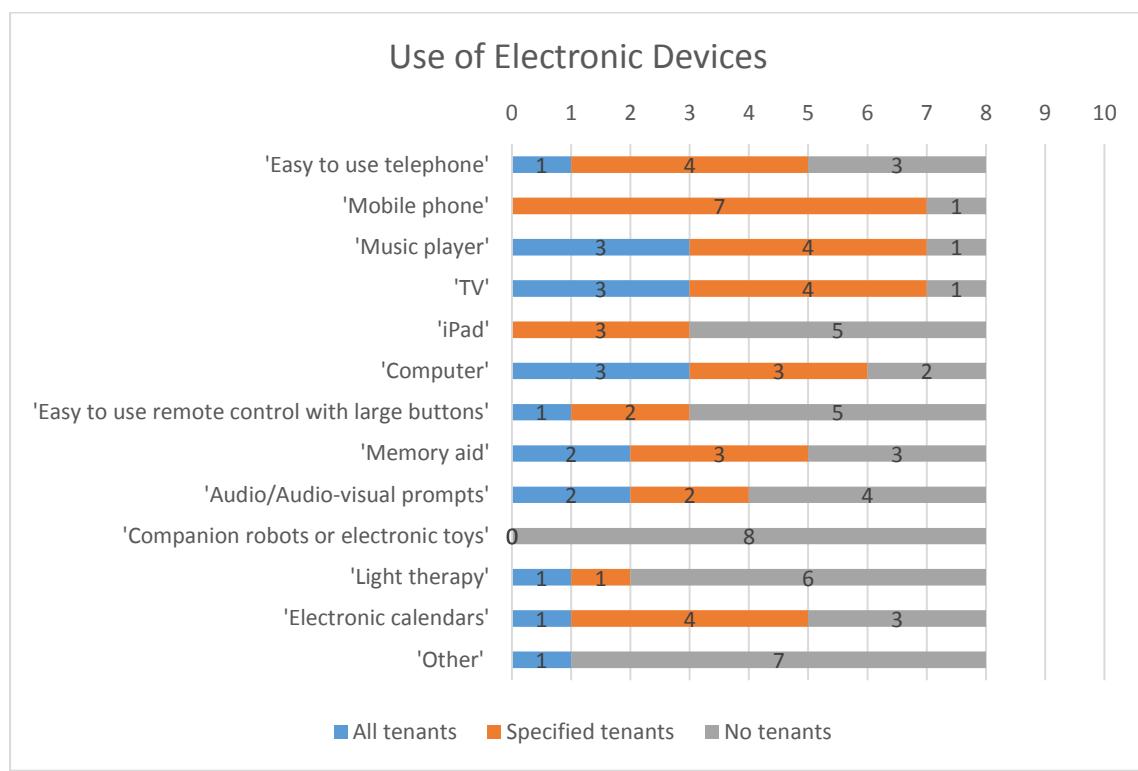


Figure 15. Electronic devices used by tenants

## Calling for Assistance

Schemes first outlined the method tenants used to get help in an emergency and then specified if this was different from routinely requesting assistance. The methods of requesting help are illustrated in Figure 16. Four schemes used a combination of methods to get help, one site used wearable devices, wall fixed buttons and pull cords, the other

three used a combination of two types of alarms, the pull cord and either the wearable device or fixed button. One scheme stated '*Wall fixed buttons are available but are not used very frequently because of the issue of lack of capacity; the tenant will not know how to use it or will become confused with it (fall detector or monitor is used instead)*' (Site I). All but one scheme reported that the tenants' method of requesting help was the same inside their flat or bungalow as it was in the rest of the scheme. However, no further detail of this difference was supplied. Finally, staff primarily received alerts through mobile phones and pagers (Table 12). At two sites, alerts also came through to a monitoring station within the scheme. No alerts or alarms came through via a tablet or web application. The tenants received an immediate response from staff in all but one housing scheme. Staff were able to speak to the tenant from their phone to the tenants' intercom. For example, they would say "Mr X are you ok?" if the tenant was able to respond. If not staff would go and assist the tenant without delay' (Site F). The majority of sites used the same method of contacting staff requesting non-emergency assistance in addition to approaching the main office or speaking with staff or family when they see them. One site stated 'There is no difference because the technology is used as a preventative measure rather than a reactive one' (Site I). Interestingly, Site B reported 'The technology would be used more in the evenings to inform staff of tenants movement at night – and on the stairs – during the day it is not really in use. Some alarms are set aligned to time for example if the water left on – this will come through to the handset.

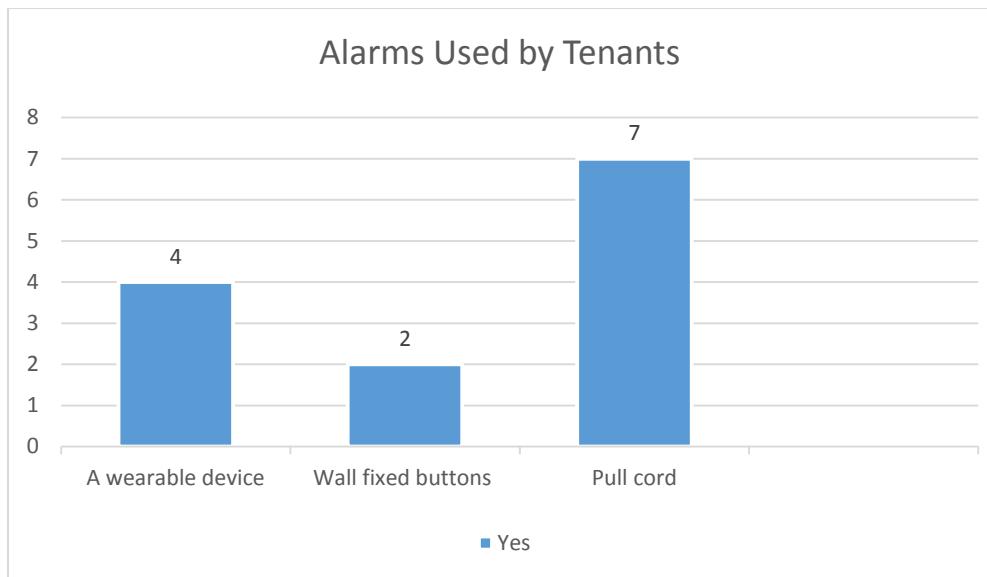


Figure 16. Alarms used by tenants to request help

## Data Management

Five sites send sensor data to management systems (Table 14). Four sites are recording data all the time in the background when the technology is triggered and the fifth sends data as required. The data is sent wirelessly at two facilities and is hardwired at two facilities. Site B does not know if it is hardwired. Two different types of information management systems were reported: health and social care information system; Paris (One scheme) and EPIC care (Electronic Pharmacist Intervention Clinical System) (two schemes). Additionally, the computer software programs were reported as: Pathlogic (1), Tunstall (2), Smart technology (1) and Telecare (1). Three sites state that they access and keep the data from the sensors and technology. Two sites report they access this data through a monitoring system and the third site does not specify. Staff report that the data is produced by the system in a readable format and used to inform care plans. The data is used at the three schemes (Site B, Site C and Site I) to identify tenants physical activity level and monitor sleep-wake pattern. Two schemes also reported the data being useful as an

indicator of changing health status by observing a '*shift in pattern of movement*'. Site I uses the data to investigate accidents for example, response times of staff. Three facilities have the ability for staff to change and adjust devices according to the time of day, for example '*door sensors time frame can be specific i.e. 8-8*' or the duration of time '*with sensors, there will be a five to ten minute-delay to allow the person to go to the toilet.*'

*Table 14. Data Management*

Technology	Site A	Site B	Site C	Site D	Site E	Site F	Site G	Site I
Collection of door sensor data	X	✓	✓	X	X	X	X	✓
Maintain electronic notes	X	✓	A combination of hardcopy & electronic	X	✓	✓	✓	✓
Keep sensor and technology data	X	✓	✓	✓	X	X	X	X
Staff access to data	X	✓	✓	X	X	X	X	✓
Ability to change parameters on devices	✓	X	✓	NA	NA	NA	NA	✓

NA= No answer

In the second part of the audit further detail is given around the management of data. One site reported that all the data is maintained and confidentially stored electronically by the company, Telecare. A second reported that no identifying details are included in the alarms and that all data is protected on the system that can not be accessed. Any other confidential data is reported to be stored in a locked office. Two out of the four schemes reported being able to access the data in a readable format and to compile a report with the data.

### Consenting to the use of Technology

Tenants were introduced to the technology within the scheme during the orientation following taking up tenancy. During this time, the various devices are explained to the tenant and their family. Site E encourage staff to discuss the technology frequently with tenants to increase awareness. All tenants were asked for consent to use technology (Table 15). As part of the tenancy agreement in Site C, the tenant consents to the use of technology within their living environment. Site E does not require family to give consent but they are informed about the use of technology.

*Table 15. Audit B Outcome Overview*

Technology	Site B	Site C	Site E	Site G
Staff training	X	✓	✓	X
Tenants consent	✓	✓	✓	✓
Family consent	✓	✓	X	✓
Data use	Individual care plans	Individual care plans	Not accessed	Not accessed

### Summary

A wide variety of technologies and devices were identified as being used in TESA, however these are primarily pervasive and not interactive. This is in keeping with the findings of the literature review (Daly Lynn et al., 2017). Drawing comparisons on the impact of technology is difficult however, as no two packages are the same. Bespoke systems were reported in three out of four of the schemes completing Audit B. Devices need to be personalised and individualised in order to provide person-centred care and yet the diverse technologies

illustrate the varied needs and requirements of PLWD. Additionally, this person-centred approach was evident in the provision of technologies to tenants according to their needs. However, a gap in learning is clear due to the heterogeneity of technologies within the housing schemes.

### [Overview of TESA in Northern Ireland](#)

The section aims to draw together the quantitative data gathered through the demographic information, environmental audit and the technology audit to give a sense of the TESA operating in Northern Ireland. Table 16 provides an overview of the data. The facilities were operating at 91% of capacity. A total of 72% were female and the age range was between 51 and 97 years (mean 79 years). Sixty-six point five per cent of tenants next of kin was an adult child and 55.2% of tenants were living on their own in advance of moving into TESA.

*Table 16. An Overview of TESA in Northern Ireland*

Name	Year Opened	Occupancy	EAT Score	CCTV use	Intercom in Tenants flat	Bed Sensors	Electronic tracking device	Wearable technology	Staff alerts	Use of electronic notes
Site A	2012	30	66.07%	✓	✓	✓	X	✓	Mobile phone	X
Site B	2005	39	64.29%	X	✓	✓	✓	X	Mobile phone Monitoring station	✓
Site C	2002	25*	71.43%	X	X	✓	✓	✓	Mobile phone Monitoring station	Electronic and hardcopy
Site D	2014	25	77.68%/75.89%	X	✓	✓	X	✓	Staff pager	X
Site E	P1:2004 P2:2009	23*	71.43%/74.11%	✓	✓	X	X	✓	Mobile phone	✓
Site F	2008	12*	76.79%	✓	✓	✓	X	✓	Staff pager	✓
Site G	2005	54	71.43%/58.93%	X	✓	✓	✓	✓	Mobile phone	✓
Site I	2001	30	75%	✓	✓	✓	X	✓	Mobile phone	✓

\*denotes occupied to full capacity; EAT= Environmental Audit Tool

The EAT indicated that the facilities were homelike environments for PLWD and supported independent living. This is in line with the person-centred principles experienced within the

schemes. Additionally, the items in the tool indicated good opportunities for social interaction, the environments support wandering and good visual access was found within TESA. Areas that scored lower were safety provision, unnecessary stimulation in the environment and the higher numbers within the schemes. The technology audit indicated varied technologies operating within the facilities, with little integration of interactive devices. The person-centred ethos was indicated through the individual and customised approach to technology provision. Tenants in all but one scheme received an immediate response from staff when they contacted them either routinely or in an emergency. Mobile phone use was common amongst the tenants. Finally, the data sent from the technology did not seem to filter into the clinical decision making and care planning of tenants.

### Summary

From this audit it is clear that the opportunity exists to support practice development of TESA by developing and promoting clear and standardised protocol for the implementation and use of technology in supported housing for PLWD. This could be made publicly available and should include;

- clarity on process consent for technology use starting prior to tenancy and reviewed during the course of the tenancy agreement
- an audit should be completed to ensure all sites are adhering to the General Data Protection Regulation (GDPR) outlining what technical and organisational safeguards are in place to protect tenants' data.
- guidelines on the types of hardware/software and information generated to inform future development. Little transfer of knowledge from one site to another was evident unless a provider had developed more than one site.

In addition there is a clear opportunity for further research on how the technology is integrated into care, informing decision making, risk management and how this information sits with notes and records. Beyond the alarms and alerts with associated services responses, opportunity exists to model these services against non-technology enriched facilities to map difference in care experience. Currently this would appear to be ad-hoc and location/staff specific. For example, a longitudinal case study from a tenant's care pathway informed by technology would be useful. As demonstrated within this chapter Northern Ireland now has a fairly impressive cluster of TESA, and whilst general policies exist to support these developments, focused policy and guidelines specifically on these builds may prove a useful addition.

## Chapter 5 Interviews with Tenants

### Introduction

There is evidence to suggest that PLWD are often not consulted on their experiences or perspectives of their lives (Novek & Wilkinson, 2017). The best way to understand the experiences of PLWD is to engage directly with them. A literature review outlined several studies that successfully engaged with PLWD in research to give a voice, an avenue to be listened to, feel valued and to be recognized (Murphy et al., 2014). Many studies have used inclusive methods to maximise the opportunity for participants with dementia to meaningfully engage in research interviews (Hubbard et al., 2003; McKillop & Wilkinson, 2004; Nygård, 2006). It is evident from the growing literature that PLWD do have the capacity to communicate their opinion and this is important when planning and delivering services. With this evidence in mind, this study sought to meaningfully engage PLWD in the supported housing schemes by working with peer researchers to authentically engage with tenants, who were research participants, in the research interviews. The peer researchers were older people with personal experience of dementia who were trained to work in partnership with the researchers. The peer researchers' role was to engage directly with the tenants during the interviews. Chapter 10 provides a detailed review of the peer researcher methodological approach and evaluation.

### Aims and Objectives

#### Aim

To describe the lived experience and perspectives of people with dementia living in TESA.

## **Objectives**

- To listen to and synthesise the perspectives of people living with dementia
- To explore the personal understandings of technology
- To explore indicators of person-centred care

## **Methodology**

This qualitative study used interviews to gather data from a sample of tenants living in TESA.

Interviews are widely used as a successful methodology to explore the experiences of PLWD (Hellstrøm et al., 2007; McKillop & Wilkinson, 2004). Providing participants with a safe, familiar environment and building an appropriate relationship are important components of the interview process. The aim was to recruit at least one but not more than three tenants for the interviews in each housing scheme. Table 17 outlines participant recruitment at each site. Peer researchers were trained to conduct the interview and the project researcher's role was to safeguard the process. Peer researchers were older people recruited to engage with the tenants. The purpose of peer researcher involvement was to move away from the academic interview and to capitalise on the peer relationship that can be built between individuals of a similar age and generation. Their role was central to the tenants' interview and is explained in more detail within chapter ten. An interview topic guide was prepared (informed by the person-centred framework) as part of the ethical governance process (Appendix 12). The interviews were undertaken at a time and place decided by the tenant, in collaboration with a staff member within the housing scheme. The duration and pace of the interview was dictated by the participant. The research team

spoke over the phone with the staff member and met this person on the day to be introduced to the interviewees.

## Recruitment

Participants for the one-to-one interviews were recruited through the housing schemes. The scheme manager identified approximately two to three participants that would be interested participating in an interview. All scheme managers were instructed on the procedure for consent and were asked to decide on the suitability of obtaining consent (Approach A) or process consent (Approach B) from tenants. This approach to consent is set out in detail in chapter three. A total of twenty-two participants consented using Approach A. At the beginning of each interview, the process of informing the tenant about the purpose of the interview was repeated and they were asked to give verbal consent in front of the researcher and peer researcher. One scheme specified that a member of staff had to be present during the tenant interviews.

*Table 17. Tenant Participant Recruitment*

Name	Tenants Interviews
Site A	N=2
Site B	N=3
Site C	N=3
Site D	N=3
Site E	N=2
Site F	N=3
Site G	N=2
Site H	N=2
Site I	N=2
Overall	N=22

## Data Collection

Each interview began in the same manner. The researcher and peer researcher were introduced to the participant by the member of staff in the location for the interview (primarily tenants flat, sometimes in a private room, and always within housing scheme). The staff member reminded the tenant about the interview and in front of the research team confirmed the tenant was still happy to take part in a one-to-one interview. The researcher then introduced the project, herself and the peer researcher. An opportunity was given to the tenant to consent to take part again and consent to the use of a voice recorder. The researcher's role of safeguarding and the peer researcher's role of directing the interview were established. Once the voice recorder was switched on, the peer researcher took the lead in the interview and asked questions based on the topic guide. The interviews were relaxed and the peer researcher aimed to build a rapport with the tenant. The aim was for the peer researcher to move the interview away from being an 'academic event' to a friendly conversation, focusing on feelings as opposed to fact and on occasion, the peer researcher would reflect on their own experiences. Each time the interview was ending, the peer researcher would focus on positive aspects of the interview to end on a high note and give the participant a sense of achievement. The researcher kept a diary of interviews to capture her own experiences and feelings and those of the peer researcher following a debrief.

## Data Analysis

All recorded interviews were transcribed verbatim by the researcher and a professional transcriber. All transcripts were inputted into the qualitative data analysis computer software package (NVivo 11). Each interviewee was given a pseudonym. The transcripts

were coded by reading and re-reading the material by one author to identify themes using a Braun and Clarke, (2006) thematic approach (Figure 17). These themes were then explored through the person-centred theoretical lens (outlined below), to develop and refine. The themes were then reviewed by the project team to discuss, modify and develop. The next step was to present the initial analysis to the peer researchers at a workshop. The peer researchers were asked to read the transcript of the interviews they completed and highlight the important components. This was then discussed within the group and key findings were developed. A summary of the analysis and proposed themes developed by the research team were then presented to the peer researchers. The similarities and differences were highlighted and the findings were validated.

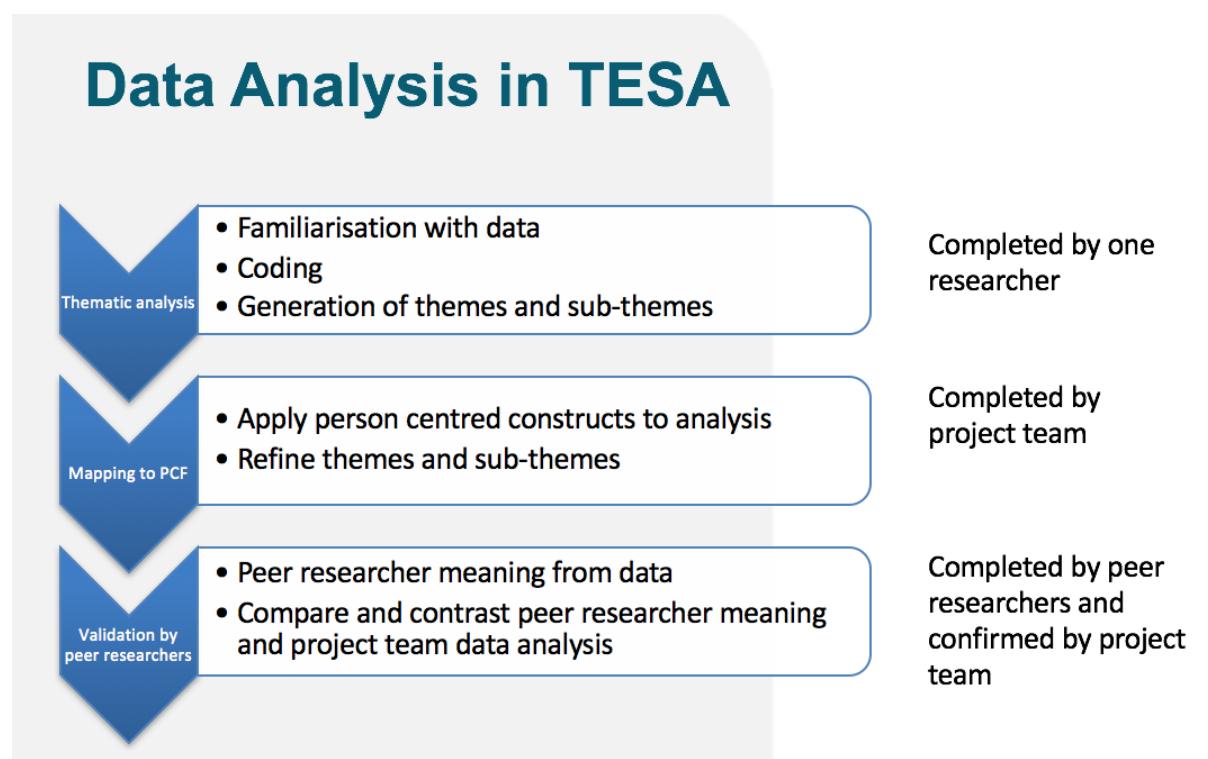
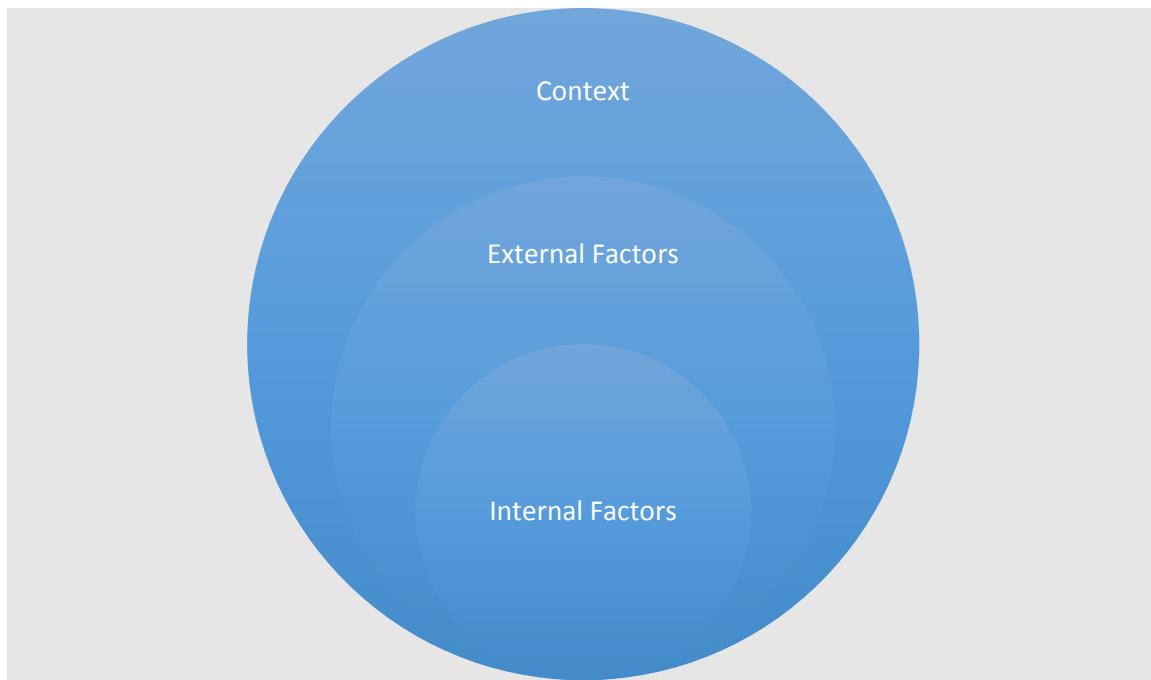


Figure 17. Data Analysis Framework

## Peer Researcher Data analysis

Three peer researchers attended a validation of the data session and a further two one-to-one meetings were held with additional peer researchers. First, peer researchers were given transcripts of the interviews to read. Primarily, they were given their own interviews but as people had completed a different number of interviews each, some were given interviews from other schemes. At least one interview from each housing scheme was read. A group discussion was undertaken around the important themes that emerged from reading the transcripts but also what people remembered from the interviews on the day. Discussions were based around the transition into the housing scheme; shared caregiving between the technology, staff, family and tenant; family providing support; and communication. A major discussion point was around the uniqueness of individuals and the importance of appreciating this individuality within a service. Safety and security, and stimulus (activities, communication, engagement and taking part) were also major themes that emerged in these discussions. After these discussions, the peer researchers were shown the coding framework used by the researcher during data analysis to identify any discrepancies. The peer researchers confirmed that they would neither add nor remove any of the codes. Finally, peer researchers were asked to generate three themes (Figure 18).



*Figure 18. Overarching Thematic Analysis based on Peer Researchers Validation*

Figure 18 conceptualised the thinking of the peer researchers and what they heard during the interviews. The first theme was the internal factors that directly impacted on the tenant such as contentment, communication, feelings, autonomy and relationships. The second theme was the external factors that impact the tenants' lives such as staff, family, security and technology. The final theme was the context in which the tenants' lives are set such as having roots in the community, the environment, and the scheme. The peer researchers were not aware of the person-centred framework that underpinned this work however, the themes that emerged reflected this practice. The findings from this validation stage were mapped against the four person-centred constructs and explored by the research team. This validation of the data was important and generated discussions to conceptualise the thinking of peer researcher.

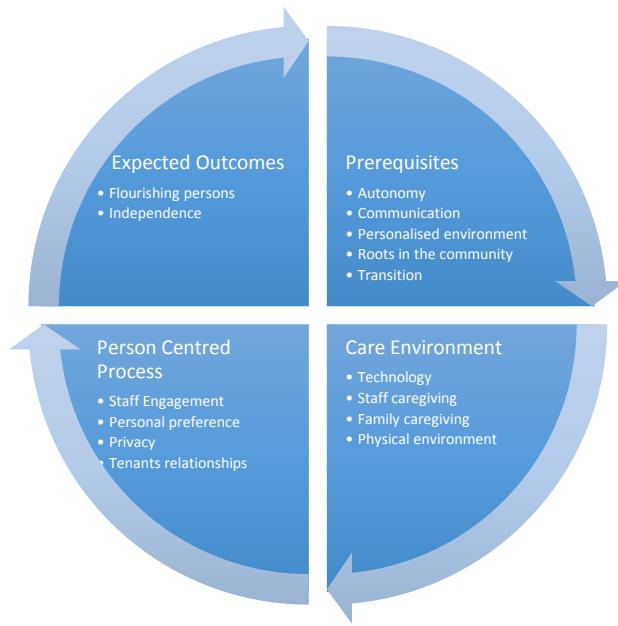
## Reliability and Rigour

The reliability of the data and rigour applied to the data analysis was set out within Figure 18. This framework enabled a process of peer validation and opportunities to reflect on the findings in the team, including the peer researchers. A data analysis journal was kept to document the journey through the data.

## Findings

A total of twenty females and two males participated in this stream of work. A quantitative measure of a person's cognitive impairment was not established. All individuals would have an established diagnosed dementia to be living within TESA. An individual would be living within supported housing if they were no longer able to live independently, however, they would have a range of residual skills deeming a nursing type home unsuitable accommodation. The interviews did not obtain any factual information, therefore, demographic information such as age and duration of stay with TESA was not gathered. This was in line with recommendations in the literature (Murphy et al., 2014).

The themes were organised into the four components of the person-centred framework (Figure 19). The prerequisites explored how the tenants should be treated and how they felt at the time of interview. The care environment construct looks at the impact of the environment and culture on the tenant. The person-centred process construct looks for evidence of person-centred care on a daily basis through the eyes of the tenant. Finally, the expected outcomes looked for evidence of outcomes in the tenants lives as a result of person-centred care within the scheme.



*Figure 19. Applying a person-centred lens to the Thematic Analysis*

#### Prerequisites

The prerequisites construct includes attributes that staff members bring into the role such as: beliefs and values, competence, commitment, interpersonal skills and knowledge of self, (McCormack and McCance, 2017). The data were examined for evidence of these prerequisites through the eyes of the tenants within the scheme as outlined in Table 18 below. The themes that emerged from the data were autonomy, communication, personalised environment, roots in community and transition.

*Table 18. Themes and Sub-themes of Prerequisites Construct*

Themes	Sub-themes
Autonomy	<ul style="list-style-type: none"> <li>- Being self sufficient</li> <li>- Freedom and choice to do what you like, when you like</li> <li>- Having a voice and being heard</li> <li>- Sense of community</li> </ul>
Communication	<ul style="list-style-type: none"> <li>- Communication with all stakeholders</li> <li>- Tenants choice to engage or not</li> </ul>
Personalised environment	<ul style="list-style-type: none"> <li>- Importance of own belongings</li> <li>- Adjustments to environment</li> </ul>
Roots in community	<ul style="list-style-type: none"> <li>- Feeling connected and sense of belonging to local area</li> <li>- Access to community services</li> <li>- Empowerment in the community</li> </ul>
Transition	<ul style="list-style-type: none"> <li>- The move into the housing scheme</li> <li>- Feeling associated with the move</li> <li>- 'Correct fit' in supported living</li> </ul>

### *Autonomy*

Some tenants reported a sense of being self-sufficient with an awareness of where to obtain help if they needed it. There was an awareness of help nearby but that tenants were living independently.

*'You're also getting help if you need it. You have your buzzer and that type of thing, but you're on your own. You can come and go when you like.'* **Denise**

Additionally, participants enjoyed doing things at their leisure when it suited them, for example, household tasks.

*'Well, just the same as I did when I had, when I lived in my bungalow before. Just getting up and getting myself ready and getting my breakfast and then just pottering about and seeing if I needed anything done.'* **Bridget**

The ability for tenants to be able to help when it suits them emphasises their autonomy but also creates a homely environment that they feel a part of.

*'I'd get up and give a hand in the kitchen or things like that.'* **Emma**

Tenants felt they had their own choice about whether to do something or not, for example take part in an activity, where to go on outings, where they would like to eat or what they would like to eat.

*'No, if you want to go out, you go out and if you don't, you don't'* **Aoife**

It was really important for individuals to be able to make decision for themselves, depending on how they were feeling at that time.

*'when I wake up in the morning I will decide what I am going to do today.'* **Stephen**

Most tenants did not cook a main meal for themselves. Their food came from several sources such as families, from the scheme, or ready meals from the supermarket or companies, such as Wiltshire foods, that provide directly to tenants within the scheme. Choice was a major factor for tenants' satisfaction with their food.

*'They have a choice. They have a form and they fill it in as to what you want. You get an option.'* **Denise**

Participants had a strong sense of self and a very clear voice. They spoke with pride about exercising control in their daily life. Equally, if they felt this sense of control was being violated they were more than capable of speaking up for themselves.

*'I don't care what everybody else is doing. If I don't want to knit, I'm not doing it, because I don't like it and I have no interest in it. Why should I sit and knit if I don't like it?' **Elma***

*'There's one who came in one night and said, 'Everyone to bed' and she switched off the TV. We were watching *The Secret*. We said, 'Hey, hey! Just put that back on again! You can't do that!', I told one of the staff.'* **Denise**

Additionally, this clear voice of tenants was very evident in one scheme as tenants gave feedback to the Trust on the scheme and comment on plans for a new building.

*'I have got to say that the trusts, do you know yourself, I do believe that they take our opinion and they have done since the start of this place I mean we were involved in the X (name of new scheme) road one as well so we were'* **Susan**

#### *Communication*

There was a strong sense of community within the schemes with communication firmly at the heart of this environment.

*'a couple of staff and a couple of the tenants who all sit round a table with tea and juice or something, a wee snack that the staff would make you. We'd sit and talk about different things and ask how we're settling in here.'* **Denise**

Effective communication between staff and tenants was essential. Additionally, good relationships with doctors, key workers and healthcare professionals were all very important.

*'I've got to know Mx, that's my key worker and I've become very friendly with her and she would come in and tell me something.'* **Jennifer**

It was very important to have the choice to engage with others or not. For some they have friends outside the scheme whom they prefer to communicate with.

*'I have friends and people that I am very friendly with and I could ring them and they would come to see me.'* **Helen**

For others, they prefer to keep themselves to themselves and maintain a sense of privacy.

*'Do you know this, I wouldn't tell anybody anything. I don't. I try to keep things to myself.'*

**Aoife**

#### *Personalised environment*

Tenants' environments were filled with personal items such as photos, books, TV's and their own furniture. Families were reported to support the move into the scheme and help decorate flats and rooms. Additionally, support was obtained through paid professionals such as painters.

*'I love my flat, that's up to me. Whenever I came into it, I still liked it but there were things that had to be done to it. Then men came in and did it in no time and would still do it.'*

**Celine**

A number of tenants noted the importance of gardens and flowers in their environment.

*'if I hadn't a garden I'll have a pot plant or, and have those wee plants out there, you know, and just keeping and admiring them, looking at them and seeing what they're doing.'*

**BrIDGET**

A number of adjustments were made to the environments to make it more accessible.

One participant spoke of items such as a yellow mat to hold plates so they do not slip off, warm water instead of hot water in taps, changing tiles to separate the floor from the wall, and different coloured walls in different rooms.

*'I mean I have the tape around there (orange tape placed around the door frame) basically because the door keeps moving (in her field of vision) so I knock myself out walking into it'*

**Susan**

#### *Roots in community*

Feeling rooted within the wider community gave the tenants a sense of belonging and connection. This was evident in many ways such as the area the scheme is situated, *'the school is just beside me here, the wee school and there's like a nursery school and if I had the door, the window open you would hear the children playing in the playground, you know, it's nice to hear the wee voices and all'*. **Bridget**

Additionally, going out into the community was important.

*'Aye. It's nice. If it's a good day we go places, rather than just sitting in here all the time.'*

**Celine**

*'I do love that, that's the highlight of my week, I always say because it just gives you such a boost sort of thing getting out and maybe looking around the shops or looking round at people even, I'm sitting in the wheelchair and peoples passing, and you look at their faces and you look at their children or... and that just takes you out of yourself too, you know.'*

**Bridget**

Tenants enjoyed members of the local community coming into the scheme, such as members of the local church coming to visit and local schools helping in the garden.

*'I think it's wonderful of the young generation coming down here to help in the garden.'*

### **Michael**

A number of tenants had a long history within the community such as having been a part of the GP surgery for a significant number of years and lived in the area for a number of years.

*'I love the church and I love being in the choir, 26 years in it.'* **Sally**

Participants also reported accessing services from voluntary and community organisations such as Age NI, the low vision clinic and home help. Additionally, tenants were keen to contribute to their local community.

*'We have a group Dementia NI and it basically is individuals having a voice to try and change things for themselves and others.'* **Susan**

### *Transition*

Participants discussed a range of different reasons for their move into the housing scheme.

Tenants spoke of moving into the scheme after experiencing a fall, having not been well or after a stay in hospital.

*'I can't remember why or when it happened that I came here. I had been in the hospital for a short time and this is where I was brought.'* **Celine**

Additionally, tenants reported moving into the scheme to take the pressure off their families.

*'I had to do it for my family because my family were going out of their minds with stress'*

### **Emma**

One individual spoke of feeling lonely and was afraid living in the community after her husband passed away.

*'Although I had carers, as I say, coming in but at night times it was a bit lonely and you got a bit afraid then, you know, and you were hearing about people getting break ins, you know,*

*and things like that so it got me a wee bit frightened then'* **Bridget**

Factors that impacted the move into that specific scheme included it being a convenient location for family to visit, having heard good things about the scheme through word of mouth and the importance of being able to have a pet such as a dog. Participants spoke of their families encouraging the move in some cases, with the choice remaining with the tenant, and in other cases, the tenant felt the choice to move into the scheme was made for them.

*'I didn't feel safe on my own environment so I was looking for somewhere to make me feel safe and secure.'* **Susan**

The majority of participants spoke positively about their transition into the housing scheme.

*'I honestly never regretted giving up my place and coming here.'* **Elizabeth**

*'When I came in here I knew... you know when you go in anywhere and you say I feel good going in there... that's the way I felt... it was so good.'* **Marie**

First impressions of the physical environment were really important,

It *'looked so modern and so nice, you know, fresh looking place.'* **Bridget**

However, grief of leaving their own home environment was still evident.

*'If I was fit and the doctors gave me the O.K, I would still like to have a wee place of my own.'* **Denise**

*'Although it's lovely here, you know, but you still think back to what you had before.'*

**Bridget**

*'I hated it, I hated it because I was on my own you see, at home and I hated in here.'* **Helen**

One of the biggest fears reported by participants was ever having to leave the housing scheme. The scheme had become home for the tenants and this is where they wanted to

live for the rest of their lives.

*'I would hate ever to go anywhere else, tell you the truth now, I would hate to go anywhere else, I love it here and I love the people.'* **Ann**

*'See if they said to me you have to leave- I would- it would kill me that is the only thing I love it that much.'* **Marie**

A number of tenants had lived for short periods in other care homes and residential settings before moving into the supported living scheme. They reported negative experiences because the other residents were not as physically capable as them, there were no activities, and felt there was limited staff support.

*'that place is very depressing'* **Michael**

Additionally, the nature of supported living care provision suited the tenants as they could access services in a way that suited them best. It was also viewed that the supported living environment was '*more homely*' **Sadie**.

*'I just couldn't go to a day centre or a nursing home there was no way and you know I gladly came here because I was well aware what it was about.'* **Susan**

#### Care Environment

The care environment construct includes attributes such as: the physical environment, appropriate skills, decision making, relationships, and innovation (McCormack and McCance, 2017). The themes that emerged from the data around the care environment were technology, staff caregiving, family caregiving and physical environment (Table 19).

*Table 19. Themes and Sub-themes of Care Environment Construct*

<b>Themes</b>	<b>Sub-themes</b>
Technology	<ul style="list-style-type: none"> <li>- Awareness of the presence of technology</li> <li>- Feeling secure with technology</li> <li>- Barriers to technology use</li> </ul>
Staff caregiving	<ul style="list-style-type: none"> <li>- Everyday caregiving</li> <li>- Tenants and staff working collaboratively</li> <li>- Empathy and genuine care</li> <li>- Respect for tenant</li> </ul>
Family caregiving	<ul style="list-style-type: none"> <li>- Everyday caregiving</li> <li>- Collaborative caregiving</li> </ul>
Physical environment	<ul style="list-style-type: none"> <li>- Positive attributes of the environment</li> <li>- Negative attributes of the environment</li> </ul>

### *Technology*

The lack of awareness about the technology was a major finding within the tenant's interviews. Many tenants were aware of the fire alarm but not every participant had an awareness of the technologies use within the schemes. There were a wide range of discussions around the use of devices such as pendant alarms, pull cords, buzzers, intercom systems, and mobile phones. A range of examples of the usefulness of technology in everyday life were illustrated.

*'If you need somebody, some help you've only got to talk there and ask for help if you need, if you had a fall or anything you can ring, cords to pull, you know.'* **Bridget**

*'I always use mine. Even if it's only for a simple thing, I find it's better to let the staff know that you're using it and you know how to use it.'* **Elma**

*'My best friend is my mobile.'* **Emma**

Alarms were not reported during the night time, however, tenants were very aware of the routine fire alarm tests. One individual spoke of using a computer, including applications like Skype and email to stay connected with her family living abroad. Another person reported that she would be lost without her iPad.

*'I got this as a present it is so easy it makes everything so easy you know for me now.'* **Susan**  
Dragon dictate was a useful application to enable one person to use speech typing as opposed to touch typing. During the interviews, participants in two separate schemes mentioned iPad training encouraged by staff within the scheme.

Many tenants were unaware of the technology within the scheme. When devices were pointed out in their environment, they were unsure of their use or tenants mentioned they did not use the devices.

*'I: Do you have any sort of system in the flat that you can use to call the staff?*

*P: No. No. I don't have anything like that.*

*I: No wee emergency buttons?*

*P: No'* **Celine** (*There was an intercom system and pull strings visible in Celine's environment*)

Additionally, tenants were required to remember to use such devices if they needed staff urgently.

*'Well at the time I fell in the bathroom, I was on the toilet and I got up and my head went dizzy and I fell. But the way I fell I never remembered about the thing you, the strings you pull, you know.'* **Bridget**

Some tenants felt they had no use for a mobile phone or else reported that a mobile phone was not given to them. One person felt they did not need a phone because they are 'safe' within the scheme. Additionally, tenants reported not wanting to disturb staff by using the technology available to them.

It was evident from the people who were aware and used the technology in their environment that it gave them a sense of security. One user of the pendant alarm stated, '*I feel comfortable because I know there's always somebody here if I need anything.*' ... '*I feel*

*secure.'* **Clare**

Another user spoke about the bed sensor and how when she gets up staff would ask her how she is through the intercom.

*'It's a good thing, because it makes you feel safe.'* **Denise**

Additionally, technology could be used in an emergency and this gave reassurance to those who would need additional support at times.

*'That's what I have the cord for if I needed anything or if I fell, I'm always very prone to falls. But then I don't mind, I don't mind falling now because if I fell or anything that's what that there's for, I just pull that.'* **Clare**

One participant spoke about using technology in the future as her dementia journey progresses. She has given her consent to the scheme for future use as she is particularly

concerned about night-time walking. When asked if she feels the use of technology would have an impact on her privacy, she responded:

*'I don't personally to be honest I think if it keeps you safe.'* **Susan**

There were also several barriers reported for using different type of technology. For example, for computers, and online accounts (email, Skype, Social media) passwords were often forgotten. Additionally, Wi-Fi was not widely available to the tenants. This really limited access to online services that would enable communication between the tenant and their friends and family.

*'They have Wi-Fi in lots of places but they don't have it here. I don't know why.'* **Denise**  
A commonly reported reason for not using the technology within the tenant's room or flat was because they did not want to disturb the staff.

*'I just don't like it, it's me, I can't go and press it because I think they've enough to do without coming up to me.'* **Helen**

Finally, there was also a belief that technology was not something they were accustom to and therefore, not relevant to them at this point in their life.

*'I'm not a computerised person.'* **Michael**

#### *Staff Caregiving*

Participants spoke fondly of the everyday care they received within the housing scheme. This satisfaction with care was reflected at all levels of staff and in various roles, such as managers, support staff, bus drivers, activity coordinators and house keepers.

*'I never was so well looked after in my life.'* **Ann**

Equally, the commitment and hardworking nature of the staff was recognised.

*'Let me tell you, the staff here never seem to stop. It's just go, go, go; 'Are you alright? Are you alright? Is this alright? Is that alright? Did you get this? Did you get that?' They are very, very good.'* **Aoife**

Tenants spoke of the support they received at meal times, getting their tablets, getting messages from the shop, communicating with family members, doing house work and general assistance when they needed it. The small touches and 'extra mile' staff went to for the tenants created a special relationship between staff and tenants.

*'One day I run out of milk, you know, and one of the carers brought me a drop of milk in, you know.'* **Bridget**

The importance of activity coordinators really shone through the interviews. Activities within the scheme were the cornerstone of the social calendar.

*'We get loads of outings, there's plenty of entertainment, it's again back to the staff, they work overtime just to keep us entertained and keep us good, they're really marvellous. I can't say anything more and they've time for us.'* **Emma**

#### *Tenants and staff working collaboratively*

Tenants spoke a lot about working alongside staff within their own environment. This was evident in the way tenants would do any tasks they could and only leave what they felt was too much for a member of staff.

*'Mx does it on Monday and she does the kitchen, well sometimes I've the dishes and all done. She hoovers and all there and the bathroom.'* **Sally**

Equally, tenants spoke of the importance of being civil and personable to staff coming in and out of their home. Many tenants spoke about having the right attitude with others to get on well with staff in the scheme.

*'I think an awful lot depends on yourself. You don't need to be the height of ignorance coming in here.'* **Aoife**

It was also important for the tenants to get to know staff members.

*'Some of them would be friendly and talking about their own family or something or whatever's happened in their day, you know, and chatting like that.'* **Brigid**

#### *Empathy and genuine care*

Tenants genuinely felt cared for in the scheme and appreciated the empathy shown to them by staff. The everyday conversations and openness of the staff was particularly important.

*'You can go to see any of them, talk to them if you want to about anything, you know.'*

**Jennifer**

Additionally, tenants felt that staff were very good at checking to see if they were ok.

*'If they thought you were a wee bit off or a wee bit upset about something, they would get round to it; 'Is there something worrying you, Elma?' If they saw you a wee bit aggravated or something, they would say, 'Did something happen? Did somebody say something?'*

**Elma**

There was a feeling of being looked after by staff and that nothing is too much trouble.

*'They really care.'* **Marie**

*'I think the staff here are wonderful, they're very devoted.'* **Michael**

These feelings of empathy are reciprocated back towards the caregiver, as tenants felt a genuine fondness towards the staff.

*'I'm crocheting at the moment for one of the carers has a baby so I'm...em... I am doing her a shawl.'* **Marie**

#### *Family Caregiving*

Families were a huge support for tenants in their daily lives. Tenants spoke of their family support for their care such as food provision, going to doctors' appointments, cleaning, decorating and as financial 'executor'. Additionally, caregiving from afar was also evident with families organising online shopping deliveries directly to the scheme.

*'They (son and daughter in law) would tidy things and make the tea for me.'* **Clare**

*'I get the meals and my brother gets me them out of one of those places and he gets them and brings it here and all I have to do is put it in the microwave.'* **Helen**

*'I know he helps me, when I come in here I give him charge to do my money and things because I just couldn't do it here.'* **Helen**

Collaborative caregiving was apparent in a number of ways. Tenants spoke of the way the tenants, staff and family caregiver all work together.

*'Everybody the staff and all, all works together.'* **Elma**

Staff were reported to maintain good communication with family members to support their role as caregivers.

*'She would chat with them before she would come up here maybe with them, you know, and they would say oh, maybe your mother wasn't so good today or she wasn't, or she needs, she was missing you or something, you know.'* **Bridget**

Families worked together to support their loved one within the scheme taking turns to do the shopping and going on outings.

*'I would go to each one of them on a different Sunday.'* **Jennifer**

Finally, tenants also supported their families and this was really important to them to feel as though they were giving something back.

*'We look after the grandson three days a week.'* **Susan**

#### *Physical environment*

Tenants spoke proudly of the physical environment they were living in, both within the scheme and their flat or room.

*'I really wanted them to come and see this lovely place, you know, because people think you're going into a home you see and then they think it's an old people's home or something, you know. They haven't seen this place and they don't know anything about it, they might know the name (scheme name) but they don't realise how modern it is and how nice it is and how, that's it an apartment, it's your own apartment within a building, you know.'* **Bridget**

There were a range of amenities outlined by the participants within the interviews such as big rooms, communal kitchens, nice views, spare bedrooms for visitors, privacy, hairdressers, gardens and balconies. Some flats have kitchens while others do not. The tenants without a kitchen did not report this as an issue.

*'When I came first I saw this –I said is this all mine?'* **Marie**

*'Here you've your privacy, you can lock the door, you've got a good bathroom.'* **Michael**

One tenant spoke with great fondness of the flowers she tends on the balcony of her flat. In one scheme the tenants were asked to name the different corridors to help tenants to orientate themselves with where they were.

There were also a number of negative attributes within the environment discussed during the interviews. Factors such as not having cupboard doors, not a nice view from their flat or room windows, limited storage and the desire to have different colours in each room to differentiate the space were all reported.

*'All I can see is the wall (from her window).' Aoife*

Finally, the warm environment of the scheme did not suit all the tenants.

*'Because it's so warm in here and it dries you up, I can feel my whole skin drying up and my mouth dries up, my eyes are drying up.' Bridget*

#### Person Centred Process

The person-centred process construct includes attributes such as: working with beliefs and value, engagement, sympathetic presence and providing for physical needs (McCormack and McCance, 2017). The themes that emerged from the data around the person-centred process construct were staff engagement, personal preferences, privacy, and tenants relationships (Table 20).

*Table 20. Themes and Sub-themes of Person Centred Process Construct*

<b>Themes</b>	<b>Sub-themes</b>
Staff engagement	<ul style="list-style-type: none"><li>- Reciprocal relationships</li><li>- Importance of connection</li><li>- Dealing with grievances</li></ul>

Personal Preferences	<ul style="list-style-type: none"> <li>- Individuality</li> <li>- Spirituality</li> </ul>
Privacy	<ul style="list-style-type: none"> <li>- Ownership over personal space</li> <li>- Enabling choice</li> </ul>
Tenants relationships	<ul style="list-style-type: none"> <li>- An extended family</li> <li>- Relationships at arm's length</li> </ul>

#### *Staff Engagement*

Communication and engagement with staff featured strongly within the interviews. There was a strong sense of compassionate relationships and comradery between the tenants and staff caregivers.

*'The two of us were sitting... killing ourselves laughing... they are full of fun they are really full of fun.'* **Marie**

*'Yes, there's a few of them I'm very fond of and as you say, they're like friends, they are very good.'* **Helen**

The reciprocal nature of this relationship was important to tenants as they felt it was important to engage and connect with the staff on a personal level.

*'They like to hear that too, because you're taking a wee bit of interest in what they're doing for you and they like that, because it gives them a wee bit of a lift.'* **Elma**

The importance of a connection with staff was highlighted frequently. This connection inspired feelings of belonging.

*'You do, you feel safe and feel wanted, that's another feeling, you feel as if people really want you and they are really helping you, that's just the feeling I've always had from the day and hour I came in here.'* **Ann**

Not all staff engaged with tenants in the same way and on the same level. It was notable that tenants often favoured some members of staff over others.

*'Yes, you've always got contact. Sometimes, there's some of them, you might think well I'll never get to know her for she never even looks at me, you know that sort of way and you sort of feel, goodness this is not going to work out.'* **Jennifer**

Additionally, grievances within these relationships can occur. Tenants felt they had the voice to address a problem with a staff member,

*'I would tell them off, and very quickly too.'* **Elma**

Or in some circumstances they are aware of the appropriate reporting procedures within the scheme.

*'Yes, a particular person you can talk to. She's a house girl. She's a very nice girl. She said that they can't do that.'* **Denise**

#### *Personal Preferences*

The individuality of tenants was reflected in the interviews and evident in the way people lived within the scheme. Some people enjoy company while others preferred to be on their own. The freedom and person-centred practice within the schemes enabled tenants to live the life of their choice.

*'I would take, sure I would have a couple of beers every night, but I'm quite happy with that you know.'* **Michael**

Additionally, schemes tried to facilitate something when it was important to tenants. For example, a number of tenants interviewed in various schemes had dogs and other pets.

*'We would not have come here if the dog was not allowed.'* Susan

Going to church and spirituality was very important to tenants. Additionally, faith gave tenants strength and contentment.

*'I really believe the joy the Lord's my strength because if it hadn't been him I wouldn't be here love, you know.'* Sally

Often the person's ability to attend their own church was impacted by the move to the scheme. Some individuals spoke about not being able to attend their church anymore, some ministers came to visit the tenants, and in some schemes a local minister would visit the scheme regularly.

*'We've a minister yea (that comes into scheme), in fact I've befriended the minister at the church round there and I got invited and I went down and it was over and me and him got into a conversation and he's coming up to see me and it's just around the corner here.'*

**Michael**

It was essential to one tenant that her minister was aware of where she moved to and that he comes to visit her now.

*'My minister knows I'm here.'* Sarah

#### *Privacy*

Privacy was reported by participants as nobody entering the tenant's personal space without permission and also, been able to close their door without being disturbed.

*'Here you've your privacy, you can lock the door.'* Michael

It was very important to tenants to have ownership over their flat or room in order to achieve that sense of privacy.

*'Yes, oh yes, you have, just it's your own apartment and you can come or go if you want, you know, or you can stay in all day, you can go out or you can intermingle with them.'* **Bridget**

One tenant felt she did not have as much privacy as she would like because staff come in and out to give her tablets.

*'It's not what I'd call very private'* **Elma**

The tenants appreciated the choice of being able to stay in their own apartment or go out and spend time with other tenants.

*'More than anything you have an awful lot of privacy. If you want your privacy you get it.'*

**Emma**

#### *Tenant Relationships*

During the interviews, the tenants close and found relationships were often reflected on.

While some noted that they *'like to be among the company'* (**Denise**), others commented on the importance of their relationships with other tenants. One tenant described the others tenants as *'an extended family'* and that there was a 'sense of caring as well which made here such a fantastic place' (**Susan**). There was also an appreciation about living in harmony with others.

*'I would hate to live in a place where people disagreed and didn't get on.'* **Elizabeth**

It was acknowledged that living harmoniously took effort from all tenants.

*'Sure, when you're living in places like this, you have to get along with people. There's no point in coming into a comfortable place and getting aggro with people.'* **Emma**

For some individuals, they were quite happy keeping the other tenants at a distance.

*'I'm friendly with everybody but I don't make chums out of people.'* **Ann**

*'The people who live here are people who you say hello to and they say hello to you, but they're not people who would invite each other.'* **Celine**

As with all living environments, not everyone gets on.

*'Some of them are very friendly and some of them are not.'* **Jennifer.**

*'They're not what you'd call neighbourly.'* **Elma**

People not being friendly, not having common interests and comments on the progression of other people's dementia journey were noted.

*'I wonder is there anything wrong with them in there with their heads, do you know what I mean, I says, I hope I'm not going to be like that.'* **Ann**

*'There are some people there and some people a bit further on.'* **Marie**

#### Expected Outcomes

The expected outcomes construct includes attributes such as: care experience, involvement with care, feelings of wellbeing, healthful culture (McCormack and McCance, 2017). The themes that emerged from data around the expected outcomes construct were flourishing person and independence (Table 21).

*Table 21. Themes and Sub-themes of Expected Outcomes Construct*

Themes	Sub-themes
	<ul style="list-style-type: none"><li>- Feeling safe &amp; secure</li><li>- A homely environment</li></ul>
Flourishing Persons	<ul style="list-style-type: none"><li>- Contentment</li></ul>

- Maintenance of relationships

- Meaningful activities

Independence

- Independent living

-Strategies for daily life

Flourishing Persons

*Feeling Safe and Secure*

Tenants spoke of feeling safe and secure within the scheme. This was very reassuring for them and enabled tenants to relax in their living environment.

*'It's something reassuring about the place... I really feel safe in here.' Ann*

*'You don't even have to lock your door.' Bridget*

*'I feel safe we all feel safe.' Stephen*

The feelings of security stem from staff caregiving, the use of technology, and the ethos of the housing scheme. One tenant felt that although she did not access very many services available to her in the scheme, due to her current level of independence and as she lives with her husband, the scheme environment and knowing people are around helped her feel safe.

*'I do feel secure in here even though you know even though we might not use much of the support all the time but I do feel very secure.' Susan*

It was also apparent that families were happy that the tenant felt safe and secure.

*'My son always says I'm rightly where I am! He's happy because he knows I'm secure'.*

**Denise**

The housing schemes had a number of procedures in place to enhance the feeling of security for tenants. These included tenants informing the scheme when they were leaving, where they were going and an approximate time for their return.

*'When you are going out you're asked about your safety of where you're going and roughly what time you'd be back and things like that, which is very reassuring.'* **Emma**

Tenants recognised that the scheme wanted to prevent any harm coming to any tenant.

This was reflected in discussions around securing medications

*'all the medications are locked in. They're not sitting about that you could accidentally take tablets a couple of times that you shouldn't take'* **Elma**

and security men on the premises in the evening

*'they patrol around and look out and make sure there is no one bad people trying to get in.'*

**Marie**

#### *A homely environment*

Tenants reported strong feelings of living in a homely environment. This is a result of a range of factors previously reported by tenants such as the relationships, staff caregiving, the atmosphere and environment.

*'This is where my heart is.'* **Susan**

*'It's such a homely place to be and there's that loving feeling, and you see when you've that loving feeling, homely feeling, you've everything.'* **Ann**

*'Living here, to me, it's just that I'm at home.'* **Elma**

Tenants spoke of families coming together in the scheme for Christmas and one tenant spoke of her daughter leaving from the scheme on the day of her wedding.

Not all tenants were able to relate to the scheme as their home. Some tenants had such a strong connection to their family home that it would be impossible for them to relate to any other environment in such a way.

*'The older people that come in here really have this sense of their own house where they have lived and been forever so it is very hard sometimes to except this place as a house.'*

**Susan**

#### *Contentment*

In all the interviews, tenants said they would recommend others to live in the scheme they were living in. Tenants stated in a number of different ways how happy they were living in the scheme. Reasons ranged from getting a good feeling about the place, to wanting to showcase the unique nature of living in a supported living environment.

*'I love it see from the minute when I came into it I knew right away I was going to be in here the rest of my life you know.' Stephen*

*'I think it is like falling into heaven being here honest to god.' Marie*

*'I don't think a lot of people realise how nice it is, you know, until they would come and see it and that's why I like them, I'm always telling any friends I have, you know, come and see what it's like, you know, because it's so nice.' Bridget*

When one person was asked about her favourite part of the scheme, she responded:

*'The privacy, the companionship and the friendliness.' Emma*

Others said:

*'I love it here and I love the people.' Ann*

*'There's a feeling of safeness and contentment now.' Bridget*

*'I love anything that makes it easier for me.' Susan*

*'I'm just so lucky I am here.'* **Marie**

These feelings of contentment resonated throughout the interviews and although issues within schemes were highlighted, satisfaction was the overriding feeling at the time of the interview.

#### *Maintenance of relationships*

Ministers, people from the church, neighbours and friends all called in to visit tenants.

*'I have different friends who come in.'* **Celine**

*'I think I probably would have more visitors than anybody, because I was very involved in my church and they've been very good about coming to visit me.'* **Jennifer**

*'I have friends and people that I am very friendly with and I could ring them and they would come to see me.'* **Helen**

Relationships with families featured very strongly in the interviews with sons, daughters, grandchildren, greatgrandchildren, sisters, brothers, all regularly spending time with tenants. Activities together included scheme visits, taking the tenant out shopping or for a Sunday meal, taking the tenant to church, as well as supporting physical needs such as bringing food, help with cleaning, travel to appointments and supporting finances.

*'She'll be down tomorrow and me and her will go down the street. We'll go shopping and go in and have a wee cup of tea somewhere.'* **Denise**

*'They take me each Sunday to each one of their homes and they arrange that between themselves.'* **Jennifer**

*'I usually go out with my daughter every Saturday.'* **Bridget**

Spouses had passed away in many cases and children (including extended family) provided a lot of love and comfort.

*'My son's marvellous, I'd be lost without him.'* **Ann**

*'I love them all and I love all the children too.'* **Sally**

*'I am the best mother in the world she says (her daughter).'* **Sarah**

Not all families lived close by and tenants spoke of alternative arrangements to stay close such as a nightly phone call.

*'My daughter phones at that time and of course I like it, she phones at seven every night.'*

**Michael**

Additionally, one tenant spoke of having moved into a scheme to reduce the pressure on her family. Therefore, she loves to see her family but is happy to see them whenever suits them.

*'I think it is a great load off you family because your family feels oh I must go and see mummy today and maybe it doesn't suit them.'* **Elizabeth**

#### *Meaningful Activities*

The importance of activities and the role of the activity coordinator was apparent throughout the interviews. Activities were undertaken by the tenants within the scheme but also included things the tenant liked to do independently or with their family and friends. This aspect of their lives was vitally important. Activities included going for walks, going to the day centre, reading, watching television, knitting, shopping (groceries and personal shopping), and gardening.

*'Activities are first and foremost of every bodies day.'* **Susan**

Within the scheme activities included live music, dances, clubs (lunch club), fish & chips night, barbeques, crafts, baking, as well as activities out in the community such as day trips and hotel visits. Maintaining hobbies such as gardening, reading and knitting was often reported.

*'I read a lot and knit a lot.'* **Elizabeth**

A number of tenants still engage in the garden, whether they are tending to the schemes garden, pots on their balcony or a small garden as part of their flat.

*'That's my hobby out there with my wee plants. I've wee pots of those, so I always loved gardening, you see, so I brought a lot of pots and plants with me.'* **Brigid**

Additionally, undertaking activities with family was really meaningful for the tenant.

*'We have been making an album of memories.'* **Ashling**

Staff supported engagement in activities, both in terms of creating an awareness of the activity and physically supporting the tenant to attend.

*'The girls come for me, they take me and come for me if there's anything on and take me down.'* **Clare**

Information about activities was disseminated through a '*wee leaflet*' **Brigid** distributed weekly to tenants, recorded on calendars within the tenants living environment and by staff reminding tenants just before the activity was about to begin.

Although, within the interviews activities in the scheme were reported, it was evident that it was not reflective of every interview. Boredom was viewed as '*an awful thing*' and tenants felt activities were at the core of reducing boredom.

*'No, very little. We need more, we need to get out because you're sitting there and you're bored to tears so you are. There's nothing you can do, I would like it if there was something*

*we could do.'* **Helen**

Tenants also spoke about a notable lack of funding for activities in recent times due to government austerity.

*'No funding now with all these carry on.'* **Michael**

Additionally, activities were more commonly undertaken during the week. Recommendations included weekend activities within the scheme.

*'Now the weekends is their own time and sometimes I think that is probably the hardest time for people because if they don't have family it can be very lonely.'* **Susan**

*'They don't let you go out on your own, just in case you're a wee bit off balance. They're afraid of you falling and getting hurt. They wouldn't be responsible for that.'* **Ann**

Often activities depended on the transport, particularly going to church or on trips outside the scheme. This was a limiting factor as it was not always available and taxi's pose a significant cost.

*'I always go for the prayer meeting on Wednesday and I'm not able to go now because it's the transport you see.'* **Sally**

Independence

*Independent living*

An expected outcome of the care delivered within the schemes was that tenants were able to live independently. Tenants reflected on making their own breakfast, going out for walks in the community, preparing meals, washing, and dressing independently.

*'I try to make a go of it on my own.'* **Aoife**

*'I can just pop things in that washing machine there and that's easy enough, you know, and I can hang them either, there's a wee thing out there to hang them on.'* **Bridget**

*'I know when a thing needs done so I don't need to ask, like I do it off my own bat.'* **Emma**

The sense of independence was also intertwined with freedom and control.

*'I can do my work here in the morning, open that door and go where I want to go and fall in with some of my friends.'* **Celine**

The very nature of the scheme was set out to maximise independence and was best suited to people who want to live their life in an independent way.

*'This place has been set up for people to live or try to live independently as much as they can so if you can't live as independently as you can I would say no but if you can live independently this place is the best place for you and that would be my opinion.'* **Susan**

#### *Living with dementia*

Throughout the interviews, participants spoke about the strategies they use to live well with dementia. These included the use of calendars, electronic reminders, writing things down and putting procedures in place for routine tasks.

*'I have my own plan to do my washing I use a procedure four steps and you will see I have the wee orange tabs on so that is specifically on for me.'* **Susan**

Additionally, tenants spoke about needing to adapt to their current circumstance. For one individual who loved to read and found books increasingly challenging, she moved to reading magazines.

*'With the magazine they're short stories and they're just wee snippets of things, letters that people write, you know, and I like that.'* **Bridget**

Additional to living with dementia, participants spoke of a number of different illnesses, fractures and issues that impacted on their health. These included broken bones such as hips, heart attacks, stroke, diabetes, and cancer. Current issues reported by participants included trying to lose weight, pain, arthritis, reduce mobility, dizzy spells, tiredness, asthma, eye degeneration, low vision, hearing impairment, fibromyalgia and reduced balance.

*'I'm not fit really now.'* **Sadie**

Mobility aids were important to support independence such as a rollator.

*'I've got a wee trailer there, you know a wee trolley the hospital give me because I was falling a lot.'* **Michael**

All the tenants were an advanced age, except for one individual who was under sixty years of age. This was a factor for the tenant and her husband choosing to live in a supported living environment.

*'The age thing in this respect because your individual apartments didn't really matter to me because if we don't want to be involved in anything we just close our door and that is it.'*

**Susan**

Tenants spoke a lot about falls that they have had before moving into the scheme and while living within the scheme. The falls prior to moving in were generally the incident that provoked the need for a new living environment.

*'I fell about 3 weeks ago, clumsy, footless, that's all it was. Pressed the button on the wall and it's not because she's here again now, but within 2 seconds 2 girls up to see if I was alright.'* **Ann**

Interestingly, some tenants reported improvements in their health since moving into the scheme.

*'I don't know how many friends I've met since I came in here just, God Ex, haven't seen you looking as well as you are.'* **Ann**

## Discussion

This study provides insight into the perspectives of PLWD in a technology enriched supported environment. It was evident from the findings that person-centred practice was experienced by the tenants within the care model in the supported living environment. Viewing the data through a person-centred lens illustrated the strong person-centred themes that were evident in terms of the constructs: prerequisites, care environment, person centred process, and expected outcomes set out by McCormack and McCance (2017). Autonomy, choice, personal decision-making, control, having a voice and sense of self were all important factors for satisfaction with living environment. The ability to get up when a person wants to, wear what they like, have a say over who comes in and out of their living space, and to vocalise how, what or why the person feels was hugely important. Additionally, a sense of belonging within the scheme and a connection to the wider community contributed to quality of life. Figure 20 below illustrates the thematic analysis through the person-centred lens.



*Figure 20. Thematic analysis through the person centred lens*

The collaboration and strong relationships between the tenants, staff and family echoed throughout the interviews. Good communication, engagement, compassion and comradery were key attributes for working together. Tenants reported feeling genuinely cared for. Tenants felt it was important for staff to be pleasant and enjoyed when they heard about their caregivers' families. Equally, tenants felt it was important that they themselves had the right attitude with others. They spoke about working alongside staff, they would do whatever they can and staff would support by doing what they were not feeling up to. Family members also provided a lot of support to the tenants in their daily lives. Tenants spoke about how the staff and family caregivers dovetail, for example, a family member brings the shopping, a member of staff informs the family member of the items required, and on the occasion the tenant was out of milk the staff member would bring some for the tenant if a family member was not able to.

The physical environment of the housing scheme was spoken about with huge admiration. Tenants were proud of their living space, the modern buildings, the facilities, their own apartment and the positive atmosphere. Personalising their living space made it feel homelier and many participants reported tending to flowers on their balcony and in the gardens. Privacy was a massive factor for tenants. The importance of being able to 'lock the door', choose who comes in or out of their personal space, or if in fact they decide to stay inside their flat or apartment. In terms of the technology within the housing scheme, many individuals were not aware of its presence. Often when the discussion about technology came up and alarms were mentioned, it would prompt a chat about the weekly fire alarm testing. One tenant recounted a story of the time she fell in the bathroom and forgot to pull the alarm cord. However, other individuals felt technology gave them a sense of security and the reassurance that they would have support when they need it. The wearable pendant, the bed sensors and alarms to contact staff were noted as useful. Some individuals reported using mobile phones, iPads and computers. These people wanted Wi-Fi to be available within the schemes. Others felt they had no need for these devices now they were 'safe' in the supported living or that technology was not relevant for them. One individual had consented to the future use of technology as part of her care as she felt it was not required yet.

The true benefit of person-centred care is the impact it has on the lives of the people receiving the care. The expected outcomes illustrated a strong sense of well-being for tenants, their ability to be independent and flourish as a person. All tenants reported having a good feeling about the housing scheme, even when it was not considered home, and feeling content. Feeling secure was also reported because of staff caregiving, use of

technology, and the ethos of the housing scheme. Maintaining relationships, forming new relationships and participating in meaningful activities all contributed to enhancing the well-being of the tenant. Additionally, living independently was noted throughout the interviews. The core of person-centred care is to enable people to live as independently as possible.

It was evident from the findings that PLWD can and are willing to engage in research. Many strategies were put in place to maximise the inclusion of individuals. Guided by the research, consideration was given to Murphy et al's (2014) four strategies: gaining consent, maximising responses, telling the story and ending on a high. A protocol was put in place to gain consent of the participant in collaboration with the scheme manager. To maximise responses, peer researchers were trained to undertake the interview. Peer researchers move away from the academic model of interviewing and focus more on building a rapport and making connections using a relaxed, flexible approach. Prompts were used during the interviews to help tell the story, for example, pointing out sensors and pendant alarms if the tenants did not appear to understand the word alone. Additionally, the interviewees own words were used to describe the findings in this study. It is worth noting that only one scheme opted to sit in during the tenants interviews ( $n=3$ ) and requested that the word dementia was never used. There was nothing remarkable or noteworthy about these interviews in comparison to the others in terms of researcher/participant observations. Finally, every interview was finished on a high to leave the person with a sense of achievement.

### Recommendations for practice, research and policy

Within this work it was possible to engage PLWD in research. Inclusive strategies helped to maximise the contribution which included peer researchers. This should be encouraged where appropriate in future research on themes relevant to PLWD. In relation to practice, it is interesting that not all tenants were aware of the technology provision. However, of those who were aware, it provided a great sense of security. Wi-Fi available to tenants within schemes would enable the use of everyday digital devices, for example, iPad's and mobile phone use to enable tenants to maintain contact with their loved ones. Use of such devices, if supported when required, could enable tenants to keep in touch with their family if feeling lonely, stressed or indeed if family live remotely and can not visit routinely.

Future planning for the use of technology is recommended and was evident within the data. One participant felt that the technology provision in TESA was not yet required, however, she had consented to its use when she reached a stage of her journey where it would reduce personal risk.

### Summary

A core focus of this research was to engage directly with the tenants of TESA all of whom had an established dementia. One method adopted to support this was working through peer researchers to link directly with PLWD exploring their lived experience in technology rich settings. Analysis of the data within the domains of the person-centred framework (McCormack and McCance, 2017) was helpful to ground the emerging themes. The data indicated that technology was not a stand out feature for participants in the study, although for some, it engendered a sense of security and reassurance. Others described how they used the inbuilt system to talk through the intercom, pulled the alarm to get assistance or

used personal mobile devices to keep in touch with families. The majority of participants were very aware that the fire alarm test was completed on a weekly basis. Technology did not emerge as a theme of concern or interest, merely an awareness that they lived in a facility with technology.

Collaborative relationships, whereby the tenants and both the staff and family caregivers all work together, emerged as key components for quality of life. Person-centred care resonated throughout the stories told by the individuals living in the housing schemes, where they had autonomy, choice and control to live the life of their choice. The expected outcomes indicated that through the care received, individuals living in supported housing can be independent and flourish as people within these environments.

## Chapter 6 Creatively engaging with tenants

### Introduction

Being inclusive to PLWD while gathering their perspectives was a core value of this research. Not all the tenants living in the housing schemes had the capacity to take part in a one-to-one interview. However, all tenants had important views and perspectives. Focus groups have been used frequently within the literature as a way of gathering rich qualitative information to develop an understanding of peoples lived experiences of dementia (Bamford & Bruce, 2000; Innes, Page, & Cutler, 2015; McCabe & Innes, 2013). This methodology can be particularly useful for PLWD as within the group people can feel supported by their peers and the discussions have the potential to trigger memories. Creative methods such as art enable people with different communication skills to engage and express themselves without language. Art can be described as expressing one's self without the use of words (Beard, 2011). Therefore, to capture a more holistic view of tenant's experiences living within TESA, art-based focus groups were undertaken, led by an artist with extensive experience of working with older people. This chapter focused on community-based engagement and is written in a format that is accessible to stakeholders and artists. Additionally, to get a feel for the experience of the focus groups significant details were given.

### Art as a Research Method

Creative methods were used as a research tool in the current study. This approach has grown in popularity in recent years (Boydell et al., 2016; Moss & O'Neill, 2017). Art based activities have been used as a research method to explore experiences in health based

research with various populations (Moss & O'Neill, 2017; Rollins, 2005). This approach creates a major shift in knowledge production towards a co-produced, collaboratively generated outcome (Fraser & al Sayah, 2011). Collaboration is a fundamental factor in this approach, as partnership is also required between researchers and artists (Noice, Noice, & Kramer, 2014). Art based research presents new opportunities for dissemination, can be used to attain deeper understanding and can be more accessible (Boydell et al., 2016). Most importantly, art is a way of giving a voice to people (Fraser & al Sayah, 2011).

## Aims and Objectives

### **Aim**

To explore perspectives of people with dementia living in the schemes through creative methods

### **Objectives**

- To interpret the perspectives of people living with dementia through creative methods
- To explore the quality of living in technology enriched supported housing
- To develop pieces of art that portray feelings, quality of life and reflect a sense of home

## Methodology

The purpose of the art-based focus groups was to explore tenants' perspectives of living in technology enriched supported living through creative methods. The focus groups in each

scheme centred around the development of one or two pieces of art work. Each scheme had six focus groups during which the art was developed. The art component was led by an artist, while the project researcher guided the discussions, however, these roles naturally dovetailed. The art methods were adapted according to the participants and materials that were considered to be appealing including felting, painting, collage and clay were used.. Questions were asked to stimulate thinking and provoke thoughts. These conversations guided the direction of the art, alongside skill building, painting and drawing feelings, emotions and the sense of home. The data were gathered through notes taken during conversations and the meaning of the final pieces of work gathered from tenants throughout the sessions.

## Recruitment

Participants for the focus groups were recruited through the schemes. The scheme manager was approached and asked if they consented to the focus groups being undertaken within their scheme and if they could identify approximately six participants for the groups. All scheme managers consented and were advised on obtaining consent from participants in line with the process set out in Chapter three. All managers were already clear on the consent approach following the recruitment of individuals for the interviews. A total of sixty-one participants consented using Approach A. The manager of one scheme felt three participants did not have capacity to give consent in this way. Approach B was adopted as a method to include these tenants.

## Data Collection

A total of sixty-four participants took part in the art-based focus groups (Table 22). The group sizes ranged from 10- 2, varying from week to week in each scheme. Seven males took part in the focus groups. Peer researchers supported three of the schemes focus groups, Site B, Site C and Site E. Due to the commitment involved in the focus groups it was not possible to recruit peer researchers for the other schemes. Participants were not required to have any previous experience of art or creative activities. The skill level in the groups varied significantly, from independently working to requiring one to one support. Additionally, some individuals had previous experience of art while others were new to the process.

At the beginning of each focus group and throughout the groups, consent was monitored by the researcher (JDL) by obtaining verbal consent, watching body language and looking for any signs of disengagement or distress. Participants were free to come and go from the group as they wished. A break with tea, coffee and biscuits was taken midway through each group which was important to minimise fatigue. An iPad was used within the groups to illustrate pictures, play music and to draw with using an App called ArtRage.

*Table 22. Participants within the TESA Art Based Focus Groups*

Name	Wk1	Wk2	Wk3	Wk4	Wk5	Wk6	Overall Participants	Male	PR*
Site A	6	6	6	3	5	2	9	2	N
Site B	7	5	10	7	6	10	10	0	Y
Site C	6	6	7	6	7	6	10	2	Y
Site D	10	9	8	8	7	8	10	1	N
Site E	4	4	3	4	4	4	4	2	Y
Site F	5	7	7	5	8	7	8	0	N
Site G	6	5	5	5	4	6	7	0	N
Site I	6	5	3	4	3	2	6	2	N

\* Peer researcher

## Data Analysis

The data from the focus groups were obtained through notes recorded during each session and the final pieces of art work. The notes from the sessions were written by the researcher and compared with the findings of the artist. A descriptive account of each focus group was outlined, detailing the process of creating the art work, and the meaning behind the piece(s) of art. This was done collaboratively between the researcher and the artist throughout the six weeks. Every week the findings from the previous session were checked to ensure they were grounded in the tenants experiences and perceptions.

## Findings

The eight focus groups were outlined descriptively, in lay terms, to illustrate the process of creating the artwork and the meaning behind it.

### Site A

A total of nine individuals attended the focus groups over a period of six weeks. Seven participants were female and two were male. The group size ranged from between six and two. The tenants' skills and experience of engaging in art work ranged considerably. Two individuals within the group were experienced artists and two participants required one-to-one support when they attended the art focus group. The creative activity began with individual projects that evolved into collaborative pieces. The materials used included cotton fabric, crayons, fabric paint, and fabric markers (Figure 21).

### The process of creating the art

During the first focus group, the discussion focused on what was important to the tenants.

The important aspects of the conversation that emerged included their personal space and own environment. Their garden area, balcony, nature and pets were also critical to tenants. Having roots in the community was very important, both being familiar with their locality but also being from the community before they moved into the housing scheme. In the second week, fabric was drawn onto to get a feel for the material and then decisions were made around the preferred methods; pastels, marker, paint or any combination of them to decorate the cushions. The tenants decided over the course of the focus groups, how to make cushions for their apartments. They would decorate the cushions on both sides with photographs, pictures or their favourite colours. Pictures that had personal meaning were collected. Tenants discussed that they felt at home in Site A because of their dogs, their family visiting and pictures.

In week three, the participants started working on the material for the final cushions. One tenant invited the researcher to her apartment to take pictures of items that were important to her, which included some glass ornaments and a vase but as these were glass it was not possible to use them for cushion. As the group started on their final piece it was necessary to spread out and take one table per person.



Figure 21. Work in progress site A

In week four and week five, the work continued on the cushions. Numbers decreased due to ill health and a clash with other activities. It was quite a challenge to create individual pieces as the numbers fluctuated so the cushions became collaborative pieces. This also accommodated the different skill sets and enabled all participants to contribute. The researcher worked one-to-one with one new participant. One person was concerned she would not be able to paint the fabric and at times did not engage. She was a music lover so she was encouraged to 'dance' with the brush as she painted each stroke. This really changed her engagement and she started to create art with a smile on her face. Interestingly, she called both the researcher and artist mummy if we suggested anything. Careful phrasing of sentences and continued use of music helped this participant to really enjoy the artistic process. Additionally, another participant continually repeated that she

did not know what to do. Gentle encouragement and repetition of instructions increased this lady's confidence and contribution to the project.

Week 6 clashed with a scheme outing as well as tenant sickness, therefore only two tenants participated in the final session. A total of seven no-stitch cushions were completed. Everyone helped to join the two pieces of material together by knotting two sides and the inserting the inner filling. The tenants were happy they would receive the cushions after the final exhibition.

The meaning of the final piece for exhibition

*No stitch cushions*

The final piece for the exhibition was based on the tenants outlining the value of having their own apartment, being able to make independent personal choices within their surroundings and enjoying their photographic memories. The cushions represented comfort in the home environment and personal space, as well as having autonomy, choice and control of how this space is decorated. Seven cushions were created as the final piece (Figure 22). Some were joint creations between tenants while others were individual. Some cushions have pictures that have great personal importance to the tenant, while others illustrate bright colours and designs to add life, lift the mood, and to enhance their environment.



Figure 22. Site A final art work

#### Site B

A total of ten people attended the focus group over the six weeks, with numbers ranging from ten to five attendees. All the participants were female. A number of materials were used throughout the six weeks including napkins, a paper press, paint, glitter, tracing templates and crepe paper. Three-dimensional letters were created by taping cardboard tape rolls between two letter templates, then creating a tape boarder and gluing crepe paper all around it (Figure 23).

#### The process of creating the art

The first group began with six women. The session went very quickly but great discussion was generated about what was important to the tenants and what they liked. This scheme does not have a lunch club like some of the other schemes. Alternatively, they had a group called X whereby they go to local cafes and restaurants and rate them for dementia friendly access. They recently stopped rating them as they found they were just constantly giving

positive reviews so they go out for lunch once a week as a group instead. The social element and being part of a community was very important to the tenants and is the area of focus for this art work.

In week two, there was a bug going around in one of the houses so the participant group was very different. Tenants created wallpaper by putting thick paper through a press after picking out their preferred design. The 'table cloth' was selected from a range of napkins that were glued onto the frame. A tea cup and a tray bake was designed and placed on top of the table cloth. A peer researcher came to support this work.



Figure 23. Work in progress Site B

During week three, the work continued on the backdrop of the frame as many participants had missed the previous week. A template of the preferred type of mug, cup or cup and saucer was selected by the tenants, they drew around it onto a piece of card, cut it out and

started to decorate with paint. In week four tenants decorated the tray bakes and attached both the cup and cake to the wall paper and table cloth backdrop. There was a breakfast barbeque on when we arrived so the session started late. One lady felt sick quite early on so we got her some water and a member of staff to support her, who brought her into another room. This week there was great laughter and singing all the way through.

Week 5 focused on creating the 3D letters for the word tea. The letters were put together by the group using tape and then tearing and gluing on crepe paper to add colour. There was a sing-song during the group this week. During the final week, finishing touches were added to the piece. Part of this included developing a menu for the café. The first job was to decide a name - suggestions included Boulavard, Café Royal, MMM..., Site B Menu, and East Side Diners. East Side Diners won the vote by participants. After this, the group put forward suggestions for the menu of drinks and snacks that would be served in the café. A range of the tenants' favourite drinks and snacks were placed on the menu. Finally, a list of important things were drawn up for the menu as sides: no queues, catch up time with friends, as often as possible, a good morning out, having a laugh, planning ahead for the next catch up, relaxation, meeting friends, making friends, and seeing someone you have not seen in a while.

The meaning of the final piece for exhibition

#### [East Side Diners](#)

The final piece of work from this scheme started with the idea of exploring choices when it came to decorating the residents' apartment. What wallpaper would they choose down to what kind of cup or mug they prefer to drink their tea from. It was soon discovered that

material things paled into insignificance compared to the value placed on friendship and socialising. Socialising is such an important part of their lives and a key component of all the conversations. So much so that it was felt the word TEA needed to be lit up like a cafe sign to emphasise this fact (Figure 24). East Side Diners is a unique concept set up for, by and with the tenants to socialise and be a part of their local community. It enables active citizenship, freedom and choice within their environment. A sense of belonging, comradery and contentment are represented through this piece of art.



Figure 24. Site B final art work

### Site C

A total of ten people engaged within the focus groups, with numbers ranging from six to seven every week. Two males and eight females consented to take part. The creative activity was based around felting with merino wool fibres (Figure 25).

### The process of creating the art

During the first week, lots of discussion was generated as the tenants created pieces of felt.

Initially, the artist walked around the scheme with a few tenants and got a sense that nature was really important to the tenants in terms of their balcony, garden space, decorations (i.e. pictures in their home) and pets. During the felt-making, conversations topics covered everything from travel to hobbies . Participants were asked to pull bits of marino wool and lay it out in a square. Once they were finished, they were asked to do the same thing again with different coloured wool placing it in a different direction. After three layers were completed, the wool was sprayed with water and then wrapped in bubble wrap. Each person rolled the wool in the bubble wrap to make it into the cloth. Tenants then rolled the felt to their favourite music. The position of the wool was changed and wrapped up again until this process was complete. Towards the end of the session, the group discussed what the finished pieces would look like. The artist showed different pictures using her iPad and the themes of trees and the seaside came up as most popular during these discussions.

In the second week, participants made felt birds for the final piece. Lots of pictures were brought in so that participants could make a strong link and relate to the pictures, to make decisions about the birds they were creating. Some participants were happy to sketch a bird with a picture as visual reference in front of them, others simply traced over the picture. This sparked the idea of using an iPad and drawing app called ArtRage to create the drawing. The original photo could be removed leaving the drawing on the iPad which was then saved and printed. The app on the iPad was used by some tenants. It was useful for a person who could not hold a pencil. There was a choice to use either a stylus or your finger as a drawing tool. The problem with a stylus was that it looks more like the end of a pencil

with a rubber attached. When the PLWD first had a stylus in their hand they were looking for a pencil point. It was hoped that technology could help release creativity or simply to engage reluctant artists. It was possible to adjust the opacity so that the person can trace a real picture onto the drawing app. It was also possible to lighten or darken the contrast to help with vision. There were mixed opinions from the participants who used this. It was agreed that it was important to provide appropriate support and not 'over support' during the group as this would take away sense of achievement and ownership of work from tenants. It was about increasing their self-confidence.



*Figure 25. Work in progress Site C*

During the focus groups, the researcher (JDL) took a more active role engaging with participants about their perceptions of living within the scheme. The peer researcher followed the researchers lead and actively engaged with the tenants she worked with. It was challenging at times to engage in conversation and complete the art work for

participants. The researcher and peer researchers moved around the table and tried to engage with different participants. The peer researcher found it hard to support individuals complete the art work and record the discussions at the same time. Overall, there was great discussions within the group and they were thrilled to see their first finished piece of artwork. They were very proud and brought members of staff in to see it. The group were creating a seaside scene in felt because a number of individuals had strong connections with the sea. Three individuals were felting the sea whilst the others created the boats. The final week focused on verifying the meaning that had emerged from the artwork. During the session, there was much discussion about the meaning of the pictures and what the tenants would like people to know about them at the exhibition. At the end, tenants were taken around the scheme to decide where the artwork might be displayed. Pictures were taken of where the final artwork would go and shared with the management.

The meaning of the final piece for exhibition

#### *Birds of a feather flock together*

The birds in the cherry blossoms represented a love of nature and the value placed on balconies and gardens in the physical environment (Figure 26). The importance of pets were highlighted and the birds signified the chitchat of neighbours within the scheme and company for each other.

#### *No matter where we go in the world, it's good to be home again.*

The second seaside piece represents feelings of being at home for a lot of the residents. There was a love of the sea within the group, love of travel, and it also provoked memories of childhood and for one resident a lifetime at sea with the merchant navy.



*Figure 26. Site C final art work*

#### Site D

The numbers in Site D were quite large each week ranging from seven to ten people, with ten people engaging in the project overall. There was one male within the group. The tenants ranged in artistic skill, some were very keen artists and others did not have confidence in their skills. Two tenants had experience of art having attended painting classes for years, but were now lacking in confidence and their dementia limited their ability to work independently. However, working one-to-one with these people enabled them to engage and actively participate within the focus group. The creative activity was based around several materials to create collage art such as crepe paper, chalk, paint, model magic, cardboard and scrap materials. Additionally, this group frequently enjoyed sketching and drawing (Figure 27).

#### The process of creating the art

The first week at Site D welcomed a mix of interesting and dynamic people. The session began by going around the group and asking individuals about themselves. The groups were sitting at two different tables and it was difficult for people at the second table to hear

those at the first so people began to talk and it got noisy. Additionally, two very strong personalities came to the fore and tended to dominate the group, therefore, careful management was required to ensure every person was heard. At one stage during the introductions, two individuals began to argue about staff- one person saying they didn't do enough and the other saying they did their best. This got quite loud so we decided to have a tea break and turn on some music. During the break, the artist handed out notepads and pencils so that the drawing activity started immediately after the break. The artist worked one-to-one with one of the individuals involved and this enabled careful management of the situation and to keep the group focused on the art activity.

The second week the tables were adjoined before starting and the individuals that argued the previous week were not sitting near each other. The session began by showing pictures to promote interest and generate conversation, both hardcopy pictures and on the iPad, from the areas of interest from the previous week. The tenants told us that '*recognition of things around them gives feelings of home*' and that '*Scabo tower makes me feel like I am home*'. Going to church was very meaningful to tenants. The tenants were asked to draw pictures and paint their home to get a sense of their skill levels. One person was initially very resistant to painting, she started to work one-to-one with the artist and created a fantastic painting, giving huge personal satisfaction. This person used to be a painter and was fearful of getting involved to begin with because she thought she had '*lost it*'. During the third week, the conversations continued about Scrabo tower '*I'm home there is Scrabo*'. Also, a number of tenants spoke of seeing Scrabo tower from their apartment in Site D. Scrabo tower is a monument and well known landmark in this area that was familiar to most of the tenants for their entire life. This week tenants started to paint the cardboard that

would be used for the houses. They also had to cut-out black card and tile the roof of their house.



Figure 27. Work in progress Site D

During week four, the houses were further developed and doors and windows were cut out of the painted card. Participants were asked to pick a number for their house and the curtains they would like. The researcher worked with two women on a one-to-one basis to create the sky backdrop with chalk for the final piece and to develop the houses. The artist worked with two others as they were more independent in their skills. The houses were both a reflection of the homes they used to live in and their apartments now. The numbers on the door were from their flats now, homes or their favourite number. Two women could not remember so the researcher counted for them and they indicated when they liked a number.

Much conversation centred around Scrabo Tower on week 5 because one of the tenants had visited it that week. She spoke about going up Scrabo and '*coming across Jenny the goat*'. She spoke about the blue bells, daisies, and buttercups she saw along the way. She also reminisced '*we used to go up for bluebells and my mother had a special vase for the blue bells from Scrabo*'. The houses required finishing touches such as choosing the curtains for the windows. The background material was changed so the blue coloured backdrop was redone. Crepe paper was added to the mid-section of the painting overlapping to create texture and different colours. Finally, a road was drawn in chalk onto the bottom of the backdrop and pieces of crepe paper were scrunched into balls to create hedges and garden plants.

The final week focused on finishing the final art piece with clouds, scrubs on the hill, trees and the goat seen by one of the tenants. The trees were made out of model magic and were rolled by the tenants as they talked. Discussions centred around living in the scheme and tenants were asked to describe what the final piece means to them for the exhibition. This group was interesting to work with as it was such a large group with strong personalities and a wide variation in capabilities. The environment became very important – who was sitting next to who in terms of clashing personalities, the temperature (i.e. some people felt very warm and preferred to sit close to the door) and having those who needed one-to-one support close together so they could be supported at the same time.

The meaning of the final piece for exhibition

*At home with Scrabo Tower*

Scabo Tower evoking feelings of recognition, belonging and creating a sense of home emerged very quickly within the group. It also brought together strong memories of

childhood and a sense of place in the tenants' current living environments. The final art piece naturally evolved around this (Figure 28). The houses were created from memories of childhood homes, and homes tenants had left to move into Site D. The past and present were brought together in this group piece.

*'You know you are home when you see Scrabo and we see it every day'*

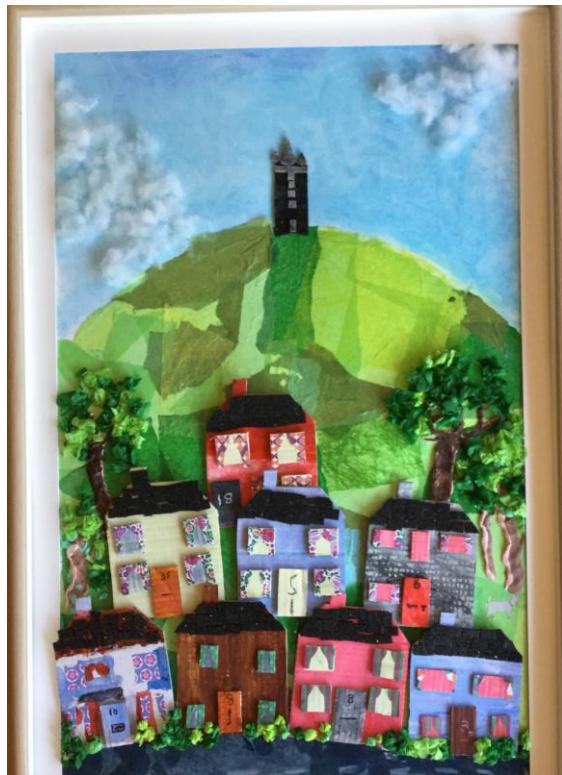


Figure 28. Site D final art work

#### Site E

A consistent number of four people attended this focus group with one woman missing a week because of illness. Therefore, numbers ranged from 3 to 4. The group was made up

of two males and two females. The creative activity was built around materials such as foam, felt fibres and painting the canvas.

#### [The process of creating the art](#)

The very first session started off asking the participants what they thought of when they think of home. Residents were asked to draw their house (Figure 29). When this was completed they were asked to open the door and draw what was inside. It was important to break down the tasks, one sequence at a time. Model magic was used to create things inside the home. Participants found it difficult to think of what to draw. It is always helpful to have visual stimulus to hand to help initiate artwork. This could be objects or photos. Week two focused on how the tenants wanted to be seen by others. The group started taking pictures on iPads. There was a lot of reminiscing during this session and tenants started to work on the foam heads to be representative of themselves. Week three and the heads were further developed. One participant did not want to create his head so he drew in his sketch book instead. The two male participants found it very difficult to be creative and to speak at the same time. Another individual found it very difficult to hear so it was important to sit close to her and repeat instructions with a demonstration. If a participant has impaired hearing it is important to be mindful of where they are seated. Communication was easiest if the person is looking directly at your face so they can lip read to aid understanding. Spontaneous thinking around the art was not easy but giving options to choose from facilitated the participants experience and was found to be less confusing. Too many choices can be overwhelming, and it was best to ask participants to select from only two options at a time.



Figure 29. Work in progress Site E

During week four, the group was very quiet and did not speak much, however, there was lots of singing. A member of staff sat in this week and great progress was made with the heads. The group discussed how facial expressions change according to our emotions and they wanted to reflect happiness or sadness in the characters they were creating. One tenant decided her lips would have lipstick, even though she said her father would not approve. Week five there seemed to be a real transformation within the group. Individuals who had found it difficult to hold conversations and engage at the beginning were finding their voices. This week the participants were painting the canvas together as a group and created a fifth head that represented a caregiver (staff member or family). It was frequently said that staff were kind and supportive, like a family member. The fifth person symbolised the importance of that support. Discussions were focused around questions such as 'What makes you happy, what makes you feel at home, and what is important to you'. These conversations were noted so that it could be added to the canvas on week six. On the final

week, the faces and writing were added to the dry canvas. The participants were really satisfied with the outcome and the staff praised their good work. It was interesting to see the residents playing and interacting with their caricature. One participant talked to the others more openly and playfully when he was holding the 'mask' in front of his face.

## The meaning of the final piece for exhibition

*This is us*

This artwork reflects how the tenants see themselves and how they recognise others living in the same environment. The faces were created in their likeness (Figure 30). It illustrated aspects of life that were important to them, made them happy and created feelings of being at home. The text flowing around the faces reflects their responses to the discussion “what is important to you?”



Figure 30. Site E final art work

## Site F

A total of eight people attended the focus group over the six weeks, with numbers ranging from five to five attendees. All the participants were female. The group varied in ability with some individuals requiring more one-to-one support but generally an independent working group. Many participants said they were not artistic, yet they have been prolific knitters, dressmakers, flower arrangers etc. There seems to be a mental block around the term artistic, that it only equates to being able to paint. Therefore, the art activity was based around felting, wool and knitting (Figure 31).

### The process of creating the art

The first week started with a sing-song and getting to know the participants around the table. Many of the tenants had experience with cloth and textiles. The discussion started with questions about the important things for tenants, what they like to do and what makes them feel at home. Participants had a range of conversations highlighting what was important to them. A draft proposal was developed for the patches on a quilt around these conversations. Participants came up with ideas for images to replace words and they were ready to begin this in week two.

The second week was busy getting the squares of felt made for the quilt. First participants selected the coloured fibre they wanted and then pulled short strands of wool placing them in the one direction in a square on a piece of bubble wrap. They then selected another colour, pulling out thin strands of wool placing it the opposite direction. This was done for a third time with a third colour. The wool was then sprayed by the participant with warm soapy water and the bubble wrap was placed over it so the water pressed through. It was then turned around and checked to see if the opposite side was wet enough. If necessary, more warm soapy water was used until the desired effect was reached. The wool was then

wrapped up within the bubble wrap and tied using elastic bands. All participants rolled in time to the music (one song) on the table or in their hands. It was then untied, stretched out and turned, before wrapping up and rolling again for one more song. A total of ten patches were made during this week. The staff gave lots of support and they really seemed to enjoy getting involved. After the tea break, several visitors arrived breaking up the group and leaving it much smaller for the second half. However, two more tenants joined the group. One participant did not like to engage in the art work but she was happy to sit and talk during the group.



Figure 31. Work in progress Site F

During the third week we decided on the colours for the quilt and where they would be placed on the backdrop (blue/green). Additionally, felt was added to the backdrop according to the gaps and colours needed. The group started with the first square and created a party scene with bunting and a cocktail glass with straw and cherry. The artist cut out pieces of felt and the tenants then used needles to attach the bunting to the backing

square. For the tea break, the staff brought scones with cream and jam. The second square was music with piano keys and music notes was begun after the break. The tenants decided all the colours and undertook all parts of putting the felt together. This square prompted one tenant to get up and start to play the piano (a tenant who had disengaged early from the previous sessions). The daughter of a tenant came to visit her mum and sat with the group. The group continued to sing and discuss the patches. The third patch required cutting out a suitcase to represent travel and put a sun in the background.

During the forth week work continued on the different patches for the quilt. One participant told us that her favourite flower was yellow sweet pea so this was used that for the flowers patch. The group also worked on the bingo theme, home is where the heart is, church and music. Individuals were engaged in different ways depending on their skills. One participant was particularly good at cutting, others would draw, others would use the needle to felt the pieces together. During this time, there was lots of group consultation about colours and movement so everyone was trying out different skills. The tenants enjoyed working and singing. Week five continued in the same vein as week four, with lots of collaborative working and using different skills. Where drawing was a barrier, another task would be suggested. The final week centred on finishing off the remaining square and attaching all the individual pieces to the backdrop. The tenants decided the positioning of each patch on the quilt.

The meaning of the final piece for exhibition

*The American Patchwork Quilt*

The American patchwork quilt brought together all the important aspects of the tenants' lives right now and their memories of the past (Figure 32). This piece was inspired by the

film "How to make an American quilt". In the movie, a group of women get together and share the story of their life, with each person making a patch to represent a significant event. In Site F, the group discussed events and memories, past and present, and joined them together to tell the collective story of the tenants' lives. It represents activities the tenants enjoy such as music, knitting, bingo and celebrations within the scheme. Love is at the centre of the quilt because it is so important, love tenants get from their families, the staff and the other tenants. Privacy is also symbolised on the quilt because of the value they place on personal space and their own environment. The church and home are also illustrated as significant aspects of the tenant's lives. The tenants spent a lot of time travelling in their youth and enjoy their memories of this travel so this was also illustrated in a square.



Figure 32. Site F final art work

#### Site G

A total of seven individuals attended the focus group over the six weeks, with numbers ranging from four to six attendees. All the participants were female. The tenants ranged in

skills, although they primarily enjoy the art process with little experience. The creative activity was based around clay, plaster and items of great importance to the tenants. The second activity was based around material shopping bags, fabric paint and fabric markers (Figure 33).

#### [The process of creating the art](#)

The group were a chatting, bubbly group of women who seemed very familiar with each other. The first week began with introductions and getting to know what was important for the tenants. The tenants reported company, friendship, the staff and going shopping as very important. They also discussed personalising their own apartments and enjoying that. One woman got upset speaking about not been able to get out more. The tenants started some initial drawing. Pictures were taken of the tenants and then, using the Art rage app, the tenants began to draw around their picture on the iPad. As the session ended, one tenant got very upset that she wanted to go home. A member of staff was called to support her. The second week began with model magic and pressing items from a bag into the model magic to start generating ideas for the model hands that would be created. A number of women described themselves as very busy with their hands, that they have 'working hands'. They stated the most important thing in life is for '*happiness and a good life*' and one woman stated '*If you have a good life, you must have happiness*'. Other conversations included the activities enjoyed by the tenants such as walks around the garden and pamper evenings. One of the participants described how '*make up makes you feel better*'. Additionally, one tenant stated that '*I like my apartment because we are together the rest of the time*'. In terms of privacy, it was important to be able to lock the door because '*if you are undressing you want to lock your door*'. The group spoke about the

pendant alarm worn by two tenants and that it is '*important because you need to press that if you need help*'. One tenant found it difficult that '*we are not allowed out of here*', that '*I like to get out*' and '*I don't like in here at all, there is no beating around the bush, I used to like it at the start*'. Additionally, there was a discussion that it is '*very important to know the local community*'. The items pressed into the hands are listed below and include the tenants reasoning for selecting the item.



Figure 33. Work in progress Site G

Week three started by rolling out the clay to the point where it fitted into the insert of the frame and was wide enough for the hand imprint. Tenants then rolled a 'thin sausage' to act as a border for when the plaster was poured. Each person pressed their hands into the clay first. They then pressed items of importance into the clay (listed below). The edge of the clay was then checked to make sure there were no holes and the plaster was poured into the clay mould. After 15 minutes, the plaster was removed from the clay and left to dry. Two people had to finish their hands in week four. The moulds were not yet dry so the

group started to make shopping bags as the participants had discussed the importance of shopping during the initial session.

During the conversations around the important aspects of shopping, participants discussed their love of shopping for jewellery, groceries, and clothes. They loved department stores and the local main street but did not like shopping in the city. They loved getting tea and a bun to give them the 'energy to shop' and satisfaction. They love shopping with people such as family to get their opinions and because shopping was seen as a social activity. Additionally, shopping can provide an opportunity to see people they had not seen in a while. When grocery shopping they joked about going straight for the cakes but loved getting fruit, meat, sweets, vegetables and ice cream. They loved shopping at Christmas time and emphasised the importance of money to enable shopping. Wax paper was placed inside the bag to make sure the paint didn't seep through. Each person painted the bag their preferred colour. A discussion was held around the most important aspects of shopping, what they liked to shop for, who they liked to shop with, why they liked to shop etc. During the final week participants painted their hands and placed them into the final frame.

The meaning of the final piece for exhibition

#### *Hands of time*

The tenants' hands are holding items and memories of great significance for each individual (Table 23). These items were important to the tenant at the time the hands were created but they also tell a story of their life (Figure 34).

*Table 23. The Hands of Time*

Participant 1	<p><b>Scissors &amp; hair clip slide with leaf</b> reminds the tenant of her time hairdressing</p> <p><b>Knitting needles</b> as it is an enjoyable pass time</p> <p><b>Key and lock</b> represents her privacy, loves to be social but she loves the privacy of her own flat</p> <p><b>Star</b> as she loves the song Perry Como Catch a Falling Star, and loves dancing</p>
Participant 2	<p><b>Bus</b> represents trips and going out and about</p> <p><b>Needles and button</b> represents time working in the shirt factory</p> <p><b>Cigarette and lighter</b> to represent time working in a cigarette factory</p> <p><b>Pendant alarm</b> as she puts this on every morning in case she falls and gives her a sense of security</p> <p><b>Leaf</b> because she loves going out for walks and likes flowers</p>
Participant 3	<p><b>Nail polish</b> as loves getting her nails done</p> <p>A <b>dice</b> with the number six because this is her favourite number and she has 6 children</p> <p><b>Teddy bear</b> because she used to knit these and also looked after lots of children</p> <p><b>Tractor truck</b> around the edge as she used to look after children on a farm.</p>
Participant 4	<p><b>Dog imprint</b> as she loves her previous dog 'Shady'</p> <p><b>Cassette</b> as likes music and attends music activities</p>

	<p><b>Knitting needles</b> as she used to knit clothes for her children</p> <p><b>Jewellery</b> as she loves her rings with her birthstone and earrings</p>
Participant 5	<p><b>Jewellery</b> as she has a special necklace she wears sent to her by her family</p> <p><b>Glasses</b> as she wears them to see</p> <p><b>House imprint</b> represents importance of family</p>
Participant 6	<p><b>Nail polish and lip stick</b> as she likes to always be 'glammed up'</p> <p><b>Jewellery</b> as she wears lots of jewellery</p> <p><b>Dog</b> as she loves dogs</p> <p><b>Knife &amp; fork</b> as she loves food</p>
Participant 7	<p><b>Tractor</b> comes from a farm</p> <p><b>Knitting needles</b> loves to knit</p> <p><b>Love heart</b> to represent her 6 kids</p>

#### *Shopping bags*

The shopping bags symbolise choice and freedom. The tenants love to socialise and a shopping trip was usually a day out with family members, an opportunity to meet other people, select goods and go for a cup of tea or coffee. Each bag reflected what the tenants like to shop for.



Figure 34. *Hands of Time*

#### Site I

A total of six people attended the focus group over the six weeks, with numbers ranging from two to six attendees. Four participants were female and two were male. One tenant died during the six weeks. One tenant was an avid artist and enjoyed painting throughout her life. The creative activity was based around drawing, printing and using the ArtRage app on the iPad.

#### The process of creating the art

Week one began in the usual fashion with introductions and getting to know the group. One person spent a lot of time speaking over the other participants. This was difficult to

manage but she left the group after around 30 minutes. Music was played in the background as the tenants spoke about enjoying music. The group were very quiet to begin with. Two participants left to get things from their rooms and only one came back a significant time later. It was clear one participant was a keen gardener and he took the artist outside showing her the gardens and what he does. They took lots of pictures and picked some flowers for the other tenants to draw. The artist showed the group pictures of the local city and particularly the male participants related to them. One participant drew a picture of a local land mark and another drew the oak leaf representing the county.

In the second week, the focus was on printing. The artist collected leaves from the garden and three individuals used the leaves as visual guidance and drew their own leaves onto polystyrene. These were then backed by cardboard to create a printing block. One individual felt they could not draw so we used prints that were previously created. A roller spread out paint and it was then rolled onto the base of the print. The tenant then pressed leaf imprints into the page. The prints were created so they could be used as the backdrop that was further developed the following week. The focus of the piece of work developed into creating windows, one outside looking in and the other inside looking out. One participant printed the background of the 'inside looking out' picture. He rolled paint onto the blue sky and then printed oak leaves to create the impression of an oak tree. The oak tree is an important symbol of the county they lived in. Yellow and blue was added to the green printing paint to create different shades of green for the tree. The other two tenants painted flowers that would be added to the backdrop. One of the women left half way through but the other person continued to create flowers. Another participant started with the flowers after they had finished making the backdrop.



Figure 35. Work in progress Site I

Week four began with creating more flowers, using paint and the iPad as visual stimulation. The flowers and leaves that had been created were cut out. Using a printing block and roller the curtains were decorated for the windows and this work was completed collaboratively by two male tenants. On the iPad using the ArtRage App, the participants drew around their picture for the 'looking-in piece', where individuals were to be sitting in the living room. Important features in the scheme environment were to feature in the art work such as the favourite rose bush, books, television and a local landmark. For the next week, the artist printed out the pictures the tenants had drawn of themselves on ArtRage onto water colour paper. The participants painted the images in likeness to themselves. Additionally, a phone box in the garden was also drawn in ArtRage, printed out and painted by participants. The final week focused on sticking all the individual components of the pieces of art onto the two final pieces.

The meaning of the final piece

*Inside out and outside in*

Indoor and outdoor spaces were equally important to tenants. A lot of the conversations were about their local city and there was a strong sense of pride and belonging to the city. The oak leaf is symbolic of the county so it is a feature of the garden. Roses were the favourite flowers followed by petunias in the window boxes. There was also an old red phone box in the courtyard which was a central feature from both inside and outside spaces in the scheme. In the indoor scene the tenants do not sit in a group. They come across very much as individuals and those individual interests are represented within the piece: reading the paper, looking out at the garden and creating artwork (Figure 36).





Figure 36. Site I final art work

## Research Findings

The themes that emerged from the focus groups are aligned to the findings from the one-to-one interviews. Tenants expressed a sense of belonging within their housing scheme. This in turn created a sense of home. 'Home is where the heart is' is a phrase used by many different tenants throughout the focus groups. Importantly, tenants often spoke of being content, *'never been so happy'*. Contentment resonated throughout the focus groups and it was evident in the pictures taken during the focus groups as well as the art work.

Autonomy, choice, independence and freedom were also very important. Tenants enjoyed their own space and privacy, *'sharing would be awful'*, choosing what they wanted to be involved with, and deciding when they wanted peace and quiet. *'Important to have our own privacy but someone is always there if we need them'*. The ability for tenants to personalise their own living environment gave a sense of control and belonging to their experience within the housing scheme. Tenants felt safe within the housing scheme, enabling comfort

and relaxation. Finally, many tenants had pets such as dogs, birds, and cats. The relationships tenants had with their pets was critical to them and for many, if pets were prohibited this would have been a barrier to moving into the housing scheme. Relationships were a major theme that emerged within the focus groups. Connections with staff, family and other tenants were of utmost importance. *'I just love the staff, we are very lucky I just love it'*. There was a great community spirit within the groups, with comradery and friendship shining through. Tenants often spoke about the importance of socialisation and activities. Activities within and outside the scheme were a real focus for tenants and provided them with an enjoyable purpose to their days.

### Key Learning from Undertaking Focus Group

During the focus groups a range of observations were made to offer as key learning points.

These are outlined below:

- There can be difficulty generating ideas to draw so it was important to stimulate memories through conversation, music or pictures. Also, giving an individual a choice between options can support them and take away the difficulty created by spontaneous thinking.
- The time period of six weeks was considered fundamental to create a relationship and engage people in a creative activity. Two-hour sessions were important to have enough time with individuals. It was essential to take a break in the middle to build relationships and for a rest period for participants.

- Consistency of participant attendance was difficult to attain hence individual pieces of work were challenging.
- People completed things at different rates so it was important to have an additional activity so that no one gets bored.
- Group activities brought people together at different stages in their dementia journey. Often one-to-one support enhanced engagement allowing a sense of satisfaction with their contribution.
- Only give one instruction at a time to avoid confusion.
- Communication was easiest when a person was looking directly at your face so they could lip read to aid understanding.
- Too many choices could be overwhelming, therefore tenants were often asked to select from only two options at a time.
- Singing naturally emerged in the majority of the focus groups. It was also used within the sessions to make participants feel comfortable.

- Dancing with the brush to encourage painting i.e. putting on favourite music and using the music as a way to feel the brush strokes engaged people who were finding it difficult.
- It was challenging for the person when they were asked questions and completing art work so in terms of research it was important not to overburden the participant.
- Environmental factors were important- can the individual see? Do you need to use a magnifying glass? Do you need to add contrast to colour paper to support the participant? Also, keeping the environment quiet and doors closed can support concentration and focus.
- Framing the art work gave it more meaning to the tenants.
- Different mediums and materials were helpful throughout as each had different properties to support the creativity. For example, using the felt was tactile, results could be visibly seen very quickly and it was cost effective.

## Recommendations for Future Work

Using creative methods to engage with PLWD is increasing. To enhance working in this way in the future we propose the following recommendations:

- Increase the number of support personal to enable one-to-one working

- Use music and dance as a method of engagement and feeling in creativity
- Group pieces of work (as oppose to individual pieces)
- Flexible in your approach to the group
- Take a break in the middle
- Individual sketch books
- Printed out words of songs could facilitate the sing-songs that occur during the groups
- All verbal instruction should include a demonstration at the same time

Additionally, the iPad was found to be an invaluable tool when creating artwork with PLWD as it can be loaded with lots of photos for reminiscence and is a storehouse full of visual imagery. A picture paints a thousand words and that helps with understanding more than using words alone. At the first session, information was gathered about everyone's favourite music, artist or song. These were uploaded to the iPad and ready for a range of situations such as to reduce tension between tenants, create an ambience, uplift mood or simply reminisce.

### Exhibitions

A key output from the study was to exhibit the work created within the community. The work was put on display at Ulster University in January 2018 during a visit by the Vice Chancellor of the University. The work was split into two and put on exhibition over the summer (2018) in the Woodstock Library and Holywood Arches Library. During the exhibition period an event was planned in both libraries to showcase the project. Members of the community were invited in for a talk based on the findings of the overall project and

the creation of the art work. Additionally, the artists (tenants) from the housing schemes attended the events and were commended for their creations. Two final exhibitions are planned for the end of the project, one in Ulster University and a second at East Belfast Network Centre. These exhibitions will be used to launch the project findings and disseminate the community-based resource leaflet developed from the focus groups (Appendix 13). The leaflet outlines key learning points to support other entities working directly with PLWD, emphasising the use art on a regular basis. Once the exhibitions are complete the art work will be returned to the housing schemes.

## Summary

A total of sixty-four PLWD took part in forty-eight art-based focus groups creating pieces of art illustrating their life experiences. The art was created through different mediums such as felt, clay, collage, and painting. During the focus groups and through the activity, participants described aspects of their world that were important to them. Relationships, socialisation, privacy, love and being content were strongly featured during these conversations. Equally, autonomy, choice, independence and a sense of belonging were of great importance. Keeping in the moment and working with art proved meaningful with this population. The engagement, conversations and contributions were very natural when working with the art materials. The art work created was put on exhibition in the community and a booklet was developed from the findings to support community-based groups to undertake creative activities with PLWD.

## Chapter 7 Family Caregiving

### Introduction

The assumption within our society is that family and friend caregivers will have, or want to have a fundamental support role in the lives of their loved ones living with dementia. Known as informal caregivers as they are usually not paid for this role, they provide support where required in the daily life of their loved ones both before and since they moved into TESA. Often family carers have put in significant emotional and physical support prior to their relative transitioning from home. Informal caregivers provide practical and emotional support as well as support decision making and with financial affairs. Caregiving can have a negative impact on the mental health of the caregiver. The chapter presents data on the exploration of informal caregiver perspectives as their loved one transitioned into accommodation enriched with technology.

### Aims and Objectives

#### Aims

To understand family or informal carers' views on transitioning to and living within the supported housing scheme

#### Objectives

- To explore the informal carers' experience of their caring role and factors influencing the move into TESA.
- To identify the informal carers' perceptions of TESA as a care environment.

- To investigate the content of person-centred care within TESA as perceived by the informal carers.

## Methodology

This was a qualitative study using semi-structured interviews to obtain data from the informal caregivers (IC). Next of kin from tenant living in TESA participating in this study were targeted for recruitment. Interviews were undertaken in the venue most convenient for the participant. Based on the research questions and the theoretical framework within the study, the research team constructed a loose topic guide (Appendix 14). This instrument was used to provide guidance during the conversation while giving participants the opportunity to richly describe their world (Kvale, 2009). The interviews explored what the participants perceived to be their role as an IC and how they felt about it; experiences of any challenges they encountered and why they felt the transition to TESA was necessary; how they perceived the quality of care provided in TESA and the impact of living in this type of accommodation for both, the participants and their relatives.

## Recruitment

A purposive sample of all registered next of kin ( $n = 243$ ) considered to be the IC of the tenants were targeted for interview. These people were sent a letter of invitation, along with an information sheet and consent form (Appendix 15 and 16) to participate in the

study by the managers of the facilities. The recruitment process consisted of the following steps:

- a) In December 2015 managers of the nine participating facilities were asked to post invitation letters and information packs to the ICs of tenants in the participating schemes. These packs were provided in prepaid envelopes that contained instructions for the potential participants to contact researchers directly if they were willing to participate in the study. A follow-up letter was sent two weeks after the initial contact.
- b) There was a general apathy around participation, therefore, in two of the facilities, in agreement with the managers, one of the researchers joined the tenants' forum meetings attended by family members in order to remind them of the research and the invitation to participate. At these meetings, some of the participants opted in and were given the chance to arrange a time and venue that best suited them to partake in the face-to-face interview.
- c) At the same time, managers in other facilities identified potential participants and asked them verbally to contact the researchers directly if they were willing to participate.
- d) Following this, 25 participants were recruited to take part in face-to-face interviews.

## Data Collection

Data were collected from February 2016 until December 2016 through semi-structured, digitally recorded interviews that lasted between 40 minutes to one hour. On the day of the interview, the researcher formalised consent and reminded the participants about confidentiality and anonymity and the right to terminate the interview at any time or not to answer all the questions. One of the 25 participants refused to have the interview recorded but agreed to have notes taken. The majority of interviews were undertaken in the supported accommodation facility where their relative resided at a time convenient to the participants – usually before or after visiting their relative. Other venues for the interviews included the participants' home, the researcher's office or a quiet area in a public venue chosen by the participant.

### **Data Analysis**

All interviews were transcribed verbatim by the researcher and a professional transcriber. After checking the transcripts for discrepancies, data were anonymised and all identifiers removed. Then, data were uploaded on to NVivo 11, a software package for qualitative data analysis (Bazeley, 2013). We used a thematic analysis approach as outlined by Braun and Clarke for analysis (Braun & Clarke, 2006). This method offers a theoretical freedom which makes it 'a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data' (Braun and Clarke, 2006: 78). This approach was favoured as it allows the rich overall description of the data when investigating an under-researched area, which is consistent with the exploratory nature of our research. Furthermore, this approach is compatible with the identification of themes or patterns in an inductive or 'bottom up' way or in a theoretical or deductive 'top down' way (Braun and Clarke, 2006: 83).

In our analysis, Braun and Clarke, (2014) systematic framework was adopted for coding all the data with the resulting codes used to identify themes across the dataset. The first analyst had a key role in the familiarisation with the transcripts and the generation of initial codes and identification of themes which captured 'something important in relation to the overall research question' (Braun and Clarke, 2006: 82) and the study's theoretical underpinnings. In keeping with the framework, all data items were coded against all the data extracts that best represented that code. Then, the same analyst created matrices in order to organise the codes and look for potential themes.

These themes were compared, refined and grouped according to their commonalities and then discussed with the team to ensure the relationships between codes and themes and themes and subthemes. The process of analysis, at this point also involved the constant comparison between transcripts, codes and themes (Glaser & Strauss, 1967) to ensure that the structure of the themes was grounded on the data. Finally, two of the researchers reviewed the agreed themes and following Braun and Clarke's (2006) framework, tested their clarity by outlining a brief description of their meaning and content. The themes were considered in terms of the extent to which they coherently and adequately represented the meaning of the data set as a whole (Braun and Clarke, 2006).

### Reliability and Rigour

To enhance the reliability and rigour of the data a number of steps were taken. First, each step of the analysis was documented in detail so that any member of the research team could view the coding and see the development of themes. Additionally, sample extracts of data were extracted and applied to codes, themes and subthemes (Table 24). Two

members of the research team reviewed the themes and tested their clarity before presenting the final analysis to the entire research team for further review.

*Table 24. Sample data extracts with application of codes and final themes and subthemes*

Data Extract*	Codes	Theme	Subtheme
<p>'A safety element, I suppose, in the house; maybe making sure that, [...] that everything was safe for her. [...] she would've been still at home. I suppose, as it progressed [the illness], mummy would've walked a lot, [she] would've gone off, left the house. [...] So, we had to try and put alarms and things to make sure that mummy was safe.'</p> <p>(Daughter 3)</p>	<ul style="list-style-type: none"> <li>• caring</li> <li>• safety</li> <li>• danger</li> <li>• walking</li> <li>• stress</li> <li>• worry</li> <li>• on alert</li> <li>• sadness</li> <li>• alarms</li> <li>• GPS</li> </ul>	<p><i>'I'm her informal carer, it's as simple as that.'</i></p>	<ul style="list-style-type: none"> <li>• Providing safety</li> <li>• Coping strategies</li> <li>• Negative feelings</li> <li>• Negative impact</li> </ul>
<p>'And we were becoming concerned about him because he seemed to becoming a bit careless about himself. And we were concerned about the apartment he was living in that it wasn't safe.'</p> <p>(Sister)</p>	<ul style="list-style-type: none"> <li>• not being well</li> <li>• higher needs (psychological)</li> <li>• higher needs (hospitalisation)</li> <li>• changing circumstances</li> <li>• concerns about safety and independence</li> <li>• discussing the move</li> <li>• where to take her/him?</li> </ul>	<p><i>'And it hit the crisis point.'</i></p>	<ul style="list-style-type: none"> <li>• Balancing safety and independence</li> <li>• Intensification of needs</li> <li>• Making the decision to move</li> <li>• Where to and why?</li> </ul>
<p>'I think because he knew he could come and go when he wanted, you know. And he had his own wee house effects. He just felt the independence.'</p> <p>(Wife 1)</p>	<ul style="list-style-type: none"> <li>• familiar objects</li> <li>• social contact</li> <li>• small setting</li> <li>• independence</li> <li>• support</li> <li>• nice flats</li> <li>• small flats</li> <li>• gardens</li> <li>• enclosed</li> <li>• security system</li> <li>• staff presence</li> </ul>	<p><i>'Just a home from home.'</i></p>	<ul style="list-style-type: none"> <li>• Approach to care</li> <li>• Characteristics of the facilities</li> <li>• Safe environment</li> </ul>
<p>'[It's] that there's 24-hour staff presence and whilst she's not in company all the time, they are aware of her normal patterns; they're with her frequently.'</p> <p>(Son 4)</p>	<ul style="list-style-type: none"> <li>• independence</li> <li>• activities</li> <li>• going out</li> <li>• safety and security</li> <li>• knowing the person</li> <li>• reassurance</li> <li>• staff presence</li> <li>• family/friends visit</li> </ul>	<p><i>'I'm glad they're looking after me.'</i></p>	<ul style="list-style-type: none"> <li>• Safe environment</li> <li>• Safety and security/Reassurance</li> <li>• Maintaining connections</li> </ul>

\*Sample extract that has been coded with one or more of the codes from the adjacent column.

## Findings

The experience of families/informal carers (ICs) caring for a relative with dementia

In total, 25 interviews were conducted with 18 females and seven male informal carers. The youngest participant was 24 years old and the oldest was over 70. These participants talked about their experience of being an IC for 19 female and five male relatives (two of the participants were siblings who talked about their mother) who have been tenants in technology enriched supported accommodation for a length of time ranging from four months to 12 years (Table 26 for full demographics). Except for one participant, the remainder lived in NI at driving or walking distance from the facilities where their relatives resided.

*Table 25. Demographic characteristics of informal carers participants*

Characteristics	n	%
Gender (n = 25)		
Female	18	72
Male	7	28
Age (n = 25)		
18 - 29	1	4
30 - 39	1	4
40 - 49	5	20
50 - 59	9	36
60 - 69	6	24
70+	3	12
Marital status (n = 22)		
Married	20	80
Single	1	4
Divorced	1	4
Relationship with the tenant (n = 25)		
Daughter	11	44
Son	6	24
Wife	3	12
Friend	1	4
Granddaughter	1	4
Niece	1	4
Sister	1	4
Sister-in-law	1	4
Employment status (n = 23)		
Professional (health and social care, business or industry)	9	36
Retired professional	7	28
Administration/Clerical/Care services	3	12
Housekeeping/Skilled trade occupation	2	8
Never worked	1	4

Four main themes were identified in the data. All the themes were named using *in vivo* codes. The themes of '*I'm her informal carer, it's as simple as that*' and '*And it hit the crisis point!*' reveal what was meaningful to the ICs and the factors impacting on their experience. The themes of '*Just a home from home*' and '*I'm glad they're looking after me*' describe the life of the PLWD in the facilities and those aspects of care in supported accommodation closely associated to person-centred care. Table 27 provides a summary of themes and subthemes identified.

#### Theme 1: '*I'm her informal carer, it's as simple as that*'

For the large majority of participants there appeared to be a natural progression into their caring role as the dementia advanced and the signs of the illness became more apparent impacting on independent living. The main signs noticed by most ICs, were the

forgetfulness, the neglect and the increased need to provide more support with practical issues, such as domestic chores, shopping and finances. Some carers, like this son reported that he saw himself 'sucked in for more and more and more caring' because of the pattern of isolation and dependence developed by his mother who found herself without a purpose in life after the death of her husband for whom she had cared for throughout many years of illness (Parkinson's disease).

Table 26. Four main themes discussed by informal carers (ICs) of PLWD and their corresponding subthemes

Themes identified in the ICs data	Subthemes
<i>'I'm her informal carer, it's as simple as that'</i> How ICs assume their role from the onset of dementia and feel about it	Providing safety Coping strategies Negative feelings Negative impact
<i>'And it hit the crisis point!'</i> The point when it is evident that changes in caring arrangements, including accommodation are inevitable	Balancing safety and independence Intensification of needs Making the decision to move Where to go and why?
<i>'Just a home from home'</i> Easing off into the technology enriched supported accommodation (TESA)	Approach to care Characteristics of the facilities Safe environment
<i>'I'm glad they're looking after me'</i> The outcomes of living in TESA	Satisfaction with care Safety and security/ Reassurance Maintaining connections

#### *Providing safety*

Regardless of the circumstances that led participants to the caregiving role, a recurrent topic of conversation was the need to ensure the safety of their relative who may have been living alone in their own independent accommodation or with their wives in the marital

home, in the case of married men. ICs appeared to focus their caring efforts on providing safety. Safety was concerned with reducing the risk of harm in the PLWD's immediate living environment and engagement in daily activities, as this daughter described:

*'The silly things. You know, like putting the milk in the kettle. Forgetting all those things that go along with that. She could've been a danger, maybe, perhaps in her own home'.*

(Daughter 6)

Also, for many ICs the safety issues became more problematic as the illness progressed and other symptoms like wandering or getting lost were more prominent and it was difficult to keep the PLWD at home. Some participants, like this daughter resorted to the use of assistive technologies to help:

*'I suppose, as it progressed [the illness], mummy would've walked a lot, you know, mummy would've gone off, left the house. There would've been, one day, we lived [in town nearby] and mummy would've been found six miles from the house. So, we had to try and put alarms and things to make sure that mummy was safe'. (Daughter 3)*

Other participants also worried about the possible risk of harm to others as a consequence of their failure to keep their relative safe at home. This son described his experience with his mother:

*'She'd walked up as far as [the dual carriageway], wandering on the road, side of the road, hadn't a clue where she was and got very tired. [...] She was putting herself at risk and as well as herself, she was putting other people at risk as well, other road users [...] with all the best intentions in the world, you can try to steer away but you might not be able to and you can just imagine what those people, the driver of that car what would have felt like if he'd hit her and killed her'. (Son 6)*

### *Coping*

Many of the participants felt they could cope well in their roles and felt supported by statutory services who helped them provide appropriate care. Mainly, social care services helped them navigate the system and provided care packages for their relative which consisted primarily of domiciliary care visitations at different times of the day including bedtime, for some, to deliver meals and administer medication. Participants found this useful for two reasons. First, they felt reassured that their relative was having at least one meal per day as some were worried about a lack of nutrition and second, participants felt some relief knowing somebody was calling on their relative when they were not available to do so, therefore an alarm could be raised in case of an emergency. This daughter succinctly explains that:

*'He [the PLWD] had the carers, not obviously at the very start, but then whenever he started to forget that he'd had lunch and that sort of thing the carer was put on ... that was a lot of relief for me [...] If there's somebody going to the house and getting into the house, I knew he was home, he hadn't wandered in the car, you know, he wasn't lying out the back. It not only was, he was getting food at the proper times, but there's someone checking that he's alive and that's quite something for you to be able to be free'. (Daughter 1)*

Nonetheless, a small number of participants expressed dissatisfaction with the arrangements of the care packages which due to the lack of empathy from the staff they described as inflexible. A son in particular found it challenging when he could not get statutory services to include personal hygiene in his mother's care package. Because this service is not considered a critical need he could not get a female carer to administer personal care. He found it awkward having to put his mother in the shower and dealing with other intimate personal care, as he explains in this excerpt:

*'I'm very frustrated because I knew what type of care I was giving mother and able to give mother and when I was looking for help from the social services they couldn't match that same level of care. There were carers coming in to get her out of bed in the morning and give her breakfast. They wouldn't or couldn't do anything for personal hygiene, they said care is based on a critical need basis'. (Son 6)*

While being in the system was the best mechanism to obtain appropriate services, it was also evident to a few participants that complementary coping strategies were needed. Mainly, these participants found it 'very hard' to deal with psychological symptoms and behavioural disturbances associated with dementia, such as the repetitive sentences or questions, confusion, agitation, paranoia, lack of motivation and personal hygiene. Given that the participants confronted these challenging situations on a daily basis and for some, for a number of years, they developed their own coping strategies to deal with them. These included: 'playing along', avoiding upsetting topics or using child psychology. For example, this son talks about saving his mother the sadness of grieving for her dead parents once more just by playing along and pretending that they were still alive:

*'And then she'll talk about her mum and dad: 'I wonder how my mum and dad are ...' In the beginning I used to say: 'Your mum and dad died a long, long time ago.' And then she used to get all upset as if it's just news to her. So, I don't tell her now, I don't correct it. [...] Before, it used to be, it was like a fresh grieving every time; but after half an hour she'll have forgotten about it but she was still getting upset.' (Son 6)*

A small number of participants appeared to use more practical coping strategies including assistive technologies, such as, bed sensors, pendant alarms, CCTV cameras or GPS trackers. Others mentioned using alternative therapies, learning new things or keeping busy; '*always having a new project*', as one participant put it. Noteworthy, a small number of participants

said that learning about dementia was helpful, and, in particular, one participant remarked on an awareness programme provided by her local GP surgery:

*'The social worker put me in contact with [this doctor] and he ran like a six-week course, right? And anybody who had parents, husbands, whatever, with dementia, went along and every week there was something different: how to take care of them, how to get carers in [...] It was very helpful'. (Daughter 4)*

#### *Negative feelings*

The great majority of participants were overcome with negative feelings. Generally, they felt guilt, sadness and a 'sense of failure.' These sentiments lingered throughout their caring career, even after they progressed into the transition into TESA. Being a witness to a parent's functional decline and the associated consequences was hard for many adult children. As one daughter said, she and her sister '*found it very hard, it was a feeling that [we] had not done a good job*' (Daughter 10). Another daughter found it nearly unbearable, she said:

*'It's very sad. It's a horrible disease, it's a horrible thing to ... it's hard to watch. It's hard to watch.' (Daughter 6)*

Again, for adult children it was very hard having to take away power and control from their parents, and this made them feel guilty, as illustrated by this account from a daughter:

*'And I felt, every time I had to make a decision, I felt that I was taking a wee bit of mummy away, you know. It was hard. And I don't think anybody really, well my sister didn't realise it, my brother certainly didn't realise it, that every decision I've made for mummy, even now, even if it comes down to mummy going into a residential home, it's...um...it'll break my heart you know.'*

(Daughter 2)

*Negative impact*

In general, it was shown that the caring role was having a negative impact on the participants. For some, life changed in dramatic ways, as this son expressed:

*'[My life] changed completely. I swapped one profession for another. I retired from gainful employment to really full-time unpaid work'* (Son 6).

Similarly, older wives, many of whom had their own health issues, found their caregiving role challenging and felt that they were vulnerable to adverse mental health and wellbeing and even had to face the criticism of their families. This wife, for example, whose physical ill-health eventually prevented her from being a full-time carer for her husband, ended up feeling guilty and as if she was being judged by family members, she explained that:

*'I do have a sense of failure that I can't [keep my husband at home] [...], especially when I hear his own brothers and sisters saying about how easy [my husband] is to manage. But I couldn't, I had to get treatment [...]. Well, I'm feeling much better now a year on. I still get very tired and I still realistically know that I probably couldn't take him on 24/7 again'* (Wife 3).

Other prevalent negative impacts amongst the majority of participants were the constant worry and pressure they were experiencing, to the point that over time the caring responsibilities became too demanding. For some, time issues and geographical distance added extra pressures and worries to their roles. As explained here:

*'Well, um, it was becoming increasingly difficult because, um ... my mother had developed a pattern, [...] where in the evening she would become quite disorientated. [...] And she*

*would've phoned me repeatedly maybe ten times in an hour, and it was difficult from such a long distance away to settle her. [...] So, if I could find the right thing to say to get her settled, you know, and get her to go to bed, I knew that the next morning she would be fine'.*

(Son 4)

It was also evident amongst many of the participants the difficulties in balancing caregiving with other family demands at the risk of neglecting their own families, as illustrated in this quote:

*'But the family are saying 'it's not my job, it's not my duty' to be looking after him; I should be putting more time into them, into my grand-children'. (Daughter 1)*

#### Theme 2: 'And it hit the crisis point!'

Over time caregiving prior to moving into TESA posed different challenges to the participants. While the majority of them were fully committed to their caring role and assumed their responsibilities unconditionally, external factors related to the physical environment (people living in their homes), the progression of the illness (higher needs) and their limited physical presence, highlighted issues of safety and risk that eventually led to a crisis point and the realisation that caregiving was difficult to maintain under such circumstances.

#### *Balancing safety and independence*

Numerous accounts illustrate the difficulties encountered by the participants who tried to balance the need for independence of their relative and their safety. The wandering, getting lost, having to be out in the streets or country lanes looking for a relative or having to report them to the police or to have them returned home by the police were common

experiences for the majority of the sample. These experiences added more stress to their role and led, in many cases to them taking extreme measures, such as preventing their relative from driving or walking unaccompanied as this participant explains:

*'And there were a couple of incidents where people brought him back because he'd crossed the road without looking or, you know, not going near the lights, just heading out on the road. And once the police brought him back; he crossed the bridge, and once that's happened I said: 'Right, that's the walking finished.'* (Wife 3)

Moreover, a few participants were confronted with moral and ethical dilemmas about the methods they employed to avoid 'wandering', which consisted mainly in locking their relatives up in their own homes:

*'I couldn't keep him in the house at that point and what I was actually doing was [...] I put him in bed in his own house, lock up and make sure he was absolutely sound and be back in the morning for him to wake him up. And that's not good.'* (Daughter 1)

Many participants expressed concern that their relatives' functional decline was putting them at risk of falls or harm to themselves or others:

*'But, you know, she could have fallen down stairs and nobody would know from the six o'clock visit in the evening to the ten o'clock visit in the morning by the carers. So, that's six, ten, 16 hours she could've fallen just after that, and 16 hours she is lying where she is lying. So, you know, the safety thing'.* (Daughter 9)

#### *Intensification of needs*

Some of the participants considered the possibility of caring for their relatives indefinitely, but as their needs intensified, they realised that it was time for change as they felt they

were incapable of providing appropriate care. This was particularly difficult for some participants who also experienced their own physical decline, as told by this wife:

*'And then, I have arthritis which I've had for years, before I retired I had arthritis, [...] and he became incontinent. And it was terrible. I couldn't manage at all. He wouldn't let me near him, he didn't really know me. Um, and it was really, I ended up ... and I was exhausted, as well. I realised then I needed the recovery time, I was very, very tired ...'* (Wife 3)

For many, the pressures of caregiving were increasing significantly as the emotional and psychological needs of their relatives increased. As a result, participants not only felt upset by their relatives disturbing behaviours, but also realised that further intervention was imminent. This is illustrated on the accounts of this daughter:

*'Well, ... then, um, I suppose it's like a lot of things; change came when there was crisis, agh!! [...] She started to get paranoid about different people coming into the house, that they were stealing off her and things like that. So, basically that was one of the reasons why she couldn't stay on her own [...] We decided that we would try and leave my mum for a few nights. I'd be staying the odd night with her and then she was phoning me constantly; she was forgetting that she had phoned me. It was very disruptive to my home life and to my brothers' as well'.* (Daughter 5)

#### *Making the decision to move.*

Once the events that prompted the decision to move the relative to more appropriate accommodation have unfolded, on some occasions this decision was made jointly:

*'Obviously, he [relative living with dementia] came to see the place before we made the decision, before he made the decision'.* (Sister)

The interviews with ICs also revealed how health or social care professionals played a part in making the decision for the transition given that they had supported the participants during their moments of crisis. As this daughter explains:

*'The crisis point was then, about whenever erm, after [my children] were born and then my sister had her children and then we were at the house one day and mummy just became, [...] very unwell, so, then, mummy was admitted to hospital. Um, so that basically was the crisis. And then mummy was in hospital [for a few months]. And then round that time, there were various meetings, and, I suppose, they knew what her circumstances were; it was only the two of us, and we had young families and we were working, we'd jobs and they were sort of saying: 'You know, the reality is, you're not going to be able to do this.' I suppose, we were starting to realise that ourselves'. (Daughter 3)*

#### *Where to go and why?*

While it appeared that safety was a key factor influencing the transition, ICs also valued the independence and autonomy that a new living environment could offer, therefore, they were careful in choosing facilities that met those conditions, as explained here:

*'We just came and had a look here [the facility] and thought it was fabulous. Because we wanted him to be independent for as long as he can be independent. We just thought that that was a step too far to be going into a residential type home environment and we knew he would hate it!' (Sister-in-law)*

While some ICs got to know about the TESA by word of mouth, in many other cases the decision to move their relative into this type of supported accommodation was facilitated

by the advice and information received through statutory services, as this daughter explained:

*'I was talking to a hospital social worker who was an absolute gem, she was lovely, so she was. And after a while she came and she said: '[XXX] I think [this facility] might be the best place for your mother.'* (Daughter 8)

One of the key enablers of the transition process in the majority of cases, was the facility ethos. For many participants, managers and staff demonstrated the right attitude and it was evident to many more that the approach to care in the facilities was based on the principles of the promotion of life skills, relations and interactions:

*'I remember them asking him why he wanted to move into his own place. Obviously he is asked a lot of questions before moving from the [nursing home], you know, 'Did he want this, and that ... ' The manager from here went to [the nursing home] and talked to him and she was able to tell me that he said that he didn't want to be in an institution. And she says: 'Whenever he can say that to you, he's not ready, you know? He needs another chance to be his own person in his own place. He still has too much ability and his own thought.'*

(Daughter 1)

It also appeared important to the participants that the staff in the facilities demonstrated to have the appropriate repertoire of skills that could facilitate the transition and life in the facility:

*'But, I mean, it's very reassuring to me, that she's in a place where staff are well trained, recognise the condition, recognise, become familiar with each resident'.* (Son 4)

More importantly, numerous participants described how the facilities offered the safety and minimisation of risk that for many led to the decision to move. In the facilities their

relatives were safe: from harm, wandering and getting lost; some of their big fears. The fact that there was a 24hr presence of staff was also reassuring:

*'I think it's a great relief for us to know that the staff are there all the time and they would pick up on things'. (Niece)*

A minority of participants stated that assistive technology was not a factor that influenced the transition of their relative to TESA although a few that mentioned this as a decisive factor. However, in general, participants were not even aware of the use of assistive technologies to support care for PLWD:

*'Well, um, I ... I don't see anything in assistive technologies here other than is a basic prerequisite of health and safety'. (Son 2)*

Whether the participants were aware of the use of assistive technologies in the facilities or not, it became apparent during the interviews that the main advantage afforded to the technologies used was the safety it provided. As the PLWD engaged with life in the facility, participants were able to describe how the various assistive technologies used in the facility appeared to have the purpose of keeping the person safe, and this, unanimously, was very reassuring, as this son explained:

*'I didn't know about what kind of technological support or systems they [the facilities] would've had. I was looking for somewhere where she would be safe, so the important thing for me was that there was staff, trained support staff. However, when we saw this and learned that there were these, that this technology was there, I found that quite a reassuring thing'. (Son 4)*

In general, the physical environment was found to be suitable and appropriate to the specific needs of the tenants. It offered gardens, spacious rooms and other features that made the dwellings and apartments comfortable and enjoyable:

*'... the apartments are well spaced out, they are not cramped and there are good grounds outside [...] It's within a housing estate. [...] It's just like a wee oasis in the middle of it all'.*

(Daughter 6)

Theme 3: 'Just a home from home'.

In general, the positive aspects of the supported accommodation model outweighed the very few barriers noted by the participants. For the majority, care in the facilities was provided in a holistic manner with the right level of engagement and participation of the tenants and the ICs. For many, the transition was described as 'smooth', and as the title of this theme suggested it appeared to be '*...just a home from home*' move. The factors that made this possible are presented in the following subthemes:

#### *Approach to care*

The supported accommodation model in small settings was found to be the preferred and most adequate model of care for PLWD. Some of the advantages of this model according to participants, included small settings where people could thrive and be buffered against social isolation; settings where people's individual needs were catered for and not restricted to a one-size-fits-all system. This is eloquently described by one participant who said:

*'I don't think there could be a business formula with dementia. [...] [To] care successfully for people that are suffering from dementia requires a slightly different cost approach from the containment that you have in a nursing home facility where people are confined in rooms or beds and there's a ratio of one to ten or one to fifteen.*

*Here you've got maybe somebody that is in need to go downtown to get to do a message and that stimulus is very important to them and that opportunity for them to get out and engage with the community and have that independence. It's something*

*that should be encouraged and patients, for want of a better description, thrive on that and we all want to encourage that.'* (Son 2)

*Characteristics of the facilities*

Independence, decision-making and choice featured as some of the most relevant characteristics of the approach to care offered in the facilities:

*'They make them do things for themselves to see how much help they would need to do them. Because, now, in the morning it would take my mother, aww, I don't know, hours to get ready in the morning to get dressed and all, you know. But they say they won't take that away from her because that's still her independence'.* (Daughter 8)

Positive staff attitudes, working together with tenants and ICs, promoting and encouraging effective communication and relationships appeared to be other features in the facility highly valued by the overall majority of participants:

*'... they all [the staff] seem not just to have what obviously people doing that job would have to have, and that is the sort of empathy and compassion that you need, and patience'.* (Son 4)

The safe environment provided, not only by the design features of some of the facilities, but also through the use of the assistive technology and the presence of staff was particularly commended by the participants. Some examples:

*'As soon as she goes to bed her sensor's on (...). She might've just sat on the bed, she might've tried to get down to the toilet, she might've fallen; they're there. And for me that's just such a safety net.*

(Granddaughter)

A small number of participants reported on negative aspects of the delivery of care. Mainly, they concerned with lack of facilities for smokers, shortages of staff and some lack of provision of activities and one-to-one:

*'I know there are times where they're short staffed and they don't have the time, really, and stuff like that. I think there have been problems when they don't have the full squad in'.*

(Sister-in-law)

*'As I said, I think definitely there needs to be more one-to-one. [...] So, that's why I think, that she probably does get restless, 'cause she's just sitting there and she's nothing to do.*

*But I've noticed that there isn't a whole lot goes on at the moment.'* (Daughter 2)

The youngest participant, one granddaughter reported on the lack of internet connection in the facilities which limited the means of communication between tenants and family members who could not visit regularly.

#### Theme 4: 'I'm glad they're looking after me'

This theme focused on the advantages or disadvantages the participants mentioned about the life in the facility for their relative. Their discussions focused mainly on the improvement of the quality of life of their relatives since their transition into the facility. Many of the participants also talked about the implicit gains or disadvantages for themselves as a result of the move.

#### *Satisfaction with care*

Overall, there was a sense of satisfaction with the care offered in the facilities with many participants commenting that they would recommend them to anyone:

*'I can't imagine why I wouldn't recommend this place to anybody 'cause for me, as I say, granny wouldn't be living if she wasn't in here; in my opinion and my family's opinion'.*

(Granddaughter)

Other examples of satisfaction with care were associated with the apparent feelings of wellbeing, happiness and contentment shown by their relatives:

*'Oh, it's very reassuring. You know, because, the number one priority, I'm sure, for every carer is that the person, that you know that they are, as far as possible, content. And she is a great deal more content, than she was in her own home, especially during those times when she didn't know where she was'. (Son 4)*

Equally, the social aspect of the facility in terms of activities and encouragement of social life (outside and within the facility) and relationships was also praised by the participants:

*'But then she's made friends here, too. Which is good, because if she was at home she wouldn't have any of that'. (Daughter 8)*

*'... she loves going to her day centre and she loves living where she's living. And she's just a different person now'. (Daughter 7)*

Again, the transition to live in supported accommodation has also offered the advantages of safety and security for the tenants and 'peace of mind' for the participants. The 24-hour staff presence is reassuring for the participants who felt more relaxed and under less pressure:

*'Benefits in my life?!! There's benefits in my life because I don't worry much! I'm not as much concerned. I'm not getting the phone calls in the middle of the night because she's pulling the cords. So, it's made my life better because it has taken a lot of pressure off me'. (Son 1)*

*'And I find the staff are very good at, um, they know her very well. It gives me such a peace of mind to get to put my head on the pillow at night and know she's happy. I sleep in peace and I can lift the phone at any time of the day or night and phone here and it's never seen as a bother.'*

(Daughter 5)

#### *Maintaining connections*

Finally, living in the facility has provided both parties with the opportunity of keeping family connections while the PLWD enjoys life to the best of their abilities:

*'I, definitely, am looking after her as much as I can from the 500-mile difference, yes, distance. [...] And, um, they [the facility] are very happy that I'm coming over every month, and I could not do that even now she is in somewhere that I know she is comfortable. I can't live with the thought that I'm not visiting'. (Daughter 9)*

#### **Discussion**

In this study, the accounts of ICs about their experiences of caring for a relative living with dementia who, eventually, moved into TESA are captured. It is interesting to note that ICs assumed this caring roles in line with Archbold's (1983) conceptualisation of caregiving into roles of either providers or managers as the dementia progressed prior to transition. As care providers, ICs identified the needs and performed the tasks necessary to fulfil them. This care provider role was dynamically evolving, through provider and manager, into a single care manager modality, which was considered to continue post transition. This is aligned to the emerging understanding of the complexity consistent within the caring role (Sao Jose, 2018). This change in caregiving role was a natural transition that emerged within necessity to support their loved one move into TESA and emerged from 'hitting the crisis point' ICs identified the provision of safety as a key issue. This is an important finding for two reasons. Firstly, it appeared to be one of the main factors associated with stress and the decision to move the PLWD into supported accommodation. And second, it is an important component within the provision of TESA which offers a safe environment, 24-hour staff presence and assistive technologies. The characteristics of TESA provide a

reasonable approximation to the content of the PCPF in terms of the constructs of care environment, person-centred processes and outcomes (Figure 37). When transition was described as 'just a home from home', ICs acknowledged that the safe physical environment enriched with smart home technologies provided the reassurance and 'peace of mind' they needed to feel that their relative was being well looked after and that the new accommodation felt like being at home. Organisational systems, positive (consultative) relationships and appropriate skill mix conducive to the provision of holistic care for which, were considered positive for both ICs and their relatives. The finding that the decision to move their relative from home was delayed in all cases until the ultimate crisis point was reached resonates with other research on family caregiving and entry to care (Nolan and Dellasega, 2000) and is important in considering how services in the community pick up such scenarios and the preparedness required in supported accommodation to support transition during crisis.

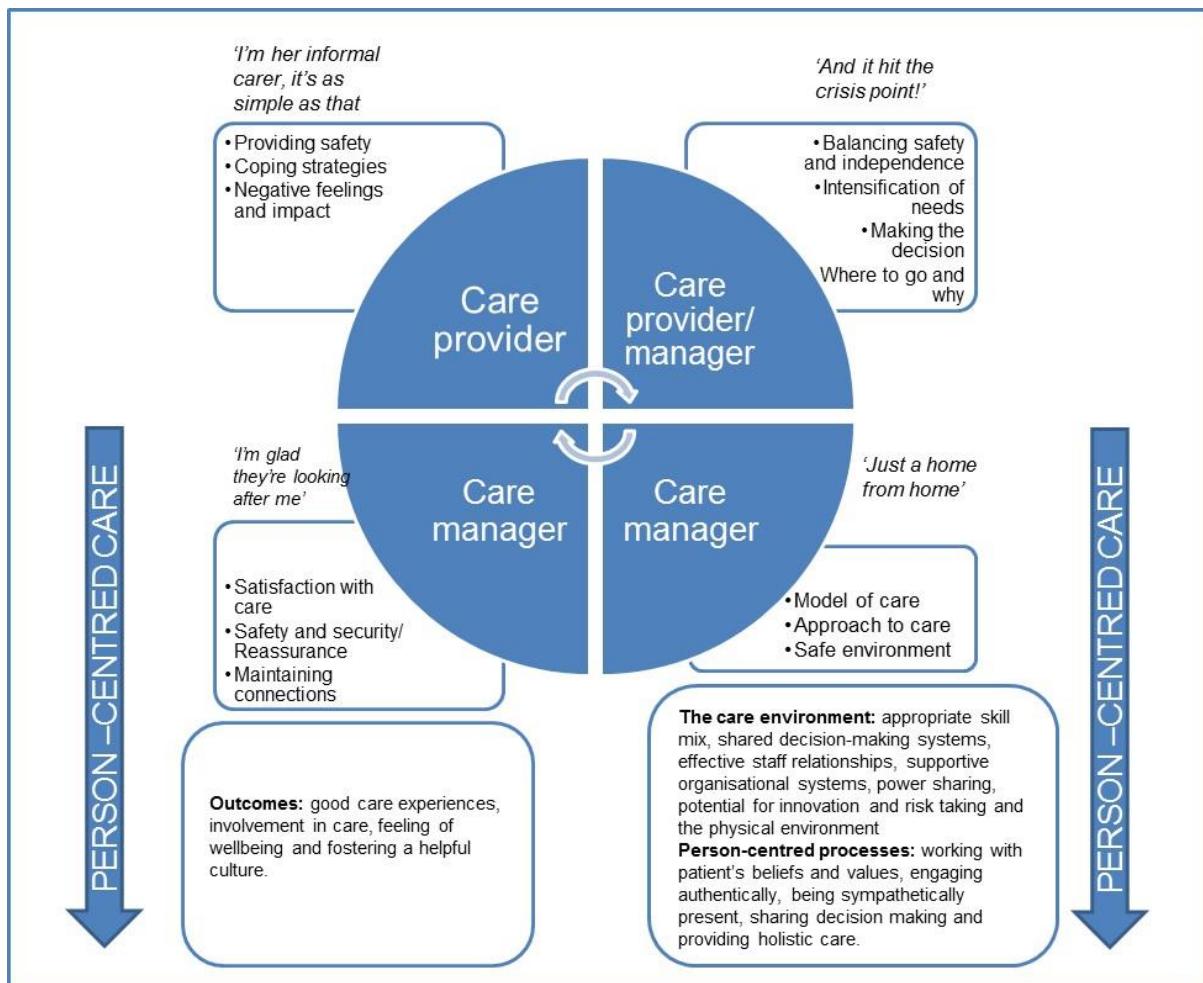


Figure 37. Comparison of the study findings to caregiving roles and content of the person-centred care framework

ICs report that when the caring responsibilities 'hit the crisis point', they feel compelled to identify the most appropriate services provided by others, especially statutory services who had supported crisis(es). The need to provide safety is a priority, with the desire to ensure physical and emotional comfort, shifting their role to focus on 'monitoring other caregivers to be sure this work was done properly' (Caron & Bowers, 2003:1261). One important aspect of our findings is that the transition to TESA was not influenced by the added value of pervasive technologies in the facilities. Only a few participants mentioned that this as a decisive factor, generally, they were not aware of these technologies to support care for PLWD residing in supported accommodation. This is an important finding in our study which adds new knowledge in the area. While technologies appeared important to the ICs

in terms of provision of safety the characteristics of the facilities most valued were those directly linked to the person-centred care ethos prevalent in the facilities. The most prominent elements of the person-centred practice framework identified in our findings are those related to the constructs of the care environment, person-centred processes and outcomes (McCormack and McCance, 2017). In the themes of '*Just a home from home*' and '*I'm glad they're looking after me*', there were numerous accounts on how focused the facilities are on the provision of holistic care. '*A home from home*' transition meant that both ICs and their relative participated in decisions regarding all aspects of care, giving their relatives control over how they wanted their home to be furnished and decorated as well as planning their care and activities within and outside the facilities according to their own choices. These exchanges not only reflected the desire of a cultivation of effective communication and relationships in the facilities as outlined in the person-centred processes of the PCPF, but are also in line with NICE guidelines on the transition of older adults from different settings which emphasise the principles of person-centred care and information sharing as overarching principles of care and support during transition (NICE, 2015). ICs referred to how the positive attitude of the staff, their awareness and knowledge of the 'normal patterns' of the PLWD and the things that were important to them helped to create an environment in which they felt encouraged, motivated and valued, demonstrating how a sympathetic presence as defined in the PCPF (McCormack and McCance, 2017) may be more important than the physical presence. Likewise, they commended the dedication of the staff at all levels who were instrumental in delivering interventions that took into account the full set of psychosocial needs of each individual tenant in the facilities. All these elements also suggested by McCormack and McCance as markers of effective person-centred practice (2017).

Safety emerged as a key finding both in the transition into the supported accommodation and the reason IC's were satisfied with the technology enriched environments. The accommodation within this study provided unique technologies to support tenants that are not available in standard supported living environments. For example, all but one scheme offered wearable devices (bracelet or pendant) to tenants, after a needs assessment, which provided IC's and tenants with a sense of security. In line with previous research (White & Montgomery, 2014), this type of technology gives tenants the freedom and independence to freely wander the accommodation but for IC to be content they can immediately get assistance if required, providing the IC with peace of mind (Alwin et al., 2013; Mao et al., 2015). Therefore, with a technology enriched setting a safe environment can be provided to wander. Equally, if the tenant wakes up and leaves their bed, the bed sensor will alert staff to the tenant leaving their bed and staff are able to check on tenant particularly if they are prone to become disorientated. Once again, all but one scheme was able to speak to the tenant through an intercom in their living space so they had immediate contact with staff in the event of urgent assistance.

The participants demonstrated how the supported accommodation model in small to medium-sized settings is an acceptable model to support PLWD and their families. The main characteristics of this model that appeal the most, consist of the use of non-intrusive assistive technologies which provide security and safety, and most of all the approach to care which is underpinned by the principles of PCC. This research adds an in-depth perspective of strategies to ensure that PLWD enjoy an independent life for longer in the community when the appropriate support from family, carers and statutory services is made available and when such support is based on a practice framework designed to enable a holistic approach to care. Services, in particular, may benefit from this type of research that

highlights the need to consider health and social care from a whole systems perspective, which advocates treatment in community settings (Bengoa et al., 2016). Dementia care based on these principles would avoid reactive solutions when things 'hit the crisis point' that may lead to unnecessary hospitalisations and/or institutionalisation. Equally, ICs may be guarded from the adverse effects of the caregiving responsibilities and could be provided with appropriate and timely information that would help them, as well as the PLWD, to make informed decisions about care provision. This would enable the PLWD to live for longer independently in the community where they could thrive and flourish and maintain meaningful relationships with people and places.

#### [Recommendations for practice, research and policy](#)

The technical provision was not an influencing feature in the decision to transition loved one into TESA. Future research should explore how the use of technology to care could be communicated to caregivers and community base services to enable them to make informed decisions. The findings highlighted a major shift for the caregiver from a care provider role to a care manager one. These findings are relevant from a health and social care point of view which emphasises the need to provide appropriate services based on a whole systems approach to care.

#### [Summary](#)

Within the qualitative study, 25 semi-structured interviews were conducted with ICs and data analysed following a thematic approach. Four main themes were identified. Two themes prior to transition reflected the shift of ICs from a care provider modality to a care manager one which appeared to be influenced by issues of burden and the perception of an inability to keep the PLWD safe. The two other themes emerged from reflections post-

transition into TESA related to aspects of person-centred care (PCC). Transition seemed to alleviate the pressures of caregiving and had positive outcomes for both the ICs and the PLWD. Assistive technologies in the facilities did not appear to impact on the decision-making during transition, however, they were valued once PLWD resided in the TESA facilities. The findings provide an understanding of the caregiving responsibilities and how ICs evolve from a care provider modality role to a care manager one where the services sought to provide the necessary care have adopted a PCC approach. These findings are relevant from a health and social care point of view which emphasises the need to provide appropriate services based on a whole systems approach to care.

## Chapter 8 Formal caregiving

### Introduction

Paid or formal caregivers provide support to enable PLWD to live as independently as possible in supported accommodation. Person-centred care is the model used to ensure tenants have choice, control and autonomy over their lives as formal caregivers endeavour to provide support that enables these principles. There is very little evidence to indicate the impact technology has on the role of a formal caregiver in a supported living setting. The present study seeks to explore the perspectives of the formal caregivers working within a person-centred technology enriched supported living environment.

### Aims and Objectives

#### Aim

To explore and understand the paid employees' knowledge, skills, understanding and attitudes towards working in a technology enriched supported model

#### Objectives

- 1) To investigate the extent to which the care practices of formal carers are person-centred
- 2) To explore the challenges associated with the promotion of person-centred care in supported accommodation
- 3) To identify the extent to which assistive technology hinders or supports person-centred practice

## Methodology

This qualitative study used semi structured interviews to obtained data from the paid staff/ formal caregivers (FC). All the interviews were undertaken in the supported accommodation facility where the FC worked at a time convenient to them. A loose topic guide (Appendix 17), was used to provide guidance during the conversation while giving participants the opportunity to provide rich descriptions of their world and their experience (Kvale, 2009). The interviews explored what the participants perceived to be their role as paid staff working in supported accommodation for PLWD; how they felt about the delivery of care in the facility and the impact of assistive technology on their role. The themes of the topic guide were aligned with the study's theoretical framework of the person-centred practice framework (McCormack & McCance, 2006; 2010; 2017). The interviews were transcribed and thematic analysis was used to explore the data.

## Recruitment

Approximately 185 formal carers (FC) at all levels working in the nine facilities taking part in the study were approached from December 2015 until May 2016 for interview. The recruitment stage proceeded as follows:

- a) Managers in the facilities were asked to inform their staff about the research and make information packs available to them at key locations where staff could have felt prompted to take an envelope.
- b) The packs included an information sheet, a consent form (Appendix 18 and 19) and a self-addressed envelope to return responses directly to the researchers.

- c) After two weeks, managers were given a follow-up call and asked if further information packs were needed. Some managers requested more, others, had materials left and told the researchers that they would remind staff about the study.
- d) A low response was generated after the initial promotion of the research and follow-up call. Managers in the facilities were then asked to identify staff members who might be willing to take part in the study. These individuals were offered the opportunity to contact the researchers directly if willing to take part.
- e) Twenty-three responses were returned and 21 participants were interviewed, including three managers.
- f) Of the two potential participants not interviewed, one ceased employment with the facility after the interview was arranged and the other one could not attend the interview as initially agreed and it was not possible to reschedule it for a later date.

### [Data Collection](#)

Data were collected from February 2016 until November 2016. The 21 semi-structured interviews conducted lasted between 40 minutes and one hour and were digitally recorded. All participants agreed to this. On the day of the interview, after taking informed consent participants were reminded of confidentiality and anonymity and their right to terminate the interview at any time or not to answer all the questions. All the interviews were undertaken in the supported accommodation facility where the FC worked, scheduled at a time convenient to them.

### [Data Analysis](#)

All interviews were audio recorded and transcribed verbatim by the researcher and a professional transcriber. After checking the transcripts for discrepancies, data were

anonymised and all identifiers removed. Then, data were uploaded to NVivo 11, a software package for qualitative data analysis (Bazeley, 2013) and were analysed using a thematic approach. An exploratory method to code the data was used. Through this process an initial list of codes was developed from the themes of the topic guide (Saldana, 2016), which, in this case, were aligned with the study's conceptual framework, the Person-centred Practice Framework (PCPF) (McCormack and McCance 2017). Then, through thematic analysis, codes were generated and categorised into key themes (Glaser and Strauss, 1967). Two researchers, separately, scrutinised the codes for internal reliability (LeCompte & Goetz, 1982). Competing and complementary themes were distinguished allowing the researcher to agree on the four themes and corresponding subthemes described in these findings.

### [Reliability and Rigour](#)

To ensure the reliability and rigour of the data two researchers examined the codes separately for internal reliability. Clear illustration of the analysis was documented. The final themes were agreed upon by the research team.

### [Findings](#)

[The transition to TESA for people living with dementia: the experience of formal carers \(FCs\)](#)  
Within the 21 participants interviewed, 17 were females and four males. The age range of participants varied between 18 to 69 years. The majority of participants were at the level of support worker (see Table 27 for details). Exploration of the data revealed that aspects of the Person-centred Practice Framework (PCPF) (McCormack and McCance 2017), mainly in the constructs of the care environment, the person-centred processes and outcomes, were reflected within the data. These aspects were categorised into four key main themes: 1)

promoting choice and autonomy; 2) staffing model; 3) using assistive technology; and 4) feeling that you're doing a good job.

*Table 27. Demographic characteristics of formal carers participants*

Characteristics	n	%
<b>Gender (n = 21)</b>		
Female	17	81
Male	4	19
<b>Age (n = 21)</b>		
18 - 29	3	14
30 - 39	5	24
40 - 49	5	24
50 - 59	7	33
60 - 69	1	5
<b>Position (n = 21)</b>		
Support Worker	13	62
Scheme Manager	3	14
Senior Support Worker	2	9.5
Activity Co-ordinator/Co-ordinator	2	9.5
Team Leader	1	5
<b>Length in post (n = 20)</b>		
6 - 11 months	2	10
1 - 5 years	11	55
6 - 11 years	5	25
12 - 13 years	2	10
<b>Years of experience in care (n = 18)</b>		
5 - 10 years	4	22
11 - 20 years	11	61
21 - 30 years	1	6
30 plus years	2	11

#### **Theme 1: Promoting choice and autonomy**

At all sites there were numerous examples where the promotion of choice and autonomy was a key element of the staff approach to care. These examples varied from valuing the person and giving them choices, through to building relationships, maximising skills and independence and providing opportunities for meaningful activities.

Staff mentioned that the facilities allowed tenants choice about when and who they interacted with, prioritising the opportunity to enjoy the privacy of their own homes. Staff appreciated the fact that tenants were able to make choices about who they let in their homes and to whom they chatted to or were friendly with. Staff mentioned that the daily routine visits to the tenants' homes within the facilities offered opportunities to build

relationships, but it was always left to the tenants' discretion to avail or not of these opportunities. For instance, this staff member described the type of interaction that could take place in one of the facilities where the tenants lived in self-contained flats and received daily calls by support staff:

*"It's just that you have your own wee flat and you're self-contained but you have a lot of, you know, you've the help there, you have your own privacy the way you would have in your own home; [...] there's the support and the girls, the staff go in and out for a short space of time and do what they need to do. And then if they want to have a chat or sit down, they'll sit and have a chat with you, but if they don't, then just go out again." (FC-C1)*

There was a general acknowledgement of respecting the tenants' choices in all contexts, particularly in relation to food, dressing, and personal hygiene, as shown in this quote:

*'Nobody is being told: 'Right, well, you're going into a shower and you're being put into a shower.' It's not about that, they all have that choice'. (FC-G1)*

It was interesting to see how some of the FCs who had worked in residential care were able to make comparisons between the two models and found themselves comparing the rigidity of the residential care system where meal schedules and menus are often decided by others without any consultation with the residents. One FC said:

*I would find it very difficult to go back to residential where you're all sitting down at this one time and you're having this for your dinner and you have no choice. They're picking what they want to eat, their families, there's consultation with them about what food they're having, they're not having a set menu, you know what I mean? So, to me, you can't compare the two, you can't compare the two, definitely not. (FC-D1)*

FCs were consistent in their view that the aim of supported living for PLWD was to promote independence while maximising the skills of the person. Thus, tenants were able to do things for themselves and with the right encouragement and support from FCs, they could maintain their skills and abilities for as long as possible. This was an attitude that was prevalent in most of the interviews and is exemplified by this staff member who said:

*... our ethos is more basically trying to promote as much independence with them as possible. So, being more, us standing back and giving them by that to promote, for them to be able to do the things for themselves, to try and keep their minds stimulated. (FC-C2)*

Some FCs suggested that while independent living was part and parcel of supported accommodation, it was also necessary to offer additional support to keep tenants safe. Therefore, in their view, the technology-enriched supported accommodation model was the most adequate intervention to achieve that, as this member of staff said:

*It's [supported accommodation] the future, people with dementia need to be able to live in their own homes, they need to be supported, they need to feel safe; they need to have, it's their right to live at home and be happy and to be supported. And all this technology and all this support staff and all the partnerships together makes it possible for them. (FC-A2)*

Many participants referred to the fluctuations of the disease and how sometimes the tenants' needs increased, therefore, on occasions, staff may be assuming a brief caring role while still supporting the tenants, as explained here:

*But, again, sometimes some of the tenants need more care, and less support. So it's just try and get the balance right. [...] But when they're better we are very much so, we are encouraging them to support them to do as much as they can for themselves. It is more*

*about supporting rather than doing for, supporting with, or prompting with, or assisting, rather than just doing it for them. (FC-E1)*

Being able to move about or go out was recognised by many of the FCs as an ability that was necessary to maintain for as long as possible, however, it was also important to consider the potential risks in doing so and assess all situations accordingly, as explained by this staff:

*Some of the tenants just go out shopping, they go to church, they do everything that they would've done in their own home; but they're assessed to see how safe they're on the road.*

*That's an important assessment because you don't want to, this is not, you know, this is just supported housing, so we want them to enjoy life and not to be feeling enclosed. (FC-C1)*

In general, it was recognised that the majority of tenants were at different stages in their dementia as evidenced by a variation and often a decline in their skills levels. However, there were examples in some of the facilities where tenants were able to develop new skills which were not only enjoyable, but also enriching and rewarding. For example, this FC talked about one lady who became a facilitator of her own class in the facility:

*... we have one lady, and after tapping into and encouraging her to do some of the different arts, music, the different activities in relation to that, she actually now has become so empowered and so interested that she herself runs a mindful colouring class for other tenants. And she's thriving because it takes her time to organise it, it gives her purpose, she's sharing her skills with other people and these are new skills she's learned. (FC-A3)*

#### [Theme 2: Staffing model](#)

The majority of FCs felt that they played a key role in establishing linkages and relationships with the tenants and family members, which in turn benefitted everyone in different ways. For example, FCs found themselves in the privileged position to gain or exchange key

information about the tenants with family members and/or amongst themselves. These exchanges were important both, in terms of ensuring FCs that they were providing good quality care and that tenants and families felt supported, as explained in this excerpt:

*Families are very appreciative of the care and support they [the tenants] get in here. They really do appreciate it, and, you know, we pick up on something we'll say [it] to the family [...] And then, the families are very grateful, and they are very open as well, like ourselves too, engage with other services. We've never had an issue with anything like that. (FC-E1)*

Some FCs mentioned how the flexibility offered by the supported accommodation model to include the input of families in the care of the tenants, appeared to give them, not only the opportunity to establish relationships with families, but also to have more control over their work and free some of their time to focus their attention on other tenants with higher needs. Specifically, one staff member talked about families getting involved in hands-on care on an *ad hoc* basis at lunch time helping their relatives with their food, which then allowed them to help those on their own who also needed more support at meal times:

*I find this approach [supported accommodation] better because the families come in and if their relatives are having lunch, they sit with them and talk with them while they're having their lunch ... Or, um, we have a couple of residents where you have to feed them, and if the relatives come in at lunch time they'll say: 'Look, we'll do that.' And then, that leaves you free to work with someone else. So, it's not just staff that are involved in that patient's welfare or needs, it's their families as well. So it is very inclusive, so it is ... (FC-H2)*

In contrast with the staff empowerment mentioned above, others felt that their work was at times overly task-oriented or that they had to spend too much time on domestic chores

or similar tasks that prevented them from engaging in more individualised care, as this example illustrates:

*We have to do a lot of different things ... A lot of stupid stuff, like cleaning and laundry ...and checks, [...] we have to do water temperatures up on our corridors; that can take time. You have to go into every room and run every hot tap and record that ... just to make sure they're [the tenants] not putting on the hot water and scalding themselves [...] So, all that stuff kind of ... it consumes you, so that you don't have time to just spend with them, or have a chat or do something nice for them. (FC-G1)*

The above quote may be related to staffing levels which appeared to be variable in the different facilities. It emerged that in those facilities with low numbers of tenants (between 12 and 25 people) staff felt that the staffing levels were adequate and they were able to provide holistic care:

*You know, I've worked in nursing homes, I've seen that, you know, the staffing level here is brilliant because we need the staffing level that we've got to do what we do. You know, if we didn't have the four or five staff on a day we couldn't take them out and why shouldn't they be taken out, you know, they're still fit to do so. (FC-F2)*

This was emphasised by some of the senior staff interviewed in the smaller facilities who were vocal in expressing how lucky they felt for having appropriate staff ratios that could allow them to implement a person-centred care approach, as noted in this quote:

*... whilst here it's, touch wood, our staff ratio is very good and enables us, our model of care, it enables us to spend a lot of time with the tenants, and they appreciate it, in other care environments that isn't not always the case ... (FC-F1)*

Indeed, in bigger facilities (of between 30 and 60 tenants) staff felt that the high ratio staff/tenant diminished the opportunities to be able to provide the holistic care they promoted:

*It's just, sometimes, you would like, if you ... maybe your staffing levels could be down a bit sometimes, you know, if there's someone off sick you can't fulfil the job the best that you would want to because you'd have more work on. (FC-A2)*

Overall, FCs felt that they were well equipped for the job. They mentioned the induction sessions and training as invaluable to enhance their skills and to help them understand the nature and principles of the person-centred approach in supported accommodation, which for many, differed from previous work experiences in the care sector, as stated by this participant:

*To me at the start, you know, the training that is given is beneficial to me because it's a model I haven't had experienced before. It's like they have their own accommodation, they have their own flats here, whereas in the private sector is not designed that way. Um, and, you know, the training, needed, I did need the training just to be in that zone where you have to be first safeguarding the tenants. Yeah, it's good learning and good experience, more experience for me to see how it works. (FC-A1)*

Most FCs felt they had a fairly good understanding of dementia issues, but most importantly, they felt competent in their understanding of the person at various levels and being attuned to their feelings and needs, including the social, emotional and psychological.

This participant illustrated this by saying:

*It [dementia] can just be so debilitating to a person, you know, and they just lose their senses that they're important and that they're an individual and if we can give them a bit of*

*comfort and a bit of love, you know, and make them feel valued and wanted because they can be so confused. (FC-B2)*

Other FCs gave examples of how collegiality and mentoring enriched their practice when they were confronting difficult situations which required the ability to see beyond the person's behaviour, as explained here by this participant talking about the agitation of a particular tenant:

*I think the staff work well together in dealing with situations. If I had an issue, I'd say: 'I find this particular ... resident very challenging ...' [...] I would say maybe to the senior: 'She seems a bit agitated today. She says she's a wee bit sore. Maybe she's got a wee UTI or something?' And the senior would say: 'Well, get a wee sample and I'll ...' It could end up that that was what would trigger her agitation. (FC-F3)*

#### Theme 3: Using assistive technology

In general, FCs appeared to favour the environmental enhancement of the facilities with assistive technologies. For many, technology was essential to their job. Universally, they found the telephone system with activation of multiple alarms and sensors vital to their job as they could swiftly be guided to the appropriate course of action in response to the specific alerts received through the system. This is illustrated by this participant:

*When it comes to ... say, the telephone ... if there's a bed sensor and they get up, that'll come through our phone [...] We know that they're out of bed, we're made alert and we don't have to be in the room to know, you know. I feel more at ease in my job. (FC-F3)*

Assistive technology appeared to have the dual role of providing safety, security or protection for the tenants and to make FCs feel more relaxed or 'at ease' in their job, as pointed out in this quote.

Unanimously, staff reported that the different types of assistive technologies in the various facilities could be used to prevent falls or the walking around or wandering, therefore, offering protection to both, the tenant and the FCs, as explained by one participant:

*To me it [the technology]’s all protection; it protects the tenants. You know, the technology that we have, the protection that we know, without intruding on them. [...] Door alarms, you get someone that would want to come out, a lock won’t let them walking around; the door alarms will let you know that. So, yeah, it protects us and it protects them. (FC-A1)*

In this sense, assistive technology had the advantage of being non-obtrusive, which was perceived by FCs as beneficial to the tenants as they did not have the feeling that they were being constantly observed or monitored:

*... the assistive technologies support the staff to enable them in order to do their job. But it also gives that, um, non-obtrusive cover for tenants that they are safe within the environment they live in. (FC-A3)*

The support offered by assistive technologies on the reduction of risk and the protection of tenants from harm to themselves or others was a topic profusely discussed by the majority of participants. For example, assistive technology enabled FCs to monitor the execution of simple tasks like making cups of tea or cooking snacks, so that accidents could be prevented while still allowing the person to do things for themselves when they wanted. This participant summed this up:

*... there was a lady in one of the flats, you know, she still maybe like to get up and try and make her own wee cups of tea and do wee things [...], they’re supported to make their own food, you know, they’ve had their meals, it’s: ‘Enjoy your meal, I’ll be back later...’ I go out*

*and I isolate that electric, so she can't be harmed, she can't be in danger, all through the technology, like, you know. (FC-A2)*

The large majority of participants suggested that assistive technology was beneficial to support tenants live independently as it helped them with day-to-day tasks that they could do for themselves at their own pace without the constant presence of someone who may otherwise be doing them for them. This participant illustrated this with the example of a person feeling confident to use the toilet by him/herself:

*You know, even their push buttons in bathrooms and stuff, they're right beside the toilet and they know to press that so I think it gives them confidence as well to live independently as much as they can, that they can go in and use the toilet by themselves [...] We don't have to be there all the time [...], it's about them being able to do the things without us constantly following them. (FC-F2)*

Some FCs referred to the speed of communication and the rapid response to potential risks or adverse incidents that were also possible with the use if assistive technologies. For many, as suggested in this example, the benefits of assistive technology outweighed its disadvantages:

*I think the advantages outweigh the disadvantages very much so. I don't think the communication would be the same if we didn't have a certain technology, the handsets ... (FC-G3)*

In general, two concerns emerged regarding the use of assistive technologies. One, it was important that technologies were not used in a restrictive way and that they were non-intrusive and implemented according to the person's needs, as explained by this manager:

*We have to be careful that all parties involved: the residents, professionals and ourselves are implementing those [technologies] for the benefit of the client and practices cannot be in any way restrictive. There's emphasis on the word 'assistive'; it's to assist them in their day-to-day and to enhance whatever they have. So, we would carefully consider it before we put any assistive technology in place. (FC-H1)*

And second, that assistive technologies did not replace the human contact that staff and tenant should enjoy in the caring relationship. In this sense, technologies were viewed as an asset that could enable FCs to engage in personalised activities with the tenants by releasing them from the constraints of task-oriented routines. As this staff described it, everyone can just get on 'living life':

*So, if there is a couple of residents in bed it means, say in the afternoon because there is a couple like lie down in the afternoon after their dinner, it means we don't have to stay in the room with them or sit outside, we can be in the close area with other residents doing something but we know if they get up off that bed the bed sensor will go off and we can go straight away to them. So it helps everybody because you're not neglecting anyone then which is a good thing, everybody's getting the same attention and just living life. (FC-F2)*

#### **Theme 4: Feeling that 'you're doing a good job'**

For many of the participants the sense of 'doing a good job' was the main aspect of their work that kept them motivated and gave them job satisfaction. 'Doing a good job' consisted of various things. For some of the FCs it was having an understanding of the person beyond their illness and doing nice things for them, as explained by this participant:

*I always think, it must be so strange to have something on your mind or to feel something but not be able to say how you feel or what's bothering you, so [...] if you could do one nice thing a day, I think if you can walk out that door and think: 'Oh, I made that person laugh',*

*or 'I helped them ...' or 'I changed their mood ...' or something, definitely you satisfy yourself in the job. (FC-G3)*

Other participants referred to the satisfaction they felt when tenants showed their appreciation for the 'little things' they did for them which could be making a cup of tea or helping them choose what to wear. For others, it was important to provide comfort, such as the one gained from a good night sleep:

*Seeing that nobody is unsettled. I always look that if you're on my shift and you got everybody organised and you got them into bed and you didn't have people ringing all night: you'd done a good job, you've got people well settled, they're comfortable and they've slept all night. That's good satisfaction. (FC-D1)*

A few participants derived job satisfaction from the belief that they were improving the quality of life of both, families and tenants through the provision of adequate support that was going to keep the person experiencing dementia living independently for longer and even perhaps preventing him/her from a premature entry into nursing care. As this participant explained:

*I just love this job. I think it's just a nice job. It's nice to give the family and the tenant a bit of support. It's nice to see them living their lives. It's nice to see them not having to go into a nursing home or anything like that. It's so nice to see they have their independence. (FC-C3).*

### **Discussion**

This study of TESA for PLWD has offered insights on the experiences of FCs working in these facilities, ranging from small dwellings for up to 12 people with shared communal areas to medium-sized facilities providing self-contained independent accommodation for 30 to 60

people. The findings identified four main themes of dementia care in these facilities: 'promoting choice and autonomy', 'staffing model', 'using assistive technology' and 'feeling that "you're doing a good job".' These themes largely reflect attributes of person-centred care contained in the PCPF proposed by McCormack and McCance (2017). The attributes most prominently represented in these findings are those associated with the 'care environment', 'person-centred processes and 'outcomes.'

These findings suggest that the practice of person-centred care is prevalent in these facilities. The emphasis on the promotion of choice, independence and autonomy reflects how the concept of personhood central to PCC (Sabat and Harré, 1992, Kitwood, 1997, Rogers, 2011) is embedded in the ethos of the facilities and demonstrates a culture veered towards the adoption of person-centred processes, that is, the provision of holistic care and the authentic engagement of the PLWD whose beliefs and values and wishes and desires should be always recognised (McCormack and McCance 2017). Brownie and Nancarrow, (2013) considered the effects of PCC on residents and staff in aged-care facilities where traditional nursing models have been dismantled, replaced by purpose-built, small-scale, home-like settings and the decision-making on care delivery has shifted to the residents. They found psychosocial benefits to both residents and staff.

FCs reported huge variant in how PLWD presented and heterogeneity of needs which impacted on the strategies to support independence and maintenance or maximisation of skills. Specifically, many of the staff referred to safety issues and potential risks which needed to be monitored and assessed to strike the right balance between safety and independence and avoid the dilemmas posed between 'too much intervention' and 'too

much risk' (Molony & Bouma, 2013:80). The key issue of independence for PLWD in supported housing schemes has been highlighted by other authors (Evans et al., 2007), and consonant with their findings, this work revealed that with the appropriate support from FCs, tenants in these facilities are given choice and autonomy in their lives to make decisions about simple things like what to wear or what to eat, or what to do or not to do, and by doing so are treated with dignity and respect.

This care delivery focused on engagement, authenticity, shared decision-making and holistic care is supported by the appropriate conditions of the care environment. While it was evident that in the smaller facilities of up to 25 tenants FCs were able to focus more on aspects of care most commonly associated with PCC practices and felt competent and empowered, those working in bigger facilities mentioned the problems they face when their time is consumed by task-oriented duties which prevent them to practice a more individualised humanistic approach to care (Brownie & Nancarrow, 2013; Rasin & Kautz, 2007; Sjogren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2017). This is a very important finding in our study given that the facilities have the added environmental enhancement which has been associated with small-scale, homelike environments proven to be successful in implementing PCC that has been highly underpinned by culture change models (Li & Porock, 2014; Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009). FCs felt competent and confident with the assistive technology available in the facilities.

There was also evidence that assistive technology supported various aspects of person-centred practice, furthermore, it also appeared that the technologies also provided an extra 'safety blanket' for the FCs. It emerged that the FC may sacrifice autonomy for the safety of

the tenants based on perceived risk. This differs from other studies in this area (Landau *et al.*, 2010), and confirms other findings reporting reduce risk for tenants and reassurance to staff who feel more relaxed in their roles (Meiland *et al.*, 2017).

Ethical issues emerged in relation to the extent to which tenants provided informed consent for the use of the technologies, specifically those used to monitor and alert staff. While managers emphasised the adoption of any assistive technology involving all parties (i.e. 'residents', professionals and the managers themselves) according to need and potential to enhance the quality of life of the tenants, it was not clear to what extent and at what stage of the dementia, the tenant was engaged in the decision making to use the technology. Was the PLWD cognitively capable of providing informed consent. By no means is there an implication that assistive technology has been used unethically, however, there appears to be a gap in relation to advanced care planning ensuring that the tenants' preferences and desires are considered in advance of their capacity to make decisions has diminished (Livingston *et al.*, 2017).

The feeling that 'you're doing a good job' was a key theme in this study mapping to reports of high levels of job satisfaction demonstrated by the participants. This is aligned to the findings of other research that confirmed the positive effects on staff job satisfaction with the provision of person-centred care (McCormack *et al.*, 2010, Brownie and Nancarrow, 2013). While some FCs expressed some concerns about the staffing levels, mainly in larger facilities (of between 30 to 60 tenants), there appeared to be a balanced ratio staff/tenant in small-scale facilities which contributed to increased opportunities to provide quality care and time to the tenants, which concurs with research undertaken elsewhere (Rasin and

Kautz, 2007). FCs in this study felt that they could have a positive impact on the life of PLWD in these facilities by doing 'little things' for the tenants and in return they derived an enormous job satisfaction from the appreciation the tenants showed.

The new knowledge derived from this study in the use of person-centred practices confirms some of the evidence that the supported housing model could assist PLWD (Evans & Means, 2006). Through the accounts of the FCs it has been shown that this model, not only is being delivered using a person-centred care approach as operationalised by McCormack and McCance (2017) in their PCPF, but also contains the added value of the environmental improvement, another feature identified by other authors as essential to person-centred care practice (Brownie and Nancarrow, 2013). This is important for policy makers and service commissioners and for the future role of the voluntary sector and formal carers and other professionals involved in the delivery of care for PLWD. It appears that careful consideration should be given to find appropriate ways to disseminate good practice and the replication of those models of care, in particular the small-scale, homelike environments conducive to better outcomes for both the PLWD and the FCs.

## Summary

Within a qualitative study 21 semi-structured interviews were conducted with FCs and data analysed following a thematic approach. Four main themes were identified that were associated with some of the attributes of the Person-Centred Practice Framework: promoting choice and autonomy, staffing model, using assistive technology and feeling that 'you're doing a good job.' Central to person-centred practice in these settings was the

promotion of choice, autonomy and independence. The dichotomy between safety and independence was evident, curtailing the opportunities to exploit the environmental improvement with embedded assistive technologies. FCs reported considerable job satisfaction working in these settings. The small-scale, homelike facilities seem to have a more the positive effect on job satisfaction. These findings are relevant to policy makers, commissioners and service providers as they highlight the facilitators of person-centred care in community dwellings for PLWD and the role of FCs in promoting this approach.

## Chapter 9 Quantitative study on the Attitudes of Formal and Informal caregivers towards technology

### Introduction

Within the literature, various ethical dilemmas emerged around the use of technology in healthcare (Daly Lynn et al., 2017; Niemeijer et al., 2010). Issues such as safety versus risk, freedom, consent, substitution of care and privacy all still need further reflection. This component of the study aimed to explore the opinions of both formal and informal caregivers around the use of technology within the healthcare setting. Staff caregivers work in conjunction with devices on a regular basis and little is known about the impact this has on their caring role. Additionally, family and friend caregivers trust that their loved ones are receiving appropriate care within a technology enriched setting and it is important to explore how they feel about this. A survey was considered the most appropriate tool to capture the opinions and experiences of technology use through the eyes of caregivers.

### Aims and Objectives

#### **Aim**

To explore caregiver's attitudes towards the role of technology in healthcare

#### **Objectives**

- To explore the attitudes towards technology use with the housing scheme.

- To identify any differences between staff and family caregiver's opinions of technologies role in healthcare.

## Methodology

A survey to explore the use of electronic assistive technology in supported living environments was developed for this project. The items were generated through a systematic literature review (Daly Lynn et al., 2017) and interviews with family caregivers (N=25) and paid caregivers (N=21). The survey included nine Likert type data items and open-ended questions (ten within family caregivers version/ eleven within the paid caregivers version) delivered as a self-administered survey through an online platform (Survey Monkey) and hard copy distributed within the housing scheme. The Likert type data items ranged from strongly disagree, disagree, neutral, agree, strongly agree. No attempts were made to combine the responses into a scale in order to create a score (Boone & Boone, 2012). Statements were balanced accordingly so N= 3 items were positive, N=4 items were negative and N= 2 were neither positive or negative. The Likert statements were the same in both family and staff caregiver questionnaires to enable a comparison of their perceptions towards the use of technology. Demographic questions and open-ended questions were set out at the beginning of the surveys (Appendix 20 and 21). Finally, an explanation of the term technology was outlined at the beginning of the questionnaire to ensure each participant was aware of the meaning within the current project.

## Recruitment

Recruitment was undertaken through the housing schemes. Participants could complete either an online or hardcopy survey. The links to the online survey were sent to the scheme manager to be distributed to both staff and family and friend caregivers. The hardcopy surveys were left in the eight housing schemes that participated in the art focus groups. Completing the survey indicated that consent was given to participate. All surveys were completed anonymously and therefore it was not possible to withdraw once it was submitted.

## Data Collection

Hardcopies of both the staff and family and friend surveys were left within the scheme during the six-week timeframe of the focus groups. A large white box was placed next to the hardcopies enabling the completed surveys to be placed inside anonymously. Additionally, an online version of the survey was available through survey monkey and the links were sent to the scheme manager to distribute further. The survey data was collected between February and September 2017.

## Data Analysis

All the completed surveys were uploaded onto survey monkey. Through this online platform, the responses from staff caregivers and family and friend caregivers were populated separately. The system enabled figures to be created from the demographic data. The responses to the open-ended questions were described descriptively. Finally, the

data from the Likert statements were compiled according to the type of caregiver and presented in Figure format through the computer program Excel.

## Findings

A total of 20 family and friend caregivers completed the survey, of which 80% (N=16) were female. The surveys were completed by family and friend caregivers from six different schemes: Site D (N=6), Site B (N=1), Site I (N=3), Site F(N=7), Site E (N=1), Site G (N=2). Respondents reported caregiving on average for 5.2 years. The age range of respondents is represented in Figure 38. The largest proportion of respondents were between 45 and 65 years of age (N= 15).

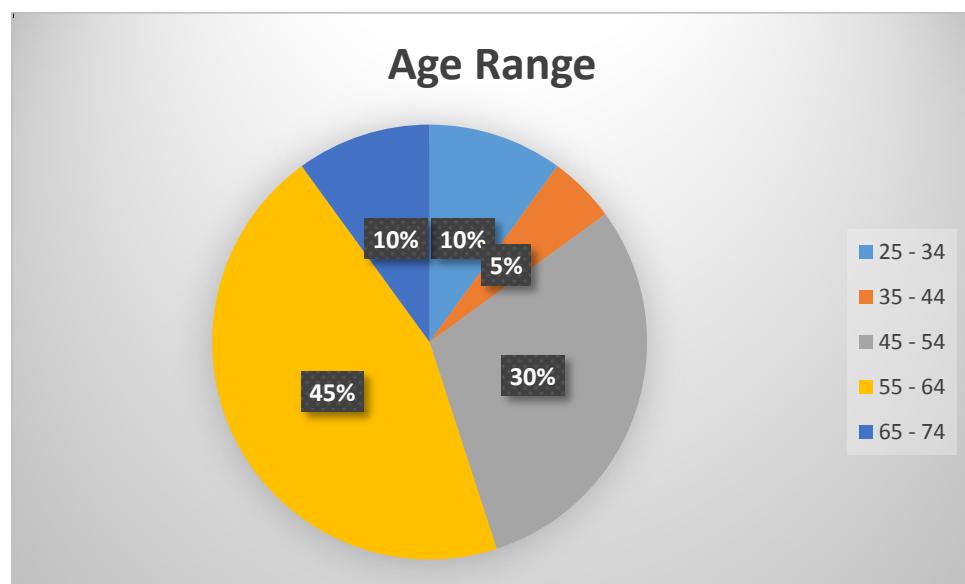


Figure 38. Age range family and friend caregivers

A total of N=31 staff caregivers completed the survey, of which 19.35% (N=6) were male. The surveys were completed by staff caregivers from four different schemes: Site D (N=9),

Site B (N=5), Site E (N=7), Site G (N=10). Respondents reported caregiving on average for 7 years. The age range of respondents is represented in Figure 39. The staff caregivers had a larger proportion of respondents within a younger demographic than the family and friend caregivers. Overall, 61% (N=19) were under 44 years of age. A total of 67.74% (N=21) of staff reported completing training on the use of technology systems and devices, however, 32.26% (N=10) had not completed any training. Training was reported to be undertaken as part of staff induction, and with technology providers. One respondent completed their ECDL driving licence and another stated that they were not able to remember much of the training from five years ago.

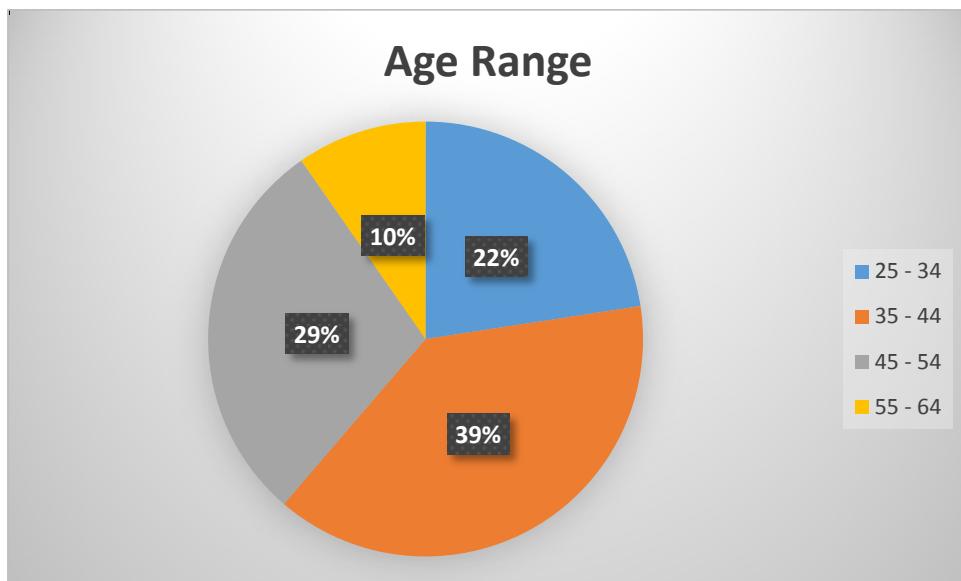


Figure 39. Age range staff caregivers

A total of 90% (N=18) of people felt there were advantages to the use of technology to support their relative or friend. Respondents reported technology provided a 'secure environment', 'cost effective care' and 'greater freedom'. It was viewed as a tool to

*'improve knowledge', enable 'privacy and independence', and 'a quick source of getting assistance if they fall'.* Alarms and sensors that prompt staff to wandering, leaving the apartment and getting up during the night were considered *'very reassuring'*. Mobile phone use was also an advantage to enable families *'keep in continual contact'*. Interestingly, 88.89% (N=16) felt there were no disadvantages to the use of technology to support their relative or friend. Some of the disadvantages reported included the ability for the tenant to remember to use the technology available to them, for example, tenants *'may not have understanding why or how to use it e.g wearable pendant, intercom system technology can go wrong. Needs to be closely monitored'*. One respondent felt technology was *'not much use'* and another stated *'the alarm watches, not sure with dementia you remember or are able to press button depending on how severe dementia is'*. Only six respondents (31.58%) reported that technology influenced their decision to support their loved one to move into the scheme. The reasons given included *'I liked the way they use all the available aids such as sensors beside the bed to indicate the patient is out of bed'*, the technology *'is useful for safeguarding'*, *'thought it was more up to date'* and *'the degree of vigilance it gives'*. Primarily, respondents reported the scheme was chosen because of *'quality of care'*, *'the secure setting'*, *'the care was needed regardless of what technology was available'*, and that they were not aware of the technology until after the move.

A total of 80% (N=24) of staff caregivers felt that technology impacted their caring role. Staff felt it makes their *'workload more manageable'* and *'alerting staff to an incident'* is important. It was also stated that *'it would be really hard to care without the use of technology'*. Technology supports staff caring role by providing alerts from the service users, cctv, ensuring the security of the building and computers for email and staff training.

Additionally, '*technology has a big impact as we can speak to tenants in rooms etc without being their which assists with making sure tenants are safe*'. The staff caregivers primarily indicated there was an advantage to using technology within their role as only two respondents felt there was no advantage. Advantages for technology according to staff included '*offering more independence and security*', '*reassurance*', '*let me know if someone needs help*', enhanced '*communication*' and provide '*quicker support*'. Staff felt it enabled them to '*give the best support for those who need it*' and to '*be aware of what is happening in places without being there*'. One respondent reported that '*it helps with promoting safety and independence of tenants and communication between tenants and staff*'. Additionally, technology enables '*quick access to information*' through emails and computers and is a '*quick means of delivering media and interaction to those not able to be social in the community*'. Only 41.94% (N=13) felt there were disadvantages to using technology to support their role, while N=18 (58.06%) felt there were no disadvantages. Some of the disadvantages reported by staff included that technology can '*take away from basic effective techniques and approaches*' in care delivery. Challenges to working with technology included '*lots of calls at the same time*' and '*black areas in the call system*' where it doesn't work, '*certain parts of the building are void to receiving calls*'. *Therefore, staff don't know if they have fallen*'. Additionally, '*false alarms or volume of alarms can be distracting*'. Staff were concerned that technology can lead to service users becoming isolated and that it can be '*difficult for individuals to remember how to use it*'.

A total of 55% (N=11) family and friend respondents felt tenants should have access to internet, 25% (N=5) felt tenants should not and N=4 20% didn't know. Comments included that '*the tenants are not fully aware of the dangers around them and I think the internet*

*would be dangerous for them*' and that '*not many older age groups actually want it*'. It was also considered an asset to support tenants '*to keep in contact with family*' and families had installed internet in their relatives flat already. Interestingly, 77.42% (N=24) of staff felt tenants should have access to internet, 3.23% (N=1) felt tenants should not and N=6 (19.35%) didn't know. Benefits to the use of internet included opening up '*more social and creative contacts*', '*being able to Skype etc to contact relatives they can't see often*' and '*online games for dementia*'. Capacity to benefit from the internet was called into question and the possibility of tenants been '*vulnerable*' online. However, one respondent felt strongly that '*I believe tenants should be able to access it if they want, it is their home at the end of the day*'.

Additionally, family and friend respondents reported staff should have access to internet (N=17/ 85%), while 68.97% of staff felt they should have access to internet. The family and friends view that staff should have access to the internet was so that it could be '*used for the resident's benefit*', and to keep staff '*up to date*'. Staff felt it could '*enable staff to have access to creative contacts to develop the needs of the service users*' and '*help tenants who are unable to use technology*'. The internet could be used for shopping, to view photos, for activity ideas and to look up answers to tenant's questions. Additionally, the internet supports the staff role through '*booking training on CEC, accessing staff net, sending emails within northern trust network*'. When asked about the impact of the technology visually on the scheme environment, 55.56% (N=10) of family and friend caregivers were visually aware while 63.33% (N=19) of staff were visually aware of technology within the scheme. Some respondents reported seeing a '*lot of alarms and call buttons for any emergencies*', '*pull*

*cords, fingerprint pads, bed sensors', 'Music players tv etc', and 'buzzers on walls finger print entry and exit telephone contact to wall buzzer'.*

Family and friend caregivers and staff caregivers were asked if they agree or disagree with nine statements about technology. Primarily, both caregivers felt technology enables tenants to be more independent in their own living environments (Figure 40). A total of 35% of family and friend caregivers were undecided compared to 12.9% of undecided staff caregivers. Only 5% of family and friend caregivers disagreed with this statement, while no staff members disagreed with this statement. Respondents primarily disagreed with the statement that tenants had less human contact with staff because of technology (Figure 40). Six staff caregivers and three family members either agreed or strongly agreed that tenants had less face to face contact, while five staff and three family and friend caregivers neither agreed or disagreed. The statement that technology enhances the quality of care provided within the scheme was largely either strongly agreed or agreed with from both sets of caregivers (Figure 40). Only 12.9% of staff were undecided about this statement, while 20% of family and friend caregivers were undecided and 5% disagreed with this statement.

Overwhelmingly, family and friend caregivers disagreed that technology reduces the privacy of tenants (Figure 40). Five staff caregivers either strongly agreed or agreed with this statement and seven were undecided. This statement indicated a difference in thinking about privacy and technology for both types of caregivers. Interestingly, 80% family and friend caregivers reported that safety was more important than the tenants right to privacy, while only 61.29% of staff agreed or strongly disagreed with this statement.



Figure 40. Outcome of Likert Statements Part 1

Caregivers were asked if tenants should give consent for the use of technology in their care (Figure 41). A larger percentage of staff caregivers agreed with this statement than family and friend caregivers. Twenty five percent of family and friend caregivers either disagreed or strongly disagreed as opposed to 12.9% of staff caregivers. Additionally, 30% of family and friend caregivers were undecided about this statement.



Figure 41. Outcome of Likert Statements Part 2

Both types of caregivers had trust in the use of technology for tenant's care (Figure 41).

Only 10% of family and friend caregivers and 12.9% of staff caregivers disagreed or strongly disagreed with this statement. Caregivers disagreed or strongly disagreed with the statement that safety and security of the tenant is not increased through the use of technology. Five family and friend caregivers and 5 staff caregivers agreed with this statement to some degree. Interestingly, 16.13% of staff caregivers were undecided about this statement. Largely, caregivers disagreed with the statement that technology has no

benefit supporting the tenant. Twenty five of the 30 staff and 14 of the family and friend caregivers either disagreed or strongly disagreed with this statement.

On completion of the survey some respondents added additional comments. Staff observations included that the usefulness of technology can be dependent '*on level of dementia*'. Family and friend caregivers made several interesting observations. Although technology was viewed as a benefit it was felt that tenants '*need human contact*'. Additionally, one respondent stated, '*I would have complete trust in the management and staff at X scheme, I feel the needs of the patient/ tenant are a priority, however in a scheme that is not so well run might find that technology is abused*'.

## Summary

Overall, technology used to support care was considered to be an advantage by caregivers insofar as it increased the quality of care, enhanced security and enabled independence. The use of mobile phones increased communication within the family. Although caregivers held relatively similar views around the benefits of technology, their views on issues such as privacy and consent vary. Safety was considered more important than right to privacy by family caregivers. It would be interesting to explore if this is because of the person-centred ethos within the housing schemes.

## Chapter 10 Patient and Public Involvement

### Introduction

Patient and public involvement in research is generally accepted as good practice (INVOLVE, 2009). Additionally, it is increasingly becoming a requirement of key research funders (Littlechild et al., 2014). Groups or individuals relevant to the research become active partners within the project as opposed to participants. Older people have been co-researchers at various stages of academic projects (Fudge, Wolfe, & McEvitt, 2007). However, the real challenges are to meaningfully foster partnerships that enhance the quality and applicability of research as opposed to tokenism (Warburton, Bartlett, Carroll, & Kendig, 2009). Peer researchers played a key role in the TESA-DRI project as they worked in partnership with the research team to explore the experiences of tenant living within TESA. Their role within the project was to undertake the one-to-one interviews with tenants living with dementia. Older people with personal experience of dementia were recruited and this section outlines their experience within the project.

### PPI within TESA-DRI Project

PPI took many different shapes and forms within the TESA project. The opportunity for the project was identified by the lead researcher in conversation with service providers. The lead researcher was aware of the existence of TESA services since 2002, with additional commissions emerging, yet no exploration of the original services. This demonstrates the motivation for the project coming directly from services. A conscious decision was made to

have a consortium with a strong voice of older people directly on the project team. This led to the invitation and subsequent integration of EWA as fully costed member of the project team. In addition, one of the researchers employed within the project was community based in EWA. The very nature of this voluntary organisation was to support older people and encourage the shared learning between the service users, employees and researcher benefited the project and the organisation. Additionally, the composition of the TESA steering group once again kept PPI at the core of the project. Within the steering group was an employee of Dementia NI, an employee of the Alzheimer's society, two individuals living with dementia and a family caregiver. Within the research methods, the integration of peer researchers to support inclusion of people with dementia kept PPI central. This required sensitive and thoughtful development, implementation and review. This chapter explores this.

## [Aims and objectives](#)

### **Aim**

To evaluate the experiences of older people as peer researchers in the TESA project

### **Objectives**

- To design, deliver and evaluate a peer researcher training programme
- To explore the experiences of peer researchers undertaking one-to-one interviews with tenants living with dementia.

## Methodology

Older people were recruited as peer researchers to engage with PLWD in the TESA project. Engage with Age were well placed in the voluntary sector with older people and had previous experience of co-research with older people, therefore, recruitment was undertaken through this organisation with external support. A training programme was development within the project and is a major outcome as a result (Appendix 22). The training programme was developed in line with current literature and was validated by the experienced project team. Figure 42 sets out the various points of engagement with peer researchers throughout the project.

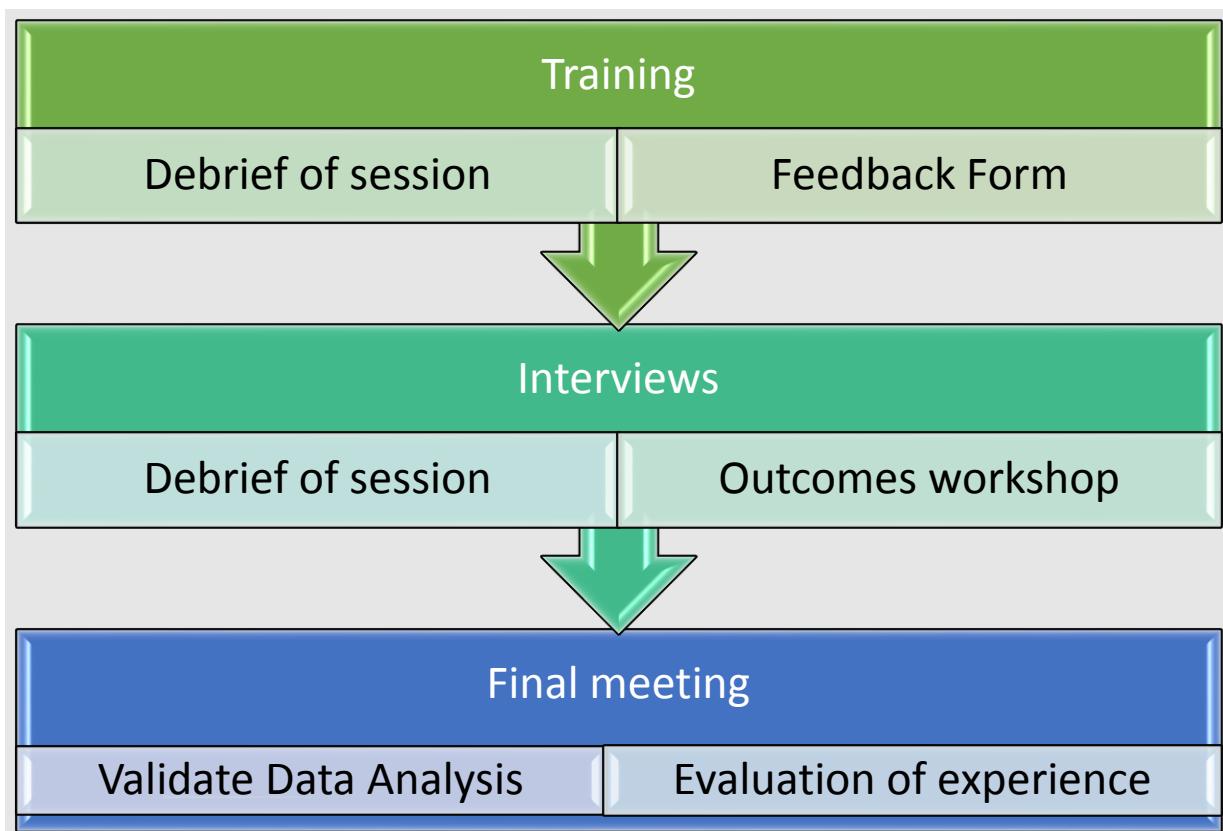


Figure 42. The Peer Researcher Engagement Approach

## Ethical Issues

Ethical approval was granted to engage peer researchers directly for the face-to-face interviews with tenants. Following this, in the design and development process a range of ethical issues were considered in partnership with peer researcher. First, it was agreed that a standardised training protocol was in place with a consistent approach to the preparation for, support during and debrief post interview for the peer researchers. Safeguarding the research participant and the peer researcher were both paramount to ethically use this methodology. Peer researchers were bound to maintain the confidentiality of the interviewee. The role of the academic researcher (who sat in during all interviews) was to safeguard via observation, supporting when required and notetaking. They ensured that process consent was being adhered to for the PLWD. During the interview debrief, the lead researcher always checked for any issues raised during the interview that may have triggered an emotional response for the peer researcher.

## Recruitment and Training

EWA, with the support of Age NI, led on the recruitment of peer researchers. Development officers, senior's forums, one-to-one contacts and social media (Figure 43) were all used as recruitment methods. Interested individuals contacted the researcher and suitable candidates were asked to meet to discuss the role. During the meeting, the TESA project and the role of the peer researcher was outlined. The older person and the researcher then discussed if the person wanted to be involved in the project as a peer researcher.

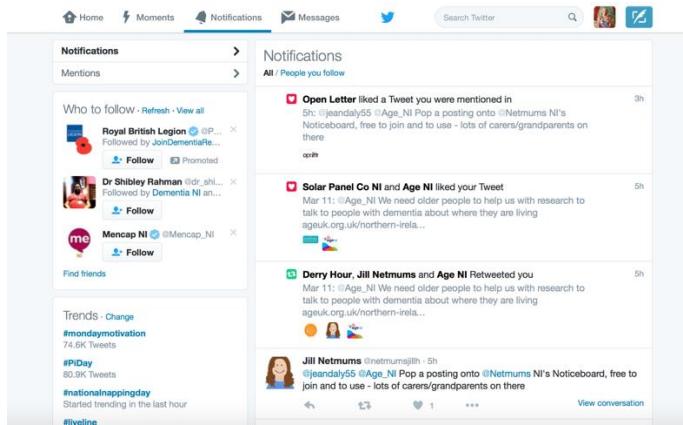


Figure 43. Twitter was one method of recruitment

A two-day training programme was developed and this was compulsory for all peer researchers. A total of N= 7 peer researchers participated in the project, five female and two male (Figure 44). A post training evaluation questionnaire was completed by all peer researchers (Appendix 23). Three peer researchers were under 65 years, three were between 65 and 75 years and under and one individual did not specify. Previous life experience included academia, community development, teacher, finance, pastoral visitor, electrician and adult education. Four of the seven individuals had cared for family members with dementia in the past and all had some personal experience of dementia. All peer researchers felt prepared for their role after the training. When asked what they would like to get out of this experience, answers included giving a voice to PLWD, job satisfaction, developing skills, having an impact, betterment as a person and a sense of doing something worthwhile.



Figure 44. Peer researchers in TESA project

## Data collection

All trained peer researchers completed at least one tenant interview for the project. Peer researchers were invited to complete a few interviews within a scheme over the course of a morning/day. Therefore, the numbers of interviews conducted ranged from one to six depending on the peer researcher's availability and the number of interviews per scheme. Peer researchers were not paid but travel expenses were covered and lunch was provided if the interviews were undertaken during this time. Where possible, the peer researchers were collected and dropped home in order to have time with the researcher to check in beforehand and debrief after the interview during this travel time.

Each interview began in the same manner. First, a staff member would confirm the tenant was still happy to take part in the interview. If yes, both the researcher and peer researcher were introduced to the participant in the location for the interview (primarily the tenant's flat). The researcher then introduced the project, herself and the peer researcher. An

opportunity was given to the tenant to consent to taking part again and consent to the use of a voice recorder. The researcher's role of safeguarding was set out and the peer researcher's role of directing the interview was established. Once the voice recorder was switched on, the peer researcher took the lead in the interview and asked questions based on the topic guide. After interviews were completed the peer researcher was asked to complete a debrief form (Appendix 24).

A total of 22 interviews were completed and resulted in N=22 debrief forms returned to the project. This enabled us to capture the peer researchers experience of undertaking the interviews. An overview of the peer researcher responses are outlined below.

- **How do you feel after the interview?**

Peer researchers reported the interviews going '*really good*', being '*pleased*', and '*a bit more challenging*'. One peer researcher reported feeling '*genuinely invigorated. I genuinely feel that we gleaned such a huge amount of information from the interview*'. The peer researchers enjoyed hearing the '*honest, valuable interesting and positive account of a lived experience*'. The process was relatable by the peer researcher, '*I could relate to as a 'peer' i.e. someone in later life.*' Sometimes it was difficult '*to establish a connection with other interviewees*' and through building this connection enabled the peer researcher to have a more '*productive*' conversation. Some tenants tended to focus on specific issues which made it more difficult for the peer researcher to glean information from other aspects of this person's life. '*I felt that perhaps I had not got direct answers to the information on how she felt about the adequacy of her support inside and outside her current environment*'.

Peer researchers felt they needed '*to put more of the training into practice*' and allow time for the participant to have '*more space and time to answer*'.

- **Did you find anything particularly interesting or striking during the interview?**

Peer researchers made several observations about the tenants they were interviewing. For example, they noted participants were '*very happy and content*' and '*I was pleasantly surprised at the choices they have*'. They made observations about the lives of PLWD, '*interesting was the coping methods of the tenant in terms of using notes diary etc*'. The peer researchers were surprised at the different stages tenants were at on their dementia journey, '*the interviewee was more lucid than I was expecting*'. Finally, the tenants' lack of awareness of technology when it was in clear view was highlighted as striking. '*Interesting that although there was clear evidence of technology in the flat, the person did not seem to have knowledge of it or to have used it.*' Making a connection with tenants and making them feel comfortable during the interview was very important to peer researchers. '*The interviewee was very comfortable in her setting and I think she enjoyed the opportunity to chat. She was very open about her situation and obviously happy in this environment. I found her easy to interview perhaps because of the informal nature of the session.*' Additionally, finding a personal connection to the interviewee supported the relationship, '*finding a link to the person's life often allows for a more interesting conversation and helps build a relationship for the short time we visit*'.

- **What strategies do you think worked/didn't work during the interview?**

A range of strategies that peer researchers found helpful during the interviews were highlighted in their debrief forms. These are list below:

- Keeping it simple
- Repeating questions again in a different way
- Give time to respond
- Prompts to explore responses
- Silence /non-immediate response are ok
- Making a connection with interviewee
- Eye contact, be affirming and interested
- Seating was important
- Interview timing (early in the morning and straight after lunch not good times)
- Using visual cues '*After questions about technology, I drew attention to the alarm on the wall, however the person's memory of what it is used for did not seem to be triggered by this*'
- **What do you think you gained from this experience?**

Overall, peer researchers viewed this experience as very positive. Interesting insights into a relatively unknown world was a fundamental gain such as '*an in-sight of the care, assistance, and flexibility offered by the Housing Scheme*'. A greater understand of PLWD was reflected in the experience and an '*appreciation of the person and their humanity*'. Additionally, '*an insight that in the home there is not a one size fits all tenant!*'. Peer researchers felt they relaxed into their role, took their time and it worked best when they '*let the whole process flow more naturally rather than trying to manage responses.*'

- **What do you think was important to prepare you for this role?**

The training was reported as key to preparing the peer researchers for their interview role.

In future, more training on building onto the tenants responses was recommended. *'This is where the training was needed to help keep the flow of responses and support for the tenant's responses and at times lack of response.'* Previous work and life experience was also helpful, particularly personal experience caring for a PLWD. The topic guide was helpful and a quick update in advance of the interview by the researcher. One peer researcher recommended getting *'a 'feel' of the housing environment where the tenant is living before starting the interview'*. It was also recommended that *'perhaps a need to reflect as we go along and use our reflective lessons to build on future experiences'* would be helpful. Getting more insight into the tenant's communication skills in advance through staff member would help the peer researchers prepare for their role. Finally, *'being flexible when the tenant does not turn out as expected'* was also considered very important.

## Evaluation of Peer Researcher Experience

Five peer researchers returned completed evaluation forms (Appendix 25). They reported enjoying *'reconnecting to the lived experience of older people'*, *'meeting older people'*, *'feeling of value'*, *'having a role in a piece of valuable research'* and *'gaining an understanding of issues concerns and contentment of people living with dementia'*. Some of the areas the peer researchers liked least were *'feeling a bit outside the project'*, *'would like to have contributed a bit more'* and *'trying to gauge the level of person being interviewed to set tone for the interview'*. Additionally, exploring different ways of asking questions and

recognising the need to listen were skills that could be built upon. Peer researchers felt it would be helpful in the future to have more information about the tenant in advance of the interview and they would like more information from the project and contact with the other peer researchers through the process. All of the peer researchers felt the experience brought value to them and were happy to have learnt new skills. The training was good preparation for the role although it was acknowledged there was a certain amount of '*learning on the job*'. The more interviews experienced, the more confident and skilled the peer researchers felt. Peer researchers felt supported during the interviews and having the researcher present for the interviews gave one peer researcher more confidence. All the peer researchers recognised the meaningful role they had within the TESA-DRI and stated that they would be interested in volunteering again. This is a significant capacity building outcome from the project.

## Summary

The role of peer researchers in the TESA-DRI project has been outlined in this section. It was the ambition that peer researchers would work closely with the participants aiming to enhance the authenticity, quality and applicability of the findings. The motivation to explore this methodological approach originated through international research literature. Overall, the experiences were reported to be positive and all participants expressed an interest in building on their role as peer researchers. Developing a relationship and a connection with the interviewee was very important to the role of the peer researcher. Within the debrief, the peer researchers identified strategies that will inform a training programme for other researcher teams interested in using this method in future studies.

## Chapter 11 Discussion and conclusion

### Introduction

This chapter presents the findings in terms of the objectives set out at the beginning of the project. The main results from this study indicate that person-centred care was indeed reflected in the TESA schemes from the perspectives of all the stakeholders. The findings from the environmental audit tool and the technology audit suggest home-like, individualised and custom environments for tenants to reside. The technology implemented was a strong feature within the data, with results indicating that staff rely on technology to provide good quality care, however, it was not a deciding factor on transition from an informal carer's perspective. A synthesis of the main findings from the face to face interviews are presented in Figure 45.

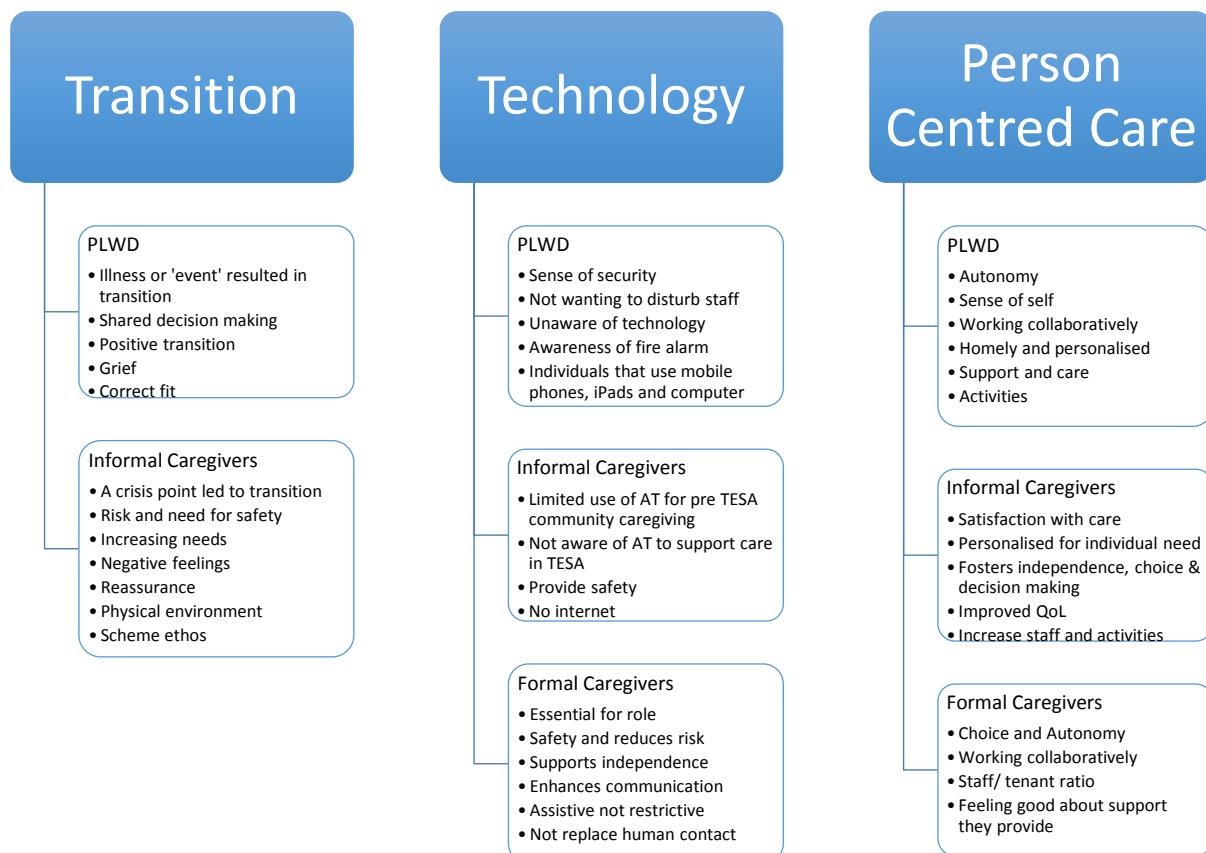


Figure 45. The main findings from the face to face interviews

### Technology Enriched Supported Accommodation in NI

The technology enriched supported housing for PLWD, evaluated in this research would appear to be unique to Northern Ireland in both design and volume. In a broad sense this accommodation model, bringing together housing, health and often non-government organisations, is now long established with the first site established in 2002. Whilst each TESA is unique in the organisational structures and funding streams scaffolding the service, there are some broad practices and principles that were evident across them all. For example, placing the PLWD as the tenant, moving away from the notion of a passive recipient being cared for. In addition to this, the family and informal caregivers are encouraged to remain actively engaged in the life of their relative. This can include picking

up the shopping and supporting their loved one with the house work. It was clear that person centredness was well rehearsed and could be mapped within each scheme.

With the exception of one of the sites, (where the Trust had been involved in the design and delivery of three TESA's), it would seem that no shared learning or collaborations were involved in supporting the design and delivery of new developments. And whilst there is a reasonable amount of information available on environmental design for PLWD, there is not clear practice guidelines on the design and implementation of pervasive technology to inform health and social care. It would seem that the opportunity exists to explore these information systems in light of the General Data Protection Regulations, consent to use pervasive technology in the tenants' home and to model and test how the data is informing health and social care decisions.

TESA were functioning at 91% of capacity, tenants were predominantly woman (72%), and although largely reported co-morbidities, it is interesting to note that 70% had not been hospitalised in the last year. Therefore, one can either assume that health was generally good and/or that the quality of care is supporting effective self-management of conditions. Interestingly, only 2% of tenants did not have a next of kin, considering the nature of migration and movement of families in today's society. It is possible this percentage will increase over time. Caregiving from a distance was made possible through technologies such as Skype and online shopping, as well as hiring domestic support.

The purpose of supported living environments is to help people live as independently as possible. The findings of the environmental audit tool indicated that TESA were 'homely'

environments that fostered the independence of the tenants. Person-centredness was set out and underpinned the built environment from the onset. In line with the literature, the facilities were built with regards to specific environmental design principles (Pierce et al., 2015). For example, good visual access and clear signposting to important features in their environment were highlighted. Safety and security scored low on the EAT. The features of supported living such as the freedom to leave the facilities (in some sites not all) and the control tenants have over their environment, which are positives in terms of lived experience, resulted in a low score on this item. The size of the facilities scored poorly and this was also reflected in the formal caregiver interviews, where in the smaller facilities staff reported more job satisfaction. Therefore, small schemes would benefit tenants as it is thought to reduce confusion, enable a more individualised approach and also benefit staff giving higher job satisfaction (Rasin and Kautz, 2007, Brownie and Nancarrow, 2013, Sjogren et al., 2017). In the interviews with tenants, the location of the scheme within a familiar community was really important, indicating this is a critical feature of the built environment for future planning.

Electronic health solutions and technology have the potential to enhance care provision in care environments (Martínez-Alcalá et al., 2016). In line with Gibson et al's (2014) review, the technology provision across the TESA was fragmented and often bespoke design, meaning that no two facilities operated in the same way. All but one site provided immediate feedback to the tenant when they requested support through an intercom system. Technology such as sensors and wearable devices were provided according to the needs of the tenant, indicating an individual and customisable approach, which is a key feature of person-centred according to the literature (Daly Lynn, 2017). Only two sites used

the data from the technologies to input into care plans. Therefore, the results would suggest that a clear plan to integrate the use of technology into caregiving for the future is required (Sugihara et al., 2013).

### Transition

One of the objectives of this research was to explore transition into TESA. Tenants reported moving into the scheme after experiencing a fall, having not been well or after a stay in hospital. Move into a care environment as a result of a 'crisis' was congruent with previous research (Nolan and Dellasega, 2000). Tenants spoke about it being a shared decision with their caregivers, both to create a better living environment personally and to reduce pressure on their loved ones caring role. Many participants spoke positively about their transition into the housing scheme, although they often grieved the home they left. Additionally, tenants felt it was important to have a correct fit. Many spoke about other long-term care environments that did not meet their needs and how the TESA environment is a place they would like to live for life.

Informal caregivers were concerned with their loved one's safety and the risk of harm while they were undertaking daily activities in advance to transitioning into TESA. Balancing the need for independence and the desire to keep their loved one safe became difficult and, therefore, the decision to transition into TESA came about. Additionally, increased support needs, both emotional and psychological needs, added to the need to change the living arrangements. Informal caregivers had a range of negative feelings around the transition. The change in the informal caregiving role emerged as a natural transition and was in keeping with Archbold's (1983) conceptualisation of caregiving into roles of either providers

or managers as the dementia progressed. Safety was an essential element in the choice of housing scheme and it was a finding reiterated in the literature (O’Malley & Croucher, 2005). Technologies within the schemes did not appear to impact on the decision-making during transition, however, they were valued as part of the lived experience for the PLWD within the TESA facilities. In line with the literature, establishing a ‘feel for’ the housing scheme, appreciating the ethos and staff attitude were also important (Rijnaard et al., 2016). Formal caregivers did not report on the transition into the housing scheme.

### Technology

Tenants and informal caregivers got a sense of security from the use of assistive technology in the care environment. This sense of security was a feature of previous research (Margot-Cattin & Nygård, 2006). Many tenants were not aware of the technology although many were aware of the fire alarming testing every week. Additionally, some tenants did speak about pendant alarms, pull cords, buzzers, and intercom systems. Individuals reported the use of iPads, computers and mobile phones. One participant had created a plan to use technology in her future care. Technology did not emerge as a theme of concern or interest, merely an awareness for some (not all) that they lived in a facility with technology. Priorities for tenants centred around relationships, activities and quality care provision from staff.

In advance of moving into TESA, a small number of informal caregivers used assistive technologies, such as, bed sensors, pendant alarms, CCTV cameras or GPS trackers to care for their loved ones. Technology was not reported by informal caregivers as influencing the decision to support the move into the facilities. However, it is now viewed as a valuable

asset to keep loved ones safe in the scheme. Many formal caregivers reported that technology was essential to their job. It helped them to be responsive and aware of who needs their support. These findings were reiterated within the survey data and within previous research (Chan et al., 2002). Once again, this element of safety, reduction of risk and protection from harm was highlighted as a core element of technology use. Technology was thought to support independent living and provide non-obtrusive support. It was considered a way to enhance the tenant's ability to communicate with staff. Formal caregivers reported that it was important technology is used as assistive not restrictive and does not replace human contact. The survey data captured key challenges for staff that included the high volume of calls, false alarms, and its failure to work in certain parts of the building. Only 11.11% of staff felt there was a disadvantage to using technology such as tenants not remembering how to use it and that it could go wrong. These fears were very much consistent with previous research (Niemeijer et al., 2014).

Primarily, the majority of caregivers trusted the use of technology and viewed it as an advantage. A divergence in thinking emerged around privacy and consent for the two caregiver groups. Safety was considered more important than right to privacy by family caregivers. Safety was a key factor in the decision of family caregivers to support their loved ones transition into TESA. Additionally, a greater percentage of staff caregivers felt tenants should give consent for the use of technology in their care. More research is needed to percolate over these human rights issues and to explore the different perspectives of all stakeholders.

## Person-Centred Care

In the UK, person-centred care is integral to care provision and this is reflected within policy and strategy. Person-centred care has been recognised as the best way to provide quality care and evidence of its attributes has filtered through this research. Each of the stakeholder interviews reflected upon the constructs of the person-centred practice framework (McCormack and McCance, 2017). These findings are supported by other research such as Brownie and Nancarrow (2013). To date, no evidence has been found in the supported accommodation model enriched with assistive technology therefore, this research offers novel insight into the person-centred approach within TESA. Overall, informal caregivers had high satisfaction with care in the housing schemes. Particularly, the person-centred elements such as supporting independence, choice, decision making and improving quality of life. Some participants reported that increasing staff numbers and activities available to tenants would enhance care. A theme that emerged in the formal caregiver interviews was choice and autonomy as a key element in their approach to care. Interestingly, staff felt they played a key role in the collaborative relationships between all three stakeholders, this is something the tenants also reflected on. Staff-to-tenant ratios were also highlighted because of their importance in provided one to one personalised care. The sense of 'doing a good job' enabled the staff to feel motivated and experience job satisfaction. In line with previous research (Rasin and Kautz, 2007), the importance of getting the correct balance of staff to tenants was essential to enable staff to provide quality care and time to tenants.

The tenants indicated that while living in supported living they can be independent and flourish as individuals. This is a significant indicator of the outcomes expected from person centred care (McCormack and McCance, 2017). The person-centred care received resonates throughout the stories told by the individuals living within the housing schemes. Autonomy, choice, and control to live the life of your choice. Working collaboratively with both formal and informal caregivers emerged as key components for quality of life.

Additionally, the homely environment, ability to personalise their living space and social activities were all very important.

## Methodology

TESA project was large in scale and scope. The data collection was extensive and presented in its entirety in Table 28 below. The sites were geographically dispersed across Northern Ireland with many stakeholders involved in the models of care. Working with the most vulnerable of populations, it was challenging and stimulating to authentically support engagement with PLWD and secure ethical approval to do so. The effort to achieve ethical approval cannot be overstated. Significant man-hours were required to develop the volume of material required for independent review. In addition, the time required from initial ethics application at Ulster University through to final HSC Trust approval took so long that it placed other aspects of this work at risk of non-completion. The team worked extremely hard to make up time on activity. The effort and patience, however, were well worth the outcomes in that people were keen to get involved in the project. It is interesting to note that moving to formal signed consent with participants was observed to create an uneasiness.

*Table 28. Overall Data Collection*

Name	Demographic	Environmental Audit	Technology audit	Tenants Interviews	Focus groups	Informal Interviews	Formal Interviews	IC Survey	FC Survey
Site A	□	□	A	N=2	N=9	N=2	N=3		
Site B	□	□	A	N=3	N=10	N=3	N=2	N=1	N=5
Site C	□	□		N=3	N=10	N=4	N=3		
Site D	□	□	A	N=3	N=10	N=3	N=2	N=6	N=9
Site E	□	□	A & B	N=2	N=4	N=3	N=2	N=1	N= 7
Site F	□	□	A & B	N=3	N=8	N=4	N=3	N=7	
Site G	□	□	A & B	N=2	N=7	N=3	N=3	N=2	N=10

Site H	□	□		N=2		N=2	N=2		
Site I	□	□	A	N=2	N=6	N=1	N=1	N=3	
Overall				N=22	N=64	N= 25	N=21	N=20	N=31

TESA is not an empirical study, rather an attempt to gather meaningful data on the lived experience of PLWD in a space and place which has been thoughtfully designed (environment, technology, care model, funding), honed in orientation to the specific and unique needs of PLWD. The methods were primarily qualitative, with some audit (demographics, environment and technology), to give foundational information and a sense of who is currently being served by these facilities. Some of qualitative methods were traditional in design, for example, the face-to-face interviews supported by topic guides. When used with the informal carers, this facilitated retrospective perspectives to come through particularly around transition. These methods also gave insight into the real-time sense of what life was like at that point in time from their perspective as a carer, this also applied to the face-to-face work with the formal carers. In our design we had planned to broaden the data gathering methods beyond face-to-face by offering focus groups with staff (at mutually convenient times) and indeed introduce methods we considered novel to support breath and opportunity within our data gathering. Some of these approaches work and others we had to review and set aside.

Providing an opportunity for PLWD to engage in the research was considered essential within the project. Guidance was taken from the literature to ensure best practice was used to create a truly inclusive research methodology. Three methodological steps were integrated into the project, 1) adapting a peer researcher approach to engaging with

tenants, 2) incorporating strategies into the one to one interviews to maximise the contribution of tenants, and 3) using creative methods as an additional way of capturing perspectives of PLWD without the focus on words. A core finding from Daly Lynn et al (2017) was that PLWD are routinely excluded from research, however, this project highlights that with careful consideration PLWD can successfully and meaningfully participate in research.

### Strengths and Weaknesses of the Study

There is no doubt there are both strengths and limitations within this study. A strength of this study was the recruitment and engagement of a large sample size of PLWD. The combinations of face-to-face interviews and art based focus groups enabled us to draw rich perspectives from individuals at different stages of their dementia journey. An additional strength is the use of peer researcher to undertake the interviews with PLWD and to support the analysis of the results. Involvement of the public (PPI) in research is currently a requirement of most research funders and this principle needs to equally apply to the participation of PLWD in research. Methodological developments need to be advanced for engaging PLWD in research, as it remains the case that too often their right to participate is judged on rational/logical criteria, rather than those that enable the lifeworld of the person to be valued as legitimate evidence in and of itself. Further work needs to be done in this area.

A limitation was the recruitment within a single region of the United Kingdom, within which there is an integrated health and social care system. Subsequently, the experiences of stakeholders may not be replicated in other areas. In addition, our limited time with participants to gather data could be considered a weakness, therefore, adopting a more immersive methodology for example ethnography may prove insightful. Furthermore, whilst the PCPF was adopted as the overarching framework for this project, that in itself may have bound our thinking. Staff at both senior management level and care staff were all extremely supportive and encouraging of our work. However, capacity of staff availability for face-to face-interviews was challenging. . There were regular issues relating to availability to meet, often related to sick leave, low staff levels and a reported high level of pressure on time for direct tenant care as an understandable priority. For one TESA, staffing was so critical they withdrew from the project. For a second TESA, there were significant delays in data gathering with senior managers on extended leave. The research team realised it would be impossible to set up the staff focus groups in a way that would be manageable within the time frame. Nonetheless, new insights have been gained and this is the first comprehensive study exploring these novel technology enriched supported housing.

### Recommendations

- Advanced care planning post diagnosis of dementia should include information and discussion on these types of accommodation so people can have explicit consent in place and triggers identified to support transition from home to these facilities.

- Shared learning across these facilities should be promoted to inform the ongoing operational delivery of care particularly on topics like GDPR, and embedding data within notes and records and evidencing how pervasive technologies inform care.
- An audit should be completed to ensure all sites are adhering to the General Data Protection Regulation (GDPR) outlining what technical and organisational safeguards are in place to protect tenants' data.

A move away from bespoke technologies and systems might be a positive progression enhancing the opportunity to standardise and understand implementation within services.

- Expertise and knowledge of designing, developing and delivering TESA schemes could be migrated into practice guidelines.
- Economic modelling on the TESA and testing against more traditional care would be useful.
- Debate and guidance on the ethical use of technologies for PLWD would be helpful.
- All research with a focus on PLWD should have their voice within it.
- Ethical governance and HSC Trust research governance in Northern Ireland should be more streamlined when multi-site research requires more than one HSC Trust approval. The single entry portal has not delivered a single point of governance.

## Conclusion

The aim of this research was to evaluate the current lived experience for people living with dementia in technology enriched supported accommodation in Northern Ireland, as well as exploring the impact on family caregivers and paid staff to inform future care. The present study is the first of its kind to explore the impact of technology within supported living settings. The discussion set out to address the aims and objectives within the project. Additionally, the methodological approach and strengths and weaknesses of the study are set out. The research indicates that these facilities do in fact promote independence, dignity and support through person centred care delivery. Technology supported the formal caregiver to provide high quality, person-centred care and provided reassurance and feelings of safety for both tenants and their next of kin. In line with previous research, the technologies used within the schemes varied greatly across the nine facilities. During 2015, it was estimated that of the 20,000 PLWD in Northern Ireland, only 64.8% had a diagnosis (Marie Curie Cancer Care, 2015). The eradication of dementia is not a realistic goal therefore emphasis on the care provided to PLWD and their families and cares requires thoughtful planning, implementation and review.

## Chapter 12 Dissemination summary

This chapter presents in list format the dissemination outputs, in process and planned.

### Academic outputs

1. Daly, J. Rondon-Sulbaran, J. Martin. S (2015) Technology in dementia care – what do we know from the research literature. Invited speaker at Integrated Care in Dementia, Ulster University, 5<sup>th</sup> of November 2015.
2. Martin, S. and Daly, J (2015) Exploring the research into smart home environments: A review of the literature and highlighting opportunities for future work In Telemedicine & eHealth 2015: Wearables and the caring home, London (23<sup>rd</sup>- 24<sup>th</sup> of November 2015)
3. Martin, S, and Daly Lynn, J (2017) Partnership working underpinning innovation. RESNA, New Orleans, June 26-30<sup>th</sup> 2017.
4. Daly-Lynn, J, Rondon-Sulbaran, J, Quinn, E, Ryan, AA, McCormack, B & Martin, S (2017), 'A systematic review of electronic assistive technology within supporting living environments for people with dementia.' *Dementia*, vol 0(0), pp. 1-65. DOI: 10.1177/1471301217733649
5. Daly Lynn, J and Martin, S. (2017) Engaging people with dementia in research: Peer

researcher experiences within aging research. International Conference in Occupational Therapy, Cape town, South Africa (June 2017). This poster can be found in Appendix 26.

6. Rondon-Sulbaran, J, Daly-Lynn, J, Quinn, E, Ryan, AA, McCormack, B & Martin, S (2019) Making the transition to technology enriched supported accommodation (TESA): the experience of families caring for a relative with dementia. Submitted to Ageing and Society. Returned to publisher October 2018 following receipt of reviewers comments and amendments.
7. Rondon-Sulbaran, J., Daly-Lynn, J., Quinn, E., Ryan, AA., McCormack, B & Martin, S. (2019) The transition to technology-enriched supported accommodation (TESA) for people living with dementia: the experience of formal carers. Submitted to Ageing and Society. Returned to publisher November 2018 following receipt of reviewers comments and amendments.
8. Daly-Lynn, J., Quinn, E., Ryan, AA., McCormack, B & Martin, S. (2019) The moral maze. Can we ethically engage people with dementia in technology research and services? Submitted to Journal of Assistive Technologies. In receipt of reviewers comments pending amendments.

Proposed papers:

1. Peer researchers: first draft nearing completion
2. Overview paper: Proposed for development on completion of report

## Dissemination in local community

Dissemination in the local community was undertaken through immersion into community events. As one researcher was employed at EWA regular engagement about the project was filtered through staff meetings, board meetings and older peoples forums. Additionally, attendance at local events and creating strong links with voluntary organisations such as Dementia NI and Alzheimer's Society strengthened the awareness of the TESA-DRI project at a local level. The Integrated Care in Dementia event at Ulster University in 2015 brought together a host of stakeholders in dementia care from across the province to exchange knowledge, experience and learning. The programme for this event can be found in Appendix 27. The researchers were immersed within the facilities for the lifecycle of the project and shared learning was a core strength of the creative arts groups. Activity coordinators supported and learnt from these groups and reported the future benefits of the skill building. Exhibitions of the art work took place at Ulster University and at two separate libraries over the summer months of 2018. During the exhibitions talks were held and community groups, the artists/ tenants and members of the public were in attendance. A final event is envisaged to hold one last exhibition before returning the artwork to the schemes for display.

## Resources

As an output from this project a creative arts booklet was developed (Appendix 13). The purpose of this booklet was to share the learning from the 42 art based focus groups undertaken within the project and to aid the continued use of art based activities in the facilities. A second output was the development of a peer researcher training pack (Appendix 22). Extensive work was put into the creation of this training to ensure peer

researchers had the skills to collect the data and engage with PLWD. This is now a resource that can be built upon and used for future projects.

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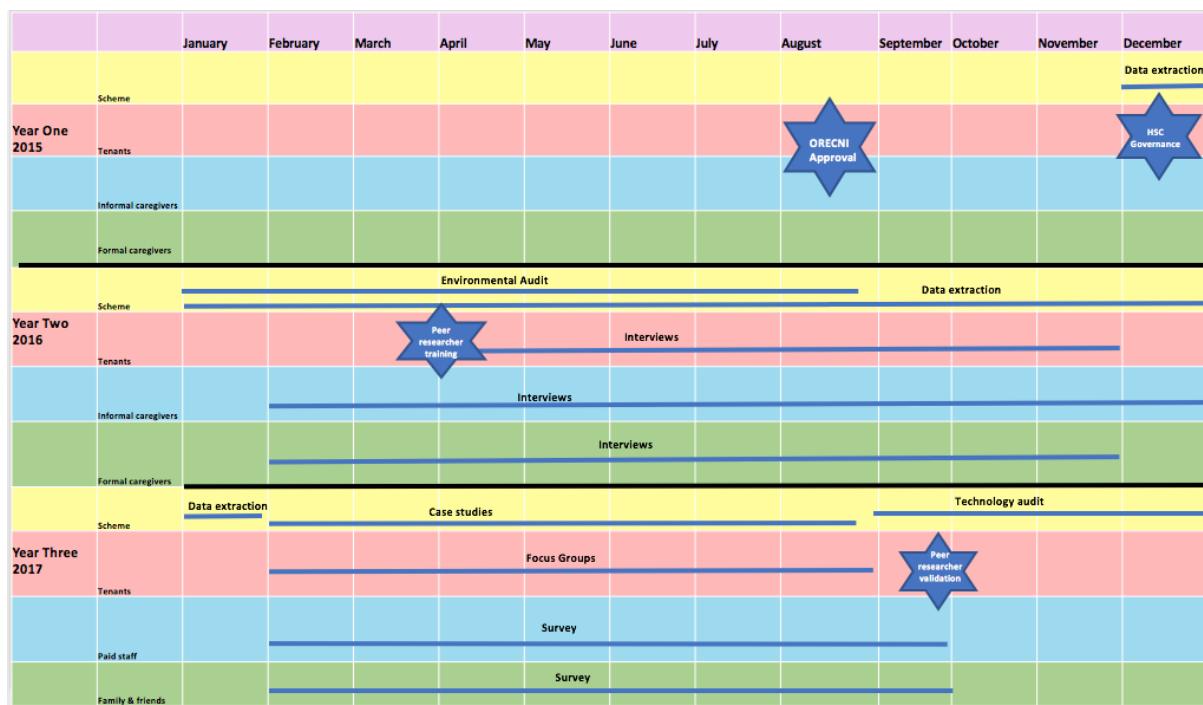
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## Appendix

### Appendix 1 Data Collection Timeline

The major focus in the first year of the project was obtaining ethical approval. This required extensive work to draw up the project protocol, complete approval forms and create supplementary project material. The completed ethical documentation first went for peer review within Ulster University, then onto the school of Health Sciences ethics filter committee and then referred onto the ORENI committee. After making the appropriate amendments at each stage the project finally obtained ORENI approval in August 2015. It was then required to obtain governance with each trust we were working within due to engaging with Trust employees (paid staff). This process was completed in December 2015 and data collection begun immediately. The Gantt chart below sets out the timeline for data collection within the project.



## Appendix 2

### Steering committee meetings

A steering group was set up and consulted with on three different occasions throughout the project as well as ad hoc contact by phone and email. The group included two individuals living with dementia, a family caregiver, individuals working in the voluntary sector providing support for people living with dementia, a director of a technology company, as well as representatives from the Northern Ireland Housing Executive, Supporting People, Housing Associations and the Trust. Three steering committee meetings were undertaken at the beginning of the project to create strong links with the numerous sectors involved and to guide the project approach.

#### Details of Steering Committee Meetings

<b>Date</b>	<b>April 2015</b>	<b>October 2015</b>	<b>October 2016</b>
<b>Meeting</b>	Overview of project	Ethical approval delays	Preliminary findings
<b>Focus</b>	Discussed methodology	Literature review Peer researcher training Assistive technology	Survey development

Although no further formal meetings were scheduled as the data collection got underway committee members were contacted to consult on any issue that arose. Furthermore, as the project developed they were asked to review and feedback on documents such as the attitudes towards technology survey. Additionally, there was an international team of three academics who were consulted during the project.

## Appendix 3 Project Leaflet

**What we hope to achieve:**

Have a picture of what it is like to live with dementia in technology supported housing from the point of view of the person with dementia.

Appreciate the views of family members and friends supporting their loved ones living in a technology enriched housing scheme.

Understand what it is like to work in paid employment in technology enriched supported housing schemes.

Combine all of the findings in order to develop best practice and influence policy in the design and evaluation of such facilities.



<b>Professor Suzanne Martin</b> Chief Investigator Ulster University	<b>Margy Washbrook</b> Director Engage With Age
<b>Professor Brendan McCormack</b> Queen Margaret University	<b>Dr. Assumpta Ryan</b> Reader Ulster University
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**Promotional Leaflet**  
Version 1: 29/05/2015

**Engage with Age**  **Ulster University** 

**TESA-DRI**  
Technology Enriched Supported Accommodation

**A Study into the Lived Experience of Older People with Dementia and Their Carers**

**Our Aim**

To explore perspectives of people with dementia living in technology enriched housing schemes, as well as their family and scheme staff.

**HSC Public Health Agency**  **The ATLANTIC Philanthropies** 

This research has been funded by HSC R&D Division, Public Health Agency (Northern Ireland) and The Atlantic Philanthropies.

**What is it like to live in this type accommodation as a person with dementia?**

Dementia is increasingly common among older people. As dementia develops over time, people may forget how to do everyday things such as:



**Technology enriched supported housing schemes provide an alternative accommodation for people with dementia.**

**Do you support a relative living in one of these schemes?**

**What is Supported Housing?**

This is an alternative housing solution that is available when living at home is no longer an option.

**It brings together the best housing design with individualised care, and often incorporates different types of technology to help people live more independently.**

The purpose of this research is to try to help us understand the good things about this type of scheme, what can be improved and what we need to change.

**Are you working in technology enriched supported housing?**

We are interested in talking to people with dementia and their carers to hear their views and experiences of living in these schemes. We want to understand what life is really like for them. We also want to hear what care workers think about these types of schemes.

**What has been your experience of technology enriched housing schemes?**

When we have this information we want to share it with all those people who are interested in using, developing and monitoring these facilities, so that good practice can be established.



#### Appendix 4 Information sheet for participant living with dementia

**Title of the Study: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

**Information Sheet for Participant with Dementia<sup>1</sup>**

We would like to invite you to take part in a research study involving people with dementia.

This participant information sheet will explain all you need to know about the study. You need to read this or ask someone you trust to read with you. If there is anything you are not clear about, we will be happy to explain it to you if you contact us.

It is important that you take your time reading this information and understand it before you make a decision. We will give you plenty of time to make up your mind.

**Thank you for reading this information!**

**Who we are**

We are Jean Daly and Janeet Rondón-Sulbarán, researchers working with the Ulster University and Engage with Age. Our supervisor is Prof Suzanne Martin, a professor of occupational therapy at Ulster University. Suzanne is an expert in using and developing electronic assistive technology to help and support people with specific requirements within health and social care settings.

<sup>1</sup> The terminology 'person with dementia'/'participant with dementia' has been adopted following consultation with the Alzheimer's Society, NI and Jan Dewing an author who has developed a method of process consent to include people who lack capacity (2002) and who has expertise in person-centred nursing practice and research with older people with dementia (2007).

This project has been funded by the Health and Social Care, Research & Development Division of the Public Health Agency from Northern Ireland and also by the Atlantic Philanthropies, an international grant awarding body.

### **What we are doing**

At the moment we are working on a research study that aims to find out about the experience of older people with dementia who live in technology enriched supported accommodation. We would like to interview people living in this type of accommodation and ask them about their life. We would like to ask you what has changed and what is not different since you came to live into the supported scheme. We would like to know what you find helpful and what not.

Also, we would like you to tell us about the assistive technology in supported accommodation for people with dementia. We are interested in your views on this topic and the difference that you think this could make on the life of a person with dementia.

We would also like to publish and present the findings of our study after we interview all the people who have agreed to take part.

### **Why have I been approached?**

You have been invited to take part in this research because of your expertise as a person with dementia living in technology enriched supported accommodation.

### **Do I have to take part?**

No, participation in the study is voluntary. It is up to you to decide whether or not to take part. If you decide to participate, you will be given this information sheet to keep.

You can ask your key worker or other member of staff in the scheme to contact the researchers by phone (Janeet: 028 90368244 or Jean: 028 90735696) or by e-mail: [jean.daly@engagewithage.org.uk](mailto:jean.daly@engagewithage.org.uk) and [j.rondon-sulbaran@ulster.co.uk](mailto:j.rondon-sulbaran@ulster.co.uk).

If you do this, one of them will come over to meet you and have a chat with you about the study. Janeet or Jean will ask you to take part in an interview and/or a focus group at your convenience. They will also ask if you agree for them to look at some information about your condition that the scheme manager has on records. If you decide to participate you can arrange a date for any of the activities with the researchers when they come to meet you. They will also be in touch with you through the staff in the scheme to remind you about the dates of the interviews and focus groups.

### **What happens if I change my mind?**

You are free to change your mind at any time even if you have first decided to take part. You just have to let us know if you have changed your mind and decided not to participate. You do not have to tell us why. Your rights and the services you receive from the scheme will not be affected.

### **How do I take part?**

Your key worker at the supported housing scheme will know about the research and will check with you after you receive this information, if you are willing to participate.

If you are interested in taking part, you can ask your key worker to let Jean or Janeet know on the phone or by e-mail (all details provided above). One of them will arrange a date to come in to the scheme to meet you, have a chat and arrange one interview or one focus group or both, whichever you want.

They will also ask you to sign the consent form included with this information pack. We would like you to contact us within two weeks of receipt of this letter to let us know your decision.

**What will I have to do if I decide to take part?**

If you decide to take part in the study you will be interviewed either individually or in a small group of six people doing a creative activity. Or you can do both interviews, if you want. The interviews will be undertaken by one researcher jointly with a peer researcher.

If you take part in the individual interview the researcher(s) will visit you in your home. We will be asking you questions about your experience living with dementia in the supported accommodation scheme and how you have adapted to living in a technology enriched environment. The researcher will be interested in knowing how you feel about your current living arrangements and what you feel is good or bad about it. They will also like to find out about your relationship with your formal carers and the kind of support provided.

At the end of the interview the researcher will use a questionnaire to gather information about the impact that some symptoms related to your illness is having on your life at the moment.

If you take part in a group interview with other five people the researchers and an artist or performer of creative arts with experience working with people with dementia will be facilitating this session. The focus group will be held at the scheme on a date

suitable to everyone. You will be asked to use a creative artistic form (e. g. painting, collage, music, dance, poetry, etc.) that you find comfortable or pleasurable to describe your experience living with dementia in technology enriched supported accommodation.

Your art product will help us understand your thoughts and feelings about your experience. We hope that this could be an enjoyable experience for you and that you feel free to express yourself.

You will be informed of the date of the focus group three weeks in advance of the interview and reminded again one week before the session.

**How long will my part in the study last?**

The individual interview will last approximately one hour – maximum one hour and fifteen minutes. The focus group will last approximately one hour and thirty minutes – maximum two hours.

**Will my taking part be kept confidential?**

All information that you give us will be kept confidential at all times. However, we have the duty to protect research participants from harm to themselves or others. So, if you disclose any information that we consider may be harmful to you or any other person, we will have to tell someone else (e.g. the scheme manager or your doctor).

We need to tell you that the interviews and focus groups will be either digitally recorded or videoed, so that we can capture exactly what we say or do during the interviews. It is OK to refuse this during the one-to-one interview; however, you have to be aware that the researcher will be taking notes during the conversation. We will always ask your permission to use any images of you.

All responses to our questions and information obtained from you will be anonymised. We will use an identity code on any files or a pseudonym on any quotations to protect your identity. No personal details or information that may identify you will be recorded anywhere.

Only members of the research team (Jean, Janeet or Prof Suzanne Martin) will have access to the information you provide or the list that connects your identity code or pseudonym to your name.

All files will be kept in a locked cabinet in the offices of the research team. Your anonymity and confidentiality will be safeguarded at all times during this study.

**What are the benefits of taking part?**

It is hoped that by participating in the study you will be sharing your experiences of living in technology enhanced supported accommodation. We hope that we can understand better the impact that living in this environment has on your life and the life of your carers (informal or formal).

What we find out from these interviews will help health and social care services providers to improve future services for people with dementia. The study will result in a care model for carers who support people with dementia living in accommodation with assistive technology.

It is unlikely that personally you will benefit from taking part in this research, but your views are very important to us.

### **What are the possible disadvantages and risks of taking part?**

We have to make you aware of the fact that you will be discussing your lived experience with dementia during interviews. It is likely that the discussion will touch on sensitive issues and private matters. You may feel uncomfortable or upset by this. If this happens you should let the researcher know immediately. You will be free to ask for breaks or to withdraw from any of the interviews you are participating in (e.g. individual or focus group). Your key worker or a trusted person can be present during the interviews to support you. They can be asked for help, if you feel upset.

After the interview you may like to talk to someone about any issues prompted by the session. We can arrange that for you.

### **What happens at the end of the study?**

All interviews will be transcribed word for word to accurately preserve what you have said. All the information will be anonymised using codes and then analysed. The results will be presented in reports, academic papers and presentations at conferences.

If we need to use any of your images we have on videos, we will ask for your permission. Your anonymity will be safeguarded and your image will not be used without your permission.

### **What happens if I change my mind during the study?**

You can withdraw from the study at any time without giving any reason. That will not affect your human rights or the services you receive. If this happens after you have given an interview, all the information will be destroyed and not included in the study in the study without your permission.

### Further information

In order to protect your interests, this study has been reviewed independently by a national research ethics committee. It was given a favourable opinion on 28/08/15 by the Office of Research Ethics Committee in Northern Ireland (ORECNI).

If you have any queries or concerns about the study you can contact the chief investigator, Prof Suzanne Martin at the address provided. Or you can contact the Research Ethics and Governance Office of the Ulster University and speak to Nick Curry, Senior Administrative Officer: Room 01H12, Research Office, Ulster University, Newtownabbey, BT37 0QB, T: +44 (0)28 9036 6629, E: [n.curry@ulster.ac.uk](mailto:n.curry@ulster.ac.uk)

If you do decide to take part, please contact Jean or Janeet (the researchers) on the telephone or e-mail addresses provided. Should you decide to take part, and you have any complaints about the conduct of the research, you can also contact Prof Suzanne Martin, who is responsible for managing and monitoring the project.

<u>Researchers:</u>	<u>Chief Investigator:</u>
<p><b>Janeet Rondón-Sulbarán</b> Ulster University School of Health Sciences Shore Road Room 01D110 Newtownabbey County Antrim BT37 0QB T: +44 (0)28 9036 8729 E: <a href="mailto:j.rondon-sulbaran@ulster.ac.uk">j.rondon-sulbaran@ulster.ac.uk</a></p>	<p><b>Prof Suzanne Martin</b> Professor of Occupational Therapy Ulster University School of Health Sciences Shore Road Room 01B114 Newtownabbey County Antrim BT37 0QB T: +44 (0)28 9036 6976 E: <a href="mailto:s.martin@ulster.ac.uk">s.martin@ulster.ac.uk</a></p>
<p><b>Jean Daly</b> Engage with Age 55 Templemore Avenue Belfast BT5 4FP T: +44 (0)28 9073 5696 E: <a href="mailto:jean.daly@engagewithage.org.uk">jean.daly@engagewithage.org.uk</a></p>	

## Appendix 5 Consent form for participant living with dementia



Consent Form PwD  
Version 2: 30/06/2015

Participant Code:

### Consent Form - Person Who Has Dementia

**Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

**Please read the following statements and initial each of them in the box, then sign your name on the space provided if you agree to participate in the study and hand in the form to the researcher**

**Please initial your confirmation below**

1. I have read and understood the information sheet I received (Version 4: 27/08/2015) for the above study	<input type="checkbox"/>
2. I have had time and opportunity to ask questions about the study or my role	<input type="checkbox"/>
3. I understand that my participation is voluntary and that I can stop the interview or withdraw from the study at any time without giving a reason and without my care or legal rights being affected	<input type="checkbox"/>
4. I understand that this interview will be recorded and that data collected will be handled only by the research team	<input type="checkbox"/>
5. I agree to anonymised data from me being included in research reports, publications and other presentations even if I withdraw from the study	<input type="checkbox"/>
6. I agree to participate in the study	<input type="checkbox"/>

Name of participant:	Date:	Signature:
Name of person who has discussed the study and provided me with information:	Date:	Signature:
Name of researcher taking consent:	Date:	Signature:

When completed: original for researcher site file, one copy for participant and one copy to be kept by scheme on record file.

## Appendix 6 Process Consent form for participant living with dementia



Process Consent Form  
Version 1: 29/05/2015

### Process Consent Form for Participant Person with Dementia Who Lacks Capacity

#### Title of the Study: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)

Participant Code: \_\_\_\_\_

Scheme Code: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

<b>PART 1. CHECKLIST FOR RESEARCHERS TO DECIDE WHETHER A PROSPECTIVE PARTICIPANT HAS THE CAPACITY TO CONSENT TO THEIR PARTICIPATION</b>	
<b>Section A - Enabling capacity:</b>  Have you made every effort to enable a prospective participant to make the decision themselves to participate or refuse?  Have you used language or methods of communication that the person is most likely to understand?  Have you given sufficient time for the person to think about the project?  Has the person conferred with others who could help explain the project?  <i>If NO to any item in Section A, return to guidance on 'enabling participation'. If YES to all items in Section A continue...</i>	
<b>Section B - Diagnostic assessment</b>  Is there evidence to demonstrate impairment of mind or brain?  Is there evidence to demonstrate that this is temporary, fluctuating or permanent?  Is there evidence to demonstrate that the impairment affects the person's ability to decide about their participation in research?  <i>If NO to any item in Section B discuss with Chief Investigator. If YES to all items in Section B, continue...</i>	
<b>Section C - Functional assessment</b>  Does the person understand that they can consent to or refuse to participate in research?  Does the person understand what the research is about?  Does the person understand and weigh-up the benefits and risks of agreeing or refusing to take part?  Has the person communicated their decision	

<p><b>If YES to any item in Section C, the person can provide INFORMED CONSENT – return to guidance on 'enabling participation' (use appropriate consent form).</b></p> <p><b>If NO to the first three items in Section C – the person DOES NOT have the capacity to consent to or to refuse to take part in the research project. Return to guidance on 'enabling participation' – A PROCESS CONSENT will be initiated (use the Process consent form').</b></p>	
--	--

The process consent designed by Dewing (2002)<sup>1</sup> will be applied throughout the research in order to continuously seek, maintain and ensure participation in the study of the PwD who lacks capacity.

**PART 2: ESTABLISHING A BASIS FOR MENTAL CAPACITY**

*(These questions can be answered by knowing some biographical details about the participant, from them, from care records and from carers and staff)*

This person's usual self-presentation is:

This person's usual level of well-being/ill-being is:

*(Include a descriptor of how the level of well-being is recognised by an observer, e.g. informal carer, staff within the scheme. Possible descriptors: smiling, laughing, positive verbal feedback, making eye contact, shrugging his/her shoulders, grunting, not making eye contact)*

A decrease to the level of this person's well-being may well be triggered by:  
*(include environmental factors, and interactions by other persons)*

Decreasing level of well-being can be recognised by:

*(try to ascertain mild signs not extreme ones and include behaviour, body language, verbal and non-verbal signs)*

<sup>1</sup> Dewing, J. (2002). From Ritual to Relationship: a person-centred approach to consent in qualitative research with older people who have dementia. *The International Journal of Social Research and Practice* 1 (2) 156-171.

Any significant conversation or behaviour that might be indicative of a deeper need/intervention could be:

*(relates to any deeper psychological needs the person has)*

How does this person usually 'consent' to other activities and procedures within their day-to-day life?

*(include existing assessments or opinions on capacity)*

Has mental capacity been formally assessed? And if so, what were the findings?

Other useful information that has been taken into account:

### PART 3. INITIAL CONSENT

Outline the approach to seeking consent from the person with dementia:

*(make notes on the location, time, information given, props or equipment used, key questions and answers)*

**In what ways did the person indicate their consent?**  
(identify verbal, non-verbal and behavioural signs. Does it match up with their usual way of indicating consent?)

**Who else was consulted (usually a family member or someone involved in the person's care and interested in their welfare)?**

Name: \_\_\_\_\_

Relationship to the person with dementia: \_\_\_\_\_

What was the advice of the consultees on whether the person should take part in the project, and what they thought the person's feelings and wishes would be, if they had the mental capacity to decide whether to take part:

#### **PART 4. ONGOING CONSENT MONITORING**

Date and Time notes made:

***If you involve the person with dementia in more than one episode of conversation you may need to treat each episode as a new interaction and make additional notes***

Was ongoing consent provided in a way that was consistent to the initial consent?  
(if not, then, consent must be revisited in full. Any decision to continue must be justified)

At the end of the interview the person's level of well-being was:  
(provide a description of behaviour, verbal and non-verbal signs and relative well-being level).

Has anyone independently tracked this person's well-being during or immediate after any of the consent process? (if so make a note of their observations in relation to the person's level of well-being/ill-being)

Feedback given to family/carers/staff: (specify if this was verbal or written)

State why you gave this feedback: (Your responsibility is to ensure the persons privacy).

Describe any interactions or interventions you made with the person in order to achieve a transition/return back into their usual environment of care

**Signature:**

**Issues to raise with project team and/or chief investigator/supervisor:**

## Appendix 7 Information sheet for participating housing schemes



Information\_Sheet\_Schemes  
Version 4: 18/11/2015

### Information Sheet for Participating Housing Schemes

#### **Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

##### **Invitation**

We would like to invite you to take part in our research study because your supported housing scheme provides accommodation for older people who have dementia and your facilities have been equipped with assistive technologies.

Before you decide whether or not to participate we would like you to understand why the research is being done and what it would involve for the scheme. This participant information sheet is for you to keep. This information explains the purpose, risks and benefits of the research. If you agree to take part, we will ask you to sign a consent form and return it to us. If there is anything you are not clear about, we will be happy to explain it to you. It is important that you take your time reading this information and understand what is being asked of you and your scheme before you make a decision. We will give you plenty of time to make up your mind.

Thank you for reading this information!

##### **Who we are**

The research is being conducted by the Ulster University working in partnership with Engage with Age. The chief investigator is Prof Suzanne Martin, professor of occupational therapy at Ulster University who has done a lot of work and research in the area integration of electronic assistive technology integration into health and social care to support people with specific care requirements. This project has been funded by the Health and Social Care, Research & Development Division of the Public Health Agency from Northern Ireland and also by the Atlantic Philanthropies.

##### **Purpose of the study**

The aim of this study is to understand the lived experience of older people with dementia who live in technology enriched supported accommodation. We have an interest in their views and those of family members/close friends and paid staff who care for an older person who has dementia and lives in this type of accommodation. Supported accommodation is an alternative home for people with dementia when they no longer can live at home. Some supported housing now use digital alarms with sensors in the flats to let staff know how people are managing within their own place. Some schemes like this have existed in



Northern Ireland for over ten years, supporting people with dementia and their families, however, we know very little about their impact.

In this study we want to talk to people with dementia, their families or informal carers and the staff caring for them formally. We want to find out what it is like living in supported accommodation enhanced with technology and what families and care workers think about these types of schemes. We would like to understand the advantages and disadvantages and the reality of living as a tenant within this accommodation. The expertise of the staff in your scheme and the insights that we can gain from them will make an invaluable contribution informing this complex subject, as well as helping us establishing good practice.

**Does the scheme have to take part?**

No, participation in the study is voluntary. It is up to you to decide whether or not the scheme takes part. If you decide to participate, you will be given this information sheet to keep and ask to contact Jean Daly or Janeet Rondón-Sulbarán, the researchers from the Ulster University and Engage with Age, appointed to undertake the study (contact details below). Either of them will arrange a visit to your scheme, at a time convenient to you, to explain and discuss the participation of your scheme in the study.

You are free to change your mind at any time even if you have first decided to take part. You just have to let us know if you have changed your mind and decided not to participate. You do not have to tell us why. If you decide to take part you can still withdraw at any time and without giving any reason.

**How do I take part?**

If you are willing to participate you should return the consent form in the SAE provided within two weeks of receipt of this letter. Jean or Janeet will contact you on the phone or by e-mail (all details provided below) and arrange to meet you.

**What will the scheme and the team have to do if I decide to take part?**

If you decide to take part in the study we will be asking you and your team to participate in different activities throughout the duration of the research – approximately 28 months commencing in September 2015. The tasks we will ask of the scheme are: 1) to allow the researchers access to information kept on records/files of the tenants to extract demographic data without disclosing personal data and protecting confidentiality and anonymity; 2) to support the researchers in selecting a purposive sample from within your scheme which complies with the criteria for participation; 3) to support the recruitment of family

members/close friends to participate in the study by posting/forwarding invitation packs on our behalf; 4) to support the recruitment of participants within your scheme by promoting the research displaying a leaflet that we will provide and asking all staff to inform and explain to your tenants about the study; 5) to help us ensure that the interests and safety of potential participants are protected during the research by advising researchers as to the capacity of potential participants within your scheme to provide consent to participate in the study; 6) to nominate a consultee who can advise the researcher about the participant's wishes and feelings in relation to the study and the suitability of their participation; 7) to share biographical and other relevant information that can allow researchers to build a rapport and communicate appropriately with potential participants using the same methods employed in your scheme; 8) to allow the display within the scheme of information packs inviting paid staff to take part in in-depth interviews and/or case studies – any interested participants are asked to contact the researchers directly; 9) to support the recruitment of all staff in your scheme to participate in an online survey; and 10) to complete an interview-based questionnaire to evaluate your facilities.

There will be one researcher (Jean or Janeet) accompanied by a peer researcher (not at all times) present to undertake all the activities. To extract data from the records they will use a proforma specifically designed for this purpose (copy attached). This will take place two months before the recruitment process of people with dementia commences.

Then, we will be asking you to advise on those potential participants who might be included or excluded in the study according to criteria established in our research protocol. When a family member/close friend is not able to assist the researchers in the process consent to interview tenants who might lack capacity, we will ask you to nominate a member of staff from your team (e. g. key worker) or other person in a professional role who knows the person with dementia to act as a consultee.

Finally, the member(s) of staff participant in the study will be invited to take part in an in-depth interview. The researcher will be asking questions about his/her experience caring for people who have dementia in your scheme. There will also be questions about what happens during the transition of the tenants from home/hospital to technology enriched supported accommodation. We are also interested in knowing about what difference, if any, assistive technologies make in your day-to-day practice. We will have some questions for the interviewee to open-up the conversation and that will help him/her/you describe his/her/your experiences. At the end of the interview the researcher will use a computer assisted personal interviewing (CAPI) method and traditional paper and pencil methods to apply two questionnaires to gather

members/close friends to participate in the study by posting/forwarding invitation packs on our behalf; 4) to support the recruitment of participants within your scheme by promoting the research displaying a leaflet that we will provide and asking all staff to inform and explain to your tenants about the study; 5) to help us ensure that the interests and safety of potential participants are protected during the research by advising researchers as to the capacity of potential participants within your scheme to provide consent to participate in the study; 6) to nominate a consultee who can advise the researcher about the participant's wishes and feelings in relation to the study and the suitability of their participation; 7) to share biographical and other relevant information that can allow researchers to build a rapport and communicate appropriately with potential participants using the same methods employed in your scheme; 8) to allow the display within the scheme of information packs inviting paid staff to take part in in-depth interviews and/or case studies – any interested participants are asked to contact the researchers directly; 9) to support the recruitment of all staff in your scheme to participate in an online survey; and 10) to complete an interview-based questionnaire to evaluate your facilities.

There will be one researcher (Jean or Janeet) accompanied by a peer researcher (not at all times) present to undertake all the activities. To extract data from the records they will use a proforma specifically designed for this purpose (copy attached). This will take place two months before the recruitment process of people with dementia commences.

Then, we will be asking you to advise on those potential participants who might be included or excluded in the study according to criteria established in our research protocol. When a family member/close friend is not able to assist the researchers in the process consent to interview tenants who might lack capacity, we will ask you to nominate a member of staff from your team (e. g. key worker) or other person in a professional role who knows the person with dementia to act as a consultee.

Finally, the member(s) of staff participant in the study will be invited to take part in an in-depth interview. The researcher will be asking questions about his/her experience caring for people who have dementia in your scheme. There will also be questions about what happens during the transition of the tenants from home/hospital to technology enriched supported accommodation. We are also interested in knowing about what difference, if any, assistive technologies make in your day-to-day practice. We will have some questions for the interviewee to open-up the conversation and that will help him/her/you describe his/her/your experiences. At the end of the interview the researcher will use a computer assisted personal interviewing (CAPI) method and traditional paper and pencil methods to apply two questionnaires to gather

information about the impact of assistive technology on working practices. Online questionnaires will be available to all members of staff to respond to a survey about their experience.

**How long will my part in the study last?**

We will remain in contact with you and arrange schedules for activities throughout the life of the research once you have responded to this invitation. At the moment all we can tell you is that the in-depth interview with staff will last approximately one hour and the completion of the questionnaires will take about 30 minutes— maximum one hour and 45 minutes (1:45hrs). The environmental tool audit that we will complete with you, will take approximately 10 minutes when completed by one person; it will take longer if it is used in a group setting with staff to stimulate the conversation about the advantages and disadvantages of the environment.

**Will my taking part be kept confidential?**

All information provided by you and your staff will be kept confidential at all times, except in case that you/they disclose information that may be considered to pose a threat of harm to yourself or others.

The researchers, Jean and Janeet, will use a digital recorder during the interview with staff, so that we can capture exactly what has been said. It is OK to refuse this, however, you have to be aware that the researcher will then be taking notes during the interviews

All responses to our questions and information obtained from you and all other participants within the scheme, will be anonymised. All identifiers will be removed from the data. We will use an identity code on any files or a pseudonym on any quotations to protect the participants' identities. No personal details or information that may identify the participants or the scheme will be recorded anywhere. Only members of the research team (Jean, Janeet or Prof Suzanne Martin) will have access to the information you provide or the list that connects your identity code or pseudonym to your name or the name of the scheme. All files will be kept in a locked cabinet in the offices of the research team on the Jordanstown campus of the Ulster University. Your anonymity and confidentiality will be safeguarded at all times during this study.

**What are the benefits of taking part?**

It is hoped that by participating in the study you will be sharing your experiences about caring in a professional capacity for a person who has dementia and is a tenant within your supported scheme.

What we find out from these interviews and questionnaires will help health and social care services providers in the future development of appropriate services for people who have dementia and their carers. The study will result on a care model for paid carers who support people with dementia who live in accommodation fitted with assistive technology. However, there is unlikely to be any direct benefit to you personally from taking part in this research, but your views are very important to us.

**What are the possible disadvantages and risks of taking part?**

We have to make you aware of the fact that you have to ensure that you have the resources to support the research. During the interviews with tenants and staff, we will be discussing the lived experience of caring for someone who has dementia and of living with dementia in supported accommodation. For some of your tenants the research might add a burden to their life making them feel upset or more anxious. Staff may feel also uncomfortable or upset by the interview. If any of this happens with any of the potential participants, they should let the researcher know immediately. They do not have to answer all the questions in any of the interviews and they will be free to ask for breaks or to withdraw from the study at any time during the research process. The scheme/manager has the right to withdraw from the study at any time without giving any reason.

Please, feel free to raise any issues with our chief investigator, Prof. Suzanne Martin (see details below), who will respond to your worries or concerns in an appropriate manner.

**What happens at the end of the study?**

All interviews will be transcribed verbatim, that is, everything that has been audio recorded will be typed to accurately preserve what has been said. We will enter data into statistical and qualitative software analysis programmes. All the information will be anonymised using codes and then analysed. Qualitative data will be analysed by the researchers who will identify common themes and will present them in a coherent and comprehensive manner. Quantitative data will be analysed for descriptive and analytical statistics, if possible. We will write-up the results in reports, academic papers and presentations at conferences. Your anonymity will be safeguarded at all times.

**What happens if I change my mind during the study?**

You can withdraw from the study at any time without giving any reason. That will not affect your human rights in any way. If this happens after you have responded to a questionnaire or given an interview, we will ask for your consent to include the information collected from you in the study.

**Further information**

In order to protect your interests, this study has been reviewed independently by a national research ethics committee. It was given a favourable opinion on 28/08/15 by the Office of Research Ethics Committee in Northern Ireland (ORECNI).

If you have any queries or concerns about this study you can contact Prof Suzanne Martin or you can contact the Research Ethics and Governance Office of the Ulster University and speak to Nick Curry, Senior Administrative Officer: Room 01H12, Research Office, Ulster University, Shore Road, BT37 0QB, Tel: +44 (0)28 9036 6629, E: [n.curry@ulster.ac.uk](mailto:n.curry@ulster.ac.uk)

If you do decide to take part, please return the consent form in the SAE provided. Also available below are contact details of the chief investigator (Prof Suzanne Martin) responsible for the monitoring and management of the research. You can contact her at any time regarding any complaints you may have about the conduct of the research, should you decide to take part.

<u>Researchers:</u>	<u>Chief Investigator:</u>
<p><b>Janeet Rondón-Sulbarán</b>            Ulster University            School of Health Sciences            Shore Road            Room 01D110            Newtownabbey            County Antrim            BT37 0QB            T: +44 (0)28 9036 8729            E: <a href="mailto:j.rondon-sulbaran@ulster.ac.uk">j.rondon-sulbaran@ulster.ac.uk</a></p>	<p><b>Prof Suzanne Martin</b>            Professor of Occupational Therapy            Ulster University            School of Health Sciences            Shore Road            Room 01B114            Newtownabbey            County Antrim            BT37 0QB            T: +44 (0)28 9036 6976            E: <a href="mailto:s.martin@ulster.ac.uk">s.martin@ulster.ac.uk</a></p>
<p><b>Jean Daly</b>            Engage with Age            55 Templemore Avenue            Belfast            BT5 4FP            T: +44 (0)28 9073 5696            E: <a href="mailto:jean.daly@engagewithage.org.uk">jean.daly@engagewithage.org.uk</a></p>	

## Appendix 8 Consent form for participating housing schemes



Consent Form Participating Schemes  
Version 2: 30/06/2015

### Consent Form for Participating Schemes

Participant Code: SECC1

#### Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)

Please initial box

1. I confirm that I have read and understand the information sheet (Version 4: 18/11/2015) that I received for the above study
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal and human rights being affected
4. I understand that data collected during the study may be looked at by the researchers and I agree to anonymised and unidentifiable data from me and the scheme being included in research reports, publications and related presentations
5. I agree to take part in the study

\_\_\_\_\_  
Name of Scheme Manager

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed: original for researcher site file and one copy for participant

## Appendix 9 Data extraction form



Extraction Form  
Version 2: 03/11/15

Appendix A

### Extraction Form

**Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

Participant Code:	Researcher extracting data:		
Housing Scheme Code:	Date of extraction:		
Scheme Manager:			
Age:	Gender:	Male <input type="checkbox"/>	Female <input type="checkbox"/>
Date entered scheme: DD/MM/YYYY			
Ethnic group:	White <input type="checkbox"/>	Pakistani <input type="checkbox"/>	
	Black Caribbean <input type="checkbox"/>	Bangladeshi <input type="checkbox"/>	
	Black African <input type="checkbox"/>	Chinese <input type="checkbox"/>	
	Black other <input type="checkbox"/>	Irish Traveller Community <input type="checkbox"/>	
	Indian <input type="checkbox"/>	Other _____	<input type="checkbox"/>
Previous address:	Next of kin:	spouse/partner <input type="checkbox"/>	adult child <input type="checkbox"/>
	brother <input type="checkbox"/>	other relative <input type="checkbox"/>	<input type="checkbox"/>
Postal code:	sister <input type="checkbox"/>	close friend <input type="checkbox"/>	<input type="checkbox"/>
Type of accommodation:	Hostel <input type="checkbox"/>	Private house (owned) <input type="checkbox"/>	<input type="checkbox"/>
	Housing association <input type="checkbox"/>	Private house (rented) <input type="checkbox"/>	<input type="checkbox"/>
	Group home <input type="checkbox"/>	Flat <input type="checkbox"/>	<input type="checkbox"/>
	Hospital ward <input type="checkbox"/>	Other <input type="checkbox"/>	<input type="checkbox"/>
	Sheltered housing <input type="checkbox"/>		
Living arrangements: (previous to moving into scheme)	With partner/spouse <input type="checkbox"/>	Marital status:	<input type="checkbox"/>
	With adult child <input type="checkbox"/>	Single (never married) <input type="checkbox"/>	<input type="checkbox"/>
	With other relative <input type="checkbox"/>	Divorced <input type="checkbox"/>	<input type="checkbox"/>
	With close friend <input type="checkbox"/>	Married <input type="checkbox"/>	<input type="checkbox"/>
	Sharing with other person <input type="checkbox"/>	In partnership <input type="checkbox"/>	<input type="checkbox"/>
	Who? _____	Widow/er <input type="checkbox"/>	<input type="checkbox"/>
		Other _____	<input type="checkbox"/>

<b>Dementia diagnosis:</b>	<b>Date/When diagnosed:</b> DD/MM/YYYY or XX yrs ago		
<b>Co-morbidities:</b>	<b>GP attendance in the last 12 months:</b> Number of times		
<b>Current medication:</b>	<b>Nº of hospitalisations in the past 12 months due to ill health (if applicable):</b>		
<b>Psycho-social treatments:</b>			
<b>Cognitive symptoms:</b>			
loss of memory	<input type="checkbox"/>	loss of the ability to recognise objects	<input type="checkbox"/>
inability to reason	<input type="checkbox"/>	loss of the ability to recognise persons	<input type="checkbox"/>
poor judgment	<input type="checkbox"/>	loss of the ability to recognise sounds, smells or shapes	<input type="checkbox"/>
disorientation	<input type="checkbox"/>	loss of mobility	<input type="checkbox"/>
wandering	<input type="checkbox"/>	speech difficulties	<input type="checkbox"/>
difficulties understanding spoken language	<input type="checkbox"/>		
difficulties understanding written language.	<input type="checkbox"/>		
<b>Functional symptoms:</b>			
angry outbursts	<input type="checkbox"/>		
depression	<input type="checkbox"/>		
delusions	<input type="checkbox"/>		
hallucinations	<input type="checkbox"/>		
<b>Psychiatric symptoms:</b>			
Other symptoms (specify):	<hr/> <hr/> <hr/>		
List of activities included in care plan:	<hr/> <hr/> <hr/>		
Briefly state outcomes:	<hr/> <hr/> <hr/>		

## Appendix 10 Technology Audit A



Version 4: 23/08/17



### **TESA-DRI: Technology Audit for Housing Schemes**

Thank you for taking the time to complete this technology audit. This is part of the research we are completing on what it is like to live and work here. Please do give expansive answers to the questions. You are welcome to attach an additional sheet and as many comments as you think would be helpful to us.

#### **How do you describe the technology used within your housing scheme?**

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#### **Within the overall housing scheme**

##### **1) How do people come in and out of the scheme?**

	Electronic code into keypad	Fingerprint enabled	Key card	No free movement	Other (Please specify)
<b>Staff</b>					
<b>Tenants</b>					
<b>Family</b>					

##### **2) Are there sensors on the door(s) to alert when a person comes in/ leaves the scheme? (Please circle)**

Main reception door      Yes      No  
Side door      Yes      No  
Doors to tenants flats/rooms      Yes      No

Other (Please specify) \_\_\_\_\_

Is data from these sensors gathered on a database?      Yes      No

3) Is there a video feed at the entrance to the housing scheme? (Please circle)  
Yes      No

4) Do you have any video feeds within the housing scheme? (Please circle)  
Yes      No  
If yes please give details \_\_\_\_\_



## 5) Information management system: Do you use: (Please circle)

Electronic notes Yes No  
Hardcopy notes Yes No  
A combination Yes No

Other or not sure (Please specify) \_\_\_\_\_

**Alarm triggers**

## 6) When a tenant needs to call for help in an emergency scenario they do this through: (Please circle)

A wearable device Wall fixed buttons Pull cord Other \_\_\_\_\_

7) Is this alarm the same when they are in or outside their flat/ bungalow/ room?  
Yes No

## 8) How does the member of staff receive this alert? \_\_\_\_\_

## 9) Does the tenant get an immediate response to know that a staff member received the alert? (i.e. Speech message, intercom or communication with staff) (Please circle)

Yes No  
Please give details \_\_\_\_\_

10) How do tenants seek non-emergency assistance?  
\_\_\_\_\_  
\_\_\_\_\_**Within individual Flats or Bungalows**11) Is there a video feed at the entrance to the tenants flat or bungalow?  
Yes No

12) Is there a speaker or communication system within the tenants flat or bungalow to central hub/ nursing station/ staff pager?

Yes  No

12) What is the value of  $\sin \theta$  in the diagram? (Please give 3 significant figures)

Alarms	Tenants flat/ home	All living environments	Customised areas	Common areas	Not within scheme
Fall alarm/ detector					
Smoke alarm					
Flood alarm					
Carbon monoxide detector					
Heat/ temperature extreme alarm					
Gas detectors					
Sensors	Tenants flat/ home	All living environments	Customised areas	Common areas	Not within scheme
Motion sensors					
Inactivity sensors					
Automatic/ motion sensitive lights					
Water temperature					
Pressure sensors: Bed					
Pressure sensors: Chair					
Pressure sensors: Floor					
Pressure sensors: Other (Please specify)					
Door sensors					
Enuresis/ continence sensor					
Monitors	Tenants flat/ home	All living environments	Customised areas	Common areas	Not within scheme
Water flow control					
Cooker monitor (turn off device)					
Close-circuit TV					

**14) What wearable devices are used within the scheme?**

	All tenants	Specified tenants	No tenants
Electronic tracking device (GPS)			
Alarm pendent			
Alarm bracelet			
Other please specify:			

**15) What other devices are found within the housing scheme?**

	All tenants	Specified tenants	No tenants
Easy to use telephone			
Mobile phone			
Music player			
TV			
iPad			
Computer			
Ease to use remote control with large buttons			
Memory AID			
Audio/ Audio-visual prompts			
Companion robots or electronic toys			
Light therapy			
Electronic calendars			
Other please specify:			

**16) Would you be aware of any tenant(s) that use any other electronic assistive devices and if so can you list what these are?**


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19) How do staff receive alerts and information from the system?

	Yes	No
Monitoring station		
Staff pager		
Web application		
Mobile phone		
Tablet		
Other (please specify)		

20) If the computer software that manages the data from the sensors and alerts has a name, can you tell us what it is?

21) Do you keep the data from the sensors and technology?

22) How often is data sent from sensors?

23) The data is transmitted through:

<b>Network</b>	<b>Yes</b>	<b>No</b>	<b>Don't know</b>
Wireless			
Hardwired			
4G			
Passive Infrared			
Zigbee			
Radio frequency transmitter			
Power line interface			

24) Do staff access the sensor and technology data?

If staff access the data, please indicate how this is done:

	Yes	No
<b>Monitoring station</b>		
<b>Staff pager</b>		
<b>Web application</b>		
<b>Mobile phone</b>		
<b>Tablet</b>		
<b>Is not accessed</b>		

25) How often is data accessed by staff?

26) Do you use the data from sensor and technology to reflect on the tenant and input into care plan?

Yes      No

27) The format of the data on the system is illustrated in: (Please circle)

A readable format (Automatically analysed)      Needs to be analysed

28) Can the data give information on:

	Yes	No
Individual tenant's physical activity level		
Give an indication of changes in health status		
Monitor Sleep/ wake pattern		
<b>Other (Please specify)</b>		

If staff can set upper or lower limits (parameters) on the system for when alerts will be sent please answer these questions.

29) Can parameters change on devices to be active at certain times of the day and off at other times?

Yes      No

Please give details \_\_\_\_\_

30) Are members of staff able make adjustments to these parameters to change when the device is active or not?

Yes    No

Please give details \_\_\_\_\_

31) If you have any other comment please feel free to leave it here.

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Thank you for taking the time to complete this technology audit. In the near future we would ask that you take the time to undertake a telephone interview to complete part two of this technical audit. If you have any further questions please feel free to contact Jean ([jean.daly@engagewithage.org.uk](mailto:jean.daly@engagewithage.org.uk)).

## Appendix 11 Technology Audit Part B



Part 2  
Version 1: 8/09/17



### **TESA-DRI: Technology Audit for Housing Schemes**

Thank you for taking the time to complete this technology audit. This is the second part of the technology audit that we will complete over the phone at a time and date that suits you.

1) What security procedures are in place to protect the confidentiality of the data?

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2) Can you outline the security measures in place when the system is accessed?

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3) Is it possible to request reports for different information needs of staff for example can the manager download an overall activity profile for the scheme or could a specific resident?

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4) Is the data presented in a way that makes sense to: (Please circle)  
All staff      trained staff      managers      no staff

5) Data is compiled into: (Please circle)  
Reports      Individual care plans      Is not accessed/ used

Please give details \_\_\_\_\_

6) Have staff received training on the use of technology within the scheme?  
Yes      No

Please give details \_\_\_\_\_

7) Is the tenant asked to consent to the use of technology in their environment?  
Yes      No

Please give details \_\_\_\_\_



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8) Is the family asked to consent to the use of technology in their relatives environment?

Yes                    No

Please give details \_\_\_\_\_

9) Please describe the process of introducing the use of technology to a new tenant.

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10) Please describe the policy and governance involved in the use of technology within the housing scheme.

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11) Was the technology within your scheme a bespoke system that was commissioned or is it commercially available? (Please circle)

Bespoke system      Commercially available

12) If you have any other comment please feel free to leave it here.

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Thank you for taking the time to complete this technology audit. If you have any further questions please feel free to contact Jean ([jean.daly@engagewithage.org.uk](mailto:jean.daly@engagewithage.org.uk)) or Janeet ([j.rondon-sulbaran@ulster.ac.uk](mailto:j.rondon-sulbaran@ulster.ac.uk)).

## Appendix 12 Topic guide interview for participants living with dementia



### **Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

#### **In-depth Interviews with Person with Dementia**

##### **Topic Guide<sup>1</sup>**

The main aim of the interview is to obtain data that relates to:

- Their experience of moving from home into technology enriched supported accommodation.
- What prompted the decision to change the living environment and what feelings and emotions they have experienced during the transition
- What they like and dislike about living in the supported housing option. What works and what needs to be changed or improved about living in TESA.

##### **Introduction**

*Thank you for agreeing to this interview. My name is [researcher introduces him/herself] and this is my colleague [introduction of peer researcher].*

*We are here to listen to your experience living in this technology enriched supported accommodation. We really appreciate you sharing your views and feelings about a person with dementia and their choice of living arrangements. We hope that as a result of this study we can tell health professionals and paid carers, informal carers and other people who have dementia about the advantages and disadvantages of this accommodation incorporating technology.*

*We would like you to tell us about what helps when you are moving from home into this type of environment and what things you have found better or more difficult with your new living situation.*

[Confirm consent and ensure that the participant keeps a copy of the signed form when you have obtained written consent] [Follow the guidelines for process consent if the participant lacks capacity. Revisit consent, as required] [Continue]

##### **General rules and procedures**

[One researcher takes the lead, as agreed prior to the interview. Tell the participant who will be conducting the interview] [Continue].

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<sup>1</sup> In keeping with the qualitative research approach this guide aims to provide an overview for ethical governance of the themes etc. We do not propose major changes but wanted to flag up that in qualitative research it may shift slightly.

*You don't have to answer all the questions. If you feel that you need to stop or leave the room please tell me. If you want to continue after a pause, that would be fine.*

*I will record the interview<sup>2</sup>, so that we capture all you are telling us. However, whatever you tell me will be anonymised for the purposes of the study. The interview will last approximately one hour. After the interview I will ask you to complete with me two short questionnaires. These questionnaires are also anonymised.*

*At the end of the interview, if you have any concerns or complaints about the conduct of the interview, you can contact the chief investigator, my supervisor, on the numbers we have provided on the information sheet. Or you can talk to the scheme manager who will deal with the matter appropriately.*

**Do you have any questions before we begin?**

- 1. Can we talk now about your experience living here (pause). <sup>3</sup>We would like to know about your feelings about living in TESA and what things you find useful. Also, we would like to hear about the things you think need to change or improve to make people with dementia feel supported when they live independently in TESA.**
  - How do you feel about coming to live here?
  - Can you tell me about the flat you live in?
  - Do you spend much time outside the scheme?
  - Have you had much help settling in?
- 2. What about the things you do in the scheme? The friends and activities that you have here or are organised for you by the staff. Can you tell me about that?**
  - What kind of things do you do every day?
  - How do you get on with people here? For example, staff/other tenants
  - What kind of social activities do you have?
  - Does the scheme organise group social activities with the tenants?
  - What about your family and/or friends? Do they visit much?
- 3. Can you tell me a little about the things that are important to you and how people in the scheme respond to them? For example ...**

<sup>2</sup> This will also be highlighted as part of the consent process and revisited. If a person does not consent to the recording it would not exclude them from the study

<sup>3</sup> Pauses will be placed in regularly to enable a response from the participant. We have only posted one for you to note.

- What kind of things does the staff in the scheme help you with?
- Do people here have the time to listen to you?
- Do you feel you are well informed about things within the scheme that matter to you?
- Do you think staff/services respond appropriately to your needs?
- Do you think staff have the right skills and knowledge to support people with dementia in TESA?

***I have finished all the questions. Before we end the interview, is there anything you would like to add that was not included in the questions?***

*Thank you for taking part in the study ... Can we continue with a short questionnaire (put in what this will be in brackets to flag this up for ORECNI) or do you want me to come back later or some other time?*

*Following our initial development these additional prompts were added to the framework to support the peer researchers.*

- Tell me what is like to live here?
- If you need help how do you get it?
- Does anything help you remember your appointments?
- How do you contact your family?
- Have you ever used a computer or iPad?
- Do you have any **technology in your home?** (alarms, alerts on door, calendar, reminders).
- Do you ever wear a **bracelet or necklace** that has an alarm in it you can press in an emergency?
- **Intercom**- how do you feel about it going off? Has anyone ever spoken to them during the night? Do the staff ever come in and check on you?
- Would anything happen at night if you fell/ went for a walk? Have you ever fallen?
- Do you ever hear any alarms going off? Do you know what they are for?
- What would you say to someone if they were thinking of coming to live here?



**TESA-DRI**  
*Technology Enriched Supported Accommodation*



## Art Workshop Guide

### Working with people living with dementia

The TESA DRI (Technology Enriched Supported Accommodation - Dementia Research Initiative 2014-2018) project - explored the experiences of people living with dementia, their family carers and paid carers in supported living environments that use technology to support care. During this research project, art activities were undertaken with over sixty people living with dementia across eight focus groups and what was learned has been used to compile this booklet. This information aims to inform anyone wishing to enhance participation and maximise the abilities of people living with dementia undertaking Visual Arts activities in a community setting.

### Setting up the Art Space

Organisational skills, focusing and maintaining attention can be challenging for people living with dementia. It is important before beginning any artwork to have a workspace that is ordered, with a clearly defined layout for activities and materials.

- A table-cover needs to be plain, not patterned, and secured with a little masking tape. A busy print distracts the eye, and patterns could be mistaken for an object on the table.
- Using a contrasting colour of page and table cover helps keep the artwork within the confines of the paper.
- Set out limited amounts of materials needed for the session, in an appropriate sequence. If drawing is the first activity lay out only the pencils and paper. If paint is to be added, introduce it after the drawing is finished.
- Undertake a Health & Safety check of the venue, including ensuring there are no trip hazards. Make adequate space for tables and chairs for ease of access, and reserve the seats nearest the door for individuals with reduced mobility.
- Good levels of lighting are important. Turn on lights even in daylight hours or plug in extra lighting if required.
- Keep materials and equipment within easy reach and if appropriate place in a small tray or on non-slip matting to prevent them rolling off the table.
- Try to work in a space that will have minimal disruption.

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## Communication

People living with dementia can have difficulty with sequential memory and processing new information. A lot of questions or verbal instruction can be confusing and hard to process so simple instructions are essential.

- Wear a name badge that just has your first name on it and introduce yourself at the start of each session and during the session as necessary.
- Each person is unique and it is important that everyone is given the chance to participate equally and do what they can within their own limitations and boundaries. Always assume capacity to participate, but do be flexible and have additional plans ready. Participation can look differently for everyone from painting a picture to making a mark on a page.
- Speak clearly and use aids to communicate your message for example show the paints you are talking about.
- The session should be guided by the person based on how they are engaging and what their emotional language is telling us. Keep things simple, one step at a time using straightforward language.
- Personal information gained from weekly group conversations, or through informal one to one chat is helpful in order to choose subject matter that the person with dementia can connect with. It can be helpful when a member of staff that knows the individuals are involved in these conversations to stimulate ideas according to personal preferences.
- A slow and steady pace is important. Incorporating a cup of tea mid session connects the activity with a sociable, relaxing experience and enables a rest time for participants.
- Remember to make good eye contact, particularly if a person has a hearing impairment, so that he or she can lip read to aid understanding. Avoid asking direct questions, try to connect with individuals through short sentences.
- Ensure that if someone needs glasses that they are wearing them and hearing aids are used if normally worn.



## Supporting Development

The object of creating artwork with people living with dementia is to enrich life experience, raise self-esteem and have fun. Process is more important than product.

- It is best to keep colours bright and contrasting to enhance the visual experience. Use ready mixed colour to eliminate the need for extra tasks.
- Keep activities short, structured and achievable.
- Singing was often spontaneous when working with groups and we encouraged it to break up activity, enhance enjoyment or diffuse a situation when there was conflict arising.
- An ipad is an invaluable tool in terms of storing images to stimulate memories through conversation or music. A drawing app was also used with great results. A rubber tipped stylus was mistaken for a rubber tipped pencil though, so use a pointed stylus if possible.
- The more support the better the experience for individuals and outcome of the creative activity. Generally, more than one person will be required to support a small group of people engage in the art session.
- Working on individual pieces of artwork can be challenging if attendance is erratic. A group piece is probably more successful because everyone works at a different speed, and can work at their own pace towards a common goal. We found six sessions to be the best time frame to complete a project successfully.
- Observe body language, facial expression and general engagement of participants.



## Additional Tips For Creating Artwork

- Shiny reflective surfaces present problems, and little pieces such as small sequins or beads are best avoided.
- While some people like clay, others find it sticky and difficult to work with. Model Magic can be a cleaner and softer alternative.
- 'Dancing across a page' with a loaded paintbrush in time to music engaged individuals who were finding it difficult to get started.
- Adapt tools and materials when necessary to ensure access for all. Cellotape added to a crayon wrapper will make it stronger and less likely to break, while the foam tube of a hair roller encasing a pencil and taped in place will improve grip in an unsteady hand.
- Experiment with a variety of materials when possible because each material has a different property and appeal. It would be easy to assume someone doesn't like art because they don't like paint. Switching to a different medium such as felt-making or clay work can totally change the experience.
- Sometimes a person with dementia will keep working at a collage or painting not knowing when it's finished or when to stop. Consequently, a completed collage could become buried under a frenzy of additional materials glued on top, or a page end up with a hole in the middle due to over use of a paintbrush. Let the person know when the artwork is complete and by gently introducing the next step of framing or adding the piece to a wall display.



### For further information on the TESA DRI Project contact:

Engage with Age, East Belfast Network Centre, 55 Templemore Avenue, Belfast BT5 4FP  
[www.engagewithage.org.uk](http://www.engagewithage.org.uk) [info@engagewithage.org.uk](mailto:info@engagewithage.org.uk)

Contributors to this leaflet were Jean Daly Lynn, Anna O Kane, Eamon Quinn, Prof Assumpta Ryan, Prof Brendan McCormack and Prof Suzanne Martin.

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## Appendix 14 Topic guide interview for informal caregiver



Topic\_Guide\_Interview\_Informal\_Carer  
Version 2: 04/04/2016

## Appendix B

### **Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

#### **In-depth Interviews with Informal Carer/Friend/Care Partner of Person with Dementia**

##### ***Topic guide<sup>1</sup>***

The main aim of the interview is to obtain the following information:

- Their experience of caring for a person who lives with dementia and has moved from home into technology enriched supported accommodation.
- What prompted the decision to change the living environment and what has been the carer's interaction with support services.
- What they would like to see changed/improved in the delivery of care for people with dementia when they make this transition into TESA.

#### **Introduction**

*Thank you for agreeing to this interview. My name is [researcher introduces him/herself] and this is my colleague [introduction of peer researcher].*

*We are here to listen to your experiences as a carer of a close relative who lives with a diagnosis of dementia and who lives in technology enriched supported accommodation.*

*This interview is about improving our understanding of the needs of people with dementia and their informal carers when the person moves to live from home to an assisted living environment.*

*We would like you to tell us about your experiences during the transition period from home to the supported living environment.*

*As a result of this research we plan to develop a model of care for people with dementia in assisted living environments which is person-centred and which promotes the person's rights and perspectives and respects their choices about suitable accommodation and environments.*

[Confirm consent and ensure that the participant keeps a copy of the signed form] [Continue]

#### **General rules and procedures**

*[One researcher takes the lead, as agreed prior to the interview. Tell the participant who will be conducting the interview] [Continue]. You don't have to answer all the questions. If you feel that you need to stop or leave the room please tell me. If you want to continue after a pause, that would be fine.*

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<sup>1</sup> In keeping with the qualitative research approach this guide aims to provide an overview for ethical governance of the themes etc. We do not propose major changes but wanted to flag up that in qualitative research it may shift slightly.

## Appendix B

*With your permission, I will record the interview, so that we capture all you are telling us. However, whatever you tell me will be anonymised for the purposes of the study. The interview will last approximately one hour.*

*At the end of the interview, if you have any concerns or complaints about the conduct of the interview, you can contact the chief investigator, my supervisor, on the numbers we have provided on the information sheet.*

**Do you have any questions before we begin?**

**1. Can I have some background information about you and your relative living in the scheme?**

- E.g.: age, gender, profession, kinship, former profession of your relative, etc.

**2. Now, can you tell me about your carer role ... Could you tell us in as much detail as possible about your role as a carer before your relative moved into the scheme?**

- What was it like for you?
- How do you remember it?
- What kind of support did you have?
- What kind of support/services did your relative have?
- Do you still consider yourself to be a carer?
- Are you listened to when you express views about care?

**3. I would now like to introduce another topic: the decision about the move to this type of accommodation (with assistive technology).**

- How did you find out about the scheme?
- How did you and your relative arrive at the decision to move into this scheme? What happened?
- How did you experience the transition? What helped/did not help?
- How do you feel your life has changed since your relative moved into the scheme?

**4. Finally, can you talk about how you feel now that your relative has settled to live in TESA?**

## Appendix B

- What is your opinion of this type of accommodation (enriched with technology)?
- How do you judge the care provided here?
- Has your relative expressed any of his/her views about living in TESA?
- How involved are you in your relative's care at present? If not, why not?
- What do you think of your relative's quality of life since he/she has been living in TESA?
- What do you think about the design of the facility?
- Are you aware of technology being used to support the care here?
- If you could make one change to this facility what would it be?
- If a friend asked you about seeking a place for his/her elderly parent here – what would you say?

**Before we finish, is there anything you would like to mention about you or XX living arrangements that we haven't covered during this interview? That is the end of the interview. Thank you.**

## Appendix 15 Information sheet for informal caregiver



Information\_Sheet\_Informal\_Carer  
Version 3: 27/08/2015

### Information Sheet for Informal Carer/Friend of a Person Who Has Dementia

#### **Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

##### **Invitation**

We would like to invite you to take part in our research study because of your expertise as carer for someone with dementia who is living in supported accommodation enriched with technology.

Before you decide whether or not to participate we would like you to understand why the research is being done and what it would involve for you. This participant information sheet is for you to keep. This information explains the purpose, risks and benefits of the research. You can read this information alone or with someone you trust and you can talk to others about the study, if you wish. If you agree to take part, we will ask you to sign a consent form and we will give you a copy of it. If there is anything you are not clear about, we will be happy to explain it to you if you contact us. It is important that you take your time reading this information and understand what is being asked of you before you make a decision. We will give you plenty of time to make up your mind.

Thank you for reading this information!

##### **Who we are**

We are Jean Daly and Janeet Rondón-Sulbarán, researchers from the School of Health Sciences at the Ulster University working in partnership with Engage with Age, an organisation in Belfast that supports older people. We are being supervised by Prof Suzanne Martin, a professor of occupational therapy at Ulster University who has done a lot of work and research in the area of electronic assistive technology integration into health and social care to support people with specific care requirements.

This project has been funded by the Health and Social Care, Research & Development Division of the Public Health Agency from Northern Ireland and also by the Atlantic Philanthropies, an international grant awarding body.

##### **Purpose of the study**

At the moment we are working on a research study with the overall aim to find out about the experience of people who have dementia, their family members/close friends and paid staff who care for them while they are living in supported accommodation enriched with assistive technologies. We are interested in understanding family and informal carers' views on transitioning to and living in this type of accommodation



We want to be able to tell other people experiencing similar circumstances about any changes and what is helpful or unhelpful about living in technology enriched supported accommodation. We would like to gain a better understanding of these issues to help us to highlight families/informal carers' support needs in the future, and to replicate what works in other technology enriched settings for people who have dementia. In order for our research to be useful, it is important to hear the views and opinions of as many carers as possible so that we can get the broadest possible perspective.

#### **Why have I been approached?**

We would like to invite you to take part in our research study because of your expertise as carer for someone with dementia who is living in supported accommodation enriched with technology.

#### **Do I have to take part?**

No, participation in the study is voluntary. It is up to you to decide whether or not to take part. If you decide to participate, you will be given this information sheet to keep and you should return the consent form included in this information pack.

#### **What happens if I change my mind?**

You are free to change your mind at any time even if you have first decided to take part. You just have to let us know if you have changed your mind and decided not to participate. You do not have to tell us why. If you decide to take part you can still withdraw at any time and without giving any reason.

#### **How do I take part?**

If you are willing to participate you should return the consent form included in this information pack in the SAE provided. Then, one of the researchers, Jean Daly or Janeet Rondón-Sulbarán will contact you to arrange an interview at a time and place convenient to you. We would like you to contact us within two weeks of receipt of this letter to let us know your decision. You will be asked to provide a contact number where we can reach you. Only the researchers will have access to your contact details so confidentiality is guaranteed.

#### **What will I have to do if I decide to take part?**

If you decide to take part in the study we will be asking you to participate in an in-depth interview. There will be only one researcher from the Ulster University present at this interview (Jean Daly or Janeet Rondón-Sulbarán). She will be asking you questions about your experience caring for your relative/friend who has

dementia and what happened during their transfer to technology enriched supported accommodation. We are also interested in knowing about what your life and that of your relative is like at present and would like to hear your opinion about technology enriched supported accommodation. We would like to be able to discuss what you think it is helpful or unhelpful about this type of accommodation.

We will have some questions for you to open-up the conversation and that will help you describe your experiences.

At the end of the interview the researcher will use a questionnaire to gather information about the impact that some symptoms related to your relative's illness is having on your life at that moment. Alternatively, you can do this on your own by filling in a paper-based questionnaire that we will provide which you can return in the post to us in a self-addressed envelope provided.

You will be reminded of the date of the interview on the phone/mobile.

#### **How long will my part in the study last?**

The interview will last approximately one hour and the completion of the questionnaire will take about 15 minutes (1:15hrs) – maximum one hour and 30 minutes (1:30hrs).

#### **Will my taking part be kept confidential?**

All information provided by you will be kept confidential at all times, except in case that you disclose information that may be considered to pose a threat of harm to yourself or others.

The researchers, Jean and Janeet, will use a digital recorder during the interview so that we can capture exactly what you say. It is OK to refuse this, however, you have to be aware that the researcher then will be taking notes during the conversation.

All responses to our questions and information obtained from you will be anonymised. We will use an identity code on any files or a pseudonym on any quotations to protect your identity. No personal details or information that may identify you will be recorded anywhere. Only members of the research team (Jean, Janeet or Prof Suzanne Martin) will have access to the information you provide or the list that connects your identity code or pseudonym to your name. All files will be kept in a locked cabinet in the offices of the research team on the Jordanstown campus of the Ulster University. Your anonymity and confidentiality will be safeguarded at all times during this study.

**What are the benefits of taking part?**

It is hoped that with your participation you will provide us with invaluable information about caring for a relative who has dementia and their transfer to live in technology enhanced supported accommodation and how you have dealt with and coped in these circumstances.

What we find out from these interviews will help health and social care services providers in the future development of appropriate services for people who have dementia and their carers (informal and formal/paid). The study will result in a care model for paid carers who support people with dementia who live in accommodation fitted with assistive technology. However, it is unlikely that there will be any direct benefit to you personally from taking part in this research, but your views are very important to us.

**What are the possible disadvantages and risks of taking part?**

We have to make you aware of the fact that during the interviews you will be discussing your lived experience of caring for someone who has dementia. You may feel uncomfortable or upset by this. If this happens you should let the researcher know immediately. You do not have to answer all the questions and you will be free to ask for breaks or to withdraw from the study at any time during the interview.

After the interview you may like to talk to someone about any issues prompted by the session. Should this be the case, you can contact the Alzheimer's Society Northern Ireland on 0300 222 11 22 or email: [nir@alzheimers.org.uk](mailto:nir@alzheimers.org.uk). If you feel that you need urgent need of professional support, please see your GP, who will be able to arrange appropriate help for you. Alternatively, please, feel free to raise this with our chief investigator, Prof. Suzanne Martin (see details below), who will respond to your worries or concerns in an appropriate manner.

**What happens at the end of the study?**

All interviews will be transcribed verbatim, that is, everything that has been audio recorded will be typed to accurately preserve what you have said. All the information will be anonymised using codes and then analysed. The data will be analysed by the researchers who will identify common themes and will present them in a coherent and comprehensive manner. They will write this up in reports, academic papers and presentations at conferences. Your anonymity and confidentiality will be safeguarded at all times.

**What happens if I change my mind during the study?**

You can withdraw from the study at any time without giving any reason. That will not affect your human rights in any way. If this happens after you have given an interview, we will ask for your consent to use the information collected from you to be included in the study.

**Further information**

In order to protect your interests, this study has been reviewed independently by a national research ethics committee. It was given a favourable opinion on 28/08/15 by the Office of Research Ethics Committee in Northern Ireland (ORECNI).

If you have any queries or concerns about this study you can contact Prof Suzanne Martin or you can contact the Research Ethics and Governance Office of the Ulster University and speak to Nick Curry, Senior Administrative Officer: Room 01H12, Research Office, Ulster University, Newtownabbey, BT37 0QB, T: +44 (0)28 9036 6629, E: [n.curry@ulster.ac.uk](mailto:n.curry@ulster.ac.uk)

If you do decide to take part, please contact Jean or Janeet (the researchers) on the telephone or e-mail addresses provided below. Also available below are contact details of the chief investigator (Prof Suzanne Martin) responsible for the monitoring and management of the research. You can contact her at any time regarding any complaints you may have about the conduct of the research, should you decide to take part.

<b>Researchers:</b>	<b>Chief Investigator:</b>
<p><b>Janeet Rondón-Sulbarán</b>            Ulster University            School of Health Sciences            Shore Road            Room 01D110            Newtownabbey            County Antrim            BT37 0QB            T: +44 (0)28 9036 8729            E: <a href="mailto:j.rondon-sulbaran@ulster.ac.uk">j.rondon-sulbaran@ulster.ac.uk</a></p>	<p><b>Prof Suzanne Martin</b>            Professor of Occupational Therapy            Ulster University            School of Health Sciences            Shore Road            Room 01B114            Newtownabbey            County Antrim            BT37 0QB            T: +44 (0)28 9036 6976            E: <a href="mailto:s.martin@ulster.ac.uk">s.martin@ulster.ac.uk</a></p>
<p><b>Jean Daly</b>            Engage with Age            55 Templemore Avenue            Belfast            BT5 4FP            T: +44 (0)28 9073 5696            E: <a href="mailto:jean.daly@engagewithage.org.uk">jean.daly@engagewithage.org.uk</a></p>	

## Appendix 16 Consent form for informal caregiver



Consent Form Informal Carer  
Version 2: 30/06/2015

### Consent Form for Informal Carer/Friend Carer

**Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

**Participant Code:**  
NTB/IC-F/30/

Please initial box

1. I confirm that I have read and understand the information sheet (Version 3: 27/08/2015) that I received for the above study
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal and human rights being affected
4. I understand that data collected during the study may be looked at by the researchers and I agree to anonymised and unidentifiable data from me being included in research reports, publications and related presentations
5. I agree to take part in the study

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Name of Participant  
Contact Number:

Date

Signature

---

Name of Person  
taking consent

Date

Signature

When completed: original for researcher site file and one copy for participant



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## **<sup>1</sup>Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

**In-depth Interviews with Paid Staff Caring for a Person with Dementia Living in Technology Enriched Supported Accommodation**

### **Topic guide**

The main aim of the interview is to obtain the following information:

- Their experience of caring for a person who lives with dementia in technology enriched supported accommodation.
- Their attitudes and beliefs related to assistive technology and people who are living with dementia.
- Their views and experience of working collaboratively/in partnership with other agencies and involving informal carers.
- Their experience of implementing an effective and appropriate model of care.

### **Introduction**

*Thank you for agreeing to this interview. My name is [researcher introduces him/herself] and this is my colleague [introduction of peer researcher].*

*We are here to listen to your experiences as a paid carer of a person who lives with a diagnosis of dementia and who lives in technology enriched supported accommodation.*

*This interview is about improving our understanding of the needs of people living with dementia and their transition from home to an assisted living environment.*

*As a result of this study we plan to develop an optimal model of care for people with dementia living in technology enriched accommodation.*

*[Confirm consent and ensure that the participant keeps a copy of the signed form] [Continue]*

### **General rules and procedures**

*[One researcher takes the lead, as agreed prior to the interview. Tell the participant who will be conducting the interview] [Continue]. You don't have to answer all the questions. If you feel that you need to stop or leave the room please tell me. If you want to continue after a pause, that would be fine.*

---

<sup>1</sup> In keeping with the qualitative research approach this guide aims to provide an overview for ethical governance of the themes etc. We do not propose major changes but wanted to flag up that in qualitative research it may shift slightly.

## Appendix C

*I will record the interview, so that we capture all you are telling us. However, whatever you tell me will be anonymised for the purposes of the study. The interview will last approximately one hour.*

*At the end of the interview, if you have any concerns or complaints about the conduct of the interview, you can contact the chief investigator, my supervisor, on the numbers we have provided on the information sheet.*

### **Do you have any questions before we begin?**

#### **1. Can you tell us a bit about yourself?**

Qualifications, years of experience, length of time working in the scheme, current position, hours (FTE), brief description of role ...

#### **2. Now, can we talk about your work here ...**

- Can you describe in as much detail as possible your working day?
- Do you remember an occasion when one of the tenants has just entered the scheme? Could you tell me about that?

*Following the answer to this question, probing will continue on the role of technology by asking:*

- *What happened with the planning of their care and activities? Was technology a part of it?*
- *How involved were the family members in the move?*

#### **3. Can we talk about the things the scheme does to ensure that tenants are settled in and adapt to their new living situation?**

- How do you believe the scheme supports quality of living and wellbeing for the tenants?
- Do you find assistive technology helpful? (...) could you expand on that?

#### **4. Can we shift the conversation, to the topic of working in partnerships and involving family members/informal carers?**

- Who are the main agencies involved in delivering this scheme (housing/health/voluntary).
  - What do you think about this?
  - Does it work? If it could be better, how?
  - What are the biggest challenges around partnership?
  - Do you see any value in working together with other agencies/bodies involved in the care of the tenants? How do you consider this issue?
- How do you perceive the involvement of families/informal carers/friends in the care of tenants?

## Appendix C

- Does it happen? What helps it happen?
- If a family is very involved, how do you deal with that?
- If a family member is remote and doesn't really engage – how do you deal with that?
- What do you do to ensure that you communicate effectively with the tenants?
- What do you do to ensure that you communicate effectively with the tenants and their families?
- What would you do differently about partnership working?

**5. Finally, can we talk a little bit about how you feel about your practice and the needs of staff working in this environment ...**

- Do you feel you have the necessary skills, knowledge and training to work in this environment? *Please expand*
- Can you describe a situation in which you have felt personally and professionally satisfied with your job? *Have you experienced the opposite? Would you like to expand on that ...?*

*The answer to the above question may lead to a conversation on their views on ways to improve, enhance or develop services in this area. Probe as necessary*

***That is the end of the interview. Thank you. However, would you like to add anything else that you think it is important and we did not include in the questions?***

## Appendix 18 Information sheet for formal caregiver



Information\_Sheet\_Paid\_Staff  
Version 3: 27/08/2015

### Information Sheet for Paid Staff

#### **Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

##### **Invitation**

We would like to invite you to take part in our research study because you are paid staff working in a supported housing scheme providing accommodation for older people who have dementia and your facilities have been equipped with assistive technologies.

Before you decide whether or not to participate we would like you to understand why the research is being done and what it would involve for you. This participant information sheet is for you to keep. This information explains the purpose, risks and benefits of the research. If you agree to take part, we will ask you to sign a consent form and return it to us. If there is anything you are not clear about, we will be happy to explain it to you. It is important that you take your time reading this information and understand what is being asked of you before you make a decision. We will give you plenty of time to make up your mind.

Thank you for reading this information!

##### **Who we are**

The research is being conducted by the Ulster University working in partnership with Engage with Age. The chief investigator is Prof Suzanne Martin, professor of occupational therapy at Ulster University who has done a lot of work and research in the area of electronic assistive technology integration into health and social care to support people with specific care requirements. This project has been funded by the Health and Social Care, Research & Development Division of the Public Health Agency from Northern Ireland and also by the Atlantic Philanthropies.

##### **Purpose of the study**

The overall aim of this study is to understand the lived experience of older people with dementia who live in technology enriched supported accommodation. We have a focus on their views and those of family members/close friends and paid staff who care for an older person who has dementia and lives in this type of accommodation. Supported accommodation is an alternative home for people with dementia when they can no longer live at home. Some supported housing now use digital alarms with sensors in the flats to let staff know how people are managing within their own place. Some schemes like this have existed in Northern Ireland for over ten years, supporting people with dementia and their families, however, we know very little about their impact.



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In this study we want to talk to the staff caring for them formally. We want to explore and understand the knowledge, skills, understanding and attitudes that paid staff have towards working in a technology enriched supported model. We would like to understand the advantages and disadvantages of a technology enriched support housing model from the perspective of paid staff; what works and what does not. Your expertise and insights that we can gain from you will make an invaluable contribution in informing this complex subject, as well as helping us establishing good practice.

**Why have I been approached?**

We would like to invite you to take part in our research study because of your expertise as carer for someone with dementia who is living in supported accommodation enriched with technology.

**Do I have to take part?**

No, participation in the study is voluntary. It is up to you to decide whether or not to take part. If you decide to participate, you will be given this information sheet to keep and you should return the consent form included in this information pack.

You are free to change your mind at any time even if you have first decided to take part. You just have to let us know if you have changed your mind and decided not to participate. You do not have to tell us why. If you decide to take part you can still withdraw at any time and without giving any reason.

**How do I take part?**

If you are willing to participate you should return the consent form included in this information pack in the SAE provided. Then, one of the researchers, Jean Daly or Janeet Rondón-Sulbarán will contact you to arrange an interview at a time and place convenient to you. We would like you to contact us within two weeks of receipt of this letter to let us know your decision. You will be asked to provide a contact number where we can reach you. Only the researchers will have access to your contact details so confidentiality is guaranteed.

**What will I have to do if I decide to take part?**

If you decide to take part in the study we will be asking you to participate in an in-depth interview. There will be only one researcher from the Ulster University present at this interview (Jean Daly or Janeet Rondón-Sulbarán). She will be asking you questions about your experience caring for people who have dementia and what happened during their transfer to technology enriched supported accommodation. We are also interested in knowing about the model of care implemented in your organisation and your understanding and attitudes towards working in a technology enriched supported housing model. We would like to be able

to discuss what you think it is helpful or unhelpful and find out about the needs of staff who work in this care environment. We will have some questions for you to open-up the conversation and that will help you describe your experiences.

At the end of the interview the researcher will use a questionnaire to gather information about the impact of technology and staff satisfaction. Alternatively, you can do this on your own by filling in a paper-based questionnaire that we will provide which you can return in the post to us in a self-addressed envelope provided. Also, all staff working in your scheme will be asked to complete an online questionnaire on the experience of caring for a person with dementia living in technology enriched supported accommodation. You will be reminded of the date of the interview on the phone/mobile.

**How long will my part in the study last?**

The interview will last approximately one hour and the completion of the questionnaires will take about 30 minutes (1:30hrs) – maximum one hour and 45 minutes (1:45hrs).

**Will my taking part be kept confidential?**

All information provided by you will be kept confidential at all times, except in case that you disclose information that may be considered to pose a threat of harm to yourself or others.

The researchers, Jean and Janeet, will use a digital recorder during the interview so that we can capture exactly what you say. It is OK to refuse this, however, you have to be aware that the researcher will be taking notes during the conversation.

All responses to our questions and information obtained from you will be anonymised. We will use an identity code on any files or a pseudonym on any quotations to protect your identity. No personal details or information that may identify you will be recorded anywhere. Only members of the research team (Jean, Janeet or Prof Suzanne Martin) will have access to the information you provide or the list that connects your identity code or pseudonym to your name. All files will be kept in a locked cabinet in the offices of the research team on the Jordanstown campus of the Ulster University. Your anonymity and confidentiality will be safeguarded at all times during this study.

**What are the benefits of taking part?**

It is hoped that by participating in the study you will be sharing your experiences about caring in a professional capacity for a person who has dementia and their transfer to live in technology enhanced supported

accommodation. We would gain a better understanding of staff needs and appropriate models of care to support independence and quality of life for people with dementia.

What we find out from these interviews and questionnaires will help health and social care services providers in the future development of appropriate services for people who have dementia and their carers. The study will result in a care model for paid carers who support people with dementia who live in accommodation fitted with assistive technology. However, there is unlikely to be any direct benefit to you personally from taking part in this research, but your views are very important to us.

**What are the possible disadvantages and risks of taking part?**

We have to make you aware of the fact that during the interviews you will be discussing the lived experience of caring for someone who has dementia and of living with dementia in supported accommodation. You may feel uncomfortable or upset by this. If this happens you should let the researcher know immediately. You do not have to answer all the questions and you will be free to ask for breaks or to withdraw from the study at any time during the interview.

After the interview you may like to talk to someone about any issues prompted by the session. Please, feel free to raise them with our chief investigator, Prof. Suzanne Martin (see details below), or with your line manager. Either of them will respond to any of your concerns in an appropriate manner.

**What happens at the end of the study?**

All interviews will be transcribed verbatim, that is, everything that has been audio recorded will be typed to accurately preserve what you have said. We will enter data into data analysis software. All the information will be anonymised using codes and then analysed. Qualitative data will be analysed by the researchers who will identify common themes and will present them in a coherent and comprehensive manner. Quantitative data will be analysed for descriptive and analytical statistics, if possible. We will write-up the results in reports, academic papers and presentations at conferences. Your anonymity will be safeguarded at all times.

**What happens if I change my mind during the study?**

You can withdraw from the study at any time without giving any reason. That will not affect your human rights in any way. If this happens after you have given an interview, we will ask for your consent to use the data collected from you to be included in the study.

#### Further information

In order to protect your interests, this study has been reviewed independently by a national research ethics committee. It was given a favourable opinion on 28/08/15 by the Office of Research Ethics Committee in Northern Ireland (ORECNI).

If you have any queries or concerns about this study you can contact Prof Suzanne Martin or you can contact the Research Ethics and Governance Office of the Ulster University and speak to Nick Curry, Senior Administrative Officer: Room 01H12, Research Office, Ulster University, Newtownabbey, BT37 0QB, Tel: +44 (0)28 90366629, e-mail: [n.curry@ulster.ac.uk](mailto:n.curry@ulster.ac.uk). For further advice on participation in research contact the Public Health Agency Northern Ireland, Personal and Public Involvement on 0300 5550114.

If you do decide to take part, please return the consent form in the SAE provided. Also available below are contact details of the chief investigator (Prof Suzanne Martin) responsible for the monitoring and management of the research. You can contact her at any time regarding any complaints you may have about the conduct of the research, should you decide to take part.

<u>Researchers:</u>	<u>Chief Investigator:</u>
<b>Janeet Rondón-Sulbarán</b> Ulster University School of Health Sciences Shore Road Room 01D110 Newtownabbey County Antrim BT37 0QB T: +44 (0)28 9036 8729 E: <a href="mailto:j.rondon-sulbaran@ulster.ac.uk">j.rondon-sulbaran@ulster.ac.uk</a>	<b>Prof Suzanne Martin</b> Professor of Occupational Therapy Ulster University School of Health Sciences Shore Road Room 01B114 Newtownabbey County Antrim BT37 0QB T: +44 (0)28 9036 6976 E: <a href="mailto:s.martin@ulster.ac.uk">s.martin@ulster.ac.uk</a>
<b>Jean Daly</b> Engage with Age 55 Templemore Avenue Belfast BT5 4FP  T: +44 (0)28 9073 5696 E: <a href="mailto:jean.daly@engagewithage.org.uk">jean.daly@engagewithage.org.uk</a>	

## Appendix 19 Consent form for formal caregiver



Consent\_Form\_Paid\_Staff  
Version 2: 30/06/2015

**Participant Code:**  
NTB/PS/30/

### Consent Form for Paid Staff

**Study Title: Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)**

**Please initial box**

1. I confirm that I have read and understand the information sheet (Version 3: 27/08/2015) that I received for the above study
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal and human rights being affected
4. I understand that data collected during the study may be looked at by the researchers and I agree to anonymised and unidentifiable data from me being included in research reports, publications and related presentations
5. I agree to take part in the study

Name of Participant  
Contact Number:

Date

Signature

Name of Person  
taking consent

Date

Signature

When completed: original for researcher site file and one copy for participant

**HSC** Public Health  
Agency  
Research and Development

Engage  
with Age

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Philanthropies

## Appendix 20 Attitudes towards technology survey informal caregivers



Version 6: 18/11/2016



### Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)

Thank you for taking the time to complete this survey. We are exploring the role that technology has in supporting people living with dementia within supported housing schemes.

When we use the word 'technology' or 'assistive technology' we are referring to any electronic device that supports the tenant and/or caregiver within their living environment to maintain independence and quality of life. This includes pull cord alarms, wearable pendants and alarms, easy to use telephones, sensors like those used in the bed or chair to detect movement, intercom system, cooker monitors, memory aids and many more.

By completing this survey, you are indicating that you consent to take part in this phase of the study. All responses are entirely anonymous. As there is no way to identify the person who completed the questionnaire it is not possible to withdraw from the survey once you have submitted your completed form.

If you would like any further details or clarification, before you decide whether to complete the questionnaire, please contact Jean ([jean.daly@engagewithage.org.uk](mailto:jean.daly@engagewithage.org.uk)) or Janeet ([j.rondon-sulbaran@ulster.ac.uk](mailto:j.rondon-sulbaran@ulster.ac.uk)).

#### 1. Are you: (Please tick)

Male  Female  Prefer not to disclose

#### 2. Which housing scheme does your relative or friend live in? (Please circle)

Cuan Court      Hemsworth Court      Mullan Mews      Sevenoaks  
Spelga Mews      St Paul's Court      Sydenham Court      The Brook

#### 3. How many years have you been a caregiver for your relative or friend who is living in the above scheme? \_\_\_\_\_

#### 4. What is your age range? (Please circle)

Under 25 25- 34 35- 44 45- 54 55- 64 65-74 75-84 Over 84

*As you move through this survey please consider the type of technology within the housing scheme your loved one is living in.*



5. Are there any advantages to the use of technology in supporting your relative or friend?

Yes  No

Please explain the reason for your answer:

---

---

6. Are there any disadvantages to the use of technology in supporting your relative or friend?

Yes  No

Please explain the reason for your answer:

---

---

7. Did the technology used within the scheme influence your decision to support your friend or relative to move into this scheme?

Yes  No

Please comment:

---

---

8. Do you think tenants should have access to internet within the scheme?

Yes  No  Don't know

Please comment:

---

---

9. Do you think staff should have access to internet within the scheme?

Yes  No  Don't know

Please comment:

---

---

10. Do you see anything in the living area that would make you aware of technology within the scheme?

Yes  No  Don't know

Please comment:

---

---

5. Are there any advantages to the use of technology in supporting your relative or friend?

Yes  No

Please explain the reason for your answer:

---

---

6. Are there any disadvantages to the use of technology in supporting your relative or friend?

Yes  No

Please explain the reason for your answer:

---

---

7. Did the technology used within the scheme influence your decision to support your friend or relative to move into this scheme?

Yes  No

Please comment: \_\_\_\_\_

---

8. Do you think tenants should have access to internet within the scheme?

Yes  No  Don't know

Please comment: \_\_\_\_\_

---

9. Do you think staff should have access to internet within the scheme?

Yes  No  Don't know

Please comment: \_\_\_\_\_

---

10. Do you see anything in the living area that would make you aware of technology within the scheme?

Yes  No  Don't know

Please comment: \_\_\_\_\_

---

In this section you will be asked to rate your opinion about the role of technology from strongly agree to strongly disagree.

**11. Technology enables the tenant to be more independent in their own living environment.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**12. A tenant living in the scheme has less human (face-to-face) contact with staff because of technology.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**13. Technology enhances the quality of care provided in the scheme.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**14. Technology reduces my relative/ friend's privacy.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**15. Each tenant should consent to the use of technology.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**16. I trust the use of technology in the care of people living with dementia.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**17. The tenant's safety is more important than their right to privacy.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**18. Safety and security of the tenant is not increased through the use of technology.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**19. The use of technology has no benefit in supporting the tenant.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

If there is anything else you would like to tell us please write it here:

---

---

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---

---

Thank you for taking the time to complete this survey

## Appendix 21 Attitudes towards technology survey formal caregivers



Version 6: 18/11/2016



### Technology Enriched Supported Accommodation – A Study into the Lived Experience of Older People with Dementia and Their Carers (TESA-DRI)

Thank you for taking the time to complete this survey. We are exploring the role that technology has in supporting people living with dementia within supported housing schemes.

When we use the word 'technology' or 'assistive technology' we are referring to any electronic device that supports the tenant and/or caregiver within their living environment to maintain independence and quality of life. This includes pull cord alarms, wearable alarms, easy to use telephones, sensors like those used in the bed or chair to detect movement, intercom system, cooker monitors, memory aids and many more.

By completing this survey, you are indicating that you consent to take part in this phase of the study. All responses are entirely anonymous. As there is no way to identify the person who completed the questionnaire it is not possible to withdraw from the survey once you have submitted your completed form.

If you would like any further details or clarification, before you decide whether to complete the questionnaire, please contact Jean ([jean.daly@engagewithage.org.uk](mailto:jean.daly@engagewithage.org.uk)) or Janeet ([j.rondon-sulbaran@ulster.ac.uk](mailto:j.rondon-sulbaran@ulster.ac.uk)).

#### 1. Are you (Please tick)

Male  Female  Prefer not to disclose

#### 2. What is the name of the housing scheme you work in? (Please Circle)

Cuan Court	Hemsworth Court	Mullan Mews	Sevenoaks
Spelga Mews	St Paul's Court	Sydenham Court	The Brook

#### 3. How long have you been working as a paid caregiver in the above housing scheme? \_\_\_\_\_

#### 4. What is your age range? (Please circle)

Under 25 25- 34 35- 44 45- 54 55- 64 65-74 75-84 Over 84

*As you move through this survey please consider the type of technology within the housing scheme you are working in.*



5. Are there any advantages to using technology in support of your role?

Yes

No

Please explain the reason for your answer:

---

---

6. Are there any disadvantages to using technology in support of your role?

Yes

No

Please explain the reason for your answer:

---

---

7. Have you taken part in training in the use of technology systems and devices?

Yes

No

If yes, please describe \_\_\_\_\_

---

8. Does technology impact on your caring role?

Yes

No

Please comment: \_\_\_\_\_

---

9. Do you think tenants should have access to internet within the scheme?

Yes

No

Don't know

Please comment: \_\_\_\_\_

---

10. Do you think staff should have access to internet within the scheme?

Yes

No

Don't know

Please comment: \_\_\_\_\_

---

11. Do you see anything in the living area that would make you aware of technology within the scheme?

Yes  No  Don't know

In this section you will be asked to rate your opinion about the role of technology from strongly agree to strongly disagree.

**12. Technology enables the tenant to be more independent in their own living environment.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**13. A tenant living in the scheme has less human (face-to-face) contact with staff because of technology.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**14. Technology enhances the quality of care provided in the scheme.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**15. Technology reduces the tenant's privacy.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**16. Each tenant should consent to the use of technology.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**17. I trust the use of technology in the care of people living with dementia.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**18. The tenant's safety is more important than their right to privacy.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**19. Safety and security of the tenant is not increased through the use of technology.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

**20. The use of technology has no benefit in supporting the tenant.**

Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

If there is anything else you would like to tell us please write it here:

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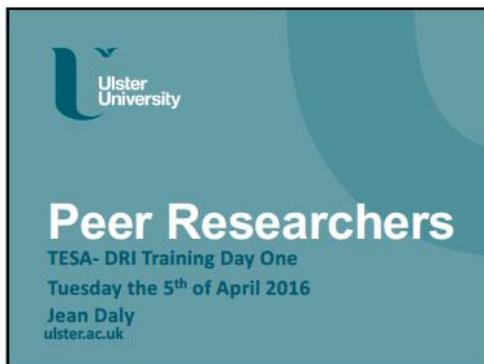
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Thank you for taking the time to complete this survey

## Appendix 22 Peer researcher training programme



### Introduction

Welcome to the training...

Day one of two training days

Housekeeping



### Outline of the day

Day 1

- 10:00 - Tea/ coffee
- 10:15 - TESA-DRI & Role of peer researcher
- 11:30 - Comfort break
- 11:45 - Exploring the experience of living with dementia
- 12:30 - Lunch
- 1:00 - Communication skills
- 2:00 - Close session



### Group Contract

How can we make this group safe and comfortable for you to contribute honestly and get the most from it?



## Research Activity

- What does the term research mean to you?



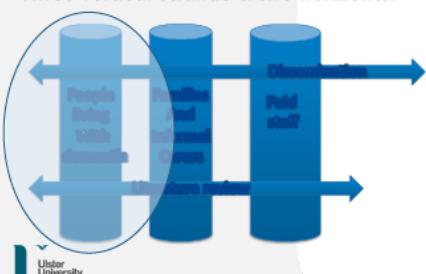
## Our purpose in TESA-DRI:

To explore the perspectives of **people with dementia** who live in person-centred, **technology** enriched housing schemes, and the opinions of their **family** and the **paid employees** at the facilities.



## Overall approach

Three vertical strands & two horizontal



## People Living with Dementia



Views on technology and how living at the facility helps with addressing loneliness or connected/feelings of wellness, contentment/sense of home, place and belonging/organisation of care/respondiveness of staff and services.

## Location of the Research



## What is a Peer Researcher?

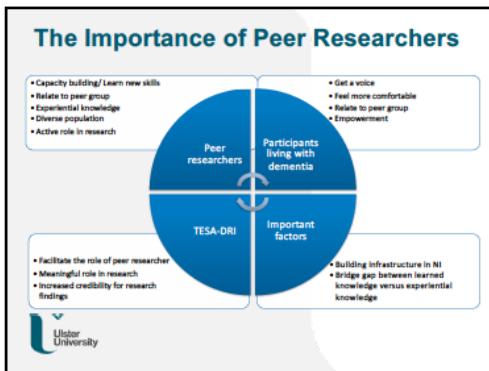
A person who...

Brings lived experiences to research

Relates to the experiences of the participant group

Belongs to the same peer group

Provides safety for participant



## Your Role within TESA-DRI

Co-researcher

*Interview a person living with dementia with a TESA researcher*

**Facilitator within a focus group**

Support the team understand the results

Tell us about your experience as a peer researcher



**Your expectations**

**Activity**

What would you like to achieve in your role as a peer researcher?

What do you need to get from this training to fulfill your role?



## Key Terms to Understand

Group Activity

Assistive technology

Telecare

Housing scheme

Technology enriched housing scheme

Person centred care



**Comfort Break**



## What is dementia

### Activity

Explore the knowledge of the group on the subject. Use the *Fact and Fiction Quiz*:

- Did you correctly separate fact from fiction?
- Did anything surprise you?



## 1. Confusion in older people is usually an indication of dementia

There are many causes of confusion, most of which are treatable. Sudden or acute confusion is called delirium. It can be caused by a physical health problem, such as an infection or constipation. Depression is another common cause of confusion in older people. Confusion can also result as a side effect of medication, or a change of environment or circumstance, such as moving home or the death of a partner.



## 2. Dementia is a normal part of the ageing process

Most older people do not develop dementia. Over the age of 80, less than 20 per cent of people have dementia. Many older people do find that their memory is not as good as it used to be, but dementia involves much more than a slight memory impairment. Therefore dementia is not a normal result of aging, but rather is the result of a disease such as Alzheimer's. There are over 100 diseases that can cause dementia.



## 3. Dementia only affects old people

While the prevalence of dementia does increase with age, many younger people also develop dementia. The more common types of dementia, including Alzheimer's disease and vascular dementia, are more likely to affect older people, but some less common dementias are just as likely to affect people at a younger age. Younger people developing dementia may face some particularly difficult issues, for example in relation to having to give up work or coping with a young family.



## 4. Difficulty retaining memories of recent events is often one of the first symptoms of dementia

In many types of dementia, a worsening in the ability to retain information is one of the first symptoms noticed. The person may, for instance, frequently forget where they have put things, or have no memory of a conversation they engaged in earlier. Some dementias, though, follow a different course and other symptoms appear first.



## 5. Physical damage to the brain occurs in dementia

Dementia is an 'organic' disorder – this means a condition in which physical impairment is present. Areas of the brain progressively affected usually include the temporal, parietal and frontal lobes. These lobes of the brain control functions such as memory, recognition, sequencing of actions, verbal communication, and regulating behaviour. Difficulties with these functions are therefore likely to arise from the physical damage occurring in dementia.



## 6. Difficulties experienced by people with dementia are sometimes preventable

While the symptoms caused by physical damage to the brain are not preventable, many people with dementia also experience difficulties that are caused by preventable factors. For example, if a person is deprived of communication, they may become withdrawn. The withdrawal is not a symptom of their brain damage, and could have been prevented. Pain and ill-health can also cause many difficulties, including those which could be mistaken for symptoms of dementia.



## Alzheimer's Society Factsheet

alzheimers.org.uk  
Alzheimer's Society

### What is dementia?

This factsheet explores what dementia is, including the causes and symptoms, and how it is diagnosed and treated. It also looks at some of the ways in which dementia can affect people.

The word dementia describes a set of symptoms that usually include memory loss and difficulties with thinking, problem-solving or language. These symptoms are severe enough to affect someone with dementia they have become aware enough to affect day-to-day life and the ability to work or manage their affairs.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or vascular dementia. These diseases are the most common cause of dementia but not all dementia is due to disease. In some cases, dementia can be caused by other factors. The experience will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

### Symptoms

Everyone's a unique and will experience dementia in their own way. The different types of dementia tend to affect people differently, especially in the early stages. How others respond to the person, and how they are supported, can affect the person's experience. This leaflet aims to help you understand what to expect.

A person with dementia will have cognitive symptoms (problems with memory and thinking). They will often have problems with some of the following:

## What is dementia?

### Available at:

<http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx>  
(01:37).

NHS Choices. Your health, your choices



## Living with Dementia

### Available at:

<http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-choices.aspx>  
(05:02)

NHS Choices. Your health, your choices



## Dementia

### Importance of Diagnosis



- Cognitive deficits typically seen in dementia
  - Memory
  - Language
  - Executive functioning and attention
  - Problem solving skills
  - Visual-spatial perception and visual processing
  - Speed of information processing
- Variation in cognitive deficits between sub-types of dementia
  - Alzheimer's: gradual, memory, disorientation, word finding, judgment
  - Vascular: memory, disorientation, 'fit' emotion, mobility challenges, fits, incontinence
  - Levy body: changes in alertness, muscle stiffness, tremor, hallucinations, falls, incontinence
  - Frontotemporal: language, behaviour, personal awareness (hygiene, etc.), planning



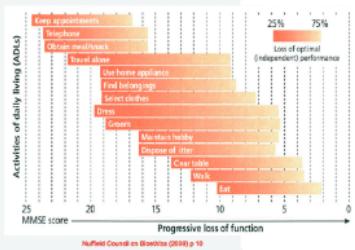
## Stages of Dementia

### Stages of Alzheimer's: exemplars

Early stage	Moderate stage	Severe stage
Forgetfulness, e.g. of names	Increasingly forgetful, e.g. of names	Difficulty eating, swallowing
Loosing thread of conversation	Increased disorientation, becoming lost	Incontinence
Loss of interest in people or activities	Increased risk events e.g. getting lost in unit	Loss of speech
Blaming others for missing items, unable to adapt to change	Making day and night, getting lost in nightclothes	Unable to recognize familiar objects or surroundings
Difficult & unable over difficultly managing tasks	Marked repetition in conversation	Considerable weight loss



## Impact on Activities of Daily Living



## Living with Dementia

<https://www.youtube.com/watch?v=Fz8ACEu7Lho>



Small changes make a dementia friendly community- Alzheimer's Society

## Discussion Point

- Do you have any questions?
- Has anybody had the experience of caring for a relative/someone with dementia?



## LUNCH BREAK

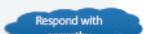
30 minutes

From 12:30 to 1:00



## Communication Skills

How can we communicate in the best way possible to help us engage with a person living with dementia?



## Communication Skills

Communication can be difficult because of:

- memory loss
- difficulty forming ideas
- difficulty understanding
- difficulty with verbal expression

Each and every person experiences this differently



## Communication and living with Dementia

<https://www.youtube.com/watch?v=mmcBmvUXScl&feature=related>



## Communication & living with dementia

### Remembering

Forget beginning of sentence/ conversation

### Understanding

What are we saying?  
Sounds like unfamiliar language

### Finding words

Difficulty finding words  
Might use descriptions instead of word



## Communication Skills- helpful tips

### Remembering, Understanding & Finding words

Keep sentences brief and to the point  
Limited choices  
Simple words  
Face the person  
No background noises  
Limit where the information is coming from



## Person Centred Communication

Respecting

Recognising

Valuing

Trusting

Listening

Acknowledging

Empowering

Remembering

How can I be a person centred researcher?

Respect the choice, values and beliefs of each person

Each person with dementia is different so get to know me

Each person is different

Each person with dementia is different when it comes to offering support, different things are helpful for different people.

Look at us in this group, we are all totally different. The only thing we have in common is the fact that we have a diagnosis of dementia. (Play)

## Communication

### Role Play

Move into pairs

Can you interview each other without asking any questions?

Focus

*Living environment*



## Introduction of MESSAGE

### Communication strategies

<https://www.youtube.com/watch?v=gl040FXKBtg>



## Message Communication Strategies

### Message

- M- Maximise attention
- E- Expression and body language
- S- Keep it simple
- S- Support their conversation
- A- Assist with visual aids
- G- Get their message
- E- Encourage and engage in communication

- Attract attention
- Avoid distraction
- One at a time
- Relaxed & calm
- Show interest
- Short, simple & familiar
- Clear choices
- Give time
- Find the word
- Repeat then rephrase
- Reminders of the topic
- Gestures & actions
- Objects & pictures
- Listen, watch & work out
- Behaviour & nonverbal messages
- Interesting and familiar topics
- Opportunities to talk



## Please read for next session

### Communicating effectively with a person living with a dementia



alzheimers.org.uk Alzheimer's Society

#### Communicating

We all need to communicate with other people. Dementia can affect our ability to do this, but this is not the same for everyone. There are different ways of communicating with people with dementia. It is important to find out what works best for them.

If much more than that, a large proportion of our communication is non-verbal. This means that what we say is not always what we mean. Non-verbal communication is particularly important when people with dementia have difficulty with words. It can be easier for them to understand what is being said if it is said in a different way.

Dementia and language

Differences with language occur in all forms of dementia, but the type and severity of the language problems will depend on the type and stage of dementia. It may be the first sign that the condition is developing. For example, a person with dementia may have trouble finding the right words, or may have trouble understanding what others say to them. They may also have trouble with reading and writing.

An early sign that someone's language is being affected by dementia is that they may have trouble with simple words and common objects. This person may suddenly be confused with it or may not find

## Debrief of the Session

### Activity

- How did you find todays experience?
- What did you enjoy?
- What did you find challenging?
- What are your hopes for the next training session?

Training Day Two is on Wednesday the 13<sup>th</sup> of April 2016



  
**Peer Researchers**  
 TESA- DRI Training Day Two  
 Wednesday the 13<sup>th</sup> of April 2016  
 Jean Daly  
 ulster.ac.uk

**Outline of the day**



10:00- Tea/ coffee  
 10:15- Communication strategies  
 11:30- Comfort break  
 11:45- Skill building  
 12:45- Lunch  
 1:15 – Ethics & safeguarding  
 2:00 – Close session



**Recap of Session One**

- The group contract
- TESA-DRI
- Your role as a peer researcher
- Living with dementia
- Communication skills



**Communication & living with dementia**

**Remembering**  
 Forget beginning of sentence/ conversation

**Understanding**  
 What are we saying?  
 Sounds like unfamiliar language

**Finding words**  
 Difficulty finding words  
 Might use descriptions instead of word



**Message Communication Strategies**

**Message**

- M- Maximise attention
- E- Expression and body language
- S- Keep it simple
- S- Support their conversation
- A- Assist with visual aids
- G- Get their message
- E- Encourage and engage in communication

- Attract attention
- Avoid distraction
- One at a time
- Short & calm
- Show interest
- Short, simple & familiar
- Clear choices
- Give time
- Find the word
- Repeat then rephrase
- Reminders of the topic
- Gestures & actions
- Objects & pictures
- Listen, watch & work out
- Behaviour & nonverbal messages
- Interesting and familiar topics
- Opportunities to talk



**MESSAGE Communication**

<https://www.youtube.com/watch?v=hV6lRnrZ6L0>



### Role Play

Remember you are on a journey of communication

Start with no questions engagement

Take 3 minutes each and feedback to the group



### MESSAGE in Action

<https://www.youtube.com/watch?v=GhbunPZSMUk>



### Activity: Communication Tennis

#### Stage of the game:

**Pre-match preparation:**  
Getting a good rapport beforehand is going to increase the likelihood that the communication between you and the person with dementia is going to be successful. The more challenging that you expect the communication to be, the more time you might want to spend getting yourself prepared.

#### The serve:

You want to ensure that the person is going to be able to reach your serve! How might you open a communication or conversation?

#### Reaching the serve to return it:

Your aim is to keep that ball bouncing back and forth between you. With someone with diminished communication skills sometimes you may be quite anxious to do that! You have to pay close attention!

#### Ensure your ball gets returned:

Once you have established the communication, you have contact. The next stage is moving into maintaining contact.

#### What would assist in success:

What do you think are important tips about making sure the communication is likely to be a success?

What might be important things to consider in your approach to ensure that you get a good response?

What do you need to be aware of when you are listening to the person's response?

What strategies can you use to continue to keep the communication going back and forth between you?

### How do you start the conversation?

- Warm friendly approach
- Think about where the person is: can they see you? can they hear you?
- How do they look?
- Be authentic
- Keep it simple



### Environment

- Sit with the person without a table in front (where possible)
- Clothing informal and with colour
- Familiar surroundings
- Eye contact
- Make sure the person can see you clearly
- Take a moment to feel calm



### Remember the Person

People living with dementia still have the same feelings as you or I, sometimes they can just find it more difficult to express them

Focus on experiences and emotions not dates and times

#### Terminology:

Living with –  
person first  
not a victim; not 'suffering' 'tragedy' etc



**Listening Skills**

- Relax
- Give space & time for person to talk
- Don't interrupt
- Respect emotional responses
- Listen actively
- Look at the person speaking
- Ask for clarification
- Repeat it back



**Important Strategies to remember**

- Repeat yourself if you not sure you were heard and rephrase in a different way
- Pause and allow time for the person to understand
- Refocus the topic by reminding the person what you are talking about 'you were just telling me...'
- Keep sentences & language short & simple
- Use gestures, & written words
- Watch out for facial expressions, gesturing & pointing



**building a relationship**  
**taking time**  
**Emphasis key words**  
**Speak slowly**  
**Active listening**  
**End the interview on a positive note**

(Murphy et al 2014; Lloyd et al., 2006; Nyerd, 2006; McElroy & Wilkinson, 2004).

**Comfort Break**



**Skill Building**

Role Play: Working in pairs to practice using MESSAGE



Getting familiar with the project focus



**TESA- DRI**  
Aim of engagement

Quality of living

- Life here
- Everyday experiences
- Likes and dislikes
- Family and caregivers



**Debrief**

How do you feel after the interview?

Did you find anything particularly interesting or striking during the interview?

What strategies do you think worked/didn't work during the interview?

What do you think you gained from this experience?



### LUNCH BREAK

30 minutes

From 12:45 to 1:15pm



### Ethics & Safeguarding

This is making sure every participant, peer researcher and researcher is treating with utmost respect and keeping wellbeing as a priority for all.

<https://www.youtube.com/watch?v=yr5ciyokVUs>



### Ethical Issues

Confidentiality

Informed and process consent

Safeguarding the participant and themselves



### What is Process Consent?

This is a method of continually monitoring that the person living with dementia is still consenting to taking part in the interview/ focus group

Responsibility for this will be on the TESA Researcher in attendance



### Recognising signs of distress

Activity

How do you recognise the signs of distress, tiredness, and disengagement?

Where can you signpost the person living with dementia go to get help and support if they need it?

What if the peer researcher gets upset?



### Peer researchers comfortable & safe

- Confidence building
- Confidentiality and anonymity
- Debrief after interview with TESA researcher



### TESA researcher role

Safeguarding for person living with dementia i.e. ensuring consent is still given by participant

Watching for signs of both verbal and non verbal communication (restlessness, agitation, and verbal fluency)

Support for peer researcher

To ensure research aims are central to interview "kept on track"



### Where do we go from here...



### Please fill out Feedback form

Any Questions?

Thank you for attending the training



## Appendix 23 TESA Peer Researcher End of Training Questionnaire



### **TESA Peer Researcher End of Training Questionnaire**

Name: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Mobile phone number: \_\_\_\_\_

Email address: \_\_\_\_\_

#### **I currently have availability on:**

	Monday	Tuesday	Wednesday	Thursday	Friday
Morning	<input type="checkbox"/>				
Afternoon	<input type="checkbox"/>				

#### **I would be interested in travelling to housing schemes in:**

Area	Yes	No
Belfast		
Lisburn		
Newtownards		
Downpatrick		
Banbridge		
Enniskillen		
Omagh		
Derry		
Coleraine		



**Age Range**

65 and under      75 and under      85 and under      95 and under

**Can you give a brief outline of your previous work experience?**

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**Have you any previous experience engaging with people living with dementia?**

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**Why have you decided to get involved as a peer researcher in the TESA project?**

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**Do you feel prepared for your role as a peer researcher?**

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**Is there anything not included in our training that you feel you need to help you in your role?**

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**Is there anything you would recommend to be changed in the training in the future?**

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**What do you hope to get out of this peer researcher experience?**

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**Do you feel prepared for your role as a peer researcher?**

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**Is there anything not included in our training that you feel you need to help you in your role?**

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**Is there anything you would recommend to be changed in the training in the future?**

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**What do you hope to get out of this peer researcher experience?**

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## Appendix 24 Peer Researcher Debrief Questionnaire Post Interview



### **Peer Researcher Debrief Questionnaire Post Interview**

- How do you feel after the interview?
- Did you find anything particularly interesting or striking during the interview?
- What strategies do you think worked/didn't work during the interview?
- What do you think you gained from this experience?
- What do you think was important to prepare you for this role?



*The*  
**ATLANTIC**  
*Philanthropies*

## Appendix 25 TESA Peer Researcher Experience Evaluation



5/9/17  
Version 2



### TESA Peer Researcher Experience Evaluation

We really value your contribution to our project. It was great to work with you all and see you work directly with the participants. You definitely made a difference to the project. We want to learn from this experience. This evaluation form is to explore what was good and what could be improved for peer researchers in the future. Thank you for taking the time to complete it.

#### 1. What did you like most about being a peer researcher?

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#### 2. What did you like least about being a peer researcher?

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#### 3. Is there anyway we could improve the experience for the peer researcher in the future?

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4. Do you feel being a peer researcher brought value to you as a person and was something you were proud to be a part of?

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5. Do you feel the training helped you prepare for your role?

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6. Do you feel you had the skills for your role as peer researcher?

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7. Do you feel that you have learnt new skills that would be helpful in other roles?

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8. Did you feel supported by the researcher during the interview?

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**9. Do you feel that you had a meaningful role in the TESA DRI research project?**

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**10. If another opportunity was available, would you volunteer to be a peer researcher again?**

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**11. Is this something you would recommend to other people to do?**

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**12. Any other comments.**

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Thank you for taking the time to complete this evaluation and for your contribution to the TESA-DRI project

## Appendix 26 Academic Poster



# TESA-DRI



Technology Enriched Supported Housing For People Living With Dementia

## Engaging people with dementia in research: Peer researcher experiences within aging research

Jean Daly Lynn<sup>1</sup> and Suzanne Martin<sup>2</sup>

<sup>1</sup> Engage With Age, Belfast, Northern Ireland

<sup>2</sup>Faculty of life and Health Sciences, University of Ulster, Northern Ireland, UK.

s.martin@ulster.ac.uk

### Introduction

This study aimed to understand the experiences of older people with dementia living in technology enriched supported accommodation. To maximise the opportunity for rich data collection from elders with dementia peer researchers were recruited, trained and supported to data collect. An open call on digital media and local amenities tapped into the rich resource available in the retired community



A Peer Researcher

### Added value of peer researchers

#### The Importance of Peer Researchers



Three peer researchers were under 65 years, three were 65 - 75 years and one individual did not specify. Previous life experience included academia, community development, teacher, finance, pastoral visitor, electrician and adult education. Four of the seven individuals had cared for family members with dementia in the past. When asked what they would like to get out of this experience, answers included giving a voice to people living with dementia, job satisfaction, developing skills, having an impact, betterment as a person and a sense of doing something worthwhile.

### Methods

The methodological approach was based on a literature review and included in our ethical governance. In total 7 peer researchers were recruited via the open call. All peer researchers attended two full days training on the project, research data gathering approach, and dementia. In total N= 22 interviews were completed by peer researchers, supported by the project research associate. Peer researchers were invited to a final validation meeting to review the interview transcriptions and v

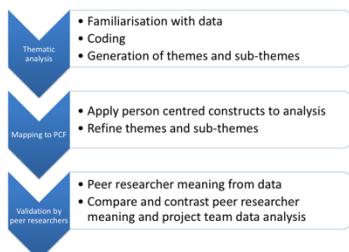


Figure1: The Analysis Framework

### Peer researchers supported data analysis

The peer researchers conceptualised the data heard during the interviews. The first theme was the internal factors that directly impact on the person such as contentment, communication, their feelings, autonomy and relationships. The second theme was the external factors that impact the tenant lives such as staff, family, security and technology. The final theme was the context in which the tenant's lives are set such as having roots in the community, the environment, and the scheme.

### Conclusion

A peer researcher is a person that brings with them their prior experiences into the research process. The process moves away from the 'expert researcher' and aims to help participants be more comfortable with the process by having conversations with their peers who are living with dementia. Peer researcher strategies to support engagement were:

- Keeping conversations simple
- Repeating questions again in a different way
- Give time to respond
- Prompts to explore responses
- Silence /non-immediate response are ok
- Making a connection with interviewee
- Eye contact
- Be affirming and interested
- Seating was important
- Interview timing (early in the morning and straight after lunch not good times)
- Using visual ques for example, 'After questions about technology, I drew attention to the alarm on the wall, however the person's memory of what it is used for did not seem to be triggered by this'

Peer researchers reported the interviews were "really good", being 'pleased', and 'a bit more challenging'.

One peer researcher felt 'genuinely invigorated'.

*I genuinely feel that we gleaned such a huge amount of information from the interview"*

This research has been funded by HSC R&D Division, Public Health Agency (Northern Ireland) and The Atlantic Philanthropies.



## Appendix 27 Program from Integrated Care in Dementia Event



### Programme

#### Integrated Care in Dementia

Thursday 5<sup>th</sup> November 2015

Room 1B122

09.30 – 3.00pm

Time	Title	Presenter
9.30-10.00	Registration	
10.00-10.10	Welcome and setting the scene	Professor Hugh Mc Kenna
10.10-10.45	Dementia Passports: Integrated care and communication for people living with dementia  Dementia friendly communities	Professor Gerry Leavey  Bethany Waterhouse-Bradley Heather Lundy & Dagmar Corry
10.45 - 11.15	Dementia: public attitudes and knowledge ARK	Professor Gillian Robinson Elizabeth Byrne McCullough Fiona Brown
11.15-11.30	Comfort break	
11.30-12.00	Apps for dementia care and prevention	Dr Ian Cleland
12.00-12.30	'Individual Specific Reminiscence in Dementia'	Professor Assumpta Ryan
12.30-13.30	Lunch	
1.30-1.45	Welcome back from lunch	Professor Carol Curran
1.45-2.15	Risk communication in dementia care: Experiences of family carers'	Mabel Stevenson (Professor Brian Taylor)
2.15-2.45	Technology in dementia care – what do we know from the research literature.	Jean Daly
2.45-3pm	Closing session one	Professor Tanya Mc Cance
3pm	Coffee	
3pm to close	Dementia Research Initiative	Adam Smith Programme Manager   NIHR Dementias and neurodegeneration

[ulster.ac.uk](http://ulster.ac.uk)

