Digital Storytelling and Dementia

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Summary

This document reports the findings of a brief literature review looking at the possible impact that digital storytelling (with a significant element of reminiscence) might have on people living with dementia and their carers. It has been carried out on behalf of the Outreach Team at Tyne & Wear Archives and Museums (TWAM). Alongside the review, conversations were held with a few people working in the field of dementia care.

Members of TWAM’s Outreach Team have undertaken digital storytelling workshops with people living with dementia and their carers. Anecdotal observations of these workshops suggested that the people with dementia demonstrated an increased ability to recognise their own recorded voices and stories, and to recognise other participants, as the workshop progressed. This literature review was commissioned on the assumption that existing academic research might provide insights that would help the Outreach Team understand what was taking place during those workshops.

The review had a number of aims:

• To provide the Outreach Team with a better understanding of dementia;
• To make suggestions about how the symptoms of different forms of dementia might affect the working practices of the Outreach Team;
• To provide some insight into the intersection between the processes of digital storytelling and the different forms of dementia;
• To begin to formulate the value of this type of work (with the aim of developing a ‘Social Return On Investment’-type argument) so that the Outreach Team could advocate their work to partners and funding bodies.

The review process highlighted how the digital storytelling process overlapped with various forms of non-pharmacological (or psycho-social) therapeutic techniques. These techniques are the focus of a great deal of research and academic study. The review draws on various meta-studies to point to the possible impact of digital storytelling and the potential mechanisms underpinning this. The discussion of impact and mechanisms is essential to developing an evidence base for improving practice and for developing an argument for the value of this type of work.

The review begins with an outline description of the different forms of dementia. This is accompanied by a separate spreadsheet which breaks down the symptoms of dementia to promote further discussion regarding the implications of these symptoms for working practices.

The review then turns to look at the possible impacts of digital storytelling. The digital storytelling process contained a significant element of reminiscence; for this reason much of the focus of the review has been on reminiscence. However, as the evaluation of Culture Shock indicated (Culture Unlimited, 2011), the digital storytelling process involves more than simply reminiscence. The impacts of digital storytelling arose out of features such as the production of the DVD, the

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1 Prof. Ian McKeith (expert in dementia with Lewy bodies), Prof. Ian James (expert in care for the elderly) & Dr. Rosie Stenhouse (lecturer in mental health nursing)

2 Originally, the reviewer intended to look at neuro-psychological research to help elucidate this topic. However, the on-going, and largely unresolved, debate about the limits and value of these studies suggested that it would be prudent not to pursue this line of inquiry too far.
screenings of the films and the validation of the stories through their inclusion within the museum collection. At this point it is better to consider the digital storytelling workshops as a very rich experience with many different elements that, individually or in concert, may have had positive outcomes for participants. By looking at research on different therapeutic techniques the review begins to make suggestions as to what those impacts might be and, where possible, why.

Finally the review builds on the discussion of impacts and value to discuss cost-benefit analyses of therapeutic approaches and the tools / data that the Outreach Team will need to piece together to create an argument for the value of their work. At the request of the Outreach Team, this section focuses on the Social Return On Investment approach.

Recommendations for future work or actions are made throughout the review and will be boxed to highlight them. The recommendations will also be collated and presented together at the end of the document.

A full Bibliography has been included. Where possible, electronic copies of documents have been collated and presented to TWAM to facilitate further reading.
Key Points

There are different forms of dementia. The most common are Alzheimer’s Disease, Vascular Dementia, Dementia with Lewy Bodies and Fronto-Temporal Dementia.

The different symptoms of these forms of dementia mean that it is important for Outreach staff to tailor their work to the capabilities of the people living with each form of dementia, where possible.

The digital storytelling workshops involved object handling, reminiscence and digital storytelling. The workshops were a ‘rich’ environment with many elements that overlapped with different therapeutic techniques.

The techniques that are most relevant to thinking about Outreach work are:

- Memory Stimulation
- Artists for Alzheimer’s programmes
- Validation Therapy
- Drama & storytelling
- Reminiscence

Overall, there is insufficient clinical quality data regarding the therapeutic value of these approaches and researchers are wary of making strong conclusions about them. Despite this anecdotal evidence suggests that they have stronger support from the caring professions.

With this in mind it seems that Outreach work could potentially impact:

- cognition in the person with dementia;
- quality of life of the person with dementia and their care-giver;
- the care-giver’s mental health.
- autobiographical memory in the person with dementia;
- quality of relationship between the person with dementia and their carer;
- depression and anxiety for both parties;
- stress in both parties;
- general functional ability of the person living with dementia.

Measuring the impact of therapeutic approaches is difficult but a body of work and tools have already been developed with museum staff could draw upon to evaluate the value of their own work. Most of these tools (questionnaires) are free to use and do not require specialist training to implement.

The tools, along with publicly available information, would enable museum staff to work with stakeholders to develop a ‘Social Return on Investment’ analysis of the value of Outreach work.
1 Dementia

1.1 Types of dementia

Whilst the incidence of dementia increases amongst older populations, ageing and dementia are two separate processes. Cognitive ageing is a normal process that occurs within everyone to a greater or lesser degree (Deary, 2009; Strauch, 2011). Dementia is an additional process that can be seen as overlaid on top of the processes of ageing. That said, the boundary between ‘normal’ ageing and dementia can be less than clear cut since a definite diagnosis may only be possible post-mortem. “At the most objective end of ‘mental’ illness […] it turns out that there is no hard scientific boundary between disease and normality. Lines can be drawn, but their exact location is a matter of evaluative judgement based on correlations between neuro-pathology and symptoms and signs. But which symptoms and signs? How much forgetfulness is pathological? What counts as normal ageing?” (Hughes, Louw & Sabat, 2006, 2)

Dementia is not a disease in itself; it is a condition characterised by a group of symptoms associated with problems with memory and thinking. There are many different types of dementia, caused by different conditions that affect the brain. Many of these conditions are described as neurodegenerative, that is, they cause a gradual deterioration of the cells in the brain (Alzheimer’s Society, 2009).

People with dementia may:

- seem very confused;
- forget names, people and places;
- have problems thinking of the right things to say;
- find it hard to do everyday things and to complete tasks;
- say or ask things over and over again;
- speak or behave in ways that are out of character for them and may be inappropriate for the situation (Alzheimer’s Society, 2009).

Alzheimer’s disease (AD) is the most common form of dementia (about 60 per cent of people with a dementia are diagnosed with Alzheimer’s disease (Alzheimer’s Society, 2009)) and the most widely studied (see Table 1, below). However there are other types of dementia: after Alzheimer’s, the 3 next-most common forms of dementia are vascular dementia, dementia with Lewy bodies (DLB) (McKeith, 2007) and fronto-temporal dementia (which itself has sub-variants (FRONTIER, 2008)).
In a review by Diaz et al. (2005) the following types were identified:

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Dementia Patients</th>
<th>% of total</th>
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<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>380</td>
<td>68.5</td>
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<tr>
<td>Vascular dementia</td>
<td>57</td>
<td>10.3</td>
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<tr>
<td>Lewy body dementia</td>
<td>25</td>
<td>4.5</td>
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<tr>
<td>Fronto-temporal dementia</td>
<td>23</td>
<td>4.1</td>
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<tr>
<td>Mixed dementia</td>
<td>31</td>
<td>5.6</td>
</tr>
<tr>
<td>Other kind of dementia</td>
<td>39</td>
<td>7.0</td>
</tr>
<tr>
<td>Total</td>
<td>555</td>
<td>100.0</td>
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</tbody>
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Table 1: Number and percentages of patients with different diagnoses of dementia found in centres participating in the European Alzheimer’s Disease Consortium (EADC). Taken from Diaz et al. (2005)

Table 1 includes ‘mixed dementia’. James commented (2011) that, in his experience, people living with dementia are often found to be suffering from a mixture of types of dementia which makes it more difficult to determine the diagnosis and appropriate therapeutic responses. Diaz and co-authors also broke down the category of ‘Other kinds of dementia’, this included:

- Depressive pseudo-dementia;
- Parkinson’s disease;
- Delirium;
- Alcohol;
- Progressive aphasia;
- Creuzfeldt Jakob disease;
- Normotensive hydrocephalus;
- Supranuclear plasy;
- Semantic dementia³.

The key point here is that there are many different causes of dementia. The significance of the different types of dementia is that they each affect the brain in different ways, damaging different locations and therefore causing different symptoms. This means that the subjective experience of a person with Alzheimer’s will be different from that of a person with DLB. For instance, a person living with DLB will have experience less damage to their short term memory (compared to someone with Alzheimer’s) but their visual experience will be considerably changed. Whilst some work has been done looking at the subjective experience of people living with Alzheimer’s (Hutchings et al., 2010), McKeith was unaware of any work on the subjective experience of people with DLB (2011). Notably, both Alzheimer’s disease and Fronto-temporal Dementia result in people experience greater difficulty in understanding verbal prompts and in expressing themselves verbally (Graham & Warner, 2009 and FRONTIER, 2008).

Consequently when working with people with dementia it is important to understand their background, the particular type of dementia & its progression. To express it positively, it is

³ Unlike Diaz et al., FRONTIER (2008) include ‘Semantic dementia’ as a sub-variant of fronto-temporal dementia. I have followed FRONTIER in this case.
important not to assume that ‘dementia’ is catch-all category but rather to respond to each person individually based on their situation. (Zeisel, 2009).

Recommendation: when working with partner organisations, Outreach staff should endeavour to determine the diagnosis of the people they will be working with and what their capabilities in order to best respond to each person’s need.

When thinking about dementia and therapeutic interventions, it must be borne in mind that (at the moment) there is no cure for dementia. The impact of any intervention has to be seen against a backdrop of declining abilities (James, 2011). So any impact will be experienced as a change in the rate of decline rather than any sort of recovery.

1.2 Symptoms of dementia
To help Outreach Team members better understand the different forms of dementia, a separate spreadsheet has been produced which breaks down the symptoms of Alzheimer’s Disease, Vascular Dementia, Dementia with Lewy Bodies and Fronto-temporal Dementia. The key points are presented below, see Section 1.2.2. The aim is not to present an exhaustive description but to highlight some significant factors, both positive and negative, that may influence Outreach staff working practices.

1.2.1 Different sorts of memory
Before proceeding to think about dementia and therapeutic techniques, it is worth pausing to think about memory. There are different forms of memory, following Murphy & Naish (2006):

- Working memory – memory for the last few seconds or minutes – used to facilitate daily activities and maintain a sense of the present;
- Short-term memory – memory for the last few minutes or hours – think of this as long-term memory that is too new to become established within the brain;
- Long-term memory – memory for the past days to years – memory that has been well-established within the brain.

Long term memory can be further broken, as in the Figure 1 (below). The point is that each of these different forms of memory has a different neural underpinning. This means that they will be affected to different extents by dementia. For example: The amygdala is not usually affected by Alzheimer’s Disease until late in its progression; the amygdala is involved in emotional responses, so we can expect that emotional responses to stimuli will remain intact until someone is suffering from severe dementia. Similarly, the cerebellum is also unaffected by Alzheimer’s Disease until its later stages (Pickutab et al., 1999) and this plays an important role in the control of learnt motor processes.

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4 The sources for each point are given in the additional spreadsheet.
1.2.2 Symptoms of different sorts of dementia

Alzheimer’s Disease

• Compared to DLB - visual perception relatively unaffected;
• Emotional sensitivity, expression and perception remain intact throughout most of the disease. This includes being perceptive of other people’s facial expressions and body language;
• Ability to compare outcomes of actions with intentions may be impaired from early in disease leading to actions being repeated despite outcomes;
• People with AD retain the ability to play social roles or respond to the social environment with appropriate scripts/schemas;
• Damage to the executive function makes it difficult for people living with AD to organise sequences of events into a single process;
• Problems with language and memory;
• Increase difficulty with scene recognition;
• Damage to the process of indexing recent memories and storing them in long term memory;
• Damage to the process of retrieving memories from long term storage;
• Damage to process that inhibit destructive or socially unacceptable behaviours;
• Problems with language - ability to understand words that are heard and recall words to express ideas;
• Despite problems with language person with AD may still have ideas and intentions that they wish to express;
• Learnt behaviours and motor processes may remain relatively intact during earlier stages of AD.

Vascular dementia

• Symptoms are not systematic - depends on the regions of the brain affected by the poor blood flow;
• Often language, memory and personality are affected early on;
• Progression of vascular dementia is step-wise, compared to the more continuous decline of other forms of dementia;
• People may have periods of lucidity in the early stages.

Dementia with Lewy Bodies

• Visual perception is strongly affected by DLB;
• Short-term memory may be relatively unaffected in a person with DLB in the early stages, but they may have greater difficulties with attention and concentration;
• People with dementia with Lewy bodies are likely to retain their own recognisable personality and knowledge throughout the course of the disease;
• Personality and knowledge be masked by drowsiness, distraction caused by hallucinations and by an inability to find words to express what they mean to say;
• The combination of cognitive, psychiatric, motor and autonomic symptoms means that DLB patients are significantly more impaired in their activities of daily living than AD patients with equivalent neuropsychological test scores;
• Visual hallucinations are another important symptom. Some people may become agitated or angry if others challenge the image as imaginary or false, however not all visual hallucinations are distressing to the person affected;
• These hallucinations consist of well-formed, detailed and animate figures, provoking emotional responses varying from fear or amusement to indifference, usually with some insight into the unreality of the episode when it has finished;
• Fluctuations in attention and alertness is the third of the three main symptoms. The person’s level of alertness and confusion can markedly change from day to day, hour to hour and even minute to minute;
• Some people with dementia with Lewy bodies experience delusions stimulated by features in the external environment.

Fronto-temporal dementia - general
• Not uncommonly, individuals with frontotemporal dementia show a limited awareness of their deficits in thinking and changes in behaviour and a reduced understanding of the impact of their condition on friends and families;
• Recent memories may be preserved. Expression may be inhibited through problems with language;
• Simple instructions and the use of simple words are likely to improve comprehension. Use of visual supports, such as drawings or photos, may also be helpful in situations where verbal expression is disrupted.

Fronto-temporal dementia – semantic dementia
• Increased difficulty with object recognition;
• Progressive breakdown in meaning systems underlying language;
• Increased difficulty with recognising familiar people;
• Abilities to do puzzles, jigsaws and sporting skills may be retained.

Fronto-temporal dementia – progressive non-fluent aphasia
• Ability to speak fluently is affected: Some patients have slurring of speech whereas others are able to articulate words but produce frequent near misses;
• Understanding of word meaning is preserved, but patients with PNFA have problems comprehending sentences and following conversations, especially if there are a number of speakers.

Fronto-temporal dementia – behavioural variant FTD
• Changes in behaviour and personality, difficulty relating to other people and difficulty organising day-to-day activities;
• The person’s mood and behaviour may become fixed and difficult to change, making individuals appear selfish and unfeeling. A loss of empathy and emotional warmth is very common;
• Apathy or lack of motivation is very common. Others lose normal inhibitions;
• Difficulty in reasoning, judgement, organisation and planning is frequent, along with a reduction in spontaneous conversation.
Hopefully this approach will help the Outreach Team respond in a more nuanced fashion to each individual’s condition. The weakness of this approach is that it focuses on the symptoms of the condition and runs the risk of losing sight of the individual.

1.3 Wider effects of dementia
One of the most traumatic aspects of dementia is that erodes our experience of self-hood... The story of our selves is maintained through our memories (James, 2011) and through our bodies (Walker Bynum, 2005) and through the community we live within (Tallis, 2011). The sense of a coherent life narrative is broken by dementia.

The breakdown of personal narrative and the increasing difficulty with communication strains the bonds between the individual and their surrounding community. This can leads to isolation and the carer’s perception that the person they knew has ‘gone’. This means that therapeutic interventions should look not only at the impact on the individual with dementia but also on the impact on the carers and the impact on the relationships between them (Moniz-Cook et al., 2008; Woods et al., 2009). See Section 3.2 for more on this.

Increased difficulty in retaining short-term memories has the side-effect that people suffering from this are less able to live autonomously and become more dependent on others. This too can corrode the person’s sense of self or personal dignity.

Prof. James (2011) suggested that it the idea of schemas / scripts is helpful when thinking about the behaviour of people living with dementia. A schema is a mix of memories or learnt behaviours. We use scripts every day in order to get through different social situations but people suffering from dementia slip in and out of them (“timeslips”) even though they might not be the ‘right’ script for that moment. For example, they might wake up and slip into a ‘getting ready to go out to work’ schema even though they retired years ago. Once in the script, people with dementia live within it and staff have to find a way to get them out with distressing them by attempting to confront them with reality. A care organisation is reported as using a fake bus-stop outside their care home as a means of ‘holding’ patients until they could slip back out of the schema (Miller, 2010). The problem is less with the fact of the timeslip and more with how the timeslip is managed.

The review did not touch on more person-centred approaches to the care of people with dementia until directed towards key authors by Dr Stenhouse. This is worthy of further study as many of the outcomes of non-pharmacological therapies address these issues of self, autonomy and relationships (see below).

Recommendation: further study of person-centred approaches to dementia care could be undertaken to understand how reminiscence / digital storytelling fits into this wider picture.

1.4 Cognitive Reserve
One of the striking features of dementia is that post-mortem studies have indicated that similar levels of damage to the brain do not necessarily result in the same levels of decline in ability and behaviour in different individuals. This has been observed in Alzheimer’s disease (Stern, 2006) and DLB (Markesbery et al., 2009). It seems safe to assume that it applies in other forms of dementia too. This has lead researchers to develop the idea of ‘cognitive reserve’ (Stern 2002 & 2006).
The mechanisms that underpin these observations are not clear. Stern developed the idea as a way of laying out different possible mechanisms by which the brain respond to the damage caused by dementia and thereby suggesting new directions of research. The 3 mechanisms (Stern, 2002) are:

- Brain reserve or threshold – a passive model that says each person has a different innate reserve and therefore each person can deal with the neurological insults caused by dementia to a different extent.
- Cognitive reserve – a more active model that each person, over the course of their life, has built up reserve through their activity through education, occupational activity and so on which enables them to withstand the assault of dementia differently
- Compensatory cognitive reserve – an active model which proposed that individual’s brains can adapt to damage by recruiting other, undamaged parts of the brain (not normally involved in the particular, affected task) to achieve the goal at hand.

The model proposed by Valenzuela et al. (2008) appears to be similar to the cognitive reserve model whilst the model developed by Park & Reuter-Lorenz (2009) is a form of the compensatory model. Valenzuela et al. (2008) and Park & Reuter-Lorenz (2009) each point to neural mechanisms at the foundation of their model but the mechanisms are different.

This topic may seem somewhat esoteric but it has practical implications. Despite their differences, all of the models agree that people with a greater life experience (i.e. higher education, people with a healthier lifestyle and people with more stimulating lives that force them to use their brains) are more likely to have a higher cognitive reserve. This implies that cultural interventions might contribute to cognitive reserve. However, Strauch (2011) rightly raises the questions – When do those interventions needs to take place? Is there an upper age limit? Can we continue to intervene and possibly improve the active reserve capacity even when a disease such as dementia has already begun to take effect?

This is where the nuances come into play. For instance, the work by Park & Reuter-Lorenz (2009) and Cherry et al. (2010) suggests that the brain will continue to adapt to damage until the point where the damage exceeds the adaptive capacity. From this we could infer that stimulating and engaging activity (such as working with the Outreach Team) throughout life and in the early- and middle-stages of dementia could have an impact on the person’s ability to respond to dementia.

This section has attempted to outline aspects of the different forms of dementia, particularly those that might shape the form of Outreach workshops. The next section builds on this by encouraging the Outreach Team to reconsider in detail what it is they are doing in their workshops by relating their practices to existing therapeutic techniques.
2 Digital Storytelling as therapy

2.1 The elements of digital storytelling
As noted earlier, the digital storytelling workshops are a rich experience many of the elements of
the process may well contribute to their impact on people with dementia and their carers. The
evaluation of the Culture Shock project (Culture Unlimited, 2011) more generally has shown how
different aspects of the project resulted in positive outcomes for participants. The aim here is not
to reiterate that work but to draw attention to what happens during a workshop (or series of
workshops) before going on to think about why these things matter.

Digital storytelling workshops might involve:

• People responding creatively to stimuli;
• People recounting stories from their lives;
• Participants listening to each-other’s stories;
• People being listened to with acceptance;
• Participants finding that their stories and their knowledge is being given value;
• People with dementia and their carers experiencing a sense of ‘being normal’.

Alongside these the workshops might feature more practical but nonetheless important features:

• People wearing name badges;
• People’s names being frequently repeated;
• Content of stories being rehearsed and repeated;
• Workshops taking place in a safe but non-institutional setting.

2.2 Overlaps with other therapeutic techniques
Some of the elements listed above overlap with existing good practice guideline for the care of
people with dementia or with existing psycho-social therapies (discussed below). For instance:

• Outreach team members may listen to participants stories in a manner that values their
  contribution and does not make judgements on it’s veracity (or otherwise) – this has some
  overlap with the ideas of Validation Therapy (VTI, n.d.);
• Workshops may focus on using objects to prompt reminiscence – this shares some features
  with Reminiscence Therapy (Woods et al., 2005a);
• Names of participants may be frequently repeated throughout the course of the
  workshops – this bears some similarity to spaced retrieval memory stimulation
  programmes (de Vreese et al., 2001), though without the controlled timing of repetitions.

It is also worth reflecting on how current Outreach practices match those developed by other
cultural organisations. An important precedent is the Artists for Alzheimers (ARTZ) programme
(Zeisel, 2009) which was the precursor to the well-known ‘Meet Me at MoMA’ programme
(Mittelman & Epstein, 2008; MoMA, 2008 & 2010). Zeisel (2009, 95-97) discusses the principles
used by the Artists for Alzheimers programme:

• Set the stage – preparatory work – use name tags;
• Introduce yourself – wear name tag and point to tag when verbally introducing self;
• Employ friendly body language;
• Alleviate participants’ anxiety about where they are;
• Alleviate participants’ anxiety about why they are there;
• Involve each participant;
• Avoid testing;
• Make the experience positive – structure workshop to reinforce self-esteem;
• Positively reinforce – when participants grasp ideas or provide insight, without seeming surprised;
• Make everything failure free.

What is interesting about Artists for Alzheimers is that it was employed in both art galleries, working with paintings, and museums, notably the Harvard Museum of Natural History and the museum of National Heritage (Lexington), working with museum objects (Zeisel, 2009, 100).

Recommendation: that Outreach Team members actively reflect on the content of workshops sessions.

Recommendation: that recordings of workshops are made to facilitate content analysis, using aspects of therapeutic techniques as a framework.
3 Non-pharmacological therapies

Non-pharmacological therapies, also referred to as psycho-social therapies are a class of treatments for aspects of dementia that, as the name suggests, don’t involve the use of drugs. There are a wide range of therapies available and there is considerable debate regarding their effectiveness. This section of the report has 2 goals: The report will discuss some of the therapeutic techniques available focusing on the ones which share some commonalities with object handling, reminiscence and digital storytelling. The report will also discuss some of the available information on the outcomes and effectiveness of these approaches and how they can be measured. Thinking about the precise nature of outcomes is helpful when beginning to formulate an analysis of the benefits of this kind of work (in Section 4)

3.1 Description of non-pharmacological approaches

A range of non-pharmacological approaches were identified by Douglas et al. (2004). They listed:

**Standard therapies**
- Behavioural therapy
- Reality orientation
- Validation therapy
- Reminiscence therapy

**Alternative therapies**
- Art therapy
- Music therapy
- Activity therapy
- Complementary therapy
- Aromatherapy
- Bright-light therapy
- Multisensory approaches

**Brief psychotherapies**
- Cognitive–behavioural therapy
- Interpersonal therapy

Junaid and Hegde (2007) would add ‘supportive psychotherapy’ to that final group in the list. Whilst Holm et al. (2005) and Lepp et al. (2003) would add drama and storytelling to the list. (Holm et al. (2005) and Lepp et al. (2003) report different aspects of the same research project.)

Douglas et al. (2004) identify common features amongst the approaches that they review: “One striking thing is the move towards more person-centred forms of care. Within this approach, greater attempts are made to understand the individual’s experience of dementia and to employ strategies to improve the person’s quality of life. A further shared feature is the systemic perspective, that is, the need to work with systems (families, professional carers, organisations, etc.). Indeed, care staff and families are usually integral to treatment strategies. It is evident, therefore, that training of carers (both professional and family) is an important part of most treatment programmes. In fact, one study study (Bird et al. 2002) suggested that the most
common interventions for psychological and behavioural symptoms of dementia were not necessarily specific therapies but working with carers or nursing home staff to change the attitudes and behaviour of those in their care."

The review by Douglas carries an “Invited Commentary” by Woods. He helpfully observes that the aims of these therapeutic approaches are not always clear or, if they are clear, they vary from therapy to therapy. So… “Reality orientation, for example, has had a clear focus on cognition, particularly orientation. In a recent trial, the changes in cognitive function were of the same order of magnitude as those reported in trials of acetylcholinesterase inhibitors. In its new form, it is associated with improvements in quality of life, but there is no suggestion that it would, or should, affect [behavioural and psychological symptoms of dementia (BPSD)]. Reminiscence work has had a variety of aims, plausibly spanning both cognition (autobiographical memory) and mood. Validation therapy, with its emphasis on the emotional content of communication, similarly should have its main impact on affect. The ‘alternative’ therapies also have a range of potential aims, although the putative impact of aromatherapy and music therapy on arousal levels is of particular interest, if this is seen as a possible factor in behaviours described as agitated.”

As noted in Section 2.2, digital storytelling seems to overlap with a number of psycho-social therapeutic techniques. The following sub-sections look in more detail at a number of approaches which appear to be relevant to the sort of work that Outreach engage in.

3.1.1 Memory stimulation (aka ‘Space Retrieval’)
As discussed earlier, in Section 1.2.1, there are different forms of memory. Memory stimulation techniques are concerned with strengthening or supporting the short-term memory of people with dementia.

Early work, by Camp and his colleagues, focused on a technique they label “spaced retrieval”, later referred to as the “expanding rehearsal technique” (Camp et al., 1996; Cherry et al., 1999). Information is repeated initially quite frequently and then with ever greater time between the repetitions with carers asking questions about the information to check that the information has been remembered. If the information is remembered then the interval between repetitions is extended. The work showed that this technique could induce people with Alzheimer’s disease to remember new information.

They suggested that the underlying mechanism is linked to ‘implicit memory’. de Vreese and co-authors (2001, 797) define implicit memory as; “the automatic acquisition of verbal and non-verbal knowledge or skills (i.e. procedural knowledge) in the absence of conscious recollection of the content and the circumstances in which learning takes place. The implicit memory which is not open to conscious introspection and is non-volitional has been shown to be relatively well preserved until the later stages of AD”

Later reviews of research into this technique (Kasl-Godley & Gatz, 2000; de Vreese et al., 2001; Grandmaison & Simard, 2003) strongly support the conclusion that it can have an effect on the ability of patients with Alzheimer’s to recall certain types of information. It should be noted that the technique is very programmatic with a tightly defined set of procedures.
The point here is that the Outreach team noted an increased ability of participants in workshops to recognise each other and to recall earlier activity. These studies suggest that participants’ capacity to remember were perhaps not as ‘broken’ (for lack of a better phrase) as the workshop leaders and caregivers thought. The studies also suggest that if we looked at a recording of a digital storytelling workshop, we might observe frequent repetition of key pieces of information (e.g. people’s names) and the presence of visual cues which may have (inadvertently) acted to rehearse and strengthen the participants’ memories...

3.1.2 Artists for Alzheimer’s (ARTZ) / Meet me at MoMa

The Artists for Alzheimer’s (ARTZ) programme could be thought of as a specific art therapy programme. Meet me at MoMA, which is often mentioned in museum circles, developed out of the ARTZ programme (Zeisel, 2009, 88). What is interesting about the ARTZ programme is that it is explicitly designed to work with museum and gallery collections and has been implemented in museum settings. A full description can be found in Zeisel’s book, ‘I’m Still Here: A New Philosophy of Alzheimer’s Care’ (2009).

The programme is based on the idea that artistic response to the arts in general, involves multiple centres distributed throughout the brain and, as such, these responses are less badly affected by damage at single locations in the brain. Consequently, even people with later stages of Alzheimer’s Disease can respond artistically if activities are carefully structured.

The programme has a specific structure:

- Preliminary research – taking images of objects / paintings into care settings to ask people living with dementia for their responses to the paintings (Zeisel, 2009, 90-91).
- First visit – museum staff visit group in their home setting with images of objects/paintings that will be seen on the tour and holds discussion with the group.
- Second visit – group visits museum with care staff and museum staff lead tour, possibly in multiple small groups running in parallel. The aim is to elicit responses from the participants about what they see and feel. The session ends with participants making their own drawings of the artwork they saw.
- Third visit – museum staff visits group in their home setting: participants encouraged to bring their own objects and tell stories before creating own artwork.

Additional advice from MoMA is available on line (MoMA, 2008 & 2010).

Zeisel (2009, 92) argues that people with dementia can respond in a variety of ways to artworks, through perceiving and describing; telling a story; linking it to their own lives; identifying emotions in the painting; identifying objects in the painting; making critical judgements.

The comments from Zeisel suggest that the programme encourages ‘re-personalisation’ (James, 2011). That is, the carers witness the re-emergence of the person through the participants responses to paintings and through their self-expression in their artworks. The evaluation of ‘Meet me at MoMA’ reaches similar conclusions (Mittleman & Epstein, 2008). The authors also point out that, for family carers, the act of being together in a culturally valued space made them feel normal again, which impacted on their sense of personal wellbeing. The Meet me at MoMA tours took place on a day when the gallery was closed to the public, this was done for pragmatic reasons but “it [suggested] to participants that they [were] V.I.P.’s, as they [were] given a private tour
when the galleries [were] empty” (Mittleman & Epstein, 2008). Again, the evaluation suggests that this has a positive impact on carer’s wellbeing.

One note of caution, from Zeisel, is that museum staff need training in how best to communicate with people with dementia.

3.1.3 Validation therapy
Validation therapy is a form of empathetic and non-judgemental listening (VTI, n.d.). It is based on a set of principles grounded in the experiences of Naomi Feil who developed and promotes the approach:

1. All very old people are unique and worthwhile;
2. Maloriented and disoriented old people should be accepted as they are: we should not try to change them;
3. Listening with empathy builds trust, reduces anxiety and restores dignity;
4. Painful feelings that are expressed, acknowledged and validated by a trusted listener will diminish. Painful feelings that are ignored or suppressed will gain in strength;
5. There is a reason behind the behavior of very old maloriented and disoriented people. These can include: Resolution of unfinished issues, in order to die in peace; to live in peace; the need to restore a sense of equilibrium when eyesight, hearing, mobility and memory fail; the need to make sense out of an unbearable reality: to find a place that feels comfortable, where one feels in order or in harmony and where relationships are familiar; the need for recognition, status, identity and self-worth; the need to be useful and productive; the need to be listened to and respected or the need to express feelings and be heard.
6. Early learned behaviors return when verbal ability and recent memory fails;
7. Personal symbols used by maloriented or disoriented elderly are people or things (in present time) that represent people, things or concepts from the past that are laden with emotion;
8. Maloriented and disoriented old people live on several levels of awareness, often at the same time;
9. When the 5 senses fail, maloriented and disoriented elderly stimulate and use their ‘inner senses’. They see with their ‘mind’s eye’ and hear sounds from the past;
10. Events, emotions, colors, sounds, smells, tastes and images create emotions, which in turn trigger similar emotions experienced in the past. Old people react in present time, the same way they did in the past.

In their systematic review of research regarding validation therapy for people with dementia, Barton & Wright (2003) comment on the relative paucity of high quality studies on this form of therapy involving randomised trials with control groups, therefore they are cautious of drawing strong conclusions from the available data. Notwithstanding this caveat, they found that the data does not show statistically significant therapeutic differences that can be attributed to the particular nature of validation therapy. What is interesting is that they highlight the common ground that validation therapy shares with other humanistic / person-centred therapeutic techniques.

Barton & Wright (2003) note that validation therapy is not theoretically grounded but makes appeal to theory to justify the approaches it takes. This tallies well with the document from the VTI (n.d.)

Malorientation is defined as behaviours where people express past conflicts in disguised forms.
The goal of Validation Therapy is to help participants resolve hitherto unexpressed internal conflicts. This is not the explicit goal of the work of the Outreach team. Here the overlap with digital storytelling is in the role of the workshop leader and other participants being empathetic and non-judgmental listeners who validate the speaker through their attention and their responses. The act of creating and celebrating films based on personal stories further addresses participants’ need for self-worth. The beneficial outcomes are therefore in the realm of personal well-being.

3.1.4 Drama & storytelling
As noted earlier, Holm et al. (2005) and Lepp et al. (2003) report different aspects of a pilot study looking at the impact of drama and storytelling workshops on the lives of people with dementia and their caregivers. The report on the drama workshop (Lepp et al., 2003) concluded that this “treatment method, involving the humanities such as drama, culture, song, dance and storytelling, seems to increase the quality of life in patients with dementia. Using a specific approach towards the patients, such as confirmation and being authentic, the caregivers began to see the importance of meeting each patient as an individual with his or her own personal history. Thus this approach helped the caregivers to grow professionally” (Lepp et al., 2003, 880). Also, the participants became increasingly able to recognise one-another and the workshop(s) leaders. The positive benefits carried on beyond the interventions themselves with participants demonstrating an increased willingness to engage with other people and their surroundings. This sounds familiar to some of the observations of TWAM Outreach staff.

One of the interesting elements of the storytelling workshop is that the progression of stories told was carefully constructed, following Erikson’s life-phases framework, with the first story beginning in an early stage of life moving, over the course of the 6 workshops to dealing with issues around the later stage of life that the participants were in (Holm et al., 2005, 258-259). A consistent procedure was maintained within each workshop. The authors argued that “without a conscious pedagogic approach focused on caring, storytelling can become nothing but entertainment” (Holm et al., 2005, 262). The stories elicited emotional responses. The participants also responded to the themes and their conversation moved via association to linked themes in their own lives and wider existential questions (Holm et al., 2005, 259-260). This progression perhaps addresses some of the reservations expressed by Woods (2005a) that reminiscence leaves a discontinuity between the memories evoked and the current, lived situation of the person remembering. As with the drama workshops the authors focus on the benefits of this approach to participants’ quality of life and well-being.

The findings of this pilot study are relevant to the digital storytelling in fairly obvious ways: The capacity of life stories to elicit associations and reflection is important. However, the difference between the structure of this study in storytelling and the structure of digital storytelling workshops is noteworthy: This pilot project was strongly structured by the project leaders with participants being encouraged to respond within that framework. The structure of Outreach workshops are developed more in response to the participants’ needs or interests. In this way, the Outreach team gives a measure of control or autonomy to the participants. The sense of autonomy may contribute to personal well-being but the participant may miss out on the therapeutic value of moving through the life-phases in a structured way.

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7 The participants were diagnosed as having ‘intermediate’ or ‘severe’ dementia.
3.1.5 Reminiscence

Reminiscence therapy can take a range of forms (Woods et al., 2005a) from a more general reminiscence discussion in a group context, usually with the aid of tangible prompts, to a more formal ‘life review therapy’ (which has its roots in psychotherapy) involving evaluation of personal (sometimes painful) memories with a therapeutic listener, usually in a one-to-one setting.

Reminiscence can be used for a variety of reasons including: as a basis for care-planning; for discussion of general memories or of more specific autobiographical memories as might be involved in creating a life-story book; involving family care-givers or volunteers; bringing the person with dementia into a group with other people with dementia or with cognitively intact older people. The aims of reminiscence might be to enhance communication, to increase a sense of personal identity, to have an enjoyable activity in company with others, to improve mood and well-being, to stimulate memories and/or to increase the individualisation of care.

There is some question about the nature of memories that are evoked by reminiscing: Woods and co-authors (2005a) suggest that the memories/stories told in the sessions are those which have already been well rehearsed (over the course of a person’s lifepath)\(^8\). They also suggest that if the memories evoked are consistently of the very distant past then this might create some cognitive issues when the person is confronted by the dissonance between the re-experienced memories and the current state of their life without there being a coherent personal narrative that links the two (Woods et al., 2005a, 3). James (2011) suggested that this was a theoretical rather than practical issue as practical experience showed that people with dementia were able to make statements about themselves which seemed incongruous with being aware of the apparent dissonance.

There is a basic uncertainty about the mechanisms that underpin reminiscence particularly the role of the objects that are used to provoke memory and the nature of the reminiscences that are evoked by the objects. This is an area of on-going study.

Given the variety of forms that reminiscence can take, it is perhaps unsurprising that the systematic reviews of the research evidence for the efficacy of reminiscence (Woods et al., 2005a and Olazarán et al., 2010) are cautious in what they say about the impact of this therapeutic technique. Both reviews by are positive about reminiscence but are nonetheless clear that the data doesn’t allow for strong conclusions about the clinical value of reminiscence. In their protocol for reminiscence therapy, Woods et al. (2009) maintain that position although they note the popularity of reminiscence amongst people with dementia and carers. (The popularity supports the bedrock of anecdotal observation suggesting the value of this type of work amongst care professionals.)

Notwithstanding the caveats, Woods et al. suggests that reminiscence therapy can have positive effects on mood/behaviour, cognitive strength and relationships between the carers and patients. (2005a). Similarly, Kasl-Godley & Gatz (2000) noted that one of the main impacts of reminiscence therapy was on the carers. “[Staff] knowledge of the residents increased significantly for both therapy groups in comparison to the control group. Staff knowledge was in turn associated with

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\(^8\) If this is true then it may link in with Nelson’s suggestion (2003) that autobiographical memory is a special sub-set of episodic memory that is important to the maintenance of a sense of self continuous over time.
increased interaction with and enjoyment of the residents, presumed ultimately to benefit the psychological well-being of the residents.”

Olazarán et al. (2010) are more cautious about reminiscence, indicating that it can have a role in improving cognition, behaviour and the capacity for independent activities for daily living if used as part of a multi-component therapeutic treatment regime. This, perhaps, points towards the value of working in partnership with other agencies to deliver such a multi-component programme.

3.2 The challenge of measuring the impact of non-pharmacological approaches

As the preceding section on reminiscence indicated there are considerable hurdles in measuring the impact of non-pharmacological approaches. The discussion mainly revolves around the type of study that is appropriate.

In 2001, de Vreese et al. noted that “[as] with all psychological interventions for AD patients, there is some disagreement among rehabilitation researchers as to the choice of single-case or randomised large-scale controlled group study design. Many investigators have acknowledged that in memory intervention research a pure double-blind trial design may be particularly difficult to achieve. Although there are many reasons for this, including ethical ones, the classical double-blind study design should remain the goal.”

As such the discussion remains one of the quality of data; Olazarán et al. (2010) defined a study as having high quality, randomised controlled trial if it met the following criteria:
(1) cognitive impairment of degenerative or mixed (i.e. degenerative + secondary) etiology was documented in all participant subjects;
(2) study groups had comparable (or statistically controlled) characteristics at baseline;
(3) a detailed description of intervention was given;
(4) effects were measured by independent and blind evaluators (nonblind assessments were accepted for institutionalization and death);
(5) validated outcome measures were used;
(6) intention-to-treat principles were applied; observed cases, last-observation-carried-forward- and regression-based analyses were accepted); exclusions from analyses on the basis of intervention compliance were not permitted;
(7) effect was assessed in at least 30 patients and 80% of randomized patients per study group, and all losses were explained.

Using these criteria, the researchers whittled down an initial body of 1313 studies to 179 studies that were of acceptable quality to be included in their review!! Of this 179, 6 studies focussed on reminiscence. Similarly Woods et al. (2005) found only 5 studies that were good enough to be included in their review.

On this basis, the majority of case studies published by museums in publications such as GEM Case Studies do not qualify as high-quality data. Nonetheless, the data may be necessary until a larger body of high quality data can be developed. In the meantime, there are academic studies that can help museum staff improve the quality of their evaluations. Tools exist with which researchers can
evaluate the impact of therapeutic interventions and concensus work has been undertaken so that researchers across Europe can draw on the same sets of tools (that is, questionnaires) so that their results are comparable; these are discussed more in Section 4. The point here is that museum staff are not working in isolation: there is a body of work “out there” which museum staff can draw on rather than inventing their own methods.

3.3 Possible outcomes for outcomes of digital storytelling
The purpose of Section 3.2 is primarily to highlight the difficulty of obtaining clinical quality data and therefore the caution that needs to be taken when talking about the impact of any form of non-pharmacological intervention. Furthermore, as noted earlier, dementia is not curable so any intervention is aimed more at reducing rates of decline rather than improving someone’s abilities.

So, with these things in mind, the comparisons with other therapeutic techniques suggest that digital storytelling could potentially affect the following.

- cognition in the person with dementia;
- quality of life of the person with dementia and their care-giver;
- the care-giver’s mental health.
- autobiographical memory in the person with dementia;
- quality of relationship between the person with dementia and their carer;
- depression and anxiety for both parties;
- stress in both parties;
- general functional ability of the person living with dementia.
4 Arguing for the benefits of digital storytelling

One aim for this review was to look into a Social Return on Investment approach to making a case for the value of digital storytelling / object handling + reminiscence therapy for people with dementia.

The Guide to Social Return on Investment (SROI) (Nicholls et al., 2009) is very helpful and takes people through the process of doing an SROI evaluation in a step-wise fashion. The key points are: keep the process transparent (include the assumptions that you make); develop the evaluation in consultation with stakeholders; ascertain the impact of your activity; work out the value of that work in a monetary equivalent. The key issues here are impact and value so these will be considered in the following sub-sections.

4.1 Impact

As noted earlier, the impact of reminiscence is an area of on-going research. In 2001, de Vreese and co-workers noted that “as with all psychological interventions for AD patients, there is some disagreement among rehabilitation researchers as to the choice of single-case or randomised large-scale controlled group study design.” (de Vreese et al., 2001). This disagreement remains: In the large-scale review papers, such as Woods et al. (2005a&b), ‘high quality’ research and ‘randomised large-scale controlled group study design’ are more or less synonymous. However, McKeith (2011) questioned whether this type of study was suitable to the subject at hand. The lack of high quality data is what causes medical researchers to be cautious about the impact of therapies such as reminiscence, despite their popularity with carers and care workers.

In 2005, Diaz et al. identified the need for a consensus approach to assessing the impact of care for people with dementia. Since then, there has been a pan-European endeavour to develop a consensus approach to researching the treatment of Alzheimer’s Disease (see Moniz-Cook et al., 2011 and Katona et al., 2007) such that the results from groups across the continent would be comparable. Woods et al. (2009) built on that to develop a protocol for randomised trials for reminiscence therapy incorporating effects on relationships (see below).

The various academics and practitioners worked through consensus approach to figure out what domains for impact should be considered and which tools could best be used to facilitate the evaluation of each domain (Moniz-Cook et al., 2008). These tools will be needed when trying to construct some bedrock of evidence on impact to feed into the SROI analysis.

Most of these are free (or easily accessible) and do not require specialist training to implement, with the exceptions of NPI, CIBIC-Plus and GBS. The paper also provides the references to help obtain the tools.
### Table 2: Domains of impact for psycho-social interventions and the tools recommended for measuring their impact. Drawn from Moniz Cook et al., 2008

<table>
<thead>
<tr>
<th>Domain</th>
<th>Tool(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition in the person with dementia</td>
<td>Alzheimer’s Disease Assessment Scale (ADAS-Cog), Nurses Observation Scale for Geriatric Patients (NOSGER), Cambridge Cognitive Examination – revised (CAMCOG-R) or the Mini-Mental State Examination (MMSE)</td>
</tr>
<tr>
<td>Patient Mood</td>
<td>Cornell Scale for Depression in Dementia (CSDD)</td>
</tr>
<tr>
<td>Family Mood</td>
<td>General Health Questionnaire (GHQ)</td>
</tr>
<tr>
<td>Patient Quality of Life</td>
<td>Quality of Life in Alzheimer's Disease (QOL-AD)</td>
</tr>
<tr>
<td>Family Carer QoL</td>
<td>World Health Organisation Quality of Life Assessment Instrument (WHOQOL)</td>
</tr>
<tr>
<td>Family Carer Burden</td>
<td>Zarit Burden Interview (ZBI)</td>
</tr>
<tr>
<td>Patient Activities of Daily Living</td>
<td>Lawson-PMS-IADL</td>
</tr>
<tr>
<td>Patient Behaviour</td>
<td>Neuropsychiatric Inventory (NPI)</td>
</tr>
<tr>
<td>Staff Carer Morale</td>
<td>Either GHQ or the Masach Burnout Inventory (MBI) – the authors are ambivalent and both of these require trained staff to implement.</td>
</tr>
<tr>
<td>Global Patient Measures</td>
<td>Either Clinicians Global Impressions of Change (CIBIC-Plus) or the Gottfreis-Brane-Steen (GBC) measures – again the authors are ambivalent and both of these require trained staff to implement.</td>
</tr>
</tbody>
</table>

Of course, with this sort of research you need to have a pre-determined idea about the domains where you expect there to be some impact. The review by Olazarán et al. (2010) found multi-component activities (involving cognitive stimulation plus other activities such as reminiscence) to have positive impacts on cognition, activities for daily living (ADL), behaviour and mood.

In the protocol for randomised trials of reminiscence therapy, Woods and co-workers (2009) have identified primary and secondary outcomes.

- **Primary outcomes anticipated for reminiscence therapy:**
  - quality of life of the person with dementia;
  - the care-giver’s mental health.

- **Secondary outcomes anticipated for reminiscence therapy:**
  - autobiographical memory in the person with dementia;
  - quality of relationship between the person with dementia and their carer;
  - depression and anxiety for both parties;
  - stress in both parties;
  - general quality of life for both;
  - general functional ability.

The protocol is very helpful in that it lays out, clearly and in detail, the way that the researchers have structured their trials and what tools they are going to use for each domain. Another interesting feature of this protocol is that it carries within it an explicit shift from ‘person-centred’ care to ‘relationship centred’ care. Note the inclusion of ‘quality of relationship’ as a domain.
What remains unclear is how much these tools are used by practitioners working in the sector in the North East.

Recommendation: that the Outreach Team members collate the ‘tools’ for measuring impact and discusses these approaches with partner organisations to discover how widely these tools are being used in the sector.

So, although it is not possible (at this point in time) to state what the impact of Outreach work is with clinical confidence –this body of consensual work is available to set up research that will investigate the impact and will have parity with other work in the field.

4.2 Value
Assume for a moment that these types of interventions do have an impact; for political and economic reasons, that impact has to be given a value in monetary terms. Putting a value on human life can feel morally difficult (Dye, 2008) but, as Hughes (2010) points out, the demand on healthcare is potentially infinite whilst the resources are resolutely finite. The solution lies in ‘health economics’.

The papers by Wimo (2007) and Knapp (2007) both outline the issues with this area very helpfully. The report by Hughes (2010) is meant to be a source of advice.

There are two approaches: either a cost-benefit analysis – working out the cost of doing something with respect to the benefit accrued by not doing nothing – or a cost-offset analysis – working out the cost of doing something one way against the cost of achieving the same goal through a different means. The cost benefit analysis might, for instance, give some indication of the value of providing reminiscence therapy against the option of not doing anything – which is the approach that Woods et al. (2009) are taking and the idea behind SROI. The cost off-set might set the costs of reminiscence against the cost of achieving the same state of wellbeing (plus side-effects) through prescribing drugs – this is the line of argument taken by Olazarán et al. (2010).

Wimo (2007) gives an equation to follow...

\[ \frac{\Delta C}{\Delta E} = \frac{(C_A - C_B) / (E_A(T_1 - T_0) - E_B(T_1 - T_0))}{(T_1 - T_0)} \]

where \( C = \) costs, \( E = \) effect (consequence, outcome), \( A & B = \) treatments, \( T_0 & T_1 = \) measurements at particular points

... so outcomes need to be quantified in a way that can be handled like this.

In a cost off-set approach it seems possible to proceed without quantifying outcomes in the same way because you merely have to agree that two treatment approaches have the same consequences, however you describe them. Knapp noted that, at the time of publication (2007), there were no published cost-benefit analyses of dementia interventions.

\[ \text{Prof. Luke Vale holds the Health Foundation Chair in Health Economics at Newcastle University and may be a good person to talk to.} \]
There are tools to help do this: the Personal Social Services Research Unit (University of Kent) compiles a report on the ‘Unit Costs of Health and Social Care’ (Curtis, 2010) which documents the financial value of different services and these could be fed into calculations of value.

However, there is a great deal of complexity lurking under the surface. As Knapp (2007) notes, “People with dementia are likely to use a number of services, each of which needs to be captured for a fully comprehensive economic evaluation. In addition, there will be many and important inputs from family and other (unpaid) caregivers. How those latter inputs are costed is a source of contention. Many studies have shown the costs of informal care to be considerably greater than the costs of services provided to people with dementia but the costing of caregiver inputs is not straightforward.” Knapp goes on to discuss the subtleties of this approach but one important point is that these decisions drift over into wider political concerns. “Bodies such as NICE are required to take a health and social care system perspective, which means that they necessarily attach a zero value to caregiver inputs.”

“An additional approach is to calculate “utility,” generated from health-related quality of life scales. Combining such a measure with information on costs allows the economist to carry out what is often called a cost-utility analysis. The best-known and most robust measure of “utility” is the Quality-Adjusted Life Year (QALY).” [...]”

“Many evaluations of new interventions find them to be both more effective (the outcome profiles are better than for old or current interventions) but simultaneously more expensive. [...] How is the trade-off to be made between the better outcomes and the higher expenditure necessary to achieve them? The methodological approach now widely used is to construct cost-effectiveness acceptability curves (CEACs). These [curves] show the probability that a new intervention will be cost-effective for each of a number of pre-specified or implicit valuations of an outcome improvement by the decision-maker. The CEAC is a comparatively recent development, and there are as yet few published applications of it in the dementia field, but its use will grow. One advantage of the approach is that it makes transparent the trade-offs faced by decision-makers.”

Helpfully, Knapp and co-workers have published an analysis of the cost-effectiveness of cognitive stimulation therapy for people with dementia that takes this approach (Knapp et al. 2006), thereby providing a precedent to follow.

Similarly the protocol devised by Woods et al. (2009) includes measures to capture the costs of the intervention, using the validated Client Services Receipt Inventory (CSRI). Again, this is another model to follow.

Despite the complexities of assessing the value, the advantage of the tools for measuring impact (listed earlier) reduce the different aspects of a person’s life into a series of numbers which lend themselves to such a quantitative approach. One of the intentions behind the consensus approach was to ensure that those numbers mean the same thing whenever they are used across Europe.

The questions that come out of this are: Are the measures advocated above common amongst practitioners working with people with dementia? Are these approaches politically persuasive?
At this point it seems sufficient to present these ideas in this current format. The SROI approach strongly advocates working through the process in collaboration with partner organisations, this would seem to be a good starting point for those discussions.

Recommendation: that TWAM staff use these tools as a starting point for discussion with partners about the tools, approaches, benefits etc leading to a provisional SROI contingent on gathering further data to feed into the analysis.
5 Summary of Recommendations

- When working with partner organisations, Outreach staff should endeavour to determine the diagnosis of the people they will be working with and what their capabilities in order to best respond to each person's need;
- Further study of person-centred approaches to dementia care could be undertaken to understand how reminiscence / digital storytelling fits into this wider picture;
- Outreach Team members actively reflect on the content of workshops sessions;
- Recordings of workshops are made to facilitate content analysis, using aspects of therapeutic techniques as a framework;
- Outreach Team members collate the ‘tools’ for measuring impact and discusses these approaches with partner organisations to discover how widely these tools are being used in the sector;
- That TWAM staff use these tools as a starting point for discussion with partners about the tools, approaches, benefits etc leading to a provisional SROI contingent on gathering further data to feed into the analysis.
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12 VTI = Validation Training Institute (Inc.)