# A research evaluation of an interactive training experience: The Virtual Dementia Tour® (VDT®)



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## **Foreword**



In Ireland, the increase in the number of people living with Dementia in the coming years will be significant and could be as high as 132,000 people by 2041, almost three times the current estimate of 47,000 in 2011. (Pierce et al. 2014). These are daunting statistics for professionals working in the Health Service Executive and indeed as individuals we all will know someone with a diagnosis of Dementia, or know someone who is involved in the caring and supporting role. This may be in our professional role or in our own day to day lives.

One of the pertinent messages within The Irish National Dementia Strategy (Department of Health, 2014) informs us that with the right supports a person with Dementia can live well. The provision of education and training opportunities for health care professionals and also for carers and people with Dementia is part of our commitment in the HSE to enable us to meet the needs of people living with Dementia in a person centred and compassionate way.

Currently, in the North West there is a wide range of programmes available at different learning levels which may be accessed by health care staff and also by individuals who are caring for people in the community. We are always exploring new and innovative ways of facilitating education around this important area of practice.

The Nursing Midwifery Planning and Development Unit (NMPD), Directors of Nursing/Service Managers and their Teams in the North West have been collaborating on this subject. Also more recently we have been working with our nursing colleagues in the Western Health and Social Care Trust in Northern Ireland to explore how we can work in partnership to build capacity in relation to skills and knowledge around Dementia care. Co-operation and Working Together (CAWT) supported The Virtual Dementia Tour® (VDT®) training experience in Donegal for two days in the autumn of 2016. This unique interactive learning experience which takes place in a mobile simulated training unit was an exciting opportunity for us. It aimed at supporting those caring for people with Dementia to have greater understanding and empathy in their caring role of what it is like to live with a Dementia diagnosis.

The National Dementia Campaign asks us to 'Understand Together' - this phrase has more meaning for us now after completing the VDT® training. Seventy-two people completed the training including health service staff from across all divisions and professional disciplines in the North West and also importantly, family carers and community carers. Participant feedback was positive. In addition, this formal research evaluation commissioned by the NMPD and undertaken by the Ulster University will provide research evidence to ascertain the efficacy of this type of approach around training and education in Dementia are.

It gives me great pleasure to present this evaluation of the VDT®, I most sincerely wish to thank everyone who attended the training and provided feedback. Also, I would like to thank the Donegal Dementia Group who contributed to the organisation of the training event.

Consideration around the findings of this research evaluation will provide the next steps in relation to supporting health care teams and carers to provide person centred and evidence informed care to people with a Dementia diagnosis.

Ms Anne Gallen

**Director NMPD** 

**HSE North West** 

## **List of Abbreviations**

**AHPs** Allied Health Professionals

**CAWT** Cooperation and Working Together

**Doha** Department of Health

**GDP** Gross Domestic Product

**HSE** Health Service Executive

NMPD Nursing Midwifery Planning and Development Unit

**RCP** Royal College of Psychiatrists

**VDE™** Virtual Dementia Experience™

**VDT**<sup>®</sup> Virtual Dementia Tour<sup>®</sup>

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## **EXECUTIVE SUMMARY**

**Background:** In 2014, the Department of Health (DoH) published the Irish National Dementia Strategy, which the Government has given a commitment to implement (Department of the Taoiseach 2016). This strategy included appropriate training for all those caring for people with Dementia. The Virtual Dementia Tour <sup>®</sup> (VDT<sup>®</sup>) is a sensory distortion programme designed to provide participants with a greater understanding of the progressive difficulties experienced by many people living with Dementia. Participants have vision, touch and sound distorted in a similar way to someone with Dementia. To date, limited research has been undertaken on the impact of the programme.

**Project and aim:** During 2016, with the support of the Nursing Midwifery Planning and Development Unit (NMPD) and the Cooperation and Working Together (CAWT) cross border partnership, the VDT® mobile simulated training was piloted by the Health Service Executive (HSE), North West. This was the first occasion on which this training intervention had been piloted within the Republic of Ireland. Seventy-two health care personnel and family carers representing hospital, community and voluntary services attended the training. The aim of this study was to explore participant perceptions of the impact of the VDT® programme upon practice and upon Dementia care in the future.

**Evaluation and findings:** The evaluation of the project involved: 1. a purposive sample of 18 participants who took part in interviews and 2. completion of a demographic questionnaire.

- Overall, the findings supported a need for new and innovative training in effective Dementia care that moves beyond traditional didactic models of training for health care professional and carers.
- VDT® programme provided a unique learning experience, to walk in the shoes of a person with Dementia, and formulate a sense of empathy among participants.
   Empathy translated into increased confidence, compassion and person-centred practice among participants.
- There is a need to examine the potential role of VDT® as a training tool to support the
  delivery of Dementia specific education as recommended in the national Dementia
  strategy.
- All training must be embedded in an overarching programme of facilitation and practice development to maximise potential for translating its impact into practice.
- Further research is required to examine the value of VDT® training, the costeffectiveness of the programme, and its wider impact on practice and service delivery.

**Conclusions:** The VDT® experience is an effective, well received training programme providing a unique interactive learning experience. There is always a risk that the impact of any training intervention can diminish over time but impact on individuals was all encompassing prompting empathetic responses. A key recommendation for augmented delivery of the training intervention merits further attention.

## INTRODUCTION

Dementia is one of the major causes of disability and dependency among older people worldwide (World Health Organisation [WHO] 2015). It is an umbrella term used to describe behavioural changes, loss of cognitive, functional and social abilities (Pierce et al. 2013). Symptoms such as memory loss, disorientation, confusion, loss of movement, hallucinations (both visual and audio), can affect the ability to undertake day-to-day activities and navigate physical environments (Alzheimer's Society 2012; Dementia UK 2012; Parsons 2001).

Alzheimer's Disease International (2016a) has reported that the number of people living with Dementia worldwide is estimated at 47 million with an expectation of an increase to 131 million by 2050. These estimates are higher than anticipated and highlight the need for countries to put plans in place to respond effectively to the burden and impact on their populations and to make Dementia a public health priority. While improvements in population health and targeted health improvement initiatives to address lifestyle behaviours such as physical inactivity, smoking and obesity may assist in reducing the onset of Dementia among some individuals, the impact of these interventions may be relatively modest (Ritchie et al. 2010). The global economic cost of Dementia is estimated to be US\$ 604 billion, or 1% of global Gross Domestic Product (GDP) (Alzheimer's Disease International 2012).

Evidence of a growing global recognition that Dementia is a major public health issue that impacts on societies in high, low and middle-income countries is apparent through the plethora of policies, strategies and national plans being developed and implemented to moderate the impact on the quality of life and wellbeing of persons with Dementia and their wider network of carers, friends and families (Alzheimer's Disease International 2016b).

The policies, strategies and national plans summarised by Alzheimer's Disease International (2016b) show the leadership of governments in many countries in recognising the need for:

- A greater understanding of how living with Dementia impacts on society the person living with Dementia, their carers and families - including raising awareness and reducing stigma;
- 2. Services that meet the needs of people with Dementia in their planning and delivery, through personal and public involvement in their co-design;
- 3. Training and education for competent and compassionate multi-disciplinary professionals;
- 4. Greater access to diagnosis and evidence based interventions at the earliest opportunity;
- 5. Further inter-disciplinary health and social care research into prevalence and treatment of Dementia which also incorporates the principles of co-design and co-production (Alzheimer's Disease International 2016b).

However, while global progress has been made in raising the profile of Dementia as a public health issue, more still needs to be done at local, national and international level. This includes

the prioritising of funding, education and research for both service users and health and social care professionals (Luengo-Fernandez et al. 2015)

Whilst many international initiatives are progressing under the WHO (2016; 2012), at a national level the Irish Government through its commitment to implement its National Dementia Strategy (DoH 2014) and the funding of research into local initiatives has shown leadership and is taking positive steps towards understanding the reality of living with Dementia in Ireland (Department of the Taoiseach 2016). This strategy has committed to appropriate training and supervision for all those caring for, or providing services to, people with Dementia, as well as promoting an increased awareness and understanding among people in general to the needs of people with Dementia (DoH 2014). This programme of work recognises the need for person-centred care, delivered across all settings and health and social care professionals, which reflects the needs and interests of stakeholders (people with Dementia and carers) (DoH 2014).

In Ireland, the increase in the number of people living with Dementia in the coming years will be significant and could be as high as 132,000 people by 2041, almost three times the current estimate of 47,000 in 2011 (Pierce et al. 2014). Statistics for County Donegal indicate that 1,929 (1.20% of the population) are living with Dementia (Central Statistics Office 2012 cited in Pierce et al. 2014), highlighting that Dementia is a major public and political challenge for governments regarding health and social care provision.

The Department of Health and the Health Service Executive have allocated dedicated funding of €27.5 million to translate the Dementia strategy into a structured programme of actions (Health Service Executive 2016). Integrated throughout these actions is the focus to encourage and facilitate the provision of Dementia-specific training to relevant occupational and professional groups and develop appropriate training courses for family and other informal carers.

At an individual level, there are significant personal, social and economic costs associated with Dementia. For example, people with Dementia generally require high levels of care, most of which is provided by informal or family caregivers, supported by community, voluntary and acute care services (Merrilees 2016; Connell et al. 2011). Research suggests that informal caregivers should learn to cope with the progressive and often unpredictable course of the disease, with a reported lack of preparedness to provide appropriate care (Ducharme et al. 2011). Similarly, there is further evidence that staff in the acute care setting often do not recognise Dementia, lack adequate skills and knowledge to care for a person with Dementia (Boaden 2016; Innes and Kelly 2016; Fukuda et al. 2015; Coffey et al. 2014; Calnan et al. 2013) and operate in an environment which is not conducive to the requirements of the person with Dementia (Waller et al. 2013). Such findings are highlighted in a national audit of 35 acute care settings in Ireland which revealed that only two hospitals included Dementia awareness training in staff induction, with no hospital providing mandatory Dementia awareness training (Timmons et al. 2016). This is despite people with Dementia being more likely to experience a decline in function and suffer three or four physical comorbidities, which necessitate hospital admission (Boaden 2016; James and Hodnett 2009; Mukaetova-Ladinska et al. 2009). Internationally it is estimated that between 25-50% of hospital beds are occupied by a patient with Dementia (Travers et al. 2013; Sampson et al. 2009; Holmes and House 2000). In Ireland, Timmons et al. (2015) suggest that 29% of older adults admitted to acute care hospitals have Dementia with an annual cost estimated to be €21 million (Cahill et al. 2012).

Unsurprisingly, hospital admission is reported to be distressing for this patient group with the quality of care being viewed as unacceptable, resulting in poor experiences and outcomes for the patient (Royal College of Psychiatrists [RCP] 2011; Cowdell 2010; Alzheimer's Society 2009; Sampson et al. 2009). For instance, poor care is associated with cognitive and functional decline (Andrews 2013; Alzheimer's Society 2009), leading to disorientation and confusion which Coffey et al. (2014) claim exacerbates the challenge of care. Irish data for Dementia patients reveal many have longer than expected hospital stays (Economic and Social Research Institute 2009); greater institutionalisation post-discharge (Manning et al. 2014; de Siun et al. 2014) and higher mortality rates (Manning et al. 2014).

In response, several reports recommend that not only acute hospital staff but also voluntary/community staff and carers should be educated to be able to recognise Dementia and care for people with Dementia when they are admitted to hospital for other conditions (Health Foundation 2011; RCP 2011).

This subsequently led to an array of training and educational programmes being developed which mainly rely on traditional educational methods such as lectures, role play, reflective practice and evidence based journals to increase the clinical skillset and knowledge of health care professionals. However, traditional didactic forms of teaching have been criticised as providing limited ability for learners to practice new skills and develop an empathic understanding of the potential experience of someone living with Dementia (Baillie et al. 2016; Cowdell 2010). Generally, empathy entails an understanding of another person's experience and feelings which Hojat et al. (2002) suggest involves two aspects, firstly, cognitively being able to understand another person's inner experience and feelings and to view the outside world from their perspective. Secondly, an affective aspect relates to entering the emotional experience of the other person. Recent advances in educational technology are offering an increasing number of innovative learning opportunities to enhance empathic understanding. Among these, simulation training packages present a promising and growing area with the potential to enhance the training of health care professionals in this area (Lateef 2010).

Virtual reality as a form of simulation training provides a vehicle for increasing understanding and empathy of living with Dementia by immersion into the world of the person with Dementia. New virtual reality programmes for health care training have recently emerged, such as the Virtual Dementia Tour® (VDT®) programme. This is a sensory distortion programme designed to provide greater understanding for people living with Dementia. Participants have vision, touch and sound distorted in a similar way to someone with Dementia. During 2016, with the support of the NMPD and CAWT, the VDT® mobile simulated programme was piloted by the HSE North West. This VDT® programme, the first to be delivered in the Republic of Ireland, was piloted in HSE North West to seventy-two nominated health care personnel and family carers representing hospital, community and voluntary services. However, to date, limited research has been undertaken on participant perceptions and impact of the VDT® programme. In response, the Nursing Midwifery Planning & Development Unit - Health Service Executive, North West, commissioned this research evaluation report. The aim and objectives of the research are detailed in the next section.

## RESEARCH AIM AND OBJECTIVES

## **Research Aim**

The aim of the evaluation can be expressed as follows:

To explore the experience from the individual carer perspective including family carers and health service carers perceptions of the impact of VDT® experience upon practice and upon Dementia care in the future.

## **Research Objectives**

The objectives of this study are:

- 1. To explore the experiences and perceptions of impact on the practice of health and social care staff and carers who participated in the VDT® training.
- 2. To explore the perceptions of impact of VDT® upon delivery of Dementia care in the future.
- 3. To consider participant reaction to how the VDT® programme was conducted and how this may be improved.

Building upon the strategic policy and research overview presented, the next section will seek to review the current evidence base regarding simulation techniques in health care, specifically for Dementia training.

## **OVERVIEW OF THE LITERATURE**

### Introduction

A rapid review examining the relevant national and international literature, research evidence and published reports with specific reference to VDT® and Dementia initiatives was undertaken. This review places the present study in the context of what is already known and is emerging about simulated Dementia training. Reviews of papers relating specifically to Dementia simulation training were selected for examination.

As there is limited robust evidence about what Dementia training and education is most effective, Surr and colleagues (2016) undertook a critical interpretative synthesis of the evidence to gain an understanding of what constitutes an effective approach. From 152 articles on training and education in Dementia care identified, Surr et al. (2016) highlighted key issues to consider in the delivery of effective Dementia care training. These include the integration of theory and practice-based learning in the delivery of training; the inclusion of discussion/reflective sessions; face-to-face sessions provided by trained instructors; and role play or simulation learning which include debriefing and reflection to support knowledge acquisition (See Box 1).

## Box 1: Key issues in the delivery of effective Dementia care training

# training

- **Effective** T Is viewed as clearly relevant to learners' role
  - Offers opportunities for discussion
  - Underpins practice-based learning with theory
  - · Has materials that are clear and easy to understand
  - Is delivered in a safe, open environment by a skilled trainer who is flexible and adapts to the needs of the group

- **Learning** T. Via reading alone or through practice-based learning without accompanying theory is unlikely to increase knowledge
  - · Using simulation or role play learning should include debriefing and reflection to support knowledge acquisition
  - · Staff attitude change is more likely through training of half-day duration or longer
  - Staff confidence is most commonly increased where training contains discussion and interaction

## behaviour change post training results from

- **Effective** T Avoidance of purely didactic delivery
  - Inclusion of a specific tool, method or approach to use when conducting assessments or delivering care
  - · Combining face-to-face delivery with a practical approach to application of learning in practice

# staff outcomes

- **Improved** 1 · Uses face-to-face delivery, discussion and activities that support application of learning to practice
  - · Is delivered by an experienced trainer
  - Is over one hour in duration
  - Is designed for a specific service setting type
  - Is usually of longer duration (8+ hours total) and provides training on a structured tool or delivery manual that assists application of learning in practice.

(Source: Adapted from Surr et al. (2016) 'What works in Dementia training and education')

For training to be most effective, Surr et al. (2016) recommended that it needs to be tailored to specific roles and service settings; delivered by an experienced facilitator; and should incorporate combined theory and knowledge opportunities to apply learning though practiced-based activities. With regards to the training duration, evidence suggests that educational programmes should be at least one-hour duration, with longer programmes being more effective. These training needs may be addressed through simulation training; an increasingly common format for skills and knowledge acquisition for health care staff.

## Simulation training in health care

Simulation is a generic term that refers to an artificial representation of a real-world process to achieve educational goals through experiential learning (Al-Elg 2010). It can involve a person, a device or set of conditions and permits repetitive practice of skills in a risk-free environment (McDougall 2015). The key goals of simulation training are to provide simulation fidelity (the reality of the experience), simulation validity (the authenticity of the various aspects of the simulation) and simulation presence (visceral feeling of being in a simulated environment) (Feinstein and Cannon 2002). Dieckmann et al. (2007) argue that these three elements, when implemented alongside proven learning pedagogies, provide the conditions necessary to provide a narrative that is a fundamental part of developing perceptions of another character and for meaningful learning to take place.

Simulation is considered an ideal educational and practice platform for the adult learner because it provides an opportunity to build on an existing knowledge base (McDougall 2015). It has been used as an effective training tool for health care professionals working in acute hospital (Sadideen et al. 2017) and community hospital settings (Prentice et al. 2011). In specialist areas such as intellectual disabilities (Billion et al. 2016); paediatrics (Wayman et al. 2007); cardiology (Harrison and Gosai 2017); and intensive care (Ballangrud et al. 2014, Corbridge et al. 2008) and in-patient training for self-management (Chan et al. 2015)

There are multiple types of simulation training used in health care settings. Qayumi and colleagues (2014) identified eight types used internationally in health care education (standardised patients, human-patient simulators (high and low fidelity), task trainers, tissue specimens, expert systems, online simulation modules and virtual reality workshops). Virtual reality workshops accounted for seven percent of simulation use and were "considered" highly resource-intensive with the added need for trained facilitators, actors and/or information technology support" (Qayumi et al. 2014 p.464).

The use of virtual reality simulation training in health care training and education has increased significantly with advances in gaming technologies and the integration of virtual reality software (Merchant et al. 2014). Virtual reality technology has also been used as a therapeutic tool in the treatment of psychological conditions such as phobias (Côté and Bouchard 2008), and anxiety (Bouchard et al. 2010) and has been used in slowing memory loss (Brooks and Rose 2003) and promoting navigational skills in novel environments (Zakzanis et al. 2009; Cushman et al. 2008) among people with mild Dementia. Larsen and colleagues (2012) used virtual reality practice surgical procedures resulting in decreased surgery times.

## Simulation training in Dementia care

In the last five years there has been a growth in the use of virtual reality simulation training in Dementia care (Adefila et al. 2016). Vottero et al. (2014) reported that virtual reality simulation holds great promise for future research and training of health care professionals, in replicating complex health care environments and focusing on immersion. Programmes such as the myShoes programme (Adefila et al. 2016), the Virtual Dementia Experience™ (VDE™) (Alzheimer's Australia Vic 2014) and the VDT® (Beville 2002) have been developed. Each focuses on the use of virtual reality to increase Dementia awareness from the perspective of the person with Dementia – to experience the world as they experience it.

Traditional training techniques whether theory-based (books or didactic lectures) or practice-based (role-play or simulation) require the participant to project the corresponding emotions for the presentation of the Dementia-related symptoms being displayed. Theory often decontextualised the patient, listing symptoms and behaviours without necessarily providing a framework of how the situation affected people socially and physically (Adefila et al. 2016). Epp (2003) commented that Dementia care which focuses only on the disease and its treatment does not attend to a patient's personhood, treats the patient as a passive object, and is damaging to the patient. Moreover Beville (2014) reported that with Dementia, the cell deterioration produces a cognitive functioning decline that results in patients' inability to voice their views and opinions. Often, therefore, the person with Dementia only has the voice of the people caring for them and whilst valuable, it is an outsider view of the disease.

The use of virtual reality programmes aims to provide an opportunity to 'walk in the persons' shoes' and promote empathic understanding of the lived condition. Empathy is defined as the "understanding, sharing and creating an internal space to accept the other person, hence helping them feel understood and not alone" (Cunico et al. 2012, p.6). Compassionate care results from having empathy for another person and responding to their needs with humanity, relieving pain and distress; hence it forms a central component of all health care (Digby and Lee 2016). Whilst there is debate whether empathy is innate or can be taught, it can be recognised and encouraged (Richardson et al. 2015).

As indicated above, our review of the evidence, has identified three virtual reality simulation educational programmes developed specifically for Dementia; namely the VDE™, the myShoes project and the VDT®. As a developing area of education and training, there is a dearth of evaluative evidence on their effectiveness and impact on patient, service and staff outcomes. The next section presents a description of each of these educational programmes and their evidence base.

The **VDE™** is an Australian based programme which uses virtual technology to promote

empathetic understanding and increase knowledge relating to issues for people living with Dementia. It is a high resource interactive environment intended as an experiential learning exercise. It involves 10 x 2.5 metre projections and uses gaming technology to draw the person into the lived world of the person with Dementia. It aims to provide greater understanding of person-centred Dementia care, increase empathy, assess the impact of the environment design on people with Dementia and on insight into practice as carers. The uniqueness of the programme means there is limited research on how it achieves these goals. Using a quasi-experimental repeated measures design and process evaluation, and comparing results to usual classroom training (Doube and McGuire 2016) reported that the VDE™ programme identified statistically significant increases in empathetic understanding and knowledge of Dementia care environments when compared to classroom training. Participants in the VDE™ described their care practice and environments from the perspective of those in their care and had an increased awareness of the thoughts and feelings of people with Dementia. The findings are encouraging; however, more robust evidence is required.

The **myShoes project** (Adefila et al. 2016) employed a different method of virtual reality simulation to increase awareness of the symptoms and lived experience of Dementia patients; support an increase in empathy; and encourage participants to reflect on their practice with respect to care and competence when dealing with people with Dementia. The developers used a stereoscopic head mounted device and gaming technology to immerse the wearer into an avatar body and this allowed them to make new connections with a persona that is not their own. This helped increase simulation fidelity, validity and presence to provide the user with a greater sense of 'being there' and it allowed the trainers to contrive situations designed to promote confusion and doubt among the participants. Participants are required to complete a few scenarios, whilst using a think aloud technique (Cotton and Gresty 2007) to provide immediate access to the thought processes occurring during immersion and reflect in real time on the experience. The session concludes with a debriefing exercise, aimed at promoting interactive learning (Rall et al. 2000).

In a repeated measure mixed methods design evaluation of the programme, Adefila and colleagues (2016) reported that student health and social care professionals (n=55) reported increased awareness of the perspective of the Dementia patient; increased empathy and compassion, confidence and competence as measured on a standardised scale. Empathy scores increased by 7.3% immediately after simulation; confidence changed from 4.35 to 5.75, competence from 4.36 to 5.84; and compassion from 8.48 to 9.10. All changes were positive and at a level that was statistically significant. Examination of the qualitative information suggested that the simulation experience can have a positive impact on the health and social care practitioners' practice, helping participants think beyond 'treatment' to considering how the person might feel and altering their approach accordingly.

Whilst both Adefila et al. (2016) and Doube and McGuire's (2016) evaluative research is relatively small scale and involves small sample sizes, the findings are encouraging and, given time, a higher volume and quality of evidence may emerge. Also, more details are required on the proof of concept for both programmes to replicate the experience of Dementia.

The **VDT**® addresses the proof of concept by setting out from the beginning that it aims to be a replication of stage four-five (moderate) Dementia. Dementia is an individual experience, with symptoms and rate of disease progression varying widely across people, however to understand the illness, it is viewed as a series of stages (Reisberg et al. 2011). One of the

most common staging scales is the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS), (referred to as the Reisberg Scale), divides the disease process into seven stages based on the amount of cognitive decline (see box 2). According to Reisberg et al. (1982), during the moderate stage (4-5) as the disease progresses the person with Dementia may require a greater level of care. Some symptoms may include functional decline, mood changes, forgetfulness, confusion, changing sleep patterns and an increased risk of wandering.

Box 2: Global deterioration scale for assessment of primary degenerative Dementia (GDS)

Stage	Diagnosis	Signs and Symptoms
Stage 1	No cognitive decline	In this stage the person functions normally, has no memory loss, and is mentally healthy. People with no Dementia would be in Stage 1.
Stage 2	Very mild cognitive decline	This stage is used to describe normal forgetfulness associated with aging; for example, forgetfulness of names and where familiar objects were left. Symptoms are not evident to loved ones or the physician.
Stage 3	Mild cognitive decline	This stage includes increased forgetfulness, slight difficulty concentrating, decreased work performance. People may get lost more often or have difficulty finding the right words. At this stage, a person's loved ones will notice a cognitive decline. Average duration: 7 years before onset of Dementia
Stage 4	Moderate cognitive decline	This stage includes difficulty concentrating, decreased memory of recent events, and difficulties managing finances or traveling alone to new locations. People have trouble completing complex tasks efficiently or accurately and may be in denial about their symptoms. They may also start withdrawing from family or friends, because socialization becomes difficult. At this stage, a physician can detect clear cognitive problems during a patient interview and exam. Average duration: 2 years
Stage 5	Moderately Severe Cognitive Decline	People in this stage have major memory deficiencies and need some assistance to complete their daily activities (dressing, bathing, preparing meals). Memory loss is more prominent and may include major relevant aspects of current lives; for example, people may not remember their address or phone number and may not know the time or day or where they are. Average duration: 1.5 years

Stage 6	Severe Cognitive Decline (Middle Dementia)	People in Stage 6 require extensive assistance to carry out daily activities. They start to forget names of close family members and have little memory of recent events. Many people can remember only some details of earlier life. They also have difficulty counting down from 10 and finishing tasks. Incontinence (loss of bladder or bowel control) is a problem in this stage. Ability to speak declines. Personality changes, such as delusions (believing something to be true that is not), compulsions (repeating a simple behaviour, such as cleaning), or anxiety and agitation may occur. Average duration: 2.5 years		
Stage 7	Very Severe Cognitive Decline (Late Dementia)	People in this stage have essentially no ability to speak or communicate. They require assistance with most activities (e.g., using the toilet, eating). They often lose psychomotor skills, for example, the ability to walk. Average duration: 2.5 years		

(Source: American Elder Care Organisation 2016; de Leon and Reisberg 1999; Reisberg et al. 1982)

The VDT® programme distorts audio, visual and touch information in an integrated manner, coupled with simulated peripheral neuropathy to mimic as much as possible the overt losses while at the same time simulating the cognitive decline using tasks within a structured environment (Beville 2014). These symptoms are achieved through goggles, which distort vision; shoe inserts, gloves and headphones. In addition to the sensory distortion participants are subject to curtness and aloofness from the VDT® facilitators, to highlight communication issues people with Dementia may experience in the healthcare environment. Participants engage in a debriefing session to help draw connection between the participant's reactions to the simulation and the behaviours exhibited by those with Dementia.

In a study of the early version of the VDT® programme, Beville (2002) used a repeated measures research design with a sample of 146 participants and reported significant increases in participants' understanding of the emotional needs of people with Dementia; increased recognition of the importance of sensitisation to Dementia symptoms and the role they play in providing good Dementia care; an increased understanding of why people with Dementia may exhibit inappropriate behaviour; and a decrease in perceptions that people with Dementia get the care they require. Overall, the intervention enabled an improved participant understanding of the symptoms experienced by some people with Dementia.

A previous evaluation (Beville 2014) of the impact of the VDT® on participant behaviours reported difficulty in following instructions; increased wandering and shadowing behaviour; increased sub-vocalisation and negative self-talk. The participants reported feeling unable to perform simple tasks and had a heightened state of stress. The ability of a person without Dementia, to feel what it must be like to have the disease while exhibiting the same behaviours, becomes an invaluable tool to assist clinicians as they develop interventions that will make 'problem behaviours' a thing of the past (Beville 2014).

### Summation of evidence

Dementia is a worldwide problem and Ireland too is facing a significant increase in cases of Dementia. To address the needs of people with Dementia, there is a need for a richer understanding of the reality of Dementia among health care professionals in all settings. Ireland has developed a National Dementia Strategy (DoH 2014) which promotes the provision of evidence based Dementia awareness training for health care professionals. However, limited robust evidence exists regarding what Dementia education and training is most effective. Traditional models of educational delivery have been criticised for not enabling participants to develop an empathic understanding of the potential experience of someone living with Dementia. Whilst, more recently, as discussed above, the development of virtual reality simulation education programmes has tried to address this criticism of Dementia specific training and education programmes for health care professionals. Underpinning evidence and programme evaluations are limited, although preliminary evidence suggests that they may be an effective educational tool (Adefila et al. 2016; Doube and McGuire 2016; Beville 2002). The next section presents the overall evaluation design and methodology adopted. It presents the data collection process, sampling criteria and the analysis framework applied.

## **DESIGN AND METHODS**

## **Evaluation design**

Given the lack of research in this area, a qualitative research design comprising of semi-structured, face-to-face and telephone interviews, was used to evaluate the perceptions of participants in the VDT® programme. Semi-structured interviews provide a standardised structure to the interview process but provide flexibility in the phasing and ordering of the questions (van Teijlingen 2014). Telephone interviews helped provide flexibility to work with participants' busy work schedules, and use economic and human resources effectively (Musselwhite et al. 2007) by reducing travelling, given the wide geographical spread of participants and the research team.

A short interview schedule was developed based on the aims and objectives of the study and a review of the literature (see Appendix 1). The schedule highlights three broad aspects to be addressed: (1) experiences of the VDT® programme (2) the benefits of VDT® Programme and (3) impact of the VDT® programme on practice. Probes were used to clarify the meanings of responses. Interviews lasted between 15-35 minutes and with the participant's permission, the discussion was digitally-recorded and supplemented by field notes.

To enable the researcher to describe the characteristics of those who participated, all participants were asked to complete a demographic questionnaire at the end of the interviews. This included variables such as age, gender, training in Dementia and work experience (see Appendices 2 and 3). Please note, the demographic details are only being used to describe the sample and are not being used to address the research objectives.

## Sample

A total of seventy two people participated in the VDT® programme drawn from across two sites and a broad range of disciplines which were further categorised into six broad disciplines: Frontline Staff such as Registered Nurses, Healthcare Assistants (43% n=31); Carers and befrienders (14% n=10); Senior Management including Service Managers and Directors of Nursing (17% n=12); Allied Health Professionals (AHPs) (8% n=6); Medical/Psychiatry staff (7% n=5) and Other such as lecturers and project managers (11% n=8). The inclusion criteria for the sample were:

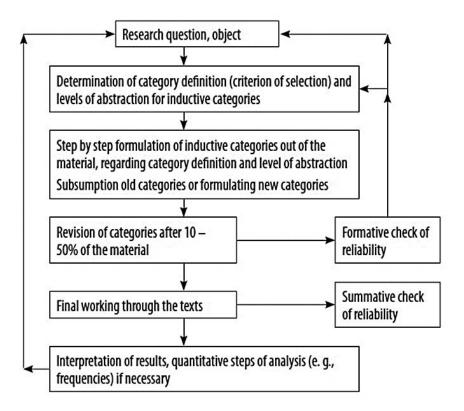
- Attended the VDT® training
- Health and social care staff representing hospital, community and voluntary services/ carers
- Aged 18 years and over
- Willing to participate and provide informed consent.

A purposive sample of fifty two participants were identified via the trainee registration list and invited to participate in the study. From this sampling frame, a total of eighteen people completed the interview; they are reflective of the range of participants involved in training programme; Frontline Staff (n=5, 28%); Carers (n=4, 22%); Senior Management (n=6, 33%); AHPs (n=1, 6%); Medical/Psychiatry Staff (n=1; 6%) and Other (n=1; 6%).

## **Data analysis**

The interview recordings were professionally transcribed. The data were analysed using Mayring's (2000, p11) approach, which is a 4-stage process for inductive category development (see Figure 1). A thematic framework was used in the initial analysis and several additional codes were added to ensure the coding framework was comprehensive. After completion of codes, the themes and sub-themes were critically reviewed across all interviews and a coherent set of themes and sub-themes were adopted enabling comparisons. Pseudonyms are used throughout to maintain anonymity.

Figure 1: Step Model of inductive category development



Data collected from the demographic questionnaires were entered into IBM SPSS Version 22; only descriptive statistics (frequency and percentages) were produced. The data were only used to describe the sample demographic characteristics of participants. Detailed statistical techniques were not undertaken.

## Rigour

Measures to ensure trustworthiness of the data were implemented (Lincoln and Guba 1985). For example, confirmability and dependability were enhanced by two independent researchers (FH and PG) analysing and reviewing the transcripts. Credibility was assured by the triangulation of data sources (HCPs and caregivers) across different clinical settings helping to increase variety of aspects. Transferability was assured by dense description of the research analysis and findings and the inclusion of quotations in the findings.

## **Ethical approval**

Ethical approval was obtained from Ulster University's Institute of Nursing and Health Research Governance Filter Committee, Research Ethics Committees in Sligo University Hospital and Letterkenny University Hospital (see Appendix 4). The participants were invited to take part in interviews on a voluntary basis. Invitation letters and information sheets were distributed and interviews took place either face to face or over the telephone (see Appendices 5 and 6) and all participants were signposted to sources of support (see Appendices 7 and 8). The participants were assured that they would only be identified by group and no individual would be identified in the report. The transcribed audio recordings were kept on password protected and encrypted university computers and all participants provided recorded verbal/written consent before interviews commenced (see Appendix 9).

The next section presents the main findings of the research as derived from interview data with 18 participants who took part in the VDT® experience and analysis of their demographic data collected by a questionnaire.

## **EVALUATION FINDINGS**

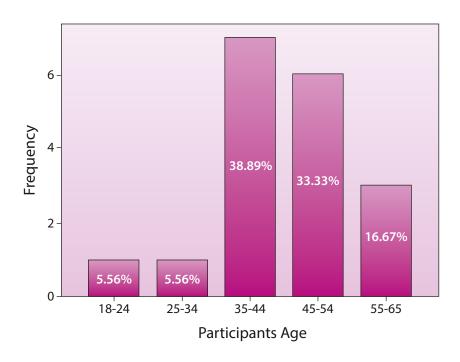
In this section, the findings from the interviews and responses to the demographic questionnaire are presented. A total of twenty one participants of the original sampling frame of fifty two responded to the invitation to participate in the interview. Of these, eighteen participants took part in the interviews. This represented a response rate of 35% of the sampling frame of fifty two participants. Half of the sample (50%) were from Letterkenny area and the remainder from the Sligo area. Most were female (83.3%: male 16.7%) and aged over 35 years of age (89%, see Figure 2). A high proportion (56%, n=10) of the sample recruited across the categories of 'Front Line Staff' and 'Senior Management' had a nursing background (See Table 1).

**Table 1: Demographic characteristics of participants** 

Age	%	Position	%	Qualification	%
18-24	5.6%	Front Line Staff	27.8%	Degree	23.1%
25-34	5.6%	Senior Management	33.3%	Diploma	30.8%
35-44	38.9%	Carers	22.2%	Masters/PhD	38.5%
45-54	33.3%	AHPs	5.6%	Other i.e. Certificate	7.7%
55-65	16.7%	Medical/Psychiatry Staff	5.6%		
		Other i.e. academic	5.6%		

Experience in caring for people with Dementia ranged from 2 years to 35 years; average length of time was 16 years. Almost two thirds (61.1%) of respondents had attended Dementia education/training (other than the VDT®) in the previous 2 years.

Figure 2: Age group of participants



There was representation from all 6 disciplines of work, with the majority drawn from Senior Management and Front-line Staff (see Figure 3). The distribution of participants was reflective of the overall sampling framework. Four informal carers were involved in a care related capacity with people with Dementia. The average length of time caring for a person diagnosed with Dementia was 45.6 months.

6 5 4 Frequency 33.33% 3 -27.78% **22.22**% 2 1 5.56% 5.56% 5.56% 0 Carers AHP's Medical/ Other Front-line Senior Staff Management **Psychiatry** 

Figure 3: Discipline of participants

As shown in Figure 4, the highest proportion of participants (30.7%) spent hardly any time caring for people with Dementia. Only 15.3% spent most of their time caring for people with Dementia.

**Work Category** 

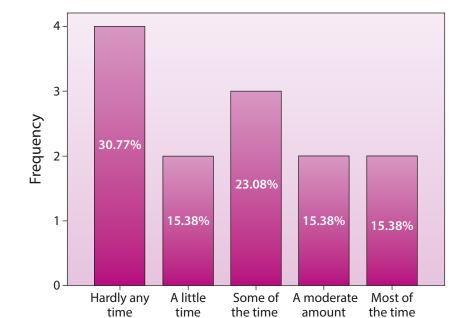
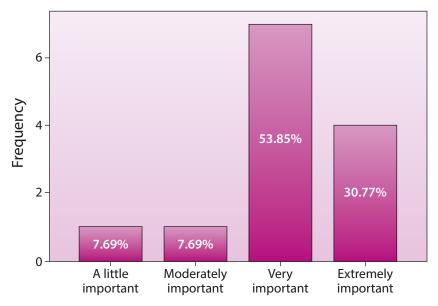


Figure 4: Time spent caring for people with Dementia

How much time at work is spent working with people with dementia

Figure 5 shows that participants felt that having a high standard of Dementia knowledge was important to enable them to do their job well.

Figure 5: Importance of Dementia knowledge in job



How important is it for you to have a high level of dementia knowledge to eneble you to do your job well?

## Themes for interview data

The results are presented according to the five themes identified from content analysis using Mayring's (2000) framework i.e. current care delivery, VDT® experience, physical and psychological reaction, impact of VDT® experience and recommendations and sustainability of the training and learning. Each theme is described and illuminated further by the verbatim comments.

## **Current care delivery**

The first theme is the current delivery of care within the acute setting to people with Dementia.

There was a perception that staff within acute care settings lack sufficient training in Dementia care that meets the integral needs of patients. Whilst some participants had previously attended specific training courses for Dementia, others indicated their exposure was a small element within their overall professional curricula which had a theoretical-medical focus on the physical and biologic aspects of the disease. This led to claims that Dementia education in professional preparation courses is inadequate.

"...almost 100% of nursing staff that I work with have got a very limited understanding of Dementia. They understand the idea that things are a bit different, but they've very little – well there's no comprehensive understanding, yet, they have a continuous attendance of clients with Dementia, year long" (Participant No 1)

"I think there's a lot of people have never had any formal training and I think... given numbers of people in our organisation who are inpatients" (Participant No 8)

Some participants identified that a range of Dementia focused education and training programmes exist in Ireland and are accessible to carers, staff and members of the public. However, existing training availability access was limited. This was further constrained due to lack of time, workload/caring responsibilities and the need to travel to training events which resulted in some having received no recent training in Dementia care.

Consequently, some participants reported that their work responsibilities focused on day to day care and administrative responsibilities. Moreover, there was an acknowledgment that current care delivery had an over-reliance on prescribed medications and referrals to psychologists for people with Dementia, which was felt, could exacerbate the symptoms of Dementia.

"..., but I do worry about falls, about fractures, about recurrent chest infections, you know – sleep/wake disturbance. Medications being given at the wrong time, you know, behaviours of staff not changing, but expecting the person with Dementia to change, as opposed to staff behaviours changing to accommodate the person with Dementia's perception of the world, or behaviours" (Participant No1)

Although health care participants identified the importance of delivering quality care, they expressed their frustrations associated with lack of time limiting their ability to meet the physical and psychological needs of people with Dementia. Some reflected upon occasions when the comfort of people with Dementia in the acute setting appeared to be overlooked but could have been addressed. There was recognition that several relatively small actions that health care workers might have taken to enhance the care of people with Dementia in the hospital. These involved taking time, using verbal and non-verbal communication skills and being aware of their unique needs.

## **VDT®** experience

The second theme reported is participants' experience and physical and emotional reaction of entering and participating in the VDT® programme.

Before entering the VDT® experience, some participants expressed feelings of apprehension, uneasiness or fear about the environment. Such feelings were attributed to the unfamiliarity with the simulator experience and fear of the unknown leading them to question their ability to manage the situation. Such anxiety was not necessarily viewed as a negative influence in having participated in the VDT® experience; some revealed how proud they were to have completed the experience.

"I was anxious to attend and also a little bit apprehensive" (Participant No 13)

"To be honest, I wasn't entirely sure that I was going to take part in it when I arrived. I knew that it would be some sort of a manipulation in terms of the person in the inside into Dementia" (Participant No 15).

All participants recalled that they were unaware that the VDT® experience began before they entered the simulator and were initially shocked and insulted by the facilitators reception to them on arrival. Most participants described facilitators as being `unfriendly' and provided them with a `cold' reception which instantly made them feel unwelcome. This caused uncertainty and embarrassment and led to them questioning the social norms, their role and expectations. However, this curtness and aloofness was a purposeful tactic of the VDT® facilitators to highlight communication issues which people with Dementia may experience in the healthcare environment.

"...the trainers were very stand offish; I was wondering what was wrong. I could see people looking at each other, as if to say, what's wrong with those guys?" (Participant No 7)

"I found the two-people delivering the programme were very aloof and unfriendly and were quite curt" (Participant No 13)

"When I went in at the start, they were very cold towards you. And I'm thinking, oh my God, they're asking people down here .... yous aren't very nice like, and I thought, that's awful" (Participant No 17)

To enable sensory distortion of vision, touch and sound to occur, participants entering the VDT® experience had to remove spectacles, wear special gloves, glasses and insoles in their shoes. The VDT® environment they entered was reported to be small and cluttered which some felt amplified the impact. During the tour trained facilitators guided and observed participants outfitted with the devices that altered their senses while allocating them tasks and exercises to complete i.e., matching socks, buttoning clothes. All participants commented on the impact of the devices and environment causing sensory distortion and their inability and frustration at not being able to complete, what they considered to be, common everyday tasks. As one participant stated:

"You were supposed to match socks, but I couldn't find - very frustrating, I was determined I had to find them, but I couldn't find them. So, you just give up then. You just leave that and go to something else" (Participant No 3)

At the end of the programme, participants had the opportunity to observe others in the simulation environment which enabled reflection on practice to occur. As illustrated:

"I found the second part of it, where you are the observer – that was huge, because I thought, my God, how quickly we become the patient" (Participant No 2)

"...it was like seeing me become a Dementia person, almost immediately. I could see the same characteristics of the patients that we would have, develop immediately.... It gives you an understanding of you know, when somebody doesn't want to come with you, when somebody doesn't want to get dressed" (Participant No 7)

Participants were then de-briefed by the facilitators which drew a mixture of responses. On one hand, it was a valuable opportunity to reflect on their experiences and connect the activities and learning to their professional/caring role. However, the manner in which it was delivered was criticised by some participants, as explained:

"....I felt he kind of talked at us a bit, you know. Like he brought us in then at the end and he kind of talked at us and 'this is the way it is' and 'this is the way it is' and I felt he could have made it into a discussion a wee bit more ...." (Participant No 6)

"Yes, just the feedback part, I just kind of thought, I suppose, maybe just that it might be given a little bit more time ... to tease out things.... I suppose a combined approach would have been more kind of a partnership, a relationship facilitation of it." (Participant No 16)

Overall both positive and negative comments were voiced about the experience. The length (2 hours) and accessibility of the training was viewed positively by the majority, however, several suggestions were made to help enhance the experience. For example, increase the

delivery to other geographic and clinical locations and provide a hand-out that people can take away to ensure the learning is not forgotten. Some also felt that they were not informed that their behaviour would be observed and recommended that all participants should be clearly told at the start.

## Physical and psychological reaction

The third theme reported participants' reactions to entering and engaging in the VDT® experience.

Participating in the VDT® led to the vivid recall of the physical and psychological responses. For example, some reflected upon the inappropriate and even bizarre behaviour they adopted in direct response to sensory distortion such as moving slowly, staying completely still, and attempting to physically withdraw from the environment. While some tried to stay close, to shadow or mimic others, several reported that they attempted to avoid physical contact, instead seeking physical surfaces to cling to. These physical responses were adopted in reaction to feelings of fear and an overriding desire to keep safe. As one participant illustrated:

"I couldn't physically move. My whole thing was, stay still. Stay safe. Don't move. Just it doesn't matter what anybody says to you, just hold your ground. "I was afraid to move and somebody brushed up against me and I could feel myself jumping away from them. So, I just stood there, literally, with my hands across, up against my chest and in fists, just ready to defend myself in a way, but just not moving" (Participant No 7)

The VDT® experience also engaged and impacted participants emotionally and mentally. For example, many stated that the unfamiliar environment and experience led them to either laugh or use inappropriate language. Whilst for others, the misinterpretation of the sensory environmental cues led them to question their mental reasoning abilities, second guessing what they saw, heard and felt. Participants also reported experiencing a wide range of positive and negative emotions during training. Negative emotions were mostly related to anxiety or fear. Acute feelings of vulnerability, disorientation, isolation and powerlessness were also widely reported. As the training progressed, anxiety shifted towards feelings of frustration, stress and annoyance. This was attributed to not being able to master simple tasks and/or lack of ability to rely on their everyday senses. In contrast, many participants also expressed positive attitudes and emotions towards training. As one participant reflected:

"You feel completely useless ... How am I meant to look for something if I can't find anything? So, I started patting about and he asked me to find, I think it was blue sunglasses or something and I felt and felt and felt, and I realised I'd got glasses and the sense of achievement that I felt! Yes, I found them, but they were the wrong colour!" (Participant No 17)

Despite the physical and psychological upset felt, there were many positive comments about the VDT® training. All participants considered the experience to be a powerful and effective learning tool, as the process enabled the participant to "walk in the shoes of a person with Dementia". Essentially this generated a shift in the emphasis of Dementia training from a theory-based perspective of Dementia to the promotion of patients' perspective. For some, this is what set the experience apart from previous training and gave it a powerful effective message:

"But misidentification, you know, misconstruing, misunderstanding, misrepresenting, misperceptions – all the 'mis' and whilst I knew this, and I've been preaching it within my role, I had never really experienced it" (Participant No 1).

"Of all the training I've ever done, having been in that ....it is as close as possible to living in a world with Dementia. It was the most powerful thing that I've ever experienced. It really gave you a completely different insight" (Participant No 8).

All participants perceived the VDT® experience as a very effective educational experience and specifically commented on it being superior to traditional educational sessions. All participants believed that delivering the VDT® experience would lead to several benefits for staff, carers and overall the quality of care delivered. For staff, it would result in increased awareness and understanding of Dementia, enhanced communication and confidence, and lead to staff becoming less judgmental in their management of challenging behaviour. For carers, it was believed it would increase understanding and ultimately reduce fear, stress and frustration, helping to inform future care options. Ultimately all participants believed the knowledge would ultimately challenge current care provision, enhancing the client care experience for the person with Dementia and their family. An array of potential clinical care benefits were cited, including, a reduction in falls, chest infections, psychiatric referrals and a reliance on medication.

However, several participants questioned the authenticity and evidence base underpinning the VDT® experience. Some questioned whether the VDT® experience was rooted in explicit research evidence and if indeed it did reflect the experiences of a person with Dementia. As stated:

".... it was very much – the information was being given to us as 'this is the case' and... the kind of sceptic in me will be saying, well what research? What evidence base is there behind what I'm being told today? It all seemed to make sense and it all rang true for what I just experienced, but I would like to know that there was an evidence base behind it" (Participant No 4).

"I suppose what I would like as well, would be a little bit more of the evidence base. I suppose I'm being a little bit sceptical, how exactly do they know that? Is that how the person with Dementia feels? I know they went through a little bit of that or whatever, but you'd like to see just a little bit more written evidence of that, if you know what I mean" (Participant No 16).

## Impact of VDT® experience

The fourth theme reported on is the perceived and actual impact on knowledge, skills, care and practice reported by participants.

The VDT® not only provided a unique learning experience, it also developed an increased awareness and understanding towards Dementia, changing underlying values and beliefs. Prior to entering the VDT® programme, many associated Dementia with predominately affecting a person's memory. However, participation helped them to understand the variety of symptoms associated with the condition. For instance, the effect on the senses leading to issues with understanding, judgement, thinking and language. For some, this confirmed existing theoretical knowledge, whilst for most it introduced new information about the condition, leading some to view Dementia in a new way. As two participants explained:

"I never – it never would have entered my head that somebody would feel like – that situation that you have with that glove on, that your dexterity is affected, I think people tend to think that the condition of Dementia is mostly related to communication and behaviour" (Participant No 2)

"I had capacity going into that room. Yes, they took away my feeling, they gave me things that hurt my feet, they put, limited my vision and my hearing, but I didn't actually lose capacity, but I lost the capacity to think, because of – and that's something that it taught me, maybe these people that we think don't have any capacity, to make a decision, are just so overwhelmed by all the noise and the stuff that we're creating around them. I didn't lose capacity going into there, but I acted like somebody who had no capacity" (Participant No 7)

In response to sensory distortion, participants adopted behavioural and psychological responses, for example, they recalled feeling aggressive and agitated leading them to call out and wander. Within the interviews many health care participants directly associated their reaction with the `challenging behaviours' related to the observations they commonly associated with a person with Dementia in the clinical setting. This had a cumulative effect as it provided participants, regardless of position, the opportunity to reflect upon their own care and management practice and that of colleagues. All participants gave many examples of their own emotional responses to the experience of how they connected to the experience personally and professionally.

"... it made me reflect on lots of interactions that I'd had. I'd think – oh my goodness – maybe that was what was going on and this is a better way of doing things. At one point, somebody tried to feed me during the thing and you're like "what the hell are you doing?" "What the hell is that? Where is it coming from? And it was just instantly like – hang on, I've seen people react like this. So yes, it has made me change the way I think about it and the way I act for people with Dementia" (Participant No 4)

"And you think, how many older people have I nursed, the critters, I never understood how that impacted on their lives, you know. You think poor circulation, you'd be thinking, oh their feet are cold, or give them a nice blanket at night. You didn't think they're actually in pain. It didn't occur to me at any time during my 40-year career, that there was actually pain associated. Nobody ever told me" (Participant No 7).

"...because I kept thinking, this is what my Daddy is going to end up like. I found myself fighting back tears, trying not to cry. You often are feeling you're looking after a stranger and you're looking after who you truly love. I think it's important that the health care professions see what is there, what it must be like for those people" (Participant No 17).

Second, the opportunity to reflect on the VDT® experience and their practice also highlighted and confirmed their professional and moral responsibilities. This led to some realising that they needed to change their practice and/or adopt a different approach to become more person-centred. Doing so, they believed, would not only result in less resistance from patients but would also improve relationships and current care practice.

"... to be able to look at it maybe not from a nursing perspective, as I've got six washes to give and a drug round and two sets of meals and beds to make etc. etc. But, to look at it from the patient's point of view and be able to think – this is a really, really freaky experience.

This is really frightening. That's not agitation, that's responsive behaviour. It can really frame the way people view a person, a client and ultimately that frames the care they get and approaches to care that are taken" (Participant No 1).

A third impact revolved around reports of feeling more confident to care, being more empathetic and viewing patients care holistically, and leading to a self-reported change in behaviour. Several examples were given of health care staff and carer participants changing their approach to interactions with patients and/or loved ones since participating in the VDT® experience. Changes included: giving more time to patients, improved communication, listening, compassion and reassurance and showing attentiveness to their surroundings.

"The effect of the noises, that has really stayed with me, – that's the one thing that has really changed how I approach patients. I just feel that we have a much greater need for quiet spaces and for time for quiet for these patients ... And, you know, every shift I have worked since, I think that's here at the very forefront of my mind. I just feel that this really, really influences what I do now" (Participant No 2)

"It has slowed me down. Whereas before, James\* doesn't like being rushed and I would pull on his coat and pull on his hat, and hand him a cup. Now I get why it's slow, so it has helped me in that way. Well naturally if I calm down and don't rush him, it's going to help him" (Participant No 6).

"So, I certainly would look at people differently. I'm more aware of my voice when I speak and getting eye contact and you know – and telling her what I'm doing, as opposed to "would you like to go" and taking her hand. Explaining things to people, because you could hear that voice" (Participant No 7)

"But I can't see how it wouldn't change your practice! I suppose I find if I go on to a ward and there's somebody with Dementia, and I'll say to the staff there, particularly where you go into this one-to-one situation, and we're providing that element of care by people who have had no training. So, I just find myself and I'll say "That's fine. Let her go" or "do this" so I'm nearly looking for it, I suppose, when I go onto the wards now" (Participant No 8)

"Again, it's just those small things like painting round the light switches red, things like that and adding colour to food. Again, we're not at that stage yet, but just being able to know that we have these tools for when things do get bad. So, when things deteriorate, that we have that knowledge on board that we can help and make life easier and make it more comfortable for daddy and that's really good" (Participant No 14).

The VDT® experience also enhanced participants' awareness and appreciation of the effect of the environment upon the person with Dementia. Many recognised how simple changes in the environment, both within the hospital and in the home, could help enhance the person–centred approach. It was believed that such changes would help people with Dementia, from becoming lost or confused or feeling emotions such as vulnerable or fearful. Participants also referred to recognising and attending to the `little things' that matter, for example, changes in signage, improvements in food provision and the use of colours would help improve the care experience. Consequently, some changes to the environment had already been undertaken, as one participant explained:

"So other simple things, if you introduce coloured cutlery and crockery, that they should

improve their eating. So, we've actually done that in one of the wards since, just to see if it has any impact. It's more that we're looking at are the staff on this specific ward, which is prominently elderly care of patients with Dementia, is the amount of time less that they have to give for supporting them with feeding. So, I just think, the benefits are for the organisation and not just for clinical staff on the wards" (Participant No 8).

Overall, participants voiced their enthusiasm with their engagement with the experience and their desire to provide optimal care to people with Dementia was apparent in all the interviews.

However, taking part in the VDT® experience led to some participants reporting feeling psychological distress related to two issues. First, some participants reported an emotional fear, worry and anxiety and thoughts regarding the perceived threat of developing Dementia. As Dementia is becoming a more common part of life, some were concerned that they could develop the condition which led to an ill effect on the participants' emotional and physical health. As reflected by one participant:

"I would be extremely fearful of ever being diagnosed with Dementia. I suppose one of the things that I came away with it, from thinking how can we make people live longer, better and my initial thing was, if I felt like that all the time ..." (Participant No 7).

Secondly, reflecting on practice led some carers and health care staff to feel shame and guilt for the way they previously cared for a person with Dementia. This led to some participants recommending that psychological support be provided to trainees. As one carer explained:

"... this particular one person that I spoke to, said "If I'd have known that, we wouldn't have maybe done certain things." But she just said, she found it upsetting because she had – her mother had had Dementia. ... we don't want to upset or traumatise people, as part of the training, but think we need to be careful, or certainly aware, that people can come out of it and find it upsetting as well "(Participant No 8).

## Recommendations regarding the VDT® and sustainability

The final theme presented is the key recommendations stemming from participating in the VDT® experience.

Although many of the participants identified their awareness of what detracts from good care for people with Dementia, such as being task-orientated, inflexible and disease focused, they did not consider the broader impact of the environment on the patient. They discussed the need for a perceived culture change within the hospital so that current practice could be challenged to enhance the care of the person with Dementia. This led many to recommend the adoption of a holistic approach to Dementia care.

Participants recognised that people who have Dementia could be anywhere within the hospital system and acknowledged that people exist outside their own clinical areas who might need help. This led to a recommendation that the VDT® experience should be rolled out to all staff within the acute care setting and wider to primary and secondary health and social care staff in community and voluntary sectors. In addition, recommendations that the training be delivered to An Garda Siochana, architects, home helps, porters, health care assistants, housekeeping, health and social care professionals and the public were also reported. Many considered that the VDT® training should be mandatory for all health

and social care staff and open to carers. However, one participant believed that the VDT® experience was not suitable for carers at post diagnosis stage or those having difficulty accepting the diagnosis, fearing this would have detrimental consequences to their health.

"I'm truly not convinced that it is that beneficial for everyone. I think it would be too frightening. Again, we were asked to think about whether or not it would be something that would be useful for people with early diagnosis of Dementia and quite frankly I'm not sure anybody could benefit from it, you know. So, I would have grave reservations about clients with Dementia actually experiencing it" (Participant No 1).

Whilst the VDT® programme was recommended, participants believed it should not be viewed as a stand-alone, one-off component of training; instead it should be built upon and incorporated into existing training modules or be viewed as an induction module.

"...for me, this is a starting point. I know we have national training days .... But I don't think in isolation, it's enough. But I think combined with other training; I think there's great merit for it. But for me, because of the number of people in the organisation, who are admitted with Dementia, and who we are asking people to care for them, with no specific training, it's a great starting point for people" (Participant No 8).

"...it would be fabulous as an induction for people who are working with people with Dementia" (Participant No 9).

The VDT® experience was viewed as laying the groundwork on which further developments could be made. The importance of building upon and sustaining the learning and developments achieved through the VDT® experience was emphasised. Suggestions for sustaining the impact of the experience included refresher courses and further training and key learning points being reinforced in a summary booklet.

The inclusivity of the VDT® experience was praised by many participants and was identified as a key factor in its success. The pilot study not only involved front line registered acute staff but also included senior managers, carers and voluntary staff which enabled the experience to be shared and a common awareness and understanding to be gained. The benefits of this approach were illustrated by one participant who explained that due to the involvement of other managers they were able to make changes to the ward environment without rationalization or delay.

A final recommendation focused on the environment within which care is delivered. Within the hospital environment, participants suggested that environmental changes were needed which should become embedded into hospital and staff practice. These initiatives included environmental improvements such as using coloured crockery, use of clear signage and appropriate paint colours within the care environment. Regarding suggested improvements, it was felt this would lead to a more personalised approach to care being adopted. The next section will present a discussion of the findings and the relevance of the results to both the aim and literature surrounding the VDT® experience.

# DISCUSSION

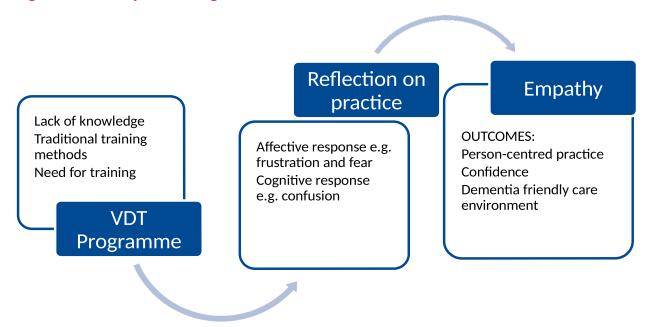
The findings from this study reflect a growing body of evidence on the effectiveness of simulation training in health care settings (McDougall 2015) and around Dementia training (Adefila et al. 2016; Beville 2014). It represents a movement away from traditional classroom based training methods in Dementia care, that tended to be disease focused and failed to address the personhood behind the symptoms (Epp 2003; Adefila et al. 2016). The VDT® programme places the participant in the realm of Dementia and provides participants with an 'insider's view' of the condition to help form a richer understanding of the daily challenges faced by the person with Dementia and consequently be a 'voice' for the person living with Dementia (Beville 2014).

The VDT® programme clearly increased individuals' understanding of the lived experience of Dementia and created a strong sense of empathy, confirming findings reported in previous research (Beville 2002; 2014) and reflective of other Dementia specific virtual reality programmes (Adefila et al. 2016; Doube and McGuire 2016). The distortion of senses and cognitive functions created by the VDT® experience among participants in this study, elicited emotional responses of fear, frustration and helplessness and when the participants had an opportunity to reflect on this experience they formed a richer understanding of the person with Dementia. It is this 'empathetic understanding' that drives change in practice.

Hojat and colleagues (2002) define empathy as an understanding of another person's experience and feelings, generated from a cognitive understanding of thoughts and placing emotional context around the thoughts. Digby and Lee (2016) considered empathy as an essential component in compassionate care and it features as a core element in personcentred care (McCormack and McCance 2017). The findings from this study support this perspective, as participants could reflect and identify previous work practices where they were not person-centred, identify how the care environment could be changed to be more Dementia-friendly, and felt they were more confident in caring for with people with Dementia.

Figure 6 demonstrates the pathway for change: (1) Participants commence with a deficiency in Dementia related knowledge; (2) Participants involvement in the VDT® programme feel affective (fear and frustration) and cognitive (confusion and uncertainty) change and (3) on reflection, the participant is able to develop a sense of empathy for the lived experience of Dementia. (4) This translates into positive outcomes in confidence and understanding of dealing with Dementia and more effective person-centred, compassionate care.

Figure 6: Pathways for change



There was a need for the training: almost two thirds (61%) of participants in this study had attended Dementia specific training programme (other than VDT®) over the past two years, yet almost half (44%) rated their knowledge on Dementia as 'very little'. There was a clear need for good Dementia training and education as 85% of participants indicated that good Dementia knowledge was important for them to do their job.

Timmons and colleagues (2016) reported few acute hospitals in Ireland provided specific Dementia care training, yet 29% of older people admitted to hospital have Dementia. This programme would help provide health care professionals with a deeper understanding of the care they provide and help create a Dementia focused care environment (Waller et al. 2013) to provide a positive hospital experience. This may have a potential knock-on effect on reducing costs (through shorter stays), less post discharge institutionalisation and reduced mortality (Manning et al. 2014). Providing health care professionals and carers with a deeper empathic understanding may help to maintain a person with Dementia living at home, reduce the burden for informal carers and reduce distress for the person with Dementia (Coffey et al 2014). Participants, upon reflection, reported a need to change their practice to better suit the person with Dementia, rather than expecting the person with Dementia to conform to their expectations. This is particularly so for frontline staff in acute settings, where, according to Timmons et al. (2016) a clear necessity for Dementia training is reported.

# **Training programme**

The VDT® programme provides a practice based learning experience delivered by a trained facilitator, core components of effective Dementia specific training programmes as identified by Surr et al. (2016). There was an opportunity for discussion in the debriefing session provided as part of the programme, however, the participants felt this was didactic in nature and was a limited opportunity for effective group reflection. Both Baillie et al. (2016) and Cowdell (2010) have reported on the tendency for Dementia training to be didactic, however Surr et al. (2016) reported that staff confidence could be increased when participatory interactive discussion took place.

The issue of simulation fidelity was raised as a concern among participants, and in simulation training this is a key aspect in guaranteeing as realistic an experience as possible (Feinstein and Cannon 2002). Whilst Beville (2014) indicates that the VDT® programme mimics the symptoms of level 4, moderate Dementia, this information was not made available to participants prior to or on completion of the programme.

The training programme itself needs to be embedded in a structured programme of training and learning in Dementia care. This echoes international (Alzheimer's Disease International 2016b) and national (DoH 2014) policy. This training must be relevant to multi-disciplinary professionals and aimed at promoting competence and compassion; VDT® programme provides both goals. A challenge will be the embedding of the VDT® programme into a wider framework and strategic implementation plan, to best maximise the potential of the training for the individual. Individual learning must be supported by organisational factors to promote implementation of new learning. Participants in the study noted that it was easier to implement change in a unit where they were supported by others within the unit who had experienced the VDT® programme.

Virtual reality training is 'highly resource intensive with the added need for trained facilitators... and technology support' (Qayumi et al. 2014, p.464). Providing this training to all health care professionals and carers would be a costly endeavor. Consideration needs to be given as to how best to maximise its potential in a cost-effective manner. It is clear from this study's findings that virtual reality training also provides a very useful training tool and change effect change.

This research was an evaluation of a small-scale study which was exploratory in design. The findings add to a growing body of evidence on the VDT® programme (Beville 2014; 2002). However, further research is required to confirm many of the claims reported in the literature (Adefila et al. 2016, Doube and McGuire 2016; Beville 2014). The Department of Health have set aside significant funding for research in Dementia care and implementation of the Irish National Dementia Strategy (DoH 2014), and some of this funding could be employed for this strand of that research programme.

# A critical reflection of the evaluation process

The limited amount of research on the VDT® experience indicates an area that is little understood. As such this evaluation sought to provide an insight, but as this is a small-scale evaluation, relying upon self-reported measures, it provides only a snapshot rather than an in-depth view. Such limitations suggest that the results need to be interpreted with caution. As this was a pilot study, further research using a triangulation of research methods such as observations, pre- and post- questionnaires and focus groups, would be needed to draw firm conclusions. Furthermore, most participants were staff; therefore, it is recommended that an increased sample of carers, families and service users are included in future studies. Further research is also recommended to enable conclusions to be drawn about the factors that may facilitate transfer of learning from VDT® experience to practice. This following section presents the key conclusions stemming from this research.

# CONCLUSION

As the number of people with Dementia increases, policy makers will be looking to make decisions about equipping staff with the correct skills and knowledge to deliver effective care. Both nationally and internationally, the VDT® experience is gaining momentum across health sectors and becoming a tool that provides staff with the opportunity to participate in a Dementia–like experience. It offers a person-centred approach to developing an awareness of Dementia from the viewpoint of the patient.

The impact of this upon participants cannot be understated. It has been found to be a highly effective learning tool with participants reporting increased awareness and understanding, leading to changes in practice interactions and movement towards Dementia friendly environments being created. In summary, whilst the VDT® experience on its own is not considered to lead to dramatic change in quality of care, it does provide one step to enable staff and informal carers who care for people with Dementia an opportunity to become more Dementia friendly. Building upon the conclusion, the following section will present the recommendations for policy, evidence based person-centred practice and future research opportunities in this area.

# RECOMMENDATIONS FOR ACTION

From analysing the findings, several recommendations have been made;

#### **Recommendation 1: Continue to invest in Dementia care**

There is a need for multi-disciplinary training and education in Dementia. It is, therefore, recommended that the health service continue to invest in training for staff to improve knowledge and understanding and therefore enhancing the provision of meaningful, personcentred support to people with Dementia.

## Recommendation 2: VDT® experience as part of an induction package

The results of this pilot study indicate that the VDT® experience is potentially a very valuable training programme for staff working in care settings and carers delivering care to a person with Dementia. VDT® training should be available to all disciplines and to carers. In the absence of mandatory training, acute care hospitals would benefit from incorporating this programme into staff training induction packages, albeit with some modifications.

#### Recommendation 3: VDT® modifications

To enhance and build upon the VDT® programme, the delivery of the training would require further refinement:

- A need to ensure the fidelity of training programmes and assure participants of the
  accuracy in representing the lived experience of people with Dementia. Failure to
  provide information on the accuracy of the programme in representing the lived
  experience of Dementia caused some participants to question its fidelity and impact
  on learning.
- Facilitate a structured debriefing session, informing participants of observation that promotes interactive discussion to maximise the learning experience for the individual and team members.
- The signposting to psychological support for all participants to access at the end of the VDT® experience.

### **Recommendation 4: Embedded learning**

The training programme needs to be embedded in a supportive structure of change management aimed at promoting the implementation of evidence based person-centred practice. Implementation science of translating evidence into evidence based practice clearly shows that for effective and lasting change to occur, appropriate support is required at the meso and macro levels within an organisation. Therefore, the VDT® programme must be part of a larger implementation strategy.

# Recommendation 5: Positioning of VDT® programme within the national strategy

Consideration is required on where the VDT® programme fits within an overarching national training strategy. This has significant implications for statutory, community and voluntary organisations in terms of resources.

#### **Recommendation 6: Further research**

Further research is required to examine the full potential of the VDT® programme. This should include process evaluations of effective methods for implementing individual learning and the impact the new learning has on outcome measures for the person with Dementia, carers, health care professionals and service delivery.

In summary, this report represents the perceptions of eighteen participants who engaged in the VDT® experience. This enabled an active empathic experience that distorted participants senses and generated feelings of fear and frustration, that some patients with Dementia may experience. Findings from this evaluation suggest it represents an innovative educational opportunity, that provides a window into the world of a person with Dementia.

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# Interview schedule: An evaluation of the Virtual Dementia Tour®

#### Warm-up

It will be confirmed that the participants have given written consent and wish to proceed to the start the interview.

# **Opening Statements**

The participants will be reminded of the aim of this study and the researcher will clarify the terms of confidentiality regarding this study as follows:

"The aim of this study is to explore the perceptions of the impact of VDT® experience upon practice and upon Dementia care in the future. All disclosed information will be treated confidentially unless required by law i.e. there is a risk to yourself or others".

The researcher will explain that the interview will take between 20-30 minutes.

The researcher will ask the participant to give verbal consent to continue and usage of a digital recorder during the interview, if the participants do not agree only notes will be taken. The researcher will countersign participant consent forms and disseminate as appropriate.

The researcher will remind the participants not to disclose specific patient cases

The researcher will start with an opening statement as follows:

`Thank you for taking your time for this interview today, I want to remind you that there are no wrong answers and the interview can be stopped at any time. ´

#### **Questions**

Please describe your experience of using the Virtual Dementia Tour® Programme.

- Did you find it useful?
- What was the most useful/least useful?
- · How? Please elaborate.

Do you feel the VDT® experience was useful?

- · What worked/didn't work?
- How could the VDT® experience be improved?
- Would you recommend the VDT® programme to colleagues?

How would your VDT® experience change your practice?

- What would you change?
- · Whv?
- What benefit would you foresee this to be a people with Dementia?

#### Final question

• Is there anything else you would like to add?

#### **End of interview**

- Questionnaire: Disseminate questionnaire to the participant.
- Support: The researcher will hand out support pack.
- Thank the participant

6.

the last 24 months?

Yes

		Demographic Q	uestionnaire	
Plea	ase tick one answer.			Ulster University
1.	Are you	Male	Female	
2.	What age are you?	18-24	45-54	
		25-34	55-65	
		66+		
3.	What is your relationship	to the person with Dem	nentia?	
		Spouse/Partner		
		Parent		
		Son/daughter (in law)		
		Sister/ Brother		
		Neighbour		
		Other (please specify)		
4.	How many times per we	ek do you provide care fo	or the person with Dementia?	,
		Daily		
		3 to 6 times per week		
		1 to 2 times per week		
		Less than once per wee	ek	
		Less than once per mor	nth	
5.	How long have you beer	n a caregiver to a person	diagnosed with Dementia?	(Years)

Thank you very much for taking time to complete this questionnaire. Please return it to the researcher.

No

Apart from the VDT® experience, have you attended any other Dementia education/ training in

		Den	nographic Qu	estionnaire		1
Plea	ase tick one answer.					Ulster University
1.	Are you	Male		Female		
2	What age are you?	18-24		45-54		
		25-34		55-65		
		66+				
3.	Please state your current	occupa	tion (i.e. Nurse, OT			
4.	Which sector do you cur	rently w	ork in?			
	Hospital	Comm	unity	Voluntary		
5.	How many years have yo	ou been	working in this sed	ctor?	(Years)	
6.	What is your highest level of education attained?					
	Degree	Diplon	na 📗	Masters/ PhD/	Professional do	oct
	Other					
Woi	rk					
7.	How much time at work	is spent	working with peo	ple with Demen	tia?	
	Hardly any time		A little time	Some	of the time	
	A moderate amount		Most of my time			
8.	How important is it for y job well?	ou to ha	ve a high level of I	Dementia knowlo	edge to enable	e you to do your
	Not at all important	A	little important		Moderately im	portant
	Very important	E	xtremely importa	nt		
9.	Apart from VDT® experie last 24 months?	nce, hav	e you attended ar	ny other Dement	ia education/ t	raining in the
		Yes (		No		

Thank you very much for taking time to complete this questionnaire, please return it to the researcher.







# General Manager's Office, Letterkenny University Hospital, Letterkenny Co. Donegal F92 AE81

Telephone: (074) 9123501 Fax: (074) 9104651

13<sup>th</sup> February 2017

Dr. Paul Slater

Lecturer

Institute of Nursing & Health Reseach

**Ulster University** 

Re: An evaluation of the Virtual Dementia Tour Programme

Dear Dr. Slater,

With reference to application listed above, your application has been considered by members of LUH Ethics Committee and I am happy on behalf of Letterkenny University Hospital Research Ethics Committee to grant Chairman's approval.

Please do not hesitate to contact me if you require any further information.

Yours sincerely

Mr. Seán Murphy

General Manager





Research Ethics Committee Sligo University Hospital Chairman: Dr. John Williams Admin: Mette Jensen Kavanagh

Dr. Paul Slater Room 12J12, Ulster University Shore rd, Newtownabbey, Belfast

17th Jan 2017

# **Re. Research Ethics Application**

Dear Dr. Slater,

The Research Ethics Committee (REC) at Sligo University Hospital has reviewed your submission for ethical review of the study "Evaluation of 'Virtual Dementia Tour" 'Programme"

The study underwent expedited review and the REC Chairman has given a **favourable ethi- cal opinion** for the study for Sligo University Hospital.

Documents reviewed:

- REC Application Form
- Protocol
- Information Sheets
- Consent forms

filh be

- · Interview and Focus Group Schedules
- · PI CV

The REC requires that approved studies submit an annual report to the REC. The annual report for the above study is due on January 25 2018.

Dr John Williams REC Chairperson

Cc Randal Parlour, NMPD

### **RG3** Filter Committee Report Form

Project title	An evaluation of 'the virtual Dementia tour®'	
Chief Investigator	Dr Paul Slater	
Filter Committee	Nursing and Health Research	

This form should be completed by Filter Committees for all research project applications in categories A to D (\*for categories A, B, and D the University's own application form – RG1a and RG1b – will have been submitted; for category C, the national, or ORECNI, application form will have been submitted).

Where substantial changes are required the Filter Committee should return an application to the Chief Investigator for clarification/amendment; the Filter Committee can reject an application if it is thought to be unethical, inappropriate, incomplete or not valid/viable.

Only when satisfied that its requirements have been met in full and any amendments are complete, the Filter Committee should make one of the following recommendations:

The research proposal is complete, of an appropriate standard and is in

- category A and the study may proceed\*
- category B and the study must be submitted to the University's Research Ethics Committee\*\* Please indicate briefly the reason(s) for this categorisation
- category C and the study must be submitted to ORECNI along with the necessary supporting materials from the Research Governance Section\*\*\*
- category D and the study must be submitted to the University's Research Ethics Committee\*\*

Signed:

George Kernohan
Chairperson of Filter Committee

Date: 14 Dec. 16

\*The application form and this assessment should now be returned to the Chief Investigator. The Filter Committee should retain a copy of the complete set of forms.

\*\* The application form and this assessment should now be returned to the Chief Investigator so that he/she can submit the application to the UUREC via the Research Governance section. The Filter Committee should retain a copy of the complete set of forms for their own records.

\*\*\* The application form and this assessment should now be returned to the Chief Investigator so that he/she can prepare for application to a NRES/ORECNI committee. The Filter Committee should retain a copy of the complete set of forms for their own records.

For all categories, details of the application and review outcome should be minuted using the agreed format and forwarded to the Research Governance section



#### Dear Sir/Madam,

### Study Title: An evaluation of the Virtual Dementia Tour (VDT)

Ulster University in partnership with the Nursing Midwifery Planning and Development Unit (NMPD) are undertaking an evaluation of the Virtual Dementia Tour ® (VDT ®). As an attendee, I am writing to invite you to participate in one telephone or face-to-face interview to explore your perceptions of the impact of VDT® upon practice and upon Dementia care in the future. Your opinions on how to develop and build on VDT® experience will also be sought. You will not be asked to disclose specific patient cases.

You are being asked to take part in one interview, lasting between 20-30 minutes. With your permission, they will be digitally recorded; otherwise notes will be taken. Your demographic details such as gender, age and work experience will also be recorded on a separate questionnaire which should take 5-10 minutes to complete. Interviews will be either via telephone or if preferred face-to face. Face-to-face interviews will take place in the Letterkenny and Sligo area and will be arranged on first come, first served basis.

If you would like to take part, please contact the lead researcher Dr. Paul Slater by telephone (**tel. 02890368400**) and/or email (**pf.slater@ulster.ac.uk**) to arrange for a time and date of your convenience for the interview to take place.

This pack aims to provide you with more information about the nature of the project and includes a participant information sheet. Participation is voluntary and you can withdraw at any stage at any time, for any reason, with no consequence. This is not a test and there are no right or wrong answers. Any information that you provide will be confidential and when the results of the study are reported, you will not be identifiable in the findings. Your name will not be recorded on tape or on the demographic sheet; instead you will be allocated a unique code that can only be identified by the researcher.

Thank you for your time and any help you may be able to offer to this study.

Dr Paul Slater

Institute of Nursing and Health Research

Ulster University Belfast, Co Antrim Tel. 028 90368400 E-mail: pf.slater@ulster.ac.uk



# **Participant Information Sheet**

## Study Title: An evaluation of the Virtual Dementia Tour (VDT°)

You are being invited to take part in a research study. Before you decide whether or not to take part it is important that you understand what the research is for and what you will be asked to do. Please take time to read the following information carefully and do not hesitate to ask any questions about anything that might not be clear to you. Make sure you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

#### What is the purpose of the study?

The aim of this study is to evaluate the Virtual Dementia Tour ® (VDT®). The study is devised of 3 strands, this strand of the study, involves face-to-face/ telephone interviews to explore the experience of those who attended the VDT ®. It seeks to explore your perceptions of the impact of VDT® upon practice and upon Dementia care in the future. Your opinions on how to develop and build on this experience will also be sought. You will not be asked to disclose specific patient cases.

#### Why have I been chosen?

You have been chosen to take part in this study because you are a health care professional aged 18 year and over, who has attended the VDT® in the HSE Donegal.

#### What do I have to do?

You will be taking part in a telephone or face-to-face interviews (20-30 min) and complete one demographic questionnaire (5-10 min).

- Interviews will be arranged on first come, first served basis.
- · With permission, the interview will be digitally recorded, otherwise notes will be taken.

If you would like to take part, please contact the lead researcher Dr. Paul Slater by telephone (**tel. 02890368400**) and/or email (**pf.slater@ulster.ac.uk**) to arrange for a time and date of your convenience for the interview to take place.

#### Do I have to take part?

It is up to you whether or not to take part. Your participation is voluntary. If you do decide to take part you will be given this information sheet to keep. If you choose to take part you can change your mind at any time and withdraw from the study without giving a reason or without any consequence. However, if you do withdraw the researcher would reserve the right to include any information that you had given prior to withdrawing from the study.

# What are the risks involved in taking part in this study?

There are no known physical risks associated with this study, however, it is recognised that talking about Dementia/VDT® experience may cause upset. If you did become upset, the interviewer will offer to terminate the interview. Data collection will only recommence if you wish to continue. A support pack will be offered at the end of the interview which outlines organisations you may wish to contact for further information.

#### Are there any possible benefits in taking part?

There are no direct benefits; however, taking part will help to inform the evaluation of the VDT®.

#### Will my taking part be confidential?

All efforts will be made by the researcher to ensure the confidentiality of information, [except as might be required by law]. The researcher will ensure that no identifying information is included in the transcripts and that no participant is identified in the final report. Any further reports or publications stemming from this study will not contain any identifying features.

# What will happen to the information that I give?

With permission, the interviews will be digitally recorded. All data will be stored in accordance with UK Data Protection Legislation (1998). The digital recording of the interview will be stored in a locked filing cabinet in the research teams' office within Ulster University. The transcript of the interview will be stored on the researcher's computer which is password protected. The digital recording and transcript will not be used for any other purpose other than this study. Data will be stored in the researchers' office for 10 years and then destroyed.

# What if something goes wrong?

In the highly unlikely event that something should go wrong, the Ulster University has procedures in place for reporting, investigating, recording and handling of complaints. Any complaints or concerns will be taken seriously and the Chief Investigator's information details can be found below.

### What will happen to the results of the study?

At the end of evaluation study the findings will be available online from the NMPD HSE North West website and the findings will be sent for publication in a peer reviewed journal and presented at a conference.

# Who is organising and funding the research?

This research is being undertaken by Ulster University and is being funded by the Nursing and Midwifery Planning and Development Unit HSE North West.

#### Who has reviewed this study?

The study has been approved by the Ulster University Institute of Nursing and Health Research Governance Filter Committee (January 2017), Letterkenny University Hospital Research Ethics Committee and Sligo General Hospital Research Ethics Committee (February 2017).

#### **Further Information**

If you wish to contact someone for further information regarding this study you can contact either:

Dr Paul Slater (Lead) Dr Felicity Hasson

Email: *pf.slater@ulster.ac.uk* Email: *f.hasson@ulster.ac.uk* Tel: 00 44 (0) 28 90 36066 Tel: 00 44 (0) 28 90 36 6895

If you are unhappy about any aspect of this study please contact Mr Nick Curry (Senior Administrative Officer) who is an independent member of Ulster University not connected with this research study. Mr Nick Curry: Telephone: 00 44 (0) 28 90 366629 E-mail: n.curry@ulster.ac.uk



### **Further Information**

If you have any queries or concerns arising from this study or from contact with the researcher, there are a number of people and organisations who would be happy to help you. They can provide information and supply to you and clarify any issues which might have arisen for you. You can contact them at any time, just after the interview, days later or even weeks after.

#### **The Alzheimer Society of Ireland**

National Helpline: 1 800 341 341 Email: helpline@alzheimer.ie

#### **Dementia Adviser Services**

The Alzheimer Society of Ireland offers Dementia Advisers who work with people with Dementia and their families and carers to provide a highly responsive and individualised information and signposting service. For the region of County Sligo, County Leitrim and South County Donegal please contact Dementia Adviser - Majella O'Donnell: Phone: 086 7796390 Email: modonnell@alzheimer.ie

### **Complaints about the Research**

If you are not satisfied with the manner in which this study was conducted, or if you have any concerns, complaints, or general questions about the research as a research participant, please contact Dr Paul Slater 00 44 (0) 28 90 36 8404 or email *pf.slater@ulster.ac.uk*. If you wish to speak to someone other than a member of the research team or if you cannot reach the research team, please contact Mr Nick. Curry on Tel: 028 90 36 6629 or email: *n.curry@ulster.ac.uk*. Mr Nick Curry is an informed individual and not a member of the research team.



# **Further Information**

If you have any queries or concerns arising from this study or from contact with the researcher, there are a number of people and organisations who would be happy to help you. They can provide information and supply to you and clarify any issues which might have arisen for you. You can contact them at any time, just after the interview, days later or even weeks after.

# **The Alzheimer Society of Ireland**

National Helpline: 1 800 341 341 Email: helpline@alzheimer.ie

Health care professionals: The Alzheimer Society of Ireland offers a healthcare professional section where you can find information about their services and where they are across the country; download our referral forms for day care, home care, respite care, case management and drop-in services; check out our family carer training programme; view all ASI publications and research and link to useful organisations involved in Dementia in Ireland. For more information please visit: https://www.alzheimer.ie/Services-Support/Health-Care-Professionals.aspx

#### **Complaints about the Research**

If you are not satisfied with the manner in which this study was conducted, or if you have any concerns, complaints, or general questions about the research as a research participant, please contact Dr Paul Slater 00 44 (0) 28 90 36 8404 or email *pf.slater@ulster.ac.uk*. If you wish to speak to someone other than a member of the research team or if you cannot reach the research team, please contact Mr Nick. Curry on Tel: 028 90 36 6629 or email: *n.curry@ulster.ac.uk*. Mr Nick Curry is an informed individual and not a member of the research team.



# **Consent Form**

Title of Study:	An evaluation of the Virtual Dementia Tour (VDT®)			
Name of Investigator:	Dr Paul Slater (PI) and Dr Felicity Hasson.			
Please tick:				
the information	I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised.			
am free to witho	<ul> <li>I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way.</li> </ul>			
<ul> <li>I understand that if I withdraw during the study the researcher would reserve the right to include any information I have given prior to leaving the interview.</li> </ul>				
<ul> <li>I understand that the researcher will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law).</li> </ul>				
<ul> <li>I understand that the information I give will be shared with the researcher and that all efforts will be made by the researcher to ensure the confidentiality of that information.</li> </ul>				
I agree to the interview being digitally recorded.				
• I agree to take p	art in the above study.			
Name of participant:				
Signature	Date			
Contact email address:				
Contact telephone numb	er:			
Name of Researcher				
Signature	Date			









