Evaluating a novel adaptation of word finding therapy for individuals with dementia.

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Abstract

Dementia is often associated with word-finding difficulties impacting on everyday life. Previous research on constraint-induced aphasia therapy (CIAT) for word-finding difficulties in people with Primary Progressive Aphasia, a language-based dementia, has reported positive outcomes. No existing research uses CIAT-based therapy with people with other forms of dementia such as Alzheimer's disease.

This study aimed to evaluate the effectiveness of CIAT-based therapy in improving communication for people with dementia and whether this generalised to more successful everyday communication.

A quantitative and qualitative mixed-methods approach was adopted, with the original described study protocol being significantly revised due to the impact of the coronavirus pandemic. The revised study protocol consisted of two main phases.

In Phase 1, two participants with Alzheimer's disease and their communication partners were recruited. Following face-to-face cognitive and communication assessment, participants completed CIAT-based therapy using 60 chosen picture items in 9 face-to-face therapy sessions with the researcher, with additional home practice encouraged. Due to restrictions relating to the coronavirus pandemic, post-therapy communication assessments were redesigned and completed by video-call.

In Phase 2, one participant with Posterior Cortical Atrophy and their communication partner were assessed using video-call, and completed self-directed CIAT-based therapy at home. This was supported by one training session, and a written guide developed with the support of a focus group.

This study's main contribution was being the first to evaluate CIAT-based therapy for people with Alzheimer's disease. Analysis suggests naming performance did not improve following completion of CIAT-based therapy, although there is some evidence of maintenance of treated nouns for one participant.

The discussion considers the findings in the context of existing research. It highlights the limitations of research on impairment-based approaches such as CIAT-based therapy for word-finding difficulties and considers how meaningful language assessment might take place in the context of wider cognitive decline.

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Declarations

I, the author, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means). This work has not been previously presented for an award at this, or any other, university.

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Chapter 1 Background

1.1 Chapter overview

This chapter describes a range of dementias, discussing in detail their neuropathology and progression, and their cognitive and communication features. It then summarises how a neuropsychological model can account for word-finding difficulties. This is followed by a review of the current literature on speech and language therapy approaches for word-finding difficulties in aphasia and in dementia. A key gap in the existing literature is identified, which forms the basis of this study.

1.2 Dementia: setting the scene

Billed 'the biggest health and social care crisis of our time', dementia is a significant, and increasing, global health concern (Alzheimer's Society UK, 2019b) The number of people living with dementia is expected to triple by 2050 from 47 million globally in 2015 (Livingston et al., 2017). In the UK alone there are approximately 885,000 people over 65 years of age living with dementia at present, with 127,000 having mild dementia, 246,000 having moderate dementia and the majority, 511,000, having severe dementia (Wittenberg, Hu, Barraza-Araiza, & Rehill, 2019). The total number of older people in the UK living with dementia is projected to increase to 1.6 million people by 2040 (Wittenberg et al., 2019).

Dementia is a term commonly used to describe a group of progressive neurological disorders. It is characterised by a progressive often widespread loss of function, including communication; this can have high personal and financial cost for the person with dementia, their family, and society as a whole (Livingston et al., 2017). Therefore, there is an important need for research not only for treatments, but also for how to live well with dementia.

1.3 Diagnostic classifications of dementia

Dementia is not a normal part of ageing, but one of its most prevalent diseases (Volkmer, 2013). The two common diagnostic classifications for dementia are provided by the Diagnostic and Statistical Manual of Mental Disorders 5 (American Psychiatric Association, 2013) and the International Classification of Diseases 11 (World Health Organisation, 2018). These two classifications contain considerable overlap, although differences in terminology and grouping exist. They are detailed further here.

1.3.1 Diagnostic and Statistical Manual of Mental Disorders 5 (DSM V) and the International Classification of Diseases 11 (ICD 11)

More recently, the DSM V has adopted ‘neurocognitive disorder’ to refer to a range of disorders, including what are commonly known as the dementias (American Psychiatric Association, 2013). In the DSM V, neurocognitive disorders can be categorised as either mild or major. Mild neurocognitive disorders are where the individual shows neurological changes beyond what would be expected in typical ageing although symptoms have not progressed far enough to reach a diagnosis of dementia (Sachs-Ericsson & Blazer, 2015). In time, some people with mild cognitive impairment may progress to major cognitive impairment (dementia), but this is not necessarily the case (Sachs-Ericsson & Blazer, 2015). Neurocognitive disorders are diagnosed if deficits are present in the absence of delirium or if not explained better by another mental disorder (American Psychiatric Association, 2013). Additionally, neurocognitive disorders are described as being related to another disease (such as neurocognitive disorder due to Parkinson’s Disease (PD) and neurocognitive disorder due to Alzheimer’s disease). This allows for more precise description of the particular features typical of the subtype of dementia.

The World Health Organisation’s (WHO) International Classification of Diseases (ICD) was updated in 2018 resulting in the ICD 11. The term dementia is retained explicitly, in contrast to the DSM V, and the dementia is a subcategory of neurocognitive disorders (World Health Organisation, 2018). Similar to the DSM V, the ICD 11 also includes a mild neurocognitive disorder category. In both the DSM V and the ICD 11 mild neurocognitive disorders are part of the neurocognitive disorder subcategory, rather than as a type of dementia itself (American Psychiatric Association, 2013).

DSM V specifies 12 subtypes of neurocognitive disorder and the ICD 11 specifies 8 subtypes of dementia. These are detailed in Table 1 below:

Table 1 - subtypes of neurocognitive disorder/dementia

DSM V (American Psychiatric Association, 2013)	ICD 11 (World Health Organisation, 2018)
Alzheimer's Disease* Vascular Neurocognitive disorder* Neurocognitive Disorder with Lewy Bodies* Frontotemporal Neurocognitive Disorder* Substance/medication-induced Parkinson's Disease* Prion Disease Huntingdon's Disease Traumatic Brain Injury HIV Infection Multiple aetiologies* Another Medical Condition	Dementia due to Alzheimer disease Dementia due to cerebrovascular disease Dementia due to Lewy body disease Frontotemporal dementia Dementia due to psychoactive substances including medications Dementia due to diseases classified elsewhere Behavioural or psychological disturbances in dementia Dementia, unknown or unspecified cause

*when affecting everyday life and functioning, in common parlance these are traditionally considered as age-related, progressive dementias.

1.4 Features of specific progressive dementias

A number of the subtypes of dementia in the DSM V are categorised within the ICD 11's 'dementia due to diseases classified elsewhere', such as prion diseases and Huntingdon's disease, where features of dementia can be added to the precipitating disease. Additionally, the DSM V includes neurocognitive disorders that are not progressive such as traumatic brain injury. Therefore, there are four main types of progressive dementia shared by both the DSM V and ICD 11 that account for the vast majority of dementia diagnoses which this study will focus on. To ensure consistent terminology in this study, the following terms will be used from hereon. With percentage proportions estimated by the Alzheimer's Society (2019a), these are:

- Alzheimer's disease (50-75% of cases),
- Vascular dementia (up to 20% of cases),
- Lewy body dementia (10-15%),
- Frontotemporal dementia (2%).

The relative numbers of people with each type of dementia is not known with certainty (Stevens et al., 2002). Clarity is difficult to ascertain due to differences both in categorising diagnoses, such as differences between the DSM V and ICD 11, but also in the assessment method used to arrive at the diagnosis. For example, a study of people aged 65 or over in a London borough found 35% of people with dementia were diagnosed with Alzheimer's disease using the DSM IV compared with 45% when using the ICD 10 (Stevens et al., 2002). However, a broad consensus suggests that, of the four types of dementia discussed in this study, Alzheimer's disease is most prevalent, followed by Vascular dementia and then Lewy body dementia, with frontotemporal dementia being least prevalent (Livingston et al., 2017).

In practice, it is important to note that an individual may share features of different dementias. Therefore a diagnosis of mixed dementia may be made, which is accounted for as neurocognitive disorders of multiple aetiologies in the DSM V (American Psychiatric Association, 2013). This category is not replicated specifically in the ICD 11.

1.4.1 Alzheimer's disease

Alzheimer's disease (AD) is the most common form of dementia, accounting for 50-75% of dementia diagnoses (Alzheimer's Society UK, 2019a). In its typical form, it is especially, and increasingly, prevalent after 60 years of age (Bayles, 2007). In the UK alone AD is the cause of dementia for over 520,000 people (Alzheimer's Society UK, 2019c).

In addition to typical AD, 3 variants of atypical AD have also been identified: posterior cortical atrophy (PCA); frontal variant AD; logopenic variant AD (Dubois et al., 2014). Although less prevalent than typical AD, atypical presentations account for around 10% of early onset (under age 65 years) AD diagnoses and 30% of late onset (over age 65 years) AD diagnoses (Boon et al., 2018). However, this may be an underestimate due to lack of wider awareness (Crutch et al., 2012).

The typical features of frontal variant AD are progressive behavioural inhibition and apathy, or with difficulties in executive functioning (Dubois et al., 2014). In any case, only a very small number of people with frontal symptoms have AD pathology resulting in frontal variant AD rather than frontotemporal dementia (Dubois et al., 2014). Despite uncertainty, it has been proposed that a greater executive dysfunction without behavioural symptoms may define frontal variant AD as distinct from frontotemporal dementia (Woodward, Brodaty, et al., 2010) . There are no definitive biomarkers to determine frontal variant AD as distinct from frontotemporal dementia and a diagnosis must be clinically made (Woodward, Jacova, et al., 2010). Due to the frequent lack of AD pathology/biomarkers, frontal variant AD may thus be considered a behavioural variant of frontotemporal dementia (FTD) (Dubois et al., 2014). Therefore, for the purposes of this study, this frontal variant will be discussed in section 1.4.4 as part of FTD.

A logopenic variant is sometimes considered a subtype of AD (Boon et al., 2018). It may also be considered as a primary progressive aphasia, a type of FTD. However, in contrast with other subtypes of primary progressive aphasia which typically do not have AD pathology, logopenic variant AD has been found to have AD pathology in all cases (Spinelli et al., 2017). Notwithstanding this ambiguity, in this study it has been discussed alongside the other primary progressive aphasias with whom it shares more obvious language-specific similarities.

Finally, PCA is generally considered within the context of AD, as AD pathology is usually found in most people with PCA (Crutch et al., 2012). However, this is not fully certain and PCA can be due to other dementias such as Lewy body dementia, or indeed have no visible brain atrophy (Crutch et al., 2012). However, in light of the general consensus, for the purposes of this study PCA will be considered in this section as an atypical type of AD.

In addition to cognitive impairments, neuropsychological conditions are frequently co-morbid with AD. For example, depression is both a risk factor and a consequence of dementia and may require separate treatment rather than being seen simply as an inevitable consequence of disease progression (Livingston et al., 2017).

1.4.1.1Neuropathology

AD is associated with an increase of beta-amyloid and tau proteins in the brain which cause breakdown and eventual death of neurons (Jin, 2015). As such neurons carry the information that results in brain function, reduction in neurons equals a reduction in brain capability which presents as symptoms of dementia. MRI scans of people with AD frequently show atrophy of the medial temporal lobe of the brain which is often an indicator of the disease (Ballard et al., 2011). Using this MRI measure has around 85% accuracy for predicting AD compared with people with typical ageing (Waldemar et al., 2007). This suggests such a presentation is common for people with AD. However, it is not always the case, and a number of studies have shown that the medial temporal lobe atrophy in AD cannot effectively be distinguished from other dementias using MRI (Ballard et al., 2011).

For people with PCA, studies of the neuropathology of disease generally attribute it to AD pathology. For example, a small retrospective study of 7 people with PCA found that all had AD pathology (Alladi et al., 2007). A larger study of 27 participants found that 13 had AD aetiology, by far the most frequent cause of PCA (Renner et al., 2004). Lewy body dementia was the cause of 2 further cases, with a range of other dementias each accounting for one case in the study (Renner et al., 2004).

There may be subcategories of PCA, but due to a small number of cases there is not universal agreement and it has been argued that this variety is simply individual presentations of PCA (Crutch et al., 2012). Two specific subtypes that have been identified are biparietal variant and occipitotemporal variant (Dubois et al., 2014). People with biparietal subtype of PCA typically show bilateral atrophy of the parietal lobe on MRI scans (Ross et al., 1996). For the occipitotemporal variant PCA, people show atrophy of the occipitotemporal region of the brain (Galton, Patterson, Xuereb, & Hodges, 2000). However, as the disease progresses, overlap with occipitotemporal variant PCA can occur, giving symptoms of both subtypes and thus a more general PCA presentation and diagnosis (Ross et al., 1996).

1.4.1.2Progression

Describing the progression of typical AD benefits from grouping symptoms into stages. However, different sources use different terms and indeed a different number of stages. A three stage progression is commonly used in both the UK and United States, with stages described as mild, moderate and severe (Alzheimer's Association, 2020; Alzheimer's Society UK, 2020). Note that these commonly used stages refer to diagnosed cases of symptomatic AD only, and asymptomatic disease pathology may exist in individuals outside of these labels. Other models with a different number of stages are sometimes used. Of note is Reisberg and colleagues' (1982) seven stage global deterioration scale (GDS), which can be applied to a range of dementias, but closely aligns with AD. Unlike the three stage approach commonly used, the seven stage GDS includes stages which cover normal cognitive and what may be considered pre-dementia presentations rather than solely focusing on stages of AD dementia (Reisberg et al., 1982). The final four stages of the GDS are considered to be consistent with AD diagnosis, with stages of cognitive impairment described as moderate, moderately severe, severe and very severe (Auer & Reisberg, 1997).

For AD generally, age of onset is typically over 65 years, with prevalence doubling every 5 years after this point, with around 7% of those age 65 years and over having AD (McDowell, 2001). For PCA, as an early onset atypical AD, age of onset is typically 50-65 years (Crutch et al., 2012). It may be more common in women, though this is uncertain (Crutch et al., 2012).

Variation of reported life expectancy differs in the literature, with studies measuring from different points, and discussing AD generally, rather than considering particular subtypes of AD.

As Zanetti and colleagues (2009) noted, some studies measure from disease onset and others from point of diagnosis. Typical life expectancy following a diagnosis of AD may be about 7-8 years (Walker, Allen, Shergill, Mullan, & Katona, 2000). Others suggest a wider range, such as 3-12 years following diagnosis (Schaffert et al., 2019). It is assumed that this is with pathology consistent with typical AD, however the study includes people with AD from age 50 who might thus be considered early onset AD. Whilst noting varying methodology, there is considerable agreement in the literature around life expectancy for what appears to be typical presentation of AD. For example, Larson and colleagues (2004) prospectively monitored 521 people with newly diagnosed AD over the age of 60 years and found median survival was 4.2 years for men and 5.7 years for women. The difference between men and women's life expectancy with AD was even greater at age 70, at 4.4 years for men and 8.0 years for women, although this difference narrowed in older age (Larson et al., 2004).

Differences between men and women and age of onset are not the only factors affecting life expectancy for people with AD, which varies based on a number of personal factors. Schaffert and colleagues (2019) examined data from autopsies of 764 people with confirmed AD and proposed 7 key personal variables which affect life expectancy for people with AD following diagnosis. These 7 factors that appear to adversely affect life expectancy are lower global cognitive performance, being male, increasing age, not being of Caucasian/Hispanic ethnicity, greater functional impairment and greater psychiatric symptoms, and having symptomatic neurological examination (Schaffert et al., 2019).

1.4.1.3Cognition

Classically, at early stage, AD symptoms are often related to loss of recent memory which can make more complex everyday tasks difficult (Jin, 2015). Indeed, memory loss was the most common initial symptom in a retrospective study of 52 people with AD (Lindau et al., 2000). These memory difficulties may result in getting lost in ordinarily familiar places, or difficulties with tasks such as paying for shopping. In early stages, some personality and mood changes may occur, and these may become more noticeable in moderate AD (Jin, 2015).

Such memory difficulties are one of the key features of AD (Bourgeois & Hickey, 2011). Episodic memory difficulties are typically related to more recent events than those from the more distant past (Snowden et al., 2011). Short term working memory is affected resulting in difficulties with temporary storage of information (Bourgeois & Hickey, 2011). This can cause people with AD difficulties affecting everyday life, such as remembering locations of objects, or the task/action in which they were involved. Additionally, people with AD can present with deficits in sensory memory, which is used to provide information on senses such as sights, sounds and smells (Bourgeois & Hickey, 2011). As the dementia progresses beyond the early stages, this can result, for example, in confusion of what is meant by the sound of a ringing telephone, which can have a sizeable impact on everyday life.

Impaired executive function is a common feature of AD (Bourgeois & Hickey, 2011). Executive function is responsible for higher-level activities such as planning, and sequencing events as used, for example, in managing financial affairs or planning a diary or an event. When combined with other memory deficits the impact is a reduced ability to carry out functions of daily life, such as getting dressed or preparing meals, which declines further throughout the individual's dementia journey.

Whereas typical AD is associated with memory loss at an early stage, atypical AD subtypes such as PCA only display memory loss at a later stage, with other symptoms noted initially (Boon et al., 2018). For PCA, the salient feature initially is impaired visuospatial skills (Boon et al., 2018).

The difference in cognitive impairments for PCA, both biparietal variant and occipitotemporal variant, can be described as follows. In contrast with typical AD, for people with parietal variant PCD, episodic memory is often intact until much later in their disease progression (Boon et al., 2018). In biparietal variant PCA, visual cognitive deficits can be summarised as inability to locate where objects are placed, whereas occipitotemporal variant PCA relates to poor visual recognition of what objects actually are (Galton et al., 2000). Thus, for people with biparietal variant PCA, impairments are considered to be visuospatial functioning and related motor perception and co-ordination, although basic vision is usually unaffected (Marques, Tábuas-Pereira, Milheiro, & Santana, 2015). For people with occipitotemporal variant PCA, cognitive deficits are typically distorted vision resulting in difficulty recognising people or places (Galton et al., 2000). Such visuo-perceptual or visuo-spatial difficulties can lead to myriad practical difficulties, for example judging distance when driving, or difficulty using stairs (Crutch et al., 2012). Additionally for some people with PCA generally, there have been reports of unusual sensations of pain, or difficulties with balance and associated orienting of themselves in space which may be due to visuospatial/perceptual difficulties (Crutch et al., 2012).

For people with both subtypes of PCA, although cognitive and other symptoms described below are the case early in the disease, as the atrophy progresses to include other areas of the brain, symptoms become more wide-ranging; for example, in a number of patients phonological difficulties have been noted, suggesting pathological atrophy has spread to the superior temporal gyrus of the brain (Ross et al., 1996).

For AD generally, at later or end stages, symptoms of AD may be widespread with significant impact on people with AD and those who care for them. Whilst noting that not all people with AD reach end-stage presentation, at this point individuals may be unable to swallow effectively, communicate at all or make decisions about their life (Livingston et al., 2017).

1.4.1.4Communication

Communication difficulties are often a key feature of AD. They can have a significant impact on the life of both people with AD and those with whom they communicate. These difficulties can be due to language or social communication impairments. Changes in the structure of the brain caused by AD (along with other types of dementia, stroke or traumatic brain injury) can lead to a language condition called aphasia. Aphasia can refer to difficulties generating and/or understanding words and sentences. The type of difficulties people with aphasia have is linked to the area of the brain and the extent to which it is affected. For people with AD, initially language impairment may not be the most noticeable deficit, with semantic knowledge being well-preserved (Bayles, 2007). Semantic knowledge refers to the properties of an object, such as what it is made of, and what and where it is used. Therefore, with intact semantic knowledge people are likely to retain communicative success. However, when language does become affected, semantic knowledge is often the first element of language to be lost (Volkmer, 2013). This can result in difficulties producing the name or label of an item, such as an everyday object, which is known as word-finding difficulties, or anomia. Anomia can significantly reduce the quality of life for people with AD, due to its impact on everyday life and relationships (Noonan, Pryer, Jones, Burns, & Ralph, 2012). Similar difficulties can present with verbs as well as nouns. For example, a study of 14 people with probable AD found that participants had difficulty with naming verbs; this difficulty increased as the semantic complexity of the verb increased (Kim & Thompson, 2004).

Although anomia is typical in AD, other communication impairments may present. In initial stages of AD, social communication skills are often retained resulting in apparently successful conversation, which may mask difficulties with expressive or receptive language (Volkmer, 2013). However, as AD progresses, social communication difficulties may appear. Social communication refers to the ability to participate effectively in communication following social rules of conversation. This can include maintaining topic in a conversation or following accepted rules for starting and ending a conversation. For example, people may be able to participate with sufficient responses leading to apparent success in conversation, without understanding what is being said, leading to people with AD appearing to understand more than they do. In severe to end-stage AD, all aspects of communication (as with general functioning) are severely impaired, and people may have no verbal or other communication (Bayles, 2007).

For people with PCA, literacy and numeracy are also typically adversely affected (Crutch, Lehmann, Warren, & Rohrer, 2013). Despite visual processing impairment being dominant, there are language features associated with PCA. As part of a wider study, Crutch and colleagues (2013) compared the language of 15 people with PCA with controls. They found that for people with PCA, language was widely impaired, but with anomia and both slowed speech rate and phonemic fluency most affected compared with a control group (Crutch et al., 2013). However, Crutch and colleagues (2013) found that there was no significant difference between controls and people with PCA for auditory discrimination of minimal pairs and areas of connected speech, specifically speech rate and word frequency. Memory, along with performance on verbal fluency tasks, may be better in PCA than in typical AD (Mendez, Ghajarania, & Perryman, 2002). There may only be a small impact on semantic memory for people with PCA (Rogers, Ivanoiu, Patterson, & Hodges, 2006). Crucially for language processing, deficits in working memory are typically more pronounced for visuospatial than for verbal working memory (Trotta, Lamoureux, Bartolomeo, & Migliaccio, 2019). Performance on category fluency tests and letter fluency tests may be similar for people with PCA, who also perform better at assessment of verbal than visual comprehension (Rogers et al., 2006).

For people with parietal variant PCA, communication difficulties may be seen early in the disease progression, in the form of dysgraphia (difficulty writing) and dyspraxia (difficulty with motor co-ordination), with phonological difficulties observed later should disease spread (Ross et al., 1996). Phonological errors happen when individual phonemes (speech sounds) are incorrect; for example, the phonemes could be swapped, deleted, or added to a word. Dysgraphia is a key feature, in contrast with typical AD where it is generally less impaired (Ross et al., 1996). For people with occipitotemporal PCA, the cognitive difficulties with visual recognition can result in alexia (difficulty reading) (Galton et al., 2000).

1.4.2 Vascular dementia

Vascular dementia (VaD) is considered the second most common form of dementia, accounting for approximately 15% of dementia diagnoses (Livingston et al., 2017; O'Brien & Thomas, 2015). VaD often occurs alongside AD as both are associated with ageing and both are associated with vascular changes in the brain (Gorelick et al., 2011; Livingston et al., 2017). Despite its prevalence, there are no clear diagnostic criteria for vascular dementia, although subtypes have been described (O'Brien & Thomas, 2015). For example, some consider VaD to be a syndrome of either stroke, or subclinical vascular disease and some form of cognitive impairment (Gorelick et al., 2011). Gorelick and colleagues argue that the term vascular cognitive impairment should be used for all such cases, including those with full dementia (Gorelick et al., 2011). The authors state that for a diagnosis of dementia (as the most severe form of vascular cognitive impairment) three points must be met which can be summarised as: a decline in cognitive function in greater than two cognitive domains affecting everyday life; a diagnosis of dementia from cognitive testing in visuospatial function, executive function, memory and language and that difficulties in everyday function must not be part of any broader sensory-motor deficit related to the vascular event (such as stroke) (Gorelick et al., 2011). The term vascular cognitive impairment has not been fully adopted, though some prefer the term vascular mild cognitive impairment to account for cases not yet at the stage of VaD (Perneczky et al., 2016). O'Brien and Thomas (2015) outlined a number of subtypes of VaD, namely:

- Multi-infarct dementia (cortical vascular)
- Small vessel dementia (subcortical vascular)
- Strategic infarct dementia
- Hypoperfusion dementia
- Haemorrhagic dementia
- Hereditary vascular dementia
- Alzheimer's disease with cardiovascular dementia

The first three listed above are the most common forms (multi-infarct; small vessel and strategic infarct) with hereditary vascular dementia considered rare (Thal, Grinberg, & Attems, 2012). There are two main subgroups of ischaemic causes of VaD: large vessel (cortical) VaD and small vessel (subcortical) VaD, with small vessel being the most frequent form (Román, 2003). Staekenborg and colleagues (2010) reviewed MRI scans of 484 people with VaD and found that 83% had small vessel form and just 17% had the large vessel form.

VaD is caused by vascular lesions and may be ischaemic or haemorrhagic (Román, 2003). Ischaemic vascular lesions are caused by blockages in arteries supplying the brain, whereas haemorrhagic lesions are caused by ruptures of arteries. Large vessel VaD may be a result of a single vascular event, and known as a strategic infarct, or may be due to lots of vascular events which is known as multi-infarct VaD (Román, 2003). These typically are the result of stroke, and cause acute onset of dementia. By contrast, small vessel (subcortical) VaD associated with slower onset is not usually caused by an obvious acute event (Román, 2003).

Pure forms of VaD, without any other forms of dementia, are rare (Thal et al., 2012). Indeed for people over age 80 years, mixed dementia involving VaD is more prevalent than pure VaD (O'Brien & Thomas, 2015). The low prevalence of pure VaD further complicates diagnosis and attempts to describe its features, as it is challenging to separate them from other forms of dementia.

1.4.2.1Neuropathology

Strokes are a particularly frequent cause of VaD (Agronin, 2014). In people over age 65 years, 20-25% of ischaemic strokes result in VaD (Román, 2004). Although brain imaging shows vascular damage, this does not translate into reliable measures of real-life cognitive deficit (Korczyn, Bornstein, & Guekht, 2012). In addition, given the wide-ranging subtypes of vascular dementia identified, there is also a wide range of neuropathological aetiology to the extent that there is no consensus on how to reliably diagnose VaD (O'Brien & Thomas, 2015). Consequently, there is no universally agreed criteria for VaD at present (Perneczky et al., 2016).

In terms of its neuropathology, VaD may be broadly split into sporadic or hereditary/familial forms. For sporadic forms of VaD, the cause is degeneration of the large arteries or small vessel disease of small arteries, or cerebral amyloid angiopathy where amyloid proteins accumulate along blood vessel walls (Thal et al., 2012). These vessel disorders can lead to vascular lesions in the brain which cause cognitive deficits (Thal et al., 2012).

1.4.2.2Progression

VaD may often present as similar to AD (Agronin, 2014). However, in VaD, declines in presentation (worsening dementia) must be associated with a vascular event, and the extent/severity of the dementia is linked to the extent/severity of the individual’s vascular disease (Gorelick et al., 2011).

Small vessel VaD may cause slow gradual onset and progression of symptoms (American Psychiatric Association, 2013). For people with multi-infarct VaD, traditionally there is a pattern of decline associated with a vascular event followed by a period of stability or plateau (Desmond, 2004). This may not always be the case though, as a study of 24 participants with multi-infarct VaD found that only one third of participants had the typical progression of a stepped decline and plateau following an abrupt onset (Fischer, Gatterer, Marterer, Simanyi, & Danielczyk, 1990). For VaD generally, there is considerable heterogeneity in features due to the wide range of possible locations, number of vascular areas affected, and their size (Desmond, 2004).

Day-to-day variation in cognitive and communicative functioning is noted too, irrespective of steps and plateaus (Volkmer, 2013). Life expectancy following diagnosis is estimated at between three and five years, which is notably shorter than for AD (Kua et al., 2014).

1.4.2.3Cognition

VaD typically affects executive function, with difficulties with higher-level skills such as planning and organising information (Korczyn et al., 2012). Speed of information processing, attention, and executive function are the foremost areas of decline according to the ICD 11 (World Health Organisation, 2018). In contrast to AD, there is a general consensus that memory difficulties are not required for a diagnosis of VaD (Gorelick et al., 2011; O'Brien & Thomas, 2015). The ICD 11 aligns with the American Psychiatric Association's DSM V criteria for vascular neurocognitive disorder requiring declines in attention, processing speed and executive function, rather than specifically requiring memory loss, following at least one cerebrovascular event (American Psychiatric Association, 2013). However, in contrast to the DSM V and the ICD 11, the criteria from the National Institute of Neurological Disorders and Stroke and the Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINDS-AIREN) research criteria for VaD do require there to be a memory loss present for diagnosis to be made which may mean some cases of VaD do not fit the NINDS-AIREN criteria (Román, Erkinjuntti, Wallin, Pantoni, & Chui, 2002). Furthermore, it can be argued that requiring memory loss to make a diagnosis reduces the sensitivity of assessment, particularly relating to slower onset (small vessel) VaD (O'Brien & Thomas, 2015).

There is much variety of cognitive functional deficits for people with VaD, as symptoms depend on the location and extent of vascular damage which may be mild or severe (Bayles, 2007). Symptoms can range from mild cognitive impairment (not meeting a threshold for dementia diagnosis) to severe difficulties (Korczyn et al., 2012). People with VaD may also have difficulties maintaining attention and information processing (Korczyn et al., 2012). As many people have both AD and VaD, known as mixed dementia, this can further affect any perceived typical profile of impairment (Bayles, 2007). Some have argued that beyond cognitive symptoms, an early sign of VaD may be impaired gait (Román, 2003).

In common with other forms of dementia, behavioural and psychological symptoms may also occur. For people with small vessel (subcortical) VaD, in common with other predominantly frontal lobe dementias, unusual or uninhibited behaviours may present, along with apathy or indecision (Desmond, 2004). In strategic infarct dementia, features are initially variable levels of alertness or attention and apathy, with memory loss and potentially severe language difficulty with left-sided involvement, or possible visuospatial involvement with right-sided involvement (Desmond, 2004).

A detailed study, which used Cummings and colleagues' (1994) Neuropsychiatric Inventory assessment, assessed 484 people with VaD and found that apathy at 65%, depressive symptoms at 45%, irritability at 42% and agitation/aggression at 40% were the most common symptoms reported (Staekenborg et al., 2010). Differences were also noted between large vessel VaD and small-vessel VaD. People with small vessel VaD had both significantly greater prevalence and greater severity of apathy, aberrant motor behaviour and hallucinations compared with people with large vessel VaD, whereas people with large vessel VaD had both significantly greater reported prevalence and severity of euphoria, and greater severity of agitation/aggression (Staekenborg et al., 2010). Notably, despite differences in prevalence and severity of different symptoms between large and small vessel VaD, Staekenborg and colleagues (2010) reported no overall difference in total number of reported symptoms or overall neuropsychiatric inventory score between the two groups.

1.4.2.4Communication

Aphasia may sometimes affect people with vascular dementia as their aetiology is similar to that of a stroke, which commonly results in aphasia (Volkmer, 2013). There is some disagreement regarding this as others argue that, although possible, language is not typically affected by VaD (Desmond, 2004). However as Desmond notes, this may be due to lack of inclusion of people with aphasia in such studies (2004). When language is affected in VaD, impairments may be noted in syntax rather than word retrieval (Desmond, 2004). Syntactic errors occur when grammatical markers are used incorrectly or are missing; for example, verbs may lack inflections or nouns may have incorrect plural markers.

Motor speech difficulties may be more associated with VaD (Desmond, 2004; Volkmer, 2013). The term motor speech difficulties refers to the physical verbal articulation of generated language, from the generation of breath support to the shaping of speech sounds using the lips and tongue. VaD may result in dysarthria, a speech condition where the nerves and muscles affecting the speech articulators including lips and tongue are unable to work effectively due to vascular damage in the brain (Volkmer, 2013). When combined with wider higher-level cognitive difficulties with executive function, the impact of dysarthria further impacts on communicative success for people with VaD.

1.4.3 Dementia associated with Lewy bodies

The term Lewy Body Dementia may be used as an overarching category label for both Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD) (Kane et al., 2018). However, this term is not used consistently in the literature, and the use of the term Lewy Body Dementia appears on occasion to refer to DLB alone. Additionally, the term Lewy Body Spectrum Disorder (LBSD) is used by some (Ash et al., 2012) to refer to people with DLB and PDD, as well as people with Parkinson's Disease without any cognitive impairment, and encapsulates the concept of all three conditions being the same disease on a continuum. In the current study, following broad consensus in the literature, the terms DLB and PDD will be used to refer to the two types of dementia associated with Lewy bodies, but will not include Parkinson's Disease without cognitive impairment.

Following AD, DLB is sometimes considered the second most frequent cause of dementia (Jellinger, 2009; World Health Organisation, 2018). Many others report it to be the third most frequent, following AD and VaD (Livingston et al., 2017). There is limited evidence around this, with a systematic review of the prevalence and incidence of DLB resulting in only 6 original studies (Zaccai, McCracken, & Brayne, 2005). The systematic review found that DLB accounted for a wide range of between 0% and 30.5% of all dementia cases, dependent on the criteria for inclusion (Zaccai et al., 2005). A more recent study found that DLB was believed to account for 3.8% of new dementia cases, with the authors noting that diagnosis was significantly higher when using newer criteria for diagnosis (Vann Jones & O'Brien, 2014). Its prevalence of the diagnosed dementias in the community was 4.2% compared with 7.5% of those in secondary care, perhaps reflecting more specialised diagnostics or increased severity of symptoms (Vann Jones & O'Brien, 2014). Differences in regional prevalence and lower than expected case numbers have led some to argue that overall prevalence figures are likely to be low due to underdiagnosis (Kane et al., 2018).

PDD is associated with Parkinson's Disease (Agronin, 2014). Around 18% to 30% of people with Parkinson's Disease may develop dementia, and up to 50% develop some cognitive difficulties (Volkmer, 2013). However, a review by Emre and colleagues (2007) found wide variation in the point prevalence of between 22% and 48% of people with Parkinson's Disease having PDD. This aligns with an earlier study of 1767 people with PD, which found that 554 people (31.3%) had PDD (Aarsland, Zaccai, & Brayne, 2005).

PDD can be differentiated from DLB as the former has physical symptoms initially, and usually lacks the early cognitive difficulties associated with DLB (Volkmer, 2013). Diagnosis of PDD is usually made if motor symptoms (tremor, rigidity, slowness of movement) precede cognitive symptoms by more than one year, whereas if cognitive symptoms precede motor symptoms by more than one year, a diagnosis of DLB is made (Lippa et al., 2007). For DLB, spontaneously developing features of Parkinsonism are common, with onset within the first year following development of cognitive symptoms (World Health Organisation, 2018). Specifically, for a diagnosis of PDD, according to the DSM V there must be neurocognitive decline of gradual onset within the context of a pre-existing Parkinson's Disease, with no other likely cause (American Psychiatric Association, 2013).

Despite being typically considered as diagnostically distinct entities, it has been suggested that as PDD and DLB have many overlaps, both in terms of features and neuropathology, attempts to separate the two are arbitrary as it is simply based on whether cognitive or motor impairments appear first (Jellinger, 2018). Given that Parkinsonism is in itself a feature of DLB, it has been argued that DLB and PDD, rather than separate diagnoses, should actually be considered as points on a continuum of one disease (Jellinger & Korczyn, 2018).

Quality of life for people with DLB may be much lower than for people with other types of dementia, such as AD (American Psychiatric Association, 2013). For example, a study of 41 people with DLB and 43 with AD found that people with DLB had greater functional difficulties particularly in mobility and self-care such as using the toilet, bathing and walking, along with greater neuropsychiatric symptoms, such as sleep disorders, than people with similar cognitive levels due to AD (McKeith et al., 2006). Indeed, McKeith and colleagues note the impact of this for relatives and other people providing care is that, in contrast with other types of dementia, they may have to manage such a wide range of issues (McKeith et al., 2006).

1.4.3.1Neuropathology

Lewy bodies are proteins that appear in cortical and subcortical neurons as people age and although they do not necessarily cause dementia symptoms, they can result in DLB (Agronin, 2014). They fall into two types, either classic brainstem Lewy bodies or cortical Lewy bodies, and they follow 3 stages: brainstem predominant, limbic/transitional and diffuse neocortical (Jellinger, 2009). People with DLB consistently show striatal beta-amyloid plaques which increase with dementia severity; this is not the case of PDD (Halliday, Song, & Harding, 2011). Instead, the cause of the progression from PD to PDD is associated with fibrillar alpha-synuclein, a protein involved in neurotransmission, spreading from the brainstem to the limbic and neocortical areas of the brain (Irwin, Lee, & Trojanowski, 2013). In up to half of cases of PDD, both amino acids forming beta-amyloid plaques and tau proteins can develop to such an extent that the dementia can also be considered as AD (Irwin et al., 2013).

There is considerable heterogeneity of neuropathology in DLB. For example, a post-mortem study of 65 people with diagnosed AD found that 8 actually had prevalence of Lewy bodies (Forstl, Burns, Luthert, Cairns, & Levy, 1993). Neuropathologically, these 8 people had greater atrophy of the frontal cerebral region in addition to loss of neurons in the substantia nigra and the nucleus basalis in the forebrain (Forstl et al., 1993). They may thus be considered to have a Lewy body variant of Alzheimer's disease rather than specifically DLB (McKeith et al., 2017). For PDD, neuropathology differs from DLB in that while for DLB, Lewy bodies are mainly in the cortex, for PDD Lewy bodies are mainly in the basal ganglia (American Psychiatric Association, 2013).

However, it is not clear how Lewy body pathology translates into signs and symptoms of dementia, with the cause most likely to be multifactorial (Walker, Possin, Boeve, & Aarsland, 2015). Unlike other forms of dementia such as AD, on MRI scans DLB does not show significant atrophy of the middle temporal lobe and this can be used to distinguish between diagnoses (McKeith et al., 2017).

1.4.3.2Progression

The average age of onset of DLB is age 68 years (Reilly, Rodriguez, Lamy, & Neils-Strunjas, 2010). Initially, symptoms may be confusion/delirium and the onset may be triggered by an unrelated illness or surgery (American Psychiatric Association, 2013). A steady decline in yearly survival following diagnosis is noted, with life expectancy of up to six years post-diagnosis (Walker et al., 2000). However, there may be significant variation in presentation over a number of days (World Health Organisation, 2018). Despite this gradual decline and day to day variation, there may be some periods where symptoms plateau temporarily before progression continues (American Psychiatric Association, 2013).

Life expectancy for people with DLB may be notably less than for AD (Price et al., 2017). Price and colleagues (2017) reported that of 251 people with DLB, median life expectancy was 3.3 years for women and 4 years for men measured from first presentation with cognitive symptoms. For PDD, although some mild cognitive difficulties may occur early in the disease, full PDD does not usually occur until later in the disease course (American Psychiatric Association, 2013).

1.4.3.3Cognition

Cognitive difficulties are often the first symptom for people with Lewy body dementia. For example, in one study of 41 people with Lewy body dementia, 63% had cognitive or behavioural symptoms first, with memory impairment the main cognitive difficulty (Doubleday, Snowden, Varma, & Neary, 2002). As discussed previously, it is this initial cognitive difficulty which distinguishes Lewy body dementia from PDD. However, both share similar core cognitive difficulties of executive function, attention and behaviour, and visuospatial judgement of objects (Lippa et al., 2007).

Lewy body dementia can present as similar to AD or vascular dementia (Agronin, 2014). However, people with Lewy body dementia may have notable fluctuations in cognition and visual hallucinations and mild motor features of a parkinsonism (McKeith et al., 1996). Such motor features may include slowness of movement, rigidity or tremor. The principal feature of Lewy body dementia which can distinguish it from AD is variable attention and cognition (Hancock, 2012).

In line with other forms of dementia, the DSM V requires there to be a decline in cognitive function in one cognitive domain (not necessarily in memory) (American Psychiatric Association, 2013). Core diagnostic features for DLB are variable cognition, attention and alertness, recurring detailed visual hallucinations and symptoms of Parkinson’s Disease that develop at least one year after the onset of cognitive difficulties (American Psychiatric Association, 2013). Suggestive features for diagnosis of DLB may be rapid eye movement sleep disorder, or severe neuroleptic sensitivity (American Psychiatric Association, 2013).

Hallucinations are associated with both DLB and PD. Visual hallucinations are more common for people with DLB than PD, with an estimated prevalence of 61.8% in DLB and 28.2% in PD (Eversfield & Orton, 2019). Auditory hallucinations are also common for people with DLB and PD, with a review estimating a prevalence of 30.8% in DLB and 8.9% in PD (Eversfield & Orton, 2019). More specifically, Eversfield and colleagues reported that for people with DLB, verbal hallucinations, which are where speech is heard, form a majority of auditory hallucinations, whereas for PD, verbal hallucinations form a minority of auditory hallucinations (2019).

Cognitive impairments in PDD are typically in memory, attention, executive function and visuospatial function (Emre et al., 2007). There may also be behavioural changes including hallucinations and delusions and apathy (Emre et al., 2007). Depression or anxiety are also common, as is daytime sleepiness and REM sleep disorders (American Psychiatric Association, 2013). Due to a combination of possible parkinsonism and dementia pathology, loss of ability to perform tasks of everyday life can be notable early in the disease progression (Doubleday et al., 2002).

1.4.3.4Communication

Initially, for people with DLB there may be no language difficulties evident. A study reviewing presenting complaints of people with DLB found that the main cognitive difficulty was expressive language for only 5% of people (Doubleday et al., 2002). However, the study did not include receptive language as a separate category, and includes language impairments as part of a broader collection of cognitive deficits (Doubleday et al., 2002).

Communicative difficulties are typically loss of logical coherence when speaking, and topic perseveration, which involves continuing to talk about the same topics repeatedly (Reilly et al., 2010). In addition to communication problems related to reduced attention, such as inability to maintain topic when speaking or to hold attention when listening, apraxia and anomia are key communication difficulties in DLB (Bayles, 2007). Added to this, communicative success may be further limited as, due to the likely parkinsonism features present, people with Lewy body dementia may have a quiet voice due to ineffective breath support (McKeith et al., 1996).

Ash and colleagues (2012) examined speech fluency in PDD and DLB. They found that people with PDD and DLB had impairments in executive function causing reduced speech rate and pauses during speech likely due to difficulties in organisation and planning of upcoming utterances (Ash et al., 2012). They also found that people with PDD and DLB had difficulty with expressive language, articulation and grammar, which they hypothesised was due to neuropathology affecting language regions of the brain (Ash et al., 2012). Similarly, a separate study concurred that people with PDD and DLB had impairment in narrative discourse (telling a story) and that this was related to impairment in executive function and speech fluency (Ash et al., 2011). Narrative discourse organisation was measured using three markers: local connectedness (relates to what came immediately before); retains the theme (is linked to the point of the story); and global connectedness (the ending of the story links to the beginning) (Ash et al., 2011). The authors found that, taken together, people with PDD and DLB maintained local connectedness half of the time, maintained the theme very rarely, and maintained global connectedness about a third of the time (Ash et al., 2011). Furthermore, people with DLB had significantly lower scores on local connectedness and maintaining the theme than people with PDD (Ash et al., 2011).

1.4.4 Frontotemporal dementia

Unlike some other dementias such as AD, Frontotemporal dementia (FTD) is a syndrome rather than a specific disease (Agronin, 2014). Initial descriptions and classifications of criteria for FTD diagnosis were summarised via the Lund and Manchester Groups in 1994. They describe symptoms for FTD, which they consider as a behavioural disorder which is distinct from yet on a spectrum with the language variants of dementia associated with frontotemporal pathology (Neary et al., 1994). In general, frontotemporal dementia typically affects personality and behaviour, as these areas are controlled by the frontotemporal region of the brain (Agronin, 2014). Symptoms of FTD can be grouped as related to behaviour, speech, emotional/affective disorder, and spatial orientation (Neary et al., 1994).

FTD can be broadly split into behavioural or language subtypes (Laforce, 2013). However, terminology describing FTD and its subtypes is variable in the literature. Firstly, the term frontotemporal lobar degeneration (or FTLD) is sometimes recommended for all conditions with pathology associated with frontal and temporal lobes (Mackenzie et al., 2009). The authors included FTD within this umbrella (Mackenzie et al., 2009). Progressive non-fluent aphasia (PNFA) and semantic dementia (SD) are considered alongside FTD by Mackenzie and colleagues (2009), but may alternatively be considered as subtypes of FTD. Mesulam (2001) notes that the term SD originally described deficits in both language and visual processing, but latterly has been used to describe a subtype of primary progressive aphasia with semantic impairment of comprehension, fluent speech but not necessarily visual processing deficit. It is this latter use, as a subtype of primary progressive aphasia, which has been adopted for the current study. However, others such as Hodges and Miller (2001) argue that FTD rather than FTLD should be retained as the overarching label, with subtypes of FTD for the different presentations. Latterly, some (Hodges & Patterson, 2007) described FTLD as being synonymous with FTD.

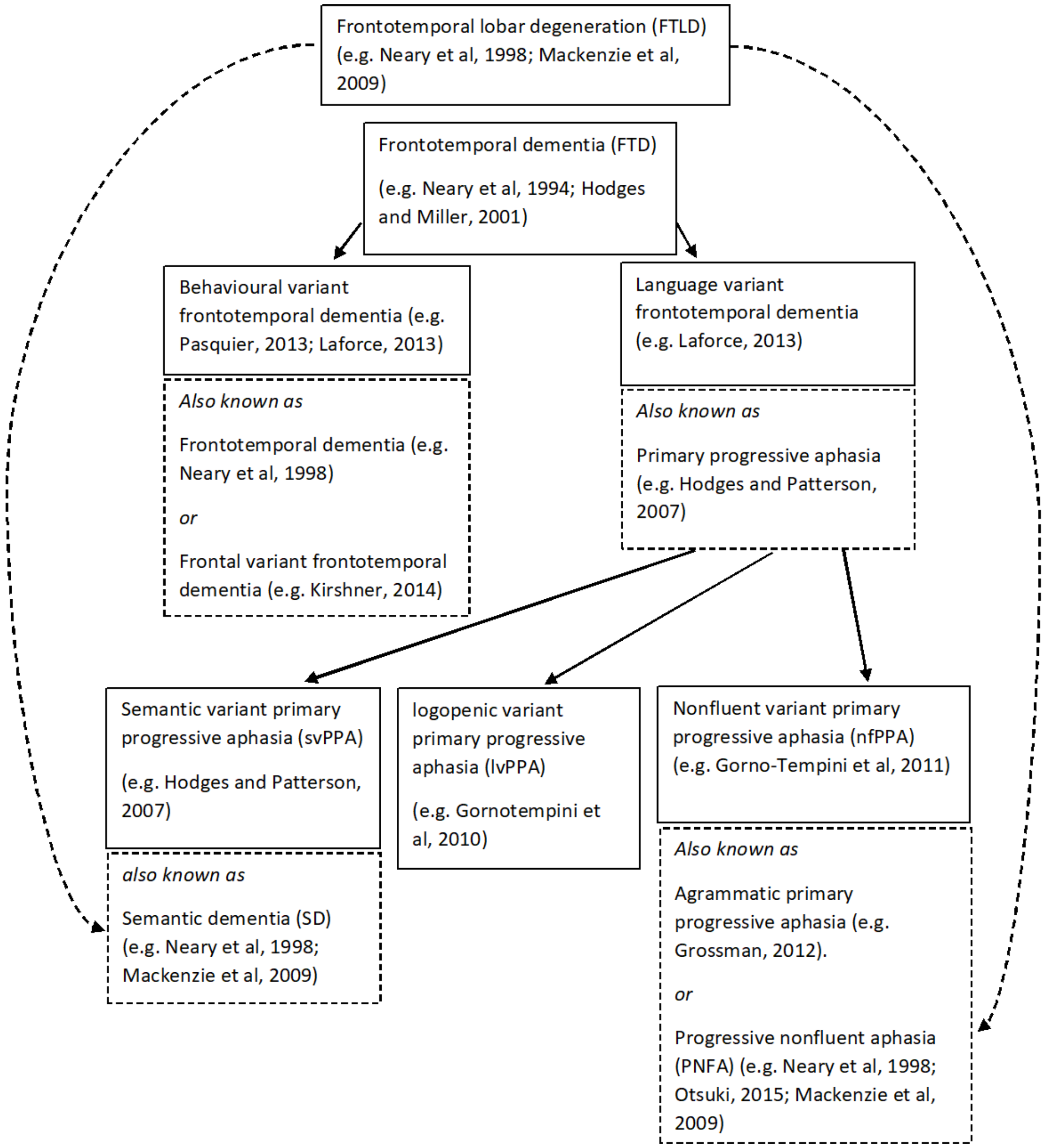
Earlier descriptions of FTD by Neary and colleagues (1998) outline what amounts to a behavioural condition, affecting ‘personality and social conduct’ (p. 1546). The authors consider it a type of FTLD alongside semantic dementia and progressive non-fluent primary progressive aphasia (Neary et al., 1998). It is closely aligned with the behavioural variant of FTD described with subtypes of FTD from section 1.4.4.3 below. In general, initial symptoms of FTD typically include disinhibited behaviour, social difficulties or impaired executive function as described following a study of 52 people with FTD (Lindau et al., 2000). General core features of FTD according to Neary and colleagues are progressive decline in social interaction, in regulation of appropriate behaviour including reduced empathy, and reduced insight into their condition (1998). In addition, FTD can result in decreased expressive language, and may also present as echolalia, with unintended repetition of certain words (Bayles, 2007). As the dementia progresses the areas of brain atrophy become more widespread resulting in a merging of the features of each type into a global cognitive impairment affecting all areas of functioning (Bang, Spina, & Miller, 2015).

Oyebode and colleagues investigated the features of bvFTD and their impact of everyday life (Oyebode, Bradley, & Allen, 2013). They found that relatives of people with bvFTD report reduced personal drive/motivation, and unusual eating patterns/habits (Oyebode et al., 2013). They also reported difficulties with planning and completing tasks, noting how this impacted on their work. Relatives reported feelings of embarrassment, due to uninhibited behaviour in social situations in addition to expressive/receptive language impairments or social communication changes such as loud voice and rhythmic chanting (Oyebode et al., 2013).

The impact on relatives can involve completing additional tasks that the individual is unable to do. They may be required to defend or explain their relative's unusual behaviour to others (Oyebode et al., 2013). As a consequence, people with bvFTD and their relatives may seek solace in physically removing themselves to avoid embarrassment, or trying to circumnavigate unusual behaviour to find mutually acceptable alternatives, sometimes using humour or other coping strategies (Oyebode et al., 2013). The relatives of people with bvFTD report feeling grief at the perceived loss due to changes in their relatives personality and behaviour (Oyebode et al., 2013). Indeed Oyeboye and colleagues (2013) report that there is a greater impact on relatives of people with bvFTD than for the relatives of people with AD, but that it is harder for relatives of people with bvFTD to find information and support than for the relatives of people with AD.

As noted above, terms associated with FTD are variable in the literature. As such, Figure 1 represents a current consensus adopted for this study regarding FTD terminology and relationship to each other, as well as providing key historical/alternative terms. Solid lines represent current consensus as used in this study whereas dashed lines represent historical/alternative terms.

Figure 1 - current/past consensus and development of frontotemporal dementia terminology



1.4.4.1Neuropathology

FTD is associated with a heterogeneous neuropathology, however atrophy is largely focussed on the frontal and temporal lobes of the brain (Mackenzie et al., 2009).

As with AD, diagnosis by MRI can be uncertain, as although FTD is assumed to affect the frontal and temporal lobes of the brain, autopsy of the brain of people presenting with apparent FTD can show, for example, AD pathology (Volkmer, 2013). In a key study, Rohrer and colleagues (2011) examined the neuropathology of 95 cases of frontotemporal degeneration. They found that certain types of FTD were associated with specific pathologies. For example, svPPA (described in earlier studies as SD) appeared to be strongly associated with pathology of a specific protein known as TDP-43 type C (Rohrer et al., 2011). Young onset appearance of bvFTD was associated with fused-in-sarcoma protein, whereas language variant PPA (named progressive nonfluent aphasia in their study) was associated with tau protein (Rohrer et al., 2011). The authors noted that bvFTD was the most frequently occurring FTD in their study, accounting for 47 of the 95 cases, but that this clinical presentation was associated with a diverse range of pathologies from multiple forms of tau pathology (total of 21) and TDP-43 type A (total of 20) (Rohrer et al., 2011). Pick's disease is sometimes considered a key example of a disease causing Frontotemporal dementia (Bayles, 2007). However in Rohrer and colleagues (2011) study, Pick's disease pathology only accounted for 13 of the 95 cases of FTD.

Neary and colleagues (1994) reported the relationship between FTD and motor neurone disease (MND). This is now considered a specific presentation, as FTD with MND, and is seen with tau negative pathology (Neary & Snowden, 2013). However, while MND is now considered to affect cognitive as well as motor function, cognitive symptoms are often mild, though they occasionally meet criteria for FTD (Strong et al., 2009). The subtype of FTD most associated with MND is behavioural variant FTD (Saxon et al., 2017). In addition, svPPA (labelled by Saxon and colleagues as semantic dementia but assumed to be PPA) and nfvPPA (labelled as progressive nonfluent aphasia) do occur but infrequently as part of MND (Saxon et al., 2017).

Alladi and colleagues provide further evidence of FTD being a distinct type of dementia (Alladi et al., 2007). They found that AD pathology was present in only 7.1% of people with bvFTD and only 10% of people with svPPA (Alladi et al., 2007). This is in contrast to lvPPA, where the authors found that 44% of people had AD pathology, thus providing some evidence that lvPPA may be a type of PPA that does not fit within the FTD umbrella (Alladi et al., 2007). Neuroimaging of people with PPA typically shows involvement of the language areas of the left hemisphere, although some cases may display atypically distributed neuropathology more similar to AD (Mesulam, 2001). Specifically, Gorno-Tempini and colleagues' (2004) study of 31 people with PPA found that nfPPA was associated with atrophy in the left inferior frontal and anterior insular region. They found that atrophy of anterior temporal lobes was found bilaterally for people with svPPA (Gorno-Tempini et al., 2004).

Notwithstanding this ambiguity, certain patterns of atrophy may reflect different types of FTD. Asymmetric atrophy may suggest FTD generally, with left-sided peri-sylvian area affected in non-fluent variant PPA, and anterior temporal lobe affected in semantic variant PPA (Waldemar et al., 2007). Here, while acknowledging the lack of neuropathological consensus, behavioural and language variants of FTD have been categorised as part of FTD.

1.4.4.2Progression

FTD is recognised as one of early onset dementia's major causes (Neary & Snowden, 2013). Some suggest FTD may start from age 50 years (Bayles, 2007). However others suggest that the typical age of onset is 60 years (Reilly et al., 2010). As such, a range of onset age seems likely, with others describing the onset of FTD as being between 45 and 65 years of age (Hodges & Patterson, 2007). A small study of 100 people with svPPA found that onset of symptoms was slightly later; 45% of cases were later onset at age 65 years and over (Hodges & Patterson, 2007). Baborie and colleagues found that late-onset FTD may exist in a slightly different form than early-onset FTD, with memory loss and behavioural change more apparent but language and semantic impairment less apparent (Baborie et al., 2012). However, it appears to be rare, accounting for 3.2% of all dementia patients who underwent autopsy at a UK hospital (Baborie et al., 2012).

In contrast with other forms of dementia such as AD or VaD, there is a reduced likelihood of developing FTD in older age (Reilly et al., 2010). Typical life expectancy for FTD is around 8 years following disease onset (Bang et al., 2015). A similar finding was also reported by Roberson and colleagues (2005) of 8.7 years following FTD symptoms starting, and 3 years from attendance at clinic. This suggests people with FTD live with symptoms for several years before seeking healthcare intervention. For people with svPPA (described below), life expectancy may be considerably longer, at 11.9 years from onset and 5.3 years from presentation (Roberson et al., 2005). Life expectancy for people with FTD does not appear to be affected by whether individuals are male or female, their age of onset of FTD symptoms, or their level of education, family background or broader neuropsychiatric status (Roberson et al., 2005).

1.4.4.3Cognition and Language – Behavioural variant Frontotemporal dementia (bvFTD)

bvFTD is also sometimes known in the literature as frontal variant FTD (Kirshner, 2014). bvFTD is considered the most common subtype of FTD (Perry et al., 2017). It can be difficult to diagnose at both early and late onset; at early onset it may be confused with psychiatric conditions, due to the behavioural changes, whereas at late onset it may be more confused with diagnosis of AD (Pasquier, 2013).

bvFTD typically presents as worsening behaviour and/or cognition (Rascovsky et al., 2011). It may be associated with disinhibited behaviour, such as flouting social norms and lack of empathy or interest in others (Rascovsky et al., 2011). However, memory and visuospatial skills may be preserved (Rascovsky et al., 2011). Although predominantly affecting behaviour, people with bvFTD may have some difficulties maintaining conversation and retaining sufficient attention when talking to others (Volkmer, 2013). Behavioural changes may include changes in eating habits. For example, a small study of 33 people with FTD and 37 people with AD found that those with FTD could be distinguished from AD as they had higher rate of both changes in eating habits and loss of social awareness (Bozeat, Gregory, Ralph, & Hodges, 2000).

1.4.4.4Cognition and Language – Language variants of Frontotemporal dementia

The language variants of FTD are the Primary Progressive Aphasias (PPAs), a type of dementia characterised by declining language skills, which are its main (and sometimes only) feature. Although presented as a subtype of FTD in this study, there is no universal agreement of this. For example, Mesulam (2001) suggested that having PPA as a subtype of FTD may be unhelpful, as early presentation can involve parietal areas of the brain rather than the frontal areas associated with FTD. There is a lack of consensus around this, however, as PPA is a set of symptoms which, although often caused by FTD pathology, may also have other causes (Reilly et al., 2010). For example, brain scans of people with features of PPA have not always reflected patterns of atrophy expected for PPA with, for example, atrophy more typically associated with AD pathology noted (Teipel et al., 2014).

As first described in detail by Mesulam (2001), PPA is characterised by gradual onset of declining word finding, naming, or comprehension of language (i.e. aphasia) which has been affecting daily function for two years or more. In addition, there must be no broader cognitive impairment, for example changes to personality, and no other causes, such as stroke (Mesulam, 2001). Age of onset is typically 55-65 years (Mesulam, 2001).

The main features of PPA are language difficulties (aphasia), yet the memory difficulties most associated with dementia are relatively unaffected (Mesulam, 2003). Word finding difficulties are almost always present in early stages of PPA; decline in word finding abilities may be the only symptom for some people as PPA progresses into middle and later stages (Mesulam, 2001). For some people, PPA may then progress with an increasing breadth of symptoms depending on the subtype of PPA, until at later stages both expressive and receptive language may be severely aphasic (Mesulam, 2001).

Unlike other forms of dementia, onset of PPA is often at a relatively young age, before 65 years (Mesulam, Wieneke, Thompson, Rogalski, & Weintraub, 2012). However, there can be a delay between developing symptoms and getting a diagnosis. For example, one study of 47 people with svPPA found that people presented with a mean symptom duration of 3.6 years, but ranged broadly from 1 year to 10 years (Thompson, Patterson, & Hodges, 2003).

People with PPA may have increased risk of depression compared with those without dementia (Medina & Weintraub, 2016). In one study, approximately one third of 61 people with PPA who were assessed using the Geriatric Depression Scale scored within the depressed range, compared with fewer than two percent in a control group (Medina & Weintraub, 2016). In addition, for those with PPA who also had depression, the number of depressive symptoms increased with lower naming performance, suggesting the impact of word finding difficulties on wellbeing (Medina & Weintraub, 2016).

As shown earlier in Figure 1, Primary Progressive Aphasias (PPA) can be subcategorised as semantic variant, logopenic variant or non-fluent variant depending on the presentation (Volkmer, 2013). Each will be considered in turn here.

1.4.4.4.1 Semantic variant PPA

Semantic-variant PPA (svPPA) was first described by Arnold Pick hence it was originally known as Pick's Disease (Hodges & Patterson, 2007). Neary and colleagues (1998) described a consensus for diagnosis of what they termed semantic dementia, where they considered it a type of FTLD alongside FTD. More recently, svPPA has been considered a subtype of FTD (Hodges & Patterson, 2007). However, there is some disagreement around the use of terminology, as others have argued that semantic dementia is caused by FTD alone, whereas svPPA can be caused by a number of aetiologies, including AD, as AD pathology has been found in people with apparent svPPA (Mesulam et al., 2009). Today, svPPA is a term often used synonymously with semantic dementia (Reilly et al., 2010). For this study, the term svPPA will be used.

Tentatively, three neuropathological patterns have been identified for svPPA, determined by involvement of tau protein and ubiquitin, a protein formed of amino acids: these are a tau-positive pattern which includes Pick's Disease; a ubiquitin-positive and tau-negative pattern; and finally a degeneration without tau or ubiquitin present (Hodges & Patterson, 2007).

Neary and colleagues (1998) first described the core features of svPPA (named as semantic dementia) as a gradually progressive language disorder with fluent speech, loss of semantic knowledge and semantic errors. In addition, they identified difficulty recognising people and objects as a core feature (Neary et al., 1998). They also reported an extensive range of 'supportive diagnostic features' which may help to determine diagnosis, including speech/language, behaviour, physical and neuropsychological signs (Neary et al., 1998).

svPPA is specifically characterised by difficulties with naming items, and with comprehension at single-word level (Gorno-Tempini et al., 2011). Both expressive and receptive language skills are affected, and decline over time (Volkmer, 2013). Understanding of less frequent words may initially be affected, but this may not appear to affect understanding of the sentence or ability to carry out successful conversation (Hodges & Patterson, 2007). Typically, people with svPPA find both repetition and grammar in spoken language is unaffected (Gorno-Tempini et al., 2011). In addition, surface dyslexia when reading, and dysgraphia (plausible spelling errors) when writing, have been noted (Volkmer, 2013). Surface dyslexia occurs when people have difficulty reading irregularly pronounced words as a whole; instead, they over apply regular speech-sound rules resulting in an incorrect pronunciation (Binder et al., 2016).

As svPPA progresses, attempts at mitigating anomia may result in use of more general terms, such as "place" or "thing" instead of the specific intended target (Hodges & Patterson, 2007). People with svPPA are typically able to repeat even complex words successfully, but may struggle to point to the correct picture to identify them (Hodges, Martinos, Woollams, Patterson, & Adlam, 2008).

For people with svPPA, speech rate may be slightly reduced, however overall speech fluency was high and comparable with a control (Wilson et al., 2010). In contrast with nfPPA, phonological errors are typically minimal, with sentence repair, filled pauses and false starts (words where the speaker stopped and restarted after the initial phonemes/syllable) all within normal limits (Wilson et al., 2010). As such, speech largely appears fluent; indeed, there may be a greater number of embedded sentences than is usual due to attempts at circumlocution of word finding difficulties (Wilson et al., 2010). There is some evidence that rate of language decline may be slower for svPPA than for either lvPPA or nfPPA. Sebastian and colleagues (2018) examined decline in naming performance and semantic knowledge and found that people with svPPA had the slowest rate of decline compared with other forms of PPA.

In contrast to AD, svPPA typically does not impact on episodic memory (Irish et al., 2016). Indeed, memory of more recent events is typically better than those from long ago (Hodges & Patterson, 2007). Therefore, people with svPPA can often recall everyday events from recent memory, for example places they have visited.

Although predominantly an expressive language impairment, some behavioural changes may occur in svPPA. For example, Thompson and colleagues' (2003) study of 47 people with svPPA found that having particular food likes/dislikes, changes in mood such as depression and irritability, and an unusual focus on completing puzzles were common behavioural symptoms. Having fewer conversations (in addition to expressive and receptive language difficulties) and problems identifying people were frequently reported cognitive symptoms (Thompson et al., 2003). Interestingly, the authors found that the prevalence of left or right sided pathology could be a strong indicator of symptoms of svPPA. For example, expressive and receptive language difficulties were associated with left-sided pathology, whereas social difficulties, loss of insight of their condition and impaired recognition of people was associated with right-sided pathology (Thompson et al., 2003).

As part of a separate small study, when 9 people with svPPA completed Cummings and colleagues' (1994) Neuropsychiatric Inventory, the most common behaviours noted were depression (78%) and irritability/liability (78%) (Rohrer & Warren, 2010). Disinhibition, anxiety, and eating changes were also reported by more than half of participants. In comparison with nfPPA and lvPPA, a much greater percentage of participants with depression, and with eating changes, was reported (Rohrer & Warren, 2010). According to a longitudinal study of cognitive symptoms of svPPA over a mean of 3 years, performance declined slowly and deficits remained language-based even after 3 years, rather than developing into a broader cognitive decline (Leyton, Hsieh, Mioshi, & Hodges, 2013).

Its impact on the lives of both people with svPPA and those around them can be profound. A single case study of the impact of svPPA on an individual's family found that the impact on the family was broad, relating to living with very set routines, efforts involved in monitoring and ensuring the individual's safety and appropriateness of interactions with others, and changes regarding likes and dislikes of hobbies and interests (Kindell, Sage, Wilkinson, & Keady, 2014).

1.4.4.4.2 Non-fluent variant PPA

Non-fluent PPA (nfPPA) is characterised by agrammatical speech, and/or effortful/apraxic speech (Gorno-Tempini et al., 2011). It is sometimes known as progressive non-fluent aphasia (PNFA) in the literature (Otsuki, 2015). Occasionally, when described as PNFA, it is considered to be a subtype of FTLD alongside FTD (Neary et al., 1998). Despite the variation in terminology, for this study, the more typical term of nfPPA will be used. Although onset of nfPPA is typically about age 60 years, there is a considerable range from age 30 years to age 80 years (Grossman, 2012). Life expectancy is variable dependent on comorbid diagnoses, but is around seven years after symptom onset (Grossman, 2012). nfPPA is associated with atrophy of the left anterior frontal and anterior superior temporal regions (Grossman, 2012).

Neary and colleagues' (1998) early descriptions identified core expressive language features of effortful speech with phonemic or grammatical errors, or word-finding difficulty. However, speech may actually be fluent, but there may be long pauses during sentences or between sentences which may give the impression of dysfluency (Grossman, 2012). Speech is typically slower even compared with other PPAs (Wilson et al., 2010). Features of apraxia of speech, such as phonological distortions, sentence repair and false starts, are sometimes seen which adds to the sense of dysfluency (Wilson et al., 2010).

Prosody may be unusual, which may affect communicative success when asking questions, which can rely on rising intonation (Grossman, 2012). Understanding of more complex sentences may be affected due to impaired grammatical comprehension (Grossman, 2012), but single word comprehension and semantic knowledge are typically spared (Gorno-Tempini et al., 2011). People with nfPPA typically struggle to repeat more complex words successfully, but are often able to identify the word by pointing to the correct picture (Hodges et al., 2008).

There is some evidence that the language skills of people with nfPPA decline more quickly than with other types of PPA. Sebastian and colleagues (2018) compared decline in naming and semantic knowledge with people with nfPPA, svPPA and lvPPA. They measured the language skills (2 naming assessments and 1 semantic knowledge assessment) of 94 people with PPA and found that the language skills of people with nfPPA declined most quickly, followed by svPPA (Sebastian et al., 2018). People with lvPPA had slowest decline, however the authors note some individual variation across all three subtypes (Sebastian et al., 2018). Interestingly, although associated with semantic impairment, decline on semantic assessment (Pyramids and Palm Trees) was actually slower for people with svPPA than for those with nfPPA (Sebastian et al., 2018).

Fewer closed class words – that is, word groups that cannot be added to, such as pronouns or determiners – along with fewer verbs are sometimes found in the speech of some people with nfPPA (Wilson et al., 2010). Although not all people with nfPPA produce syntactic errors, many demonstrate reduced length of utterance and reduce number of embedded sentences (Wilson et al., 2010). When combined, these features appear as reduced complexity of expressive output, which may limit the communication of people with nfPPA. At later stage, more severe expressive language impairment may be evident for people with nfPPA, such as being unable to speak or having highly apraxic output leading to unintelligibility (Wilson et al., 2010).

Beyond communication, nfPPA can also affect individuals' behaviour. Rohrer and Warren (2010) completed Cummings and colleagues' (1994) Neuropsychiatric Inventory with 14 people with nfPPA and found that the most frequently reported behavioural symptom was apathy/indifference which was present in 64% of participants. Depression and agitation/aggression were also fairly common, being present in 57% and 50% of participants respectively (Rohrer & Warren, 2010). Notably, the percentage of participants with irritability/lability was low at 29% compared with 78% for those with svPPA and 71% with lvPPA (Rohrer & Warren, 2010).

In common with other forms of PPA, Grossman (2012) notes there is controversy over nfPPA diagnosis due to a heterogeneity of anatomy and neuropathologies, and difficulties defining the key language impairments (Grossman, 2012). For example, considering pathology of nfPPA, Alladi and colleagues (2007) retrospectively examined 26 cases of nfPPA and found that 12 (approximately 44%) had pathology consistent with AD.

Interestingly, the relatively recent classification of the PPAs and the subsequent research has led to further diagnostic labels. As such, nfPPA is sometimes considered an apraxia of speech, with individuals having difficulty with physical articulation of speech rather than specifically the language problem of aphasia (Volkmer, 2013). Primary progressive apraxia of speech (PPAoS) may be considered as a separate neurodegenerative condition, as there may be no aphasic features and the location of atrophy falls within the superior lateral premotor cortex rather than frontal lobe associated with PPA (Josephs et al., 2012). PPAoS has been used to describe progressive apraxia in the absence of other significant neurological decline (Josephs et al., 2012). This appears to place greater emphasis on apraxic features compared with Neary and colleagues criteria, where apraxia of speech is a supportive rather than core feature (Neary et al., 1998). The authors acknowledge that although it may appear to share many features with non-fluent PPA, its lack of the cardinal feature of PPA, namely aphasia, renders the new diagnostic label of

PPAoS beneficial (Josephs et al., 2014). Josephs and colleagues found that the most prevalent features of PPAoS were slow speech rate, with distorted speech arising from increased pauses such as between phonemes or syllables (2012). Such findings are clearly similar to the presentation of halting speech in nfPPA hence the initial diagnostic ambiguity, although the absence of any true aphasia may rule out nfPPA.

1.4.4.4.3 Logopenic variant PPA

Logopenic variant PPA (lvPPA) may also be known as logopenic progressive aphasia (Henry & Gorno-Tempini, 2010). This variant was described in detail more recently than other forms of PPA, initially by Gorno-Tempini and colleagues (Gorno-Tempini et al., 2004). lvPPA may be associated with atrophy of the left temporoparietal region of the brain (Gorno-Tempini et al., 2004). Furthermore, others argue that lvPPA may present with AD pathology and therefore lvPPA should be considered a presentation of AD (Kirshner, 2014).

lvPPA typically presents with difficulties retrieving single words in speech and difficulty with repetition of sentences; there may also be phonological errors noted (Gorno-Tempini et al., 2011). In addition to naming difficulties, people with lvPPA may have difficulty with repetition of spoken words (Henry & Gorno-Tempini, 2010). Comprehension of spoken sentences can be impaired too, sometimes resulting in an apparent global aphasia (Volkmer, 2013).

However, in lvPPA there is typically no apraxia, and expressive language is often grammatically correct, and both comprehension and semantic knowledge of single words is good (Gorno-Tempini et al., 2011). People with lvPPA do not typically have semantic impairment or difficulties forming sentences, nor do they have any dysarthric features (Henry & Gorno-Tempini, 2010). However, there is some disagreement regarding the extent of expressive grammatical competence. For example, Wilson and colleagues (2010) suggested that while people with lvPPA tend to use full sentences, syntactic errors are often present. Others have also noted that, despite retained semantic knowledge, expressive output may appear impaired due to phonological and syntactic errors (Ahmed, de Jager, Haigh, & Garrard, 2012).

The speech of people with lvPPA may show both fluent and dysfluent qualities; typically, there are no speech distortions or other apraxic features, but there may be some phonological errors, such as substituting or omitting speech sounds (Wilson et al., 2010). Compared with other types of PPA, people with lvPPA may produce more frequent dysfluent features such as false starts, filled pauses, and sentence repair (Wilson et al., 2010).

Notably, features of lvPPA may extend beyond language. Rohrer and Warren (2010) completed Cummings and colleagues' (1994) Neuropsychiatric Inventory with 7 people with lvPPA and found that agitation or aggression, anxiety, apathy, and irritability or lability were the neuropsychological features found in more than half of participants. Interestingly, although the findings may be impacted by a small number of study participants, rates of depression were notably lower at 29% for lvPPA compared with 57% for nfPPA and 78% for svPPA (Rohrer & Warren, 2010). Although precise rates of depression for people with dementia are not available due to the interrelationship and considerable overlap between symptoms of the two conditions, some reports estimate that 20-30% of people with dementia have depression, however much higher or lower estimates may be plausible (Bennett & Thomas, 2014). This is notably higher than the estimated 9% prevalence of depression in the general population in the UK over the age of 65 (McDougall et al., 2007)

As lvPPA progresses, although limited to language difficulties at first, symptoms progress within 12 months to a broader cognitive decline (Leyton et al., 2013). Leyton and colleagues' longitudinal study assessed participants' cognition using two assessments, the Addenbrookes Cognitive Examination-revised (ACE-R) and the Mini Mental State Examination (MMSE), yearly for a mean of 3 years and found that, in addition to the expected decline in language-based skills, for all participants with lvPPA, attention, orientation and visuospatial skills also declined (Leyton et al., 2013). The rapidly broadening cognitive decline reported by this study appears in contrast to the FTD diagnosis criterion of cognitive decline being language-focussed for at least 2 years. Such broader cognitive decline appears to give support to the classification of lvPPA as under the AD umbrella.

1.5 Chapter summary

While noting considerable heterogeneity of impairments of people with different types of dementia, its impact typically progresses to involve a wide range of cognitive and communication deficits, affecting all areas of life. Based on the literature review above, the key communication features of the dementias are summarised in Table 2 on the next page.

Table 2 - typical key communication features of the dementias

Dementia type	Typical key features of communication impairment
Alzheimer's disease (typical presentation)	• Widely impaired language, in particular semantic breakdown leading to word-finding difficulties. • Slowed speech rate. • Social communication skills initially retained leading to apparently successful communication; at later stages social communication skills break down.
Alzheimer's disease (posterior cortical atrophy)	• Slowed speech rate and reduced phonemic fluency. • Semantic memory may only be minimally affected. • Dysgraphia may be more prevalent than for typical AD.
Vascular dementia	• Language not always affected, though stroke-like aphasia may occur. • Dysarthria of speech may be present. • Expressive errors may be in syntax rather than word-finding.
Dementia with Lewy bodies	• No initial language difficulties, although anomia may be present. • Apraxia of speech may be present. • Loss of logical coherence in communication with perseveration or loss of topic focus.
Frontotemporal dementia (behavioural variant)	• Social communication impairment is key, with difficulties such as maintaining sufficient attention when communicating.
Primary progressive aphasias	• Aphasia is the key feature at early stages. • For svPPA initial difficulties are word-finding and single-word comprehension with intact grammar. • For nfPPA language may be agrammatical with apraxia features and unusual speech prosody. • For lvPPA, word-finding difficulties, errors in expressive syntax and phonology may be present. Receptive language skills may also be impaired.

As detailed earlier in the chapter and summarised above, communication impairment is a key feature of many of the dementias, with word-finding difficulties often having a particularly significant and negative impact on the quality of life for people with dementia and their communication partners. Given the wide prevalence, severity of impairment, and extent of the impact of word-finding difficulties for people with dementia, it is important that there are effective speech and language therapy interventions available in this population group. The speech and language therapy approaches and interventions currently available will be discussed in the next chapter.

Chapter 2 Word-finding difficulties and interventions for people with dementia

This chapter outlines the neuropsychological theory of aphasia and links between aphasia and wider memory and cognition. It then discusses the broad philosophies of intervention for word-finding difficulties for people with dementia, including both functional and impairment-based approaches, before evaluating existing speech and language therapies for word-finding difficulties in the literature.

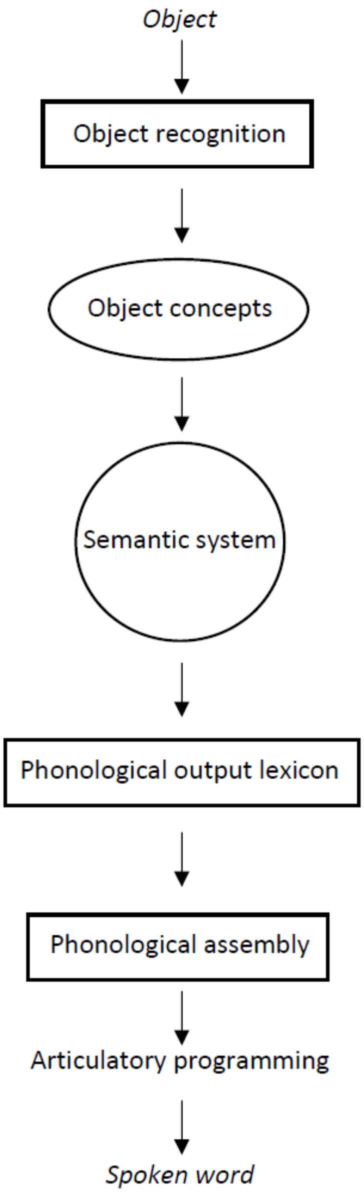
2.1 Theory of word-finding difficulties: neuropsychological model

As discussed in Chapter 1, word-finding difficulties, or anomia, are found in different forms across the different dementias (Beales, Whitworth, & Cartwright, 2018). They often occur early in the progression of dementia, and have a significant impact on the life of those with dementia and their family and friends. This section discusses the theory underpinning word-finding difficulties.

To help explain and quantify the processes that might determine language and thus language breakdown, theoretical frameworks have long been developed. A number of models have been developed, such as connectionist models, which seek to account for processing and breakdown in language (Dell, Chang, & Griffin, 1999).

Alternatively, one prominent model of language processing is the cognitive neuropsychological model, originally developed by Patterson and Shewell (1987) and more recently described by Whitworth, Webster and Howard (2014). The model is based on earlier models and consists of an interlinking flow diagram from input to output. Input is hearing the spoken name of the object, reading the written word for the object, or seeing the object itself, and output is either spoken or written word (Whitworth, Webster, & Howard, 2014). Between each input and output point the model consists of a set of stages representing the cognitive processing which theoretically takes place. These stages in the flow diagram are depicted as arrow lines connecting boxes. While only a theoretical representation, such a model is useful in supporting assessment of aphasia to identify the specific area of language breakdown (Whitworth et al., 2014). Here we will examine the parts of the neuropsychological model linked to verbal naming of physical objects as this reflects the scope of this study.

Figure 2 - extract from the full neuropsychological model by Whitworth et al (2014)



As shown in Figure 2 above, there are several theoretical steps in the neuropsychological model of language processing that concern the verbal naming of an object, or picture of an object. Firstly, the object must be seen and recognised as an object, which involves processing both the individual elements of the object and being able to combine these elements to recognise the object (Whitworth et al., 2014). Familiar objects may then be recognised, and the concept of the object is recognised which allows access to the full semantic knowledge of the object. Following access to the semantic system, the phonological output lexicon provides the access to the phonology required to say the word; the individual phonemes are subsequently assembled in the phonological assembly. The final stage, in order to produce speech, happens during articulatory programming, where the phoneme sequence is converted into a motor sequence combining the active and passive articulators resulting in the spoken naming of the object (Whitworth et al., 2014).

While the neuropsychological model provides a theoretical pathway for word-finding and can explain the impact of impairment at different stages of naming, the cause of any difficulties can be complex. This may be especially the case for types of dementia which cause a more global impairment – in essence this is all dementias other than the language-specific primary progressive aphasias.

2.2 Aphasia and memory

As described in Chapter 1, short-term or working memory impairment is a feature of many dementias. Reduced short term memory is also known to correlate positively with reduced expressive (and receptive) language production (Minkina, Salis, & Martin, 2018). The term working memory is usually used to describe the active dynamic use of the content contained within the short term memory, although the terms are sometimes used synonymously (Baddeley, 2012).

Two divergent approaches have emerged regarding the relationship between short term memory and language. One approach suggests short-term working memory could be separate from language. Proponents of such an approach have suggested that short term episodic and phonological storage could link between language function and long term memory (Baddeley, 2003). In contrast, others have argued that short term working memory and language function are very closely associated (Cowan, 2008). Evidence has also been found for a combination of both approaches. For example, a small case series of two participants examined their ability to manipulate different psycholinguistic variables in memory tasks and found that short term memory and language were separate although linked (Howard & Nickels, 2005). They also reported evidence of short term phonologic and semantic stores linked to language function (Howard & Nickels, 2005). Irrespective of the approach taken, some have suggested that the importance of short-term working memory is such that, for post-stroke aphasia at least, it should be specifically treated in addition to language as part of aphasia therapy (Salis, Kelly, & Code, 2015).

As described in Chapter 1, attention deficit is also a noted cognitive feature of a range of dementias. Attention generally refers to an individual's capacity to sustain attention which is appropriately selective and can exclude irrelevant stimuli, and move cognitively between different tasks requiring attention (Lee, Kocherginsky, & Cherney, 2020). Murray (2012) examined the relationship between aphasia and cognitive factors in 39 people with aphasia following stroke and found some evidence that attention deficit appeared to exacerbate aphasia. However not all participants with aphasia performed poorly on attention measures; in particular, those with anomia performed well, suggesting that attention deficit does not necessarily cause aphasia (Murray, 2012).

Executive function may also interact with aphasia. It has long been known that executive function is important for successful conversation, by being able to retain information from another speaker, to plan a response and inhibit inappropriate responses (Fridriksson, Nettles, Davis, Morrow, & Montgomery, 2006). However, there are also links between executive function and language ability, including word-finding. For example, Murray (2017) compared 36 participants with left-sided brain injury causing aphasia, 15 participants with right hemisphere brain injury, and compared their executive function with that of 36 controls. The study found that executive function correlated with both language and wider cognitive capabilities for both the group with aphasia and with the group with right hemisphere brain injury (without aphasia), suggesting that impairment in executive function is associated with aphasia, rather than brain injury per se (Murray, 2017). Similarly, a study of 47 individuals with post-stroke aphasia found that impairment in executive function was present in 79% of participants (Olsson, Arvidsson, & Blom Johansson, 2019). The authors found that impairment in executive function had a moderate to strong positive correlation with language ability (Olsson et al., 2019).

It is clear that there are strong links between aphasia and cognition, and that both are prevalent in many dementias. Taking into account the relationship between aphasia and cognition is therefore a key challenge when considering aphasia therapies for people with dementia.

2.3 Intervention for word-finding difficulties

Historically, speech and language interventions for people with dementia tended to be based on the idea that the declining prognosis meant impairment-based input would not be effective (Holland, 2003). However, despite this perception, research evidence has for some time found that impairment-based therapy has provided successful results with people with dementia. Indeed a 2009 review found that with impairment-based intervention for word-retrieval in progressive aphasia, almost all studies showed some improvement in naming of treated items, although gains were likely to be lost without continued practice (Croot, Nickels, Laurence, & Manning, 2009). Research has examined a range of different therapy techniques applied to people with dementia. However, almost all such studies have focussed on individuals with progressive aphasias such as PPA, as it was assumed that memory and associated cognitive factors in dementia such as AD would pose difficulties for language re-learning (Bayles & Kim, 2003). For example, a recent systematic review of lexical retrieval interventions resulted in 28 studies for PPA, but only 9 for people with AD (Beales et al., 2018). This reflects the historical lack of research of impairment-based intervention with people with AD.

Research involving people with PPA has often involved only a small number of participants. For example, a review of anomia therapy for people with PPA noted a small number of participants generally, and that this was limited further by the very recent addition of the diagnosis of logopenic variant PPA (lvPPA) (Jokel, Graham, Rochon, & Leonard, 2014). In terms of behavioural therapy (i.e. not related to pharmacological treatment), mostly semantic therapy, and occasionally phonological or spaced-retrieval therapies, were noted in the review. These are discussed in section 2.5.

One main limitation of these studies was that maintenance of treatment gain was not adequately considered. Sometimes maintenance was not considered, or was as little as 1 week; very occasionally, maintenance of gains at 6 months was considered (Jokel et al., 2014). Typically, follow-up was a maximum of one month, which only provides limited evidence for taking part in often extensive, time consuming, therapy programmes (Jokel et al., 2014). In part, this is likely to be due to the progressive nature of the dementias, both linguistically and cognitively, which makes long-term follow-up more difficult.

Studies of anomia therapy often consider generalisation to untreated items – that is, whether following therapy, the naming of items not practised improved. Where these PPA studies considered generalisation to untreated words, generalisation did not appear to happen for people with svPPA; however in the few studies available of anomia therapy for nfPPA available, generalisation was successful (Jokel et al., 2014).

As can be seen, there is a historical lack of research of impairment-based communication therapy for people with dementia, despite the significant impact of word-finding difficulties and the positive findings of impairment-based approaches for people with types of dementia where broader cognitive abilities are largely spared. This has meant practical focus for speech and language interventions has often been from a functional (activities/participation) perspective rather than impairment-based therapy. Activities/participation refers to an approach to therapy where focus is on improving individuals' ability to complete their daily activities successfully, as opposed to focussing on directly remedying their impairment or deficit (World Health

Organisation, 2002). In the next sections, functional therapy approaches will be discussed briefly, followed by more detailed examination of current impairment-based interventions.

2.4 Functional approaches

A functional/participation approach focusses on supporting the full biopsychosocial life participation of people with dementia, making person-centred goals in conjunction with family/friends (Rogalski & Khayum, 2018). Central to this, from the perspective of speech and language interventions, is developing communication support strategies to effectively support communication for both people with dementia and their key communication partners (Rogalski & Khayum, 2018). In practical terms, interventions may involve, for example, frameworks such as Supported Conversation for Adults with Aphasia, through which communication partners are trained to support the communication of people with aphasia (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001). Such training has been shown to result in improved communication, though it is important to note that it was developed for chronic moderate-severe aphasia following stroke, rather than dementia (Kagan et al., 2001). It is notable that significant improvement in communication for people with (moderate-severe) dementia and for communication partners was achieved despite only the latter receiving training (Kagan et al., 2001). This finding gives encouragement for use of this type of approach for supporting people with aphasia due to dementia who could not directly participate in speech and language therapy due to broader cognitive impairment.

This optimism largely continued in a review of speech and language interventions for progressive aphasias by Croot and colleagues (2009). They found that increased communicativeness and communication success was noted when using activities/participation approaches. Moreover, activities/participation approaches appeared to have greater impact on everyday communication than impairment approaches, but the authors note that more research is needed (Croot et al., 2009). This is perhaps notable as their review focussed on studies involving people with progressive aphasias which initially typically spare broader cognitive difficulties and are therefore often considered more appropriate for successful impairment-based interventions.

The limited nature of studies in this field too is summed up by a 2018 review of speech and language interventions for people whose dementia had advanced to moderate-severe, rather than mild-moderate stage. Despite seeking both direct (impairment-based) and indirect approaches, only 11 studies were included in the review, of which only one (conversation partner training) was categorised as indirect therapy (Swan et al., 2018). The authors found that there was considerable heterogeneity in therapy type, frequency and duration of therapy, but there was tentative evidence that cognitive stimulation therapies (where individuals take part in group activities designed to promote communication) were beneficial direct therapy options for people with moderate to severe dementia (Swan et al., 2018).

2.5 Impairment-based approaches

Four key impairment-based interventions for language impairment associated with dementia are detailed here. These interventions have been included here as they feature heavily in the literature evaluating impairment-based approaches (Hopper et al., 2013).

2.5.1 Read/repeat therapy

Reading/repeating is a therapy technique where participants view a picture of an item and repeat verbally its name, reading it if necessary (Croot et al., 2015). In a study of read/repeat therapy for people with PPA, 2 participants (both with good receptive language but impaired naming) used personally important words and found that treated items improved, and that this generalised to different pictures of the same item (Croot et al., 2015). However, this improvement did not result in improvement in conversation, as measured by a structured interview (Croot et al., 2015).

Another small study of 4 participants svPPA examined a simple therapy of looking at a picture, listening and then repeating, aiming for an errorless approach (Savage, Ballard, Piguet, & Hodges, 2013). Participants practised at home, with personally meaningful items selected. Improvements were reported for all participants after 3 weeks of therapy, even for participants with severe impairment of semantic knowledge (Savage et al., 2013).

2.5.2 Spaced retrieval therapy

Spaced retrieval therapy (SR therapy) typically involves correctly naming an item (or being told the name before being asked to repeat it) followed by naming again, and again, with increased time between each time named successfully (Bier et al., 2009). Hopper and colleagues (2013) completed a systematic review which included speech and language interventions (not specifically interventions for anomia). They found that SR therapy has shown promising results (Hopper et al., 2013). It is worth noting that this review was predominantly of therapy for people with AD, whereas in the literature available for specific anomia interventions, frontotemporal dementia (specifically PPA) predominates. For example, a small study involved 1 participant with semantic dementia and used SR therapy, combined with formal-semantic therapy (Bier et al., 2009). Naming of treated items improved, however no generalisation was noted, and SR therapy for this study was not statistically better than simple repetition (Bier et al., 2009). Naming of items was maintained over a 5-week follow-up period post-therapy. Significantly, the study found that SR therapy was more effective for re-learning semantic properties of items, than specifically for naming (Bier et al., 2009).

A practical advantage of SR therapy is that it can also be administered remotely, by using computer software, with minimal training for the individual. In one study, participants with svPPA were asked to practice at home for 30 minutes per day, 3-4 times per week with some clinic sessions for training purposes (Evans, Quimby, Dickey, & Dickerson, 2016). The study found some evidence that therapy early in the disease process may help retain words, and that re-learning forgotten words was possible too (Evans et al., 2016). Some slight generalisation to semantically similar items was noted, though the authors noted that successful treatment appeared to require episodic memory being intact, and some semantic knowledge being intact (Evans et al., 2016). Consequently, this may limit its success for people with types of dementia which do not spare episodic memory, such as AD.

However, there is some evidence that SR therapy may have a positive impact on people with AD. A study of SR therapy with people with likely AD found that following an intense period of therapy (6 one-hour sessions every other day) over 2 weeks, length of recall time for items, and errors made, both reduced (Cherry & Simmons-D'Gerolamo, 2004). Similarly, SR therapy for people with AD has been shown to improve naming of people in a photo, with improvements also translating to the real people (Cherry, Hawley, Jackson, & Boudreaux, 2009).

Due to the progressive nature of AD, and in light of the time commitment to SR therapy, it is important that there are longer term benefits to SR therapy. With this in mind, it appears that there is some longer term benefit; participants with AD receiving additional SR therapy within a year had longer retention intervals than they had previously, and longer than people having SR therapy for the first time (Cherry & Simmons-D'Gerolamo, 2005). The same study found that having a general conversation about the object before doing SR therapy produced better SR results than just naming, which the authors hypothesised may be due to added benefit of triggering semantic information about the object (Cherry & Simmons-D'Gerolamo, 2005). This finding supports Bier’s (2009) findings that SR therapy was effective at relearning semantic properties and may provide a rationale for the longer term benefits of SR therapy over simple read-repeat therapy.

2.5.3 Cueing therapy/strategy

Cueing involves presenting a piece of linguistic information which aids naming of an item (Meteyard & Bose, 2018). These can be semantic information, or phonological or orthographic cues; all can be useful for people with PPA (Beales, Cartwright, Whitworth, & Panegyres, 2016).

Beales and colleagues (2016) investigated 4 participants who had 2 sessions of cueing therapy per week for 4 weeks. Unlike many similar studies, a range of word categories was included (noun/verb/adjective). Treated items all improved regardless of the category of the word (Beales et al., 2016). In addition, in a subjective measure, all participants reported improved confidence communicating following therapy (Beales et al., 2016). The treatment gains did seem to generalise to untreated words, though the authors note that this could be due to effectively self-cuing on each occasion, rather than true reactivation of the item name (Beales et al., 2016).

Looking specifically at verbs, a single case study of phonological and semantic cueing therapy in svPPA also found that semantic-phonological cueing of treated items led to improvements in verb naming (Macoir et al., 2015). These changes were maintained up to 4 weeks after therapy, but there was no generalisation to untreated verbs found (Macoir et al., 2015).

Traditional phonological and orthographic cueing therapy (errorful learning) has also been compared with reading/repeating of items (errorless learning) for people with anomia due to AD, with naming assessed 1 and 5 weeks after intervention (Noonan et al., 2012). Neither therapy approaches were better than the other, but both therapy approaches resulted in naming performance better than baseline (Noonan et al., 2012). Participants with better semantic memory made bigger improvements, as did participants who performed better at pre-intervention assessment (Noonan et al., 2012).

Similarly, a small study of 2 people with PPA (one with lvPPA and one with svPPA) received both therapy sessions and home practice of therapy involving a self-cueing hierarchy, Lexical Retrieval Cascade therapy (Henry et al., 2013). This involved participants following a 7-step self-cueing hierarchy starting with semantic self-cuing and leading to recall. Both participants showed maintenance after 4-months and generalisation to untreated items, and both self-rated as much more successful communicators (Henry et al., 2013).

In a similar study, following therapy involving semantic and phonological cues with a participant with svPPA, there was an initial increase in naming with both semantic and phonological cues being beneficial, however treatment gains declined following the end of therapy (Dressel et al., 2010). Additionally, unlike most studies, functional magnetic resonance imaging (fMRI) was used to show changes in areas of brain activation during therapy. When using the fMRI, following treatment, right sided changes were noted in the brain, which suggests that new areas are activated as a consequence of therapy, resulting in improved naming (Dressel et al., 2010).

2.5.4 Semantic therapy

Semantic therapy involves treating anomia by focussing on restoring semantic knowledge; that is, knowledge of and access to semantic properties of an item. There is extensive discussion in the literature of a type of semantic therapy known as Conceptual Enrichment Therapy (COEN). COEN is a type of semantic therapy based upon choosing an item important to the individual and then developing the semantic/contextual links to the object by building on existing episodic memory and semantic knowledge (Suarez-Gonzalez, Savage, & Caine, 2018).

A single case study of COEN compared simple naming therapy (look at a picture and say the word) with COEN therapy for an individual with svPPA (Suarez-Gonzalez et al., 2015). Both naming therapy and COEN had significant improvements in treated items following therapy, however COEN appeared to have better results in terms of generalisation to different examples of the same object (Suárez-González et al., 2015). In particular, COEN therapy had greater success at looking at a different picture of an object, naming from a description and, to a lesser extent, describing an object after it was named by the researcher (Suarez-Gonzalez et al., 2015). Although only a single case study, working on semantic concepts appears to lead to greater generalisation of learned items than naming therapy (Suarez-Gonzalez et al., 2015).

COEN has also been shown to be more effective than simple (look and say) therapy at maintaining re-learned words when followed up at 6 weeks (Suarez-Gonzalez et al., 2018). Naming improved using both traditional naming and COEN, though COEN showed greater generalisation (as measured in the 2015 paper above) (Suarez-Gonzalez et al., 2018). Both traditional therapy and COEN were better than baseline performance at 4 weeks following therapy, but only COEN remained above baseline at 6 weeks (Suarez-Gonzalez et al., 2018).

Comparing COEN with standard therapy of repetition and reading with a picture for a participant with svPPA, one participant was studied using personally chosen items and undertook home practice with a relative (Krajenbrink, Croot, Taylor-Rubin, & Nickels, 2018). For repetition and reading therapy, treated items improved, but did not maintain (beyond 2-4 weeks) following the end of therapy. Including writing as part of this therapy increased gains, however there was no generalisation to connected speech (Krajenbrink et al., 2018). In this study, COEN therapy (which was delivered following repetition and reading therapy) had no positive effect on word retrieval or comprehension (Krajenbrink et al., 2018).

A review of anomia therapy for people with PPA noted a small number of participants generally, and that this was limited further by the very recent addition of logopenic variant diagnosis, which meant few studies considered this variant specifically (Jokel et al., 2014). In terms of behavioural therapy (i.e. therapy not related to pharmacological treatment) semantic therapy, was the predominant therapy noted. Participants showed immediate gain following semantic therapy, maintenance of treatment gain sometimes was not examined, or was as little as 1 week (to a maximum 6 months); one month was a typical follow-up period (Jokel et al., 2014). Generalisation to untreated words did not appear to happen for people with svPPA, but in the few studies of semantic anomia therapy for nfPPA available, generalisation was successful (Jokel et al., 2014).

A review of generalisation of semantic therapy by Cadorio and colleagues found that following semantic therapy for people with PPA, generalisation to untreated items did not happen for SvPPA, but can happen for nfPPA and lvPPA (Cadorio, Lousada, Martins, & Figueiredo, 2017). Maintenance of naming gains can happen if practice is continued following therapy; this does not appear to differ depending on particular PPA subtypes (Cadorio et al., 2017).

2.6 Constraint-induced aphasia therapy

This section describes constraint-induced aphasia therapy (CIAT) and explains how CIAT was developed. It details the key features of CIAT and how these manifest to participants in therapy sessions. An in-depth search of the literature attempts to identify available research of CIAT with people with dementia.

2.6.1 Development of CIAT

CIAT was first introduced in 2001 as a therapy for naming words in chronic post-stroke aphasia, with positive results (Pulvermüller et al., 2001). It was based on the principles of constraint-induced therapy used in limb rehabilitation. This involved high intensity practice over a shorter period than typical aphasia therapy, that people should be forced to use the word being practised (as opposed to circumlocution or gesture), and that words should be personally important to the individual (Pulvermüller et al., 2001). In comparison to a group completing traditional aphasia therapy (same amount of traditional naming therapy over a longer period), a CIAT group showed much improvement in overall language, and a subjective significant increase in communication in everyday life (Pulvermüller et al., 2001).

The CIAT approach was further developed as CIAT-plus (Meinzer, Djundja, Barthel, Elbert, & Rockstroh, 2005). This involved including written words with the picture cards and using pictorial scenarios to show the item in context. Importantly, CIAT-plus introduced daily functional exercises and also daily home-practice of the named items to be completed with a relative (Meinzer et al., 2005). In a comparison of CIAT and CIAT-plus for individuals with post-stroke aphasia, both CIAT and CIAT-plus showed significant improvements following the therapy and remained above baseline at follow-up. There was no difference in general language assessment results between the two groups, and relatives for both groups rated communication effectiveness as increased following the block which remained above baseline at follow-up (Meinzer et al., 2005). Relatives also reported increase in the actual amount of communication by the individual post the therapy (i.e. they were engaged more in conversation) (Meinzer et al., 2005). However, Meinzer and colleagues (2005) reported that the participants and relatives of the CIAT-plus group noticed a greater increase in the amount of everyday communication and comprehension than that seen in the CIAT group (who also noted some improvement). In addition, participants in the CIAT-plus group showed greater communicative effectiveness at 6-month follow-up, suggesting that improved performance of participants in the CIAT-plus group was maintained over time. The authors suggested that intensity (for both CIAT and CIAT-plus) is the important factor, as following the research study when intensity drops, no further increase in language is noted (Meinzer et al., 2005). Also, educating relatives to provide supportive practice seems to be an effective way of increasing the amount (and therefore intensity) of therapy provided, given the increase in performance of the CIAT-plus compared with the CIAT group (Meinzer et al., 2005). Indeed a review of the CIAT literature found that high intensity was the only feature of CIAT that was shown to be beneficial in therapy (Meinzer, Rodriguez, & Gonzalez Rothi, 2012).

Further investigation of the benefits of educating relatives in carrying out CIAT has found that there is no significant difference in effectiveness of CIAT when therapy is provided for 3 hours per day for 10 consecutive days by either an expert or by a trained relative (Meinzer, Streiftau, & Rockstroh, 2007). This suggests that the high intensity approach required by CIAT can be carried out efficiently, as it does not require expert/clinician time to complete all therapy.

In addition to CIAT plus, others have also sought to extend the original CIAT approach. One such approach is known as CIAT II, and involves key aspects from early CIAT research combined with other aphasia therapy features known to be effective, particularly for chronic aphasia (Johnson et al., 2014). The key features of CIAT II are intensity of therapy, the involvement of a communication partner (such as a friend/relative), and ensuring the aphasia therapy activity is embedded in functional communication tasks in everyday life (Johnson et al., 2014). The authors emphasise that although CIAT II contains some features of CIAT plus, there are key additions which may contribute to the improvement in communication noted post-therapy (Johnson et al., 2014). These features are designed to support the transfer of therapy gains to functional real-life situations and include a greater range of functional home practice tasks than the CIAT card game, more involvement of communication partners, completing a log of communication and discussion of barriers to functional communication (Johnson et al., 2014). In their initial study of CIAT II, Johnson and colleagues found that communication activity improved significantly in real-life contexts, although this was not reflected in formal aphasia assessment and may be attributed to CIAT II's focus on transfer of gains from therapy sessions to real life (Johnson et al., 2014).

A key criticism of the CIAT method in general is the negative connotations of constraint implicit in the term CIAT, and in its perceived use as limiting or restricting communication – the term and the approach of Intensive Language Action Therapy (ILAT) was introduced to mitigate this (Difrancesco, Pulvermüller, & Mohr, 2012). Difrancesco and colleagues also argue that ILAT emphasises the two key features of this therapy, namely its intensity (typically three hours daily) and its link to motor action (including, but not limited to, giving and receiving cards in a game) (2012). Indeed one of the additional features of ILAT compared with traditional CIAT is that it allows for an increasing use of conversation acts from just giving and receiving of cards (Difrancesco et al., 2012).

2.6.2 Key features of CIAT methodology

Studies under the umbrella of CIAT show considerable heterogeneity in terms of application of the core features of CIAT. Likewise the terms constraint-induced aphasia therapy (CIAT) and constraint-induced language therapy (CILT) are used interchangeably in the literature, but both refer to the same set of principles for therapy (Meinzer et al., 2012).

The basic premise is that CIAT, as described by Meinzer and colleagues (2012), involves participants and therapist (or communication partner) playing a card game using cards with photographs of personally important words. A barrier is placed between each player so that they can't see each other's cards**.** There are two sets of each card, which are distributed ensuring no player has two of the same cards. Players then have to ask each other if they have a particular card. This means participants have to practise saying the word. The level of difficulty is manipulated by the communication partner or therapist by altering the core features of CIAT. Core features in the CIAT literature are:

- Use of therapeutic constraints
- Shaping of therapy tasks to increase difficulty as appropriate
- Massed practice
- Cueing

The use and importance placed on these core features in the CIAT literature are discussed below.

2.6.2.1Constraint

The emphasis and importance of therapeutic constraint has evolved considerably since CIAT was first applied to aphasia, and there is no fixed consensus on what and how constraint should be applied. Initially, constraint was central and overarching. For example in their seminal study, Pulvermuller and colleagues (2001) reported constraints as being use of more difficult picture cards involving lower frequency words and more demanding requests in the game (such as politeness markers) being required. Their study specified further specific constraints, in that participants were required to use spoken language in the absence of gesture.

In the development of the enhanced CIAT-plus, the version of CIAT involving home practice and functional exercises, gesture was still not permitted (Meinzer et al., 2005). Indeed, such was the perceived importance of maintaining constraint at all costs, participants have been forbidden from self-cueing and encouraged to sit on their hands to prevent them gesturing (Maher et al., 2006). However, in subsequent studies there is evidence of a shift in the importance of constraint, with gesture being allowed, provided it is used to support spoken communication (Kirmess & Maher, 2010; Meinzer et al., 2007). This was following a review of features of constraint-induced movement therapy, which found that use of constraint had only minor impact on therapy outcomes (Morris, Taub, & Mark, 2006).

Despite this, there continues to be variation on permitting gesture and other similarly constrained communication support. In general, CIAT studies continue to consider constraint in terms of promoting spoken language and eliminating gesture or other forms of communication (Ciccone et al., 2016; Hameister, Nickels, Abel, & Croot, 2017). Further specific constraints are sometimes made, such as a study of CIAT for verbs, in which responses were constrained to a verb (Goral & Kempler, 2009).

2.6.2.2Shaping

In contrast to use of constraint, there is a large consensus on the use of shaping in the CIAT literature. Shaping is defined as the therapist (or other person) gradually increasing the level of complexity of the participant’s required response as part of a language game, while moving towards pre-morbid levels of communication (Meinzer et al., 2005; Pulvermüller et al., 2001). However, it stands to reason that shaping may at times involve reducing the required complexity of response to allow a participant to communicate successfully in the game.

Shaping typically happens on either of two levels, or both. Firstly, shaping can happen at an intra-word level. This can be by altering the complexity of the target items, for example by using concrete items (such as common physical objects) stepping up to abstract items (such as feelings) (Barthel, Meinzer, Djundja, & Rockstroh, 2008). Secondly, shaping can also happen at an inter-word level, where participants are requested to build from a single word to form grammatical sentences (Maher et al., 2006). For example, communicative complexity may be increased by requiring specific word categories, such as having to include an adjective (e.g. the colour red) or adverb (e.g. quickly) in responses/questions (Kirmess & Maher, 2010). In some studies, pragmatic and social aspects of communication were requested, such as use of politeness markers like please and thank you (Ciccone et al., 2016; Hameister et al., 2017). Typically, previous studies have managed this by setting a hierarchy of shaping levels, through which participants are led by the therapist/communication partner role (Hameister et al., 2017).

2.6.2.3Massed practice

A central feature of CIAT is massed practice, both of therapy sessions and of home practice. Massed practice is most often defined in the CIAT literature as therapy for 3 hours per day for 10 days (Barthel et al., 2008; Kirmess & Maher, 2010; Meinzer et al., 2012; Pulvermüller et al., 2001). In addition, following the introduction of CIAT-plus approach, studies sometimes required participants to complete further home practice (Hameister et al., 2017; Meinzer et al., 2005). This varies in the literature, but can include 30 minutes per day self-practice of naming items via computer software (Hameister et al., 2017) or daily functional communication tasks to consolidate learning (Meinzer et al., 2005). Examples of functional communication tasks may involve going to a café and ordering a drink, or answering the telephone, depending on the participant’s ability.

2.6.2.4Cueing

The use of cueing to support naming is a central part of traditional aphasia therapy but is directly mentioned only occasionally in the CIAT literature. Cueing commonly refers to being offered a small prompt to help the person to successfully retrieve the word (Conroy, Snell, Sage, & Lambon Ralph, 2012). For example, the seminal study by Pulvermuller and colleagues (2001) allowed for help to be provided, but did not specify cueing. Some studies did not explicitly state/accept cueing, although it could be argued that limited use of constraints operated as a cue, as some studies gave permission to use gesture during the CIAT game (Kirmess & Maher, 2010; Meinzer et al., 2007). Where studies did mention cueing, there was considerable heterogeneity. For example, written cueing was allowed in some studies (Meinzer et al., 2005) but forbidden in others (Hameister et al., 2017).

Some studies did detail the explicit cueing hierarchy used. Hameister and colleagues (2017) explained a four-stage hierarchy of cues to be used systematically should an individual not be able to name the item. This involved the communication partner/therapist giving the initial phoneme, then the initial syllable followed by the full word and finally the full sentence for the participant to repeat if necessary (Hameister et al., 2017). Interestingly, not all studies that specified the cues used the term cue to refer to the same type of action as in other studies. Goral and Kempler (2009) for example, reported that the initial cue was a reminder to the participant to say a verb if this had been omitted from their utterance, and the second cue was a 'confirmation question', such as 'are you asking about the picture with the man surfing?' (p. 1388). This variation in cueing, both in terminology and practice, and the links between constraints and cues, is further highlighted in a review of CIAT by Meinzer and colleagues (2012). The review reported that, for example, some studies allowed gesture, and some allowed prompting by giving an initial letter of the target word (Meinzer et al., 2012). As such, the phrasing of the latter suggests it may theoretically be the lack of constraint as much as the permission of a cue.

2.6.3 Methodological limitations of existing research

The key methodological limitation of the impairment-based therapy studies is that participants typically had types of dementia such as PPA/SD which generally spare wider cognitive impairment beyond language. This limits the extent to which the findings can be applied to people with other forms of dementia such as AD where there are wider cognitive deficits which may also impact on word-finding. Additionally, many studies contain a small number of participants which limits the ability to generalise meaningful conclusions to people with dementia more widely.

As described above, many of the studies of each type of therapy, although broadly similar, had differences in both the amount and specific detail of therapy involved. This, alongside a lack of consensus of approach to assessment, has resulted in challenges attempting to compare findings between studies in a meaningful way.

2.6.4 Theoretical basis of CIAT and rationale for its application to word-finding difficulties in dementia

In line with ILAT more generally, the theoretical basis of CIAT stems from linking the naming of items to physical motor action at a neurological level (Difrancesco et al., 2012). The key neurological theory is that action and language are dependent on each other and that activating both areas strengthens language activation (Pulvermüller & Fadiga, 2010). Specifically, for individuals with lesions affecting the frontal (language) regions of the brain, neurological activity has been shown to reroute via motor regions (Pulvermüller & Fadiga, 2010). This link between strengthening neuronal connections by activating different areas of the cortex, such as language and motor areas simultaneously, known as Hebbian learning, gives strong neurological support for anomia therapy that involves a physical motor component (Pulvermüller & Berthier, 2008). By harnessing the power of additional motor circuits, it is argued that people with aphasia can gain functional benefit by avoiding reliance on language areas of the frontal cortex which may be unavailable (Pulvermüller & Berthier, 2008). By extension, it is argued that activating one area alone, such as the neuronal pathway involved in naming, weakens the link with the motor area, and reduces the ability to recruit the motor area to support naming (Pulvermüller & Berthier, 2008). This provides evidence in support of CIAT approaches, which focus on intensity of naming relating to a physical transaction, as it is argued that the high intensity means there is less time in between therapy sessions for attempts at naming to be made in isolation, potentially weakening the links between the activation of different neuronal pathways (Difrancesco et al., 2012).

For CIAT therapy, the aim is to activate phonological, lexical, semantic and conceptual pathways together (Difrancesco et al., 2012). Assuming that this co-activation is important to relearning, it is argued that high frequency of practice is significant as it reduces the scope for inadvertent activation of a reduced number of pathways in using the words in everyday life in between therapy sessions (Difrancesco et al., 2012).

An additional advantage to the CIAT card game is that, as well as activating motor-related areas, it also involves participants being asked to give more information to describe an item, depending on their communicative level, for example by giving semantic and personally relevant information about it. This appears important in harnessing non-language areas to support naming, as describing such features activates the relevant area, for example auditory area for how an item sounds, and gustatory for how it tastes (Difrancesco et al., 2012). This can be completed as part of language games, which involve different communicative acts such as requesting and giving information, and telling stories, and are consistent in the CIAT literature from Pulvermuller and colleagues (2001) onwards. These games help to promote the behavioural relevance of the item and activate the area of the brain which fires during the item's related motor/sensory action (Difrancesco et al., 2012). For example, the activation pathway for the word *salt* also activates the areas of the brain associated with taste, leading to the theory that the pathway activating the gustatory area extends into the area processing semantics (Barrós-Loscertales et al., 2012). Crucially, it is also argued that the opposite is true – that activating the area of the brain associated with motor movement results in faster responses to the naming of related items (Pulvermüller, Hauk, Nikulin, & Ilmoniemi, 2005). Pulvermuller and colleagues' (2005) study showed that stimulation of the area of the brain associated with arm movements produced faster responses to recall of arm-related words than leg-related words, with the opposite being observed during activation of areas of the brain associated with leg movement.

For CIAT-based therapy, it is hypothesised that the giving and taking of cards that is central to CIAT-based therapy operates in a similar way, creating links between the lexical item and the motor action of handing over the item card (Difrancesco et al., 2012). CIAT-based therapy can then utilise these links to support naming by circumnavigating neurological damage (Difrancesco et al., 2012). Such neurological damage may be caused by a number of brain injuries, such as stroke, for example, or in the context of the current study, by dementia.

There are some encouraging findings from studies of CIAT-based therapies which suggest it may prove successful for people with a range of dementias, including AD. A number of studies have shown CIAT-based therapies to be effective for people with chronic aphasia following stroke, not least seminal studies by Pulvermuller and colleagues (2001) where mean duration of aphasia was 98.2 months (for the CIAT group) and Meinzer and colleagues (2005) where mean duration of aphasia was 45.6 months. This suggests that CIAT-therapy is effective even where initial spontaneous post-stroke improvement has likely ceased, and thus offers encouragement for the efficacy of CIAT therapy with people with dementia who also cannot benefit from spontaneous improvement.

2.6.5 Evaluating and comparing CIAT outcomes with other therapy approaches for aphasia

A number of studies have sought to compare CIAT-based therapy with other aphasia therapies to determine whether the CIAT shows superiority over other different approaches to aphasia therapy following stroke. In one study. CIAT was compared with a multi-modal aphasia therapy using a crossover design where 5 participants received CIAT-based therapy followed by a multi-modal aphasia therapy and 6 participants received multi-modal aphasia therapy followed by CIAT-based therapy (M. L. Rose, Attard, Mok, Lanyon, & Foster, 2013). The key difference between the two therapies investigated was the use of supportive cues such as gesture, writing, reading for the multi-modal therapy and constraints restricting anything other than verbal responses in the CIAT-based therapy. The authors found that there was no difference in the effectiveness of either approach for the 11 participants (M. L. Rose et al., 2013). Among participants, the multi-modal therapy was preferred by 6 participants and CIAT-based therapy by 3 participants (M. L. Rose et al., 2013). Similarly, a later systematic review compared CIAT-based therapy and multi-modal therapy by examining 14 single case studies and found no clear advantage for either therapy over the other (Pierce, Menahemi-Falkov, O'Halloran, Togher, & Rose, 2019). The authors found that the outcome measures used such as confrontation naming were limited as they did not measure meaningfully the experience of people with aphasia and their families (Pierce, Menahemi-Falkov, et al., 2019). Pierce and colleagues also note a key and recurring theme with CIAT research; that what constitutes a constraint and how this is applied differs markedly between studies (Pierce, Menahemi-Falkov, et al., 2019). This presents challenges for determining which aspects of CIAT are key for word-finding therapy. However, this ambiguity is not unique for CIAT-based therapy – similar variance has been noted for other therapies, not least multi-modal therapy (Pierce, O’halloran, Togher, & Rose, 2019). Further evidence of the similar effectiveness of CIAT-based therapy and a multi-modal approach was highlighted following a large randomised controlled trial of 201 participants which compared CIAT, multi-modal therapy and typical community therapy of either no therapy or low-intensity therapy of up to one hour per week (M. L. Rose et al., 2022). The authors found that both CIAT-based therapy and multi-modal therapy, but not typical low-intensity community therapy, resulted in significant improvements in word-finding difficulties, effective real-life communication and quality of life associated with chronic post-stroke aphasia (M. L. Rose et al., 2022).

In a separate study, CIAT-based therapy was also compared with conventional aphasia therapy, with both carried out to the same intensity of 3 hours per day for a total of 30 hours (Sickert, Anders, Münte, & Sailer, 2014). Conventional therapy included read-repeat approaches and other typical tasks such as sentence completion. The study found that both CIAT-based therapy and conventional aphasia therapy produced equal improvements in aphasia measured by formal assessment, and that this improvement was maintained at one year follow up (Sickert et al., 2014). Notably, the improvements seem to have generalised to everyday conversation, with participants and relatives reporting improved everyday conversation. As Sickert and colleagues note, the results suggest that intensity in therapy is an important factor in its success, rather than other factors, such as rule-based constraints and shaping (2014).

CIAT-based therapy has also been directly compared with a form of lexical-semantic therapy involving strengthening semantic links via tasks to determine whether or not there are semantic relationships between words in a sentence (Wilssens et al., 2015). A total of 9 participants with chronic aphasia were divided into two group and received either CIAT-based or semantic-based therapy delivered intensively for 2 to 3 hours per day for 9 or 10 consecutive working days (Wilssens et al., 2015). The authors report that although both types of therapy produced improvements, the semantic-based therapy showed greater improvement in assessment of communicative effectiveness and everyday language (Wilssens et al., 2015). Each type of therapy appeared to result in improvement focussed on different areas of communication, with the semantic-based therapy impacting positively on comprehension and semantics, and improvements following CIAT-based therapy focussing on expressive language and phonology (Wilssens et al., 2015).

Wilssens and colleagues' findings, although based on a small number of participants, provide further evidence that intensity of therapy is a key factor, but suggest tentatively that semantic therapy may have greater impact on expressive language than CIAT-based therapy (2015). A systematic review by Zhang and colleagues examined 8 randomised controlled trials (RCT) of CIAT-based therapy compared with other aphasia therapies not based on CIAT (Zhang et al., 2017). Zhang and colleagues found that generally intensity was a key factor, as discussed earlier, and non-CIAT therapies that were carried out intensively generally produced positive outcomes (2017). The effect of constraints, a key feature of CIAT, was also assessed by Zhang and colleagues who found that the heterogeneity of constraints applied in the studies limited conclusions that could be drawn, but that there was no clear evidence for constraints (2017).

It is clear from the existing literature on CIAT that there is considerable variation, and considerable development, from the initial approaches described by Pulvemuller and colleagues (2001), which has led to the term CIAT-based therapy being used in the current study. As described above, the relative weighting of constituents within the CIAT-based therapy approach has moved from emphasising constraints, to giving greater prominence to intensity of practice, while still being labelled as CIAT therapy. This makes comparisons between CIAT studies earlier or later in its development challenging, as is comparing studies labelled CIAT with other therapy approaches. Despite a lack of clarity in the literature around the combination and importance of key features, Hameister and colleagues argue that the key CIAT features of intensive practice in a context that is motivating for individuals may translate into effective therapy for people with the language-focussed dementia PPA (Hameister et al., 2017). This study found that 2 participants with PPA showed statistically significant improvement in naming of treated nouns and verbs following a CIAT-based therapy (Hameister et al., 2017). It is this interpretation of CIAT-based therapy reported to be successful with people with PPA by Hameister and colleagues (2017) that forms the basis of the methodology of the current study.

2.7 Systematic literature search

Given the reported success of CIAT-based approaches with people with word-finding difficulties due to aphasia principally following stroke, a systematic search of the literature was performed to identify all existing studies examining CIAT and dementia.

2.7.1 Provisional searches

The specific search aim was to determine the availability of research on the use of CIAT with people with dementia. Initial scoping suggested that the following terms were used synonymously:

- Constraint-induced aphasia therapy (with or without hyphen) abbreviated to CIAT
- Constraint-induced language therapy (with or without hyphen) abbreviated to CILT

The term *dementia* appeared sufficient to include a large range of types of dementia. Therefore, this search term *dementia* aimed to include all dementia subtypes including, but not limited to, AD, FTD, PPA, VaD, and mixed dementia.

2.7.2 Electronic searches of the literature

The Scopus, Web of Science, Medline, CINAHL and Psychinfo databases were searched on 15/10/18, with the following search terms used:

Dementia AND (constraint-induced aphasia therapy OR constraint induced aphasia therapy OR constraint induced-language therapy OR constraint induced language therapy).

The title, keyword and abstract fields were searched, with the topic field searched in Web of Science. The search was further limited to only display articles written in the English language.

2.7.3 Manual refinement of the literature including inclusion/exclusion criteria

The requirements for inclusion were articles involving speech and language therapy-based interventions for anomia in people with a diagnosis of dementia.

Three articles were removed during manual screening as they focussed on pharmacological intervention and CIAT post-stroke. They initially met the search criteria as they included reference to combining drugs typically used for dementia (e.g. memantine) alongside CIAT in treatment of post-stroke aphasia.

One additional article focussed on a specific feature of aphasia (echolalia) and the effect of a combination of pharmacological and CIAT treatment. Therefore, although the article noted echolalia to be a feature of aphasia (including aphasia associated with dementia) it was removed from this review as it did not consider anomia. No further inclusion/exclusion criteria were set.

2.7.4 Results of the systematic literature search

Following manual screening based on the inclusion/exclusion criteria, one result was found:

> Hameister, I., Nickels, L., Abels, S. and Kroot, K. (2017) “Do you have mowing the lawn?” – improvements in word retrieval and grammar following constraint-induced aphasia therapy in primary progressive aphasia. Aphasiology (31) 3, 308-331.

Manual searching of the references of this paper did not reveal any further studies fitting the search criteria. Therefore, only one article remained following application of search criteria: this study investigated the impact of a constraint-induced aphasia therapy programme on 2 participants with a less frequently occurring type of dementia, primary progressive aphasia (Hameister et al., 2017).

2.7.5 Summary of the systematic literature search

The database searches resulted in a total of 5 articles as follows

Scopus – 0

Web of science - 5

Medline via Ovid - 0

Cinahl – 0

Psycinfo – 0

There were no duplicates.

Therefore n= 5

Articles were manually screened based on title and abstract.

3 articles were removed as they concerned post-stroke aphasia only.

(Barbancho et al., 2015; M. L. Berthier et al., 2009; Marcelo L. Berthier, Pulvermueller, Davila, Garcia Casares, & Gutierrez, 2011)

1 article was removed as it was specifically about echolalia.

(Marcelo L. Berthier et al., 2018)

Therefore n= 1

(Hameister et al., 2017)

Manual search based on the title listed via the references section of this article resulted in no additional articles

Therefore n= 1

2.8 Chapter summary

The literature review for CIAT-based therapy shows that although there are a broad set of principles or philosophy of CIAT, there is considerable variation. Each of the features of shaping, constraint, massed practice, and cueing are given varying importance in each study. As such, when planning future interventions, each of the CIAT features should be acknowledged, though the extent of their inclusion is not pre-determined.

Despite there being many studies of CIAT-based therapy showing positive results in the treatment of post-stroke aphasia, only one published article of CIAT-based therapy with people with dementia was identified during the systematic search. This suggests that there is considerable opportunity for further research to develop and extend the use of CIAT-based speech and language therapy with people with different, more frequently occurring types of dementia such as AD. This is the focus of the current study, which is introduced in the next chapter.

Chapter 3 Development of materials for naming and for therapy

As the main study aim was to measure participants' naming performance, a set of pictures of objects and actions was needed to support this. As such, these materials were developed prior to the start of the main study.

3.1.1 Materials

The Object and Action Naming Battery (OANB) (Druks & Masterson, 2000) provided a pool of 162 everyday nouns and 100 everyday verbs with associated psycholinguistic data. This included phoneme length, syllable length, imageability and frequency. Such data were used in the main study analysis to draw psycholinguistic trends of naming. To ensure participants had a pool of items to choose from, the researcher manually selected 124 items (82 nouns and 42 verbs) based on subjective likelihood of participants selecting them for therapy. That is, these were subjectively judged by the researcher to be the more commonly used, useful everyday words in the OANB. These 124 items underwent a naming agreement process.

Permission was received from the OANB authors to use the data and items from the OANB in conjunction with alternative pictures. Alternative pictures were used as those in the OANB are line drawings; for this study colour photographs were required as these are more similar to the real objects than line drawings. The researcher then sourced a photograph for each item, using freely available online photographs from Pexels (www.pexels.com) or Pixabay (www.pixabay.com).

The 124 photographs were uploaded onto a google form. Each photograph was preceded by the text 'what is this?' for nouns or 'what are they doing?' for verbs. After each photograph, a free text box for typing the answer was provided. All nouns were presented first (in a random order for each participant) and then all verbs were presented (in a random order for each participant). An accompanying email was sent to participants with instructions and information about inclusion/exclusion criteria. See Appendix A for the email text.

3.1.2 Participant inclusion/exclusion criteria

Participants were people over the age of 18 years and were recruited via opportunity sampling from the researcher's email contacts. Participants were asked (in the email text) to only complete the task if they had British English as an everyday language, and did not have any known language difficulty.

3.1.3 Procedure

The email text containing the link to the google form was emailed to participants. The google form was closed once 20 participants had responded. Participants completed the form by typing in the name of the noun/verb in the text box for each item. No personal data were sought, and responses were anonymous.

3.1.4 Results (items for naming and for therapy)

The results were analysed in order to support the removal of photographs that were ambiguous: that is, fewer than 85% of participants named either the intended target name, or an acceptable variant. These photographs were therefore unsuitable for the therapy task. As a consequence, 4 nouns (hospital; mouse; nest; wheel) and one verb (combing) were removed from the pool to be offered to participants in the main therapy task. Thus, a total of 78 objects and 41 actions were retained.

In addition, the results were analysed to determine the percentage naming agreement of each of the acceptable variants for each item. It is important that the level of naming agreement is identified, as a large body of research suggests naming speed is faster for pictures with higher naming agreement (Cheng, Schafer, & Akyürek, 2010).

Of the 119 items, 102 had naming agreement of 100%. Lower naming agreement was found for skating (skating = 60%; rollerskating = 40%) and weights, which was the only item with three acceptable variants given (weights = 85%; dumbbell = 10%; barbell = 5%).

See Appendix B for the full analyses for each item, and for the final list of 119 items.

Chapter 4 Original protocol

4.1 Chapter overview

This chapter describes the original study, which was designed and commenced pre-pandemic. Following initial assessment and a number of the planned therapy sessions, this protocol was revised as a consequence of the coronavirus pandemic. Chapter 4 includes the original study questions and hypotheses (section 4.1.1 and 4.1.2), the design (section 4.7) and explanation of outcome measures (starting from section 4.15). Planned therapy intervention is described (starting from section 4.17). Planned data analysis is described with each assessment, and projected overarching analysis is described in section 4.18. The changes made to this protocol following restrictions on research due to the coronavirus pandemic are described in Chapter 5.

4.1.1 Aims and research questions

The main aim of this study was to evaluate a novel adaptation of CIAT in improving communication for people with dementia and their communication partners. The secondary aim of this study was to investigate the impact of severity and type of dementia on outcomes.

It was hypothesised that CIAT-based therapy would result in people with dementia successfully naming more of their chosen words more often, and that this would generalise to better everyday communication.

The specific research questions for this study were:

- Does a speech and language therapy programme based on the principles of constraint-induced aphasia therapy result in:
    - participants with dementia successfully naming more of their chosen words more often?
    - generalisation of naming of chosen words to everyday conversation?
    - participants with dementia and their communication partners using their chosen words to have better, more successful everyday conversations?
- Does severity and type of dementia impact on outcomes following a speech and language therapy programme based on the principles of constraint-induced aphasia therapy?

4.1.2 Objectives

The objectives of this study were:

- To compare participants with dementia's naming of chosen words before and after a CIAT-based therapy intervention.
- To evaluate the success of the CIAT-based therapy intervention at improving participants with dementia's recall of words in everyday conversation.
- To compare the communication partner's thoughts of the effect of the CIAT-based therapy intervention based on the success of their communication with the participant with dementia.

4.2 Methods

This section details the intended methods planned for this study. The intended methods were revised in light of the coronavirus restrictions to face-to-face research.

4.3 Participants

The study aimed to recruit 20 people with dementia and their communication partners (thus 40 participants in total) who matched the inclusion/exclusion criteria.

4.3.1 Inclusion/exclusion criteria

All participants met the required inclusion/exclusion criteria to be recruited to the study. These criteria were different for people with dementia and their communication partners.

4.3.1.1Participants with dementia

To be included in the study, participants with dementia had to present with:

- A diagnosis of dementia by an appropriate professional as reported by the person with dementia or their communication partner.
- mild-moderate acquired aphasia with word-finding difficulties as reported by the person with dementia or their communication partner.

In addition, participants with dementia had to:

- be age 18 years or over
- have no significant psychiatric history other than a dementia diagnosis
- have no other acquired neurological history
- have no developmental language or communication difficulties

- have sufficient hearing, vision, and attention to enable them to complete the assessment and therapy sessions
- have British English as their everyday language
- be able to give informed consent to take part in the study.

4.3.1.2Communication partners

To be included in the study, communication partners had to:

- be age 18 years or over
- have no significant psychiatric history which would affect (or be affected by) them taking part in the study
- have no neurological history leading to language or communication difficulties which would prevent them taking part in the study
- have no significant communication difficulties which would affect them taking part in the study
- have sufficient hearing or vision to complete the assessment and therapy sessions
- have British English as their everyday language
- be able to give informed consent to take part in the study.

4.4 Ethical approval

Main ethical approval for this study was received from the University of Sheffield's Ethics Review Procedure, as administered by the Department of Human Communication Sciences (Reference: 024499). See Appendix C for the ethical approval confirmation letter. In addition, minor ethical amendments to the study were received where appropriate.

4.5 Recruitment process

In order to ensure potentially vulnerable participants were not inadvertently coerced into joining the study, the researcher typically undertook an initial discussion with the organisers of local non-NHS dementia groups. This was to identify possible participants who were likely to be appropriate for the study. To support this, the researcher discussed the study with group leaders and explained a broad summary of the inclusion/exclusion criteria, which must be met for both participants with dementia and communication partners to join the study. Group leaders were sent an email and a flyer promoting the study to support this process, which is shown in Appendix H and Appendix I respectively.

Appropriate participants (who appeared likely to be suitable for the study) were approached by leaders of such groups. They were asked if they would consider discussing participating in the study, and that they consented to their contact details being given to the researcher for this purpose. The group leaders informed the researcher of the contact details of interested/possible participants. As detailed on the flyer, potential participants could also contact the research team directly.

These potential participants were then approached informally by the researcher either in person (ideally) or via phone to discuss the study in more detail. If in doubt, the researcher discussed how best to approach potential participants with the dementia group leader.

Further information was provided informally to potential participants and the researcher sought to build a good rapport with the person with dementia (and their communication partner) as a basis for starting to create a safe and positive research context for the person with dementia throughout the study (Hellström, Nolan, Nordenfelt, & Lundh, 2007).

The researcher informally discussed eligibility for the study and determined whether participants were interested in participating. Potential participants either informally agreed to participate at this point by informing the researcher, or had further time to consider, in which case they were asked to contact either the dementia group leader or the research team directly if they were interested in participating. They then met with the researcher to complete the consent process as detailed in section 4.6.

The recruitment process also contained plans for if, at any point, potential participants did not meet the inclusion criteria. They were to be informed by the researcher, with full explanation and individual support offered, such as signposting to organisations including Human Communication Sciences' Memory and Life Story Clinic or other local services as appropriate.

4.6 Consent

The Mental Capacity Act 2005 makes explicit the assumption that all people are presumed to have capacity to make their own decisions (to consent) unless it is proven otherwise (Mental Capacity Act c.9., 2005). The act details a two-part test to assess capacity. For a person to lack capacity, firstly (part one), they must have an 'impairment' or 'disturbance' in brain function. Secondly (part two), they must be unable to do any of the following four stages: understand relevant information; retain the information; be able to weigh up the information; and communicate their decision. Information can be presented in any format in order to maximise the opportunity to demonstrate capacity, and individuals only need to retain the information for as long as is necessary to weigh up the options and make the decision. Participants with dementia may find that their capacity is variable along with their general presentation, therefore decision makers should where possible postpone the decision until a time when the individual has capacity, for example choosing a time when they are more alert.

In this study, informed consent was taken for both participants with dementia and their communication partner. They were provided with separate participant information sheets (see Appendix D and Appendix E) and consent forms (see Appendix F and Appendix G), and opportunity was given for participants to discuss any part of the study, with supportive communication where necessary. Consent forms involved a set of options to ensure participants could opt in/out of each point, in particular regarding use of their data.

4.6.1 Ethical considerations and consent process for participants with dementia

Investigating possible new speech and language therapy interventions for people with dementia requires their involvement and they are central to the process. In order to maximise participation in research by people with dementia, a number of approaches and frameworks for best practice have been developed. People with dementia have an impairment/disturbance in brain function (capacity test part 1) because of their diagnosis of dementia. Therefore, the four-point capacity assessment should be used when a capacity assessment is required for people with dementia.

People with dementia should be given full and genuine opportunity both to consent to take part and to withdraw that consent at any time should they wish. To support this, this study used a process model of consent which aims to support maximum involvement in research by people with dementia (Dewing, 2007). Process consent starts with the ‘background and preparation’ stage with the researcher approaching those people around the people with dementia, such as relatives or carers, to seek their support and agreement and attempt to determine when and how would be a good time to approach the people with dementia about participating in the research (Dewing, 2007, p. 15). In the next stage of process consent, the researcher should then ‘establish the basis for consent’, by taking time to note how the people with dementia show agreement or wellbeing in their everyday life (Dewing, 2007, p. 17). For participants who were at very early stages of dementia, this meant no more than checking with them and their friend/relative that they are having a good day and are open to discussing the study further.

Informed consent was taken for each participant with dementia in the study via an interview facilitated by the researcher and supported by the study information leaflet for participants with dementia. Participants with dementia were made aware of the study plan (when the different stages will happen) to allow them a sense of control in their participation (Hubbard, Downs, & Tester, 2003). They were informed that they could withdraw consent at any time.

People with dementia were able to verbally articulate their agreement or wellbeing to the researcher or others involved. They took part in discussing the study and their involvement and were able to ask any questions to the researcher. Following demonstrating capacity, people with dementia gave 'initial consent' for participating in the study, (Dewing, 2007, p. 19). They then completed and signed the consent form.

Traditionally, consent has now been agreed and would not be revisited, however the process consent method used in this study then required the researcher to continually monitor consent to ensure that the behaviours and actions of the people with dementia suggested that they still consented to be involved in the research (Dewing, 2007). This is particularly important where the people with dementia may no longer have capacity, or have varying capacity.

It is widely observed as important to create a comfortable/safe environment to maximise the involvement of people with dementia (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). In practice, this involved monitoring their consent by observing for any signs of distress or other behavioural indications that they no longer consented to taking part in the study, in consultation with their communication partner or others who know them. This, like capacity, might vary on a day-to-day basis.

People with dementia may be at increased risk of psychological or emotional distress when completing assessment/therapy, particularly if their communication skills decline. In discussion with people with dementia and their communication partner or others who know the person with dementia, they were monitored to ensure their involvement in the study could be rescheduled for another day/time, or the research be completed in a different way.

In accordance with the process consent model, following the assessment/therapy sessions in this study, the researcher took time where appropriate to provide feedback on the session to the participant with dementia or others such as their communication partner (Dewing, 2007). The researcher also ensured that the people with dementia left the session feeling positive that they had achieved/accomplished something in the session (Hellström et al., 2007). As such, the researcher ensured that the person with dementia was supported at the end of the session, depending on their individual needs, so that they felt positive about the session and ready and able to resume their daily activities.

If participants with dementia had demonstrated that they no longer wanted to be involved in the study, then they would have been supported to exit the study. This might have involved being signposted to other appropriate groups, such as the University's Memory and Life Story Group.

If participants had lost capacity, or had fluctuating capacity, a consultee would have been identified (likely to be the communication partner also participating in the study) who would have been asked their views on whether the person with dementia would like to continue with the study, specifically what decision they would have made if they still had capacity (Mental Capacity Act c.9., 2005). If the consultee had believed that the person with dementia would no longer want to participate, then they would have been withdrawn from the study. The views of the person with dementia would be central in deciding whether to participate.

4.6.2 Consent process for communication partners

Informed consent was taken for each communication partner in the study. This was via discussion with the researcher. Communication partners were provided with an information sheet specific to their role in the study, explaining the study in full detail. They were given the opportunity to discuss in person with the researcher the study and their involvement, plus the role of the person with dementia. If they demonstrated capacity and agreed to participate, the communication partner signed the consent form. If communication partners no longer wanted to be involved in the study, then they would not be involved.

4.7 Design overview

The study involved assessment and therapy. Therapy was based on the principles of CIAT as described earlier. Both people with dementia and their friend/relative (communication partner) were recruited to the study. The overarching design was planned as a cross-over study, with delayed and immediate treatment groups: Group A would have had immediate therapy and Group B delayed therapy (see Table 3 below, where Y is completed and N is not completed).

Table 3 - Original design overview

	Assessment Point / Therapy Block						
	Point 1	Point 2	Immediate Therapy Block	Point 3	Delayed Therapy Block	Point 4	Point 5
Immediate Therapy Group	Y	Y	Y	Y	N	Y	Y
Delayed Therapy Group	Y	Y	N	Y	Y	Y	Y

Therapy used personalised vocabulary in face-to-face sessions with the researcher and additional home practice. Participants were quasi-randomly allocated by the research team to ensure similar participant profiles in each group. While in the delayed phase, the delayed therapy group did not undertake any practice. This allowed for the evaluation of the effects of the therapy by comparing group scores at Assessment Point 3. It also provided an additional comparison of the effect of therapy by comparing the immediate and the delayed therapy group performance at Assessment Point 4. In addition, it provided ethical assurance by ensuring all participants received therapy input regardless of group allocation. For a summary design flowchart of assessment and therapy schedule, see Figure 3.

4.7.1 Allocation to immediate/delayed therapy group

Following assessment, participants were to be quasi-randomly allocated to 2 groups (an immediate treatment group and a delayed treatment group). This was to be done collectively by the research team. The primary aim when allocating was to try to ensure the groups were comparable, but also to take into account participants' personal circumstances. This was to be discussed and explained with participants.

4.8 Schedule of assessments

The assessments were scheduled as follows, with full detail of each assessment provided starting in section 4.15.

4.9 Assessment Point 1 and 2 (double baseline)

- Picture item naming: Picture item naming test of full set of 139 items – a double baseline assessment to determine participants' naming ability before therapy intervention.

4.10 Assessment Point 1 or 2

- Connected speech (monologue): Story recall by the person with dementia.
- Conversation analysis (dialogue): 15 minutes functional conversation between the person with dementia and their communication partner.
- Communication interview: Interview by the researcher with the communication partner.
- Cognitive Assessment: ACE-III full version (for cognitive/dementia severity).
- Cognitive Assessment: Category Comprehension and Cactus and Camel sections of the Cambridge Semantic Memory Test Battery.

4.11 Assessment Point 3

- Picture item naming: Picture item naming test of full set of 139 items.
- Connected speech (monologue): story recall by the person with dementia.
- Conversation analysis (dialogue): 15 minutes functional conversation between the person with dementia and their communication partner.

4.12 Assessment Point 4

- Picture item naming: Picture item naming test of full set of 139 items.
- Connected speech (monologue): story recall by the person with dementia.
- Conversation analysis (dialogue): 15 minutes functional conversation between the person with dementia and their communication partner.

4.13 Assessment Point 5

- Picture item naming: Picture item naming test of full set of 139 items.
- Connected speech (monologue): story recall by the person with dementia.
- Conversation analysis (dialogue): 15 minutes functional conversation between the person with dementia and their communication partner.
- Communication interview: Interview by the researcher with the communication partner.

4.14 Procedure

The study intended to involve the following procedure, described below, for each pair of participants.

4.14.1 Screening and background/case history

The inclusion/exclusion criteria were translated into yes/no questions in order to screen participants (both participants with dementia and their communication partner) for the inclusion/exclusion criteria as detailed in section 4.3.1. See Appendix J for the rationale for the inclusion/exclusion criteria. Questions asked in the background information/case history section were based on existing studies, as detailed in Appendix K, and provided key information pertinent to this study. The eligibility screening and the background questionnaire/history data were collected using the separate forms for the participant with dementia and the communication partner, as shown in Appendix L and Appendix M respectively.

To collect background history and eligibility data, participants (both participants with dementia and their communication partner) were interviewed by the researcher. The researcher asked the questions as part of a discussion in an appropriate conversational style to ensure participants could most easily respond accurately. Participants were interviewed together, with responses written by the researcher on the form, by circling or noting the appropriate response.

4.14.2 Choice of items for naming

Following successful recruitment to the study, participants with dementia (with support of their communication partners as necessary) chose their set of treated items, which they practised throughout the therapy block. To do this, participants were given a list of 119 standard items derived from the OANB as described in Chapter 3, and asked to choose 40 of these. They were also asked to choose 20 personally important items, as using personally significant items may be important for therapy success (Jokel et al., 2014). Personally significant items could be, for example, names of friends/family, places, pets, sports or other items the person with dementia may use on a regular basis. To support this, participants with dementia were asked to complete a document (see Appendix O) where participants circled 40 items and provided a list of 20 personal items. A flowchart showing the full process by which items originally from the OANB were selected and offered for participants to select is shown in Appendix N.

4.14.3 Determining most effective cue

As discussed in Chapter 2, CIAT-based therapy games involve participants with dementia receiving cues from other participants to support item-naming. In order to maximise the effectiveness of therapy, and to provide consistent advice to communication partners, it was beneficial to determine whether a phonological or semantic cue was most effective at cueing successful retrieval of the target item for the person with dementia. This section details the process for determining which type of cue was most successful: a phonological cue (initial phoneme or initial syllable) or a semantic cue (most appropriate semantic information).

4.14.3.1 Design

The Cambridge Semantic Memory Test Battery (CSMTB) (Adlam, Patterson, Bozeat, & Hodges, 2010) contains 64 items for naming, but is not designed to assess whether a phonological or semantic cue (or combination) is most effective in allowing the participant being assessed to recall the word. The 64-item naming test in the CSMTB was adapted to allow for assessment of effectiveness of cueing as follows.

14 of the 64 items were removed from the list as they are also within the pool of items to be selected by the participants to learn during therapy. These were: strawberry; cat; cow; dog; cherry; basket; pear; banana; piano; key; plug; scissors; envelope; comb.

The 50 items were then grouped by semantic category; this information was provided as part of the CSMTB. The categories were as follows: domestic animals; foreign animals; birds; fruit; large household items; small household items; vehicles; tools.

Items were then split into 2 matched Item Groups within each semantic category. These Item Groups were successfully matched for: frequency (t(df=48) = 0.54: p>0.05); number of phonemes (t(df=45) = 0.21: p>0.05); concreteness (t(df=45) = 0.19: p>0.05); familiarity (t(df=46) = 0.54: p>0.05).

Item Groups received either a semantic or phonological cue first, as described here. A 5-second pause was given between each cue if required:

- The first participant recruited received:
    - For Item Group 1: a semantic cue (if not named); then the initial phoneme cue (if not named); then initial syllable cue (if not named).
    - For Item Group 2: the initial phoneme cue (if not named), then initial syllable cue (if not named) followed by a semantic cue (if not named).

  Scoring Sheet A was used – see Appendix P.

- The second participant recruited received:
    - For Item Group 1: the initial phoneme cue (if not named); then initial syllable cue (if not named); then a semantic cue (if not named).

- For Item Group 2: a semantic cue (if not named); then an initial phoneme cue (if not named); then initial syllable cue (if not named).

Scoring Sheet B was used – see Appendix Q.

This sequence then alternated through the immediate and delayed treatment groups, as shown in Table 4 below.

Table 4 - planned allocation of immediate and delayed treatment groups

	Participants in immediate treatment group	**Participants in delayed treatment group**
First participant	scoring sheet A	scoring sheet B
Second participant	scoring sheet B	scoring sheet A
Third participant	scoring sheet A	scoring sheet B

(This sequence to be continued for all participants)

4.14.3.2 Materials

The materials consisted of the set of 50 black line-drawing picture cards from the CSMTB. These were printed out on white paper that were approximately a quarter of A4 size. Answers were recorded on specially designed scoring sheets A and B (Appendix P and Appendix Q).

4.14.3.3 Procedure

The researcher began this assessment by stating (based on the published CSMTB instructions): ‘I’m going to show you some pictures. I want you to tell me what they are’.

The person with dementia was shown a picture card by the researcher. Picture cards were presented in the order that they appear in the CSMTB. If necessary, the researcher stated: ‘what is this?’. If the person with dementia made an attempt at naming this item the researcher recorded this on the score sheet by writing the response, and transcribing any notable phonological errors. Where there were any uncertainties with noting the response or transcribing real-time, the researcher checked for accuracy later. For this purpose, audio recording took place using a Sony Pioneer PCM A10 device, with the audio file subsequently transferred to a secure university computer storage space. The audio recording was then removed from the device.

If the item was named correctly, the researcher removed this card, and turned over the next one, until all cards had been shown. If the person with dementia did not answer correctly within an approximate 5 second time-frame, the researcher offered a phonological or semantic cue (depending on which cue was scheduled to be offered first). If the item was then named correctly, the researcher removed this card, and turned over the next one. If the person with dementia did not answer correctly within an approximate 5 second time-frame, the researcher offered a phonological or semantic cue (the opposite to the type of cue offered previously). If the item was not named correctly following the offering of both semantic and phonological cues, the researcher named the item and moved on to the next item.

When offering a semantic cue, the researcher offered an appropriate cue, which included: what the item is used for (e.g. ‘you use it for cooking’); what the item is made of (e.g. ‘it is made of metal’); where you find it (e.g. ‘you find it in the kitchen’). One or more semantic cues was used in combination as one more detailed cue (e.g. ‘it’s found in the kitchen and you use it for cooking’) depending on what is most appropriate for the item and the researcher’s knowledge of the participant.

When offering a phonological cue, the researcher offered the initial phoneme. If not named successfully following approximately a 5 second time-frame, the researcher offered the initial syllable. If not named successfully following a further 5 second time-frame, the researcher then named the item and moved on to the next item. See Table 5 for more information.

Table 5 - cueing schedule (determining the most effective cue)

Group 1 items	Name without prompt	5 second pause	Semantic cues given			5 second pause	Initial phoneme given	5 second pause	Initial syllable given
Group 2 items	Name without prompt	5 second pause	Initial phoneme given	5 second pause	Initial syllable given	5 second pause	Semantic cues given		

4.15 Cognitive assessment

In this study, cognitive assessment was used to provide a measure of the severity and pattern of participants' dementia, as well as providing a general profile of their cognitive abilities. This aimed to provide a context for participants' performance following the therapy sessions.

4.15.1 ACE-III (full version)

The ACE-III is validated for use with people with frontotemporal dementia (primary progressive aphasias) and AD (Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013). It includes assessment of, attention, memory, language and visuospatial skills and can therefore be used to assess cognitive skills related to dementia (Hsieh et al., 2013).

The ACE-III English-UK version was used. This was available freely at https://sydney.edu.au/brain-mind/resources-for-clinicians/dementia-test.html. Three equal versions (A, B, C) are available, to allow for retesting with different material. For this study version A was used. Participants with dementia completed all sections of version A of the ACE-III in accordance with the instructions provided with the test material.

4.15.2 Cambridge Semantic Memory Test Battery sections

The CSMTB is used to assess semantic memory, in terms of verbal and non-verbal and input and output (Adlam et al., 2010). In this study, the CSMTB is used to provide further information regarding participants' semantic language deficits. The full CSMTB was available at http://www.ftdrg.org/cambridge-semantic-battery/ .

The following sections of the CSMTB battery were used with participants in this study:

- Category comprehension (comprehension of single spoken words by semantic category)
- Camel and Cactus picture stimulus (awareness of semantic properties, by matching one picture given with another out of a choice of four)

For the Category Comprehension assessment, the materials were the CSMTB pictures printed in A4 size in black and white as available from the website. The official CSMTB scoring form was used. For the Camel and Cactus picture stimulus, the materials were the CSMTB pictures printed in A4 size in colour as available from the website. The official CSMTB scoring form was used. These two sections of the CSMTB were completed in accordance with the instructions provided at the start of the picture items for the Camel and Cactus picture stimulus and on the Category Comprehension page of the Test Instructions on the CSMTB website.

4.16 Communication assessment

Communication assessment was completed, which aimed to provide broad assessment of participants' communication success in its fullest sense. Therefore, participants with dementia were assessed by naming of picture items, and by telling a story by themselves. The success of their communication was also evaluated by the researcher interviewing their communication partner. Each element of communication assessment is described in detail below.

4.16.1 Picture item naming

4.16.1.1 Design

The assessment consisted of naming the 119 items from the OANB and the 20 person-specific items. Participants were allowed one attempt to name without any cue by themselves or others. To generate a random order for presenting the items, all 139 items were assigned a random number using =RAND() function in MS Excel, before sorting in ascending order.

4.16.1.2 Materials

Item cards were created with each of the photographs of the 139 items printed in colour on white paper; each photograph was approximately a quarter of A4 size (approximately 15cm by 10.5cm).

4.16.1.3 Procedure

The researcher began by explaining the assessment, and that the participant with dementia would be shown pictures to name. Participants with dementia were shown a picture card by the researcher. These were presented individually with the researcher stating: 'what is this?' for noun or 'what is/are he/she/they doing?' for verbs, as appropriate.

If the person with dementia made an attempt at naming this item, the researcher recorded their first response by writing the response given, and transcribing any notable phonological errors. Following each item, the researcher removed this card and turned over the next one, or clicked to move to the next screen during the video call, until all pictures had been shown. Where there were any uncertainties with noting the response real-time, the researcher checked for accuracy later. For this purpose, audio recording took place using a Sony Pioneer PCM A10 device, with the recording file transferred to a secure university computer storage space. The audio recording was then removed from the device.

4.16.1.4 Scoring and analysis of individual naming data

Participant responses were scored either correctly named or not correctly named. To be scored as correct, responses had to be the target or acceptable variant. As described by Roach and colleagues (1996), difficulties in scoring naming assessments may arise when a participant gives more than one response. This may be more likely given the wider cognitive deficit of some participants with dementia, who may be less likely to remember instructions or to limit their responses. However, such multiple attempts may constitute a self-cue, therefore, only first responses were scored. Thus, for example, "our grandson… [pause] [name]" was scored as incorrect. When naming verbs, verb form with the correct stem was accepted as a correct response, for example "getting weighed" was scored as correct for weighing. Where a response had phonemic errors, these were counted as incorrect, except where sounds varied due to accent or other similar difference. Regional or other appropriate lexical variants were permitted as correctly named responses as were any variants determined as acceptable during the development of the materials described in Appendix B. Examples of acceptable variants include weights/dumbbells; wireless/radio; glasses/spectacles; fastening/tying (shoe laces); coach/bus.

Statistical analyses and subsequent tables for Cochran's Q tests, post-hoc McNemar tests and correlations with linguistic variables were completed using SPSS statistics software. A Cochran's Q test is used to determine if there are differences between the proportion of items named correctly at each assessment point. The Cochran's Q test, although similar to an ANOVA, can be used when the dependent variable is a nominal variable, as in this case where the dichotomous dependent variable is naming of items between the three assessment points. Cochran's Q test can be considered an extension of the McNemar test which can be used for a dichotomous variable for only two groups or conditions. Cochran's Q test is an appropriate statistical technique as it satisfies the two main assumptions, namely: the categorical dependent variable (naming) has two mutually exclusive categories (named correctly or not named correctly); the independent variable has three or more related groups (in this case a nominal variable of time points).

Post-hoc testing, in the form of McNemar Tests, was completed where Cochran's Q test reported a statistically significant outcome. This was to determine between which assessment points the statistically significant change in naming occurred.

To complete correlations, linguistic variables were taken from the OANB assessment and as such refer to the original line drawings from the OANB (Druks & Masterson, 2000). The frequency variable was from Francis and Kucera (1982) as reported by Druks and Masterson (2000). To ensure consistency and comparability between participants and across assessment points, linguistic variable data used in the analysis are based on the target name for the item rather than any acceptable variant scored as correct. Participants' 20 personal items were not included in analysis of correlations with linguistic variables.

4.16.2 Connected speech (monologue)

This assessment aimed to provide a measure of functional ability and use of words in sentences while being audio recorded. Participants with dementia were asked by the researcher to tell the story of Cinderella.

In face-to-face assessment, to support the story recall a traditional children's Cinderella picture book was provided, with the main text covered up. If participants felt they could not attempt the story of Cinderella supported by the storybook, they were able to tell a personal story of their choosing to ensure an appropriate connected speech sample was obtained for analysis.

The sample aimed to be at least 150 narrative words long, but not more than 10 minutes of recording time. Audio recording took place using a Sony Pioneer PCM A10 device, with the audio file transferred to a secure university computer storage space. The audio recording was then removed from the device.

Quantitative Production Analysis (QPA), was used to analyse the content of a sample of connected speech in terms of word types used and sentence structures employed (Berndt, Wayland, Rochon, Saffran, & Schwartz, 2000). It therefore provided a way of comparing changes in participants' connected speech at the various assessment points before and after CIAT therapy sessions. At least 150 narrative words were recorded as recommended for QPA (Berndt et al., 2000).

4.16.2.1 Scoring and analysis of individual participant data

Key analyses from the QPA were calculated using the spreadsheet provided by Berndt and colleagues (2000) as described in Table 6 below.

Table 6 - Quantitative Production Analysis of connected speech: description of key analyses

Descriptions of each of the key measures of the QPA contained in the results section is described here; descriptions are based on the work of Berndt and colleagues (2000). The number of words per minute: refers to the number of complete words spoken by the participant per minute of connected speech. The time taken by speech from the researcher

or communication partner (such as encouragement or comment) was deducted from the total time.

The proportion of closed class words: derived from dividing the number of closed class words by the number of narrative words in the sample. Closed class words are in categories of words where the number of words is fixed and cannot typically be added to; they include prepositions, pronouns, auxiliary verbs and conjunctions. Narrative words, as defined by Berndt and colleagues (2000), refers to the speech which is for telling the story, and as such excludes a range of stated words/phrases. Examples include phrases stereotypically used in storytelling, any habitual phrases used by the speaker, any descriptions about the task or story, and co-ordinating conjunctions.

The proportion of pronouns: derived from dividing the number of pronouns by the combined number of pronouns and nouns. Similarly, the proportion of verbs is derived by dividing the number of verbs by the combined number of verbs and nouns.

The verb inflection index: derived from dividing the number of inflectable verbs actually inflected by the number of inflectable verbs. Inflectable verbs in the context of the QPA are defined by Berndt and colleagues (2000) as regular verbs which could be inflected or irregular verbs which could be inflected in a regular manner (such as: am thinking).

The auxiliary complexity index: initially derived from dividing the auxiliary score (the complexity of the verb and auxiliary components) by the number of matrix (main) verbs; finally, the total is then reduced by 1.0 to reflect the fact that a matrix verb must have a minimum score of 1.0 – i.e. the matrix verb itself.

The sentence elaboration index: a measure of overall sentence complexity. It is derived from combining the values of the mean verb phrase length (minus 1.0) and the mean subject phrase length (minus 1.0).

4.16.3 Communication interview with the communication partner

With the agreement of the person with dementia, the communication partner was interviewed by the researcher. The interview was to capture communicative success in a broadest sense – that of whether communication is perceived to be successful and what happens during communicative breakdown. This was done using the interview questions in Part A of the Conversation Analysis Profile for People with Cognitive Impairment (CAPPCI) (Perkins, Whitworth, & Lesser, 1997). For the baseline assessment completed face-to-face, the researcher followed the instructions for Part A of the CAPPCI, by asking the questions and recording the participants' responses (Perkins et al., 1997). The materials used were the interview questions in Part A of the CAPPCI. In addition, the researcher asked the participant to point to the supporting cards listing the response choices (Perkins et al., 1997).

4.16.3.1 Scoring and analysis of individual participant data

Data from the interview have been grouped into the eight categories noted on the CAPPCI interview form as detailed in Table 7. Scores determined by the CAPPCI interview form were totalled for each topic section. This is intended to show any trends for changes between assessment points for each topic area.

In the CAPPCI, Perkins and colleagues (1997) assigned scores to each of the 3 categories of response (0,1,2) with higher score representing greater impairment. For some questions, Perkins and colleagues did not assign a scoring of 1 for the middle option as the scoring was designed to reflect any deviation from typical conversation by people with typical non-impaired communication as part of the wider CAPPCI assessment (Perkins, Whitworth, & Lesser, 1998). This refers to questions 1 and 29. However, in order to compare more accurately baseline and post therapy changes, a score of 1 was assigned to all middle category responses, as has been used previously (Kindell, 2015).

Selected comments made during the post-therapy interview were included to add a qualitative aspect to the interview data. To do this, with participants' consent, an audio recording was made of post-therapy interview, which was subject to an abridged transcription of key points made both in response to the questions determined by the CAPPCI and other comments made in between questions. Text in square brackets was added by the researcher to ensure anonymity or to ensure comments are clear in the context presented in the results. An ellipsis in square brackets was used to represent where part of the transcribed speech has been removed and not included in the results. Points were selected for inclusion if they added further richness to the understanding of the communication partner's perspective on communicative success with the participant with dementia. The comments should therefore be considered as additional detail alongside the rating scores given by the communication partner.

Table 7 - CAPPCI communication partner interview: summary of question categories

As described by Perkins and colleagues (1997) and summarised here, related questions were grouped into eight categories.

Initiation and turn-taking: includes starting up a conversation; failing to respond when it's their turn to speak; leaving a long pause before answering; stopping and leaving a long pause in the middle of their turn; interrupting someone else's turn; giving replies that are excessive; restricting responses to minimal acknowledgements

Topic management: includes introducing new topics and wondering where they fit in; being able to maintain topic for a while; talking about imaginary people/places as though real; repeatedly bringing up a favourite topic.

Repair: being able to indicate when they haven't understood; trying to correct errors they make in speech and whether this is successful; making speech more specific if they are not understood.

Memory and attention: includes saying the same statement/question repeatedly; forgetting knowledge of familiar people/events; stopping in the middle of a sentence as if distracted; forgetting things they are asked to do.

Linguistic abilities: includes word-finding difficulties and strategies for overcoming these; using the wrong word for something; difficulties comprehending spoken language; using referential markers (such as him/there) without it being clear who they refer to.

High level linguistic abilities: includes taking things at their literal meaning; understanding what someone really means by reading between the lines of what they say; understanding jokes made by others and showing a sense of humour themselves.

Articulation and prosody: includes being able to speak clearly; having an appropriate volume; not having monotone speech; able to emphasise certain words in a sentence when required for meaning.

Fluctuations: includes how communication abilities fluctuate throughout the day and throughout the week.

(Perkins et al., 1997)

4.16.4 Conversation analysis

People with dementia and their communication partner aimed to talk for approximately 15 minutes together on a topic of their choosing. This assessment aimed to find a baseline and then to subsequently measure conversational changes that occurred throughout the study. In particular, this conversation analysis assessment aimed to consider whether there was any carry-over of the learned words to general conversation.

This conversation was to be an audio recorded conversation. The topic did not matter, and they could be supported where necessary, for example by using photographs. Optional materials were to include any personal conversation starters (e.g. personal photos) chosen by the participants to facilitate conversation.

4.16.4.1 Scoring and analysis of individual participant data

Conversation analysis was to be completed using the framework and process described in part C of the Conversation Analysis Profile for People with Cognitive Impairment (CAPPCI) (Perkins et al., 1997). Analysis was to be completed using the Profile of Word Errors and Retrieval in Speech (POWERS) (Herbert, Best, Hickin, Howard, & Osborne, 2013). The materials were to be the CAPPCI Part C conversation analysis form and the and the POWERS form for post-recording analysis.

4.17 Therapy task

This section describes the constraint-induced aphasia therapy task completed by participants. This was completed during the face-to-face therapy sessions with the researcher. Participants also aimed to complete the therapy task as described here during their home practice.

4.17.1 Design

Participants with dementia and communication partners planned to complete 10 therapy sessions with the researcher. These were to be arranged as 2 sessions per week on consecutive weeks, to be flexible depending on personal commitments. Sessions lasted up to 1½ hours, but more typically an hour, depending on participants' abilities and levels of fatigue. Communication partners attended all therapy sessions alongside the person with dementia and took part in the therapy task. This reinforced their understanding of how to complete the therapy to enable them to replicate this during home practice.

4.17.2 Materials

The participants' 60 chosen items were made into photograph cards. Each of the photographs of the 60 items was printed in colour on white paper; each card was approximately a quarter of

A4 size. Two complete sets of the 60 cards were printed for each set of participants. In preparation for the therapy session, the 120 cards were sorted into 60 matching pairs and then divided into 6 groups of 10 pairs of cards. Each of the 6 groups of cards was then shuffled individually. This resulted in 6 piles of shuffled cards, with 20 cards in each pile. Each pile of cards constituted one game, therefore 6 games were played in each therapy session in total. During therapy, the researcher noted naming success, level of shaping and cueing required using the therapy session notes form, as shown in Appendix R, which was supported by audio recording with participants' agreement.

4.17.3 Procedure

Each therapy session consisted of 6 games, hence the 6 piles of cards described above. The basic procedure for each game during the therapy session was as follows:

1. A barrier was placed between each participant, or participants held their cards to prevent them from being seen by other players.
2. Each participant was dealt 5 cards from the pre-prepared pile of 20 cards. The remaining cards were placed face down at the side.
3. Participants then took it in turns to ask each other if they had a certain card: "do you have…?" followed by the name of the picture on the card.
    a. If yes, they then gave the card to the participant who asked, and these 2 cards were removed from the game.
    b. If no, then the participant who asked had to pick up another card from the pile at the side.

The aim of the game was for the person with dementia to practise saying the word. In order to individualise the game to provide maximum therapeutic benefit, the CIAT features of constraints, cues, and shaping were followed, as described below, based on previous studies. During the therapy sessions, the researcher trained the person with dementia and the communication partner by demonstrating these features and supporting the communication partner to use these when practising with the person with dementia.

4.17.3.1 Constraint rules

During the therapy game, participants with dementia and communication partners were advised to use spoken language only (Ciccone et al., 2016; Hameister et al., 2017). Gesture was neither encouraged nor discouraged (Kirmess & Maher, 2010; Meinzer et al., 2007). Written language or other forms of communication were not permitted (Hameister et al., 2017).

4.17.3.2 Cueing

Participants received semantic and/or phonological cues from the researcher/communication partner influenced by the most effective cue for them, however often a combination of semantic/phonological cues were used with the aim of supporting successful naming depending on the item itself or personal preference.

4.17.3.3 Shaping

Participants were initially asked to name the item, but when/if successful, were then encouraged to add more details or build a more communicative response.

For example, if the item was “book”, the shaping hierarchy was used similar to that detailed in Table 8 below (but was based on the person with dementia’s specific communication skills).

Table 8 - description and examples of shaping

Shaping level	Target word	Example: book
1	Single word	Book? / Book.
2	Word in a short grammatical sentence	Do you have book? Yes, I have book.
3	Word in a sentence with some additional description.	Do you have the small/green book?
4	Word in a sentence with additional description and some further communication.	Yes, I have the small/green book. I like reading, do you?

During the therapy sessions, the researcher trained the person with dementia and the communication partner by demonstrating shaping specific to the person with dementia and supporting the communication partner to practise cueing with the person with dementia.

4.17.4 Scoring and analysis of individual participant data

Although assessment was conducted formally, therapy sessions were, as is to be expected, more informal, as their purpose was to deliver therapy for word-finding difficulties. As such, the analyses and results cannot be directly compared to the assessment results. Instead, they provide a valuable stand-alone indication of the naming performance of participants with dementia in therapy sessions. This is particularly valuable as immediate post-therapy assessment was delayed by approximately 6 months as a consequence of coronavirus restrictions, therefore therapy sessions data may give an indication of any immediate improvements to picture item naming due to taking part in therapy.

Criteria for accepting naming responses as correct was based on that for the formal naming assessment completed. However, there were a number of differences in order to reflect the focus on successful functional naming in conversation rather than the restricted naming sought in assessment. A fuller answer or description which contained the target item was acceptable, as this was part of the aim of the therapy task – for example further description or explanation. However, a fuller answer which left ambiguity was not accepted as correct. Immediate self-correction without prompt was considered as named successfully, and flexibility was given regarding acceptable variants of responses, in particular for items personally chosen by participants.

If participants used a similar but appropriate word, which was not typically an acceptable variant to the target, a prompt may be given, such as ‘what would you normally call it?’, or ‘what else could it be?’. Similarly, if the participant did not name the intended part of the picture, signposting the participant to a particular part of the picture was allowed, such as “what’s this bit?” or “what is it altogether?”. These types of prompt were sometimes spontaneously given by the communication partner too. A prompt was often given if the participant with dementia named a noun where a verb was the target response or vice versa. These prompts were not considered a cue, therefore items named in this way were considered named without a cue for the purposes of this analysis.

If any cards remained at the end of each game, occasionally the researcher or the communication partner asked the participant with dementia to name them informally (who’s this?/what’s this?). This was included in the naming analysis where possible, in order to maximise the number of responses. Any repetition by the participant with dementia of naming by another participant was not included; this repetition was typically as part of the participant with dementia’s response to being asked a question by another participant.

It is also worth noting that the participant with dementia might name the item more than once, by asking another participant if they have a certain item on a number of occasions/turns in a game. Each occasion was counted as a naming attempt in the analysis. Equally, naming of every item would not have been attempted by the participant with dementia in the therapy sessions due to the random chance of the cards in the game.

4.18 Planned overarching statistical analyses

The study was to be a mixed methods study, involving quantitative and qualitative components. Data for each of the participants were to be analysed as an individual case series as described in sections 4.16. In addition, picture item naming and connected speech would have been subject to overarching statistical analysis. Conversation analysis of the dialogue and the interview with the communication partner was to be analysed in qualitative manner. Analyses would be based on analyses completed by Varley and colleagues whose study involved a similar cross-over design with delayed treatment group (Varley et al., 2016). However, naming data in the current study was on a nominal scale, therefore a Cochran's Q was completed instead of an ANOVA.

4.18.1 Picture item naming

Baselines 1 and 2 were to be assessed for stability using Cochran's Q with the two baseline assessment points and item naming (named and not named) as the repeated measures, and treatment (immediate therapy and delayed therapy) as the between-group factor (Varley et al., 2016).

Having separate immediate and delayed analyses would have allowed the groups to be compared directly with each other at the point where one will have had treatment and one will have had no treatment. Treatment effects were to be assessed using Cochran's Q with assessment point (AP1, AP2, AP3, AP4 and AP5 as described on page 85-86) and item type (treated and untreated) as repeated measures and treatment (immediate therapy and delayed therapy) as the between-group factor (Varley et al., 2016). This would allow the evaluation of the treatment effects by comparing group scores at post therapy assessment AP3. It also provides additional treatment effect by comparing group scores at post therapy assessment AP4. Finally, picture naming data for those participants in the immediate therapy group and those in the delayed therapy group were to be combined. This aimed to measure the impact of therapy on participants' naming with added power reducing the likelihood of type 1 errors. To achieve this, a McNemar test was to be completed to determine whether statistically significant differences occurred comparing treated items with untreated items before and after therapy. Pre-therapy assessment was to be taken by combining AP2 for the immediate treatment group and AP3 for the delayed treatment group, with post-therapy assessment taken by combining AP3 for the immediate treatment group and AP4 for the delayed treatment group.

In addition, it would allow maintenance of any changes in naming of treated items to be assessed with Cochran's Q, comparing immediate post-treatment naming assessment with the maintenance assessment points (for immediate therapy group – AP3, AP4 and AP5; for delayed therapy group – AP4 and AP5).

4.18.2 Connected Speech

The measures of connected speech were to be analysed using a repeated measures ANOVA (rather than Cochran's Q) as the data are continuous rather than nominal. Sentence elaboration index, number of words per minute, proportion of closed class words; proportion of pronouns; proportion of verbs; verb inflection index; auxiliary complexity index; sentence elaboration index would be subject to a repeated measures ANOVA followed by post-hoc McNemar test to determine between which assessment points statistically significant differences occurred.

4.19 Home practice

In addition to therapy sessions, home practice was completed by the communication partner and the participant with dementia.

4.19.1 Materials

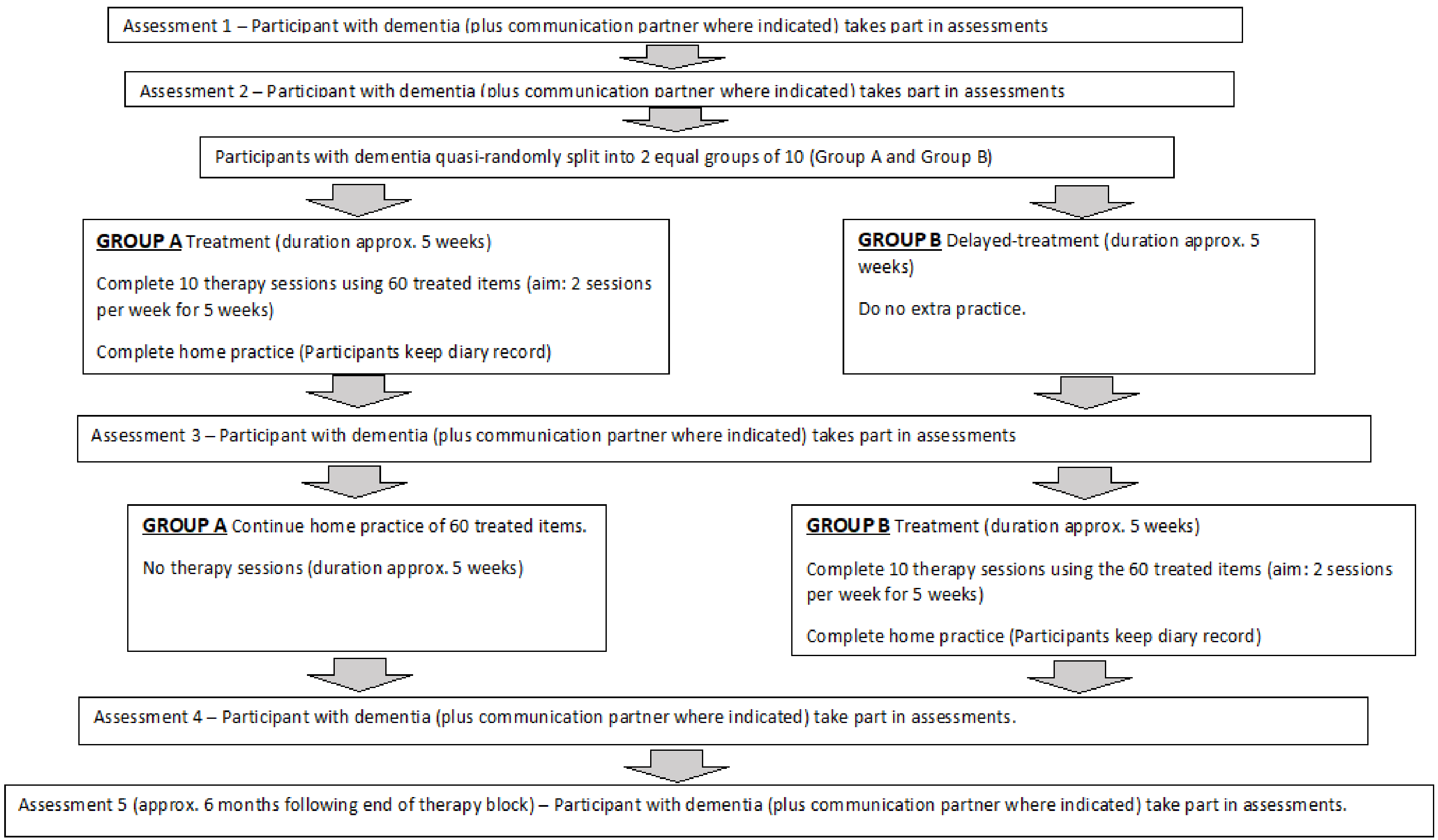
The materials involved in home practice were two copies of the participant's photograph cards of the full set of 60 words (totalling 120 cards) participants had chosen to use in the therapy sessions.

4.19.2 Procedure

Participants (both participants with dementia and communication partners) were trained in the CIAT-based therapy as part of the therapy sessions. They were then asked to practise at home in between sessions for the duration of the therapy block and beyond. In keeping with encouraging findings of previous studies, participants were asked to practice this game at home for 30-45 minutes per day if possible, though this varied depending on the participants' individual circumstances (Hameister et al., 2017).

Due to projected significant variation in the amount and quality of home practice completed, participants were asked to record the amount and type of home practice completed on a daily basis. In addition, on a weekly basis, participants were asked to rate how their communication has been generally during the week, on a scale of 0 to 10. A home practice record form was provided for this purpose, as shown in Appendix S. Completed home practice forms were returned to the researcher.

Figure 3 - original protocol summary of assessment and therapy schedule



Chapter 5 Revised protocol – Phase 1

5.1 Chapter overview

In March 2020, in the context of national restrictions due to the coronavirus pandemic, face-to-face research was suspended. These restrictions on face-to-face research meant a pause to assessment and therapy sessions for current participants.

Therefore, the study was revised and now consisted of two phases. The original protocol was adapted and renamed as Phase 1, where data collection had been completed face-to-face, except for post-therapy assessment which was now completed remotely by video-call. With the support of a focus group, a new Phase 2 was developed and introduced, where data collection was completed remotely via video call, with self-directed therapy.

This chapter describes revised Phase 1 of the study. The subsequent focus group is described in Chapter 7 and the new Phase 2 is described in Chapter 8.

5.2 Aims and research questions

The main aim of this study was to evaluate a novel adaptation of CIAT in improving communication for people with dementia and their communication partners.

It is hypothesised that CIAT-based therapy results in people with dementia maintaining or improving their naming of their chosen nouns and verbs, and that these changes generalise to everyday communication.

The specific revised research questions for this study were:

- Does CIAT-based therapy maintain or improve naming of treated items for people with dementia?
- Does CIAT-based therapy maintain or improve naming of nouns or verbs specifically?
- Is performance in item-naming associated with specific psycholinguistic features for people with dementia?
- Does CIAT-based therapy result in changes to features of connected speech?
- Does CIAT-based therapy result in people with dementia and their communication partners having better, more successful, everyday conversations?

5.2.1 Objectives

The objectives of this study were:

- To compare people with dementia’s naming of chosen words before and after a CIAT-based therapy intervention, including word class.
- To examine whether performance in item-naming was associated with specific psycholinguistic features.
- To examine whether people with dementia had changes to their connected speech following CIAT-based therapy.
- To analyse communication partners’ perspectives of the effect of the CIAT-based therapy intervention on the success of their communication with the person with dementia.

5.3 Methods overview

In summary, the study involved recruitment of people with dementia and their communication partners. They undertook assessment before and after completing CIAT-based therapy. Results were analysed qualitatively and quantitatively, with findings reported as case studies. Protocol for assessments and therapy sessions were described in full detail from section 4.15.

Prior to restrictions, the original planned methodology was to have a post-therapy assessment immediately following therapy block, with follow-up assessment to assess maintenance at 6 months following the end of the therapy block depending on allocation to immediate or delayed therapy group as described in Figure 4. These post-therapy assessment points were combined as delayed post-therapy assessment at approximately 6 months following the end of face-to-face therapy sessions.

The number of therapy sessions was reduced from 10, as originally planned, to 9 sessions. As such, all 9 therapy sessions were completed face-to-face. Participants continued to complete home practice to varying extents throughout the time between the end of the therapy block and the post therapy assessment.

As it became clear that face-to-face research would not be resuming for the foreseeable future, amendments to the existing ethical approval were sought to facilitate completion of assessments indirectly via video call software. Ethical approval for these amendments was received from the Health Sciences School Ethics Lead in September 2020. Therefore, with participants’ consent, the delayed post-therapy assessments were completed using video-call software.

Audio recording of assessment by video-call took place using an external device, a Sony Pioneer PCM A10 device. This recorded the sound from the researcher's computer which was subsequently stored securely on the university shared data area. The audio recording was then removed from the recording device.

There were 3 participants with dementia and their communication partners recruited to the study, thus 6 participants in total. Of those, 2 pairs of participants completed Phase 1 of the study. One pair of participants had completed part of the initial background testing when face-to-face research stopped as a consequence of coronavirus restrictions. They were then subsequently re-recruited to Phase 2 of the study and are reported in Chapter 6.

5.4 Design overview

The study involved assessment and therapy. Therapy was based on the principles of CIAT as described in Chapter 2 of the literature review. Both participants with dementia and their communication partners were recruited to the study. The overall design of the study is shown in Figure 4 below, with indications of when each stage was completed, subject to participants' personal circumstances.

Figure 4 - Phase 1 study design

Baseline assessments

(Start – completed face-to-face)

↓

Pre-therapy assessments

(Approx. 3 months from start – completed face-to-face)

↓

Total of 9 therapy sessions

(Approx. 4-5 months from start – completed face-to-face)

↓

Post-therapy assessments

(Approx. 11 months from start – completed via video call due to coronavirus restrictions)

Note: timings are approximate, influenced by participants' personal circumstances.

Therapy used personalised vocabulary in face-to-face sessions with the researcher and additional home practice. No practice was undertaken between baseline and pre-therapy assessments. Participants completed some home practice where possible between the end of the therapy sessions and the post-therapy assessments.

5.4.1 Schedule of assessments

The following assessments were included in the revised analysis. Full detail of each of the individual assessments below was provided starting in section 4.15.

5.4.1.1Baseline assessments

The following baseline assessments (completed in person) and included in the analysis:

- Picture item naming test of the full set of 139 items.
- Connected speech (monologue): story recall by the person with dementia.
- Cognitive Assessment: ACE-III full version (for cognitive/dementia severity).
- Cognitive Assessment: Category Comprehension and Cactus and Camel sections of the Cambridge Semantic Memory Test Battery.

5.4.1.2Pre-therapy assessments

The following pre-therapy assessments (completed in person) were included in the analysis:

- Picture item naming test of the full set of 139 items.
- Connected speech (monologue): story recall by the participant with dementia.
- Communication interview: interview by the researcher with the communication partner

5.4.1.3Post-therapy assessments

The following post-therapy assessments (completed remotely by video-call) were included in the analysis:

- Picture item naming test of the full set of 139 items. Post-therapy assessment was completed by video-call using Whereby or Google Meet software. Photographs of the 139 items were displayed on Microsoft PowerPoint slideshow software using a screenshare facility, with one picture alone on each slide on a white background. Participants were advised to display the image in a large window on their computer device. The researcher presented each slide in turn as when previously completed face-to-face using cards.
- Connected speech (monologue): story recall by the person with dementia. In post-therapy (video-call) assessment, participants with dementia were asked to tell the

Cinderella story as completed during the face-to-face sessions with varied support. Participants either used their own copy of a traditional Cinderella storybook with the words covered up, or the researcher displayed on the video-call a copy of a traditional Cinderella story book with words covered up, turning the pages as the story progressed.

- Communication interview: interview by the researcher with the communication partner. For the post-therapy (video-call) assessment, changes were made to how the interview was completed. In addition, for post-therapy assessment, the interview was completed more informally. The participant did not have access to the card describing the response options; discussion was freer with consensus gained with participants selecting from one of the 3 categories of response. Although participants continued to select from a 3-point scale representing the severity of impairment, the terms used for each of the scale points (originally: frequently; occasionally; nearly never/never) were used more flexibly in discussion by both researcher and participant than when pointing to the response card in the baseline assessment.

5.4.2 Revised statistical analyses

Data analyses for individual participants were completed as described in the original protocol in Chapter 4, except for the Conversation Analysis which was not included at all in the revised protocol. However, due to the reduced number of participants recruited, and the removal of immediate and delayed treatment groups, overarching statistical analysis was not completed. Instead, each pair of participants (participant with dementia and communication partner) were presented as case studies.

Chapter 6 Phase 1: Results

This section details the results of the case study for two participants with dementia and their communication partners who took part in Phase 1 of the study involving face-to-face therapy sessions.

6.1 Participant A

Participant A (henceforth P-A) and their communication partner completed Phase 1 of the study.

6.1.1 Reported case history and background assessments

The case history was completed by the researcher face-to-face in one sitting. It was reported by P-A and his communication partner.

P-A was a 76 year old right-handed male who used British English as his everyday language. Now a retired engineer, he received a diagnosis of Alzheimer's disease 1 year and 1 month prior to commencing the study. P-A lived with his communication partner, who was retired at the time of the study and able to support regular practising of the therapy task. His vision was corrected by wearing glasses all the time, and he wore bilateral hearing aids all the time to support his hearing loss. He took medications including memantine, donepezil and statin.

P-A first started noticing difficulties participating in daily life in 2013, approximately 5 years prior to his dementia diagnosis. He currently felt loneliness due to a lack of confidence going out alone. However, his social context resulted in him having a full conversation each day, with family or friends, or with others such as in shops. He continued to enjoy a varied range of hobbies and activities, including walking, going to the cinema/theatre/ballet and going out for meals.

In terms of his communication, P-A first noticed some word-finding difficulties in March 2019. At the start of the study, P-A reported no difficulty with understanding spoken language, or with understanding written words. However, within the previous 6 months P-A had noticed some difficulty with writing, and checked with others if he was not confident of what he had written.

ACE-III

P-A's domain and total scores were as follows, with interpretation provided in the summary of background assessment below.

Table 9 – ACE-III results (P-A)

Domain	Score	Percentage (to 1dp)
Attention	10/18	55.6
Memory	10/26	38.5
Fluency	4/14	28.6
Language	23/26	88.5
Visuospatial	12/16	75.0
ACE III total	**59/100**	**59.0**

Camel and Cactus Test

This assesses participants' semantic knowledge without any naming or language comprehension skills, by looking at a target picture and pointing to the most appropriate/relevant picture from a choice of four.

Table 10 – Camel and Cactus Test results (P-A)

Category	Number correct out of total	% correct (to 1dp)
Domestic animals	7/7 *	100
Foreign animals	7/8	87.5
Birds	6/8	75
Fruit	8/8	100
Large household items	8/8	100
Small household items	7/8	87.5
Vehicles	7/8	87.5
Tools	8/8	100
Total living	**28/31**	**90.3**
Total manmade	**30/32**	**93.8**
Overall total	**58/63**	**92.1**
Control mean published with the assessment for comparison.	58.95/64	92.1

* Domestic Animal category out of 7 due to recording omission.

Word-to-picture matching

Taken from the Camels and Cactus Test, this assesses participants' spoken word to picture matching, by asking the participant to point to the correct picture as named by the researcher out of a choice of 8 similar options.

Table 11 – Word-to-picture matching results (P-A)

Category	Number correct out of total	% correct (to 1dp)
Domestic animals	8/8	100
Foreign animals	8/8	100
Birds	8/8	100
Fruit	7/8	87.5
Large household items	8/8	100
Small household items	8/8	100
Vehicles	8/8	100
Tools	8/8	100
Total living	**31/32**	**96.9**
Total manmade	**32/32**	**100**
Overall total	**63/64**	**98.4**

Summary of background assessment

It has been proposed that a score of 61 on the ACE-III is the cut-off point for determining whether dementia is mild or moderate (Giebel & Challis, 2017). Therefore, by this measure, with a score of 59, P-A's dementia appears to be moderate severity. P-A's relatively high score in the language domain (88.5%) is perhaps unsurprising given his diagnosis of AD, in contrast to the expected profile for other dementias such as FTD which affect language more (Hsieh et al., 2013). Verbal fluency (28.6%) and memory (38.5%) were areas of relative weakness for P-A.

People with AD may have impairment of only marginal statistical significance compared to controls when completing the Camels and Cactus Test (Adlam et al., 2010). Indeed, P-A's performance reflects this, scoring in line with the published control mean of 58.95. Therefore, this assessment suggests that P-A's semantic knowledge is within normal limits.

P-A's high performance on word-to-picture matching assessment suggests that he has a good understanding of single spoken words when given a choice of picture options. This is expected, as people with AD do typically score highly at this assessment when compared with, for example, lower performance noted in people with semantic dementia (Adlam et al., 2010).

6.1.2 Determining the most effective cue

P-A received their cues in the sequence as determined by scoring sheet A.

Table 12 – Effectiveness of cues for naming (P-A)

P-A		Cue (or cueing sequence) successful	Specific cue (or cueing sequence) offered	% (to 2dp)
First cue	Semantic cue	4	11	36.36
	Phonemic / syllabic cue	2	3	66.67
Second cue	Semantic cue (following unsuccessful phonemic / syllabic cue)	0	1	0
	Phonemic / syllabic cue (following unsuccessful semantic cue)	6	6	100
Overall	Semantic cue	4	12	33.33
	Phonemic / syllabic cue	8	9	88.89
	TOTAL named with a cue	24	42	57.14

In summary, phonemic/syllabic cues were most successful based on this assessment with P-A. This may be due to P-A having relatively intact semantic knowledge, meaning that semantic cues do not provide additional support.

6.1.3 Picture item naming

Table 13 below compares naming performance at 3 assessment points for both treated and untreated items. It shows the naming performance (number (n) and percentage (%) named correctly without cue/prompt by self/others).

Table 13 – naming of treated/untreated items (P-A)

P-A		Baseline assessment (Start)	Pre therapy (Approx.. 3 months after start)	Post therapy (Approx.. 6 months after therapy)
Treated items (Total = 59)	n	44	48	45
	%	74.58	81.36	76.27
Untreated items (Total = 79)	n	65	67	63
	%	82.28	84.81	79.75

Note: As post-therapy assessment was completed approximately 6 months after therapy due to coronavirus restrictions, section 6.1.6 gives a more immediate indication of P-A's naming performance in therapy sessions.

As can be seen in the table above, untreated items were named more successfully than treated at each assessment point. Although post-therapy naming performance was similar to baseline for both treated and untreated items, there was a mild decline in naming performance between pre-therapy and post-therapy assessment point, which appears similar for both treated and untreated items.

6.1.3.1Cochran's Q test of treated and untreated items

For P-A, 59 treated items were used to examine performance at the three time points: baseline, pre-therapy and post-therapy. Cochran's Q test determined that there was not a significant difference in the proportion of items that were named at the three test times, $\chi^2(2) = 1.083$, $p = .582$.

A separate Cochran's Q test was completed for untreated items. 79 untreated items were used to examine P-A's performance at the same three time points: baseline, pre-therapy and post-therapy. Cochran's Q test determined that there was not a significant difference in the proportion of items that were named at the three test times, $\chi^2(2) = 1.333$, $p = .513$.

6.1.4 Picture item naming – nouns/verbs

Table 14 shows the naming performance (number (n) and percentage (%) named correctly without cue/prompt by self/others).

Table 14 – naming of noun/verbs (P-A)

P-A		Baseline assessment	Pre-therapy assessment	Post-therapy assessment
Noun-untreated (Total = 50)	n	47	48	42
	%	94.00	96.00	84.00
Noun-treated (Total = 47)	n	33	37	35
	%	70.21	78.72	74.47
Verb-untreated (Total = 29)	n	18	19	21
	%	62.07	65.52	72.41
Verb-treated (Total = 12)	n	11	11	10
	%	91.67	91.67	83.33

P-A's naming performance on untreated nouns, treated nouns and treated verbs declined between pre-therapy and post-therapy assessment points, although treated nouns were higher at post-therapy assessment than at baseline. However, P-A's naming performance on untreated verbs, although lowest at baseline and pre-therapy, actually increased between pre-therapy and post-therapy. To determine significance of change between pre-therapy and post-therapy assessment points, McNemar Tests were completed for nouns and verbs, both treated and untreated.

6.1.4.1Nouns treated

Table 15 – Nouns treated (P-A): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	4	6
Named	8	29

An exact McNemar Test of P-A's 47 treated nouns showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .791 (2-tailed).

6.1.4.2Verbs treated

Table 16 – Verbs treated (P-A): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	0	1
Named	2	9

An exact McNemar Test of P-A’s 12 treated verbs showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = 1.000 (2-tailed).

6.1.4.3Nouns untreated

Table 17 – Nouns untreated (P-A): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	1	1
Named	7	41

An exact McNemar Test of P-A’s 50 untreated nouns showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .070 (2-tailed). However, it may be considered as approaching statistical significance.

6.1.4.4Verbs untreated

Table 18 – Verbs untreated (P-A): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	6	4
Named	2	17

An exact McNemar Test of P-A’s 29 untreated verbs showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .687 (2-tailed).

6.1.5 Picture item naming – naming performance correlation with linguistic variables

In order to determine correlation between overall naming performance and linguistic variables Pearson’s correlations were completed for all items (both treated and untreated) combined. Overall naming was determined assigning a score of 1 at each of the three assessment points when an item was named correctly. Thus, each item was assigned a score between 0 (never named correctly) and 3 (named correctly at each assessment point). There was a statistically significant positive correlation between P-A’s overall naming performance of all items and imageability.

Table 19 – All items overall naming (P-A): Correlations

		Naming change	Length phonemes	Length syllables	F-K frequency	Familiarity mean	Age-of-acquisition mean	Imageability mean
Overall naming	Pearson Correlation	1	-.040	.011	-.047	-.015	-.003	.289**
	Sig. (2-tailed)		.668	.902	.610	.874	.975	.001
	N	119	119	119	119	119	119	119

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

A further Pearson’s correlation was completed to determine any correlation between change in naming performance on linguistic variables.

Change in naming was defined by assigning a score of 1 to any item where naming improved between pre-therapy and post-therapy assessment points, a score of 0 to any item where naming was unchanged between pre-therapy and post-therapy assessment points, and a score of -1 to any item where naming declined between pre-therapy and post-therapy assessment points. There was no statistically significant correlation between change in P-A’s naming performance of items and the stated linguistic variables.

Table 20 – All items naming change (P-A): Correlations

		Naming change	Length phonemes	Length syllables	F-K frequency	Familiarity mean	Age-of-acquisition mean	Imageability mean
Change in naming	Pearson Correlation	1	.072	.106	-.096	-.139	-.025	-.118
	Sig. (2-tailed)		.435	.253	.298	.131	.783	.200
	N	119	119	119	119	119	119	119

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

6.1.6 Naming performance in the therapy sessions

Table 21 below shows naming performance in therapy sessions (number and percentage named correctly without cue by others). Although not directly comparable with assessment, this allows for a valuable indication of naming performance in therapy sessions given that post-therapy assessment was delayed as a consequence of the coronavirus restrictions.

Table 21 – naming of treated items in the face-to-face therapy sessions (P-A)

P-A	Therapy session number								
	1	2	3	4	5	6	7	8	9
Named correctly/ total	25/29	25/26	19/20	28/28	21/21	27/28	28/29	19/19	31/32
%	86.21	96.15	95.00	100	100	96.43	96.55	100	96.88

6.1.7 Summary of picture item naming

Overall, P-A named untreated items more successfully than treated items. P-A’s naming performance showed a slight decline between pre-therapy and the 6-month post-therapy assessment, for both treated and untreated items. This decline was not statistically significant. For both treated items and for untreated items, the difference between the means at the different assessment points was not statistically significant. While noting the caveats around data analysis of therapy sessions detailed earlier in section 4.17.4, in the absence of immediate assessment following therapy, P-A’s performance of treated items in therapy sessions provides an indication of possible maintenance of naming during the therapy sessions.

There was no statistically significant correlation between naming performance and the linguistic variables. However, there was a positive correlation between P-A's overall naming performance and the imageability mean for each item, suggesting that overall, P-A named more imageable items better than less imageable items.

P-A's naming performance on untreated nouns, treated nouns and treated verbs declined between pre-therapy and post-therapy assessment points. However, P-A's naming performance on untreated verbs, although lowest at baseline and pre-therapy, actually increased between pre-therapy and post-therapy. For both nouns and verbs, both treated and untreated, the change in naming before and after therapy was not statistically significant, although for untreated nouns the change in naming before and after therapy was approaching statistical significance. As the decline in naming of untreated nouns was approaching statistical significance, but the naming of treated nouns was not significant, this may very tentatively suggest maintenance of naming of treated items, and thus some treatment effect and benefit to completing the therapy for nouns.

6.1.8 Connected speech (monologue)

Quantitative Production Analysis (Berndt et al., 2000) was completed of a sample of connected speech at each of the assessment points. The results from key analysis measures are reported here; the description of each measure is outlined earlier in the methodology in Table 6. Values in tables are presented to 2 decimal places. Control values from healthy controls included for comparison are as reported by Berndt and colleagues (2000).

6.1.8.1Number of words per minute

Table 22 – words per minute in connected speech (P-A)

	Baseline	Pre-therapy	Post-therapy	Control
Number of words per minute	112.28	106.50	81.98	160.82

6.1.8.2Proportion of word categories

Table 23 – proportion of word categories in connected speech (P-A)

	Baseline	Pre-therapy	Post-therapy	Control
Proportion of closed class words	0.60	0.52	0.52	0.54
Proportion of pronouns	0.30	0.21	0.33	0.41
Proportion of verbs	0.40	0.44	0.45	0.48

6.1.8.3Verb complexity

Table 24 – verb complexity in connected speech (P-A)

	Baseline	Pre-therapy	Post-therapy	Control
Verb inflection index	0.75	1.00	1.00	0.92
Auxiliary complexity index	2.13	3.06	1.38	1.26

6.1.8.4Sentence complexity

Table 25 – Sentence complexity in connected speech (P-A)

	Baseline	Pre-therapy	Post-therapy	Control
Sentence elaboration index	1.33	2.38	2.13	3.06

6.1.8.5 Summary of connected speech analysis

For P-A, between pre-therapy and post-therapy assessment the speech rate declined, and was below published typical control at all three assessment points. The proportion of pronouns increased but the proportion of closed class words and the proportion of verbs remained unchanged between pre-therapy and post-therapy assessment. However, the proportion of closed class words and proportion of verbs were largely in line with reported controls, with proportion of pronouns being below reported controls at all assessment points. The auxiliary complexity and sentence complexity both increased between baseline and pre-therapy assessment, before declining at post-therapy assessment. Sentence complexity was below reported controls, whereas auxiliary complexity was notably above controls at all three assessment points.

These findings suggest that P-A's speech at post-therapy assessment had more pauses. They suggest P-A's expressive language remained relatively complex, although P-A's increased proportion of pronouns may cause difficulty if it is not clear to whom or what they refer.

6.1.9 Interview with the communication partner

The analysis and reporting of the interview with the communication partner is comprised of two parts. Firstly, changes in the communication partner's rating from baseline assessment to post-therapy assessment are shown in Figure 6 and Figure 7. Secondly, key comments from the post-therapy interview which provided extra insight about communicative success are considered. These comments are not designed to be exhaustive, but to qualitatively reflect key themes and salient insights given by the communication partner in addition to that captured in the quantitative analysis of the rating scores.

6.1.9.1Comparing rating scores at baseline assessment and post-therapy assessment

A higher score means greater frequency of impairment or greater severity of problem. The specific question topics contained within each of the eight categories reported on the next page is described earlier in the methodology in Table 7.

Figure 6 – communication partner interview (P-A; part 1)

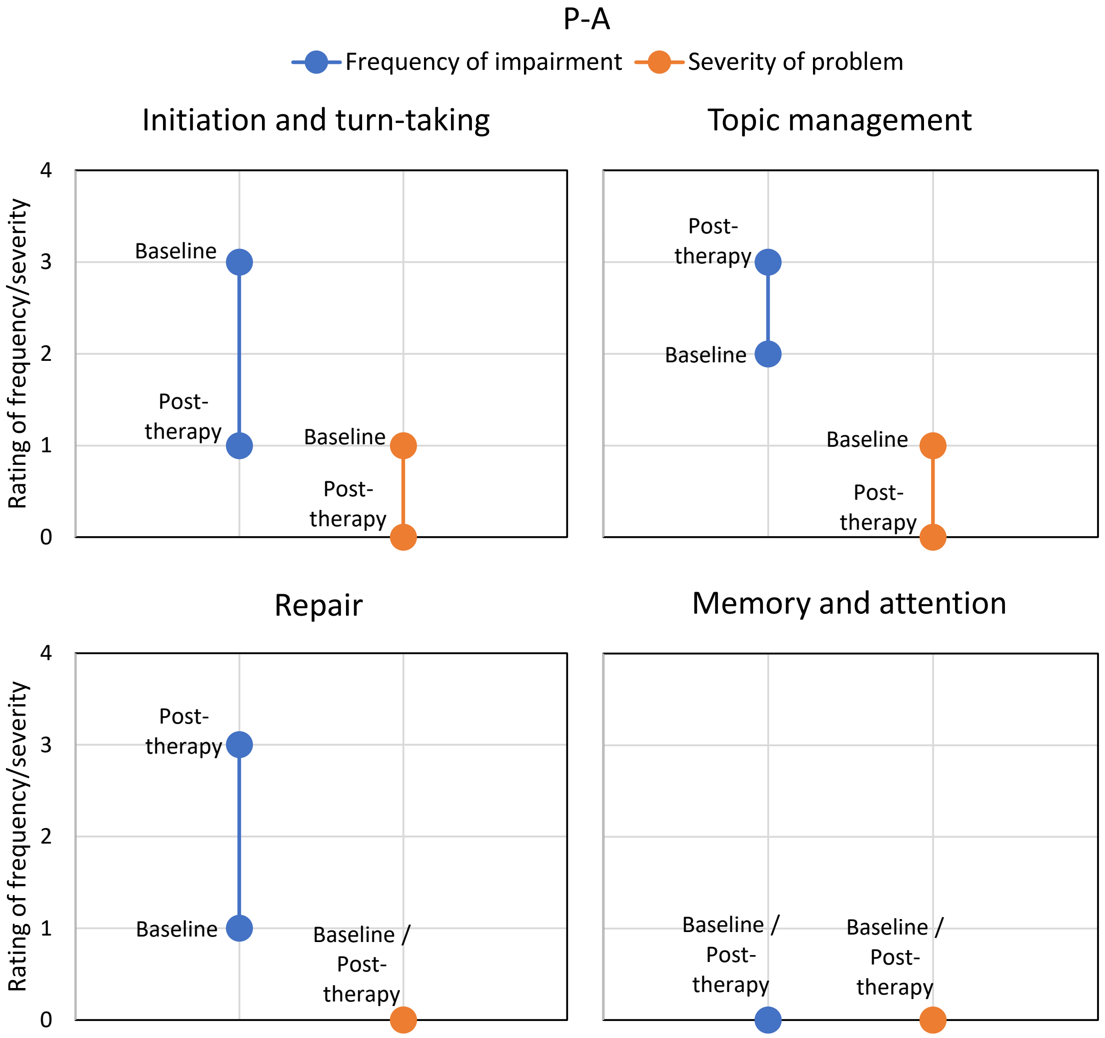
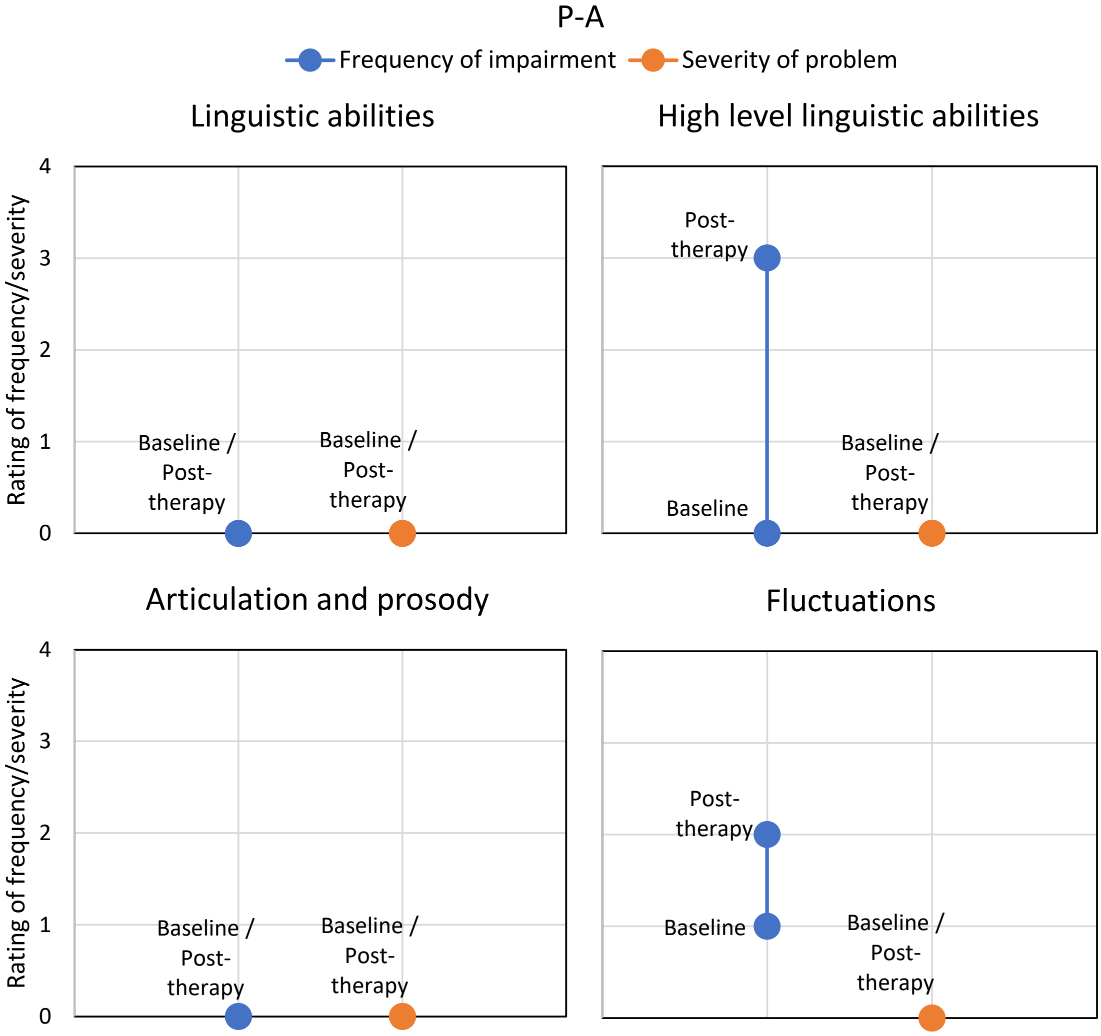


Figure 7 – communication partner interview (P-A; part 2)



6.1.9.2Comments made during the post-therapy interview

Communication for P-A could break down, although reasons for this were not necessarily due to dementia but may have other influences. For example, their communication partner (henceforth CP-A) noted that P-A did generally respond in a timely manner *“unless he’s not put his hearing aids in”.*

When considering whether P-A persisted with certain topics, CP-A noted that on occasion this happened *“frequently, sometimes to the point that it’s almost on a loop”.* However, although the CAPPCI questionnaire scoring system assumed having repeated themes of conversation was undesirable, this was not always perceived negatively by CP-A.

They noted that topics were often repeated, but:

> CP-A: *"that is because we have the same interests, the same things concern us so we discuss them regularly […] like the wellbeing of our family would be a regular topic that we would regularly talk about […] Fortunately we have all the same favourite topics".*

The topics of conversation were valued by CP-A, as they were *"talking about things that are relevant to our lives now"* and that P-A *"doesn't talk about things that are no longer relevant".* However, it was felt that P-A nearly never introduced new topics, or that new topics were sometimes random. A strategy for managing this was described as:

> CP-A: *"We either move to the new topic […] or we go back and come back to that topic after we finish getting to the bottom of what we were trying to talk about".*

Significantly, CP-A felt that it was most important that P-A continued to want to talk, and that taking time to ensure they had quality conversations was beneficial. CP-A described how a communicative environment was effectively orchestrated to maximise conversation:

> CP-A: *"[P-A] can be very quiet now so we almost prepare to talk, you know, like I'll make a cup of coffee, both sit down and talk […] rather than just chit-chatting".*

Indeed, having a reason to talk was reduced as a consequence of limited social opportunities due to the coronavirus restrictions. In addition to dementia, this societal change impacted on conversation as there was limited scope for new topics:

> CP-A: *"There weren't enough people to talk to […] we just weren't doing anything and anything we were doing we were doing together so there was nothing to tell each other".*

CP-A reflected on their own personal communication style and how this interacted with that of P-A to contribute to overall communicative success. For example, if P-A is on their own with someone else, CP-A observed that they are quite communicative, but this dynamic is different when CP-A is present:

> CP-A: *"If I'm there he's very quiet and I never shut up […] I think maybe it's me that's just too chatty".*

Similarly, when P-A experiences word-finding difficulties, CP-A described how they would offer the likely intended word or several possible options. They find this effective, and the conversation continues. This appears to fit in to a wider collaborative approach to communicative success as noted by CP-A:

CP-A: *"We've always sort of helped each other in whatever way we needed to so it's just part of being supportive".*

When considering higher-level linguistic ability, CP-A felt P-A is *"really good about reading between the lines"*. However, CP-A reported trying to ensure they use accurate terms with P-A, and do not use non-literal phrases such as when describing a time-frame:

CP-A: *"I do try and be more specific when I think about it, and say actually it'll be more like fifteen [minutes]".*

In general, CP-A's rating scores suggested that any communication difficulties were typically not perceived as a problem. CP-A felt that comparing communication skills with those prior to dementia was "not helpful to us so we just find the word and carry on". Living in the moment was considered important to CP-A, as was not overthinking any communication or word-finding difficulties:

CP-A: *"If I dwelled on why then it could become a problem because I would start to be worried or upset, […] and the danger is you over watch and over judge how things are".*

Despite this, CP-A felt it was rare that P-A couldn't find the word, and sometimes the intended word was clear due to gesture such as pointing at the object. If they could not find the word to enable conversation to continue, CP-A tried to maintain a conversation and not dwell on any communication difficulty.

CP-A: *"I would just say well let's not worry about it – talk about it later".*

CP-A: *"I don't know what else to do! […] Try and move on and think well it'll resurface".*

When considering general everyday memory of events, CP-A felt that even when key facts such as where an event was, or who attended had been forgotten, P-A retained *"all the sort of emotional memory of how nice it was".* CP-A elaborated further, explaining that:

CP-A: *"In a lot of ways the things that really matter [P-A] will remember […] so again, you can't worry about it can you? […] It doesn't matter if the details have got lost […] the happiness […] of it is there".*

Regarding fluctuation of communication abilities, CP-A felt that although P-A did not experience weekly fluctuations, daily fluctuations did occur as P-A would get quieter when tired. CP-A acknowledged the impact of tiredness on communication and did not then attempt a conversation.

CP-A: *"If we haven't had a busy day, I would say have a glass of water […] and then make a bit more effort! If we have had a busy day I would probably think, yeah, he's tired fair enough.*

In this situation CP-A felt it would be unfair to expect P-A to talk more, so they would just sit quietly rather than trying to generate conversation. To mitigate the impact of tiredness on communicative success, CP-A described managing their social schedule to ensure that P-A can participate as effectively and fully as possible.

CP-A: *"I'm a bit more careful at planning the day."*

CP-A: *"Whatever we are doing, our friends and family get the best of [P-A]."*

Therefore, when planning social opportunities, it appeared that CP-A prioritises P-A's conversations with his family and friends.

6.1.9.3 Summary of interview with the communication partner

CP-A felt the frequency of P-A's impairment had increased between baseline and post-therapy for 4 of the 8 topic areas reported. Only initiation and turn-taking was reported to have improved, with a decrease in frequency of impairment. However, despite this, CP-A reported that the severity of the problem was generally very slight and did not worsen between the two assessment points. Indeed, improvements in CP-A's perception of the severity of the problem were reported for initiation and turn-taking and topic management, the latter of which was despite an increased frequency of impairment. This aligns with the reported comments made during the interview, where CP-A generally reported that they did not perceive communication difficulties as problematic.

6.1.10 Key features of P-A's communication

Background testing suggested P-A's semantic knowledge was unimpaired. P-A's naming performance declined for both treated and untreated items between pre-therapy and post-therapy assessment, although performance of treated items in therapy sessions suggests some tentative improvement throughout therapy. Connected speech measures generally declined from pre-therapy to post-therapy, but were frequently similar to reported controls with the exception of speech rate which was notably reduced compared with controls. CP-A described a collaborative approach to communicating with P-A, with communication impairments generally not perceived as a problem.

6.2 Participant B

Participant B (henceforth P-B) and their communication partner completed Phase 1 of the study.

6.2.1 Reported case history and background assessments

The case history was completed by the researcher face-to-face in one sitting. It was reported by P-B and his communication partner.

P-B, a right-handed male aged 83 years old at the time of the study who used British English as his everyday language, had a diagnosis of AD dementia made around 3 years previously at age 80 years old. Although P-B did not live with his communication partner, a friend, who was retired at the time of the study, the communication partner was able to support effective frequent practising of the therapy task alongside other family members. P-B wore glasses for long distance and for reading and had a longstanding deafness in one ear. He wore a hearing aid in his other ear. He reported having two previous heart attacks, although the most recent was more than a decade prior to their involvement in the study. He reported taking medications including donepezil, gabapentin, paracetamol and statin.

A retired engineer, P-B's first sign of dementia was an apparent inability to process information about everyday life, such as meeting times. However, the first evidence of word-finding difficulties was approximately 2 years prior to diagnosis when he was 78 years old. P-B had a number of hobbies including singing in a choir.

In terms of his communication, P-B reported understanding what others say, but having to seek clarity due to misunderstandings. He reported having good reading and being able to write sufficiently to complete everyday tasks, but could produce lots of spelling errors. P-B also reported difficulty maintaining a topic. He had opportunities to communicate daily with neighbours, friends and family, either face-to-face or on the phone.

ACE-III

P-B's domain and total scores were as follows:

Table 26 - ACE-III results (P-B)

Domain	Score	Percentage (to 1dp)
Attention	11/18	61.1
Memory	10 /26*	38.5
Fluency	4/14	28.6
Language	19/26	73.1
Visuospatial	13/16	81.3
ACE III total	**57/100**	**57**

*Memory – address trials: initial attempt scored due to researcher error.

Camel and Cactus Test

Table 27 - Camel and Cactus Test results (P-B)

Category	Number correct out of total	% correct (to 1dp)
Domestic animals	7/8	87.5
Foreign animals	5/8	62.5
Birds	6/8	75.0
Fruit	6/8	75.0
Large household items	5/8	62.5
Small household items	7/8	87.5
Vehicles	7/8	87.5
Tools	5/8	62.5
Total living	**24/32**	**75.0**
Total manmade	**24/32**	**75.0**
Overall total	**48/64**	**75.0**
Control mean published with assessment for comparison	58.95/63	93.6

Word-to-picture matching

Table 28 - Word-to-picture matching results (P-B)

Category	Number correct out of total	% correct (to 1dp)
Domestic animals	7/8	87.5
Foreign animals	8/8	100.0
Birds	6/8	75.0
Fruit	6/8	75.0
Large household items	8/8	100.0
Small household items	8/8	100.0
Vehicles	8/8	100.0
Tools	8/8	100.0
Total living	**27/32**	**84.4**
Total manmade	**32/32**	**100.0**
Overall total	**59/64**	**92.2**

Summary of background cognitive assessment for P-B

When measured with the ACE-III, P-B’s overall cognitive performance (57%) appears to be of moderate severity, as per a proposed cut off point of 61 for differentiating mild or moderate dementia (Giebel & Challis, 2017). Relative strengths were noted in visuospatial skills (81.3%) and language skills (73.1%), with particular weakness in verbal fluency (28.6%).

P-B’s semantic knowledge appears to be notably impaired, with a score of 75% compared with a 93.6% control score. Performance for living and manmade items were the same (75%).

P-B’s performance on assessment of word to picture matching when semantically categorically similar items are also presented suggests that he has a good understanding of single spoken words when given a choice of picture options. This appears particularly the case for manmade items (100%) compared with living items (84.4%). A high score may be expected, as people with AD do typically score highly on this assessment when compared with, for example, lower performance noted in people with semantic dementia (Adlam et al., 2010).

6.2.2 Determining the most effective cue

P-B received their cues in the sequence as determined by scoring sheet B.

Table 29 - Effectiveness of cues for naming (P-B)

P-B		Cue (or cueing sequence) successful	Specific cue (or cueing sequence) offered	% (to 2dp)
First cue	Semantic cue	3	4	75
	Phonemic / syllabic cue	6	6	100
Second cue	Semantic cue (following unsuccessful phonemic / syllabic cue)	0	0	0
	Phonemic / syllabic cue (following unsuccessful semantic cue)	1	1	100
Overall	Semantic cue	3	4	75
	Phonemic / syllabic cue	7	7	100
	TOTAL named with a cue	10	11	85.71

In summary, both semantic and phonemic/syllabic cues were successful in supporting naming, although phonemic/syllabic cues were most successful based on this assessment with P-B. Semantic cues may have value in supporting P-B's impaired semantic knowledge.

6.2.3 Picture item naming

Table 30 compares naming performance at 3 assessment points for both treated and untreated items. It shows the naming performance (number (n) and percentage (%) named correctly without cue/prompt by self/others).

Table 30 - naming of treated/untreated items (P-B)

P-B		Baseline assessment (Start)	Pre therapy (approx. 3 months from start)	Post therapy (approx. 6 months after therapy)
Treated items (Total = 60)	n	39	42	37
	%	65.00	70.00	61.67
Untreated items (Total = 79)	n	56	62	49
	%	70.89	78.48	62.01

Note: As post-therapy assessment was completed approximately 6 months after therapy due to coronavirus restrictions, section 6.2.6 gives a more immediate indication of P-B's naming performance in therapy sessions.

As can be seen in Table 30 above, untreated items were named more successfully than treated at each assessment point (although minimally so at post-therapy assessment). However, there appears to have been a steeper decline in naming performance for untreated items than for treated items, suggesting greater maintenance of treated items which may indicate some benefit from completing the therapy.

6.2.3.1 Cochran's Q test of treated and untreated items

For P-B, 60 treated items were used to examine performance at the three time points: baseline, pre-therapy and post-therapy. Cochran's Q test determined that there was not a significant difference in the proportion of items that were named at the three test times, $\chi^2(2) = 1.727$, p = .422.

A separate Cochran's Q test was completed for untreated items. 79 untreated items were used to examine P-B's performance at the same three time points: baseline, pre-therapy and post-therapy. Cochran's Q test determined that there was a statistically significant difference in the proportion of items that were named at the three test times, $\chi^{\underline{2}}(2) = 7.938$, p = .019. To determine between which assessment points a statistically significant change in naming occurred, post hoc testing, using McNemar Tests, was completed. An exact McNemar Test of P-B's 79 untreated items showed that there was no statistically significant difference in naming performance between baseline and pre-therapy assessment, p = .238 (2-tailed). An exact McNemar Test of P-B's 79 untreated items showed that there was no statistically significant difference in naming performance between baseline and post-therapy assessment, p = .189 (2-tailed). However, an exact McNemar Test of P-B's 79 untreated items showed that there was a statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .015 (2-tailed).

6.2.4 Picture item naming – nouns/verbs

Table 15 shows the naming performance (number (n) and percentage (%) named correctly without cue/prompt by self/others).

Table 31 - naming of nouns/verbs (P-B)

P-B		Baseline	Pre-therapy	Post-therapy
Noun-untreated	n	37	40	31
(Total = 48)	%	77.08	83.33	64.58
Noun-treated	n	30	32	28
(Total = 49)	%	61.22	65.31	57.14
Verb-untreated	n	19	22	18
(Total = 31)	%	61.29	70.97	58.06
Verb-treated	n	9	10	9
(Total = 11)	%	81.82	90.91	81.82

P-B's naming performance on untreated nouns, treated nouns, untreated verbs and treated verbs all showed a small increase between baseline assessment and pre-therapy assessment, but declined between pre-therapy and post-therapy assessment. To determine significance of change between pre-therapy and post-therapy assessment, a McNemar Test was completed for nouns and verbs, both treated and untreated.

6.2.4.1Nouns treated

Table 32 - Nouns treated (P-B): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	13	4
Named	8	24

An exact McNemar Test of P-B's 49 treated nouns showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .388 (2-tailed).

6.2.4.2Verbs treated

Table 33 - Verbs treated (P-B): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	0	1
Named	2	8

An exact McNemar Test of P-B’s 11 treated verbs showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = 1.000 (2-tailed).

6.2.4.3Nouns untreated

Table 34 - Nouns untreated (P-B): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	7	1
Named	10	30

An exact McNemar Test of P-B’s 48 untreated nouns showed that there was a statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .012 (2-tailed).

6.2.4.4Verbs untreated

Table 35 - Verbs untreated (P-B): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	4	5
Named	9	13

An exact McNemar Test of P-B’s 31 untreated verbs showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .424 (2-tailed).

6.2.5 Picture item naming – naming performance correlation with linguistic variables

In order to determine correlation between overall naming performance and linguistic variables Pearson’s correlations were completed for all items (both treated and untreated) combined. Overall naming was determined assigning a score of 1 at each of the three assessment points when an item was named correctly. Thus, each item was assigned a score between 0 (never named correctly) and 3 (named correctly at each assessment point). There was no statistically significant correlation between P-B's overall naming of all items and any of the linguistic variable data.

Table 36 - All items overall naming (P-B): Correlations

		Overall naming	Length phonemes	Length syllables	F-K frequency	Familiarity mean	Age-of-acquisition mean	Imageability mean
Overall naming	Pearson Correlation	1	-.082	-.087	.075	.100	-.178	.102
	Sig. (2-tailed)		.374	.346	.416	.279	.053	.269
	N	119	119	119	119	119	119	119

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

A further Pearson's correlation was completed to determine any correlation between change in naming performance on linguistic variables.

Change in naming was defined by assigning a score of 1 to any item where naming improved between pre-therapy and post-therapy assessment points, a score of 0 to any item where naming was unchanged between pre-therapy and post-therapy assessment points, and a score of -1 to any item where naming declined between pre-therapy and post-therapy assessment points. There was a weak statistically significant negative correlation between change in naming performance and age-of-acquisition mean.

Table 37 - All items naming change (P-B): Correlations

		Naming change	Length phonemes	Length syllables	F-K frequency	Familiarity mean	Age-of-acquisition mean	Imageability mean
Naming change	Pearson Correlation	1	.035	.057	.110	.177	-.192*	-.029
	Sig. (2-tailed)		.704	.538	.234	.054	.036	.756
	N	119	119	119	119	119	119	119

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

6.2.6 Naming performance in the therapy sessions

Table 38 below shows naming performance in therapy sessions (number and percentage named correctly without cue by others). Although not directly comparable with assessment, this allows for a valuable indication of naming performance in therapy sessions given that post-therapy assessment was delayed as a consequence of the coronavirus restrictions.

Table 38 - naming of treated items in the face-to-face therapy sessions (P-B)

P-B	Therapy session number								
	1	2	3	4	5	6	7	8	9
Named correctly/ total	13/15	24/25	24/27	25/29	26/30	29/32	17/17	31/35	21/25
%	86.67	96.00	88.89	86.21	86.67	90.63	100	88.57	84.00

6.2.7 Summary of picture item naming

Overall, P-B named untreated items more successfully than treated at each assessment point, with a steeper decline visible in naming performance for untreated items than for treated items. This may suggest some treatment effect as the level of naming performance was maintained more for treated items than for untreated items. While noting the caveats around data analysis of the therapy sessions data detailed earlier in section 4.17.4, P-B's performance on treated items in the therapy session appears very variable, without any discernible trend, although performance was above that of the formal naming assessments.

For treated items, both the change in naming before and after therapy, and the difference between the means at the different assessment points, were not statistically significant. In addition, there was no statistically significant correlation between overall naming of treated items, or change in naming of treated items, and any of the linguistic variable data.

Crucially, for untreated items a Cochran's Q and post hoc McNemar test suggested there was a statistically significant decline in naming performance between pre-therapy and post therapy assessment points. As the treated items did not decline significantly, in contrast with the untreated items, this tentatively provides statistical support for there being a possible benefit to receiving the therapy.

There was a statistically significant negative correlation between change in naming performance and the mean age of acquisition of each item. There was no statistically significant correlation between overall naming performance and any of the linguistic variable data, although overall naming performance and mean age of acquisition was approaching a statistically significant negative correlation. This suggests, P-B's naming performance was better for items with a lower age of acquisition.

Untreated and treated nouns and verbs showed a small increase between baseline assessment and pre-therapy assessment, but declined between pre-therapy and post-therapy assessment. There was no statistically significant change in either untreated or treated verbs. There was no statistically significant change in naming for treated nouns. However, there was a statistically significant decline in naming for untreated nouns. That the treated nouns did not decline significantly unlike the untreated items, provides statistical support for there being a possible benefit to receiving the therapy specifically for nouns.

6.2.8 Connected speech (monologue)

Quantitative Production Analysis (Berndt et al., 2000) was completed of a sample of connected speech at each of the assessment points. The results from key analysis measures are reported here; the description of each measure is outlined earlier in the methodology in Table 6. Values in tables are presented to 2 decimal places. Control values from healthy controls included for comparison are as reported by Berndt and colleagues (2000).

6.2.8.1Number of words per minute

Table 39 - words per minute in connected speech (P-B)

	Baseline	Pre-therapy	Post-therapy	Control
Number of words per minute	123.64	102.72	142.00	160.82

6.2.8.2Proportion of word categories

Table 40 - proportion of word categories in connected speech (P-B)

	Baseline	Pre-therapy	Post-therapy	Control
Proportion of closed class words	0.55	0.59	0.59	0.54
Proportion of pronouns	0.50	0.52	0.62	0.41
Proportion of verbs	0.58	0.52	0.72	0.48

6.2.8.3Verb complexity

Table 41 - verb complexity in connected speech (P-B)

	Baseline	Pre-therapy	Post-therapy	Control
Verb inflection index	0.73	0.27	0.53	0.92
Auxiliary complexity index	2.06	1.00	1.00	1.26

6.2.8.4Sentence complexity

Table 42 - Sentence complexity in connected speech (P-B)

	Baseline	Pre-therapy	Post-therapy	Control
Sentence elaboration index	2.35	1.12	1.96	3.06

6.2.8.5Summary of connected speech analysis

For P-B, sentence complexity, speech rate and verb inflection index all increased from pre-therapy to post-therapy assessment, but all remained below reported controls. The proportion of verbs and the proportion of pronouns both increased from pre-therapy to post-therapy assessment, with both being above reported controls. This suggests that P-B may have appeared more fluent at post-therapy assessment, producing more complex verbs, although the increase in pronouns may impact on understanding if it is not clear to whom or what they refer.

6.2.9 Interview with the communication partner

The analysis and reporting of the interview with the communication partner is comprised of two parts. Firstly, changes in the communication partner’s rating from baseline assessment to post-therapy assessment is shown in Figure 8 and Figure 9. Secondly, key comments from the post-therapy interview which provided extra insight about communicative success are outlined, with quotes from the communication partner where notable. These comments are not designed to be exhaustive, but to qualitatively reflect key themes and salient insights given by the communication partner in addition to that captured in the quantitative analysis of the rating scores.

6.2.9.1Comparing rating scores at baseline assessment and post-therapy assessment

A higher score means greater frequency of impairment or greater severity of problem. The specific question topics contained within each of the eight categories reported below is described earlier in the methodology in Table 7. Overall, for P-B, their communication partner felt there had generally been a small decline in both frequency of impairment and severity of the problem between baseline assessment and post-therapy assessment.

Figure 8 - communication partner interview (P-B; part 1)

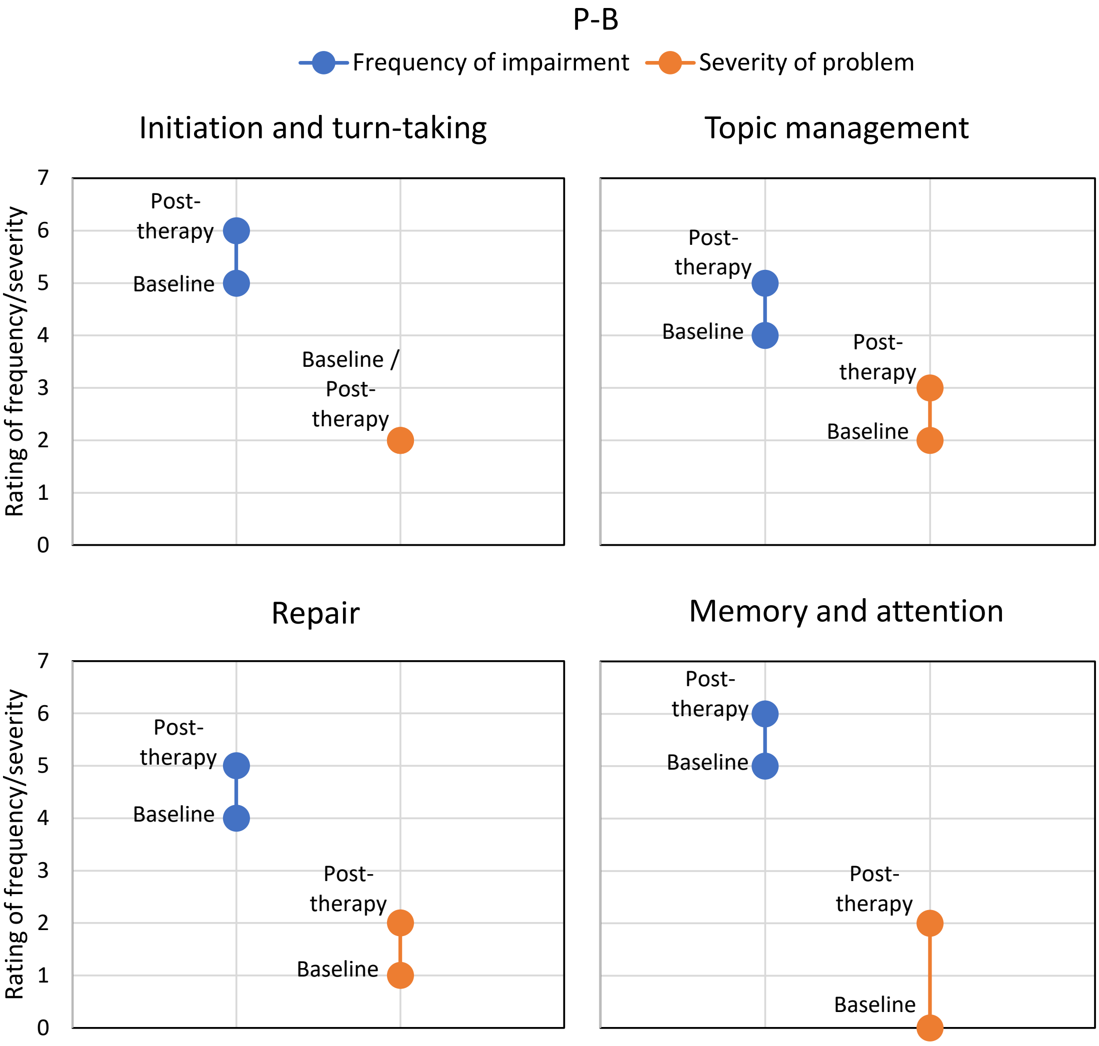
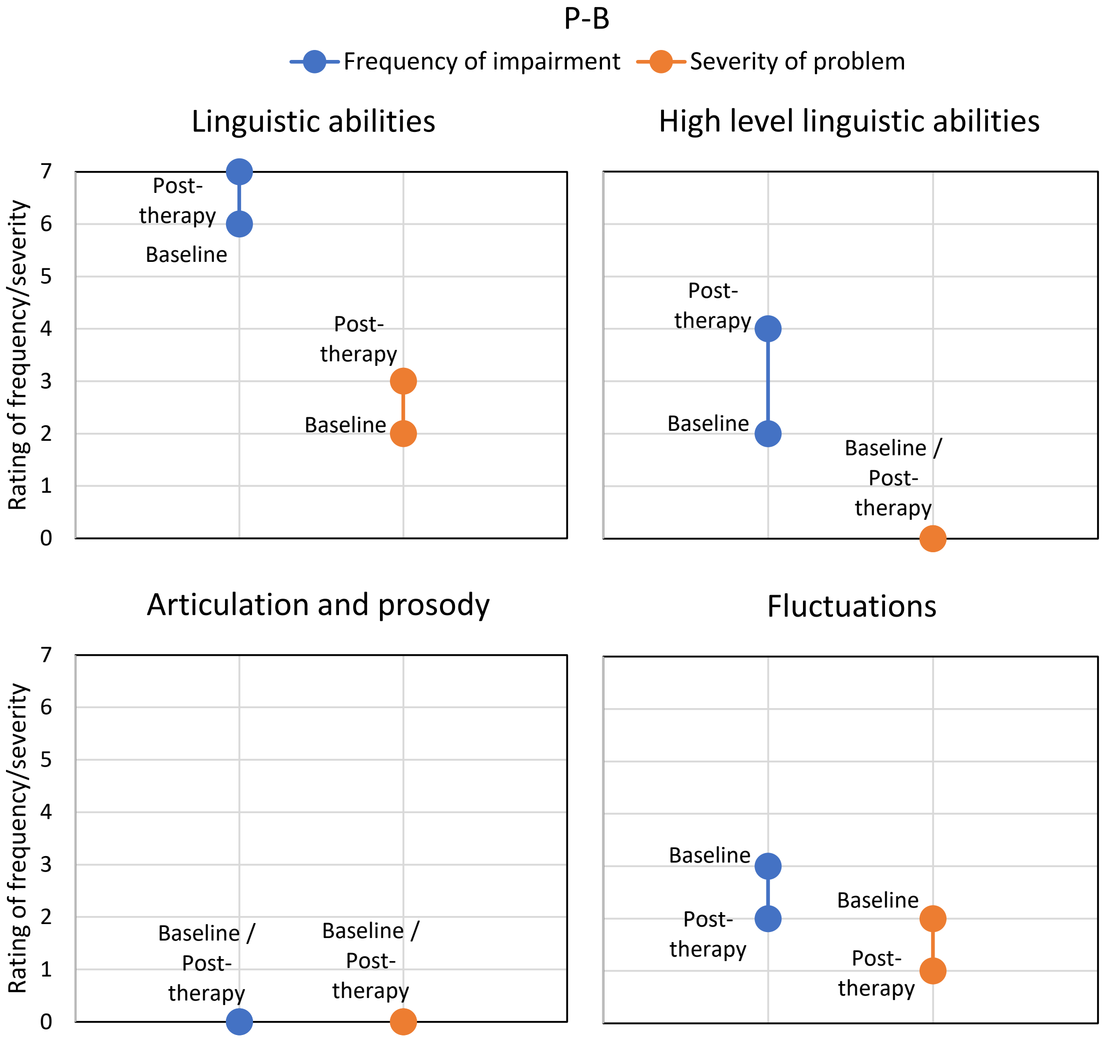


Figure 9 - communication partner interview (P-B; part 2)



6.2.9.2Comments made during the post-therapy assessment

When considering how P-B responds to a question, their communication partner (henceforth CP-B) noted that although there might be response given, it is not always as expected:

> CP-B: *"The response might not be [...] a direct answer to my question but he'll say something that might be a bit oblique [...] but he will say something".*

CP-B described a similar situation when P-B would introduce new topics; CP-B would have to *"try and sort of untangle things a bit"* as the link to the preceding conversation may not be obvious:

> CP-B: *"In the middle of talking about one thing his mind will jump to something else [...] I can usually see what the connection is, but it does go off at a tangent [...] It's frustrating sometimes [...] if there's something I'm trying to find out".*

However, CP-B felt that at times a long pause was left in a sentence by P-B. In this instance, CP-B tried to give P-B some time to think, however CP-B acknowledged this has variable success:

CP-B: *"Sometimes [P-B] will continue and sometimes I need to prompt […] if he forgets the name of something or someone"*.

Although sometimes a prompt is needed, CP-B also described how P-B sometimes gives a response perceived as excessive in amount. CP-B attributes this to P-B having limited communication opportunities:

CP-B: *"You've just got to appreciate that [P-B] is actually on his own for […] a lot of time so I think it's important when he's got an opportunity to talk that you just […] let him talk".*

If P-B is required to talk about the same thing for a while, CP-B observed that "*sometimes there might be a few false starts* […]. If he doesn't have an immediate comprehension of what I'm talking about he'll change the subject". Similarly, CP-B reported managing the conversation to ensure key facts are discerned:

CP-B: *"Maybe I'll be trying to find something out and [P-B] will go off at a tangent, so we'll talk about the tangent for a bit and then come back to where we started".*

CP-B: *"If he's got that new idea in his head, that's where he's at, so you've got to like get to the end of that and then go back to […] the original conversation".*

Interruptions to the conversation by P-B can affect communication success. CP-B described how the conversation may have *"gone in a different direction and you have to retrieve it a bit",* which can cause frustration. However, CP-B felt that it is important to be flexible with interruptions:

CP-B: *"My thinking is that [P-B] needs to say what he's got in his head, because if he doesn't say it then he will have forgotten it by the time it's his turn to speak again. So he needs to get it out while it's […] there in his mind".*

CP-B noted how certain favourite topics of P-B were frequently discussed, which could be challenging, however *"you just have to accept that it's part of the illness and that's […] how it is".*

The time of day affected P-B's communication, with CP-B noting that there was a noticeable decline later in the day:

CP-B: *"In an evening I might try and talk to him about something and he's obviously not understanding and I just say to him look, let's leave it for now and I'll talk to you about this in the* *morning because I know that his mind is fresher in the morning […] and that he's more likely to understand".*

This might impact on communication, however CP-B described mitigating this by avoiding contradicting P-B:

CP-B: *"The easy thing is to contradict […] so I just let him talk and […] he was happy".*

If P-B is unable to make his speech more specific CP-B offered possible words or explained that they did not understand. Consequently, they are *"both kind of left a bit frustrated"* when they cannot successfully get the message across.

If favoured topics are repeated by P-B, CP-B tries to *"pretend that it's the first time he's asked me and act in the same way".* Acknowledging that this is a feature of P-B's dementia, along with a flexible approach, were key for CP-B:

CP-B: *"It's hard […] sometimes to keep your patience, but it's part of the illness isn't it".*

CP-B: *"You've got to go along with things otherwise […] you'd get upset".*

If word-finding difficulties occur, CP-B outlined how P-B would likely, if prompted, give further description around the target word, though it *"might not always be a very good description*". CP-B also attempts to repair the conversation with variable success:

CP-B: *"I try and figure out what it is that he's talking about […] sometimes I do and sometimes I don't".*

When considering P-B's comprehension, CP-B noted that "*I often have to go over things several times"*. This *"works better if I keep calm*"; if not *"then he would be more likely to switch off*". If P-B hasn't understood what has been said, CP-B observed different responses:

CP-B: *"He would either say 'I don't understand what you mean' […] which is easy to deal with or […] sometimes if he doesn't understand he just changes the subject".*

Similarly, if jokes were misunderstood, CP-B described how they would attempt to explain it to P-B, although this was not always successful:

CP-B: *"Sometimes he'll say 'oh yes I understand you' and I can tell sometimes from the way he says things that […] he doesn't understand".*

6.2.9.3 Summary of interview with the communication partner

For P-B, in 6 of the 8 topic areas the frequency of communication impairment increased slightly. From CP-B's perspective, articulation and prosody remained unchanged, with fluctuations being the only topic area that improved between baseline and post-therapy assessment. In addition, fluctuations was the only area where the perceived frequency and severity of the problem improved. All other topic areas remained unchanged or were reported to have increased frequency or severity of problem.

6.2.10 Key features of P-B's communication

Background testing suggested P-B's semantic knowledge was notably impaired. P-B's naming of items in assessment may show some treatment effect of completing the therapy, although their performance in therapy sessions was more variable. Measures of connected speech showed increases in complexity of verbs and sentences between pre-therapy and post-therapy, but were below reported controls. Increases in pronouns were noted, which were above reported controls. From CP-B's perspective, the frequency of impairment generally worsened slightly between assessments, with the perceived extent of the problem also slightly increasing.

6.3 Phase 1 – interim discussion

The following interim discussion considers key findings from Phase 1 of this study in relation to the study questions. Phase 1 consisted of four participants (two people with dementia and their respective communication partners). Therefore, this interim discussion considers the performance of P-A and CP-A, and P-B and CP-B, with the study research questions. Further, more detailed discussion and methodological evaluation is contained in Chapter 9.

6.3.1 Does CIAT-based therapy maintain or improve naming of treated items for people with dementia?

P-A's naming of treated and untreated items declined, although not to a statistically significant extent, from pre-therapy to post-therapy assessment. For P-B, however, from pre to post therapy assessment there was a greater decline in naming of untreated items than treated items. A McNemar test of untreated items showed that this change was statistically significant, in contrast to the decline of treated items, which may provide some tentative evidence of a benefit to receiving the therapy in maintaining naming of treated items. This finding is very tentative due to the high level of naming performance from P-B, but can be compared with the other key study involving CIAT-based therapy and people with dementia, where Hameister and colleagues found large statistically significant improvements in naming performance (Hameister et al., 2017). However, there is no immediate post-therapy measure for P-A and P-B, therefore direct comparisons with Hameister and colleagues' (2017) study are not possible.

Interestingly, untreated items were named more successfully at all assessment points for both participants P-A and P-B. Other similar studies such as Hameister and colleagues (2017) study found that participants named treated items markedly better than untreated items at post-therapy assessments. In the current study, naming untreated items better than treated items may be due to the reason for participants' choice of items to practise – they may have chosen more challenging items which they wanted to recall better.

In Phase 1, both participants' naming increased from baseline to pre-therapy assessment point. This may be attributed to daily variation or perhaps to increased confidence with the researcher or understanding of the format the assessment sessions would take. Daily variation was found in Hameister and colleagues' study, where participants with PPA had variable naming performance between assessments before therapy intervention (Hameister et al., 2017). Similarly, daily variability may be evidenced in the therapy sessions performance for P-B, although for P-A performance was high throughout therapy. There are many possible reasons for apparent day-to-day variation; for example, participants may have felt less motivated due to tiredness, or it may reflect daily variation in their overall AD presentation. This links with comments made by the communication partner of both participants with dementia, who reported noticing variation in communication ability of the person with dementia.

6.3.2 Does CIAT-based therapy maintain or improve naming of nouns or verbs specifically?

For both P-A and P-B there was no statistically significant change in naming of either treated or untreated verbs, or of treated nouns between pre-therapy and post-therapy assessment. However, for untreated nouns the decline in naming was statistically significant for P-B and approaching statistical significance for P-A. Although the evidence of difference in naming of nouns and verbs is not particularly strong, the findings may provide tentative evidence that nouns may be more successfully treated by CIAT-based therapy than verbs.

There is some debate in the existing literature around whether naming of verbs or nouns is more successful for people with dementia. For example, a single case study assessed naming and found 17.5% success at nouns but 80% at naming verbs (Robinson, Rossor, & Cipolotti, 1999). By contrast Druks and colleagues compared naming of nouns and verbs by 19 people with AD and found that nouns were named more successfully than verbs (Druks et al., 2006). Bird and colleagues have argued that the higher naming of nouns than verbs is due to nouns having higher imageability than verbs rather than simply due to a noun/verb distinction (Bird, Howard, & Franklin, 2003). This will be discussed further in the context of this study in Chapter 9.

6.3.3 Is performance in item-naming associated with specific psycholinguistic features for people with dementia?

In Phase 1 of this study, participants' naming performance was generally high. This means attributing naming performance with psycholinguistic features should be undertaken cautiously.

Notwithstanding this caveat, for P-A there was a strong positive correlation between overall naming of items and imageability. This aligns with multiple previous research which shows that items with higher imageability are named more successfully than those with lower imageability (Bastiaanse, Wieling, & Wolthuis, 2016).

For P-B there was a weak statistically significant negative correlation between change in naming performance and age of acquisition. In addition, P-B's overall naming performance and age of acquisition was approaching a statistically significant negative correlation. The existing literature suggests that, as with P-B, people with AD name items with earlier age of acquisition better than those with later acquisition (Cuetos, Rodríguez-Ferreiro, Sage, & Ellis, 2012).

For P-A and P-B there was no correlation between overall or change in naming performance and number of phonemes. This aligns with existing literature; for example, a study of 9 people with AD found that the number of phonemes (not syllable number or complexity) influenced naming performance (Nickels & Howard, 2004).

Overall in Phase 1 of this study, there does not appear to be strong links between naming performance and psycholinguistic variables. It is likely that the generally high naming performance across all items for both participants with dementia limits the scope for variation in naming performance.

6.3.4 Does CIAT-based therapy result in changes to features of connected speech?

Connected speech in the current study was measured using the QPA assessment (Berndt et al., 2000). The speech rate between pre-therapy and post-therapy assessment contrasted for both participants in Phase 1 of this study. For P-A speech rate declined from 106.5 to 81.98 which was markedly below control (160.82), but for P-B there was an increase in number of words per minute between pre-therapy (102.72) and post therapy assessment (142.0) albeit remaining a little below published control figures. As both participants have AD, this finding is not surprising as previous studies show that people with AD generally speak more slowly than typical controls, with Slegers and colleagues finding this happened in 78% of cases (Slegers, Filiou, Montembeault, & Brambati, 2018).

For both participants with dementia, the proportion of pronouns increased between pre-therapy and post-therapy (from 0.21 to 0.33 and 0.52 to 0.62) with reported controls being 0.41. This aligns with previous research, which reports that people with AD generally use more pronouns than typical controls (Slegers et al., 2018).

For P-A the proportion of verbs remained unchanged between pre-therapy and post-therapy assessment, however for P-B it increased between pre-therapy (0.52) and post-therapy (0.72) assessment points, which was above published control (0.48). Previous research has found that participants did not have any greater difficulty producing verbs of increased syntactic complexity (more arguments) but did have more difficulty producing verbs of greater semantic complexity (Kim & Thompson, 2004). This aligns with the findings of the current study, where P-B's greater semantic impairment is mirrored by lower verb complexity; this significance is discussed further in Chapter 9.

For both participants with dementia, there was no statistically significant change in the naming of treated or untreated verbs before or after therapy. Thus, there is no evidence that CIAT-based therapy improves verb production either in naming assessment or in connected speech.

6.3.5 Does CIAT-based therapy result in people with dementia and their communication partners having better, more successful, everyday conversations?

Communication partners' perspectives on their communication with the person with dementia were obtained using the CAPPCI interview, which involved quantitative and qualitative components (Perkins et al., 1997). Interestingly, for participants in the current study, change in the frequency of impairment perceived by communication partners was not always reflected in the perceived severity of the problem. Specifically, for P-A, the perceived severity of the problem for their communication partner improved despite a perceived worsening in frequency of communication difficulty over the same period. This contrasts with P-B, where both severity and frequency of problem increased by a small amount according to their communication partner.

The CAPPCI interview tool as used in this study has not been used with people with AD, although it has been used with people with PD and its associated cognitive impairment (Whitworth, Lesser, & McKeith, 1999). Therefore, specific comparisons are difficult to make with any existing research literature. Other studies have considered the impact of communication partners views of communicating with people with dementia. For example, Small and colleagues measured the impact of communication difficulties on everyday life, but did not consider language skills specifically as in the current study (Small, Geldart, & Gutman, 2000).

In Phase 1 of the current study, both communication partners prioritised ensuring the participant with dementia could talk when they had something to say. In addition, the communication partners reported flexing their communication to maximise and support this. When Small and Gutman (2002) reviewed guidance for supporting communication for those supporting people with dementia, they identified ten strategies, and reported that avoiding interrupting the participant with dementia and allowing them time to talk was a popular strategy among relatives, despite being less frequently found in published guidance for supporting the communication of people with dementia (Small & Gutman, 2002).

Both communication partners in Phase 1 of this study felt that communication with the person with dementia was typically worse in an evening or when tired. Communication partners reported that at these times they gave opportunities to speak but opted not to initiate important conversations.

It is notable how both communication partners in Phase 1 of this study generally approached communication with the person with dementia in a similar manner, despite differences in communication outlined throughout Chapter 6. Both reported having a strategy that could be summarised as attempting to reduce potential upset, both for themselves and also for the participant with dementia, and not dwelling on any communication breakdowns.

6.3.6 Interim evaluation of Phase 1

Evaluation of assessments and approaches, including a number of limitations around assessment of communication, particularly for people with dementia, are discussed as part of a full detailed discussion and evaluation in Chapter 9. In Phase 1, key features of the methodology were in line with best practice for intervention studies as described by Howard and colleagues (2015). Specifically, pre-therapy testing was completed on two occasions even if results were unstable (Howard et al., 2015). Furthermore, participants completed the same specified number of therapy sessions in the current study, regardless of performance (Howard et al., 2015). During data analysis, the results were analysed by item and were tested for statistical significance (Howard et al., 2015). Some of Howard and colleagues’ recommendations were not included in the current study, such as random allocation of picture stimuli, however in the current study participants were able to choose their own stimuli as this is a key feature of CIAT- based therapy (Pulvermüller et al., 2001).

The changes made to the original protocol resulted in the removal of the cross-over element of the study, which has resulted in the loss of the experimental control implicit in this methodology. In a cross-over design, each participant acts as their own experimental control (Sedgwick, 2014). In the current study, a cross-over design would have meant that the effect of completing the therapy block and not completing the therapy block was measured on the same participant. Therefore, in Phase 1, the effect of the therapy block and not receiving the therapy block was not measured on the same participant as was intended in the original protocol. Future studies should ensure experimental control, for example by adopting the cross-over design described in Chapter 4.

In addition, a further change to the medium of assessment from in-person to remote administration by video-call was required due to the coronavirus restrictions. There are limitations to changing the mode of delivery between pre and post therapy assessment, with the results confounded by, for example, displaying the items for naming virtually on a screen. Although the pictures were the same, it is unclear whether viewing the items on screen or on physical cards has any effect on naming. Future studies should adopt one approach, or may seek to compare the two approaches systematically. People with wider cognitive impairment such as those with AD as in Phase 1 may find the assessment more challenging by video-call, especially if they are unfamiliar with this.

Chapter 7 Development of a guide for participant-directed CIAT-based therapy

7.1 Chapter overview

Phase 1 of this study measured the effect of a face-to-face therapy intervention based on the principles of CIAT for people with dementia. The impact of the coronavirus pandemic meant that face-to-face therapy or research was not possible. Therefore, being able to effectively complete the therapy remotely with the support of a written guide and with minimal expert involvement was a necessary adjustment. There is potential to impact on large numbers of people with dementia by developing a simple set of guidelines that family members can use to support the person with dementia to practise words following the CIAT principles at home. It can be argued that the restrictions to daily life due to the coronavirus pandemic have only heightened the importance of completing speech and language therapy, and associated research, via more distant means. This chapter describes the process of using a focus group to devise a guide to support completion of the therapy with direct expert involvement, and details the changes made to ensure an accessible yet robust consent process in light of the change to remote research by video-call.

7.2 Focus groups

A focus group is similar to a group interview, but where participants discuss a topic with each other (Bryman, 2015). Beyond that, there is a lack of clarity or agreement regarding the detail of what may constitute a focus group (McLafferty, 2004). However one key feature that distinguishes focus groups from other similar methodologies such as group interviews is that focus groups encourage discussion between members of the group not just with the facilitator (Kitzinger, 1994). This is advantageous as it allows focus group participants to discuss their views with others and is valuable by allowing participants to query each other with the facilitator encouraging debate between participants (Kitzinger, 1994). A small number of questions are typically discussed (Massey, 2011). To support participants in the focus group these questions are used as a guide, however they should not limit discussion beyond this (Massey, 2011). Focus groups have previously been carried out successfully with people with communication difficulties and with dementia. For example, focus group methodology has been used with people with post-stroke communication difficulties and their relatives (Boger, Demain, & Latter,

2015) and with people with mild cognitive impairment or dementia, along with their relatives and professionals (van der Wardt et al., 2020).

A more recent development, is the use of focus groups completed online, which have been seen as advantageous for people with illness or disability (Synnot, Hill, Summers, & Taylor, 2014). In addition, online focus groups can be useful if people are unable or unwilling to attend a group in person (Dendle, Buys, & Vine, 2021). This is perhaps particularly relevant during the changes to everyday life during the coronavirus pandemic.

7.2.1 Focus groups with people with dementia

There is little pre-existing literature around the methodological considerations of focus groups with people with dementia. Van der Wardt and colleagues' study, referenced above, recruited people with dementia as part of the group, although no detail is provided around how full participation in discussion was supported (2020). Similarly, a separate study included a focus group of people with dementia and carers, including people with dementia who did not verbally communicate but participated by appearing to follow the session (Sutcliffe, Roe, Jasper, Jolley, & Challis, 2015). Sutcliffe and colleagues described these as silent participants, although no detail was given of attempts to support fullest participation in these or the other participants with dementia (2015).

However, Bamford and Bruce (2002), noting the lack of previous literature on focus groups and dementia, describe in practical terms how to organise and deliver focus groups, and evaluate their success, specifically with people with dementia. The authors summarise potential benefits of using a focus group methodology, noting that many of these benefits also apply particularly to participants with dementia. Specifically, focus groups can provide a supportive, controlled communication environment, without the pressure to participate as in a one to one interview (Bamford & Bruce, 2002). One clear limitation of Bamford and Bruce's focus group is that people with difficulties communicating were excluded from the group, as were those who had cognitive difficulties or whose behaviour was deemed likely to disrupt the group (Bamford & Bruce, 2002). The extent to which any support was given to the participants to maximise their scope to be involved was not described. However, a number of features to consider when involving people with dementia in focus group were considered. The authors discussed the importance of ensuring that the environment and context for the focus group were familiar for participants while being separate from their everyday activities, but noted that while a neutral venue is sometimes recommended, there may be advantages for people with dementia in being in an environment that is relevant to the topics discussed (Bamford & Bruce, 2002). Within the group itself, care should be taken to mitigate possible dominance of one or more participants, and participants having parallel conversation, which may be more likely for people with dementia (Bamford & Bruce, 2002). Additionally, Bamford and Bruce argue that when participants with dementia present idealised accounts, such as their independence in daily activities, and storytelling of past events, attempts may be made to interpret the overarching message being conveyed (2002). While a focus group can be successful for people with dementia, the authors argue that achieving a focus on a topic could be a challenge due to cognitive demands (Bamford & Bruce, 2002). However, given that participants with significant communication/cognitive difficulties were excluded, this may not provide further insight on maximising the participation of people with dementia.

There is a paucity of description in the focus group literature regarding adaptations made to support people with dementia. For example, a different focus group which included people with dementia made an adaptation to the size of the group, reducing numbers to three or four participants, though no further adaptations were described (Stephan et al., 2018).

7.3 Aim and objective

This part of the study aimed to develop a guide for people living with dementia and their communication partners to support completion of CIAT-based therapy with minimal expert involvement. The objective was to involve a focus group of people with dementia and/or their communication partners in the development of the guide, by providing feedback on a version of the guide.

7.4 Focus Group: methods overview

A focus group was convened to support development of an effective guide. The researcher was the group facilitator and guided the session (Bryman, 2015). The focus group was semi-structured, with open questions asked by the researcher.

7.5 Participants

When developing new therapy materials or processes, it is important that people with dementia and their communication partners are fully involved. Therefore, participants who had completed Phase 1 of this study (completed assessment and therapy sessions) were asked to complete the focus group. Four people who had completed the therapy face-to-face already (i.e. participants in Phase 1 of the study) were invited, as they were able to comment on whether the guide would allow them to self-complete the therapy they had received. Four people is an acceptable number of people for a focus group (Bryman, 2015), or 3-4 people with dementia (Stephan et al., 2018).

Participants had already expressed an interest in being kept informed of other opportunities to participate within the study overall, including the focus group. Three participants (2 communication partners and one person with dementia) accepted the invitation and were recruited to the study. Participants in the focus group are subsequently referred to as P1 (a communication partner), P2 (a communication partner) and P3 (a participant with dementia).

7.6 Ethical approval

Main ethical approval was received from the University of Sheffield's Ethics Review Procedure, as administered by the School of Health Sciences (Reference: 037086). See Appendix T for the letter confirming ethical approval.

7.7 Recruitment process

Participants who had completed Phase 1 and expressed interest in this focus group were emailed directly by the researcher and asked if they would consider taking part in a small number of focus group sessions as they were able to comment on whether the guide would allow them to self-complete the therapy they had received. It was made clear that this focus group was a separate task from Phase 1 that they did not have to complete. They were emailed two versions of an information leaflet (Appendix U and Appendix V) and a copy of the consent form (Appendix W). One version of the information leaflet was an easier-read version, with the other being a longer version. It was made clear that the consent form was just for information and would be completed together with the researcher. Three participants were recruited to the focus group.

7.7.1 Consent

All three participants, including participants with dementia, had capacity to consent to take part in the focus group, so were able to complete the consent process. Due to the limitations of research conducted remotely in light of the coronavirus restrictions, a process of obtaining and recording consent remotely via video-call was devised. Advice was sought from the relevant university ethics lead to support the development of a consent process that allowed people with dementia the maximum opportunity to demonstrate their capacity to take part in the study, while ensuring there was no scope for inadvertent coercion.

Firstly, after receiving the participant information and having had time to read the leaflets, those interested in taking part had a video call with the researcher to discuss the focus group and ask any questions. The researcher took verbal consent by discussing the focus group consent form verbally with each individual, with the support of their friend/relative where necessary, with the researcher marking on the form if the person gave consent. Verbal completion of the consent form was audio recorded with each person's agreement. Therefore, consent consisted of the audio recording plus the consent form completed by the researcher. These were saved securely together but kept separate from the actual focus group research data. A copy of the completed consent form could be sent to the participants via their chosen email address for their record if they chose. Although not required by the recruited participants, the option was available to complete the initial consent process across more than one sitting on different days/times if individuals were not able to complete at one attempt, for example due to tiredness.

In line with best practice, and detailed in section 4.6 of this study, a process consent approach was in place which aimed to support maximum involvement in research in particular by people with dementia (Dewing, 2007). Therefore, the researcher continually monitored the behaviours and actions of the participants to ensure that they still consented to be involved in the research (Dewing, 2007). Thus, at each video call contact with the researcher, participants including those with dementia verbally articulated both their wellbeing and their agreement to participate to the researcher.

Ethical approval was given on the condition that if a participant lost capacity during the period of the focus group then they were withdrawn from the focus group. Throughout the focus group, the views of the individual were central in deciding whether they would continue to participate.

7.8 Design

The design of this focus group phase was in three stages. Firstly, the researcher drafted a guide for completing the therapy. Secondly, a single session semi-structured focus group was convened to provide feedback on the guide and the practicability of completing the therapy with minimal expert involvement. Thirdly, the researcher completed a thematic analysis of the content of the focus group session following which the researcher then amended the guide based on the appropriate themes identified in the focus group. The final guide was quality checked by another member of the research team.

7.9 Materials: development of the initial draft of the guide

Participants were sent a copy of the draft of the therapy guide in electronic form via email. The therapy guide aimed to support participants with dementia and their communication partners to complete the therapy with minimum involvement from a Speech and Language Therapist.

Available literature on accessible written information for people with aphasia has sought to identify key features which support successful written communication. For example, a set of semi-structured interviews completed with people with stroke-related aphasia found important features of both content and design (T. A. Rose, Worrall, Hickson, & Hoffmann, 2011). Particularly important content features reported by Rose and colleagues included using short words, short sentences and limited text to read and small amounts of information overall (2011). Participants reported that language should be clear, without jargon and with good explanations and contain content which is appropriate to the reader (T. A. Rose et al., 2011). Particularly important features of content reported by participants included having large font, spaced out with bullet point lists (2011). Emphasis should be placed on highlighting key points/words by using bold font, with clear headings that link to the information below. The paper itself should be large. Participants reported that black text should be used, but otherwise some colour was considered particularly important as was some appropriate graphics with captions (T. A. Rose et al., 2011).

One limitation of Rose and colleagues' study is the lack of specific detail of the key features identified, which makes translating the findings into a guide for the current study more challenging. This limitation was considered by a focus group-based study which aimed to determine more specific features of maximum accessibility for people with aphasia (Herbert, Gregory, & Haw, 2019; Herbert, Haw, & Gregory, 2012). Herbert and colleagues (2012) devised a set of practical guidelines for how to communicate with people with aphasia following stroke, based on consultations with people with aphasia. Although this was with people with aphasia following stroke, they constitute a set of principles of accessible communication, which can be applied with people with dementia. Although the guide being devised for the current study is for both people with dementia and their communication partners, these principles are still appropriate to maximise accessibility.

A number of key points from Herbert and colleagues (2012) are used to inform the current guide draft. Firstly, the guide has been produced in as short and logical an order as possible. Only information pertinent to completing the CIAT-based therapy task has been included, and everyday language is used, avoiding unnecessary technical terms. If included, technical terms are explained succinctly. The font used is calibri, and key words are included in bold, with heading being bigger font size. Finally, a small number of appropriate and relevant pictures are included to support the text.

7.10 Procedure

Participants were emailed a copy of the therapy guide and a summary of focus group discussion topics at least 1 week prior to the focus group. At the focus group, participants considered the therapy guide and process via the questions, which were grouped into three topics, as stated here:

- What are your thoughts on using a guide to complete therapy yourselves at home?
- Could you complete the therapy using just the guide, and one training session? What are your thoughts on the guide itself? What about the language and the layout?
- How could the guide be improved?

The focus group session took place lasting approximately 1 hour in length and started with approximately 10 minutes for participants to be introduced and greet each other, which was not audio recorded. The questions were displayed using the screen share facility for participants to read. This followed a semi-structured format with open questions asked by the researcher. It was intended that each of the three questions would be given equal time of approximately 15 minutes, however these timings were not strictly enforced by the researcher with some flexibility given to allow participants’ dialogue to flow.

The participant with dementia, who was known to the researcher from Phase 1 of this study, was supported to participate as fully as possible in the discussion. This was done by the researcher (or the participant with dementia’s communication partner) specifically prompting and inviting the participant with dementia if they had any comments/thoughts. For example, this could be achieved by re-reframing a specific question for the participant with dementia, such as in response to a general comment made by another participant. At this point, processing time was also given to support them to contribute as much as possible. It was also important to be open to any comment made by the participant with dementia and to build upon this by asking more questions where possible.

The focus group was carried out remotely in light of the coronavirus restrictions, using Whereby video-call software. With participants’ permission, the focus group was audio recorded, with notes made by the researcher as back up.

Following the focus group, the audio recording was subject to an abridged transcription, based on the description by Onwuegbuzie and colleagues (2009), which involved efficient transcribing of key themes. Text in square brackets was added by the researcher to ensure anonymity or to ensure comments are clear in the context presented in the results. An ellipsis in square brackets was used to represent where part of the transcribed speech has been removed and not included in the results.

There is no set agreed way to analyse data obtained in focus groups (Massey, 2011). Although a number of approaches to analysis of focus group data have been outlined, in practice researchers typically use a combination of these (Doody, Slevin, & Taggart, 2013). For example, classical content analysis may be used in which the data are reduced to similar themes which are then assigned a code, which can then be used both qualitatively, and quantitatively by counting the number of time that each code is used (Onwuegbuzie et al., 2009). Developing previous theories, a micro-interlocutor analysis was proposed by Onwuegbuzie and colleagues (2009), which sought to account for the perspectives of all participants, regardless of the extent to which they contributed to the discussion, for example by noting their non-verbal responses (Onwuegbuzie et al., 2009). In the current study, a qualitative rather than quantitative approach was selected due to the small number of participants and subsequent themes, along with the general agreement between participants. Similarly, a micro-interlocutor analysis was not of additional benefit in the current study, as the small number of participants meant that the researcher was able to ensure all participants were involved, as much as they were able, by inviting them to contribute to the session, and any consensus could be informally identified.

The content of the focus group meeting was thus collated thematically and used to further develop the guidelines. The thematic analysis was completed based on general steps outlined by Doody and colleagues (2013) as follows:

1. Generating rich data
2. Familiarising oneself with the data
3. Writing memos
4. Indexing
5. Formation of themes
6. Mapping and interpretation

Informal notes were made by the researcher of any statements within the abridged transcript which appeared to align with emerging themes. This is described as ‘writing memos’ by Doody and colleagues (2013). Indexing of quotes, described by Doody and colleagues (2013) as sorting and making comparisons between quotes, was completed informally. The researcher then devised themes based on the quotes – themes were broadly aligned with the focus group questions asked, although additional themes emerged during participant-led discussion which reflected participants’ perspectives of what they considered important even if it was not a pre-determined focus group question. Finally, the researcher mapped quotes to one of the established themes and interpreted the findings by giving a descriptive analysis of quotes made both within each theme and overarchingly across the focus group.

7.11 Results

The following key themes were identified, with theme 1 having 2 sub-themes:

1. Changes to the therapy process
    a. Changes to the therapy process for Phase 2 of the study
    b. Changes to the therapy process for future use of the therapy
2. Benefits of completing therapy face to face.
3. Reflections on completing the therapy game in general
4. Improvements to the guide itself

7.11.1 Changes to the therapy process

Changes to the therapy process were frequently discussed by participants in the focus group. Analysis of the focus group data suggests these were either changes that could be applied within the constraints of Phase 2 of the research study (participant-directed therapy via video call), or those requiring greater flexibility that could be applied should the therapy process be extended to a future clinical setting.

7.11.1.1 Changes to the therapy process for Phase 2 of the study

Provisionally, the guide to therapy outlined that one training session would be offered to participants with dementia and their communication partners. At the focus group, participants were in agreement that they did not feel one session would be enough.

P1: *"I'm not sure with just one session that you would have learnt enough to remember how you did it".*

P2: *"I think you would definitely need more than one training session. I suggest perhaps 3 spaced out".*

When it came to the number and duration of the home practice sessions, originally proposed to be daily for 1.5 hours, opinion was a little more divided. On one hand, P2 felt that the duration of time was too long if completed all at once:

P2: *"I think one and a half hours in one session is quite a long time so I would split that into 3 half hours or two forty-five minutes".*

However, another participant noted that if each of the 6 games was to be played each day, then that would result in a significant amount of time:

P1: *“[It took] perhaps just over an hour to play all of [the games]”.*

Participants commented on whether the guide accurately reflected what they considered to be the overarching philosophy of CIAT-based therapy. There was agreement around the importance of emphasising that completing the therapy game is about giving a longer, more descriptive answer and, where possible, engaging in an extended chat based on the picture card.

P2: *“I felt you could have turned it more into a discussion about the pictures [I would have] prompted a bit of conversation by asking questions [about the card]”.*

Furthermore, P1 reported that they actively encouraged others in the therapy game to give full answers and to expand where possible to generate conversation.

P1*: “I always gave [person with dementia] the pep talk – don’t just give me a one-word answer! […] That’s the whole point – more words!”.*

Thus, participants felt that the overall aim needed to be clearly articulated – that the therapy game was not solely about improving naming specific words, but was also for generating conversation, and that the communication partner had a key role in facilitating this.

7.11.1.2 Changes to the therapy process for future use of the therapy

A frequently visited theme throughout the focus group was the changes that participants felt would be beneficial when delivering the therapy in future, outside of the necessary methodological constraints of Phase 2 of the research study. Choosing personal items (limited to 20 for this study) to practice (rather than selecting predetermined items from a list) generated a mixed response, from it being an acceptable number, to being hard to choose that many friends/family or similar. P2 queried why the therapy was only designed to run for 2 weeks, rather than for as long as is needed. However, P1 felt that carrying on for an extended period might require more flexibility to enable motivation to be sustained:

P1: *“If there’s a value to carrying on [after 2 weeks] I think perhaps just play one hand a day; we might have done that but after 2 weeks of all of them all the time I knew the cards off by heart – it was getting really hard. After a month I just wanted to rip my own arm off! But because we’d not played for months [today] we really enjoyed it”.*

Concern was raised that people who live on their own were not able to practice as much as they would like. It was suggested swapping cards if words become well known or irrelevant or new words become important or '*to make it a bit more interesting*'. Similarly, it was suggested that allowing participants to focus on cards that were more difficult to name may be more useful than playing them all. Thus, P2 suggested:

P2: *"[Putting the cards] he had most difficulty with in one pack, so that he could play that more frequently".*

Therefore, there was a tentative consensus in that participants felt that continuing for an extended period would be beneficial, but only if this was combined with greater flexibility on which cards to use during the sessions. Being able to choose cards that were more difficult, or to swap cards for new ones were considered important motivators to playing the game over an extended period.

7.11.2 Reflections on completing the therapy game in general

Participants agreed that completing the therapy had broader benefits in increasing communication with family and friends when playing the game together. As P2 explained, this was notable when completing the therapy with children and grandchildren:

P2: *"It helped communication between the generations".*

Participants also felt that completing the therapy game was an inclusive way in which people with dementia could engage with friends/family on a more equal basis than usual.

P1: *"Before we went into lockdown we did use it with anybody that came to the house – do you want to play this game with us … and that was nice because it was a game [the person with dementia] were good at compared to a lot of other games we may play with grandchildren".*

P2: *"[The participant with dementia] got pleasure out of, like they've just said, of something that he can achieve, that's achievable for him and he felt that he was doing well at".*

One participant felt that the memory of the person with dementia benefitted from playing the game.

P2: *"It sparks his memory [..] playing the game has definitely improved his memory".*

Overall, the participants reported their experience of playing the game positively. For example, P3 noted that:

P3: *"I didn't expect to enjoy it as much as I did".*

7.11.3 Benefits of completing therapy face to face.

The benefits of completing the therapy sessions face to face were noted. Firstly, it was perceived that participants would be able to facilitate the therapy game in greater detail following face to face sessions rather than reading the guide.

P1:" *I certainly felt I learned quite a lot from you about the prompting because I certainly didn't realise there were different ways of doing that. […] So I felt I learned quite a lot from being with you, possibly a lot more than I would learn from just this [guide]".*

In addition to this, one participant in particular felt that the face-to-face therapy sessions provided something more than simply giving more instruction on playing the game, but that the wider therapeutic aspect of attending in person had value too.

P1: *"It's easier to appreciate the full value of coming in to the university and seeing you having had nearly a year of lockdown how much added value you get […] and actually having that stimulus of the building and meeting you and looking forward to seeing you every week has a value on top of the game".*

The issue of motivation was also raised, with concern that if therapy was completed solely using the guide it may be difficult to maintain motivation.

P1: *"I am not sure how motivated you would be [without the face-to-face sessions]. We certainly didn't want to let you down and that's a massive motivator".*

Indeed, for P3 the enjoyment appeared to be in meeting and completing the therapy with the researcher.

P3: *"All the pleasure would have gone out of it!"*

7.11.4 Improvements to the guide itself

Focus group participants made a number of specific comments about the guide itself, both around clarity of the detail and whether it accurately reflects the philosophy behind the therapy game. Participants felt that the guide was to support the communication partner rather than the person with dementia.

P2: *"The guide is not aimed at the person with dementia but the person that is with them".*

Similarly, P1 considered that some people with dementia may not be able to play the game using the guide by themselves.

P1: *"I don't think [the participant with dementia] would have been able to play it from the guide".*

Specific points were raised by participants concerning typographical errors and the benefit of having the pages numbered. The guide included a template to support participants to produce their own therapy game cards. Both participants reported that the template for producing the cards was too big.

P2: *"The template you have drawn is about twice the size of the cards that we've had. […] It would be difficult to shuffle a pack of cards that size".*

Further discussion elicited that participants had printed the guide in A4 size, rather than an A5 booklet which accounted for the difference in size.

Participants spent some time discussing the section of the guide describing prompting/cueing. Opinion varied regarding how effective the guide was at describing how to prompt or cue each other if they found the therapy game too easy or too difficult. One participant felt that the guide could not replace the face-to-face therapy sessions they had received.

P1: *"I thought the guide was good in the way it described about the prompting […] Although it does say about it begins with 'h' […] there's no explanation about the different ways of prompting and how people react to it. All that knowledge you gave us, without writing a book, it's quite difficult to share!"*

There was some uncertainty around the sections on making the game easier or more difficult.

P2: *"Saying [..] 'do you have the boy eating the chocolate cake' seemed easier than 'eating'. I thought they were the wrong way round!"*

P1: *"For us they are the right way round".*

The researcher and participants discussed ways to improve the section on making the game easier or more difficult. The idea was put forward that a ladder could be used to represent how to increase and decrease the level of difficulty in the game, which was met with agreement:

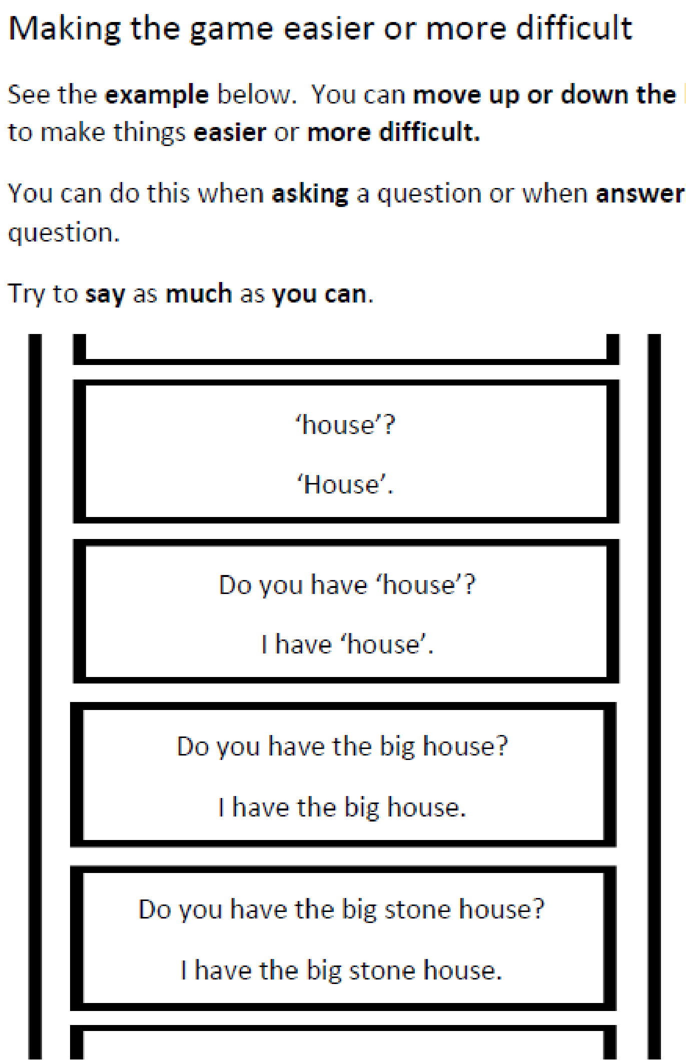
P1: *"That would work well if it was a ladder because [the other participant] was saying that [they] would start the other way round to the way I would start […], so the fact that the ladder goes up and down means that you can tailor it […] to whatever the person needs".*

7.12 Conclusion: changes made to the guide and study methodology

Following the focus group and the subsequent analysis of the content, changes were made to both the guide and the process.

Regarding the therapy process, the number of potential training sessions for participants in Phase 2 of this study was raised from one to a maximum of three. As highlighted by the focus group, in Phase 2 of the study, the researcher highlighted an additional overarching aim of playing the game, namely generating conversation with the person with dementia.

In addition to minor changes such as adding page numbers and correcting typographical errors, the principal change made to the guide was to better explain how to change cueing. This involved developing a ladder graphic to better describe how cueing can be increased or decreased as appropriate, as shown here.



Making the game easier or more difficult

See the **example** below. You can **move up or down the ladder** to make things **easier** or **more difficult.**

You can do this when **asking** a question or when **answering** a question.

Try to **say** as **much** as **you can**.

'house'?

'House'.

Do you have 'house'?

I have 'house'.

Do you have the big house?

I have the big house.

Do you have the big stone house?

I have the big stone house.

For the full copy of the final version of the guide, see Appendix X.

7.13 Focus Group – discussion and evaluation

The overarching finding of the focus group was that completing the therapy guide with some amendments would support completing the therapy task at home. However, further support was requested in the form of additional training sessions. One particularly notable finding of the focus group was that participants found completing the therapy task to be a positive experience in general, despite the amount of therapy completed both with the researcher and independently at home. Also, despite the focus group questions being centred on the guide and the process of completing the therapy task with the guide, it was interesting that participants (P1 and P3) felt that completing the therapy task in person with the researcher had additional benefit to simply completing the therapy at home. It is unclear whether this would translate into improved naming of items, or whether participants (and by extension others receiving speech and language therapy) may value a different outcome measure related to wider perceived benefits to attending in person.

However, the foremost benefit of running the focus group online was allowing the research to continue, despite the restrictions on face-to-face research due to coronavirus. As noted previously, there is very limited research of the effectiveness of online focus groups. For people with dementia, research on the use of video call software has been investigated more extensively. In recent research on the use of video call for telehealth, key advantages reported by families of people with dementia using telehealth were not having to travel and lack of disruption to daily routine and associated stress (Gately et al., 2022; Moo, Gately, Jafri, & Shirk, 2020). There is also some tentative suggestion in the literature that having a visual component as in video-calls (rather than phone calls) may be more effective for people with dementia by gaining attention and reducing agitation (Van der Ploeg, Eppingstall, & O'Connor, 2016).

The group was made up of two communication partners and one person with dementia. Although this was lower than is typically the case in focus groups, smaller groups of three participants can be useful to successfully facilitate involvement with people with dementia (Stephan et al., 2018). Despite this, as the results of the current study show, the communication partners participated to a notably greater extent than the participant with dementia. One reason for this may be the use of video-call software rather than face-to-face participation. However, it may be that other factors impacted on the participant with dementia's participation. For example, the impact of hearing loss, or the quality of the sound on the participant's device may have contributed to less accessibility. However, it should be noted the participant with dementia joined the video call on a device shared with their communication partner. This dynamic may have resulted in the communication partner describing the experience of both themselves and the participant with dementia when completing the therapy. This can perhaps be seen in the results, where comments from communication partners referred to how playing the game went (e.g. "*We certainly didn't want to let you down[…]")* or referred to how they noticed their associated participant with dementia reacted to the therapy (e.g. "*It sparks his memory")*. The nature of a focus group in allowing discussion without pressure to participate directly appeared to elicit comments by the participant with dementia who was able to comment on fellow participants' comments, including those by their communication partner (e.g. *"All the pleasure would have gone out of it!"*).

Nonetheless, the sharing of one screen by a pair of participants is a possible limitation of completing the focus group remotely using video call. It seems that due to the nature of turn-taking on video-calls, each screen rather than each individual participant counts as a turn, thus diluting the turn of individuals sharing a screen. Furthermore, communication using video-call is subject to well-documented difficulties with turn-taking, due to latency in transmission. Such latency can be perceived as a silence, which speakers try to fill, resulting in overlaps (Seuren, Wherton, Greenhalgh, & Shaw, 2021). As Seuren and colleagues (2021) note, managing this latency can be effortful to resume normal turn-taking. It may be that this additional complexity results in participants such as those with dementia finding this an extra barrier to navigate. The impact of this when some participants are sharing the same screen, so are not subject to latency, is unclear. These changes to the processes of conversation may have contributed to the participant with dementia making fewer comments in the current study, and may be areas for future study.

A further limitation of the current study was that the same researcher completed both the therapy sessions and the focus group with participants. This gives the potential risk of bias in that participants, having built up rapport with the researcher, may feel less able to give honest feedback. While accepting this limitation, in the current study which aimed to recruit participants with dementia, the familiarity of the researcher and rapport built between researcher and participants may have encouraged participation.

The data analysis completed was analysed solely by the same researcher who completed the group. Consequently, it may be argued that there is a risk of unintentional bias in that the researcher inadvertently selects themes which may reflect their own thoughts. However, due to the limited scope of this focus group, and the practical nature of the questions, this is perhaps less likely. That said, comments on the experience of completing the therapy may have been more susceptible to selection bias, in particular those which directly and positively referenced the researcher (e.g. "*We certainly didn't want to let you down […]"*) which were included in the analysis. Likewise, the process of completing an abridged transcription, although rooted in the focus group analysis literature (Onwuegbuzie et al., 2009) may be susceptible to researcher bias regardless of whether a separate researcher completed this.

As Massey (2011) notes, there is no set agreed way to analyse focus group data. However, one possible solution to mitigate potential for bias in future research may be to complete the focus group on two occasions, one with the researcher who completed the therapy and one with a separate researcher unknown to the participants. This would allow for the advantages of familiarity during discussions, along with giving participants a second opportunity to talk freely, without the impact of pre-existing rapport, with an independent researcher. Equally, an independent researcher might have been asked to independently analyse the data using the same methodology. For the current study it seems likely that there was general consensus on a practically focused topic, which succeeded in providing meaningful feedback on developing participant-led therapy in Phase 2 of this study.

Chapter 8 Phase 2: participant-directed CIAT-based therapy

8.1 Chapter Overview

This chapter describes Phase 2 of the study, which investigated the effectiveness of completing the CIAT-based therapy with the support of a written guide, but with minimal expert involvement via video-call. In addition to adhering to restrictions relating to the coronavirus pandemic, this aimed to represent a more time/cost effective way of widening accessibility and increasing the number of people with dementia able to benefit from participating in the therapy. Furthermore, such an approach may provide an option for people who find it difficult to attend clinic sessions in person. Encouragingly, previous research suggests some evidence that there is no difference between CIAT therapy delivered by a professional and that delivered by a lay person such as a relative who has been trained by a professional (Meinzer, Streiftau, & Rockstroh, 2007).

8.2 Aims and research questions

The aims and research questions of Phase 2 of this study were the same as for the revised Phase 1. However, Phase 2 aimed to evaluate CIAT-based therapy delivered with minimal clinician-support for people living with dementia. The main aim of this study was to evaluate a novel adaptation of CIAT in improving communication for people with dementia and their communication partners.

It is hypothesised that CIAT-based therapy results in people with dementia maintaining or improving their naming of their chosen nouns and verbs, and that these changes generalise to everyday communication.
The specific research questions for this study were:

- Does CIAT-based therapy maintain or improve naming of treated items for people with dementia?
- Does CIAT-based therapy maintain or improve naming of nouns or verbs specifically?
- Is performance in item-naming associated with specific psycholinguistic features for people with dementia?
- Does CIAT-based therapy result in changes to features of connected speech?
- Does CIAT-based therapy result in people with dementia and their communication partners having better, more successful, everyday conversations?

8.3 Objectives

The objectives of Phase 2 were the same as for Phase 1. However, Phase 2 investigated the effectiveness of completing therapy by self-practice with online/remote support. The objectives of this study were:

- To compare people with dementia's naming of chosen words before and after a CIAT-based therapy intervention, including word class.
- To examine whether performance in item-naming was associated with specific psycholinguistic features.
- To examine whether people with dementia had changes to their connected speech following CIAT-based therapy.
- To analyse communication partners' perspectives of the effect of the CIAT-based therapy intervention on the success of their communication with the person with dementia.

8.4 Method

This section describes the method for Phase 2 of the study. It covers an overview of the study design and recruitment of participants, before describing in detail what each of the assessments and therapy task involved.

8.4.1 Participants

1 pair of participants was recruited (therefore 2 people in total). As in Phase 1, the pair of participants consisted of a person with dementia along with their communication partner.

8.4.1.1Inclusion/exclusion criteria

Inclusion criteria were that all participants must:

- be age 18 years or over
- be in the UK
- have sufficient hearing, vision, attention (and speech/language for communication partners) to enable them to complete the therapy
- have no significant neurological history
- have no significant mental health difficulties (except for dementia diagnosis for the person with dementia)
- have British English as their everyday language
- be able to give informed consent to take part in the study

- have a computer with camera/microphone able to utilise video call software.

In addition, participants with dementia were required to:

- have a diagnosis of dementia by an appropriate professional as reported by the person with dementia
- have mild-moderate word-finding difficulties as reported by the person with dementia or their communication partner, and as demonstrated at initial assessment.
- have no developmental speech or language difficulty

8.4.2 Ethical approval

Ethical approval was received through the University of Sheffield's Ethics Review Procedure, as administered by the School of Health Sciences (Reference: 037202). See Appendix Y for the letter confirming ethical approval. In addition, minor ethical amendments to the study were received where appropriate.

8.4.3 Recruitment process

The researcher contacted leaders of non-NHS dementia groups or related organisations nationally to request that they advertise the study as they choose, such as by sending details of the study to their members. The researcher could also make use of other mailing lists, such as charity mailing lists.

Potential participants could also be recruited informally, through hearing about the study through word of mouth, for example directly from the researchers or from other participants.

A recruitment flyer (see Appendix EE) and standard email texts for use by group leaders or for direct recruitment were used where appropriate (see Appendix CC and Appendix DD). It was anticipated that group leaders may wish to use the direct recruitment email text in their communication with their members/mailing list (along with the flyer), but there was flexibility to agree if/how best to advertise the study for their mailing list/organisation.

Following distribution of the flyer and email, potential participants could then contact the researcher directly by email (or the group leader to pass on their details) should they wish to discuss taking part. Participants were given full written information in the form of a copy of the Participant Information Sheet for participants with dementia (Appendix Z) and the Participant Information Sheet for communication partners (Appendix AA) detailing their involvement in the study. A copy of the consent form was also sent to participants (Appendix BB).

If initially interested in taking part, potential participants gave the researcher their contact information, such as postal address, phone and email, which were stored securely on the

University's research data area, shared only with the research team.

Potential participants were then contacted by video-call by the researcher to discuss the study in more detail and determine whether they were interested in participating. Eligibility relating to the inclusion/exclusion criteria was informally discussed. Ample opportunity was given to ask questions during this discussion. This video-call may be with the person with dementia, their communication partner or both as is individually appropriate. Potential participants could either agree to participate at this point by informing the researcher, or they could take further time to consider whether to participate. If interested in taking part in the study, potential participants then undertook the initial consent process described in section 4.6.

If, at any point during the recruitment process, it was learned that possible participants did not meet the inclusion/exclusion criteria, they or their communication partner would be informed by the researcher, with full explanation given. They would be offered individual support around this, in particular explanations and signposting to organisations including Human Communication Science's Memory and Life Story Clinic or other local services as appropriate.

8.4.4 Consent

Informed consent was taken for both participants with dementia and their communication partner. All participants, including people with dementia, were required to have capacity to consent to take part in the research study.

Consent was obtained via video-call. This aimed to provide maximum opportunity for people with dementia to demonstrate capacity to consent despite the barriers of research conducted remotely, while not being at potential risk of undue pressure from friends/relatives.

Initially, participants received an information leaflet and copy of the consent form via email. Following receipt of this and having had time to read the information, participants with dementia and/or their communication partner took part in a phone or video call with the researcher to discuss the study in more detail. As is good practice, this allowed people with dementia to be made aware of the study plan allowing them a sense of control in their participation (Hubbard, Downs, & Tester, 2003). Participants were able to take part in discussing the study and their involvement and were able to ask any questions to the researcher. They were informed that they could withdraw consent at any time.

Participants could choose to verbally consent to the study at that point, or they could take further time to consider their involvement. For people who demonstrated capacity in the video call and who consented to taking part in the study at this point, the researcher took verbal consent by going through the consent form verbally with participants, with the researcher marking on the form if the participant gave consent. The video-call of completing the consent form was audio recorded with participants' agreement. Therefore, consent consisted of the audio recording plus the consent form completed by the researcher. These were saved securely together on the university research data area (shared with the research team), but kept separate from the actual research data. A copy of the completed consent form could be sent to the participants via their chosen email address for their record if requested. Participants were able to complete this initial consent over more than one session if required.

As described in detail in section 4.6, Phase 2 followed a process consent approach outlined by Dewing (2007) to support maximum involvement in research by people with dementia. In addition to completing the consent form giving 'initial consent' to participate in the study the researcher was required to continually monitor consent to ensure that the behaviours and actions of the people with dementia suggested that they still consented to be involved in the research (Dewing, 2007, p. 19). At each video call contact with the researcher, participants including those with dementia were able to verbally articulate their agreement or wellbeing to the researcher. If a participant lost capacity at any point in the study, then they would be withdrawn from the study.

8.4.4.1Participants recruited

Two participants were recruited to Phase 2 of the study. They consisted of one person with dementia and their communication partner.

8.5 Design

The participant-directed therapy part of Phase 2 of the study sought to assess participants before and after a period of CIAT-based therapy. Therefore, the overall design was as shown in Figure 10 over the page with each part following directly on from the previous:

Figure 10 - Phase 2 study design

Pre-therapy assessments with the researcher

↓

One to three training session(s) with the researcher

↓

Participant-directed therapy at home with minimal researcher involvement

↓

Post-therapy assessments with the researcher

8.5.1 Schedule of assessments

For Phase 2, the number of assessments was reduced from Phase 1. This ensured that participants were involved in the study less frequently, over a shorter duration, which aimed to minimise fatigue when completing assessments by video-call.

Pre-therapy assessments consisted of:

- Background case history
- ACE III for remote administration
- Picture item naming (119 standard items plus optional 20 personal items)
- Connected speech (monologue)
- Interview with the communication partner

Post-therapy assessments consisted of:

- Picture item naming (119 standard items plus optional 20 personal items)
- Connected speech (monologue)
- Interview with the communication partner

8.5.2 Procedure for assessments

All elements of assessment and the training sessions were completed remotely by the researcher using Google Meet video-call software. To support participants' wellbeing, assessment sessions completed via video-call lasted no longer than approximately 1 hour, but this was led by the participants' individual needs. Participants were given the opportunity to stop at any point. Unless described otherwise, all data analyses were completed as described for Phase 1 to allow some comparability of results between Phase 1 and Phase 2.

8.5.2.1Screening and background case history

Screening was completed based on the inclusion/exclusion criteria for both participants with dementia and their communication partner. See Appendix FF for the eligibility screening and background/case history form for participants with dementia and Appendix GG for the eligibility screening form for communication partners.

8.5.2.2Choice of items for therapy

To support evaluation of the therapy game, participants were asked to choose 60 items to practise learning. The same standard list of 119 items was used as in Phase 1. As part of their 60 items to practise, participants could choose up to 20 personal items, such as pictures of family, or important places or objects instead. Photographs of any personal items were sent electronically to the researcher. The decision of which items to choose was made in conjunction with the researcher.

8.5.2.3ACE-III for remote administration

ACE-III for remote administration is specifically designed to be completed via video-call, using screenshare facility where required. It is freely available via https://www.sydney.edu.au/brain-mind/resources-for-clinicians/dementia-test.html

For this study version A was used. The researcher completed all sections of version A with the participant with dementia in accordance with the instructions provided with the test material.

8.5.2.4Picture naming

Participants attempted to name 119 items from the OANB and their optional 20 person-specific items.

8.5.2.4.1 Materials

Photographs of the 119 standard items and up to 20 personal items were added to Microsoft PowerPoint slideshow presentation software in a random order. Pictures were displayed on the screen for the participant to name using the Google Meet screenshare facility.

8.5.2.4.2 Procedure

The researcher began by explaining the assessment, and that participants would be shown pictures to name using the screen share facility. Participants with dementia were shown a picture by the researcher. These were presented individually, with one picture per slide with the researcher stating: ‘what is this?’ for nouns or ‘what are he/she/they doing?’ for verbs. The researcher clicked to move to the next screen to display the next item until all items had been presented to the participant with dementia for naming.

Audio recording took place using a Sony Pioneer PCM A10 device, with the audio recording transferred to secure university computer storage space. The audio recording was then removed from the device. Participant responses were recorded on a recording form.

8.5.2.5 Connected speech (monologue)

Participants with dementia were asked by the researcher to tell the story of Cinderella, however where this was not possible, participants were encouraged to tell a story they knew. The sample aimed to be at least 150 narrative words long, and could be comprised of separate shorter stories if necessary. Samples totalled 150 narrative words (+/-10 words) as recommended for QPA (Berndt et al., 2000).

Audio recording took place using a Sony Pioneer PCM A10 device, which was transferred to secure university computer storage space. The audio recording was then removed from the device. As described fully in Phase 1 of this study, analysis was completed according to the QPA instructions as described by Berndt and colleagues (Berndt et al., 2000).

8.5.2.6Interview with communication partner

With the agreement of the participant with dementia, the communication partner was interviewed by the researcher. This was done using the interview questions in part A of the CAPPCI (Perkins et al., 1997). The researcher followed the instructions for Part A of the CAPPCI, by asking the questions and recording the participant’s responses. The interview is designed to be completed face-to-face, with participants pointing or referring to a set of responses on a card to support their answering of the questions. However, for completing via video call, questions and, where necessary, response options were read out to the communication partner by the researcher. Therefore, the interview was completed more informally as described in the post-therapy assessment for Phase 1. The materials used were the interview questions in part A of the CAPPCI.

Audio recording took place using a Sony Pioneer PCM A10 device, which was transferred to secure university computer storage space. The audio recording was then removed from the device.

8.5.3 Training session(s)

Participants received one training session from the researcher via the Google Meet video-call software on how to complete the therapy game. The content and number of these training sessions was dependent on participants' requirements but involved support with practising completing the therapy task. Specifically, training involved explaining an overview of the aims and philosophy of CIAT-based therapy. The specific way of completing the therapy task was also explained based on the content of the guide. Participants could choose to practise the therapy task with the researcher watching if required. Participants were also offered the opportunity to ask any questions about completing the therapy task. This was in addition to the participants having a copy of the guide to completing the therapy.

8.5.4 Participant-directed therapy

Using their 60 pairs of cards, participants were asked to practise completing the therapy by playing the therapy game at home.

8.5.4.1Materials

To enable participant-directed therapy, participants' total of 60 chosen items were made into photograph cards by the researcher. Each of the photographs of the 60 items was printed in colour on white card; each card was approximately a quarter of A4 size. Two complete sets of the 60 cards were printed for each set of participants – therefore 120 cards in total. Cards were sent to University of Sheffield Print Services for printing before being completed and assembled by the researcher and posted to participants. A copy of the therapy guide developed in the focus group phase of this study (Appendix X) was also posted in A5 booklet size to participants.

8.5.4.2Procedure

The researcher discussed a target schedule for the amount of time to spend completing the participant-directed therapy. Participants were asked to complete the therapy game for up to 1.5 hours daily if possible, for 14 days depending on their individual circumstances, including levels of fatigue. If this was not possible, a part-time version was considered such as aiming for 3-4 times per week for 4 weeks, highly dependent on participants' personal factors and individual circumstances. Participants did not receive any scheduled involvement in therapy from the researcher other than the initial training session, but were able to contact the researcher via email if they had any queries. Participants completed the CIAT-based therapy game as described in Phase 1 of the study with the support of the guide to completing the therapy. Although participants were made aware that they could contact the researcher during the home practice period if required, the aim was to complete the therapy with minimum researcher involvement.

8.6 Results: Participant C

Participant C (henceforth P-C) and their communication partner completed Phase 2 of the study. Due to personal circumstances, P-C completed participant-directed therapy at home over a period of 4 weeks. P-C's communication partner reported that this was completed 2 times per week for approximately 40 minutes each time.

8.6.1 Reported case history and background assessment

The case history was completed by the researcher by video-call. It was reported by P-C and their communication partner (CP-C).

P-C was a left-handed male aged 54 years at the time of their involvement in the study. A retired telephone engineer with British English as their everyday language, P-C had a reported diagnosis of posterior cortical atrophy made two years previously. He did not wear glasses for his vision and did not have any hearing difficulties. He had been retired from work for approximately 4 years. Although P-C did not live with his relative who was his communication partner in this study, they were able to commit to some support of the therapy task approximately twice weekly during visits.

P-C's first sign of dementia was difficulties with his vision around 5 years previously. Word-finding difficulties were first noted around 2 years ago. P-C reported no difficulties with comprehension of spoken language. P-C no longer often did much writing or reading, and noted some difficulties with these. P-C typically had a full conversation, even if just for 10 minutes, every day with carers or relatives. He enjoyed watching football, listening to music, and walking.

ACE-III for remote administration

P-C's domain and total scores were as follows:

Table 43 - ACE-III for remote administration results (P-C)

Domain	Score	Percentage (to 1dp)
Attention	5/18	27.8%
Memory	5/26	19.2%
Fluency	1/14	7.1%
Language	4/26	15.4%
Visuospatial	0/16	0%
ACE III total	**15/100**	**15%**

Given that the cut off for dementia is widely agreed to be a score of less than 82 (Hsieh et al., 2013), and that a score of less than 61 has been proposed for moderate dementia (Giebel & Challis, 2017), P-C's score of 15 implies significant cognitive impairment. Relative strengths were noted in attention skills (27.8%).

8.6.2 Picture item naming

Table 44 compares naming performance at pre-therapy and post-therapy assessment points for both treated and untreated items. It shows the naming performance (number (n) and percentage (%) named correctly without cue/prompt by self/others).

Table 44 - naming of treated/untreated items (P-C)

P-C		Pre-therapy	Post-therapy
Treated items (Total = 57)	n	17	13
	%	29.82	22.81
Untreated items (Total = 79)	n	15	17
	%	18.99	21.52

As can be seen in Table 44 above, treated items were named more successfully than untreated items at pre-therapy assessment and marginally more successfully than untreated items at post-therapy assessment. However, performance on treated items declined and untreated items increased between pre-therapy and post-therapy assessment.

8.6.2.1Treated items

For P-C, 57 treated items were included in the analysis. Three personal items were removed as they proved too vague a concept to determine from the physical object in the photograph.

Table 45 - Treated items (P-C): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	37	3
Named	7	10

A McNemar Test was completed of treated items named correctly without prompt by self or other at pre-therapy and post-therapy assessment points. An exact McNemar Test of P-C's 57 treated items showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .344 (2-tailed).

8.6.2.2Untreated items

For P-C, 79 untreated items were included in the analysis. A McNemar Test was completed of untreated items named correctly without prompt by self or other at pre-therapy and post-therapy assessment points.

Table 46 - Untreated items (P-C): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	58	6
Named	4	11

An exact McNemar Test of P-C's 79 untreated items showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .754 (2-tailed).

8.6.3 Picture item naming – nouns/verbs

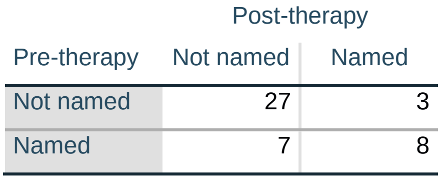
Table 47 shows the naming performance (number (n) and percentage (%) named correctly without cue/prompt by self/others).

Table 47 - naming of nouns/verbs (P-C)

P-C		Pre-therapy	Post-therapy
Noun-untreated	n	12	11
(Total = 47)	%	25.53	23.40
Noun-treated	n	15	11
(Total = 45)	%	33.33	24.44
Verb-untreated	n	3	6
(Total = 32)	%	9.38	18.75
Verb-treated	n	2	2
(Total = 12)	%	16.67	16.67

8.6.3.1Nouns treated

Table 48 - Nouns treated (P-C): Pre-therapy & Post-therapy

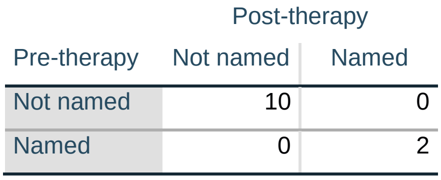


	Post-therapy	
Pre-therapy	Not named	Named
Not named	27	3
Named	7	8

An exact McNemar Test of P-C’s 45 treated nouns showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .344 (2-tailed).

8.6.3.2Verbs treated

Table 49 - Verbs treated (P-C): Pre-therapy & Post-therapy



	Post-therapy	
Pre-therapy	Not named	Named
Not named	10	0
Named	0	2

An exact McNemar Test of P-C’s 12 treated verbs showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = 1.000 (2-tailed).

8.6.3.3Nouns untreated

Table 50 Nouns untreated (P-C): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	32	3
Named	4	8

An exact McNemar Test of P-C’s 47 untreated nouns showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = 1.000 (2-tailed).

8.6.3.4Verbs untreated

Table 51 - Verbs untreated (P-C): Pre-therapy & Post-therapy

	Post-therapy	
Pre-therapy	Not named	Named
Not named	26	3
Named	0	3

An exact McNemar Test of P-C’s 32 untreated verbs showed that there was no statistically significant difference in naming performance between pre-therapy and post-therapy assessment, p = .250 (2-tailed).

8.6.4 Picture item naming – naming performance correlation with linguistic variables

In order to determine correlation between overall naming performance and linguistic variables Pearson’s correlations were completed for all items (both treated and untreated) combined. Overall naming was determined by assigning a score of 1 at each of the two assessment points when an item was named correctly. Thus, each item was assigned a score between 0 (never named correctly) and 2 (named correctly at both assessment points). There was a strong negative correlation which was statistically significant between overall naming performance and age of acquisition, and a weak negative correlation which was statistically significant between overall naming performance and both syllable length and phoneme length. There was a strong positive correlation which was statistically significant between overall naming and imageability.

Table 52 - All items overall naming (P-C): Correlations

		Overall naming	Length phonemes	Length syllables	F-K frequency	Familiarity mean	Age-of-acquisition mean	Imageability mean
Overall naming	Pearson Correlation	1	-.202*	-.197*	.176	.117	-.296**	.310**
	Sig. (2-tailed)		.027	.031	.055	.207	.001	<.001
	N	119	119	119	119	119	119	119

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

A further Pearson's correlation was completed to determine any correlation between change in naming performance on linguistic variables.

Change in naming was defined by assigning a score of 1 to any item where naming improved between pre-therapy and post-therapy assessment points, a score of 0 to any item where naming was unchanged between pre-therapy and post-therapy assessment points, and a score of -1 to any item where naming declined between pre-therapy and post-therapy assessment points. There was a weak positive correlation which was statistically significant between change in naming performance and age of acquisition.

Table 53 - All items naming change (P-C): Correlations

		Naming change	Length phonemes	Length syllables	F-K frequency	Familiarity mean	Age-of-acquisition mean	Imageability mean
Naming change	Pearson Correlation	1	.131	.127	-.028	-.070	.198*	-.157
	Sig. (2-tailed)		.157	.170	.765	.450	.031	.089
	N	119	119	119	119	119	119	119

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

8.6.5 Summary of picture item naming assessment

Overall, P-C named treated items more successfully than untreated at both pre-therapy and post-therapy assessment points, although naming of treated items declined and untreated improved between the two assessment points. This suggests there was no treatment effect on the naming of items. Furthermore, for both treated and untreated items, the change in naming before and after therapy was not statistically significant.

For P-C, there was a weak negative correlation which was statistically significant between overall naming performance and both syllable length and phoneme length, suggesting items of lower syllables and phonemes were named more successfully. There was a strong positive correlation which was statistically significant between overall naming and imageability, suggesting P-C was more successful in naming more imageable items. There was a strong negative correlation which was statistically significant between overall naming performance and age of acquisition, however, there was a weak statistically significant positive correlation between change in naming performance and age of acquisition. As such, links between age of acquisition and naming performance are unclear for P-C.

For P-C, there was no notable change in treated verbs and untreated nouns between pre-therapy and post-therapy assessment, while treated nouns showed a small decline and untreated verbs, although a very low number, showed an improvement. There was no statistically significant change in untreated or treated verbs or nouns. Due to the small number of items named correctly overall, no further analyses were completed.

8.6.6 Connected speech (monologue)

Quantitative Production Analysis (Berndt et al., 2000) was completed of a sample of connected speech at each of the assessment points. The results from key analysis measures are reported here; the description of each measure is outlined earlier in the methodology in Table 6. Values in tables are presented to 2 decimal places. Control values from healthy controls included for comparison are as reported by Berndt and colleagues (2000).

8.6.6.1Number of words per minute

Table 54 - number of words per minute in connected speech (P-C)

	Pre-therapy	Post-therapy	Control
Number of words per minute	102.79	102.52	160.82

8.6.6.2Proportion of word categories

Table 55 - proportion of word categories in connected speech (P-C)

	Pre-therapy	Post-therapy	Control
Proportion of closed class words	0.56	0.6	0.54
Proportion of pronouns	0.45	0.49	0.41
Proportion of verbs	0.5	0.49	0.48

8.6.6.3Verb complexity

Table 56 - verb complexity in connected speech (P-C)

	Pre-therapy	Post-therapy	Control
Verb inflection index	1	0.67	0.92
Auxiliary complexity index	1.42	1.19	1.26

8.6.6.4Sentence complexity

Table 57 - Sentence complexity in connected speech (P-C)

	Pre-therapy	Post-therapy	Control
Sentence elaboration index	1.45	2.44	3.06

8.6.7 Summary of connected speech analysis

For P-C, speech rate was largely unchanged between pre-therapy and post-therapy assessment point, although notably lower than reported controls. The proportion of closed class words, pronouns, and verbs were all largely unchanged and comparable with controls. Verb complexity and auxiliary complexity both declined from just above to just below reported controls. However, sentence complexity (elaboration) increased notably between pre-therapy and post-therapy assessment, but remained below reported controls.

8.6.8 Interview with communication partner

The analysis and reporting of the interview with the communication partner is comprised of two parts. Firstly, changes in the communication partner's rating from pre-therapy assessment to post-therapy assessment shown in Figure 11 and Figure 12 . Secondly, key comments from the post-therapy interview which provided extra insight about communicative success are outlined, with quotes from the communication partner where notable. These comments are not designed to be exhaustive, but to qualitatively reflect key themes and salient insights given by the communication partner in addition to that captured in the quantitative analysis of the rating scores.

8.6.8.1Comparing rating scores at pre-therapy assessment and post-therapy assessment

A higher score means greater frequency of impairment or greater severity of problem. The specific question topics contained within each of the eight categories reported below is described earlier in the methodology in Table 7. Overall, for P-C, the communication partner felt there had been a decline in the frequency of impairment in some areas, however the severity of the problem between pre-therapy and post-therapy assessment was typically very low and largely unchanged.

Figure 11 - communication partner interview (P-C; part 1)

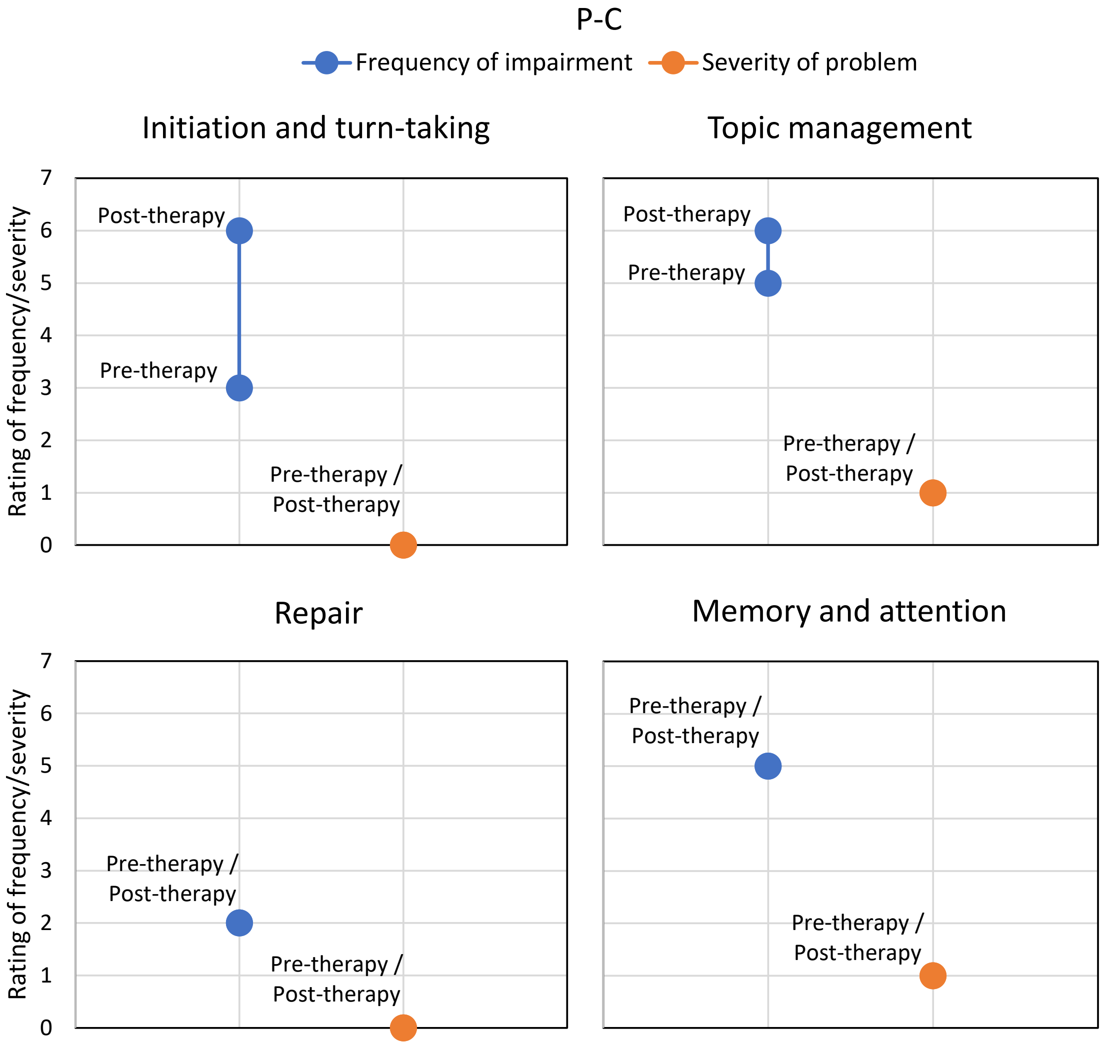
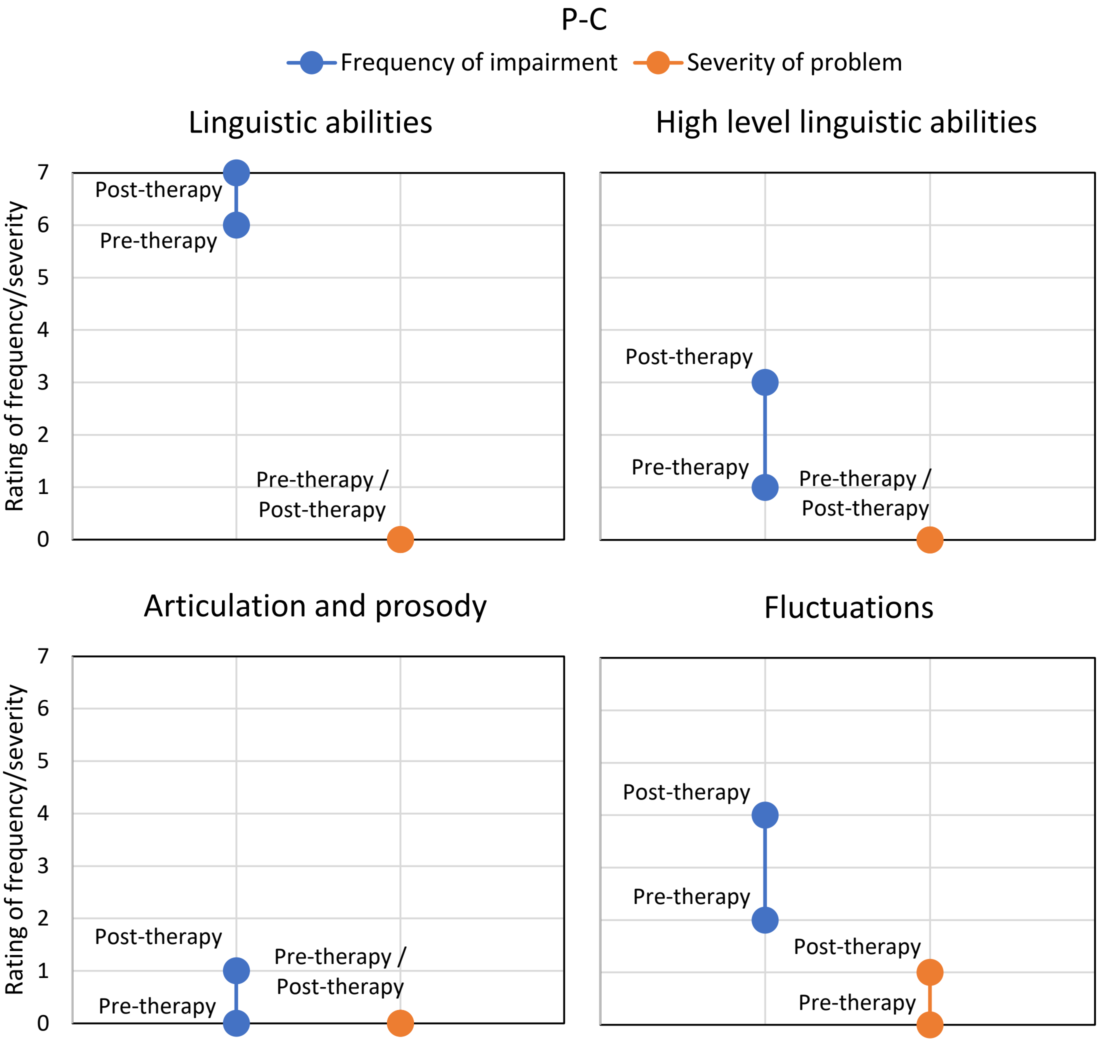


Figure 12 - communication partner interview (P-C; part 2)



8.6.8.2Comments made during the post-therapy assessment

The communication partner (CP-C) described a pragmatic approach to communicating with P-C, in which the perceived importance of the conversation topic is taken into account often. CP-C feels that it “*depends how much I want his answer”.*

CP-C: *“If it’s small talk then I’ll just leave it, but if I want information from him then I’ll repeat myself”.*

Likewise, if conversation breaks down for other reasons such as interruptions, or P-C using the wrong word, CP-C reports determining how important the conversation is before deciding how to respond.

CP-C: *“[I] let him talk […] unless it’s something important [then] I talk over him. I don’t think he recognises either way".*

P-C might occasionally leave a long pause before answering. In this situation, CP-C reported that they simply wait for a response, and that P-C may then seek help from CP-C with what he is trying to say:

CP-C: *"He'll try and elicit off me what he's trying to say".*

If P-C uses a wrong word, CP-C reported only correcting it if it was judged to be important. If CP-C did not understand P-C, CP-C might *"just nod and pretend"* that they have understood because P-C will be satisfied with this.

Similarly, if P-C uses him/her or here/there without it being clear, CP-C reports that:

CP-C: *"[It] depends how invested I am. If I want to know I will ask him to be specific. A lot of the time I'll just let him talk […]".*

Dealing with P-C's frequent favourite topics can be a bit of a problem for CP-C:

CP-C: "[I] often close it down because I've just heard it too many times".

CP-C reports trying to support P-C to remember people or events by describing them to him with variable success. Although this was not a problem for CP-C, it was a problem for P-C:

CP-C: *"For him, he hates when he doesn't remember people or things".*

According to CP-C, the success of the conversation in conveying information appears to be more important than facilitating P-C to complete his turn himself. This functional approach is evidenced when P-C leaves a long pause in a sentence, as CP-C reports they *"finish his sentence for him", or* if P-C makes mistakes in speech that he does not correct then CP-C reports correcting the mistake. Likewise, if P-C struggles with word-finding, CP-C reports giving him the word as *"I know what he's trying to say"*. If P-C describes a target word, CP-C reports offering a word based on the description. This strategy appeared to work well for both P-C and CP-C:

CP-C: *"He's normally quite happy when I finally give him the word [following a description]".*

CP-C: *"He'll repeat or sometimes say thank you [if mistakes are corrected]".*

CP-C: *"He'll be happy about it [if CP-C repeats a word P-C has been struggling with]".*

The communication partner appeared to follow P-C's lead when communicating. For example, if P-C only gives a minimal response in a conversation, CP-C reports that he will not pursue it, and that P-C then moves on to another topic. Similarly, if P-C introduces a new topic, CP-C reports that they just follow P-C's topic. However, when trying to talk about the same thing for a while, CP-C reported that P-C found this difficult:

CP-C: *"[P-C] struggles to stay on have a conversation about the same thing for, say, more than three, four minutes probably".*

Although CP-C viewed almost all difficulties when communicating with P-C as unproblematic, CP-C did acknowledge that responding to multiple repeated questions/remarks could be a challenge:

CP-C: *"Sometimes I get annoyed, other times I will just answer the question. It depends what mood I'm in".*

CP-C notes that when this happens *"he'll get upset that I'm annoyed",* however, if CP-C provides an answer P-C will accept the answer.

CP-C felt that P-C's communication frequently fluctuated throughout the day and particularly from week to week, which could be occasionally frustrating. When this happens, CP-C reported having to adapt to P-C's communication ability on the day.

CP-C: *"There's nothing really I can do to make his speech better – it depends completely on him".*

There were a number of questions within the interview which CP-C felt were difficult to answer as they assumed a high level of conversational complexity. For example, CP-C initially felt unsure whether P-C would be able to understand non-literal meanings used in conversation as these were not really used:

CP-C: *The conversation is so limited these days that […] I can't think of an instance where he would have to read between the lines.*

Equally, CP-C noted that P-C's humour did not typically involve jokes, therefore although P-C did laugh, this was not specifically relevant.

8.6.8.3Summary of interview with the communication partner

For P-C, the frequency of impairment slightly increased between pre-therapy and post-therapy assessment in all topic areas except for repair and memory and attention which were unchanged. The extent of the problem was rated very minimal and unchanged for all topic areas, except for a slight worsening on fluctuations.

8.6.9 Key features of P-C’s communication

P-C’s naming performance showed no statistically significant change between pre-therapy and post-therapy assessment for treated or untreated items. Connected speech measures were largely unchanged, with the exception of sentence complexity (elaboration) which increased from pre-therapy to post-therapy assessment although remained below reported controls. CP-C felt that the frequency of impairment worsened slightly for P-C between pre-therapy and post-therapy assessment, but that any communication impairment was generally perceived as a minor problem at most.

8.7 Interim discussion of Phase 2

Phase 2 consisted of two participants (one person with dementia and one communication partner). Therefore this interim discussion considers the performance of P-C and CP-C with the study research questions. A full discussion of Phase 1 and Phase 2 of this study is detailed in Chapter 9.

8.7.1 Does CIAT-based therapy maintain or improve naming of treated items for people with dementia?

P-C has a diagnosis of PCA, a less frequently occurring form of AD, which although associated with visual impairment, can also result in word-finding difficulties at an early stage (Crutch et al., 2013). In the current study, P-C’s naming of treated items declined whereas untreated items increased between pre and post therapy. This contrasts with CIAT therapy used for PPA, where treated items showed significant improvement, unlike untreated items (Hameister et al., 2017). A possible reason for this is that P-C may have chosen items to practise which they found more difficult to name in the first place, however P-C's naming of treated items was better than untreated at pre-therapy and post-therapy assessment points, rending this explanation unlikely.

It is important to note that P-C’s naming for both treated and untreated items was low (around 20% for untreated items pre and post therapy and for treated items post-therapy, up to 29% for treated items pre-therapy), and that there was only minimal difference between pre-therapy and post-therapy assessment for 57 treated items (difference of 4) and 79 untreated items (difference of 2). It is therefore likely that there is some floor effect present, and it is unlikely that such minimal difference can be attributed to meaningful change in naming.

Given the visual component of PCA, it is unclear to what extent P-C’s naming was confounded by visual impairment in recognising objects. As discussed fully in Chapter 9, confrontation naming of picture cards has limitations for people with PCA.

8.7.2 Does CIAT-based therapy maintain or improve naming of nouns or verbs specifically?

For P-C with PCA, both treated and untreated nouns were named more successfully than treated or untreated verbs at both pre and post therapy assessment points. As noted above, only a small number were named correctly limiting the conclusions that can be drawn. This aligns with existing general aphasia literature, where verbs are typically considered less likely to be named successfully than nouns (Mätzig, Druks, Masterson, & Vigliocco, 2009). As noted in Phase 1 discussion and considered more fully in the overall discussion in Chapter 9, this may be due to the specific features of verbs being less imageable than nouns or having greater morphological, semantic and syntactic complexity. In keeping with the general paucity of research in PCA, there is no existing research on whether nouns or verbs are named better for people with PCA.

8.7.3 Is performance in item-naming associated with specific psycholinguistic features for people with dementia?

For P-C, there was a strong positive correlation between overall naming of items and imageability and change in naming performance and imageability was approaching statistically significant positive correlation. This is not surprising, as there is much previous research showing that words of lower imageability are more difficult to process than those of higher imageability, adversely impacting on naming (Bastiaanse et al., 2016).

For people with AD, rather than specifically PCA, items with earlier age of acquisition are more successfully named than those acquired later (Cuetos et al., 2012). This is partly reflected for P-C who had a statistically significant negative correlation between overall naming performance of items and the mean age of acquisition of each item. However, for change of naming performance, there was weak positive correlation with age of acquisition, suggesting items acquired later were named more successfully at post-therapy assessment. As noted previously, this ambiguity may be due to P-C's impaired naming performance both pre and post therapy, with only minimal change in naming.

P-C's overall naming performance was approaching a statistically significant positive correlation with item frequency, a finding which tentatively links to the findings of other studies of picture naming in people with AD (Ahmed & Garrard, 2012). However a study of 54 people with aphasia due to causes other than dementia, typically stroke, found that word frequency was only of minor importance in determining naming ability (Bastiaanse et al., 2016).

P-C showed a weak negative correlation between number of syllables and overall naming, which while acknowledging P-C's low naming performance aligns with limited pre-existing research that number of syllables is not associated with picture naming success (Nickels & Howard, 2004). In addition, P-C's weak negative correlation between overall naming and number of phonemes is in line with the findings reported in Nickels and Howard's (2004) study.

8.7.4 Does CIAT-based therapy result in changes to features of connected speech?

Connected speech in this study was measured using the QPA assessment (Berndt et al., 2000). For P-C, speech rate was unchanged from pre-therapy to post-therapy at 102.79 and 102.52, all of which were notably below control (160.82). Having lower speech rate than controls may be expected; for example, a study comparing speech rate of people with AD and healthy controls found people with AD spoke more slowly in 78% of cases (Slegers et al., 2018).

The proportion of pronouns in P-C's connected speech were largely unchanged (0.45 to 0.49), and slightly higher than reported controls at 0.41. Slegers and colleagues' (2018) systematic review found that people with AD used more pronouns than healthy controls in 88% of cases, which may be attributed to word-finding difficulties of the intended pronoun. However, for P-C it may be a feature of their personal story, in that the reference was clear due to the small number of characters.

P-C was unable to tell the Cinderella story assessment, and consequently told a personal story, which was different at pre-therapy and post-therapy assessment. P-C's sentence complexity increased profoundly from pre-therapy to post-therapy, in contrast to the other features of connected speech. It is possible that P-C's personal story at post-therapy compared with pre-therapy assessment point was told in an inherently more complex way and, speculatively, may have been told a number of times before leading to use of potentially more learned phrases inflating sentential complexity. Therefore, such a profound change should be interpreted with caution for P-C.

8.7.5 Does CIAT-based therapy result in people with dementia and their communication partners having better, more successful, everyday conversations?

The communication partner's perspective of communicating with the person with dementia in the current study was measured using the CAPPCI interview (Perkins et al., 1997). A particularly striking feature of CP-C's interview responses regarding communicating with P-C, was a marked difference between the frequency of a communication impairment, and the corresponding severity of the problem, with the latter being very low (0 or 1 in all eight response categories). This suggests that for CP-C, any work done to mitigate frequent communication impairment is considered acceptable, and does not affect their overall experience of communicating with P-C.

Based on the interview, it appears CP-C appears to value communicative success as specifically relating to transfer of information between themselves and P-C. It appears that if P-C has word-finding difficulties, CP-C offers what they consider to be P-C's intended target, which is accepted when correct by P-C, rather than engaging in word-finding strategies. In this regard it appears that communication between C-P and CP-C is successful. This simplicity contrasts with that often observed of conversations with people with dementia, where test questions or similarly atypical features are used which may cause confusion to the person with dementia (Kindell, Keady, Sage, & Wilkinson, 2017).

8.7.6 Interim evaluation of Phase 2

This section evaluates the key points from Phase 2 of this study. A full evaluation including study limitations is included in Chapter 9.

Howard and colleagues (2015) summarised key methodological features in the design of intervention studies. When considering these features, one limitation of Phase 2 of the current study is that baseline testing only took place once, whereas twice may be considered best practice (Howard et al., 2015). Therefore, it is uncertain whether P-C's initial baseline assessment represented their typical performance as the baseline assessment results may be higher or lower than is typical due to any particular personal factors on the day of the assessment. As in Phase 1, following best practice, during data analysis, the results were analysed by item and were tested for statistical significance before any claims of effectiveness of the intervention (Howard et al., 2015).

P-C and CP-C completed the therapy practice at home without direct intervention from the researcher, which meant that although an indication of practice completed was provided, the number and quality of therapy sessions, including fidelity to the guide, could not be guaranteed. Best practice for robust intervention studies suggests that a set number of therapy sessions should be completed (Howard et al., 2015). These limitations could be mitigated in future studies involving participant-directed therapy by setting clear reporting processes for participants to record specific details of the therapy sessions completed, rather than solely the number of sessions which may not all be equal in length or quality.

As in Phase 1, a notable limitation in the current study was that the adoption of a pre-therapy post-therapy assessment design has resulted in a lack of experimental control, meaning that any changes in naming performance can less reliably be attributed to the therapy intervention. Future studies could address this by adopting a cross-over design with immediate and delayed therapy groups, which was described in the design of the original protocol in Chapter 4. In a cross-over design, each participant acts as their own experimental control (Sedgwick, 2014). The risk of confounds is reduced as, in addition to immediate and delayed treatment groups being matched, the effect of the therapy block and not receiving the therapy block are measured on the same participant.

As previous studies of CIAT-based therapy involved participants with language-focussed dementias such a PPA, the current study has provided an opportunity to consider feasibility and acceptability for people with other forms of dementia, such as PCA with its typical visuospatial deficits, in Phase 2. Feasibility/acceptability is discussed as part of the focus group, and described in Chapter 7, and is evaluated in detail as part of the overall study evaluation in Chapter 9. Furthermore, with assessment completed remotely by video-call followed by self-directed therapy, Phase 2 allows for reflection of the feasibility/acceptability of completing assessment/therapy distantly by video-call and without direct involvement from the researcher.

The focus group participants in this study reported that they valued the nature of the in-person therapy sessions. However, in similar situations reported in other studies, communication partners of people with dementia reported benefits to therapy beyond improved word-finding (Beales, Bates, Cartwright, & Whitworth, 2019). These included the opportunity to communicate with the person with dementia, and acquiring knowledge and understanding of how to communicate with the person with dementia (Beales et al., 2019).

The research questions and outcome measures for Phase 2 of the current study are focussed specifically on measuring communication changes related to CIAT-based therapy, and do not consider the wider impact of completing therapy, such as the benefits of in-person or researcher-led therapy compared with distant therapy. This should be addressed in future studies, which may also consider whether participants' perceptions of the benefits of in-person researcher-led therapy translate into objectively improved naming performance.

Chapter 9 Overall discussion (Phase 1 and 2)

9.1 Chapter overview

This study aimed to investigate the impact of a CIAT-inspired therapy programme on word-finding for people with dementia. It was derived from Hameister and colleagues' (2017) study which is the only other study involving this approach and which reported improvements in naming attributed to the therapy. This study sought to answer the research questions which are discussed in this chapter.

9.2 Does CIAT-based therapy maintain or improve naming of treated items for people with dementia?

For both P-A and P-B, naming performance showed a slight increase for both treated and untreated items between the baseline and pre-therapy assessment points despite no therapy being delivered. This is perhaps within normal daily variation, and is found in a similar study of participants with PPA where the change in naming performance between the equivalent of baseline assessment to pre-therapy assessment was variable (Hameister et al., 2017).

P-A and P-B both improved in naming of treated and untreated items between baseline and pre-therapy assessment. This may be attributed to increased understanding and familiarity with the assessment process. For P-A, naming performance declined for both treated and untreated items between pre-therapy and post-therapy assessment points, although the decline was not statistically significant. However, for P-B, there was a steeper decline in naming performance for untreated items than for treated items between pre-therapy and post-therapy assessment.

In the current study P-C had PCA, which although associated with AD pathology, can be considered a distinct syndrome of AD due to the difference in typical features (Crutch et al., 2012). Thus, in the current study P-C can be considered as distinct from P-A and P-B who had typical AD. Another important distinction is that post-therapy assessment for P-A and P-B was delayed due to coronavirus restrictions, whereas for P-C post-therapy assessment took place immediately following therapy. P-C's naming of treated items declined whereas untreated items increased between pre and post therapy.

Interestingly, both P-A and P-B named untreated items more successfully than treated items at all 3 assessment points. This is in contrast to other similar studies such as Hameister and colleagues (2017) study where, although baseline/pre-therapy assessment was variable, in post-therapy assessments both participants named treated items better than untreated items. Naming untreated items better than treated items may be due to methodological reasons. Firstly, participants may have chosen items to practise which they found more difficult to name on an individual basis. However, comparing linguistic variables for both treated and untreated items found that for P-B and P-C, treated items were statistically significantly higher in familiarity and imageability, and lower in age of acquisition (see Appendix JJ and Appendix KK). For P-A treated items had statistically significantly higher imageability than untreated items (see Appendix II). This analysis suggests that for age of acquisition, participants chose items that should be named more effectively (Cuetos et al., 2012). Imageability may be strongly associated with naming success (Druks et al., 2006), although there is not a consensus (Cuetos et al., 2012), and familiarity may have limited independent effect (Nickels & Howard, 1995). Therefore, it appears the impact of linguistic variables alone cannot explain why untreated items were named more successfully than treated items. The impact of linguistic variables on naming success is discussed separately later in the discussion. Perhaps more significantly, also within the treated group were 20 personal items (such as important people/places) which were not subject to this analysis due to the lack of linguistic variable data. Participants may have chosen these items because they wanted to name them more consistently, which implies that they may not have been able to name them as successfully all the time. Additionally, pictures chosen by participants may not have reflected their intended target item as accurately as the standard items, which were subject to a naming agreement exercise to remove any ambiguities. Indeed, to mitigate the impact of this, one of P-A's personal items and three of P-C's personal items were removed prior to analysis as they were ambiguous or referred to concepts such as feelings which were not directly represented by the photograph.

For P-B, although change in naming before and after therapy was not statistically significant for treated items, for untreated items a McNemar test showed change was statistically significant, which may provide some tentative evidence of a benefit to receiving the therapy. However, comparably large statistically significant improvements were reported in naming performance by Hameister and colleagues (2017) for the two participants with PPA in their study; by contrast, in this study it may be that the rate of decline was slowed for P-B as a consequence of therapy. However, it is important to note that the post-therapy assessment in the current study was completed approximately 6 months following the final face-to-face therapy session with the researcher, whereas in Hameister and colleagues' (2017) study, several post-therapy assessments were completed, with the final one at 2 months following therapy when maintenance of treatment effects was reported. As a consequence, there is no comparable post-therapy measure for participants in Phase 1 of this study (P-A and P-B) with Hameister and colleagues' (2017) study.

Additional methodological differences between the current study and Hameister and colleagues' (2017) study may also account for the difference in findings. Unlike the current study, Hameister and colleagues' participants used a computer program to support home practice; however, home practice was done with support from the communication partner in the current study. Consequently, although the communication partners in Phase 1 had taken part in multiple therapy sessions and the communication partner in Phase 2 had undertaken a training session with the researcher, it may be that the quality of home practice was more consistent in Hameister and colleagues' (2017) study. However, it is likely that communication partners had a good grasp of completing the therapy from the therapy sessions with the researcher; furthermore it appears that trained relatives may be as effective as an expert at supporting CIAT-based therapy (Meinzer et al., 2007). Perhaps more crucially, in Phase 1 of the current study participants undertook face-to-face therapy with the researcher twice per week for approximately 5-6 weeks, rather than 9 days over 2 weeks as in Hameister and colleagues (2017). As a consequence, the amount of practice was much greater per day than the current study, as in addition to the daily face-to-face therapy sessions, participants also completed the computer based learning at home. It is perhaps significant that the participants in Hameister and colleagues (2017) study had PPA and therefore had cognitive difficulties largely limited to language. In the current study, participants P-A and P-B had AD and therefore such intensive daily practice both in clinic and at home may not be realistic due to wider cognitive decline of AD. Indeed, during the communication partner interview, communication partners of both P-A and P-B noted a decline in communicative effectiveness later in the day, and being aware of managing fatigue especially on busier days.

In the therapy sessions in Phase 1, performance for P-B appeared variable, though P-A's performance was more consistent and may be subject to a ceiling effect. Some of the session-by session variability may be due to personal factors such as fatigue on the day, or factors related to chance in the therapy game such as which cards the participant with dementia was required, or chose, to name. Both participants appeared to name treated items more successfully in therapy sessions than in the formal assessments, which is likely influenced by the necessary difference in data analyses between assessment and therapy due to the inherent difference in the nature of formal assessment and therapy sessions. In addition, differences may be due to the less formal environment in therapy sessions, and participants being encouraged to discuss items which may have a self-cueing effect, rather than being asked to simply name them as in assessment.

To support naming for effective CIAT-based therapy, participants in Phase 1 of the current study were assessed for which cue was most effective at supporting naming. For both P-A and P-B, a phonemic/syllabic cue was the most effective cue based on the cueing assessment completed. However, the results are tentative due to the small number of cues required by both participants – cues were generally not needed, and when they were needed, they often resulted in correct naming regardless of the type of cue. Participants also instinctively self-cued on occasion, which likely confounded results, a feature discussed in section 9.5 which evaluates confrontation naming with people with dementia. Therefore, during the therapy sessions, both types of cue were used with participants, depending on whether they appeared beneficial for each individual item or in each game, with the aim of supporting successful naming.

Notwithstanding the likely self-cueing confounds, the cautious findings align with those from larger studies comparing semantic or phonological cueing. For example, Meteyard and Bose (2018) asked 10 participants with aphasia to name 175 items 4 times. They found that phonological cues significantly improved naming compared with other cue types, including semantic cues which did not affect naming (Meteyard & Bose, 2018). However, Meteyard and Bose recruited people with aphasia following stroke, rather than people with aphasia related to dementia as was the focus of this study, therefore it is not clear what impact wider cognitive features of dementia may have on cueing. Considering types of dementia and cueing, one study of people with semantic dementia found that phonemic cueing did not improve naming performance, although following a period of practice relearning the items, phonemic cues were more effective at supporting naming than they were initially (Mayberry, Sage, Ehsan, & Lambon Ralph, 2011). Their study was limited to 2 participants with only one language-specific dementia (compared with P-A and P-B who had AD and P-C who had PCA in the current study), however it does support the view that cueing may become more effective following therapy practice. Both participants in Phase 1 of the current study each had forms of AD, however searches of the literature did not find evidence of research on the effectiveness of semantic or phonological cues for people with AD, nor for PCA specifically. However, naming of items on verbal fluency tasks has shown that people with AD have greater impairment when asked to name items related to a semantic topic than items that begin with a particular phoneme, thus providing evidence for greater semantic than phonological impairment (Ahmed & Garrard, 2012). Therefore, it may be assumed that as semantic knowledge is more likely to be impaired, then a phonemic cue would be more effective, as is the case with both P-A and P-B in the current study.

9.3 Does CIAT-based therapy maintain or improve naming of nouns or verbs specifically?

In a key previous study, naming performance varied depending on whether an item is a noun or verb. Hameister and colleagues (2017) reported that nouns were named more successfully than verbs at the pre-therapy assessment points and at post-therapy assessment for the untreated items for both participants in that study. For treated items post-therapy, Hameister and colleagues found that the percentage of items named correctly was very high for both nouns and verbs (all >=90%). For both P-A and P-B in the current study there was no statistically significant change in naming treated or untreated verbs or treated nouns between pre-therapy and post-therapy assessment. However, for untreated nouns the decline in naming between pre-therapy and post-therapy assessment was approaching statistical significance for P-A and achieved statistical significance for P-B. This provides some tentative evidence that nouns may be more successfully treated using the CIAT-based therapy than verbs, but that there is no clear difference between naming success for nouns and verbs for P-A or P-B. However, for P-C with PCA, both treated and untreated nouns were named more successfully than treated or untreated verbs at both assessment points, although only a small number were named correctly limiting the conclusions that can be drawn.

For people with aphasia due from any cause including stroke, verbs are typically considered less likely to be named successfully than nouns (Mätzig et al., 2009). As summarised by Matzig and colleagues (2009), this may be due to a range of factors, verbs being less imageable than nouns, verbs having greater morphological complexity, greater semantic complexity and a greater number of possible syntactic arguments. However a previous study of noun and verb naming compared nfPPA, fvPPA and FTD related to motor neurone disease (MND) and found that people with fvPPA named verbs more successfully than nouns (Hillis, Oh, & Ken, 2004). By contrast, people with nfPPA and FTD related to MND performed better naming nouns than naming verbs. The authors noted that the different types of dementia affect different areas of the brain and hypothesised that success in naming nouns or verbs was due to the location of the particular dementia (Hillis et al., 2004).

For people with AD, there have been conflicting reports that verbs may be named more successfully than nouns. This was first noted in a case study of an individual with AD who had severe impairment at naming nouns, as may be expected (17.5%) but much higher score (80%) naming verbs (Robinson et al., 1999). However only concrete verbs were included, and the nouns and verbs were only matched for frequency rather than other variables, such as imageability. Indeed as others have noted, it is possible that the difference in verb/noun naming in AD is actually due to imageability differences, with nouns typically being more imageable than verbs (Bird et al., 2003). For example, when matched for imageability, Bird and colleagues (2003) found that nouns and verbs were named equally successfully in people with aphasia following stroke. These findings have been extended to people with AD too, with imageability being the variable that most strongly predicted naming success, although the authors noted some limitations in attributing imageability to items (Druks et al., 2006). Others have noted that AD is associated with temporal lobe atrophy which is associated with naming nouns, but spares frontal regions of the brain which are associated with naming verbs (Druks et al., 2006) which provides some neurological support for verbs being named better than nouns. However, a study comparing naming of nouns and verbs by 19 people with AD reported that fewer errors and faster response times were observed for nouns than for verbs (Druks et al., 2006).

For P-C (with PCA, a form of AD), the numbers of nouns and verbs named correctly were low, so no meaningful conclusion could be drawn. No research currently exists on whether nouns or verbs are named better for people with PCA.

9.4 Is performance in item-naming associated with specific psycholinguistic features for people with dementia?

As described above, there are conflicting reports that naming of verbs may be better than nouns for people with dementia, and that this may be associated with increased imageability rather than being a verb per se. In the current study, for all three participants with dementia there was no statistically significant correlation between imageability and changes in naming of items. However, for P-A and P-C, there was a strong positive correlation between overall naming of items and imageability. However, for P-C both treated and untreated verbs were named less successfully than treated and untreated nouns at both pre-therapy and post-therapy assessment, suggesting that for P-C imageability in general is the key factor, rather than imageability associated with verbs.

Interestingly, as shown in Appendix HH, the one way ANOVA of the means for imageability for the 119 standard items in this study found that the group of nouns was more imageable than the group of verbs and that the difference was statistically significant. This was the only linguistic variable where there was a statistically significant difference between nouns and verbs. As such, it may be that imageability contributes to the successful naming of nouns in the study, as some have described previously.

Previous research has consistently found that people with AD name items with earlier age of acquisition more successfully than those acquired later (Cuetos et al., 2012). To some extent this is reflected in the current study, where for P-C there was a statistically significant negative correlation between overall naming performance of items and the mean age of acquisition of each item. However, by contrast, change in naming performance and age of acquisition was subject to a weak positive correlation for P-C, suggesting items acquired later were subject to a positive change in naming success. For P-B there was a statistically significant weak negative correlation between change in naming performance and age of acquisition and P-B's overall naming performance and age of acquisition is approaching a statistically significant negative correlation, which aligns with previous research (Cuetos et al., 2012).

In the current study, for P-C, there was a weak negative correlation between number of syllables and overall naming, and no other participants' naming of items had a significant correlation with number of syllables. This aligns with the pre-existing research which, although limited, suggests that number of syllables is not associated with picture naming success (Nickels & Howard, 2004). The authors compared the effect of the number of syllables, the syllabic complexity and the syllable frequency individually on picture naming for nine people with aphasia and found that it was the number of phonemes, not syllable number or complexity, that influenced naming performance (Nickels & Howard, 2004). In the current study P-C had a weak negative correlation between overall naming performance and number of phonemes, which supports Nickels and Howard's findings, however for P-A and P-B there was no correlation between overall or change in naming performance and number of phonemes.

The participants in this study had no correlation between change in naming and item frequency. However, P-C's overall naming performance was approaching a statistically significant positive correlation with item frequency, a finding which tentatively links to the findings of other studies of picture naming (Ahmed & Garrard, 2012). As Cuetos and colleagues (2012) note, frequency of items is difficult to measure accurately as the source material is traditionally based on written language, such as from published books and magazines, which causes results of frequency to be skewed against items from everyday conversation. The authors compared these traditional methods of measuring frequency with a more modern approach using film subtitles which may better represent everyday item occurrence, but found that measuring frequency in the traditional way better predicted naming ability in people with AD (Cuetos et al., 2012). This is in contrast to other studies where television/film subtitles have proven to more successfully predict naming (Brysbaert & New, 2009). The frequency data provided by the OANB materials used in the analysis of this study are taken from an earlier traditional source (Francis, 1982), however given the everyday nature of items in the OANB it seems likely that this will be affected minimally by using traditional written sources. Indeed, Brysbaert and colleagues (2009) suggest that traditional methods of obtaining word frequency, such as print media, may be more accurate for older people such as those in the current study. This may be due to the subtitled films being used to calculate the item frequencies being more popular with younger than older audiences, and more similar to the speech of younger people (Cuetos et al., 2012).

There is a paucity of research investigating the impact of familiarity on naming for people with AD specifically. In picture naming tasks, studies typically show that low familiarity items are least likely to be correctly named by people with AD (Ahmed & Garrard, 2012). However, a number of studies have investigated the effect of concept familiarity on naming in semantic dementia, which involves deficits in semantic knowledge (Woollams, Cooper-Pye, Hodges, & Patterson, 2008). Significant deficits in semantic knowledge were observed in the background testing of P-B in the current study, whereas in P-A semantic knowledge was relatively spared. Interestingly, for P-B the positive correlation between change in naming performance and the familiarity mean was approaching statistical significance, meaning that P-B's naming performance may have improved for more familiar items than less familiar items. Given the large deficits in semantic knowledge in P-B, it is interesting to compare the impact of familiarity in naming in people with semantic dementia. A number of studies have shown that people with semantic dementia name more familiar items more successfully than less familiar items (Rogers, Patterson, Jefferies, & Lambon Ralph, 2015). For example, a study of 78 people with semantic dementia found that increases in familiarity positively correlated with naming success and that the correlation was statistically significant (Woollams et al., 2008). Thus, the findings for semantic dementia appear to support those in the current study for P-B, although it is important to note that despite retained semantic knowledge, overall naming success for P-A did not strongly correlate with familiarity.

9.5 Methodological limitations of confrontation naming with people with dementia

There is an important distinction between measuring naming performance in a research context in isolation and measuring naming and subsequent changes in communicative success at a functional level with real life benefits for people with dementia. For example, for people with PCA, although a form of AD, the main feature is impairment of visuospatial and visuoperceptual processing (Ramanan et al., 2018). P-C with PCA scored 0 for visuospatial skills on the ACE-III for remote administration. It is clear that these visual impairments of PCA may confound naming tasks. Despite this there remains a paucity of research on how to mitigate this in naming assessment and therapy. In the current study, the participant with PCA was presented with colour photographs via slideshow software. Crutch and colleagues (2013) report that their study was the first to study language in PCA in detail, and was designed specifically for people with PCA. Their study measured naming by giving participants with PCA a verbal description, rather than by using pictures as in this study. As such, this limitation affects the results of the naming of items in this study and is perhaps a consequence of attempting to compare language in types of dementias with otherwise very different features.

As discussed in the literature review, the existing studies that use confrontational picture naming with people with AD (as used in the current study) do not describe the way in which participant responses are described as correct, or acceptable responses. Thus, there appears to be no standardised way of coding across the different studies. Where studies have described the scoring/coding principles and rules, these have been for people with stroke. For example, Roach and colleagues (1996) describe a framework for coding, although this was completed with people with stroke, rather than with broader cognitive or behavioural features of dementias. Unlike for people with stroke whose broader cognition may be intact, people with AD may have considerable difficulty in following the instructions of the naming assessment and their score, if coded on the same measures for people with language specific impairment, may understate their functional naming ability. For example, when completing a naming assessment, people with wider cognitive impairment may give multiple answers, make a comment about the picture or explain what they know about the image. This was especially true for participants A and B, who during the therapy games were aware that one of the aims when asking for a card was not just to name it (as in assessment) but to extend the question descriptively, by adding adverbs/adjectives or other comment. This may confound the naming score when measured strictly, as it cannot be determined what constitutes a self-cue or a description which was used to successfully name the item, or what was extra information volunteered by the participant. This is reflected in the difference between apparently higher name scores in therapy than in formal assessment in Phase 1, where different criteria were necessarily used to determine a correct response.

It is notable that a number of studies included in the literature review were for people with dementias more limited to language impairment, such as PPA and semantic dementia, which although aimed to limit the impact of other cognitive processes tangential to naming also meant participants may be more easily able to follow the assessment instructions. Therefore, for people with dementias that cause broader cognitive impairment, there appear to be limitations of conventional confrontational naming methodology for assessing word-finding. For such individuals, it seems likely that confrontational naming measures core naming ability, but that results may be lower as they are confounded by related impairments, such as the ability to remember and follow the instructions, to understand the aim of assessment itself, and to concentrate for long enough inhibiting other communication or behavioural features.

Future research may usefully develop a standardised way of recording confrontational picture naming scoring and coding for people with AD to more easily ensure studies can be accurately compared. Alternatively, it may be that such measures of picture naming, even when standardised, are not the most useful or accurate way to measure naming performance for people with AD, and that other measures focussing beyond single word naming are more appropriate. Two options, measures of connected speech and communication partner reports of communicative success, are addressed in the following sections of this discussion.

9.6 Does CIAT-based therapy result in changes to features of connected speech?

For both P-A and P-B, the speech rate (number of words per minute) declined between baseline and pre-therapy assessment. The speech rate between pre-therapy and post-therapy assessment for P-A declined from 106.5 to 81.98, and remained unchanged for P-C at 102.79 and 102.52, all of which were notably below control (160.82). But for P-B there was an increase in number of words per minute between pre-therapy (102.72) and post therapy assessment (142.0). Having lower speech rate than controls is expected, as typically AD is associated with a reduction in speech rate. For example, a systematic review of connected speech found that people with AD spoke more slowly than healthy controls in 78% of cases, although this was based on a small sample size of 9 people in total (Slegers et al., 2018). Slegers and colleagues' (2018) reported that decline in speech rate is not related to progression of AD. This reflects earlier studies. For example Ahmed and colleagues examined the speech fluency of 15 people with AD confirmed at autopsy and found that speech rate is not reliably linked to progression of AD (Ahmed, Haigh, de Jager, & Garrard, 2013). These earlier findings are supported by the results of this study where the connected speech measures for P-A and P-B, which were taken at three points over an extended period of approximately 11 months, were lower than controls but did not show notable decline over that timeframe. For P-C, there was a much shorter duration of only circa 2 months between pre-therapy and post-therapy assessment, as post-therapy assessment was completed immediately following the period of participant-directed therapy.

For P-A and P-B, the proportion of pronouns increased between pre-therapy and post-therapy (from 0.21 to 0.33 and 0.52 to 0.62), whereas for P-C they were largely unchanged (0.45 to 0.49).

Reported controls were 0.41, therefore for P-A this was less than controls and for P-B and P-C it was greater than controls. Slegers and colleagues' (2018) systematic review found that people with AD used more pronouns than healthy controls in 88% (7 of 8) cases. Similarly, Ahmed and colleagues (2013) found that the decline in lexical content by 15 people with AD was attributed largely to an increase in the use of pronouns. Pronoun increase may be due to semantic impairment or lexical retrieval impairment (Slegers et al., 2018). As such, the increase in pronouns for both P-A and P-B between pre-therapy and post-therapy assessment is to be expected. However P-A showed a decline in pronouns between baseline and pre-therapy assessment; it could be that this difference represented daily variation and that the approximate 3 months between these assessment points was not long enough for meaningful decline in this measure. Increases in pronoun use appears to occur from the onset of AD pathology and diagnosis, rather than declining during pre-clinical stages. For example, a study of the pronoun use of people who subsequently developed AD from up to 12 years pre-diagnosis found that their pronoun use only reduced from the onset of AD (Wendelstein, Stegmeier, Frankenberg, Felder, & Schröder, 2015). Increase in pronoun use is associated with challenges for the listener if the pronoun has not been clearly attributed at an earlier stage (Sandoz, Iglesias, Achim, Démonet, & Fossard, 2020). Although, as Sandoz and colleagues (2020) note, increase in pronoun use itself may be reflective of the communicative context which does not involve new referents and therefore does not necessitate a more specific noun. In this study, participants were specifically asked to tell a story (ideally the Cinderella story) but flexibility was given if participants were not aware of this. Thus, only a small number of referents may be needed due to the constrained number of characters. However, an increase in pronouns across the assessment points may be expected alongside wider progression of AD. Many studies have found people with AD use more pronouns than controls. For example, a study comparing picture description of 20 people with AD and 20 controls found that people with AD produced more pronouns as a percentage of all words than healthy controls (Kavé & Goral, 2016). Additionally, the authors found that pronoun use in connected speech correlated negatively with picture naming (Kavé & Goral, 2016). This aligns with the results of this study, whereby for both P-A and P-B naming declined between pre-therapy and post-therapy and pronoun use increased between the same points.

Some studies, as noted in Slegers and colleagues' review, attribute a reliance on pronouns to difficulties with semantic impairment and difficulties with lexical access. Alternatively, for others the increase in pronouns may be due to working memory deficit, rather than semantic impairment (Almor, Kempler, MacDonald, Andersen, & Tyler, 1999). A study by Almor and colleagues (1999) compared semantic memory impairment and pronoun comprehension in people with AD and found no link, however reduction in working memory was associated with increased pronoun use. This led the authors to conclude that declining working memory is key to increased production of pronouns while noting the caveat that this assumes receptive and expressive language skills are theoretically indistinct (Almor et al., 1999). In the current study, both P-A and P-B had scores of 38.5% on the memory section of the ACE-III during background assessment, suggestive of significant memory impairment. However, semantic knowledge as measured by the Camel and Cactus test of the CSMTB varied considerably with P-A scoring 92.1% (compared to 93.6% control) but P-B scoring only 75% suggesting notable semantic impairment. P-A had pronoun proportion of 0.3 at baseline remaining similar at 0.33 at post-therapy assessment, whereas P-B had 0.5 at baseline increasing to 0.62 by post-therapy assessment, compared with reported control of 0.41. In light of similarly impaired memory, P-A's score of close to control on semantic knowledge with lower proportion of pronouns, compared with P-B's greater semantic impairment and higher pronoun proportion gives tentative support to the importance of semantic knowledge in reducing pronoun use. This is as summarised by Slegers and colleagues (2018), rather than the focus on working memory being key as posited by Amor and colleagues (1999).

Slegers and colleagues (2018) review found that measures of open/closed class words were not sensitive to the extent of word-finding difficulties for people with AD. This aligns with the current study, where despite decline in other areas of communication, the proportion of closed class words remained largely unchanged between pre-therapy and post-therapy assessment for all three participants with dementia.

For P-A and P-C, the proportion of verbs remained unchanged between pre-therapy and post-therapy assessment, however for P-B it increased between pre-therapy (0.52) and post-therapy (0.72) assessment points, which was above published control (0.48). Previous research has identified impaired semantic knowledge as a crucial factor in reduced complexity of verb use. As part of a wider study, Kim and Thompson (2004) compared verb use with differing syntactic and semantic complexity for 14 people with probable AD. They found that participants did not have any greater difficulty producing verbs of increased syntactic complexity (more arguments) but did have more difficulty producing verbs of greater semantic complexity (Kim & Thompson, 2004). For the current study, P-A's auxiliary verb complexity increased between baseline and pre-therapy assessment points before declining between pre-therapy and post therapy assessment points and their verb inflection index was broadly unchanged between each assessment point. Specifically, P-A who had minimal semantic impairment had a consistent verb inflection index between pre-therapy and post-therapy assessment of 1.0 (compared with 0.92 for reported healthy controls). Their auxiliary complexity index declined from 3.06 to 1.38 between pre-therapy and post-therapy assessment, but this compares favourably against a reported 1.26 for healthy controls.

However, for P-B, both the verb complexity and auxiliary complexity declined between baseline and pre-therapy assessment, before increasing between pre-therapy and post-therapy assessment for verb complexity (0.27 to 0.53) and being unchanged (1.00) for auxiliary complexity all of which were lower than controls, which may indicate some improvement in verb complexity following therapy. Specifically, P-B, who had notable semantic impairment, had a higher proportion of verbs than P-A or reported healthy controls with increase from 0.52 to 0.72 between pre-therapy and post-therapy assessment. However, measures of verb complexity were lower for P-B, with verb inflection index being 0.27 pre-therapy increasing to 0.53 post-therapy and auxiliary complexity index being 1.00 at pre-therapy and post-therapy. As such, unlike P-A, for P-B all measures of verb and auxiliary complexity both pre-therapy and post-therapy were below the reported healthy control measures. In light of P-B's greater semantic impairment when measured using the Camel and Cactus test, this aligns with Kim and Thomson's (2004) finding that retained semantic knowledge is important for higher verb complexity. However, despite differences in verb complexity used (and semantic knowledge retained) by P-A and P-B, there was no statistically significant change in the naming of treated or untreated verbs before or after therapy suggesting the therapy task did not improve verb production either in naming assessment or in connected speech.

Finally, it is interesting to note that P-C's sentence complexity increased notably from pre-therapy to post-therapy as it did with P-B to a much lesser extent, which contrasts with P-A where complexity declined. However, when comparing baseline assessment with post-therapy assessment the trend is reversed, with sentence complexity declining for P-B and increasing for P-A, suggesting that as with other areas such as naming assessment, performance is variable for P-A and P-B. This aligns with reports from the communication partner interview where communication fluctuations were noted. Regarding P-C, none of the other connected speech measures showed notable improvement between pre-therapy and post-therapy. One possible explanation is that P-C told a personal story rather than the Cinderella story for both pre-therapy and post-therapy assessment of connected speech. It is therefore possible the story told by P-C at the post-therapy assessment was predisposed to greater sentential complexity due to idiosyncratic reasons, perhaps due to it being a favourite story told more often than at pre-therapy assessment.

9.7 Methodological limitations of connected speech analysis with people with dementia

Although the QPA aimed to assess grammaticality of speech, it may more accurately measure the overall level of aphasia or fluency rather than grammaticality itself (Gordon, 2006). For example, Gordon (2006) found that inter-rater agreement for the number of narrative words in a sample averaged 88% (range 69%-97%) and that agreement of what constituted an utterance was 94% (range 83%-100%) of a sample selected. Additionally, Gordon (2006) found that scoring of utterances had an inter-rater reliability of 94% (range 81%-100%).

Interestingly, there may be a methodological bias implicit in asking people with dementia to use a constrained story supported by pictures. A comparison of picture description versus interview subjected to quantitative production analysis as a means of eliciting a connected speech sample found that grammatical errors were more prevalent in an interview, whereas the necessary constraints of picture description increased the number of closed class words such as pronouns and exposed semantic difficulties associated with word retrieval (Sajjadi, Patterson, Tomek, & Nestor, 2012). However, for P-A and P-B, this potential bias has not translated into greater proportion of pronouns or closed-class words more generally.

Previous studies of CIAT with people with aphasia following stroke have used a number of different approaches for acquiring a spoken language sample, such as describing a picture, telling their own stories or interviews, with associated limitations when comparing results (Griffith, Dietz, Ball, Vannest, & Szaflarski, 2017). Indeed, in the present study, participants ideally told the Cinderella story with pictorial support, but if they reported they did not know this story, then they told their own narrative, with the implicit limitations accepted.

9.8 Does CIAT-based therapy result in people with dementia and their communication partners having better, more successful, everyday conversations?

In the current study, the CAPPCI interview was used to gain a measure of communication partners' perspectives of whether participants with dementia were having more successful conversations following CIAT-based therapy. For P-A, although reported frequency of communication difficulty generally increased between baseline and post-therapy assessment, the severity to which it was a problem sometimes improved. This was not the case for P-B, where overall a small increase in both frequency and severity of the problem was generally reported by their communication partner. For P-C, there was often a notable difference between the frequency of a communication impairment, and the corresponding severity of the problem, with the latter being very low (0 or 1 in all eight response categories).

The CAPPCI interview tool has been used very infrequently with people with dementia. One such example is a profile of people with PD with associated cognitive impairment (Whitworth et al., 1999). As part of a wider study, carer reports on communicative success using the CAPPCI interview were reported for people with PD and subcortical dementia and PD and DLB. Perhaps reflecting the motor speech impairment associated with PD rather than dementia, articulation and prosody was the category reported to have the highest mean percentage difficulty for both PD with subcortical dementia (45.8%) and PD with DLB (52.3%) (Whitworth et al., 1999). P-A and P-B in the current study both had AD, and therefore reported frequency of communication difficulty and the severity of the problem was scored as zero at both baseline and post-therapy assessment for both participants.

In Whitworth and colleagues' study, topic management was the question category with the second highest mean percentage difficulty for both groups at 41.2% and 51.7% respectively (Whitworth et al., 1999). However, in the current study, linguistic ability for P-B, and high level linguistic ability, repair and topic management at post-therapy for P-A, were the question categories with the greatest reported frequency of communication difficulty.

More specific comparisons are difficult to make as there is no existing literature specifically using the CAPPCI with people with AD, nor using the CAPPCI to measure change over time with any form of dementia. Where studies of communication partners' views of communicating with people with dementia do exist, they refer to the impact of communication difficulties on activities of daily life rather than the communication difficulties specifically. For example, in one study, focus groups of 22 caregivers reported that key daily activities of people with dementia most affected by communication difficulties were having a personal conversation and using the phone, with getting dressed being mentioned least often (Small et al., 2000). However, specific cognitive/language skills are not measured.

Notwithstanding these caveats, several points shared by both CP-A and CP-B at post-therapy interview are discussed here. CP-A and CP-B both discussed the importance of allowing the participant with dementia to talk when they had something to say and flexing to facilitate this. For CP-A, this was because P-A was typically quieter, and for CP-B it was an awareness that P-B had fewer opportunities to talk and would feel more relaxed if given the time to talk about something that was troubling them. This aligns with studies of strategies for supporting communication with people with dementia. For example, Small and Gutman (2002) reviewed guidance for supporting communication for the carers of people with dementia and found 10 key strategies were used. Twenty relatives of people with dementia were then asked which of these they actually used in practice. Of the ten strategies, avoiding interrupting the participant with dementia and allowing them time to talk was the third most popular strategy among relatives, but was only the sixth most popular strategy in the published guidance examined (Small & Gutman, 2002). This suggests it is more frequently used to support communication than the literature suggests and is perhaps unsurprising that it is mentioned by both CP-A and CP-B in this study.

Continuing the approach of following the participant with dementia's lead, both CP-A and CP-B discussed a similar strategy for managing the introduction of unexpected or random topics by the participant with dementia. Both communication partners explained that they typically flexed to follow the newly introduced topic to continue before reverting to the previous topic if desired. Interestingly, this or a similar approach was not listed in Small and Gutman's (2002) review of the ten most commonly published communication strategies. However this may be due to limitations in the methodology in only including language and environmental factors and not, for example, non-verbal communication (Alsawy, Mansell, McEvoy, & Tai, 2017).

As well as flexing to allow management of topics within a conversation, both CP-A and CP-B also reported how they managed the timing of conversations. Both CP-A and CP-B reported fluctuations in communication abilities throughout a typical day and followed this up with further comments that communication was typically worse in an evening or when tired. On such occasions, the communication partners altered their expectations of the participant with dementia's communication in an evening, giving participants with dementia opportunities to speak but did not typically engage in more complex or important, effortful conversations. CP-A reported scheduling communication events to minimise P-A's fatigue and ensure maximum participation, whereas CP-B noted that they did not ask questions of P-B or query them in the evenings due to the participant with dementia's fatigue.

Finally, both CP-A and CP-B explained an overarching approach to communicating with the participant with dementia. This centred around minimising potential upset for themselves and the participant with dementia by not thinking too much about any communication breakdown or errors, but just adapting and without giving overdue attention to the bigger implications behind any difficulties. Additionally, as Alsawy and colleagues (2017) report, it is not clear how communication partners feel about or experience using communication strategies. This may influence both the choice of strategy and their perception of its effectiveness.

It is interesting to note how CP-C appeared to adopt a subtly different approach to facilitating successful conversation than CP-A and CP-B. Based on the interview, it appears that P-C and CP-C adopt an approach whereby the successful transaction of information is the most important outcome of communication. For example, in contrast to P-A and P-B, if P-C has word-finding difficulties, CP-C typically offers the word, which is happily accepted by P-C. It appears that this is more important than P-C being able to solve the word-finding themselves with the support of strategies.

A key finding from the quantitative section of the CAPPCI interview was that communication partners generally did not view the participant with dementia's communication difficulty as a problem. Given that communication partners are discussing their friends/relatives with dementia, asking how big a problem is it, may be confounded by biases in favour of the participant with dementia. This was extended in the qualitative comments made by communication partners, who reported that they were glad the participant with dementia was communicating and were aware that any communication difficulties were a consequence of dementia. Given the apparent diversion between the greater frequency of the reported impairment and lesser severity of the perceived problem, it may be that the frequency of the impairment is not the most salient measure of functional communicative success. This argument could equally be applied to the findings of the assessment of item naming in this study. Determining what constitutes communicative success, and the extent to which successful naming or perception of success is important, is part of a wider discussion around the interaction between functional or impairment-based therapy and assessment, as discussed earlier.

9.9 Methodological limitations of structured communication partner interviews

There is an important methodological limitation to using a quantitative measure of communicative success such as the CAPPCI in that the response scores of the CAPPCI are pre-determined and stipulated in the interview tool. As such, they do not necessarily represent the perceptions of the communication partners being interviewed. For example, as alluded to by CP-A, a prescriptive interview with set response choices may and pre-assigned values may not reflect the values of the communication partner. As CP-A noted, favourite conversation topics were discussed very regularly. The pre-determined scoring of the CAPPCI assumes this to be negative, however for CP-A this was actually viewed positively as an opportunity to talk about family or interests and did not represent an impairment at all.

As such, there appears to be considerable value in reporting qualitatively key comments made by communication partners in the interview, even if not in direct response to a question, not least because they are indicative of what the communication partner considers important, rather than having value pre-assigned. This aligns with previous reviews of the limitations and restrictions of quantitative approaches to seeking opinions of successful strategies when communicating with people with dementia (Alsawy et al., 2017). Indeed, Alsawy and colleagues recommend seeking qualitative reflections to further understand the caregivers' experiences (2017). It should be noted that very often comments were influenced by preceding questions from the CAPPCI and therefore such trends are likely to be influenced by the CAPPCI questions.

A note of caution is that the strategies reported and rated highly by communication partners may not necessarily result in improved communication by objective measures. This may be especially the case for middle and later stage AD, however those with early-stage AD such as P-A and P-B, communication partners may be better at judging strategies that are objectively successful (Savundranayagam & Orange, 2014). This assumes that strategies are employed solely with the aim of facilitating more successful communication. However, evidence from the current study suggests that this may not always be the case. For example, both CP-A and CP-B describe how they do not give great thought to every error or inconsistency in communication, as that may cause the communication partner distress about the participant with dementia and their wider dementia impairment.

Some communication partner responses suggested that the questions were constraining, for example by asking about jokes for P-A and P-C, whose personality was not to make jokes. Therefore, this was scored negatively, despite not being a change in communication for the participant with dementia. Similarly, for P-C, their communication partner observed that it was difficult to make judgements regarding P-C's ability to read between the lines in conversation, as the communication partner had adapted their conversation to ensure this skill was obsolete for P-C. As such, the CAPPCI questions may on occasion set communication priorities which may not exist for the individual communication partner or participant with dementia. For example, for P-C, their communication partner noted that forgetting places/people could be perceived as a problem by the participant with dementia, although was scored on the basis that it was no problem for the communication partner.

9.10 Methodological limitations of participant-directed research/therapy and use of video-call with people with dementia

Significant changes to research processes were required due to restrictions on face-to-face data collection as a consequence of the coronavirus pandemic. The post-therapy assessments for Phase 1 were amended to ensure data collection could be meaningfully completed ensuring parity with pre-therapy assessments as much as possible. However, as these changes delayed the assessment by several months from the end of therapy, it is difficult to be certain how much impact this may have had on assessment outcomes, given that the progressive nature of their dementias meant that participants were likely to have declined in that time period. Additionally, it is conceivable that reduced social contact generally may have accelerated cognitive decline for people with dementia (Tondo, Sarasso, Serra, Tesser, & Comi, 2021). An accelerated decline between the end of therapy and the post-therapy assessments could further confound the results.

The focus group comprising participants from Phase 1 supported the development of both the guide to completing the therapy, and provided valuable perspectives from dementia stakeholders on the change to completing therapy independently with minimal expert involvement in Phase 2. A key outcome from the focus group was the perspective that completing the therapy online, although possible, would not be as beneficial as completing it face-to-face, specifically that there was value in attending the clinic in person, as well as receiving face-to-face input from the researcher. Qualities of successful therapeutic relationships have been widely studied. For example, Fourie (2009) interviewed adults about their experience of speech and language therapy and found that positive values associated with therapists were being understanding, erudite, gracious and inspiring. Following the interviews, Fourie also described therapeutic actions of being confident, soothing, practical and empowering, all of which were considered important from the patients/participants' perspective (Fourie, 2009). Similarly, participants with aphasia following stroke were asked for important features in the therapeutic relationship, with responses grouped into five perspectives (Lawton, Haddock, Conroy, Serrant, & Sage, 2020). Although all may be affected by not receiving researcher/therapist led sessions, one of the five viewpoints was that therapists should challenge and direct participants/patients (Lawton et al., 2020). This is likely to be particularly challenging when completing therapy by video-call and with communication partner-directed sessions. Even when such values and actions may be debated by specific individuals or patient-groups receiving therapy, it is clear that there are perceived to be features of successful therapy regardless of the type of therapy undertaken. As alluded to by the current study's focus group, it is unclear the extent to which these values/actions could be developed as easily during video call or, in particular, by communication partner led therapy without direct researcher/therapist involvement. In summary, Fourie (2009) notes, it is important to consider how therapy is delivered as well as what therapy is delivered. Despite the latter being feasible, the former may present a greater challenge without direct face-to-face therapy sessions.

People with dementia may face additional practical barriers when using video-call technology, either to participate in research or speech and language therapy. Although research is limited for people with dementia, a study involving people with the language-specific dementia PPA reported that teletherapy for aphasia produced comparable outcomes to face-to-face therapy (Dial et al., 2019). A different study of teletherapy for anomia in people with PPA also found positive results (Meyer, Getz, Brennan, Hu, & Friedman, 2016). Although the study only involved three participants one, who was described as requiring assistance with accessing the software and screensharing suggesting some wider cognitive impairment, did show improvement in naming following tele-therapy (Meyer et al.). However, neither study takes into account the full wider cognitive challenges associated with other forms of dementia such as AD, which may involve greater difficulty understanding the concept of a video-call.

Other cognitive-sensory impairments associated with dementia may be more likely to confound outcomes when using video-calls rather than in face-to-face therapy/research. These include sensory deficits associated with dementia such as hearing loss and visual impairments (Livingston et al., 2017). Such deficits can impact on assessment of people with dementia, as described, for example, by Cohen-Mansfield (2003) for symptoms of psychosis. These require further study to understand their impact on research and therapy for people with dementia.

9.11 General study-wide evaluation

This study sought to evaluate the effectiveness of CIAT-based therapy for people with dementia, and was the first study to do this with people with AD. Previous studies had examined CIAT-based therapy with people with language-focussed dementias such as PPA, therefore, this study exposed a number of limitations around feasibility and acceptability of using CIAT-based therapy with people with AD. Some challenges were highlighted in the focus group discussion (see section 7.13); specifically, the time taken to practice a number of picture items on a daily basis was reported to be a barrier to people with dementia. Likewise, for communication partners this meant repeated practice of items that they often could predict, with motivation therefore sometimes a challenge. Other studies have focussed on CIAT-based therapy following stroke (Meinzer et al., 2005) or PPA dementias (Hameister et al., 2017) for which there is typically less decline in general cognitive functioning and greater preserved attention, meaning an increased likelihood that participants could participate in the therapy task on a more equal basis with communication partners.

A preference for in-person therapy sessions with the researcher was reported by focus group participants. This aligns with finding from other studies such as that by Beales and colleagues who interviewed communication partners of people with dementia following word-finding therapy and found that communication partners reported benefits to therapy beyond improved word-finding, such as valuing the opportunity to communicate with the person with dementia, and reporting having gained more knowledge and understanding of how to communicate with the person with dementia (Beales et al., 2019). Therefore, due to the unexpected cessation of Phase 1 of the study leading to the subsequent focus group, useful initial insight was gained on the feasibility and acceptability of CIAT-based therapy for people with AD. Future studies should build upon this by seeking to determine the optimum number of picture-items and the amount of practice required to achieve results with an acceptable level of participant involvement.

Meinzer and colleagues (2012) have reported that the key feature of CIAT appears to be intensity of treatment. Therefore, future studies should seek to determine the relationship between intensity and naming (or wider communicative success), with the aim of identifying the extent to which a lower intensity of therapy achieves positive outcomes. Based on tentative observations in the focus group in this study, reducing intensity of practice may increase acceptability for people with AD and their communication partners and include people whose cognitive attention would otherwise limit their involvement in CIAT-based therapy. Herein lies a key limitation of CIAT-based therapy for some people with AD in that therapies seeking to address impairment may not be palatable or possible for some people due to their focus on time-consuming and cognitively demanding intense therapy practice.

As discussed in section 2.3, research on aphasia therapy for people with dementia has often been considered ineffective (Holland, 2003), and others have noted that cognitive decline associated with dementias such as AD may make re-learning items challenging (Bayles & Kim, 2003). There is also a paucity of research on impairment-based lexical interventions for people with dementia; Beales and colleagues (2018) review found just 28 studies for people with PPA, and only 9 for people with AD. In the current study, the focus group participants noted the impact of completing the therapy task on a regular basis, especially during self-directed practice at home; sessions with the researcher in-person appeared to be considered more acceptable. It may be that impairment-based therapy is most suited to PPA, rather than AD or other forms of dementia with broader cognitive deficit, however the current study is unable to address this due to the small number of participants and the generally high performance of P-A and P-B with AD.

At present, the limited nature of other studies in the available dementia literature mean that it is not possible to identify the specific conditions which make aphasia-related therapies successful, and acceptable, for people with AD. While ultimately an individual decision of each person with dementia, future studies should seek to address this, for example by considering how the type of dementia, the stage of dementia progression compared with word-finding abilities, and individuals' personal motivations affect the success of CIAT-based therapy. Further, in order to fully explore personal factors relating to acceptability and feasibility, future studies should collect more demographic information, particularly for communication partners given their extensive involvement in the study. Collecting information on participants with dementia and communication partners' occupational situation or educational background, for example, could help to highlight factors influencing therapy success. This would allow people with dementia and clinicians to identify the most appropriate therapy on each occasion.

In this study, the researcher was unblinded regarding whether participants had completed the therapy sessions. This may have resulted in inadvertent bias during data analysis. To counter this, the data analyses could have undergone a full second analysis by an individual who was unaware of whether the assessment point was before or after therapy. In addition, in future studies, the allocation to group could be completed by a member of the research team who was not completing the assessment, therapy or data analysis, to minimise the awareness of which group participants were in, or whether they had completed the therapy intervention.

Participants themselves, who are unblinded to whether items were treated or untreated, may introduce further inadvertent bias if they recognise whether items presented during naming assessment are ones they have practised. For example, some participants in the early stages of dementia may recognise the item and make greater attempt to name the item than one they have only previously seen on assessment and so may not recall, possibly as they may subconsciously feel they ought to be able to name it.

Similarly, in the communication interview completed by communication partners, participants who had built up rapport with the researcher and were committed to the study, may be more inclined to give positive reports of communication success following completion of the therapy sessions than before therapy. However, the declining nature of dementia meant that participants' overall communication was generally reported to have declined between pre and post therapy assessment points. Despite this, it may be that the extent of the decline was masked in interviews with communication partners due to confirmation bias, where having spent time completing therapy tasks and language assessment, communication partners felt motivated to notice positive changes in their interactions with the participant with dementia.

The monologue may also be subject to bias due to the Hawthorne effect where participants, aware that they are being assessed, alter their storytelling from that of their normal everyday life. Despite this risk of bias, such impact would be felt at both pre and post therapy assessment points and so may more accurately be used to compare between assessment points than reflect everyday life. Instead, participants could be given audio/video recording equipment and asked to record the participant with dementia when telling a story at home without the researcher present and in a more authentic setting, with the aim of achieving a more accurate measure of genuine everyday performance.

The overarching design of the study satisfied a number of desirable features for intervention studies. Pre-therapy testing was completed on a limited number of occasions, irrespective of whether the results were stable, and the number of therapy sessions was set in advance and not determined by change in participants' performance (Howard et al., 2015). Results were analysed by item, and had to achieve statistical significance in order to infer a positive impact of the therapy intervention (Howard et al., 2015). In addition, Howard and colleagues recommended that stimuli be allocated randomly to treated and untreated groups, which should be matched to baseline performance (2015). This was not part of the current study's methodology, as precedence was given to participants being able to choose their own items, taking into account previous evidence that choosing personally important items is important for naming success (Jokel et al., 2014). Furthermore, using personally important words is a key feature of CIAT-based therapy having been initially described by Pulvermuller and colleagues (2001) therefore removing this would have meant the intervention was notably different from other CIAT-based studies. Features such as having a set/limited number of baseline assessments is intended to reduce the risk of type one errors implicit in other approaches such as response-guided approaches where stability and consistency of participants' responses determines when, for example, baseline assessments would end (Byun, Hitchcock, & Ferron, 2017). This is perhaps significant in the current study where both P-A and P-B showed increases in naming ability between the baseline and pre-therapy assessment points, and it is unclear whether the increase is due to a baseline trend. However, while Byun and colleagues suggest employing such flexibility could be mitigated by the researcher being blinded, in the current study the small number of participants and analysis and therapy sessions by a sole researcher mean full blinding was not possible, with the risk of bias acknowledged.

The revised version of the study in Phase 1 necessitated a change from in-person assessment pre-therapy to assessment distantly by video-call for post-therapy assessment. Although this change was required in order to provide a post-therapy assessment measure, there are limitations to changing the mode of delivery particularly for people with AD who may find the assessment more challenging by video-call. Interestingly however, research comparing in-person and teletherapy for anomia in people with PPA found both were successful and that teletherapy did not appear to be disadvantageous and may actually have produced slightly better outcomes (Dial et al., 2019). In Dial and colleagues' study, assessment was carried out in the same mode of delivery as therapy – participants completing tele-therapy were assessed using video-call and participants completing in-person therapy were also assessed in person. While acknowledging that people with PPA are often spared the wider cognitive decline of those with AD, this gives some confidence that there may be limited difference in the current study between the two modes of assessment at pre and post therapy. For people with AD, a study comparing lexical-semantic stimulation therapy delivered in-person with that delivered by teletherapy, found that both were effective for improving language performance (Jelcic et al., 2014). However, while it should be noted Jelcic and colleagues' study only including participants in the very early stages of AD, with limited associated cognitive decline, this does suggest that there is scope for meaningful and comparable assessment to be completed both in-person and by video-call.

9.12 Overarching conclusions and considerations for future research and clinical practice

This study was the first to evaluate CIAT-based therapy with types of dementia that typically cause wider cognitive decline beyond language. Although Hameister and colleagues' (2017) study of CIAT with people with PPA showed clear benefits to completing therapy, in the current study in both Phase 1 and Phase 2 there was overall no certain, clear measurable benefit to completing therapy on naming of items, analysis of connected speech or interview with the communication partner on functional communicative success. However, there is some tentative evidence of maintenance of treated nouns for one participant. Given the small number of participants recruited, the hypotheses that CIAT-based therapy results in people with dementia maintaining or improving their naming of their chosen nouns and verbs, and that these changes generalise to everyday communication, can be neither accepted nor rejected.

This may not be unexpected given the wide cognitive decline associated with AD and PCA; this may confound the impact of therapy, in contrast to the language-specific decline of PPA.

This study provides evaluation of the process of both assessment and CIAT-based therapy for people with dementia, both face-to-face and remotely via video-call. Furthermore, the re-design of the study to include participant-directed therapy and video-call assessment in Phase 2 ensured the study was relevant and contemporaneous, allowing for more effective application in the current clinical context.

A number of areas for future research have been identified. Firstly, in common with many of the studies identified in the literature review, a key limitation of the current study is the small number of participants which reduces confidence that the findings are representative. Therefore, future studies should recruit a greater number of participants with a range of different dementias to allow firmer conclusions to be drawn.

Secondly, it is challenging to assess the impact of language therapy when overall decline is a feature of dementia. As accurately demonstrating successful outcomes may be difficult, this may contribute to the paucity of research on impairment-based therapy such as CIAT. Therefore, future research should determine how to meaningfully measure the effectiveness of impairment-based aphasia therapy where language decline is expected as part of disease progression and thus slowing the decline in word-finding ability, rather than measuring improvement, may constitute success.

Thirdly, this study has identified limitations regarding how to assess communication, in particular word-finding, in an accurate and meaningful way for people with AD and similar dementias that cause wider cognitive decline. Therefore, future research should determine a systematic way to assess functional language abilities in people with dementia where typical aphasia assessments such as confrontation naming and connected speech analysis may not accurately reflect communicative success. Future research may include devising a systematic way of measuring naming ability that takes into account impairment to executive function, and so allows for accurate comparison between studies. In addition, future research may determine an effective way of assessing the language and cognition of people with PCA where visuospatial and visuoperceptual impairments predominate and confound current assessment.

Relating to clinical practice, at present a key limitation of impairment-based therapies for people with dementia is the likelihood that notable cognitive decline with functional impact has already taken place to enable the diagnosis to be made. This impacts on the ability to complete direct therapy, and thus highlights the importance of early discussion regarding referral to speech and language therapy. This study also reinforces the continuing need to consider wider cognitive and perceptual abilities when assessing and delivering therapy either face-to-face or remotely.

In conclusion, this study provides a basis for further exploration of how to deliver research-driven therapy which meaningfully enhances the lived experience of people with dementia and those with whom they communicate.

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Appendices

Appendix A - Phase 1 email text to potential participants

Subject: Picture naming of objects and actions – research questionnaire.

Hello.

You are invited to take part in an online research questionnaire as part of a PhD study at the Department of Human Communication Sciences, University of Sheffield.

About the questionnaire

The questionnaire is in a google form – the link is at the bottom of this email.

You will see photos of everyday objects and actions. Your task is to type the name of these everyday objects or actions in the text box provided. We want to find out if all participants agree with the name of the object/action shown in the photo.

There are 124 photos in total. The task should take approx. 20 minutes.

Requirements for taking part

You do not have to take part. Responses are anonymous, so we will not know if you have taken part or not. The first 20 responses received will be used in the research.

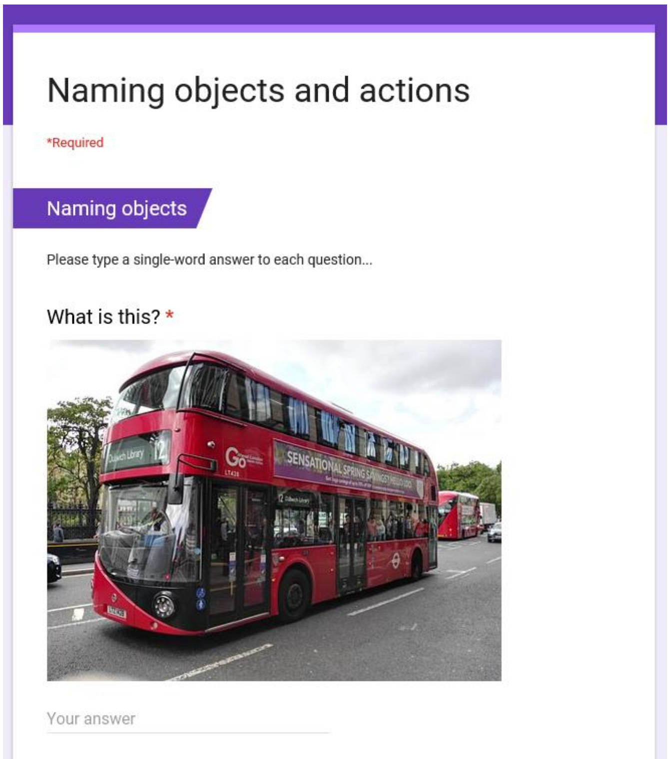
In taking part, you are confirming that you:

- have British English as an everyday language, and
- do not have any known language problem.

If you have any questions, please contact: pjmumberson1@sheffield.ac.uk.

Completing the questionnaire

Questions will appear like this – this is just an example.



Naming objects and actions

*Required

Naming objects

Please type a single-word answer to each question...

What is this? *

Your answer

Please type single-word answers to questions. In this example, the answer would be "bus". Please do not discuss your responses with anyone else.

In clicking on the link and completing the questionnaire, you are confirming that you understand the information in this email and are giving consent for your anonymous responses to be used in the research, and to be published and presented at conferences. The data you provide may be used again by members of the research team for research/teaching in the future.

To participate please click on the following link: [link to google form].

Thank you for taking part.

Philip Mumberson (PhD student)

Appendix B - Object and Action items: analyses for each item, and for the final list of 119 items

Target response	Acceptable variants given by participants	Rejected variants given by participants	% respondents who successfully identified picture (including target and acceptable variants)	Naming agreement (of target and acceptable variants) %	Picture retained or removed from the final list
arm		hand	90	arm 100	Picture retained
ball	football		100	ball 20; football 80	Picture retained
banana			100	banana 100	Picture retained
basket			100	basket 100	Picture retained
bath		sink	95	bath 100	Picture retained
beard			100	beard 100	Picture retained
bed		duvet	95	bed 100	Picture retained
bee	bumblebee		100	bee 90; bumblebee 10	Picture retained
belt			100	belt 100	Picture retained
bridge			100	bridge 100	Picture retained
bucket			100	bucket 100	Picture retained
butterfly		moth	95	butterfly 100	Picture retained
camera			100	camera 100	Picture retained
castle			100	castle 100	Picture retained
cat	kitten		100	cat 85; kitten 15	Picture retained
chair			100	chair 100	Picture retained
cheese			100	cheese 100	Picture retained
cherry			100	cherry 100	Picture retained
church	cathedral		100	church 90; cathedral 10	Picture retained
clock			100	clock 100	Picture retained
comb			100	comb 100	Picture retained
cow			100	cow 100	Picture retained
curtains			100	curtains 100	Picture retained
dog			100	dog 100	Picture retained
door		room	95	door 100	Picture retained
drum			100	drum 100	Picture retained
envelope			100	envelope 100	Picture retained
eye			100	eye 100	Picture retained
fence			100	fence 100	Picture retained
fish	salmon		100	fish 95; salmon 5	Picture retained
flower			100	flower 100	Picture retained
fork		spoon	95	fork 100	Picture retained
fruit		vegetables	95	fruit 100	Picture retained
gate			100	gate 100	Picture retained
guitar			100	guitar 100	Picture retained
hammock		don't know	95	hammock 100	Picture retained
hospital		ward; hospital ward	65	hospital 100	Removed due to lack of picture clarity

house	cottage		100	house 90; cottage 10	Picture retained
iron			100	iron 100	Picture retained
kettle			100	kettle 100	Picture retained
key			100	key 100	Picture retained
knot			100	knot 100	Picture retained
leaf			100	leaf 100	Picture retained
lion			100	lion 100	Picture retained
box			100	box 100	Picture retained
map			100	map 100	Picture retained
money			100	money 100	Picture retained
mouse		gerbil; hamster; rat	65	mouse 100	Removed due to lack of picture clarity
nest		eggs; eggs in a nest	75	nest 100	Removed due to lack of picture clarity
pear			100	pear 100	Picture retained
pencil		pen	90	pencil 100	Picture retained
piano			100	piano 100	Picture retained
picture			100	picture 100	Picture retained
plug		????	95	plug 100	Picture retained
pocket			100	pocket 100	Picture retained
pram			100	pram 100	Picture retained
pyramid			100	pyramid 100	Picture retained
radio		cassette player	95	radio 100	Picture retained
road	street		100	road 95; street 5	Picture retained
roof			100	roof 100	Picture retained
sandwich			100	sandwich 100	Picture retained
scissors			100	scissors 100	Picture retained
sheep			100	sheep 100	Picture retained
shirt		t-shirt	95	shirt 100	Picture retained
shoe			100	shoe 100	Picture retained
shower	showerhead		100	shower 85; showerhead 15	Picture retained
spoon	teaspoon		100	spoon 95; teaspoon 5	Picture retained
strawberry			100	strawberry 100	Picture retained
sun	sunset		100	sun 85; sunset 15	Picture retained
table			100	table 100	Picture retained
tent			100	tent 100	Picture retained
tie			100	tie 100	Picture retained
tractor			100	tractor 100	Picture retained
tree			100	tree 100	Picture retained
trumpet		saxophone; trombone	90	trumpet 100	Picture retained
umbrella			100	umbrella 100	Picture retained
watch			100	watch 100	Picture retained

weights	barbell; dumbbell		100	weights 85; dumbbell 10; barbell 5	Picture retained
wheel		tyre; alloys	70	wheel 100	Removed due to lack of picture clarity
whistle			100	whistle 100	Picture retained
window			100	window 100	Picture retained
stamp			100	stamp 100	Picture retained
barking			100	barking 100	Picture retained
catching		playing	90	catching 100	Picture retained
climbing	rock climbing		100	climbing 95; rock climbing 5	Picture retained
crawling			100	crawling 100	Picture retained
combing		cutting; shaving; working; trimming	75	combing 100	Removed due to lack of picture clarity
crying			100	crying 100	Picture retained
cutting			100	cutting 100	Picture retained
dancing			100	dancing 100	Picture retained
digging		hoeing	95	digging 100	Picture retained
diving			100	diving 100	Picture retained
drinking	sipping		100	drinking 90; sipping 10	Picture retained
driving			100	driving 100	Picture retained
drawing			100	diving 100	Picture retained
eating			100	eating 100	Picture retained
fishing			100	fishing 100	Picture retained
kicking		playing football	95	kicking 100	Picture retained
knitting			100	knitting 100	Picture retained
laughing		hiding; covering; facepalming	85	laughing 100	Picture retained
painting			100	painting 100	Picture retained
peeling			100	peeling 100	Picture retained
pointing			100	pointing 100	Picture retained
pouring		watering	85	pouring 100	Picture retained
pushing		stretching	95	stretching 100	Picture retained
raking		leaves; prodding; gardening	85	raking 100	Picture retained
reading			100	reading 100	Picture retained
ringing	bellringing		100	ringing 95; bellringing 5	Picture retained
running	sprinting		100	running 95; sprinting 5	Picture retained
sewing		threading	95	sewing 100	Picture retained
shaving			100	shaving 100	Picture retained

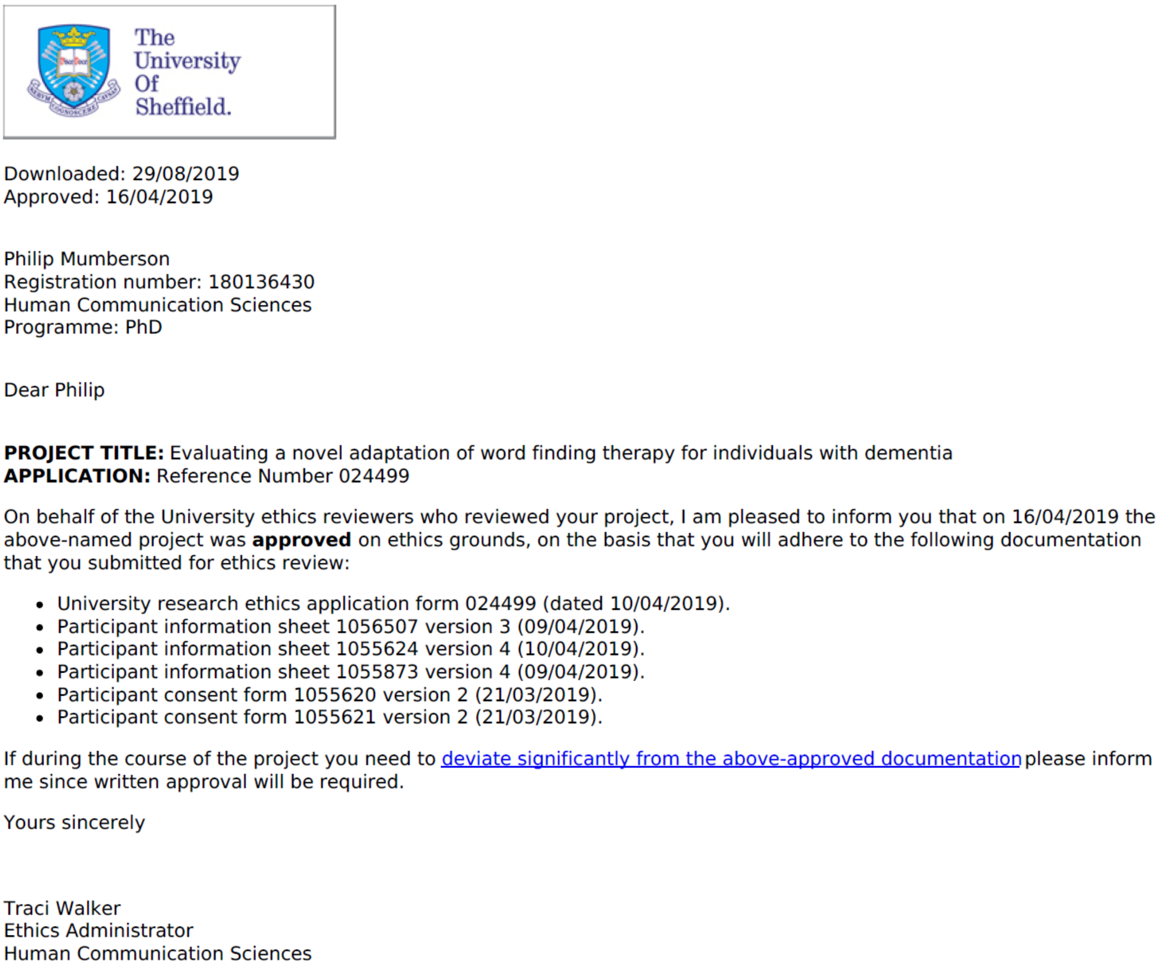
skating	roller skating		100	skating 60 roller skating 40	Picture retained
skiing			100	skiing 100	Picture retained
swimming			100	swimming 100	Picture retained
tying	lacing shoes	dressing	90	tying 94.7; lacing 5.3	Picture retained
walking			100	walking 100	Picture retained
washing			100	washing 100	Picture retained
watering			100	watering 100	Picture retained
waving			100	waving 100	Picture retained
weighing			100	weighing 100	Picture retained
writing			100	writing 100	Picture retained
yawning		crying; shouting	90	yawning 100	Picture retained
smiling		sitting	95	smiling 100	Picture retained
singing			100	singing 100	Picture retained

Total number of accepted object picture items = 78

Total number of accepted action picture items = 41

Total number of picture items = 119

Appendix C - Phase 1 ethical approval confirmation letter



Downloaded: 29/08/2019
Approved: 16/04/2019

Philip Mumberson
Registration number: 180136430
Human Communication Sciences
Programme: PhD

Dear Philip

PROJECT TITLE: Evaluating a novel adaptation of word finding therapy for individuals with dementia
APPLICATION: Reference Number 024499

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 16/04/2019 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 024499 (dated 10/04/2019).
- Participant information sheet 1056507 version 3 (09/04/2019).
- Participant information sheet 1055624 version 4 (10/04/2019).
- Participant information sheet 1055873 version 4 (09/04/2019).
- Participant consent form 1055620 version 2 (21/03/2019).
- Participant consent form 1055621 version 2 (21/03/2019).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Traci Walker
Ethics Administrator
Human Communication Sciences

Appendix D - Phase 1 participant information sheet for people with dementia

The University Of Sheffield.

Alzheimer's Society United Against Dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Information for people with dementia

Research team

PhD student

Philip Mumberson pjmumberson1@sheffield.ac.uk

Project leads
Dr Catherine Tattersall c.tattersall@sheffield.ac.uk

Dr Ruth Herbert r.herbert@sheffield.ac.uk

Place

Human Communication Sciences

University of Sheffield

362 Mushroom Lane

Sheffield

S10 2TS

Project

People with **dementia** can **forget words**. This makes talking more difficult.

We are trying a new way of **remembering words.** We want to **find out** it will help people with dementia.

People with dementia can **take part**.

We also need your **friend or relative**

What will happen

You will usually come to the Human Communication Sciences Department clinic about **15 times.**

Each time will take up to **1 ½ hours**.

You will do **assessments**. You will do **practice sessions**. These will be with **Philip**.

You will be involved for about **8 months.**

You will **choose 60 words** that are important to you. We will help you choose.

Assessments

Assessments will happen **5 times**.

We will **record your voice** on some of your assessments.

Practice sessions

You will do **practise sessions** naming words. There will be **10 practice sessions**.

In the practice sessions you will play games with the picture cards.

We will see if it helps you **name the word**.

You will also **practise the word games at home.**

We will ask your **friend/relative** to help. They will help with **assessment** and in **practice sessions**.

Philip will **interview** your friend/relative at different times to find out how well they feel you talk.

Taking part

You **don't** have to take part. You can **choose.**

You can still go to your **usual activities or groups** even if you don't take part.

You can **stop** at any time.

You can have a **rest** at any time.

What are the possible risks of taking part?

You may find sessions are **tiring** or **repetitive**.

You may find it **upsetting** when answering questions.

You can take a break, or stop the session completely.

What are the possible benefits of taking part?

There might be **no benefits** of taking part. We hope you will be able to name the cards better at the end.

However, you will be helping with **dementia research** treatments for communicating with dementia.

You may **enjoy** the assessment and the opportunity to take part in **therapy sessions**.

Your information

We will use your information to **tell people** about the research. This includes your **voice recording** if you say this is ok.

Your information will be used in **published reports** and **conference presentations**. It may also be used for **teaching.**

We will **not use your name** in reports. We will use a **code** instead. This means **you won't be identified** in reports.

'John' ✗

'PwD1' ✓

We will store your information on a **secure computer** or in a **locked cabinet**.

Your information may be **used again in future if you say this is ok**, but you won't be identified. This includes your **voice recording**.

Your information may be used by **members of the research** team for **research**, or for **teaching**.

The **legal basis** to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). **Further information** can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

As we will be collecting some data that is defined in the legislation as more sensitive (information about your health), we also need to let you know that we are applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

The University of Sheffield will act as the **Data Controller** for this study. This means that the University is responsible for looking after your information and using it properly.

This project has been **ethically approved** via the University of Sheffield's Ethics Review Procedure, as administered by the Department of Human Communication Sciences.

Questions

If you have questions, you can ask:

Philip - pjmumberson1@sheffield.ac.uk (email)

Catherine - c.tattersall@sheffield.ac.uk (email) 0114 22 22446 (phone)

Ruth – r.herbert@sheffield.ac.uk (email)

Complaints

Contact Catherine or Ruth to complain about this project at first.

Appendix E - Phase 1 participant information sheet for communication partners

PhD Project: *'Evaluating a novel adaptation of word finding therapy for individuals with dementia'.*

Department of Human Communication Sciences, University of Sheffield.

Information for friends/relatives of people with dementia

Would you like to take part in our research project?

Before you decide, please read this leaflet. It explains why the research is being done, and what is involved.
Ask us if anything is not clear or if you would like more information. Take time to decide whether you want to take part.

What is the project for?

People with dementia may struggle to think of the words they want to say. This can make talking more difficult, causing frustration and loneliness.

This project involves trying a particular type of speech and language therapy mostly used with people who have difficulty talking after a stroke, when it can be very successful. We want to use this therapy for people with dementia to see if it can help with their word finding difficulties as well.

This research is part of a PhD project, which is planned to finish by October 2021. Participants would be involved for about 8 months.

Why have I been chosen?

You have been chosen to take part in this project because your friend/relative with dementia is interested in taking part and you are a have regular conversations with them.

You are able to participate in home practice with the participant with dementia and can comment on their communication skills.

Do I have to take part?

No – you do not have to take part in the research. It's up to you to decide. This will not affect your care or that of your friend/relative with dementia in any way. For example, you will still be able to come to the Memory and Life Story Clinic at the university.

If you choose to start the project, you can still change your mind at any time, even after signing your consent form. You can do this by telling us that you don't want to be involved. If you leave the project part way through, and you would like us to remove your information from the project we will try to do this. However, we may not be able to take your anonymous information out of project reports.

What will happen to me if I take part?

You will take part in assessments, therapy, and home practice with your friend/relative with dementia.

Assessment sessions and therapy sessions will be with the with the PhD student, Philip, who is a qualified Speech and Language Therapist.

They will usually take place at the clinic in the Department of Human Communication Sciences, University of Sheffield. If you are unable to get to clinic, such as if you are house-bound or live in a care home, sessions can be arranged for somewhere convenient.

There will be about 15 sessions. Sessions will last no longer than 1 ½ hours. You can take a break or stop at any time.

Travel expenses are available for you to travel to the University clinic on every occasion.

What is the assessment?

Assessment will involve having a conversation with your friend/relative with dementia. This is to see how your friend/relative with dementia communicates with you in everyday conversation.

What is the therapy?

This speech and language therapy aims to help people with dementia remember important words, and use these to have better conversations.

This is done by playing a game using picture cards. To play the game, each person has a set of the picture cards and puts a barrier between each other. This means they can't see each other's cards.
People then ask each other if they have a certain card: "do you have...?" followed by the name of the picture on the card. If yes, they then give the card to the person who asked. This means they have to practise saying the word.

You will help your friend/relative with dementia choose 60 words that are important to them. Words might be important objects like 'coffee', or 'dog'. We then make picture cards with photographs of each object.

You will both also complete home practice to try to help your friend/relative to learn as many of the 60 words as they can.

What are the possible risks of taking part?

You may find that some of the assessments are tiring or repetitive. You may find it distressing when answering questions. You may find it upsetting if your friend/relative's communication skills decline throughout the process. If you become tired or have any concerns, you can take a break, or stop the session completely.

What are the possible benefits of taking part?

There may not be any immediate benefits of taking part, but we hope to see improvements in word retrieval by the end of the therapy. However, you will be helping to research treatments for communicating with dementia. You may enjoy the assessment and the opportunity to take part in therapy sessions.

When will I be involved?

You will have a conversation with your friend/relative with dementia. This is to see how well they communicate at the start.
You will talk to Philip about how successfully your friend/relative with dementia communicates.

Group A	**Group B**
Take part in therapy sessions with home practice **now.**	Take part in trial therapy and home practice in **6 weeks' time**. (Everyone will have the same amount of therapy).

You will have a conversation with your friend/relative with dementia. This is to see how well they communicate.

Group A	**Group B**
Continue home practice – no therapy sessions now.	Take part in trial therapy and home practice now

You will have a conversation with your friend/relative with dementia. This is to see how well they communicate with you at this point.

At about 6 months following the therapy sessions, you will have a conversation with your friend/relative with dementia. This is to see how well they communicate with you at this point.
You will talk to Philip about how successfully your friend/relative with dementia communicates.

Will I be recorded? How will this be used?

At the assessment sessions, if you agree, we will record your voices only. We will tell you each time before we record. Recordings help us look back at what was said later.
A written script will be made of your audio recordings. This written script will not identify you. Your audio recording will be kept securely during and after the project.

With your agreement, we may also use your audio recording in conference presentations or for future research and teaching. You will not be identified. We will delete your recording at the end of the project if you ask us.

Will my information in this project be kept confidential?

All the information that we collect about you will be kept strictly confidential. Your responses to the case history and assessment questions will be written down. Your information may be used in reports, publications or conferences, but you will not be identified. Audio recordings will not identify you by name, but it may be possible for someone to recognise your voice or know who you are from something you say.

You will not be identified in any reports or publications. If you agree to us sharing the information you provide, your personal details will not be included.

What will happen to the data collected, and the results of the research project?

At the end of the project, if you agree, we will keep your audio recordings and the other information we have collected about you. This will be stored securely. This information may be used by members of the research team for other research or for teaching after the project has finished, but it won't be able to identify you.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who is organising and funding the research?

This project is funded by an Alzheimer's Society PhD studentship.

The project leads are Dr Catherine Tattersall and Dr Ruth Herbert at the Department of Human Communication Sciences, University of Sheffield.
The PhD student is Philip Mumberson.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the Department of Human Communication Sciences. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

What if something goes wrong and I want to complain about the project?

If you would like to make a complaint about the research project, in the first instance you should contact Dr Catherine Tattersall or Dr Ruth Herbert (project leads).

If this complaint has not happy with this, you can contact the Head of Department, Professor Patricia Cowell, who will then escalate the complaint. Email: p.e.cowell@sheffield.ac.uk

If your complaint relates to how the participants' personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Contact for further information

Philip Mumberson (PhD student)
Email: pjmumberson1@sheffield.ac.uk
Phone (reception): 0114 222 2418

Dr Catherine Tattersall (Project lead)	Dr Ruth Herbert (Project lead)
Email: c.tattersall@sheffield.ac.uk	Email: r.herbert@sheffield.ac.uk
Phone: 0114 22 22446	

Thank you for taking part in this project

Appendix F - Phase 1 consent form for people with dementia

The University Of Sheffield.

Alzheimer's Society
United Against Dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Consent form for people with dementia

Participant code

Consent Form	Tick ✓
I understand the **Information Sheet**	
I have asked any **questions**	
It is my **choice** to take part. I know **I don't have to** take part.	
I know **I can stop** taking part at any time.	
I agree that information I give will be used for **telling people about this research** and for **teaching**. This includes **published reports** and **conferences.** This information will be **anonymous**. My **name** will be kept **private.**	
I agree that my **voice** can be **recorded**. The **research team** will **listen** to the recording and **write down** what I say.	
I agree that **information** I give may be kept and used by members of the research team for **future research**. This information will be **not have my name**.	
I agree that **information** I give may be kept and used by members of the research team for **teaching.** This information will be **not have my name**.	
I agree that my **voice recording** may be kept and used by members of the research team for **future research**. This information will be **not have my name**.	
I agree that my **voice recording** may be kept and used by members of the research team for **teaching**. This information will be **not have my name**.	

I agree to take part in this research project

Participant name: ____

Participant signature: ____

Date: ______________________

Researcher name____

Researcher signature ____

Date______________________

Appendix G - Phase 1 consent form for communication partners

The University Of Sheffield.

Alzheimer's Society
United Against Dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Consent form for friends/relatives of people with dementia

Participant code

Consent Form	Tick ✓
I understand the **Information Sheet**	
I have asked any **questions**	
It is my **choice** to take part. I know **I don't have to** take part.	
I know **I can stop** taking part at any time.	
I agree that information I give will be used for **telling people about this research** and for **teaching**. This includes **published reports** and **conferences.** This information will be **anonymous**. My **name** will be kept **private.**	
I agree that my **voice** can be **recorded**. The **research team** will **listen** to the recording and **write down** what I say.	
I agree that **information** I give may be kept and used by members of the research team for **future research**. This information will be **not have my name**.	
I agree that **information** I give may be kept and used by members of the research team for **teaching.** This information will be **not have my name**.	
I agree that my **voice recording** may be kept and used by members of the research team for **future research**. This information will be **not have my name**.	
I agree that my **voice recording** may be kept and used by members of the research team for **teaching**. This information will be **not have my name**.	

I agree to take part in this research project

Participant name: ____

Participant signature: ____

Date: ______________________

Researcher name____

Researcher signature ____

Date______________________

Appendix H - Phase 1 email to group leaders explaining the project

Subject: Participants sought for dementia research.

Dear colleague.

I am a PhD student in the Department of Human Communication Sciences at the University of Sheffield.

We are researching whether a particular speech and language therapy approach can help people with dementia who have difficulty thinking of words when speaking.

We are recruiting participants to the project. We are looking for people with dementia who have a mild-moderate difficulty recalling the words they want to say. We also need to recruit their friend/relative to the study at the same time.

For more information, please see the attached flyer.

Please could you discuss this study with anyone at your group whom you think may be suitable? If suitable participants agree, please could you seek their permission to pass on their contact details to me, so that I can contact them to discuss it further? Alternatively, they can contact me directly by email.

If you have any queries, please contact me by return of email.

Many thanks for your time.

Philip Mumberson. PhD student on the project.

Appendix I - Phase 1 flyer promoting the project

The University Of Sheffield.

Alzheimer's Society United Against Dementia

Do you have **dementia**? Do you sometimes **forget words**?

Are you the **friend/relative** of someone with dementia?

Take part in dementia research

'Adapting word-finding therapy for people with dementia' – a PhD research project.

Who is needed?

1. **People with dementia** who have some **difficulties recalling words**.
2. Their **friend or relative** (or someone who they talk to regularly) is needed too.

They should have:

- No other medical history affecting their communication
- British English as their everyday language
- Understand the project plan and what is involved.

Who are the research team?

Dr Catherine Tattersall (Project Lead)

Dr Ruth Herbert (Project Lead)

Philip Mumberson (PhD student)

What will happen?

Choose words and practise trying to learn them.

Take part in **assessments** and **therapy** sessions with a qualified speech and language therapist.

Practise at home.

It will usually take place at **Philippa Cottam Communication Clinic** (University of Sheffield).

Attend about 15 times in around 8 months. Each time will be 1½ hours.

How do I find out more?

Talk to **[name]** at the **[name of group]**.

If you agree, [name] will give your contact details to the research team who will contact you to discuss being involved.

If you prefer, you can contact the research team directly – see below.

'Evaluating a novel adaptation of word finding therapy for individuals with dementia' / PhD Project / Department of Human Communication Sciences / University of Sheffield

Project leads: Dr Catherine Tattersall c.tattersall@sheffield.ac.uk / Dr Ruth Herbert r.herbert@sheffield.ac.uk

PhD student: Philip Mumberson pjmumberson1@sheffield.ac.uk / Phone: 0114 222 2418 (Reception)

Appendix J – Phase 1 rationale for the inclusion/exclusion criteria

Inclusion/exclusion criteria (source study in parenthesis)	**Participant response options**	**Required response for inclusion in this project**	**Rationale for inclusion**
Diagnosis of dementia (for people with dementia only)	Reported: Y/N	Y	To ensure that people with dementia have a diagnosis of dementia.
British English is everyday language (e.g. Bier 2009).	Reported: Y/N	Y	To enable assessments to be carried out in English.
Mild-moderate acquired language difficulty (for people with dementia only)	Reported: Y/N	Y	To ensure that a suitable level of acquired language difficulty exists, but which still allows for participants to consent and take part in assessment/therapy.
Any acquired language difficulty (for communication partner only)	Reported: Y/N	N	Participants must not have other significant acquired language difficulty as this may affect their ability to support assessment/therapy.
Any significant mental health difficulties (for people with dementia this does not include their dementia).	Reported: Y/N	N	To ensure no additional mental health conditions impact on (or are impacted on by) assessment/therapy/practice.
History of developmental speech/language disorder	Reported: Y/N	N	For people with dementia: to ensure no known developmental speech/language disorders are present to confound results. For communication partner: to ensure the communication partner is able to participate in therapy/practice sessions.
Sufficient vision and hearing (with correction if necessary etc) to take part in assessment/therapy.	Reported: Y/N	Y	Participants must have sufficient vision to see the study materials.

Any neurological conditions (in the case of people with dementia another than dementia).	Reported: Y/N	N	Participants must not have other neuro history as this may confound results.

Appendix K - Rationale for background/case history questions

Background case history question topic (example source study in parenthesis)	Participant response expected	Rationale for inclusion
Personal factors: age (Beales et al., 2016) ; sex (Hameister et al., 2017).	Reported by participant.	To identify which personal factors that are most important predictors of successful therapy (Jokel et al., 2014).
Left/right handedness (Bier et al., 2009)	Right/left; further discussion may include comment such as preferred kicking foot etc.	To compare participants' handedness on language performance.
Vision (with correction if necessary)	Reported: description	To provide contextual information regarding ability to complete therapy and home practice.
Hearing status	Reported: have hearing aids? If yes, routinely wear them?	To consider impact of hearing status on language. It was previously reported that management of hearing loss could prevent/delay dementia and that hearing loss increases dementia risk, although it is not clear whether hearing aids can alter this risk factor (Livingston et al., 2017)
Type of dementia diagnosis (other studies have specified specific type, e.g. PPA variant).	Alzheimer's disease, vascular, PPA (and variant), frontotemporal	Studies should determine and consider which type of dementia participants have and impact of therapy and language as different types of dementia may have different mechanisms/pathways for re-learning (Jokel et al., 2014).
Medications taken	Names of medications taken; further info may be given regarding when taken.	To consider impact of medication (in particular for dementia) on participants' performance.
Age at receipt of dementia diagnosis (Hameister et al., 2017) (and thus calculated time since diagnosis).	Years and months	To identify which personal factors are most important predictors of successful therapy (Jokel et al., 2014)

What dementia signs/symptoms did you first notice and when?	Reported: comment with times.	To compare performance with duration of reported dementia signs/symptoms (as distinct from age at diagnosis above).
Main difficulty because of their dementia	Reported: comment	To obtain a global context of the person with dementia's functional abilities/difficulties.
Length of time for noticeable word-finding difficulties (Hameister et al., 2017).	Reported: years and/or months.	To determine which personal factors (e.g. time post-onset) are most important predictors of successful therapy (Jokel et al., 2014).
What is/was your main employment? (Beales et al., 2016; Hameister et al., 2017)	Reported: Name of main occupation; to generate further comment possibly around education/training/career options available.	To determine which personal factors are most important predictors of successful therapy (Jokel et al., 2014) To consider whether lower education level increases relative risk of dementia as previously reported (Livingston et al., 2017).
Any other communication difficulties noted and length of time (Beales et al., 2016) Specifically: understanding of spoken language; understanding of written words and writing.	Reported: Difficulties understanding spoken language: Y/N plus comment. Difficulties understanding written words: Y/N plus comment. Difficulties writing: Y/N plus comment Other.	Provides subjective reported communicative context to any word-finding difficulties.
How many days per week do you usually have a full conversation e.g. with friend/relative/neighbour? When, how and with whom does this normally happen?	Reported: number of days and description.	To consider whether use of words in general conversation (without actually practising) may be enough for maintenance of learned words as previously reported (Heredia, Sage, Ralph, & Berthier, 2009).
Typical other social involvement/interaction/contacts	Reported: number of days per week; further	To consider whether use of words in general conversation (without actually practising) may

in a typical week (Bier et al., 2009).	comment of what this involves.	be enough for maintenance of learned words as previously reported (Heredia et al., 2009).
Is there anything else you want to tell us?	Reported: comment.	

Appendix L - Phase 1 eligibility screening and background/case history form for people with dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'
People with Dementia

Eligibility (as reported):

Diagnosis of dementia?	YES / NO
Any significant mental health difficulties?	YES / NO
Any other neurological history?	YES / NO
Sufficient hearing and vision to complete the assessment and therapy sessions?	YES / NO
Mild-moderate acquired language difficulty?	YES / NO
Any developmental speech or language difficulties?	YES / NO
British English is everyday language?	YES / NO

Eligible for project? YES / NO

Assigned participant code:

Background history (as reported):

About you:

1. How old are you?

2. What is your gender?

3. Are you right or left handed?

4. Do you need/wear glasses?

'Evaluating a novel adaptation of word finding therapy for individuals with dementia' / PhD Project / Department of Human Communication Sciences / University of Sheffield

Project leads: Dr Catherine Tattersall c.tattersall@sheffield.ac.uk / Dr Ruth Herbert r.herbert@sheffield.ac.uk
PhD student: Philip Mumberson pjmumberson1@sheffield.ac.uk / Phone: 0114 222 2418 (Reception)

5. Do you have any hearing difficulties or wear hearing aids?

6. What type of dementia do you have?

7. What medications do you take?

8. How old were you when you received your dementia diagnosis?

9. What dementia signs/symptoms did you first notice and when?

10. What is your main difficulty because of your dementia?

11. What is/was your main employment?

About your communication:

12. How old were you when you/others first noticed you forgetting words?

13. Do you have any other communication difficulties? When did these start?
    a. understanding what others say?

    b. understanding written words?

    c. Writing?

    d. Other?

14. How many days per week do you usually have a full conversation e.g. with friend/relative/neighbour? When, how and with whom does this normally happen?

15. Do you have hobbies that you are continuing to do?

16. Is there anything else you want to tell us?

Appendix M - Phase 1 eligibility screening for communication partners

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Communication Partner

Eligibility (as reported):

Any significant mental health difficulties?	YES / NO
Any significant neurological history?	YES / NO
Sufficient hearing and vision to complete the assessment and therapy sessions?	YES / NO
Any acquired language difficulty?	YES / NO
Any developmental speech or language difficulties?	YES / NO
British English is everyday language?	YES / NO

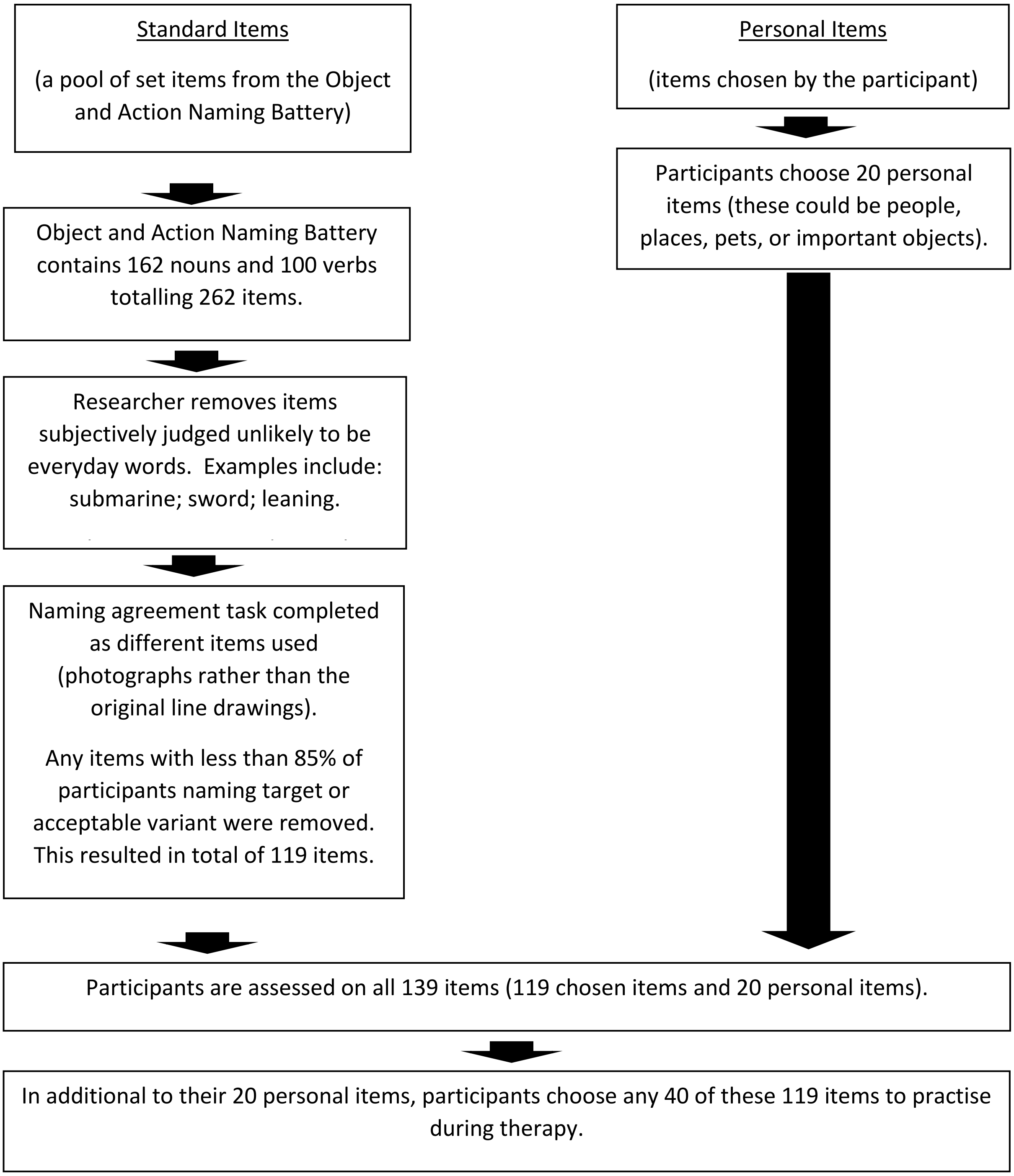
Eligible for project? YES / NO

Assigned code:

'Evaluating a novel adaptation of word finding therapy for individuals with dementia' / PhD Project / Department of Human Communication Sciences / University of Sheffield

Project leads: Dr Catherine Tattersall c.tattersall@sheffield.ac.uk / Dr Ruth Herbert r.herbert@sheffield.ac.uk
PhD student: Philip Mumberson pjmumberson1@sheffield.ac.uk / Phone: 0114 222 2418 (Reception)

Appendix N - Phase 1 flowchart for item selection



Standard Items

(a pool of set items from the Object and Action Naming Battery)

Object and Action Naming Battery contains 162 nouns and 100 verbs totalling 262 items.

Researcher removes items subjectively judged unlikely to be everyday words. Examples include: submarine; sword; leaning.

Naming agreement task completed as different items used (photographs rather than the original line drawings).

Any items with less than 85% of participants naming target or acceptable variant were removed. This resulted in total of 119 items.

Personal Items

(items chosen by the participant)

Participants choose 20 personal items (these could be people, places, pets, or important objects).

Participants are assessed on all 139 items (119 chosen items and 20 personal items).

In additional to their 20 personal items, participants choose any 40 of these 119 items to practise during therapy.

Appendix O - Choosing words to practise form

Choosing words to practise

1. Please choose 40 words to practise from the list below. Please circle these 40 words below.

Arm	Flower	Shirt	Eating
Ball	Fork	Shoe	Fishing
Banana	Fruit	Shower	Kicking
Basket	Gate	Spoon	Knitting
Bath	Guitar	Strawberry	Laughing
Beard	Hammock	Sun	Painting
Bed	House	Table	Peeling
Bee	Iron	Tent	Pointing
Belt	Kettle	Tie	Pouring
Bridge	Key	Tractor	Pushing
Bucket	Knot	Tree	Raking
butterfly	Leaf	Trumpet	Reading
Camera	Lion	Umbrella	Ringing
Castle	Box	Watch	Running
Cat	Map	Weights	Sewing
Chair	Money	Whistle	Shaving
Cheese	Pear	Window	Skating
Cherry	Pencil	Stamp	Skiing
Church	Piano	Barking	Swimming
Clock	Picture	Catching	Tying
Comb	Plug	Climbing	Walking
Cow	Pocket	Crawling	Washing
Curtain	Pram	Crying	Watering
Dog	Pyramid	Cutting	Waving
Door	Radio	Dancing	Weighing
Drum	Road	Digging	Writing
Envelope	Roof	Diving	Yawning
Eye	Sandwich	Drinking	Smiling
Fence	Scissors	Driving	Singing
Fish	Sheep	Drawing	

2. Please choose 20 personally relevant words to learn. These do not need to be in the list above. They may be important to you personally. Examples are names of your family, pets, places or hobbies. You can choose what they are. Please write them here:

1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
11.	
12.	
13.	
14.	
15.	
16.	
17.	
18.	
19.	
20.	

Please provide a photo of each of these 20 personal words.

Appendix P - Phase 1 50 item naming test data scoring sheet A

Naming and determining the most effective cue. **Scoring sheet (A)** (Participant code:_________)

No.	C	Item	Item group (1 or 2)	Without cue	First cue		Second cue	
1	V	Helicopter	2		Phoneme	Syllable	Semantic	
2	DA	Mouse	2		Phoneme	Syllable	Syllable	
3	LH	Toaster	1		Semantic		Phoneme	Syllable
4	LH	Suitcase	1		Semantic		Phoneme	Syllable
5	V	Bicycle	1		Semantic		Phoneme	Syllable
6	F	Apple	1		Semantic		Phoneme	Syllable
7	DA	Rabbit	1		Semantic		Phoneme	Syllable
8	V	Sledge	1		Semantic		Phoneme	Syllable
9	LH	Dustbin	2		Phoneme	Syllable	Semantic	
10	DA	Frog	2		Phoneme	Syllable	Semantic	
11	F	Tomato	1		Semantic		Phoneme	Syllable
12	V	Lorry	1		Semantic		Phoneme	Syllable
13	LH	Watering can	2		Phoneme	Syllable	Semantic	
14	F	Pineapple	2		Phoneme	Syllable	Semantic	
15	V	Bus	1		Semantic		Phoneme	Syllable

16	LH	Stool	2		Phoneme	Syllable	Semantic	
17	V	Train	2		Phoneme	Syllable	Semantic	
18	DA	Squirrel	1		Semantic		Phoneme	Syllable
19	DA	Horse	1		Semantic		Phoneme	Syllable
20	V	Motorbike	2		Phoneme	Syllable	Semantic	
21	LH	Barrel	1		Semantic		Phoneme	Syllable
22	V	Plane	2		Phoneme	Syllable	Semantic	
23	F	Orange	2		Phoneme	Syllable	Semantic	
24	FA	Tortoise	2		Phoneme	Syllable	Semantic	
25	T	Pliers	1		Semantic		Phoneme	Syllable
26	B	Penguin	2		Phoneme	Syllable	Semantic	
27	T	Axe	1		Semantic		Phoneme	Syllable
28	FA	Monkey	1		Semantic		Phoneme	Syllable
29	SH	Toothbrush	2		Phoneme	Syllable	Semantic	
30	B	Eagle	1		Semantic		Phoneme	Syllable
31	T	Saw	2		Phoneme	Syllable	Semantic	
32	FA	Rhino	1		Semantic		Phoneme	Syllable
33	B	Chicken	2		Phoneme	Syllable	Semantic	
34	T	Spanner	2		Phoneme	Syllable	Semantic	

35	FA	Kangaroo	1		Semantic		Phoneme	Syllable
36	SH	Glass	1		Semantic		Phoneme	Syllable
37	B	Duck	2		Phoneme	Syllable	Semantic	
38	FA	Camel	2		Phoneme	Syllable	Semantic	
39	B	Owl	1		Semantic		Phoneme	Syllable
40	T	Paintbrush	2		Phoneme	Syllable	Semantic	
41	FA	Tiger	1		Semantic		Phoneme	Syllable
42	B	Swan	2		Phoneme	Syllable	Semantic	
43	T	Screwdriver	1		Semantic		Phoneme	Syllable
44	FA	Elephant	2		Phoneme	Syllable	Semantic	
45	SH	Candle	1		Semantic		Phoneme	Syllable
46	B	Ostrich	1		Semantic		Phoneme	Syllable
47	FA	Alligator	2		Phoneme	Syllable	Semantic	
48	SH	Brush	2		Phoneme	Syllable	Semantic	
49	B	Peacock	1		Semantic		Phoneme	Syllable
50	T	Hammer	2		Phoneme	Syllable	Semantic	

Appendix Q - Phase 1 50 item naming test scoring sheet B

Naming and determining the most effective cue. **Scoring sheet (B)** (Participant code:__________)

No.	C	Item	Item group (1 or 2)	Without cue	First cue		Second cue	
1	V	Helicopter	2		Semantic		Phoneme	Syllable
2	DA	Mouse	2		Semantic		Phoneme	Syllable
3	LH	Toaster	1		Phoneme	Syllable	Semantic	
4	LH	Suitcase	1		Phoneme	Syllable	Semantic	
5	V	Bicycle	1		Phoneme	Syllable	Semantic	
6	F	Apple	1		Phoneme	Syllable	Semantic	
7	DA	Rabbit	1		Phoneme	Syllable	Semantic	
8	V	Sledge	1		Phoneme	Syllable	Semantic	
9	LH	Dustbin	2		Semantic		Phoneme	Syllable
10	DA	Frog	2		Semantic		Phoneme	Syllable
11	F	Tomato	1		Phoneme	Syllable	Semantic	
12	V	Lorry	1		Phoneme	Syllable	Semantic	
13	LH	Watering can	2		Semantic		Phoneme	Syllable
14	F	Pineapple	2		Semantic		Phoneme	Syllable
15	V	Bus	1		Phoneme	Syllable	Semantic	

16	LH	Stool	2		Semantic		Phoneme	Syllable
17	V	Train	2		Semantic		Phoneme	Syllable
18	DA	Squirrel	1		Phoneme	Syllable	Semantic	
19	DA	Horse	1		Phoneme	Syllable	Semantic	
20	V	Motorbike	2		Semantic		Phoneme	Syllable
21	LH	Barrel	1		Phoneme	Syllable	Semantic	
22	V	Plane	2		Semantic		Phoneme	Syllable
23	F	Orange	2		Semantic		Phoneme	Syllable
24	FA	Tortoise	2		Semantic		Phoneme	Syllable
25	T	Pliers	1		Phoneme	Syllable	Semantic	
26	B	Penguin	2		Semantic		Phoneme	Syllable
27	T	Axe	1		Phoneme	Syllable	Semantic	
28	FA	Monkey	1		Phoneme	Syllable	Semantic	
29	SH	Toothbrush	2		Semantic		Phoneme	Syllable
30	B	Eagle	1		Phoneme	Syllable	Semantic	
31	T	Saw	2		Semantic		Phoneme	Syllable
32	FA	Rhino	1		Phoneme	Syllable	Semantic	
33	B	Chicken	2		Semantic		Phoneme	Syllable
34	T	Spanner	2		Semantic		Phoneme	Syllable

35	FA	Kangaroo	1		Phoneme	Syllable	Semantic	
36	SH	Glass	1		Phoneme	Syllable	Semantic	
37	B	Duck	2		Semantic		Phoneme	Syllable
38	FA	Camel	2		Semantic		Phoneme	Syllable
39	B	Owl	1		Phoneme	Syllable	Semantic	
40	T	Paintbrush	2		Semantic		Phoneme	Syllable
41	FA	Tiger	1		Phoneme	Syllable	Semantic	
42	B	Swan	2		Semantic		Phoneme	Syllable
43	T	Screwdriver	1		Phoneme	Syllable	Semantic	
44	FA	Elephant	2		Semantic		Phoneme	Syllable
45	SH	Candle	1		Phoneme	Syllable	Semantic	
46	B	Ostrich	1		Phoneme	Syllable	Semantic	
47	FA	Alligator	2		Semantic		Phoneme	Syllable
48	SH	Brush	2		Semantic		Phoneme	Syllable
49	B	Peacock	1		Phoneme	Syllable	Semantic	
50	T	Hammer	2		Semantic		Phoneme	Syllable

Appendix R - Phase 1 therapy session recording form

Therapy session notes

Participant code:__________ Date:___________________ Session number:_____________

Game	Item	Shaping level (1, 2, 3, 4)	No cue	Cue (Phon/Syll/Sem)		
				1st	2nd	3rd
ONE						

Game	Item	Shaping level (1, 2, 3, 4)	No cue	Cue (Phon/Syll/Sem)		
				1st	2nd	3rd
TWO						

Game	Item	Shaping level (1, 2, 3, 4)	No cue	Cue (Phon/Syll/Sem)		
				1st	2nd	3rd
THREE						

Game	Item	Shaping level (1, 2, 3, 4)	No cue	Cue (Phon/Syll/Sem)		
				1st	2nd	3rd
FOUR						

Game	Item	Shaping level (1, 2, 3, 4)	No cue	Cue (Phon/Syll/Sem)		
				1st	2nd	3rd
FIVE						

Game	Item	Shaping level (1, 2, 3, 4)	No cue	Cue (Phon/Syll/Sem)		
				1st	2nd	3rd
SIX						

Appendix S - Phase 1 home practice recording form

Home practice record   Participant code(s):

Please record your home practice here. Thank you.

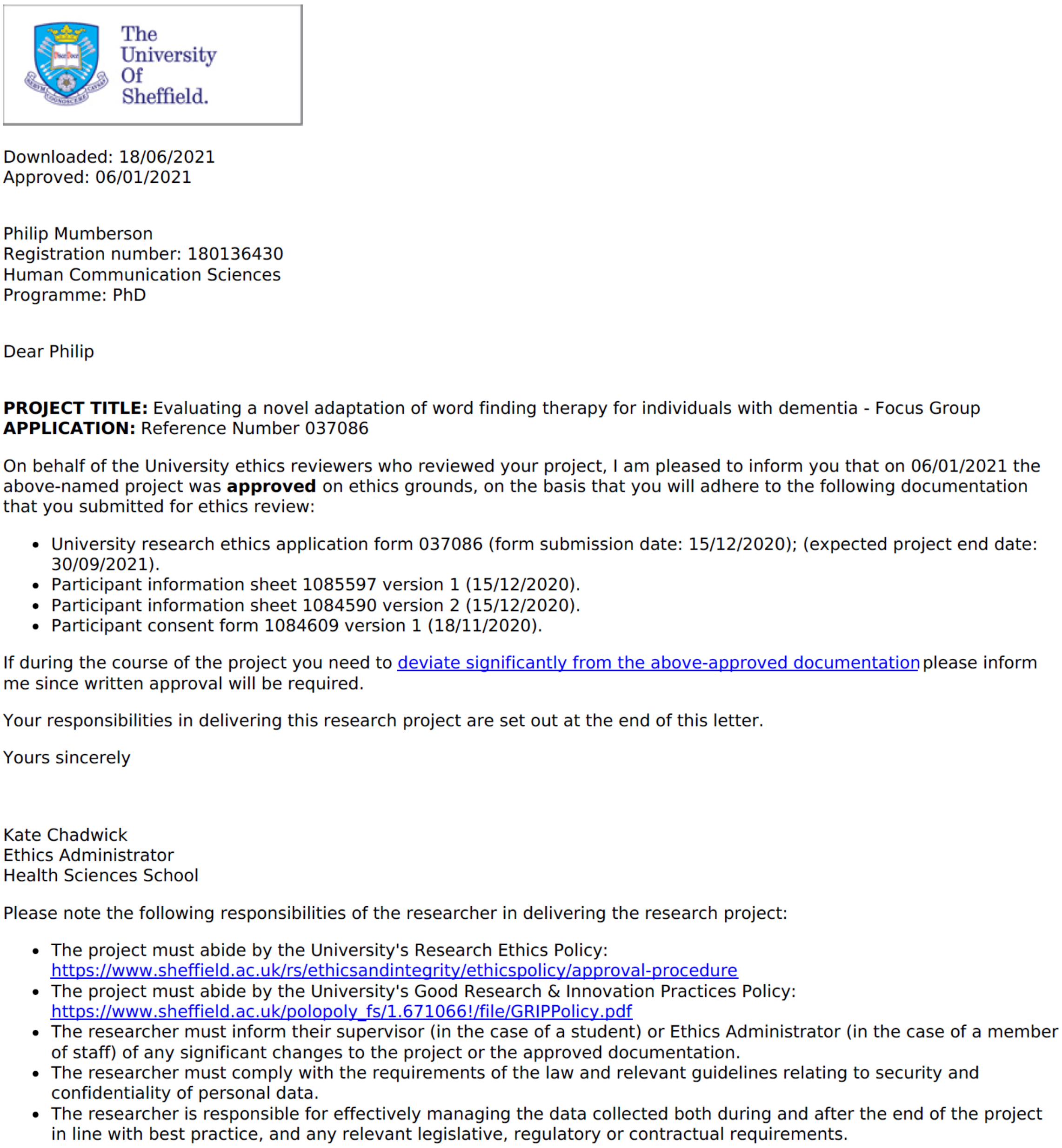
Date	Time practised (for example: twice for half an hour each time)	Any comments on the game today?

Weekly rating scale

In general how has your communication been this week? Please circle one number.

0	1	2	3	4	5	6	7	8	9	10
Very Poor					Average					Very good
☹					😐					☺

Appendix T - Focus group ethical approval confirmation letter



The University Of Sheffield.

Approved: 06/01/2021

Philip Mumberson
Registration number: 180136430
Human Communication Sciences
Programme: PhD

Dear Philip

PROJECT TITLE: Evaluating a novel adaptation of word finding therapy for individuals with dementia - Focus Group
APPLICATION: Reference Number 037086

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 06/01/2021 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 037086 (form submission date: 15/12/2020); (expected project end date: 30/09/2021).
- Participant information sheet 1085597 version 1 (15/12/2020).
- Participant information sheet 1084590 version 2 (15/12/2020).
- Participant consent form 1084609 version 1 (18/11/2020).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Kate Chadwick
Ethics Administrator
Health Sciences School

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix U - Focus group participant information sheet

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Phase 2: Focus Group

Information for participants

Research team

PhD student

Philip Mumberson pjmumberson1@sheffield.ac.uk

Project lead
Dr Catherine Tattersall c.tattersall@sheffield.ac.uk

The Project

People with **dementia** can **forget words**. This makes talking more difficult.

Recently, you spent time playing a **card game** to practise remembering words. You saw Philip at the University to play the game. .

Since then, we have made a **guide** to help people **play the card game** with someone at **home**.

We would like **your help** to **improve the guide**.

What will happen

1. We will send you a **copy** of the **guide** we have made. You will have time to look at it carefully.

2. You will join **a focus group**. A focus group is when a **small group** of people **meet up** to talk about something.
   We want to know what you think about playing the game at home. We also want to know what you think about the guide we have made.

You will have **one or two video calls**, depending on how long they last**.**

Philip will be on the video call. There will be **other participants** on the video call.

This means **other participants** on the video call can **see you** and **hear you.**

You will use **your computer** at **your home.** The video call will take up to about **1 hour**.

If everyone at the meeting agrees, we will **record your voice**.

What are the possible risks of taking part?

You may find session **tiring**.

You can take a **break**, or **stop** the session completely.

What are the possible benefits of taking part?

There might be **no benefits** of taking part.

However, you will be helping with **dementia research**.

You may **enjoy** taking part.

Taking part

You **don't** have to take part. You can **choose.**

❌

You can still get involved in other **activities or groups** even if you don't take part.

You can have a **rest** at any time.

You can **stop the video call** at any time. If you stop the video call, it may continue with the other participants, or it may be rearranged for another day.

Your information

We will use your information to **tell people** about the research. This includes your **voice recording** if you say this is ok.

Your information will be used in **published reports** and **conference presentations**. It may also be used for **teaching.**

We will **not use your name** in reports. ⊗

We will use a **code** instead. This means **you won't be identified** in reports.

We will store your information on a **secure computer system**.

Your information may be **used again in future if you say this is ok**, but you won't be identified. This includes your **voice recording**.

Your information may be used by **members of the research** team for **research**, or for **teaching**.

The **legal basis** to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). **Further information** can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

The University of Sheffield will act as the **Data Controller** for this study. This means that the University is responsible for looking after your information and using it properly.

This project has been **ethically approved** via the University of Sheffield's Ethics Review Procedure, as administered by the School of Health Sciences.

This project is funded by the **Alzheimer's Society** with support from **Healthcare Management Trust**.

This is a **PhD** project.

Questions

If you have questions, you can ask:

Philip - pjmumberson1@sheffield.ac.uk (email)

Catherine - c.tattersall@sheffield.ac.uk (email)

Complaints

Contact Catherine to complain about this project at first.

If you are not happy with this, you can contact the Head of Division, Dr Judy Clegg, who will then escalate the complaint. Email: j.clegg@sheffield.ac.uk

If your complaint relates to how the participants' personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Appendix V - Focus group participant information sheet (extended version)

Participant Information Sheet

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Phase 2: Focus Group

You are being invited to take part in a research project. Before you decide whether or not to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

1. What is the project's purpose?

People with dementia can forget words. This makes talking more difficult.
Recently, you spent time playing a card game to practise remembering words. You saw Philip at the University to play the game. Since then, we have made a guide to help people play the card game with someone at home.
We would like your help to improve the guide.
This is part of a PhD project.

3. Why have I been chosen?

You have been chosen because you have experience of completing the therapy game face-to-face with the researcher. This means you can comment on how well the guide works.

4. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and we will audio record your consent) and you can still withdraw at any time without any negative consequences. You do not have to give a reason. If you wish to withdraw from the research, please contact the researcher.
You can still get involved in other activities or groups even if you don't take part.
You can have a rest at any time.
You can stop the video call at any time. If you choose to end the video call the video call may continue with the other participants, or it may be agreed to rearrange for another day.

Please note that that by choosing to participate in this research, this will not create a legally binding agreement, nor is it intended to create an employment relationship between you and the University of Sheffield.

5. What will happen to me if I take part? What do I have to do?

We will send you a copy of the guide we have made. You will have time to look at it carefully. You will join a focus group. A focus group is when a small group of people meet up to talk about something.

We want to know what you think about playing the game at home. We also want to know what you think about the guide we have made.
You will have one or two video calls, depending on how long they last.
Philip will be on the video call. There will be up to four other participants on the video call too.
This means other participants on the video call can see you and hear you.
You will use your computer at your home. The video call will take up to about 1 hour.
If everyone at the meeting agrees, we will record your voice.

6. What are the possible disadvantages and risks of taking part?

You may find session tiring. You can take a break, or stop the session completely.

7. What are the possible benefits of taking part?

There may be no benefits from taking part. However, you will be helping with dementia research. You may enjoy taking part.

8. Will my taking part in this project be kept confidential?

We will use your information to tell people about the research. This includes your voice recording if you say this is ok.
Your information will be used in published reports and conference presentations. It may also be used for teaching. We will not use your name in reports. We will use a code instead. This means you won't be identified in reports.

9. What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general

10. What will happen to the data collected, and the results of the research project?

We will store your information on a secure computer system.
Your information may be used again in future if you say this is ok, but you won't be identified. This includes your voice recording.
Your information may be used by members of the research team for research, or for teaching.

11. Will I be recorded, and how will the recorded media be used?

If everyone at the meeting agrees, we will record your voice. Your information may be used again in future if you say this is ok, but you won't be identified. This includes your voice recording.
Your information may be used by members of the research team for research, or for teaching.

12. Who is organising and funding the research?

This project is funded by the Alzheimer's Society with support from Healthcare Management Trust.

13. Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

14. Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the School of Health Sciences.

15. What if something goes wrong and I wish to complain about the research?

Contact Catherine to complain about this project at first.
If you are not happy with this, you can contact the Head of Division, Dr Judy Clegg, who will then escalate the complaint. Email: j.clegg@sheffield.ac.uk

If the complaint relates to how the participants' personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

16. Contact for further information

If you have questions, you can ask:
Philip - pjmumberson1@sheffield.ac.uk (email)
Catherine - c.tattersall@sheffield.ac.uk (email)

You will be given a copy of this information sheet to keep.

Thank you for taking part in the project.

Appendix W - Focus group consent form

The University Of Sheffield.

Alzheimer's Society United Against Dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Phase 2: Online Focus Group

Recording of verbal consent form

Participant Name: Click or tap here to enter text.

Consent Form – questions for participant	**Yes, I agree**	**No, I disagree**
Do you understand the **Information Sheet about this project?**	☐	☐
Have you asked any **questions you have?**	☐	☐
Do you know it is your **choice** to take part and that you **don't have to** take part?	☐	☐
Do you know you **can stop** taking part at any time?	☐	☐
Information you give will be used for **telling people about this research** and for **teaching**. This includes **published reports** and **conferences.** This information will be **anonymous**. Your **name** will be kept **private.** Do you agree?	☐	☐
Information you give may be kept and used by members of the research team for **future research**. This information will be **not have your name**. Do you agree?	☐	☐
Information you give may be kept and used by members of the research team for **teaching.** This information will be **not have your name**. Do you agree?	☐	☐
Do you **agree** to **take part** in **this project?**	☐	☐

For Researcher Use

The information leaflet has been provided and the project discussed with the participant named above.

Verbal consent to take part in the project has been agreed with the participant named above.

Researcher name: Click or tap here to enter text.

Researcher typed signature: Click or tap here to enter text.

Date : Click or tap here to enter text.

Appendix X - Final version of the guide to completing the therapy

Word-finding therapy for people with dementia:

Guide to playing the game

Division of Human Communication Sciences,

University of Sheffield.

The author is funded through a PhD studentship grant from the Alzheimer's Society with support from Healthcare Management Trust.

Word finding difficulties

People with dementia may **struggle to think of the words** they want to say. This makes it **harder to make their needs known**

This is caused by a language difficulty called **aphasia**.

It can mean **isolation** and **frustration** for both the person with dementia and their friends/family.

What might help?

You can try a type of **speech and language therapy** It is called **constraint-induced aphasia therapy (CIAT).**

It has been used for people with **aphasia** following a **stroke**. We want to see whether it helps people with **dementia**.

It is based on the following **principles** during **therapy sessions**:

- Only saying the **actual name** of the object
- Having lots of **intensive practice at home** with **someone you know**
- **Choosing words** that are **important** to the person.

This is often done by **playing a game** using **picture cards.**

Before you start

You should **choose words** that are **important** to you. Words might be **important objects** like 'coffee', or 'dog'. Or, they might be the **names of friends**.

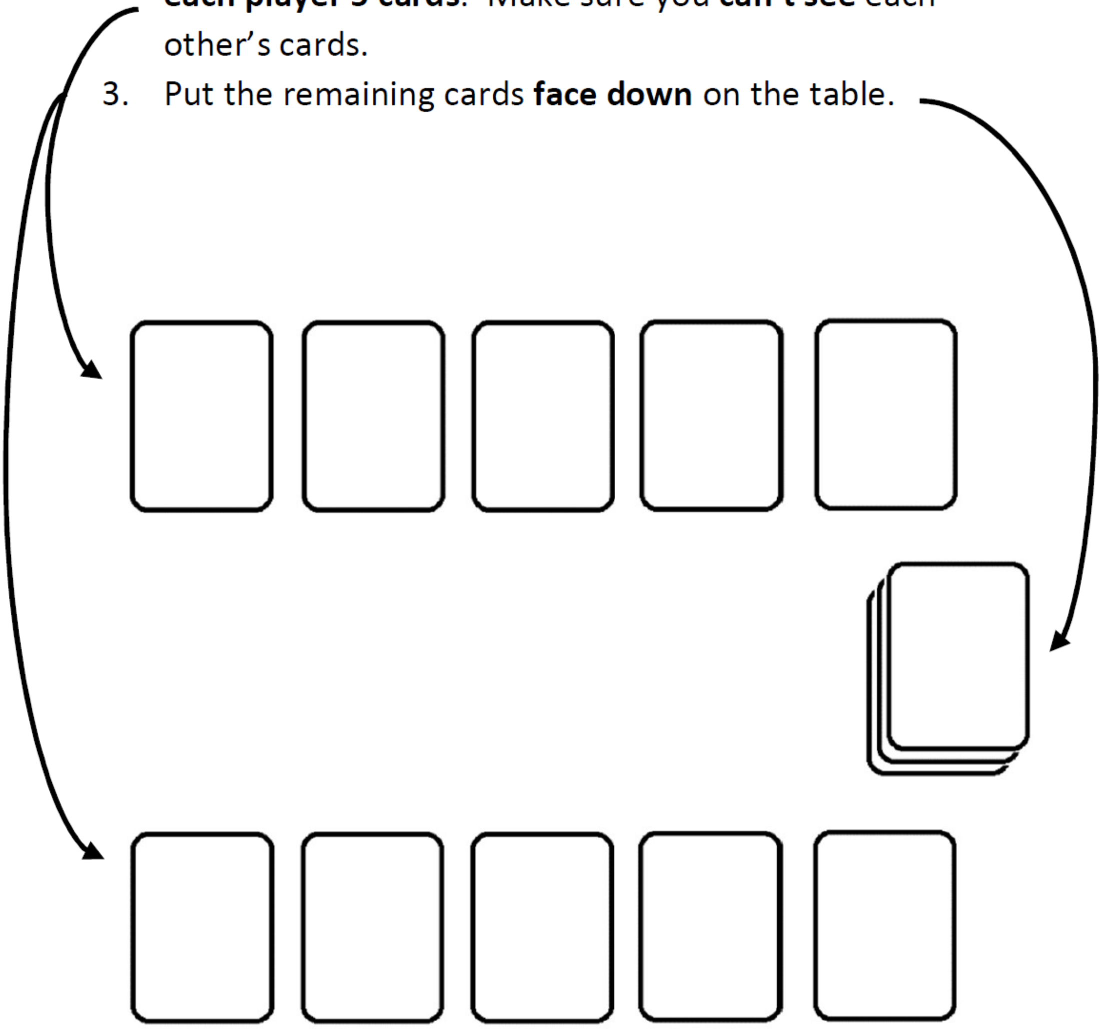
Choose 60 words, if you can.

Find a **photo** for **each word**. For example, you could take a photo of your friend, or items around your house.

You need **2 copies** of each **picture card**. Each card should be about this size.

Getting started

1. **Sort** the cards into **matching pairs**. **Split** them into **equal groups** of **10 pairs** of cards. This means there will be 20 cards in each group. **Each group** of cards is for **one game**.
2. Take **one group** of 20 cards. **Shuffle** the cards. Give **each player 5 cards**. Make sure you **can't see** each other's cards.
3. Put the remaining cards **face down** on the table.

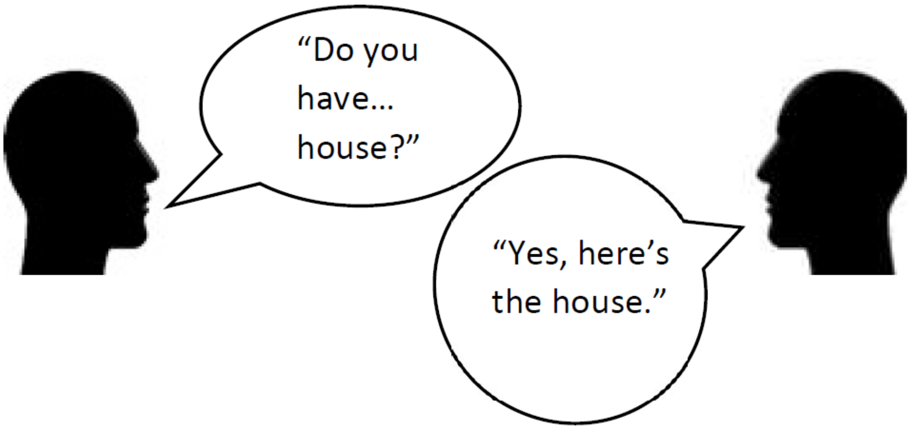


The therapy game

The therapy game is based on the popular Go Fish card game.

Take turns to ask each other if they have a certain card:

"do you have…?" followed by the **name of the picture** on the card. This means they have to **practise saying the word**.



- If **<u>Yes</u>**, give the card to the player who asked. These 2 cards are **removed** from the game.
- If **<u>No</u>,** the player who asked **picks up** another card from the pile at the side.

The **game ends** when **one player** has **no cards** left. Try to include each pair of cards at least once when you play the game.

If you can, try to **practise** for **1½ hours each day** for **2 weeks**. **You** can **choose** how you do this. For example, you could practise for **30 minutes 3 times a day** if this is better for you.

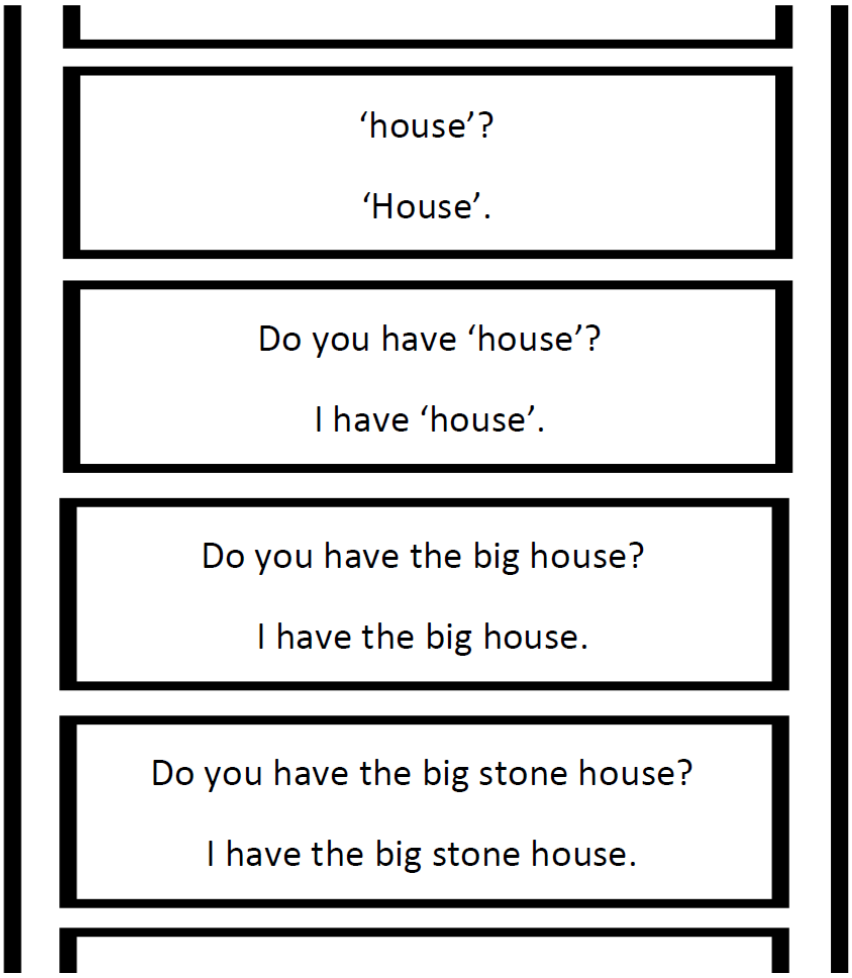
But if you get **tired**, or **don't want to continue**, you can **stop** at **any time.**

Making the game easier or more difficult

See the **example** below. You can **move up or down the ladder** to make things **easier** or **more difficult.**

You can do this when **asking** a question or when **answering** a question.

Try to **say** as **much** as **you can**.



‘house’?

‘House’.

Do you have ‘house’?

I have ‘house’.

Do you have the big house?

I have the big house.

Do you have the big stone house?

I have the big stone house.

How to help with naming a picture

If someone is **struggling to name a picture card,** you **can look** at their **card** to help them. Here are things **you could try**, with the **example** of **‘house’.**

- give the **first sound** of the word. If this doesn’t help, give the **first syllable**. For example:

  “It begins with ‘h…’”
  “It begins with ‘hou…’”

- **ask** the other person a **question** to help them **describe** it. This may **help** them to **remember** the word. For example:

  “What does it do?”
  “What is it made of?”

- **describe** it yourself, to see if this **prompts** the other person. For example:

  “It’s where people might live…”
  “It’s made of stone walls, with a tiled roof…”

If these **don’t work**, it is okay to **say the full name** of the **picture card** for the other person.

You could **encourage** the other person to **repeat saying the name** after you.

Tips for playing the game

If you can, try to ensure you **practise all the cards** during the therapy sessions.

If you can, try to **have a conversation** about the picture.

Try to **say** as **much** as you can.

Try to use **spoken language** only, if you can.

If possible, **don't** encourage **gesture, writing or drawing**.

If you need help with the therapy game

Please **contact**:

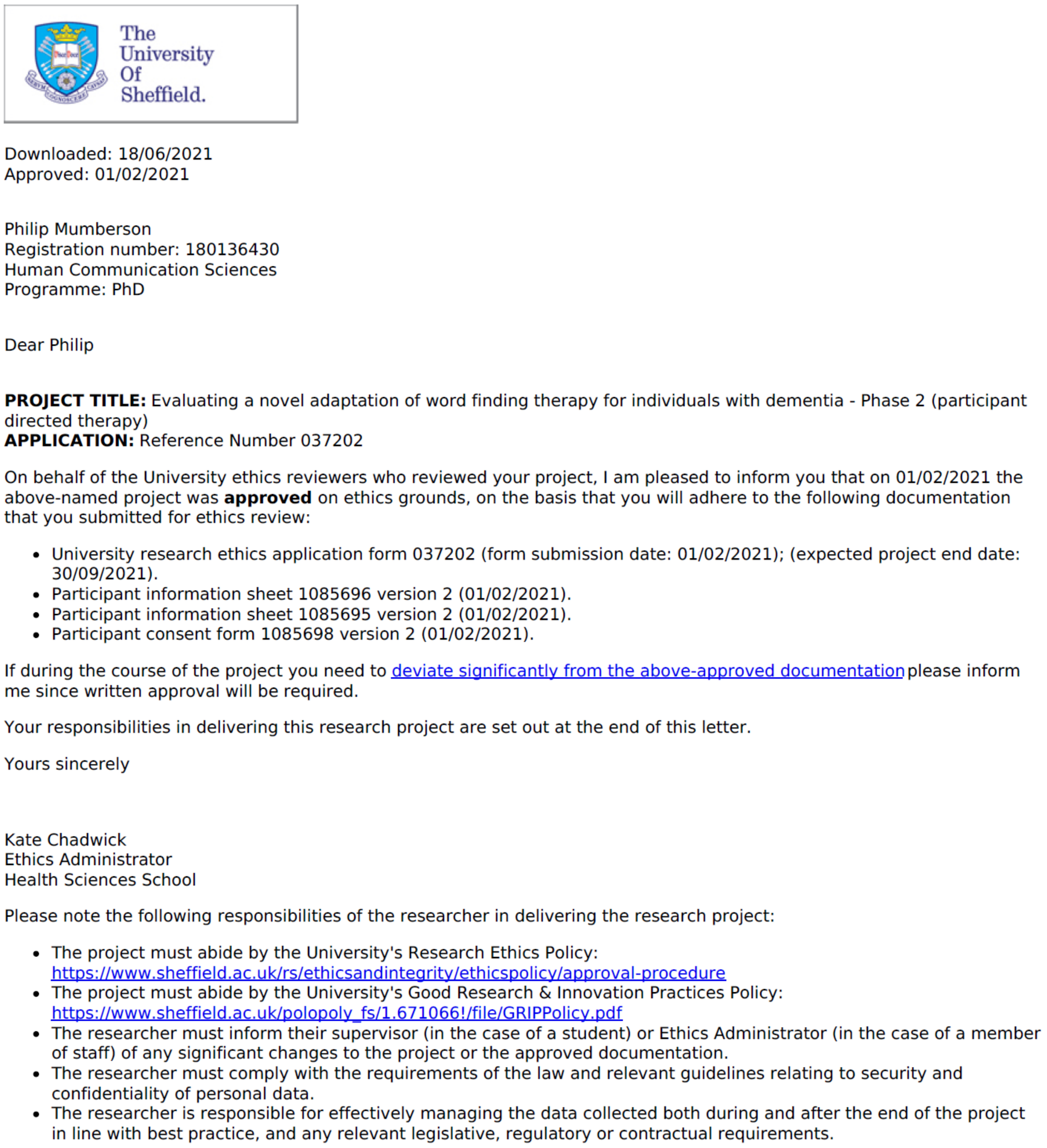
Philip Mumberson (PhD Student)

pjmumberson1@sheffield.ac.uk

Dr Catherine Tattersall (Research Lead)

c.tattersall@sheffield.ac.uk

Appendix Y - Phase 2 ethical approval confirmation letter



The University Of Sheffield.

Downloaded: 18/06/2021
Approved: 01/02/2021

Philip Mumberson
Registration number: 180136430
Human Communication Sciences
Programme: PhD

Dear Philip

PROJECT TITLE: Evaluating a novel adaptation of word finding therapy for individuals with dementia - Phase 2 (participant directed therapy)
APPLICATION: Reference Number 037202

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 01/02/2021 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 037202 (form submission date: 01/02/2021); (expected project end date: 30/09/2021).
- Participant information sheet 1085696 version 2 (01/02/2021).
- Participant information sheet 1085695 version 2 (01/02/2021).
- Participant consent form 1085698 version 2 (01/02/2021).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Kate Chadwick
Ethics Administrator
Health Sciences School

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix Z - Phase 2 participant information sheet for people with dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Phase 2

Division of Human Communication Sciences, University of Sheffield.

Information for people with dementia

Research team

PhD student

Philip Mumberson pjmumberson1@sheffield.ac.uk

Project lead
Dr Catherine Tattersall c.tattersall@sheffield.ac.uk

Version 1 PD – 28/01/2021

Project

People with **dementia** can **forget words**. This makes talking more difficult.

We are trying a new way of **remembering words.** We want to **find out** it will help people with dementia.

People with dementia can **take part**.

We also need your **friend or relative**

What will happen

You will have **video calls** with **Philip .** You will use **your computer** at **your home.**

Each time will take up to about **1 hour**.

You will do **assessments**. You will do a **practice session**. These will be with **Philip**.

You will **practice playing the game** at home. Practise for **1½ hours per day for 2 weeks.**

This will be with a **friend** or **relative.** There will be **written guidelines** to help you.

You will be involved for about **3 or 4 weeks** in total**.**

You will **choose** to **practise 60 words** that are important to you. We will help you choose.

Assessments

Assessments will happen **before and after doing practice at home**.

You will try to **name pictures** of everyday words. You will do a **memory** assessment

Philip will **interview** your friend/relative at different times to find out how well they feel you talk.

We will **record your voice** on your assessments.

Practice session

You will do a **practise session** naming words. In the practice session you will learn to play a game with the picture cards.

Home practice

You will then practise playing the **word game** at home.

We will ask your **friend/relative** to help. They will help with **assessment** and doing **home practice**.

We will see if it helps you **name the words**.

Taking part

You **don't** have to take part. You can **choose.**

You can still get involved in other **activities or groups** even if you don't take part.

You can have a **rest** at any time.

You can **stop** home practice at any time.   You can **stop the video call** at any time.

What are the possible risks of taking part?

You may find sessions are **tiring** or **repetitive**.

You may find it **upsetting** when answering questions.

You can take a break, or stop the session completely.

What are the possible benefits of taking part?

There might be **no benefits** of taking part. We hope you will be able to name the cards better at the end.

However, you will be helping with **dementia research** treatments for communicating with dementia.

You may **enjoy** the assessments and playing the card game.

Your information

We will use your information to **tell people** about the research. This includes your **voice recording** if you say this is ok. It may also be used for **teaching.**

Your information will be used in **published reports** and **conference presentations**. It may also be used for **teaching.**

We will **not use your name** in reports. We will use a **code** instead. This means **you won't be identified** in reports.

'John' ⊗

'PwD1' ✓

We will store your information on a **secure computer** or in a **locked cabinet**.

Your information may be **used again in future if you say this is ok**, but you won't be identified. This includes your **voice recording**.

Your information may be used by **members of the research** team for **research**, or for **teaching**.

Any **personal photographs** you provide will be sent to the **University of Sheffield Print and Design Service** to produce the **therapy cards**.

The **legal basis** to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). **Further information** can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

As we will be collecting some data that is defined in the legislation as more sensitive (information about your health), we also need to let you know that we are applying the following condition in law: that the use of your data is **'necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j))**.

The University of Sheffield will act as the **Data Controller** for this study. This means that the University is responsible for looking after your information and using it properly.

This project has been **ethically approved** via the University of Sheffield's Ethics Review Procedure, as administered by the School of Health Sciences.

This project is funded by the **Alzheimer's Society** with support from **Healthcare Management Trust**.

This is a **PhD** project.

Questions

If you have questions, you can ask:

Philip - pjmumberson1@sheffield.ac.uk (email)

Catherine - c.tattersall@sheffield.ac.uk (email) or 0114 22 22446 (phone)

Complaints

Contact Catherine to complain about this project at first.

Appendix AA - Phase 2 participant information sheet for communication partners

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'. Phase 2

Division of Human Communication Sciences, University of Sheffield.

Information for friends/relatives of people with dementia

Would you like to take part in our research project?

Before you decide, please read this leaflet. It explains why the research is being done, and what is involved.

Ask us if anything is not clear or if you would like more information. Take time to decide whether you want to take part.

What is the project for?

People with dementia may struggle to think of the words they want to say. This can make talking more difficult, causing frustration and loneliness.

This project involves trying a particular type of speech and language therapy mostly used with people who have difficulty talking after a stroke, when it can be very successful. We want to use this therapy for people with dementia to see if it can help with their word finding difficulties as well.

This research is part of a PhD project, which is planned to finish by October 2021. Participants would be involved for about 3 or 4 weeks.

Why have I been chosen?

You have been chosen to take part in this project because your friend/relative with dementia is interested in taking part and you have regular conversations with them.

You are able to participate in home practice with the participant with dementia and can comment on their communication skills.

Do I have to take part?

No – you do not have to take part in the research. It's up to you to decide. This will not affect your care or that of your friend/relative with dementia in any way.

If you choose to start the project, you can still change your mind at any time, even after signing your consent form. You can do this by telling us that you don't want to be involved. If you leave the project part way through, and you would like us to remove your information from the project we will try to do this. However, we may not be able to take your anonymous information out of project reports.

Version CP 1 – 28/01/2021

What will happen to me if I take part?

You will take part in assessments and a therapy practice session. The therapy practice session will show you how to play a card game with your friend or relative with dementia. This will be done through video call from home using your computer. You will then complete word games with your friend/relative with dementia for 2 weeks. After this you will take part in more assessments to see if the therapy card game has worked.

Assessment sessions and the therapy practice session will be with the with the PhD student, Philip, who is a qualified Speech and Language Therapist. They will be via computer video calls from home.

You should try to practice at home for about 1½ hours per day for 2 weeks. However, you can take a break or stop at any time.

What is the assessment?

Assessment will involve discussing how your friend/relative with dementia communicates with you in everyday conversation. You may also support your friend/relative with their assessments.

What is the therapy?

This speech and language therapy aims to help people with dementia remember important words, and use these to have better conversations.

You will help your friend/relative with dementia choose 60 words that are important to them. We will help you choose. We then make picture cards with photographs of each object.
You will both complete home practice to try to help your friend/relative to learn as many of their chosen words as they can.

This is done by playing a game using picture cards. To play the game, each person has a set of the picture cards and puts a barrier between each other. This means they can't see each other's cards.
People then ask each other if they have a certain card: "do you have…?" followed by the name of the picture on the card. If yes, they then give the card to the person who asked. This means they have to practise saying the word.

What are the possible risks of taking part?

You may find that some of the assessments are tiring or repetitive. You may find it distressing when answering questions. You may find it upsetting if your friend/relative's communication skills decline throughout the process. If you become tired or have any concerns, you can take a break, or stop the session completely.

What are the possible benefits of taking part?

There may not be any immediate benefits of taking part, but we hope to see improvements in word retrieval by the end of the therapy. However, you will be helping to research treatments for communicating with dementia. You may enjoy the assessments and playing the therapy game.

Will I be recorded? How will this be used?

At the assessment sessions, if you agree, we will record your voices only. We will tell you each time before we record. Recordings help us look back at what was said later.
A written script may be made of your audio recordings. This written script will not identify you. Your audio recording will be kept securely during and after the project.

With your agreement, we may also use your audio recording in conference presentations or for future research and for teaching. You will not be identified. We will delete your recording at the end of the project if you ask us.

Will my information in this project be kept confidential?

All the information that we collect about you will be kept strictly confidential. Your responses to the case history and assessment questions will be written down. Your information may be used in reports, publications or conferences, but you will not be identified. Audio recordings will not identify you by name, but it may be possible for someone to recognise your voice or know who you are from something you say.

You will not be identified in any reports or publications. If you agree to us sharing the information you provide, your personal details will not be included.

Any personal photographs you provide will be used by University of Sheffield Print and Design Service to produce the therapy cards.

What will happen to the data collected, and the results of the research project?

At the end of the project, if you agree, we will keep your audio recordings and the other information we have collected about you. This will be stored securely. This information may be used by members of the research team for other research or for teaching after the project has finished, but it won't be able to identify you.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who is organising and funding the research?

The project is funded through a PhD studentship grant from the Alzheimer's Society with support from Healthcare Management Trust.
The project lead is Dr Catherine Tattersall at the Division of Human Communication Sciences, University of Sheffield. The PhD student is Philip Mumberson.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the School of Health Sciences. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

What if something goes wrong and I want to complain about the project?

If you would like to make a complaint about the research project, in the first instance you should contact Dr Catherine Tattersall (project lead).

If this complaint has not happy with this, you can contact the Head of Division, Dr Judy Clegg, who will then escalate the complaint. Email: j.clegg@sheffield.ac.uk

If your complaint relates to how the participants' personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Contact for further information

Philip Mumberson (PhD student)
Email: pjmumberson1@sheffield.ac.uk

Dr Catherine Tattersall (Project lead)
Email: c.tattersall@sheffield.ac.uk

Phone: 0114 22 22446

Thank you for taking part in this project

Version CP 1 – 28/01/2021

Appendix BB - Phase 2 consent form

The
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Sheffield.

Alzheimer's Society
United Against Dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'

Phase 2

Recording of verbal consent form

Participant Name:
Click or tap here to enter text.

Consent Form – questions for participant	**Yes, I agree**	**No, I disagree**
Do you understand the **Information Sheet about this project?** Information sheet provided: Version CP 1 – 28/01/2021 ☐ Version PD 1 – 28/01/2021 ☐	☐	☐
Have you asked any **questions you have?**	☐	☐
Do you know it is your **choice** to take part and that you **don't have to** take part?	☐	☐
Do you know you **can stop** taking part at any time?	☐	☐
Information you give will be used for **telling people about this research**. This includes **published reports** and **conferences.** This information will be **anonymous**. Your **name** will be kept **private.** Do you agree?	☐	☐
Optional: **Information** you give may be kept and used by members of the research team for **future research**. This information will be **not have your name**. Do you agree?	☐	☐
Optional: **Information** you give may be kept and used by members of the research team for **teaching.** This information will be **not have your name**. Do you agree?	☐	☐
Do you **agree** to **take part** in **this project?**	☐	☐

For Researcher Use

The information leaflet has been provided and the project discussed with the participant named above.

Verbal consent to take part in the project has been agreed with the participant named above.

Researcher name: Click or tap here to enter text.

Researcher typed signature: Click or tap here to enter text.

Date : Click or tap here to enter text.

Appendix CC - Phase 2 email to group leaders explaining the project

Subject: Participants sought for dementia research.

Dear colleague.

I am a PhD student in the Division of Human Communication Sciences at the University of Sheffield.

We are researching whether a particular speech and language therapy approach can help people with dementia who have difficulty thinking of words when speaking.

We are recruiting participants to the project. We are looking for people with dementia who have a mild-moderate difficulty recalling the words they want to say. We also need to recruit their friend/relative to the study at the same time. They will take part from home by video call using their computer.

For more information, please see the attached flyer.

Please could you advertise this study (with the flyer) via your email lists as you feel appropriate? Also, please feel free to discuss this study with anyone at your group whom you think may be suitable. If suitable participants agree, please could you seek their permission to pass on their contact details to me, so that I can contact them to discuss it further? Alternatively, they can contact me directly by email.

If you have any queries, please contact me by return of email.

Many thanks for your time.

Philip Mumberson. PhD student on the project.

Appendix DD - Phase 2 email text for direct recruitment

Subject: Speech and language therapy research for people with dementia.

Hello.

I am a PhD student in the Division of Human Communication Sciences at the University of Sheffield.

People with dementia sometimes have difficulty thinking of words when speaking. We are researching whether a type of speech and language therapy can help.

We are now recruiting people with dementia who have a mild-moderate difficulty recalling the words they want to say. We also need to recruit their friend/relative to the study at the same time.

Participants will take part using their computer to receive video calls from the PhD student.

Participants will practise learning words at home by playing a therapy game using picture cards. Support will be given via a practice session video call with the researcher. A written guide will be provided to help. Participants will be assessed before and after playing the therapy game. This will be done by computer video calls between the researcher and the participants.

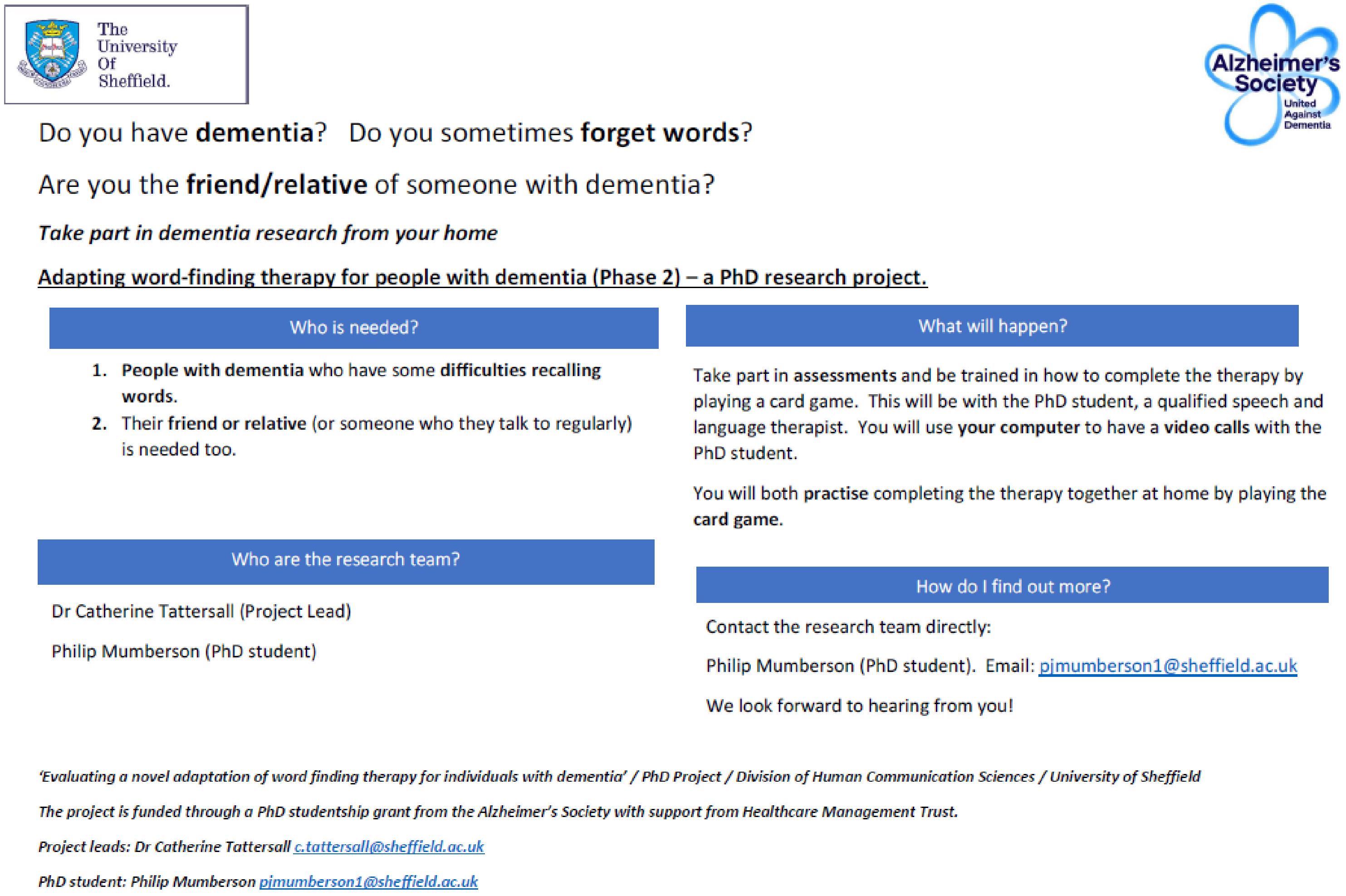
For more information, or for an initial chat about taking part in the project, please email me at pjmumberson1@sheffield.ac.uk

I look forward to hearing from you. Many thanks for your time.

Philip Mumberson. PhD student on the project.

This study has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the School of Health Sciences. The study is funded through a PhD studentship grant from the Alzheimer's Society with support from Healthcare Management Trust.

Appendix EE - Phase 2 flyer promoting the project



Do you have **dementia**? Do you sometimes **forget words**?

Are you the **friend/relative** of someone with dementia?

Take part in dementia research from your home

Adapting word-finding therapy for people with dementia (Phase 2) – a PhD research project.

Who is needed?

1. **People with dementia** who have some **difficulties recalling words**.
2. Their **friend or relative** (or someone who they talk to regularly) is needed too.

Who are the research team?

Dr Catherine Tattersall (Project Lead)

Philip Mumberson (PhD student)

What will happen?

Take part in **assessments** and be trained in how to complete the therapy by playing a card game. This will be with the PhD student, a qualified speech and language therapist. You will use **your computer** to have a **video calls** with the PhD student.

You will both **practise** completing the therapy together at home by playing the **card game**.

How do I find out more?

Contact the research team directly:

Philip Mumberson (PhD student). Email: pjmumberson1@sheffield.ac.uk

We look forward to hearing from you!

'Evaluating a novel adaptation of word finding therapy for individuals with dementia' / PhD Project / Division of Human Communication Sciences / University of Sheffield

The project is funded through a PhD studentship grant from the Alzheimer's Society with support from Healthcare Management Trust.

Project leads: Dr Catherine Tattersall c.tattersall@sheffield.ac.uk

PhD student: Philip Mumberson pjmumberson1@sheffield.ac.uk

Appendix FF - Phase 2 eligibility screening and background/case history form for people with dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'
Phase 2: Indirect Therapy

People with Dementia

Eligibility (as reported):

Age 18 years old or above YES / NO

Be in the UK YES / NO

Any significant mental health difficulties? YES / NO

Any significant neurological history? YES / NO

Sufficient hearing and vision to complete the assessment and therapy sessions? YES / NO

Have sufficient speech/language to complete therapy sessions? YES / NO

Any developmental speech or language difficulties? YES / NO

British English is everyday language? YES / NO

Have a computer with camera/microphone able to utilise video conferencing software. YES / NO

Have a diagnosis of dementia by an appropriate professional. YES / NO

Have mild-moderate word-finding difficulties as reported by the person with dementia or their communication partner (This will be confirmed at initial assessment). YES / NO

Eligible for project? YES / NO

Assigned participant code:

Background history (as reported):

About you:

1. How old are you?
2. What is your gender?
3. Are you right or left handed?
4. Do you need/wear glasses?
5. Do you have any hearing difficulties or wear hearing aids?
6. What type of dementia do you have?
7. What medications do you take?
8. How old were you when you received your dementia diagnosis?
9. What dementia signs/symptoms did you first notice and when?
10. What is your main difficulty because of your dementia?
11. What is/was your main employment?

About your communication:

12. How old were you when you/others first noticed you forgetting words?

13. Do you have any other communication difficulties? When did these start?
    a. understanding what others say?

    b. understanding written words?

    c. Writing?

    d. Other?

14. How many days per week do you usually have a full conversation e.g. with friend/relative/neighbour? When, how and with whom does this normally happen?

15. Do you have hobbies that you are continuing to do?

16. Is there anything else you want to tell us?

Appendix GG - Phase 2 eligibility screening form for communication partners

The
University
Of
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Alzheimer's
Society
United
Against
Dementia

'Evaluating a novel adaptation of word finding therapy for individuals with dementia'
Phase 2: Indirect Therapy

Communication Partner

Eligibility (as reported):

Age 18 years old or above	YES / NO
Be in the UK	YES / NO
Any significant mental health difficulties?	YES / NO
Any significant neurological history?	YES / NO
Sufficient hearing and vision to complete the assessment and therapy sessions?	YES / NO
Have sufficient speech/language to complete therapy sessions?	YES / NO
Any developmental speech or language difficulties?	YES / NO
British English is everyday language?	YES / NO
Have a computer with camera/microphone able to utilise video conferencing software.	YES / NO

Eligible for project? YES / NO

Assigned code:

Appendix HH - Comparing linguistic variables of nouns and verbs for naming

Group Statistics

	Noun/verb	N	Mean	Std. Deviation	Std. Error Mean
Imageability	Noun	78	5.9895	.51775	.05862
	Verb	41	4.4749	.51977	.08118
F-K Frequency	Noun	78	77.6282	119.85783	13.57123
	Verb	41	98.2439	119.46208	18.65684
Familiarity	Noun	78	4.4022	1.38798	.15716
	Verb	41	4.1783	1.51205	.23614
Age of acquisition	Noun	78	2.2873	.59211	.06704
	Verb	41	2.4790	.71163	.11114

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Imageability	Equal variances assumed	1.483	.226	15.145	117	.000	1.51461	.10001	1.31655	1.71267
	Equal variances not assumed			15.126	81.140	.000	1.51461	.10013	1.31539	1.71383
F-K frequency	Equal variances assumed	.096	.758	-.893	117	.374	-20.61570	23.09461	-66.35337	25.12197
	Equal variances not assumed			-.894	81.654	.374	-20.61570	23.07067	-66.51353	25.28214
Familiarity	Equal variances assumed	.038	.846	.811	117	.419	.22389	.27616	-.32303	.77080
	Equal variances not assumed			.789	75.579	.432	.22389	.28366	-.34112	.78889
Age of acquisition	Equal variances assumed	2.420	.123	-1.564	117	.121	-.19172	.12259	-.43450	.05107
	Equal variances not assumed			-1.477	69.620	.144	-.19172	.12979	-.45061	.06718

Appendix II - Comparing linguistic variables with treated and untreated items for P-A

Group Statistics

	Treated / untreated	N	Mean	Std. Deviation	Std. Error Mean
Length phonemes	Treated	40	4.30	1.506	.238
	Untreated	79	4.51	1.329	.150
Length syllables	Treated	40	1.68	.616	.097
	Untreated	79	1.71	.623	.070
F-K frequency	Treated	40	106.38	128.084	20.252
	Untreated	79	73.77	114.377	12.868
Familiarity mean	Treated	40	5.0140	1.27534	.20165
	Untreated	79	3.9762	1.38261	.15556
Age of acquisition mean	Treated	40	2.2013	.64930	.10266
	Untreated	79	2.4304	.62434	.07024
Imageability mean	Treated	40	5.5930	.77503	.12254
	Untreated	79	5.4042	.93866	.10561

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Length phonemes	Equal variances assumed	.519	.473	-.765	117	.446	-.206	.270	-.741	.328
	Equal variances not assumed			-.734	70.364	.465	-.206	.281	-.767	.354
Length syllables	Equal variances assumed	.001	.978	-.281	117	.779	-.034	.120	-.272	.205
	Equal variances not assumed			-.282	79.323	.778	-.034	.120	-.273	.205
F-K frequency	Equal variances assumed	2.253	.136	1.410	117	.161	32.603	23.116	-13.178	78.384
	Equal variances not assumed			1.359	71.059	.179	32.603	23.994	-15.240	80.446
Familiarity mean	Equal variances assumed	.115	.735	3.968	117	.000	1.03780	.26155	.51981	1.55578
	Equal variances not assumed			4.075	84.301	.000	1.03780	.25468	.53137	1.54422
Age of acquisition mean	Equal variances assumed	.008	.928	-1.866	117	.065	-.22913	.12279	-.47232	.01406
	Equal variances not assumed			-1.842	75.761	.069	-.22913	.12439	-.47690	.01864
Imageability mean	Equal variances assumed	5.679	.019	1.096	117	.275	.18882	.17222	-.15225	.52990
	Equal variances not assumed			1.167	92.838	.246	.18882	.16177	-.13243	.51008

Appendix JJ - Comparing linguistic variables with treated and untreated items for P-B

Group Statistics

	Treated / untreated	N	Mean	Std. Deviation	Std. Error Mean
Length phonemes	Treated	40	4.47	1.432	.226
	Untreated	79	4.42	1.374	.155
Length syllables	Treated	40	1.73	.679	.107
	Untreated	79	1.68	.589	.066
F-K frequency	Treated	40	90.35	100.928	15.958
	Untreated	79	81.89	128.566	14.465
Familiarity mean	Treated	40	5.4768	.93360	.14762
	Untreated	79	3.7419	1.27714	.14369
Age of acquisition mean	Treated	40	2.1675	.55160	.08722
	Untreated	79	2.4475	.66306	.07460
Imageability mean	Treated	40	5.7420	.67375	.10653
	Untreated	79	5.3287	.95312	.10723

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Length phonemes	Equal variances assumed	.232	.631	.212	117	.833	.057	.270	-.478	.593
	Equal variances not assumed			.209	75.609	.835	.057	.274	-.489	.603
Length syllables	Equal variances assumed	1.115	.293	.344	117	.731	.041	.120	-.197	.280
	Equal variances not assumed			.329	69.386	.743	.041	.126	-.210	.293
F-K frequency	Equal variances assumed	.178	.674	.363	117	.717	8.464	23.299	-37.678	54.606
	Equal variances not assumed			.393	96.755	.695	8.464	21.538	-34.285	51.212
Familiarity mean	Equal variances assumed	4.666	.033	7.616	117	.000	1.73485	.22779	1.28372	2.18599
	Equal variances not assumed			8.422	102.091	.000	1.73485	.20600	1.32625	2.14345
Age of acquisition mean	Equal variances assumed	2.042	.156	-2.297	117	.023	-.27997	.12189	-.52136	-.03857
	Equal variances not assumed			-2.439	92.253	.017	-.27997	.11477	-.50790	-.05204
Imageability mean	Equal variances assumed	12.366	.001	2.448	117	.016	.41327	.16883	.07890	.74763
	Equal variances not assumed			2.734	104.455	.007	.41327	.15116	.11353	.71300

Appendix KK - Comparing linguistic variables with treated and untreated items for P-C

Group Statistics

	Treated / untreated	N	Mean	Std. Deviation	Std. Error Mean
Length phonemes	Treated	40	4.20	1.400	.221
	Untreated	79	4.56	1.375	.155
Length syllables	Treated	40	1.58	.636	.101
	Untreated	79	1.76	.604	.068
F-K frequency	Treated	40	90.23	124.603	19.702
	Untreated	79	81.95	117.730	13.246
Familiarity mean	Treated	40	5.1980	1.27466	.20154
	Untreated	79	3.8830	1.30018	.14628
Age of acquisition mean	Treated	40	2.1000	.59527	.09412
	Untreated	79	2.4816	.62587	.07042
Imageability mean	Treated	40	5.8188	.67728	.10709
	Untreated	79	5.2899	.93219	.10488

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Length phonemes	Equal variances assumed	.004	.952	-1.330	117	.186	-.357	.268	-.889	.175
	Equal variances not assumed			-1.322	77.216	.190	-.357	.270	-.895	.181
Length syllables	Equal variances assumed	1.559	.214	-1.547	117	.125	-.184	.119	-.421	.052
	Equal variances not assumed			-1.520	74.910	.133	-.184	.121	-.426	.057
F-K frequency	Equal variances assumed	.003	.959	.355	117	.723	8.276	23.299	-37.868	54.419
	Equal variances not assumed			.349	74.604	.728	8.276	23.740	-39.021	55.573
Familiarity mean	Equal variances assumed	.034	.853	5.246	117	.000	1.31496	.25067	.81852	1.81140
	Equal variances not assumed			5.280	79.836	.000	1.31496	.24903	.81936	1.81057
Age of acquisition mean	Equal variances assumed	.016	.901	-3.193	117	.002	-.38165	.11951	-.61832	-.14497
	Equal variances not assumed			-3.247	82.028	.002	-.38165	.11755	-.61548	-.14781
Imageability mean	Equal variances assumed	10.780	.001	3.185	117	.002	.52888	.16606	.20001	.85774
	Equal variances not assumed			3.528	102.531	.001	.52888	.14989	.23159	.82617