Adherence to a community based 8-week programme for stroke-related dysarthria: an exploratory study of clients' views of therapy

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This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

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Abstract

Background

Many dysarthria treatments require adherence to tasks which may have little obvious relevance to people's lives. There is growing interest in patients' experience of dysarthria and its remediation, but little is known about patients' views of therapy, and factors that may impact on their adherence to it.

Research Question

This study asks: what factors, related to patients' perspectives of a therapeutic programme for dysarthria, impact on adherence to treatment recommendations?

Methods & Procedures

Fifteen people with post-stroke dysarthria participated, all former patients in an eight-week SLT programme. Data sources comprised: interviews which gathered patients' views; timelogs of patients' self-recorded minutes spent practising; case-notes; Communicative Effectiveness Surveys (Donovan, Velozo, & Rosenbek, 2007) in which participants rated their communication.

Analysis

Interviews and case notes were transcribed and all potentially interesting data coded. Four coded interviews were quality-checked by an experienced researcher. Cogent groups of themes/subthemes were developed and arranged into two over-arching themes relating to factors impacting on adherence. The timelogs informed as to who had adhered/not adhered to practice recommendations. CES scores were compared to examine any differences between adherers/non-adherers.

Outcomes & results

Ten patients adhered, and five did not. There were suggestions of relationships: adherers tended to be cohabiting and have support at home, while non-adherers tended to live alone, have more severe dysarthria and rate their communicative effectiveness as lower. Including non-speech oromotor exercises in therapy did not increase adherence. People valued a good therapeutic relationship and tasks tailored to their needs and interests. Several explicitly linked these factors to their adherence.

Conclusions & implications

The finding that support may have impacted on adherence has implications for practitioners, particularly those working with isolated patients. Therapists should recognise the support of family/partners as a valuable therapeutic tool. Monitoring therapeutic relationships may maintain them, and this, in addition to the provision of person-centred therapy; focussing on the person rather than tasks, and enabling patients to set person-centred goals, may also improve adherence.

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Chapter 1. Introduction

Dysarthria is a motor speech disorder common after stroke, with which an estimated 69.5% of stroke patients present acutely; of these 27% demonstrate persistent dysarthria after 3-months (Ali, Lyden, Brady, and on behalf of the VISTA collaboration, 2013). People with dysarthria report that its impact on their lives can be distressing, leading to changes in their self-identity and perceptions of how others see them, as well as isolation and exclusion from society, through stigmatisation and a restriction in participating in life roles (Dickson, Barbour, Brady, Clark & Paton, 2008; Brady et al, 2011b; Walshe, 2011; Walshe & Miller, 2011).

Intervention for dysarthria is provided by speech and language therapists (SLTs), whose role is described in Chapter 2, while methods for treating dysarthria are described in Chapter 3. There is a lack of robust evaluations of outcomes of SLT for stroke-related dysarthria in the literature. The current study interviews patients about their participation in a randomised feasibility trial of post-stroke dysarthria intervention (Mackenzie, Muir, Allen & Jensen, 2014).

Patients' views of their treatment are instructive, and are considered to be one of the central pillars of quality in healthcare (de Silva, 2013). A recent systematic review demonstrated a link between patients' reported experiences and therapy outcomes (Doyle, Lennox & Bell, 2013). Issues that influence the gathering of views of people with communication difficulties, so often excluded in the literature, are explored in Chapter 3.

This study gathers the views of fifteen patients with stroke-related dysarthria who participated in an eight-week long intervention programme, referred to here as “NONSPEX” (Mackenzie et al., 2014, see Appendix 1). The RCT examined and compared outcomes from two randomly allocated groups, both of which participated in articulation-focussed behavioural therapy, with one having an added component of non-speech oromotor exercises (NSOMEs), a common component of dysarthria intervention (Mackenzie, Muir & Allen, 2010) .

The prescribed therapeutic regime required all patients to participate in forty-five minutes of SLT weekly, and encouraged them to devote 10-15 minutes two/three times daily to home-practice at least 5 days each week. Adhering to such therapeutic regimes gives them the chance to be clinically effective, and comprise an efficient use of public resources (Enderby et al 2009; Marsh, Bertranou, Suominen & Venkatachalam, 2010; Wenke, Cornwell & Theodoros, 2010), so SLTs need to know which factors can impact on, or enhance, patients’ adherence. Adherence is defined and related literature is examined in chapter 3.

This study investigates the factors, related to patients’ views of NONSPEX, which impacted on their adherence to treatment recommendations. Adherence was calculated by totalling the amount of minutes spent practising (patients recorded minutes spent practising in timelogs) and relating them to the amount recommended, enabling comparisons of adherers/non-adherers.

Patients were interviewed about their views on the therapy they received, and the interviews and case-notes of adherers/non-adherers were analysed and compared to uncover any factors which may have impacted on their adherence to the prescribed regime. The Communicative Effectiveness Survey (CES) (Donovan, Velozo, & Rosenbek, 2007) scores (each participant rated their communication in specific situations at different points throughout the NONSPEX programme), were compared to examine any differences between adherers/non-adherers.

The methods are described in Chapter 4, the data analysis and results in Chapters 5 and 6, respectively. Chapter 7 discusses the clinical implications of the study, its methodological strengths/limitations, ending with suggestions for further research. Chapter 8 concludes the thesis.

There follows, in Chapter 2, an introduction to definitions of stroke, its resultant communication difficulties, and a description of the burden of stroke and dysarthria.

Chapter 2. Background

2.1 Stroke

The National Institute for Health and Care Excellence (NICE) defines stroke as: “The damaging or killing of brain cells starved of oxygen as a result of the blood supply to part of the brain being cut off. Types of stroke include ischaemic stroke caused by blood clots to the brain or haemorrhagic stroke caused by bleeding into/of the brain” (NICE, 2008 p21).

2.1.1 Global and national burden

Using the Global Burden of Disease Study data set, Feigin et al. (2014) estimated that in 2010, numbers of people world-wide with a first stroke, and those who died from stroke (16.9 million/5.9 million, respectively) had significantly increased from 1990, with low- and middle-income countries experiencing most of the disease burden. The proportion of deaths globally from cardiovascular disease, including stroke, is projected to increase from 28% (1990) to 34% in 2020 (Levenson, Skerrett, Gaziano, 2002). In 2010, stroke was the third most common cause of disability-adjusted life-years (DALYs) lost (102 million in 2010, Feigin, et al 2014); one DALY is considered as one lost year of "healthy" life (World Health Organization (WHO) n.d.).

In Scotland, preventing and reducing stroke is a public health priority (NHS Scotland, 2009), where the prevalence of risk factors such as smoking, hypertension, and excessive alcohol consumption is high (Information

Services Division (ISD), 2011). There are major health inequalities in Scotland (NHS Scotland, 2009), with a positive relationship between deprivation and mortality rates for stroke (ISD, 2011). It is estimated that around 15,000 people in Scotland have a stroke each year (The Scottish Stroke Care Audit, 2012), of which 5,000 die as a result (ISD, 2011). Although the number of deaths due to stroke decreased by 34.6% between 2000/01 and 2009/10 (ISD, 2011), stroke is the third commonest cause of death and the most frequent cause of severe adult disability in Scotland, with 70,000 individuals living with the burden of its consequences (SIGN, 2010)

2.1.2 The personal burden

The WHO (2011, pp3-5) defines disability as “an umbrella term”, covering impairments, activity limitations, and participation restrictions. Impairment describes a problem in body function, or alteration in body structure, and strokes can be responsible for devastating impairments of physical, sensory, cognitive and emotional functioning. Some common impairments include: limb/trunk/facial weakness and paralysis; gait and balance problems; perceptual and cognitive impairments; sensory loss; swallowing/chewing difficulties and communication disorders. An activity limitation is a difficulty encountered in executing a task or activity; while a participation restriction is a problem experienced by an individual in involvement in life situations.

The potentially devastating personal impact of stroke can be lost amongst the lists of sequelae and clinical outcomes. Hartley et al. (2014) gathered personal first-hand experiences from the literature and from a focus group of stroke survivors. The barriers people described included: functional problems related to activities of daily living; cognitive issues; over-solicitous families; social, leisure, occupational and mobility restrictions, and consequent reductions in independence. They described psychosocial difficulties such as lack of control; anger; guilt; low self-esteem and motivation levels; poor sexual relationships, lack of understanding; uncertainty about the future and stress on the family.

Supporting family members with stroke can have positive aspects, but it can be a burden or indeed be perceived by the person with stroke to be a burden (White, Lauzon, Yaffe & Wood-Dauphinee, 2004; Rochette, Desrosiers, Bravo, Tribble & Bourget, 2007; McPherson, Wilson, Chyurlia, Leclerc, 2010). In a systematic review of caregiver burden, Rigby, Gubitz and Phillips (2009) found the most consistent characteristics associated with burden to be anxiety, depression, and emotional distress. Caregivers in another study also rated communication problems such as understanding and expressive difficulties as highly stressful (Haley et al., 2009).

2.1.3 Associated communication disorders

The current study examines communication problems that result from stroke, and their rehabilitation – the treatment provided by professionals. Stroke can result in a number of communication impairments in addition to disorders of cognition, any of which can co-exist with dysarthria - the specific impairment upon which this study focuses - and impact mutually upon each other. The acquired disorders briefly described below have the potential to impact on an individual’s ability to carry out activities of everyday life, such as conversation, negotiation, the expression of humour, maintaining social relationships, focusing attention, understanding others, and participating in life roles (Hartelius & Miller, 2010).

Aphasia is a disturbance of the comprehension and formulation of language, which can affect all modalities of communication, including the understanding and expression of spoken, written or signed language, caused by dysfunction in specific brain regions (Damasio 1992).

Stroke can impact on motor speech skills - the ability to produce and control the physical movements required for speech. Dyspraxia (or apraxia) of speech can occur in the absence of language disorder or dysarthria and is “a neurological disorder that reflects an impaired capacity to plan or programme sensorimotor commands necessary for directing movements that result in phonetically or prosodically normal speech”(Duffy 2012 p.4).

Dysarthria is the collective term for a group of neurogenic speech disorders resulting from abnormalities in the strength, speed, range, tone or accuracy of the movements required for control of the respiratory, phonatory, resonatory, articulatory and prosodic aspects of speech production. It can occur in isolation, or co-exist with the communication impairments described above. Due to central or peripheral nervous system abnormalities, these most often reflect weakness, spasticity, or excessive, reduced or variable muscle tone. Dysarthria can affect speech by impacting on its audibility, naturalness, intelligibility and its overall effectiveness. The severity of dysarthria can range from an absence of speech/complete unintelligibility, to mild changes perceptible only to the speaker, and these can be assessed through a comprehensive speech evaluation (Duffy, 2012).

Dickson, et al (2008) interviewed people with stroke-related dysarthria about their personal experience of the disorder (further explored in Chapter 3). Their reports expose consequences of dysarthria that extend well beyond the impairment, from avoiding participating in communication situations, to impacting on their relationships, self-identities, and psychosocial wellbeing. They described feelings of stigmatisation, fear, helplessness, reduced confidence, and of being abnormal. Commonly, people reported these negative impacts of dysarthria irrespective of impairment severity, age, gender, socioeconomic circumstances or perceived recovery. In conclusion, the authors recommended that rehabilitation clinicians address the psychosocial sequelae of dysarthria as well as its resultant impairments, activity limitations and participation restrictions.

2.1.4 Rehabilitation

The following description of rehabilitation is taken from the World Report on Disability (WHO, 2011), and from the best practice guidelines of the Scottish Intercollegiate Guidelines Network (SIGN, 2010). It is defined as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (WHO, 2011 p96). Rehabilitation typically occurs over "a specific period of time…delivered by an individual or a team of rehabilitation workers, and can be needed from the acute or initial phase immediately following recognition of a health condition through to post-acute and maintenance phases" (WHO, 2011 p96). The process of rehabilitation is driven by the needs of the individual, requiring that his/her impairments, activity limitations and participation restrictions are identified through assessment (WHO, 2011). SIGN guidelines (2010) recommend that the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) is used as a framework around which to structure the assessment of needs and the planning of rehabilitation, a key feature of which is defining and setting person-centred goals. This is described as central to effective rehabilitation, and it is recommended that the process is patient-centred, with patients having their expectations explored and acknowledged, and participating in the process of setting goals. It is also recommended that to enable patients to define and articulate their own personal goals, they should be given help to understand the nature and process of goal setting (Intercollegiate Stroke Working Party (ISWP), 2012; Levack, Dean, Seigert & McPherson, 2011; Leach, Cornwell, Fleming & Haines, 2010).

2.2 Speech and language therapy

SLTs are responsible for the rehabilitation of speech, language, communication and swallowing disorders. According to the Royal College of Speech and Language Therapists (RCSLT), they assess people with communication difficulties to establish the level of their impairments, the limitations/restrictions these place on their activities and participation in life situations, and provide treatment. Key service provision aims include health promotion, prevention of communication difficulties and preventing their exacerbation, in addition to promoting participation. SLTs are responsible for training, and liaising with, other health professionals, as well as families and carers (RCSLT, 2006). SLTs treat disorders arising from a variety of conditions, including stroke, and there is a considerable body of literature relating to post-stroke *aphasia,* its management, and the views of aphasic people. Some of this literature is described in chapter 3 in relation to dysarthria therapy (e.g. in the sections dealing with adherence). The current study, however, attempts to address the paucity of studies which aim to put the person with *dysarthria* centre-stage, and the literature relating to this is examined below.

Chapter 3. Literature Review

The focus of the present study is narrow, justified by a lack of research into the study's questions of interest. It examines people's experiences of participating in a treatment programme for dysarthria, and their motivations to work independently on improving their speech by following a recommended course of treatment. The study also examines the use of practice records as a means of measuring patients' adherence to recommended amounts of practice. The following chapter reflects this focus, by reviewing relevant available literature regarding treatment for stroke-related dysarthria; the importance of listening to the views of people with dysarthria; and issues relating to people's adherence to SLT.

3.1 Dysarthria

Dysarthria is reported to be the most frequently acquired speech and language disorder (Enderby & Emerson, 1995). Although no consensus exists in the literature regarding prevalence of dysarthria in the *general* population, a few studies suggest its incidence and prevalence in specific populations. Recent primary data from systematic reviews is not available for dysarthria in traumatic brain injury (TBI) in adults, although Sarno, Buonaguro & Levita (1986) report an incidence of 33%, while Yorkston, Honsinger, Mitsuda & Hammen (1989) report a 65% prevalence in acute TBI. Ramig, Fox & Sapir (2004) report an incidence, increasing with disease progression, of 50-90% among patients with Parkinson’s Disease. In motor neurone disease, prevalence is estimated at 80% (Tomik & Guiloff, 2010).

Quantifying the extent of the problem in stroke is challenging; the use of prevalence as a measure for acute disorders is controversial, prevalences based on a single point in time tend to underestimate the condition's total frequency (Coggon, Rose & Barker, 1997). Measuring the incidence of new cases of first-ever stroke in hospital-based studies increases the risk of selection bias; as not all strokes are treated in hospitals, samples may not be representative of the population to be analysed (Appelros, Hogeras & Terent, 2003; Hollander, Koudstaal, Bots, Grobbee, Hofman & Breteler, 2003; Pendlebury, Giles & Rothburn, 2009)

The few existing studies that examine dysarthria use either point prevalence or first-ever stroke as measures, and a variety of inclusion/exclusion criteria (e.g., first-ever stroke versus everyone admitted with stroke in a given timeframe). Additionally, as patients must be alert enough to attempt the production of speech to determine the existence of dysarthria, some are unable to be assessed, as in Lawrence et al (2001), who found 23.5% (n=280) of the study’s 1,259 patients were not assessable.

Despite the challenges of determining dysarthria prevalence, studies with large sample sizes may increase the validity of the findings. The Virtual International Stroke Trials Archive (VISTA) is a resource of data pooled from completed clinical trials in acute stroke. A retrospective analysis of data derived from the raw datasets was performed to explore recovery from aphasia/dysarthria in the acute stages of stroke (Ali, et al. 2013). The data from 8,904 patients was analysed (the time period in which they were admitted is not made clear). Aphasia and dysarthria were defined as a score of ≥1 using the Best Language (item 9) and Dysarthria (item 10) domains of the National Institutes of Health Stroke Scale (NIHSS) (NIH 1983), respectively. These involve picture/object naming, description, and reading/repeating words and phrases.

At baseline, 45.4% (n=4,039/8,904) presented with aphasia, and 69.5% (n=6,192/8,904) presented with dysarthria (4,257 with mild-moderate dysarthria, and 1,935 classified as severe). By three months post-stroke, 7,731 patients remained (1,076 had died; 97 were lost to follow-up). Of those patients 2,892 (37.4%) were classified as having recovered from dysarthria, and 27% were classified with “persistent dysarthria” (n=2,085/). Of the latter category, 1,799 had mild/moderate dysarthria (24.5%); and 539 (7.4%) had severe dysarthria. Although the NIHSS has been found to yield low inter-rater reliability in the assessment of dysarthria due to scoring and sensitivity (Meyer & Lyden 2009), these findings highlight not only the extent of the problem of dysarthria but also its pervasive nature. The following section describes the literature relating to the impact of dysarthria on the person.

3.1.1 Dysarthria's impact on the person

People report that dysarthria's impact can be significant and distressing (Dickson et al., 2008; Walshe, 2010; Brady et al., 2011b). As well as impacting on the intelligibility of people's speech, it can alter people's *style* of communication: in order to be understood and to enable them to participate in communicative situations, participants told Walshe and Miller (2011) that they used more non-verbal communication and sought to keep conversations brief, avoiding small-talk. They reported avoiding a wide range of social situations through fear of listener reactions and discriminatory attitudes. Unsurprisingly, people with dysarthria express feelings of social exclusion, stigmatisation, isolation and a restriction in their ability to participate in life roles, the extent of which, as Dickson et al. (2008) suggest, is not related to the severity of the impairment. Some describe a fundamental shift in their self-identity and perceptions of how others see them, all of which has significant implications for the planning and delivery of treatment for people with dysarthria (Brady et al., 2011b), common approaches to which are reviewed in the following section. The impact of dysarthria is explored in more detail in relation to adherence to therapeutic regimes, below.

3.1.2 Interventions and their evidence base

Yorkston and Beukelman (2004) describe the field of dysarthria as having moved through a series of phases, starting in the 1970s with the era of diagnosis: classic types of dysarthria and their speech characteristics were identified and distinguished from one another. The second is characterised by the development of intervention procedures. As there is no one-size-fits-all intervention, they describe the field as entering a phase of clinical decision-making; evidence must be provided to enable the selection of appropriate interventions (Yorkston & Beukelman, 2004).

Despite this, the majority of studies relating to dysarthria focus on means of assessing and describing the impairment, and rarely pay specific attention to dysarthria secondary to stroke (Mackenzie, 2011), despite its prevalence. In a review of the literature pertaining to treatment for stroke-related dysarthria, Enderby and Palmer (2007) state this “has not been a popular area of research” (p. 141), and Bowen et al (2012a, p. 8) describe people with dysarthria as badly neglected in research. A systematic review of the literature was unable to find conclusive evidence of the effectiveness of dysarthria therapy (Sellars, Hughes & Langhorne, 2005).

Few published randomised-control trials (RCTs) focus on intervention for stroke-related dysarthria, although some single case and small group series papers provide evidence of positive change following intervention. Throughout the literature, stroke cases are often mixed with other aetiologies. Impairment-based approaches predominate, and there is only one published report of group management currently (MacKenzie, Paton, Kelly, Brady and Muir 2012).

Due to the lack of stroke-related studies, the following review of the literature relating to therapeutic approaches and principles in SLT for people with dysarthria is not limited to stroke aetiologies. It is presented in line with the ICF framework (WHO 2011).

Impairment-focussed approaches

The RCSLT describes the aims of SLT in the management of dysarthria as enabling individuals to achieve a mode of communication appropriate to their age, gender, social circumstances and desires, within the imposed limitations of their neurological condition (RCSLT 2006. In assessing its impacts on the individual, Miller (2010) suggests that a full understanding of dysarthria is to be gained only by moving beyond the confines of the neuromuscular view of dysarthria impairment, to encompass its effects on activities in which the individual wishes to engage and on his/her psychosocial well-being and participation in society.

A combination of approaches to treatment can be used, and Murdoch (2013) describes how within the framework of the ICF (WHO 2001) they can be broadly divided into those following an impairment-based approach and those involving a functional approach targeting the activity limitations/participation restrictions levels, and including altering the communicative environment, teaching strategies such as: modifying utterance lengths; maximising gestural cues to aid the listener; using effective repair and self-monitoring strategies; orientating listeners to topics; in addition to dysarthria education. The former approach targets the impairment level of the framework, and typically aims to increase intelligibility by enhancing the physiological support for speech and teaching compensatory speech behaviours.

The RCSLT's professional standards suggest that "aiming for optimum intelligibility may involve work at impairment level on e.g. range, force, sustainability of movements, but intervention and aims at this level are subordinate to effecting change in activity limitation and participation restriction" (RCSLT 2006 p251). Despite these recommendations, many SLTs continue to focus intervention at the impairment level. Collis and Bloch (2012) surveyed the practices of 119 UK SLTs in relation to their assessment and treatment of people with progressive (ie: not stroke-related) dysarthria. They found that as severity of dysarthria increased, SLTs were less likely to agree that impairment-focussed approaches were important. They found more experienced therapists were more likely to provide therapy of a functional nature. Replicating this survey with SLTs treating stroke-related dysarthria could provide information about current practice lacking in the literature. This section continues by describing the literature relating to a number of areas of focus in the management of dysarthria, starting with behavioural approaches which have targeted specific parameters, such as articulation.

Behavioural interventions

These have the aim of compensated intelligibility, rather than normal speech (Deane & Whurr, 2001), and the reduction of the impact of dysarthria impairment. They entail the teaching of new skills, facilitative strategies, compensations or adjustments. (Yorkston et al. 1999; Murdoch 1998). Strategies can include: repetition; emphasising key words; speaking in short phrases; environmental modification; facing the person when speaking and using an alphabet chart for speech supplementation (Enderby & Palmer 2007 p.148). For a catalogue of individualised behavioural interventions for eight patients with dysarthria, see Mackenzie & Lowit (2010), in whose study five participants demonstrated improvements in at least one of the study's three outcome measures. The study did not aim to impact on the psychosocial sequelae of dysarthria, so it is perhaps unsurprising no change in the group data was indicated in the Dysarthria Impact Profile (Walshe, Peach & Miller 2009) sections relating to the effects of dysarthria on the person, how it affects communication and how others react to it. Interestingly, however, a significant difference was noted in the section relating to acceptance of dysarthria, suggesting that a behavioural approach to remediating dysarthria might help the person come to terms with its existence.

As intelligibility can be affected by imprecise articulation of consonants, "a hallmark of dysarthria" (Kent & Kim 2003, p437) and vowels, articulation is frequently a focus of treatment, involving teaching the correct placement and manner of production of affected phonemes (Wenke et al., 2010). Patients are required to attempt the production and repetition of word sets, from CVC words to complex utterances, and receive performance-related feedback, with the aim of achieving maximal clarity of production. The therapeutic tasks are then practiced independently (Robertson 2001).

Documenting the amount of independent practice executed by participants was an integral feature of Robertson's 2001 study of the effectiveness of traditional therapy for post-stroke dysarthria, consisting of 10 weekly forty-five minute sessions of oral-facial and articulation exercises which participants practised independently. Six of the eight participants, who self-reported practice amounts in diaries, improved their intelligibility scores. The study has some limitations, however. Although those who demonstrated the biggest improvement in scores had carried out the most practice, it was not possible to extrapolate the extent to which each type of exercise was responsible. Additionally, as the stability of dysarthria at baseline was not ensured - time post-stroke ranged from only 1.5-6 months – it could be argued that gains were down to natural recovery. There was no means of checking the extent to which patients' self-reports accurately reflected either the quality or quantity of their practice, as compared to their prescribed regimes, an issue discussed in more detail later. Finally, an increased score on intelligibility tests does not necessarily equate with an improvement in *functional communication*.

Wenke, Cornwell and Theodoros (2010) compared the effects of traditional articulation therapy and LSVT on articulation. This therapy approach aims to improve loudness and self-monitoring through a controlled, intensive regime of vocal exercises. Commonly used with people who have Parkinson's disease, it does not focus on articulation but requires the person with dysarthria to consistently employ increased vocal loudness and maximum physiological effort in speaking (Ramig, Countryman, Thompson & Horii, 1995).

Mahler and Ramig (2012) investigated the impact of LSVT on acoustic and perceptual measures of speech in four people with stroke-related dysarthria. Following a four-week course of intensive input, all participants demonstrated increased loudness and larger vowel space areas, while listener ratings suggested improved voice quality and more natural speech. However possibly due to a ceiling effect, as scores were relatively high prior to treatment, only one participant demonstrated improved speech intelligibility scores.

Following from a study by Wenke, Theodoros & Cornwell (2008) in which improvements to articulatory precision were observed in 10 dysarthric individuals after participating in Lee Silverman Voice Therapy (LSVT), twenty-six people with non-progressive acquired dysarthria (including stroke) participated in intensive therapy comprising hour-long sessions (four days a week for four weeks), in addition to maintenance exercises (for a recommended 5-10 minutes a day, 3-5 days a week, over six months) (Wenke, Cornwell & Theodoros, 2010). One group received LSVT therapy; the other received “traditional” therapy (TRAD) focussing on articulation and, depending on individuals’ needs, additional approaches such as improving resonance and providing oral/facial exercises.

The expectations that one therapy would show a significant benefit over the other were not upheld, although there were individual improvements in the articulation and intelligibility measures of many of the participants post-therapy. Due to the variability of therapeutic approaches within the TRAD group, it is impossible to extrapolate which approach/combination of approaches effected change. It is however important to note the amount of intensive input and independent practice required of the study participants to improve their speech.

Another approach to increasing intelligibility is through teaching patients new strategies to modify the speed of their speech, and to help them carry over gains made in therapy into real conversations. In a small-scale study Pilon, McIntosh & Thaut (1998) found that helping patients pace their speech by maintaining a rate of one word per metronomic beat resulted in increased intelligibility in two out of three brain injured patients. However, in a larger study, including patients with dysarthria secondary to different aetiologies, van Nuffelen, de Bodt, Vanderwegen, van de Heyning & Wuyts, (2010) found that although rate control measures tended to result in rate reduction, in only half of their patients did it effect an increase in intelligibility.

Patel, Connaghan & Campellone (2013) compared the prosodic speech patterns of a small sample of seven people with cerebral palsy-related dysarthria with those of healthy controls, in a task requiring participants to reduce their rate of speech when producing “naturalistic” affirmative/contrastive statements and asking questions. Among those with dysarthria, rate reduction generally dampened prosodic contrasts, and the authors suggest that reducing the rate of dysarthric speech may unintentionally impact on its naturalness and effectiveness. This is echoed by Mackenzie and Lowit (2012), who found that their single-case study participant's utterance lengths increased two months post-therapy, but improvement in communication effectiveness was maintained. The authors suggest that increased utterance lengths may have aided listeners to make better sense of any unintelligible segments by providing more contextual information for them to use in comprehending his messages.

Motor learning principles

In Schmidt's (1975) Schema Theory, the memory representation of components of a movement and how they interact to execute it are encoded in schemas. Related to speech, the components include proprioceptive information relating to the positions of the articulators prior to speaking; the environment; the movement specifications, their consequences and outcomes. Other schemas retain the memory of component interactions needed to produce speech sounds, and evaluate outcomes by comparing expected results with actual speech consequences; resulting mismatches are errors necessitating updates of the schemas, negating the need for external feedback in correcting future speech errors (Maas et al 2008).

In impaired systems, as in dysarthria, premorbid schema may not produce their intended outcomes: the processing of somatosensory feedback may be damaged and/or result in poor error detection, requiring the feedback of a therapist to assist the dysarthric person in calibrating speech movements with those of an externally provided model and modifying schemas.

Maas et al. (2008) report there is limited empirical evidence of effectiveness of motor learning (ML) principles relating to motor speech disorders, and those which they state may be expected to be effective in dysarthria remediation are listed here (for brevity, it is not possible to describe them in detail), and include: *large amounts of time spent practising* (vs small); *distributed practice* (vs massed) - a given number of trials or sessions over a long, rather than short, period of time; *variable practice* (vs constant) on different targets, in different contexts; *random schedule* (vs blocked), with different targets practiced in the same session; *external attentional focus* (vs internal), in which the focus is on the effects of movements; *complexity of targets* (vs simplicity); *feedback focusing on the knowledge of results* (vs focusing on performance), such as whether a sound was correct/incorrect; *low frequency of feedback* (vs high regardless of accuracy) only after some attempts at production, regardless of accuracy; and *delayed timing of feedback* (vs immediate).

Maas et al (2008) caution that the motor learning principles described in the preceding paragraph has limitations: the principles emerged from studies involving non-speech tasks performed by individuals with intact motor systems. They state that although it is a “reasonable hypothesis” (p278) that speech motor control is sensitive to the same principles as non-speech motor control, and that impaired motor systems respond in the same way as intact systems to principles of ML, further research is necessary to establish this. One study of dysarthria in Parkinson’s disease (Adams et al., 2002) demonstrated that skill retention is aided by low-frequency feedback (versus high), however the effects of the use of motor-learning principles have not been explored in stroke-related dysarthria.

Non-speech oromotor exercises

Exercises targeting the oral-facial muscles, such as those used in Robertson (2001), are commonly referred to as non-speech oromotor exercises (NSOMEs) as they do not use speech as a medium to exercise the muscles. Their aim is to increase the strength, range and speed of movement, and consequently the function of the weakened or disrupted speech musculature (which include those of the mouth, tongue, larynx, soft palate and face). NSOMEs may include activities described as “active muscle exercise, muscle stretching, passive exercise, or sensory stimulation” (McCauley, Strand, Lof, Schooling & Frymark, 2009). Controversy surrounds these exercises (McCauley et al., 2009): Lof (2009) suggests that while the exercises may impact on the targeted discrete non-speech movement, this will not translate to an improvement in speech articulation. In addition, he claims that as speech comprises complex, organised and integrated movements it cannot be enhanced by learning constituent parts of the movement alone. No consensus exists regarding NSOMEs’ role in reducing the impairment of dysarthria, as there is no robust evidence to indicate their effectiveness (Clark, 2003; Bowen, 2005; Mackenzie, Muir & Allen 2010; Lof, 2011; Mackenzie, et al., 2014).

Despite the lack of evidence of effectiveness, the therapeutic use of these exercises is longstanding and widespread. In a survey of SLTs working with adults with acquired dysarthria in Scotland, Wales and Northern Ireland, 81% (n=155) of respondents reported using NSOMEs in their management of adult patients with dysarthria (Mackenzie et al., 2010). Over 90% (n=125) of respondents in a survey of SLTs working in a variety of settings in England reported using NSOMEs (Dean & Heron, 2010).

In their systematic review of the effect of NSOMEs on speech, McCauley et al. (2009) called for well-designed studies comparing NSOMEs with traditional treatment approaches. Many articles could not be included in their review because they did not address the effectiveness of NSOMEs in isolation, targeting instead their use in combination with other treatment; determining the impact and added value of an intervention is not possible if the research design does not allow it to be examined separately.

Addressing these concerns, Mackenzie et al. (2014, see Appendix 1 for the NONSPEX paper) randomly assigned 39 participants with stroke-related dysarthria of differing severities membership of one of two groups. The “SPEECH” group received articulation-focussed behavioural intervention, and the “NSOME” group received NSOMEs in addition to the intervention. All participants who completed the programme received eight individual sessions of therapy.

All patients, regardless of the group to which they were allocated, were encouraged to devote 10-15 minutes, 2-3 times daily to home-practice (including: conversation; a core word/sentence set; speech maximization strategies; individually relevant stimuli; and for the NSOME group - practising along with the modelled exercises on the DVD), at least 5 days each week. Patients self-recorded the amount of minutes spent practising on timelog sheets (appendix 4). Practice amounts were informed by clinicians’ typical practice relating to NSOMEs (Mackenzie et al. 2010), and documented levels of participant adherence (Robertson 2001).

It is from the NONSPEX study that the participants in the current study were recruited. All were treated by a single therapist (the author of the present study), and raters were blind to group membership. Measures of speech intelligibility, communicative effectiveness and lip/tongue movement were examined at four points (two pre-intervention, two after) and outcomes were compared. Externally and self-rated communicative effectiveness measures (Donovan et al., 2007) showed statistically significant gains for the whole sample, which were maintained two months after intervention. However, no group effect was indicated and no intervention-related gains in lip/tongue movement were demonstrated, suggesting that the NSOMEs, as used in the intervention programme did not affect outcome.

One factor which proved difficult to control in this study, as in Robertson (2001), described in section 3.1.2, was the *quality* of the practice undertaken by the participants when the therapist was not around to monitor and provide support (only the *amount* of practice undertaken – in minutes - was logged). Although participants were advised to replicate the work carried out in therapy sessions, to what extent they did cannot be known; a factor which may have influenced outcome. The outcome of the study has implications for SLTs who routinely require of their patients the high levels of adherence and independent practice needed to undertake a programme of NSOMEs.

Improving resonance

During speech, velopharyngeal closure allows speakers to generate sufficient air pressure and flow for the production of pressure consonants and permits the production of voiced sounds without hypernasal resonance (Ruscello 2006). Although much of the literature relating to resonance disorders focuses on cleft palate, Yorkston et al (2001) reviewed the existing evidence base relating to (non-stroke specific) velopharyngeal function in dysarthria and identified that palatal prostheses were found to be effective in small cohorts of individuals with dysarthria (eg, in TBI: McHenry, Wilson & Minton, 1994; and in stroke: Light, Edelman & Alba, 2001).

Current (non-stroke specific) literature does not support sensory stimulation or passive exercise as viable treatments for velopharyngeal insufficiency (Ruscello 2006), however, the improvement of resonance through the use of continuous positive airway pressure has been reported among a small number of carefully selected subjects (Kuehn, 1997), and some biofeedback techniques have been found effective (Ysunza et al., 1997) among cleft palate patients

Acute stroke and impairment-based interventions

Bowen et al. (2012a) reported an interesting finding relating to impairment-based therapy for dysarthria. With the aim of examining the effectiveness, cost-effectiveness, and patients' views of SLT for stroke-related communication difficulties, they compared the outcomes of two randomised groups (each n=85) of patients in acute stages of stroke with dysarthria (treatment group n=8/controls n=9), aphasia (n=53/n=51), or both (n=24/n=25). The treatment group receive therapy from SLTs in hospital, delivered in line with agreed best practice (the authors describe the therapy as “enhanced” although in fact patients in the treatment group received on average 1.5 hours of therapy per week (Nouwens 2012), which falls below the minimum recommended amount of two hours/week by SIGN (2010) for the management of aphasia). The control group received social contact of comparable frequency and duration from nine employees, described as having “excellent” social skills (p4).

The RCT aimed to evaluate the clinical effectiveness of the SLT intervention, compared with the control, six months after entry to the study. The primary outcome comprised the ratings of therapists, blinded to group allocation, of participants’ functional communication, and the results suggested no added benefit of therapy. This was also the case for the other outcomes, namely: participants’ self-reported functional communication and quality of life; carers’ perceptions of participants’ functional communication; carers’ own wellbeing and quality of life; and adverse events.

Impairment-based approaches were found to have predominated in the treatment group, accounting for half of the direct contact activity, which in itself only comprised 53% of SLT contact time. In contrast, 100% of the employees’ time was spent in direct contact with patients, usually in conversation. Meteyard (2012) argued that the primary outcome measure, which rated communication during conversation, was biased towards the activities of the control group, namely conversation. There was no corresponding measurement of impairment-level changes; had there been, and it had shown an improvement at the impairment level, the authors reasoned that "…even if an intervention has a strong impairment focus, it needs to prove itself by producing a meaningful impact" (p8). In other words the impairment-focussed approaches were not effective at impacting on the patients' functional communication.

As the specific aspects of the interventions used by the treating SLTs are not outlined in the paper, and no distinction is made regarding differences in the outcomes of dysarthria versus aphasia, it is impossible to say which treatments may/may not have been effective. However, the authors hypothesise: "it is the quality of the everyday communicative interaction with a therapist/visitor/assistant, and not the impairment-based therapy approach, that may be the active ingredient in early communication intervention and warrants further exploration" (Bowen et al 2012b, letter). They recommend the re-evaluation of acute stroke services, and replacement of impairment-based approaches to the remediation of dysarthria/aphasia with those that specifically target functional communication.

The preceding section described some approaches and methods used in SLT to target the impairment of dysarthria, most of which involve a considerable commitment from the patient, in time and effort. As the reader will see, this is highly relevant to the current study, which investigated the views of patients regarding their therapy programme, which comprised a selection of the therapeutic approaches described above. This section continues to describe briefly approaches for intervention at the activity/participation level of the ICF (WHO 2001)

Activity-focussed approaches

These focus at the level of the communicative activity, and can include the use of biofeedback enabling patients to monitor and modify speech (Pinto et al., 2004), or assistive devices ranging from alphabet boards to computerised communication systems used as augmentative and alternative communication (AAC).

AAC

A comprehensive review of AAC for adults with acquired communication disorders (Beukelman, Fager, Ball, & Dietz, 2007) detailed issues relating to acquired and progressive disorders but neglected to cover stroke. However, clinicians providing AAC intervention must be mindful of the stable/improving nature of stroke-related dysarthria, compared to the deteriorating nature of progressive dysarthria, and the possible differences in AAC intervention for stroke-related dysarthria compared to that of progressive dysarthria. Re-assessment and monitoring of progress in the use of the selected AAC device is required, particularly as stroke patients may be aiming to have “normal” speech again (Walshe & Miller 2011), which may impact on their acceptance and use of AAC.

Other AAC techniques include alphabet supplementation, involving cueing the listener by indicating the first letters of the words being spoken. In topic/gesture supplementation the listener is provided with a written/gestural cue regarding the topic. Some small-scale studies involving people with cerebral palsy and TBI (Hustad Jones & Dailey 2003; Hustad & Garcia 2005; Hustad & Lee, 2008, and see Hanson, Yorkston & Beukelman 2004, for a critical review) have found these strategies to be useful in enabling people with dysarthria to increase the intelligibility of their speech; albeit in tightly controlled, less naturalistic situations. Alphabet cues were found to be generally the most effective strategy, with consistent effects on speech production, including reduced speech rate, reduced articulation rate, and increased frequency and duration of pauses.

Participation-focussed approaches

Eyssen, Steultjens, Dekker and Terwee (2011) examined in a systematic review the extent to which assessments focussing on participation (from the general health field) actually do so, according to their working definition, concluding that many do not. The domains of the ICF (WHO 2011) they included “required a social context and a combination of multiple activities that are related to a role” (p989). That the authors chose not to consider communication as an appropriate item for inclusion demonstrates the need for future research to focus on operationalising the measurement of participation, to enable the assessment of participation levels of people with dysarthria, and inform clinical practice (Miller & Walshe 2011).

Currently, interest in developing tools to examine the psychosocial impacts of dysarthria is growing (Donovan et al. 2007; Hartelius, Elmberg, Holm, Lövberg & Nikolaidis, 2008; Walshe et al. 2009), and adopting a social approach to dysarthria is advocated by Walshe and Miller (2011). They recommend tackling diminished social networks and ameliorating societal barriers, starting with inputting into training of service providers, although how the authors expect clinicians to achieve this is not articulated.

Some of the psychosocial impacts of dysarthria might be addressed in group situations, in which there are opportunities for natural interaction (Elman 2007), discussion of experiences, and peer support. MacKenzie, et al. (2012) described the implementation and feasibility of a group intervention programme called *Living with Dysarthria.* Designed for people with chronic stroke-related dysarthria and their main communication partners, the programme comprised eight weekly sessions of two hours, and aimed to address the “broad life implications” (p720) of dysarthria, particularly those associated with psychosocial wellbeing in relation to communication. It aimed to effect change at the level of activity and participation (WHO 2001) rather than the impairment, through discourse, role-play, conversation, and practicing communication maximisation strategies. Shared discussion of participants’ experiences of *Living with Dysarthria* was also an important component of the programme.

The outcomes of the group were positive: group median scores increased, and significant improvements were seen in both intelligibility scores and knowledge of stroke/dysarthria. Participants all reported some progression toward achieving their goals, and reported that attending the programme was a positive experience. Reported benefits were consistent with the main components of the programme and included learning and increased insight, the support of peers and professionals, and improved speech and confidence.

Individual tailoring of intervention

Treating a person with dysarthria typically involves using a combination of treatment techniques and approaches tailored to the nature and severity of the dysarthria and to the goals and preferences of the individual (Enderby & Palmer, 2007). As previously described, the aims of Mackenzie & Lowit (2007) were to determine whether an individually-tailored behavioural intervention addressing the functional limitations of dysarthria would result in a change in intelligibility and communication effectiveness, and reduce the impact of dysarthria on the participants. The treating therapists applied motor learning principles (see section 3.1.2), including: repeated modelling; high amounts of practice; a variety of stimuli; and frequent immediate and specific feedback. Of the eight participants, five demonstrated improvement in at least one of the three speech measures, while for the remaining three no intervention-related change was apparent. However, the individually tailored aspect inherent in the therapy, and the fact that therapy was provided by different therapists, meant that the therapeutic experiences of participants were not comparable. Additionally, no relationship could be established between independent practice carried out and any consequent improvement in speech as there was little control over how the independent practice was conducted, and no documentation was made of amount or quality of practice.

The following section examines factors which have the potential to impact on patients' adherence to therapy for dysarthria, beginning with an examination of the concept of *adherence* generally, and how it is relevant to SLT for dysarthria.

3.2 Adherence

Adherence in this study is used in line with the WHO's definition: "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (Sabate 2003 p3). The agreement of patients is what differentiates adherence from "compliance", which does not require that "patients are active partners with health professionals in their own care" (WHO 2003 p3), as "adherence" does.

Adherence is discussed in this study in relation to the dysarthric patient carrying out the activities and exercises which were recommended by the SLT with the patient's agreement.

3.2.1 Measurement

As literature specifically regarding adherence to SLT regimes is sparse, it is necessary to consider in the following section issues relating to adherence from other health fields in addition to that of SLT.

There is no gold-standard for measuring adherence behaviours, although there are various ways of doing so (WHO 2003). Studies which measure adherence in SLT have included a number of diverse methods. One study examined records retrospectively and classified as adherers those discharged from voice therapy (the assumption was that they had completed their programme to the satisfaction of the SLT) and those that drop-out as non-adherers (Duarte de Almeida, Santos, Bassi, Teixeira & Côrtes Gama 2013). This measure does not capture information on the *quality* of adherence – to what extent they engaged in and followed the therapists' recommendations. Using this measure a patient who came to an appointment but refused to participate in any way would still be "an adherer".

Shinn et al, (2013) classified as adherers all patients who demonstrated adequate competency in carrying out swallowing exercises, although it could be argued that such a measure is not evidence of adherence but is rather a measure of patients' ability to demonstrate the exercises. In another study, Portone, Johns & Hapner (2008) classified as non-adherers those who did not attend first/follow-up voice appointments, thereby not adhering to recommendations by their physician/SLT. Adherence was measured by van Leer & Connor (2012) through patients' self-report regarding the amount of voice practice undertaken, aided by a tally counter attached to key chains. Similarly, Gunther & Hautvast (2010) measured adherence through parents of children participating in articulation therapy logging amounts of time spent on "homework".

None of the above studies use methods which provide comprehensive information regarding the *quality* of adherence – the extent to which the therapeutic regimes were followed in terms of consistency, time, effort, precision, and so on. These are aspects that are difficult to measure when patients are carrying out their programmes at home, unsupervised. Indeed, Bollen, Dean, Siegert, Howe & Goodwin (2014) systematically reviewed the literature relating to measuring adherence to home-based, unsupervised rehabilitative exercise regimes for people with long-term health conditions and found a lack of validated and reliable self-report measures. Frost, Williams, Brady & McClurg (2014) assert that methods used to measure adherence in home-based therapies, including SLT, have limited evidence and recommend that adherence measurement decisions need to relate to the parameters and features specific to the interventions.

Recent developments in home-based therapy, however, provide means of measuring adherence electronically thereby negating the need for self-reports, as in a feasibility study by Palmer et al (2012). They offered training to people with aphasia in the use of computer software which provided them opportunities for independent practice in tasks aimed at improving word retrieval. One of the primary outcome measures of the study was participants' ability to adhere, or "carry out the intervention per protocol" (p1906), measured by amount of time spent on the programme. This was automatically stored by the software, in addition to details of the work carried out, such as the levels that had been successfully completed, providing a more descriptive picture of participants' adherence.

Outside the field of SLT, in pharmacological interventions, objective measures of adherence are frequently used. Counting remaining pills is one method, although it is prone to inaccuracies and can result in overestimating adherence (Matsui, et al. 1994). Electronic means of monitoring adherence are also possible, such as through incorporating microcircuitry into either packaging (Arnet, Walter, & Hersberger 2013) or medical equipment like nebulisers (Daniels, et al. 2011), to provide adherence data. Objective measurement of physical activity can be achieved through the use of instruments such as accelerometers to record movement (van Poppel, Chinapaw & Mokkink 2010). However (as may be the case with the computer software used in the Palmer et al. 2012, study), many of these technologies have limited usefulness in large clinical populations, are often expensive and can be intrusive (Prince, et al 2008).

Subjective measures can take the form of ratings of patient adherence by self-report, or by healthcare providers. A number of studies have found discrepancies and inaccurate reporting of adherence by comparing patients' subjective self-reports to the results of electronic monitoring of their adherence in a variety of populations. For example, Zeller, Ramseier, Teagtmeyer & Battegay (2008) found that 79% of their 78 participants overestimated their adherence to cardiovascular medication when self-reporting retrospectively. Similarly, Daniels, et al, 2011, found a group of 78 patients with cystic fibrosis overestimated their use of nebulisers over the previous three months. A systematic review of 176 articles (Prince, et al 2008) aiming to determine the extent of agreement between subjectively and objectively measured physical activity in adults found only low-moderate correlation between the two measures. Although overall effect sizes could not be calculated because heterogeneity in units of reporting across the studies made them incomparable, the authors concluded that self-reports can be problematic as patients can, and do, overestimate or underestimate adherence levels.

One of the factors impacting on measures of adherence may be the reliance on memory, as in the studies above in which the self-report relates to events in the past. Jeffrey et al (2012) found that among 135 elderly participants in an RCT investigating the effectiveness of an exercise machine to increase bone-density, there was good agreement between electronically monitored adherence and self-reported adherence through the use of contemporaneous logs (without the need for recall). Similarly, Wilbur, Chandler & Miller (2001) measured the adherence of 156 women to a prescribed walking regime by the use of contemporaneous time-logs, and electronic cardio-monitoring. The measures were highly correlated (although some monitors malfunctioned, possibly impacting on the results). It is possible that eliminating the need for the patients to *recall* how many times they carried out an exercise, and instead record it as it happens, enabled them to log adherence accurately.

In the papers reviewed by Prince et al (2008), trends of agreement differed by the measures employed, the levels of activity measured and the participants' gender. Women tended to overestimate their adherence levels, while men tended to be more accurate. This finding was mirrored in those of Ferrari et al (2007), who examined 154 study subjects' (51% women, aged 35–65) self-reports relating to exercise adherence and compared them to the objective data gathered from accelerometers used when exercising. The males' self-reported adherence levels were more accurate, while the females tended to over-estimate adherence (Ferrari et al, 2007*).* This may be due to socially desirable responding - the tendency to present a favourable image of themselves (van der Mortel, 2008) which risks confounding results by creating false relationships or obscuring the relationships between variables. Hebert et al (1997) found that when self- reporting their nutritional intake, women were more likely to respond in socially desirable ways. People being interviewed about adherence to regimes may feel a similar need to provide a socially acceptable view of themselves.

Finally, when requiring that patients keep diaries as a means of self-report to inform on adherence it is worth recognising that the logs themselves can be considered as aids to adherence, acting as a cue to carrying out the exercises in question (Mosely 2006), This can be advantageous to the therapist but for the researcher it can be a limitation, as it is not offering a true measure of the patient's unprompted adherence (Bassett 2003). Bollen et al (2010) suggest that tightly monitored supervision of adherence to exercises could give a false view of adherence as the patient may experience reduced autonomy and a compulsion to comply; in which case the resulting measure is one not of adherence but of *compliance*

3.2.2 Its role in rehabilitation

Patients' adherence to rehabilitation tasks and activities is thought to be essential to enable the achievement of optimum gains from therapy. Inpatients who "participate well" in rehabilitation programmes have been found to enjoy better functional outcomes, shorter inpatient stays and a lower risk of discharge to institutional care than those who were rated by their therapist as having participated poorly (Lenze 2004). Adherence is essential to give therapeutic programmes the chance to be clinically effective, and comprise an efficient use of public resources (Enderby et al, 2009; Marsh, et al., 2010; Wenke, Cornwell & Theodoros, 2010). SLTs need to ensure they are supporting their patients to achieve maximal adherence. To do so, it is necessary that the factors which impact on patients' adherence to treatment are known. Literature relating to adherence in terms of therapy-related, personal and interpersonal factors is examined below. As there are few studies specific to dysarthria treatment, findings from the general field of SLT and other disciplines with some comparable approaches to management are examined.

3.2.3 Personal factors

The WHO describes personal factors that can influence adherence to medical interventions as including psychosocial factors such as stress, anxiety, low motivation, hopelessness and negative feelings. Other internal barriers such as forgetfulness, inadequate knowledge about the disorder, lack of beliefs or low expectations about its treatment and misunderstanding of treatment instructions can also impact on patients' adherence levels (Sabate 2003). The following section examines depression, apathy and some other personal factors, and their relation to adherence.

Post-stroke depression (PSD)

There are no available studies relating to how PSD impacts on adherence in patients with communication difficulties, there is some evidence to suggest that it impacts on *participation* in rehabilitation, if not specifically on adherence. Skidmore et al (2010) measured the “rehabilitation participation” (RP) (the degree to which patients actively participate in and follow recommended therapeutic activities) of patients with stroke through ratings by occupational and physical therapists. They found that depressive symptoms were correlated with low RP, but were not predictive; only baseline disability and executive functions predicted RP. As SLTs were not involved in rating patients’ RP, it is implied that participation in speech therapy was not rated, therefore these results cannot easily be generalised to SLT.

A systematic review of 20 studies found that depression and anxiety are barriers to treatment adherence in physiotherapy outpatient clinics (Jack, McLean, Moffett & Gardiner, 2010). Gordon et al. (2004) described PSD as a primary barrier to post-stroke therapy, and recommended that the initial steps of designing a regimen for stroke patients should include an assessment for depression. PSD requires early identification and management (Dafer, Rao, Shareef & Sharma 2008), as it is associated with poorer rehabilitation outcomes (Gillen, Tennen, McKee, Gernert-Dott & Affleck 2001), more functional disability (Cully, et al 2005), increased morbidity and mortality in the first year after stroke onset (Williams, Ghose, & Swindle 2004).

The reported prevalence of PSD varies; but from the 43 studies (including 20,293 patients) in a systematic review by Ayerbe, Ayis, Wolfe, & Rudd (2013) which reported incidence/prevalence figures, PSD's prevalence was calculated at 29% (95% CI 25–32), and major predictors included disability, pre-morbid depression, cognitive impairment, stroke severity and anxiety. A number of factors resulted in a large variation of prevalence across studies, including heterogeneous methods of diagnosing depression, a variety of assessment timings and sources of recruitment, in addition to the diversity of settings. Ayerbe et al. caution that more methodological consistency is needed to determine whether the variability in findings demonstrates real differences in population characteristics. Additionally, they highlight the potential for underreporting abnormal mood among patients with communication impairments and the difficulties in assessing them.

Turner-Stokes & Hassan (2002) note that many of the symptoms listed among diagnostic criteria used in studies may arise directly from stroke itself, rather than from PSD; communication difficulties can impact on the ability to describe or express the emotions they are experiencing, and neurobehavioural sequelae of stroke can cause features associated with depression such as crying, fatigability, insomnia or intellectual decline.

In terms of the co-occurrence of depression and communication problems, more attention has been paid in the literature to depression associated with aphasia than dysarthria (e.g. Starkstein & Robinson, 1988; Kauhanen, et al. 2000; Fucetola, et al. 2006). Studies into communication problems may exclude patients with depression (as in Brady, et al. 2011), and many depression studies exclude people with communication problems (as in Hackett, Yapa, Parag, & Anderson 2005), all of which impacts on the extrapolation of data regarding depression in people with communication impairments**.**

Some papers consider dysarthria in the catch-all category of speech-language problems. De Ryck et al. (2014) found no association between depression and speech-language problems at 18-month follow up. However of the two measures used, one - FIM (Dromerick, Edwards & Diringer 2003) - has been criticised for its lack of sensitivity to communication problems (Frymark 2003). The other, the Stroke Impact Scale (Duncan 1999) requires self-rating/rating via a proxy, potentially limiting its use with people with communication difficulties. A similar issue was noted by Turner-Stokes & Hassan (2002) regarding the use of interviews to establish the existence of depression.

De Ryck et al. (2013) report a higher prevalence of “speech and language problems” (p11) observed in patients with PSD, compared to non-depressed patients. They describe the risk of developing depression as increased in patients with more functional and cognitive impairment, greater dependency in activities of daily living, and with co-occurrence of speech-language dysfunctions.

Apathy

Caeiro, Ferro & Figueira (2013) describe apathy as a disturbance of motivation affecting goal-directed behaviour, characterised by a decrease in activities, inattention to usual interests, and reluctance to initiate conversation. In their systematic review of 19 studies (including 2,221 patients), they reported a pooled prevalence of 36.3% for apathy, three times higher than their finding of 12.1% prevalence of depression (lower than the prevalence estimate of Ayerbe, et al., 2013, at 29%). Depression and cognitive impairment were more frequent and severe in apathetic patients, and the rate of “pure” apathy (in the absence of depression) was twice that of “pure” depression.

Mayo, Fellows, Scott, Cameron & Wood-Dauphinee (2009) found that cognitive impairment, low functional status, and high comorbidity predicted greater apathy, which in turn impacted on participation in rehabilitation (and by extension, it could be argued, adherence).

Internal barriers

The participants in Dickson et al. (2008) reported that the approaches that they judged to have led to success in the rehabilitation of their dysarthria were “taking the initiative to improve … speech, being determined and practising” (p145). Voice therapy patients have described encountering “external barriers” such as the therapy itself, lack of time and difficult environments, and “internal barriers” which were of a cognitive and emotional nature (van Leer & Connor 2010). These included negative attitudes to the therapeutic tasks, forgetting to practice and a lack of motivation to participate, a possible result of a lack of confidence in their own ability to alter their voice (van Leer, Hapner & Connor 2008). Thus it is suggested that patients' beliefs about both therapy and their own abilities may indirectly affect outcomes via their participation in treatment.

3.2.4 Therapeutic relationships

Unfortunately, establishing an association between the quality of therapeutic relationships and the outcomes of SLT is challenging (Simmons-Mackie & Damico 2011 p46); more research into this area would be instructive clinically, as discussed in section 7.1. The therapeutic relationship has been described as a "co-constructed process" (Walsh & Duchan, 2011 p 53), which is dynamic and must be maintained and developed throughout therapy, rather than a construct which can simply be established in a few minutes at the start of a session. Using data gathered from interviews with former SLT patients, Fourie (2009) generated a theoretical framework to describe the components of an effective therapeutic relationship as constructed by the interplay between the therapeutic actions and qualities of therapists. Therapeutic actions comprised being confident, soothing, practical and empowering. The qualities the patients described incorporated those of: being understanding, gracious, inspiring and erudite. The participants in the *Living with Dysarthria* programme (Mackenzie, Kelly, Paton, Brady & Muir 2013), reported that they appreciated their therapists' supportiveness, and their encouragement and help, and also 'being valued' as a participant.

When interviewed about *aphasia therapy*, patients felt a positive relationship with their therapists to be crucial (Worrall et al., 2011). Their therapists, when interviewed, also felt this was important and that *lack* of a therapeutic relationship had impacted negatively on outcomes (Sherratt et al., 2011). Similarly, another group of SLTs cited rapport as the feature of therapy with the greatest power to impact both positively and negatively on treatment outcomes (Ebert & Kohnert, 2010).

It is not possible to establish from the SLT literature how therapists' qualities and therapeutic relationships impact on adherence, but there is evidence to suggest that the communication styles of *medical staff* can impact on adherence to treatment by influencing patients' satisfaction with consultations. Charlton, Dearing, Berry and Johnson (2008) reviewed the nursing literature relating to this, and describe how patient-centred communication, in which patients are engaged in discussion and in decision-making processes regarding their care, can positively influence patient outcomes, through increased adherence to treatment plans. Ohya et al. (2001) found that a good doctor-patient relationship (measured by parents' opinions of their ease of communicating with their doctor) influenced parents' adherence to advice regarding management of their children's dermatitis.

Byrne and Deane (2011), report on a training programme aimed at increasing medication adherence, for clinicians working with people with psychosis. The training places an emphasis on the establishment of a strong therapeutic alliance (TA) with patients and a non-judgemental clinical attitude and, following training, levels of adherence among the clinicians' patients increased, suggesting that doctor-patient relationships can impact on adherence.

The therapeutic relationship needs to be resilient enough to enable the clinician to clearly convey expectations to the patient, give honest feedback about performance and challenge the person, holding them accountable for their own progress when necessary (Plexico, Manning & DiLollo, 2010). People who stammer described their strong TA as motivating them to engage in therapy and achieve goals, as they felt the desire to please their therapists: "When the clinician builds a friendship with you…you don't want to let them down" (Plexico et al, 2010 p. 344).

3.2.5 Therapy-related factors

As discussed earlier, a number of studies have looked at adherence to *voice therapy* (eg Van Leer & Connor, 2010; van Leer, Hapner & Connor, 2008; Portone, Johns & Hapner, 2008), which is in many ways comparable with behavioural interventions for dysarthria, as it comprises the modification of behaviours, learning new strategies, a programme of exercises, and independent self-directed activities. Involvement in such therapy is not passive; patients are required to adhere to a specified treatment regime, actively participate during sessions and practice at home, as in the therapy programme in Mackenzie & Lowit (2007). Voice patients felt that therapy was challenging due to the high levels of attention, awareness, and adherence it demanded, and because some perceived the exercises as "silly" (van Leer &

Connor, 2010). All these factors can comprise barriers to adherence to therapy, and they are not unique to voice therapy.

When twenty-four dysarthric patients were interviewed about their experiences of dysarthria and its impact, many described therapeutic tasks undertaken with the aim of reducing their dysarthria, such as NSOMEs and articulation exercises (Brady, Clark, Dickson, Paton, & Barbour 2011a). They reported that the functional relevance of such tasks relating to the improvement of speech was not always apparent to them, and a lack of engagement with these activities was expressed in terms of embarrassment, boredom, indifference or derision. The tasks were perceived by some as childish activities, and as humiliating and stigmatizing, and participants did not adhere to those not perceived to be challenging, functional or reflective of their interests.

Participants on the *Living with Dysarthria* programme expressed their appreciation of therapeutic tasks which were tailored to meet their individual needs precisely and flexibly, and provided variety to keep them engaged (Mackenzie, Paton, Kelly, Brady & Muir, 2012). They were also provided with tasks to practice at home, and although the group leaders believed that some participants were not interested in the practice and had not carried it out, the factors that impacted on the participants' adherence to those recommendations were not explored. No participant acknowledged *not* having adhered, although reference was made to the difficulties faced by people who lived alone.

Endeavouring to meet the individual needs of stroke patients and make therapy reflective of their interests is a key premise of the theory behind goal-setting. Most of the theoretical underpinnings of goal-setting come from studies carried out in occupational and work settings (see Locke & Latham (2002) for a review), and there is a paucity of literature pertaining directly to goal-setting for the management of communication disorders, with fewer addressing setting goals for dysarthria therapy specifically. However, Mackenzie et al (2012) encouraged participants in the *Living with Dysarthria* programme to establish goals, with most choosing to aim for improved speech. Despite the focus of the programme being the “broad life implications of acquired dysarthria” (p720), an increase in intelligibility was demonstrated. The authors suggest this may be because the participants had “engaged maximally” (p720) with the speech practice components of the programme over others.

It is recognised that having goals to work toward can effect a change in behaviour (Locke & Latham, 2002) and, in occupational settings, a high level of involvement and commitment to goals has been found to have a strong positive effect on performance (Klein, Wesson, Hollenbeck & Alge 1999). Wade (2009) stresses that in rehabilitation it is the setting of goals in addition to high levels of patient and family engagement that effects behaviour change.

The outcomes of two groups of patients with acquired neurological impairments at a rehabilitation unit were compared (Holliday, Cano, Freeman

& Playford 2007). The groups comprised those who had been highly involved in setting their own goals and those who were in the “usual practice” group in which staff members set goals for patients in their absence. When compared, the goals set by the groups differed qualitatively and quantitatively; those in the group who were highly involved in the goalsetting process set significantly fewer goals, in addition to setting a higher proportion of goals related to participating in life roles. There were no differences between the two groups in their functional outcomes or in the proportion of goals achieved. However patients in the “increased participation” group reported significantly higher satisfaction with the rehabilitation process and the authors suggest that this was due to a greater perceived relevance, feelings of autonomy, and the precise targeting of goals. Clearly, there are benefits to patients setting their own goals for therapy, or at least participating jointly in their setting.

Leach et al. (2010) found that, of the goals set by a multi-disciplinary group of stroke rehabilitation therapists, those targeting the level of the impairment were not commensurate with those they actually believed the patient wanted to aim for. Despite this, impairment-based goals predominated, due to ease of measurement, time and service restrictions and communication difficulties impacting on patients’ participation in goal-setting.

So what *do* people with communication difficulties want from therapy? People with aphasia reported that they have a wide variety of goals (Worrall et al., 2011) categorised by the authors as: a return to pre-stroke life; restoring communicative function (including working on tasks that were relevant to their real lives); understanding their condition; receiving speech therapy and health services (including good relationships with therapists); control and independence (with some describing how they used home practice tasks as a means of having control over their progress); dignity and respect; social, leisure, and work; altruism and contribution to society; improving physical function and health. It is apparent that people with communication difficulties are very capable of identifying goals to aim for in therapy.

Sherratt et al. (2011) interviewed the SLTs responsible for the management of the patients in the Worrall, et al. study (2011). SLTs discussed the therapeutic goals, and framed the goals in terms of two approaches to rehabilitation: what they described as “impairment-level face-face therapy” and functional therapy at aimed at ‘‘vocational/life reintegration”. Therapists reported employing both approaches in their patients’ rehabilitation. However family members were often not included in either goal-setting or the process of therapy, at odds with the wishes of the patients who reported they wanted to be able to speak to their families.

Outlined above are some of the therapy-specific issues which are relevant to patients’ participation in therapy and their adherence to the tasks and activities therein. These include the importance of activities and goals which are relevant, address the person’s everyday life and functioning, and include the people with whom they communicate in “real-life”. It is apparent patients are able to participate in setting their own agendas for therapy, even with communication impairments; thus it is imperative that healthcare providers and institutions *listen* to the patient’s voice. The final section of this review discusses briefly some of the issues relating to gathering patients’ views of therapy.

3.3 The patient’s voice

Patients’ opinions and experiences of their treatment have the potential to “transform healthcare” (Black 2013), and are considered by some researchers as one of the central pillars of quality in healthcare (Doyle, Lennox & Bell 2013; de Silva 2013). Patients’ full involvement in healthcare is promoted in government policies; their right to having their opinions heard is enshrined in The Patient Rights (Scotland) Act 2011 (Scottish Government 2011).

Research is beginning to suggest a link between the patient’s individual experience of treatment, and its outcome: a systematic review of 55 studies in primary care and hospitals found consistent positive associations between patient experience, clinical effectiveness and patient safety, in a range of diseases, settings, outcome measures and study designs (Doyle et al., 2013). Listening to the patient’s voice is clearly of clinical significance, and there is a range of methods to facilitate this.

3.3.1 Gathering data

There is considerable literature on seeking patients’ views; on involving them in the piloting and development of materials which gather feedback; and implementing that feedback in the improvement of services. The NHS has developed a significant amount of instructional materials regarding methods of gathering opinions and feedback, the wording of questions, how to analyse, understand and use feedback to develop health services and clinical care (e.g. Picker Institute 2009; and http://www.nhssurveys.org).

Patient involvement has moved on from simply asking people about satisfaction with their care. Patient Reported Outcome Measures are now routinely used in some clinical areas to measure patients' health through ascertaining their views of their symptoms, their functioning, and health-related quality of life (Black 2013), without interpretation by a clinician (Patrick, Guyatt & Acquadro 2008). It is asserted that by comparing a patient's health at different time-points, the outcome of treatment they received can be determined (Black 2013*).* Patient Reported Experience Measures focus on aspects of the humanity of care (Black 2013), by seeking patients' views on their experience while receiving care (de Silva 2013; Whelan, Reddy, & Andrews 2011).

Methods of gathering feedback can be considered in terms of the type of information they gather; quantitative or qualitative (Coulter, Fitzpatrick & Cornwell, 2009), and these are examined briefly below.

Quantitative methods

Methods of gathering quantitative information regarding patients' experiences/opinions include: postal surveys; interviewer-administered face-to-face surveys; live or automated telephone surveys; web-based/email questionnaires; administrative data/routine statistics; and on-site surveys using hand-held portable devices/touch-screen kiosks/bedside consoles (Coulter et al., 2009). The aim of such methods is usually to examine patterns and trends from a large sample; a breadth of information can be gathered, although predetermined questions and response options preclude the gathering of a depth of information (Coulter et al., 2009), as the ability to probe is limited. However, surveys can gather more information related to socially undesirable/sensitive behaviours than situations in which an interviewer is present (Duffy, Smith, Terhanian & Bremer, 2005; Bronner & Kuijlen, 2007; Turner et al, 2009; Langhaug, Sherr & Cowan, 2010).

The following section describes more methods of gathering qualitative data on patients' experiences.

Qualitative methods

These differ in their focus on obtaining an in-depth understanding of people's experiences and opinions. As they usually consist of words, rather than numbers, it is more difficult to compare or make generalisations. Methods include: in-depth face-to-face interviews; discovery interviews, by clinical staff; focus groups; web-based free text comments; on-site comment cards or suggestion boxes/video boxes; complaints and compliments; patient diaries; mystery shopping; customer journey mapping and direct observation (Coulter et al., 2009).

Asking the right questions

The face-face interview is commonly used in health-related research, and usually the topic is controlled by the interviewer seeking information from an interviewee, who has freedom to respond to open-ended, but focused, questions (Bredart, Marrel, Abetz-Webb, Lasch & Acquadro 2014). Interviews commonly aim to gather rich data; Ogden & Cornwell (2010) attempted to operationalise “richness” by examining 10 studies to find out what type of questions predicted the gathering of “rich” data - that which relates not simply to context and structure, but also to feelings, thoughts, intentions, and actions. They summed up richness in terms of length of response; action responses; and personal, descriptive and analytical richness. Their analysis suggested that open questions, positioned towards the end of the interview (when interviewees may be more comfortable, and warmed to the topic), gather richer data than closed questions at the start.

As described by Bredart et al (2014), interviewing is a skill that needs practice to improve and requires close attention to aspects of non-verbal/verbal communication to continually monitor the quality of interaction. Depending on the responses of the interviewee, skilled interviewers will prompt, repeat, rephrase and check answers. They will utilise specific listening techniques, such as: active listening; attentive silences; reflecting; synthesising and recognizing resistance. These skills and techniques require the interviewer to rely on his/her own experience and imagination - all the while keeping the interview’s objectives in mind. Interviewing people with communication difficulties may require additional techniques and knowledge, as discussed in the following section.

3.3.2 Listening to people with communication difficulties

Kovarsky (2008) has condemned what he describes as the marginalisation and silencing of people with communication difficulties in research, calling for researchers to enable them to discuss their experiences of disability (as in Walshe & Miller 2011), and the therapy in which they participate, and for these narratives to be considered as legitimate “quantitative unit(s) of analysis” (p 48), intrinsic in the research alongside traditional objective measurements. However, people with communication difficulties are often deemed difficult to interview, and overlooked in favour of articulate interviewees (Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg 2007).

To ensure that views of people with communication difficulties are heard, specialist skills and approaches may be needed. To facilitate interviews with people with aphasia/dysarthria regarding their experience of SLT (Young et al., 2013), the interviewer required training in using supported-conversation techniques, and “communication ramps” to enable participants to give their views. In other research projects (eg Parr, Byng, Gilpin & Ireland 1997) SLTs carried out interviews, as they have specialist knowledge of facilitating communication.

Togher, Power, Rietdijk, McDonald & Tate (2012) used SLTs to interview people with TBI-related communication impairments about their experiences of group therapy, and described their accounts as providing additional evidence for the effectiveness of the programme and demonstrating the usefulness of qualitative research in evaluating clinical outcomes. The SLTs who interviewed the participants had also carried out the therapy programme, a fact which they conceded increased the risk of bias and a possible desire among participants to please the researcher by reporting positive outcomes.

The potential pitfalls of dual roles in therapy are well documented (e. g. Kitchener 1988; Syme 2003; Gabriel 2005). Because of the boundaries of therapeutic relationships (Sherratt & Hersh 2010), research with former/current patients can raise ethical issues (Gabriel 2005). The dual practitioner-researcher role carries with it a potential power imbalance (Etherington 2007; Nunkoosing 2005), which can be abused or used to manipulate. However, Nunkoosing (2005) describes how, as with much human interaction, interviews consist of dance-like interplays of power; the power potentially rests with both the interviewer (the seeker of knowledge) and the interviewee as the expert, privileged with knowledge.

Dual-roles are not always inappropriate. Morse (2006) describes how the researcher must approach research armed with “the knowledge gained from insight…as without insight, our research can be mundane, obvious, and atheoretical” (p1). She describes the practice of “researcher-as-the-instrument” as fundamental to qualitative inquiry, and reasons that insight is crucial to understanding what is going on. Savage (2000) suggests that, “researchers who bodily place themselves in the same situations as those who they study will gain a deeper understanding of their informants' world" (p 332).

Nunkoosing (2005) describes the building of enabling relationships as vital for interviews, and both Etherington (2007) and Johnson, Avenarius & Weatherford (2006) suggest that the context of an existing relationship between interviewer and interviewee, characterised by trust, facilitates collection of more meaningful and rich data. The SLT-researcher is in an ideal position to possess insight and understanding of their patients' situation to inform and guide research. Togher et al. (2012) maintained that the existing relationship and consequent insight of their therapist-researchers enabled them to adapt the protocol for each interviewee by adding relevant probes and topics pertinent to each, based on observations and notes made during the intervention.

To minimise practitioner–researcher role conflict Gabriel (2005) suggests clear information be provided for participants, and an unambiguous confidentiality policy. Universities also offer guidance to researchers carrying out research in dual-roles, including recognising the structure of dual-relationships to assess the extent of the power differential, and including participants in the study only when the researcher is no longer in a "power-over" position, in which undue influence can be exerted over the participant's ability to freely consent (University of Victoria 2008).

3.4 Summary

To summarise, many people with dysarthria experience a disability which can have a momentous impact on their lives In addition, they face the challenge of participating in therapy to remediate the disorder. This is not a passive undertaking; a considerable amount of effort is expected of patients participating in most treatment approaches for dysarthria, requiring motivation to comply with tasks which may be demanding or are perceived as having little relevance to their daily lives. Extrapolated from the findings of studies of other communication difficulties, and patients involved in rehabilitation, it seems that, just as they may face barriers to participating in life activities and roles (WHO 2001) as a result of their dysarthria, they may also face barriers to adhering to therapeutic recommendations, which can include depression, cognitive difficulties, feelings of apathy and other affective and mental health related disorders. People who have more positive feelings about themselves can stand a better chance of actually doing so, as may those who have a good relationship with their therapist.

Patients who participate well in therapy have been found to enjoy better outcomes than those who do not (Lenze 2004). As the aim of speech and language therapy is to achieve positive outcomes, it is in the interest of therapists to consider how outcomes can be improved. People with dysarthria hold the key to this, and the current study aims to examine their views and experiences of therapy by paying attention to the speaker's perspective, as advocated by Walshe & Miller (2011).

3.5 Research Question

What factors, related to patients' perspectives of a therapeutic programme for dysarthria, impact on their adherence to treatment recommendations?

3.6 Aims

- To investigate patients' views on personal, inter-personal and therapy-related factors which facilitated or acted as barriers to adherence to an eight-week course of community-based SLT for stroke-related dysarthria.
- To ascertain treatment adherers/non-adherers by comparing the amount of time spent by patients following recommendations, as self-reported in timelogs.
- To compare the patients' reports of their experiences, gathered from interviews and case-notes, to identify any commonalities or differences between adherers/non-adherers.
- To compare self-ratings of patients' communication to identify any patterns relating to adherers versus non-adherers

Chapter 4. Method

The following section describes the method of the study, its design, ethical approval, the patients and their recruitment. The reader is referred to Appendix 1 for more information regarding the NONSPEX programme, from which the participants in this study were recruited. Methods of data collection and how interviews were planned, conducted and transcribed are also outlined.

4.1 Study design

The current study is of a mixed qualitative/quantitative design, and included the auditing of case-notes.

4.2 Ethical approval

Ethical approval was sought and received from the University of Strathclyde and the NHS for an additional interview to be carried out for the purposes of the current study, with participants of NONSPEX (Mackenzie et al, 2014) underway at that time.

4.3 The NONSPEX programme

NONSPEX is the clinical feasibility trial from which participants were recruited; every patient in the current study participated in and completed the NONSPEX programme. The reader is therefore referred to the NONSPEX paper (Mackenzie et al 2014) in Appendix 1 for a full description of the therapy, as summarised in Table 1.

Table 1. Structure of therapy sessions for the two NONSPEX groups

SPEECH group		**NSOME group**	
5 mins	Session opening/review	5 mins	Session opening/review
20 mins	DVD minus NSOMEs	10 mins	DVD + NSOMEs
	Speech practice: - Modelling of targets + written stimuli - Attempts ≥5 per stimulus → new stimulus on 80% success - Reinforcement of desired responses/correction of non-desired responses - Verbal reward, encouragement, feedback, re: clarity, speed, precision and quality of targets. - Communication strategies	10 mins	Speech practice (as per SPEECH group)
10 mins	Conversation practice	10 mins	Conversation practice
5 mins	Discuss future goals, close session	5 mins	Discuss future goals, close session

Practice:

10-15 minutes, 2-3 x daily, ≥ 5 days weekly. Mins spent practicing noted in timelogs.

4.4 Recruitment, in/exclusion & participant information

Participants in this study were recruited from the 24 patients who at the time of receiving ethical approval were still participating in NONSPEX (Mackenzie et al, 2014). Participants who had completed the programme were not eligible for inclusion as the amount of time between the therapy and the interviews - several months - may have compromised accurate recall. Although no specific health-related exclusion criteria existed, two of the 24 eligible patients were not approached as they were experiencing significant health problems requiring inpatient treatment at that time.

At the time recruitment began, participants were at various stages in the programme (ie; some near the beginning and some nearing the end of therapy). Participants came from two treatment groups, to which they had been randomly assigned membership at the outset of NONSPEX (Appendix 1); one received therapy consisting of articulation-focussed behavioural intervention (hereafter referred to as “SPEECH”), the other group received the same therapy, in addition to NSOMEs (“NSOME”) (therapy is outlined in Table 1).

At their final assessment, 22 patients were invited verbally and in writing by the assessor to participate in interviews with the treating therapist to discuss their experiences and opinions of the therapy. Patients were informed of: the interviews’ purpose and general aims; their right to refuse to participate or withdraw at any point; that interviews would last no longer than one hour; that confidentiality would be maintained, and that recorded interviews would be transcribed, securely stored and listened to only by the researcher and a supervisor (CA) before deletion. Fifteen patients consented to participate and signed consent forms.

Of the six who declined, three gave health-related reasons, and three reported they were unable or unwilling to participate. One patient could not be contacted after being invited. See Table 2 for numbers approached, and their reasons for participating/not participating.

Table 2. Number of NONSPEX patients approached for participation in current study, and reasons for participating/not participating

Eligible patients	**24**
Not approached due to significant health issues	2
Patients approached	22
Agreed	15
Could not be contacted	1
Declined	6
Due to new/worsened health issues	3
Due to unable/unwilling	3
Patients interviewed	**15**

Fifteen patients participated (for details see Table 3; all are assigned pseudonyms for confidentiality). All had completed 8 sessions with AJ. Each patient was involved with NONSPEX, including the interview for this study, for 25 weeks (recruitment → completion). Fourteen were interviewed within a week of the final NONSPEX assessment and one had a break of three weeks between assessment and interview to accommodate hospital treatments.

Table 3. Patients recruited for current study, in alphabetical order

Patient (pseudonym)	Age at start of NONSPEX	Months post stroke at start of NONSPEX	Dysarthria severity at start of NONSPEX*
Adrian	58	17	Severe
Andy	60	3	Severe
Anna	46	4	Severe
Anthony	56	11	Profound
Arthur	79	7	Moderate
Dean	76	7	Moderate
Des	66	4	Mild
Harry	72	3	Mild
John	71	3	Moderate
Laura	66	5	Mild
Mary	80	7	Severe
Neil	46	14	Severe
Paul	72	18	Severe
Sarah	68	14	Severe
Terry	60	15	Moderate

**Dysarthria severity was qualitatively rated at point of referral by referring SLTs using the mild, moderate, severe and profound descriptions applied in Mackenzie et al. (2010).*

The following section describes the sources of data and how they were gathered, focussing on the interview procedures, including their challenges, and the questions.

4.5 Data collection

The current paper examines data collected as part of NONSPEX, as well as that which was collected specifically for the current study. Data was collected from the following sources:

4.5.1 Timelogs

The advice to participants was to undertake two/three practice sessions (comprising NSOME practise if in the NSOME group; Speech Practice; and Conversation Practice) of 10-15 minutes, five days per week. Patients noted in timelogs the number of minutes spent practicing daily. If unable to write, they were assisted by a partner/friend/AJ to fill them in. Timelogs were discussed with the patients and collected weekly. Patients were encouraged to adhere by executing their home practice as modelled by the therapist. The timelogs offer some information regarding adherence: as monitoring *how* patients carried out tasks between sessions was not possible, the only information about adherence is the amount of time each patient spent practising. This was recorded in their timelogs, which for the two groups were identical, except for the omission of the column “Lip & tongue exercises” for the speech group (Appendix 3 and 4).

4.5.2 CES

Self-ratings of patients’ communication in specific situations were gathered by the NONSPEX assessor during its four assessment sessions, via the CES (Donovan et al, 2007). Eight items such as “*Conversing with a stranger over* *the telephone*" are rated on a scale of 1 (not at all effective) to 4 (very effective), with a maximum possible score of 32 (Appendix 5).

4.5.3 Case-notes

Written immediately after each therapy session, these contained: brief descriptions of progress; ratings of success in realising target sounds/words and comments about relevant issues arising in sessions (e.g. what people said about their practice, or ideas for the following session). Also contained in these notes was patient-related information, including: age; sex; family information and severity of dysarthria. Some case-notes data were excluded, as described in section 5.3.

Case-notes were written by the treating therapist, in compliance with the RCSLTs professional standards (RCSLT 2006), and monitored by the NONSPEX team.

4.5.4 Interviews

These were carried out solely for the current study and gathered information on patients' perceptions and experiences of dysarthria therapy (see Appendix 6 for "Laura's" interview). The following section describes, in the first person, as recommended by Sheldrake (2001), how the interviews were carried out, and outlines the reasons for the dual-role of therapist-interviewer.

4.5.5 Therapist as interviewer

I performed the dual-role of treating therapist on the NONSPEX programme and interviewer for the current study. All the participants had dysarthria with varying levels of intelligibility. To successfully and sensitively carry out interviews with these patients, it would have been necessary to employ someone with experience of working with/interviewing people with communication difficulties, or to employ someone with less experience and provide training in the use of strategies to support participants' communication (Carlsson, et al 2007; Philpin, Jordan & Warring 2005). Both options required a prohibitive financial commitment, and would have prevented the study from being carried out. The disadvantages and advantages of the dual-role in this case are addressed in section 7.3.1.

4.5.6 The interview guide

The interview guide (appendix 7) was generated by the researcher to address the study aims, based on evidence presented in the Literature Review, thought to impact on adherence. The questions related to:

- Therapy tasks/materials: Did tasks impact on adherence? (Brady et al., 2011a; van Leer & Connor 2010).
- Involvement/adherence in therapy: Did therapy meet patients' needs/did they feel engaged (Dickson et al., 2008) and understand recommendations (Sabate 2003)? Did any of these constitute barriers? (van Leer & Connor 2010).
- Goals: Did goal-setting impact on adherence (Holliday et al., 2007)? Had patients worked toward any specific goals, and if so was there a link with adherence?

- Therapeutic relationships: Did the patients feel this to be important? (Worrall et al., 2011). Did it impact on adherence? (Plexico et al., 2010)

4.5.7 Preparation for the interviews

In preparation I practised asking questions using the interview guide with a colleague experienced in interviewing, and practised using the digital recorder.

4.5.8 Conducting the interviews

The interviews were recorded on a hand-held digital recorder, and stored under password protection on a secure computer at the University of Strathclyde, to be deleted after completion of the study. Some limited contemporaneous notes were taken to assist transcription and interpretation of data.

I interviewed participants in a quiet room in their homes; we sat next to each other with the digital recorder placed close by. Before each interview participants looked through their therapy manuals, to re-acquaint themselves with the material before discussing it in the interview.

I explained that it may be necessary to repeat back what the interviewee had said, to help the transcription process. To facilitate the interviews and make participants feel comfortable, I maintained an informal attitude throughout, and attempted to be responsive to the differing circumstances and needs of the individual participants. This was enabled by varying the manner of delivery and the presentation and wording of the questions, such as by asking for less information from participants who fatigued quickly, or limiting the use of technical or low-frequency words with some participants more than others. In the following example "Des" is asked what he understood to be the reasoning behind the NSOMEs:

Des, 98-9:

AJ: "*What did you think was the purpose of those exercises? How would you describe the reasoning behind them?*

Des: Well, the reasoning behind them is…"

Des understood the question and responded accordingly. Compare this to the same question asked of Anna who, from her answer, misunderstood what she was being asked. It was necessary to adapt the question to help her to answer appropriately.

Anna, 60-75:

AJ: "What did you think was the purpose, then of…the exercises that I gave you …

Anna: Mm hmm

AJ: What do you think was the purpose?

Anna: Actually quite good

AJ: Why do you think I gave you those particular exercises em for what benefit do you think?

Anna: Helps you talk better"

To facilitate the process for those participants who fatigued quickly and/or significantly struggled to speak, more closed questions were used and interviews were kept short (Carlsson, et al. 2007). In some cases, this impacted on the richness of the data collected, and although I persisted in trying to gather more information by requesting elaboration, some patients were simply unable or unwilling to articulate elaborate ideas or give detailed opinions.

The following section from Anthony's interview is indicative of the barriers to gaining opinions which may limit the inclusion of people with dysarthria in research (Carlsson et al. 2007). Anthony, profoundly dysarthric, struggles to get his point across, and I repeat back his words to check understanding (and to support the transcription process). I also tell him the section of the sentence that I understood, so he is not required to repeat it. Both open and closed questions are used to reduce the effort required to express his thoughts (note that *x* = 1 syllable of unintelligible speech):

Anthony 42-50:

AJ: Uh huh and how did that feel?

Anthony: xxxx I thought

AJ: You didn't, sorry?

Anthony: xxxxxx to it

AJ: "To it" that's what I got. What did you say before that?

Anthony: Realised

AJ: You realised. When you thought about it?

Anthony: Yes"

4.5.9 Transcription

The recordings were orthographically transcribed verbatim, including my interjections. Breaks in the interview (for example when participants discussed unrelated topics) are indicated in the transcriptions, as are nonverbal events, such as laughs, gestures and contextual comments. For anonymity, all participants are assigned pseudonyms. Every line is numbered, to allow responses to be referred to in the text (See Appendix 6 for Laura’s interview). Box 2 presents the conventions used for presenting the qualitative data.

4.5.10 Validation

Two recorded interviews were made available for quality control purposes to a supervisor (CA), who listened to them while referring to the transcripts, to check for anomalies or mis-transcriptions. The first interview that was carried out (Paul, see Table 2 for a list of patients) required amendments to the transcription (fillers such as “um” and “eh” and repetitions of words had been omitted), which were duly incorporated into the text. CA also suggested changes to the manner of questioning (more open questions, for example) and better control of the flow of the interview, which helped me in the subsequent interviews. The second interview CA quality-checked (Anthony) adhered better to transcription protocols, but had gone off-topic (there was discussion of Anthony’s experience of dysarthria; not an interview aim). This prompted me to be wary of veering off-topic, so as not to miss opportunities to gather relevant data. Following thorough re-checking for errors or omissions, the amended versions of the interviews were analysed.

During interviews, there was constant checking of what had been said, to ensure the participant's meaning was clearly represented. Some messages were summarised and repeated back to the participant to check accuracy, as in these excerpts:

Sarah 917-923

AJ: *"OK So basically if I can summarise…you were super-motivated and keen to work on your speech*

Sarah: ***Yes***

AJ: *Yes. And you didn't know what to expect em initially. Em you didn't think it would be so much hard work but yet you really really applied yourself to the hard work didn't you? Em and as a result, possibly, some of the work was boring... Yeah? Is that right?"*

Des 112-133

Des: ***"It's got a theoretical basis, but no practical basis…They were useful because you were pointing out that I had difficulty to (pronounce) multisyllables and I had to slow down and I had to take care, and these were all very good. Good advice.***

AJ: *So you liked the practical advice didn't you?*

Des: ***Yes***

AJ: *And you liked, if I'm paraphrasing you, you liked it when things seemed to have a purpose...*

Des: ***Yes.***

AJ: *..and were practical and not theoretically based.*

Des: ***Yes."***

Chapter 5. Data Analysis

The four sources of data analysed in the current study are introduced in the following section, with the results of the data analyses described in Chapter 6. The data sources comprise timelogs, the Communicative Effectiveness Surveys, case-notes and the interviews, described in section 4.5.

5.1 Timelogs

For the purposes of the current study, “Adherers” are those who carried out the recommended amount of practice or more; “non-adherers” spent less time practicing than was recommended, as described in Box 1. A total practice time of 1050 minutes was deemed by NONSPEX team (Mackenzie et al., 2014) to be consistent with recommendations. The number of minutes each patient spent practicing were totalled.

Box 1. How adherence was calculated

Recommended: 10-15 minutes, 2-3 x daily, ≥ 5 days per week over 7 weeks

Adherers spent: **total ≥ 1050** minutes* practicing

Non-Adherers spent: **total < 1050** minutes* practicing

* 1050 minutes derived as 30 minutes/day x 5 days/week x 7 weeks

5.2 CES

For each assessment point the average CES score was calculated for adherers and non- adherers and the results presented both graphically and in a table (see Table 5 and Figure 1 in Chapter 6).

The following subsections describe the analysis of the qualitative data, and the conventions used in the transcription of this data.

5.3 Case-notes

Box 2. Key to conventions used for presenting the interview data

Convention	Example
Quotes from the transcripts are italicised; words of patients and family members are in bold	***"Patient's words"***
The interviewer's words are not bolded.	*"AJ's words"*
Line numbers from the original transcriptions are provided for reference, in brackets.	(563-72)
Where words have been removed for brevity it is indicated with three stops.	…
Where words have been added for explication it is indicated with square brackets.	[ ]
The letter x in a quote represents one syllable of unintelligible speech.	x

Any reported speech or information relevant/potentially relevant to the patient's practice or adherence which was documented in the final *"Other comments"* section was transcribed, and stored with the transcribed interviews. Data relating to specific phonemes or progress were considered irrelevant to the aims of the study and were excluded. The remaining data was subsequently coded, treated in the same systematic way as the data from the interviews. Some data were not eventually assigned codes, and have been retained in the corpus of data, uncoded (see Appendix 8).

5.4 Interviews

The analysis conformed to methodological guidelines provided by Braun and Clarke (2006), and to their description of good practice (Braun & Clarke 2014; Braun & Clarke n.d.) thus: data were transcribed to a high level of detail, and checked against recordings, for accuracy. Each item received equal attention in the coding process, which was thorough and comprehensive. All relevant extracts for each theme were collated, all themes were checked against each other and the original data set. The themes are internally coherent, and distinctive. Data was analysed and interpreted, rather than just paraphrased/described, and extracts illustrate the analytic claims. Their thematic analysis approach is recommended for novice and experienced researchers alike (Braun & Clarke 2014) and has been used successfully in respected studies, e.g. Mackenzie et al. (2013)

For consistency the following description uses Braun and Clarke's (2006) terminology. There were no pre-formulated codes at the outset of the research, in order to unearth relevant findings from dominant themes within the raw data. Although the data collection was guided by a research question influenced by existing literature and research findings, the themes are strongly linked to and driven by the data. In the terminology of Braun and Clark (2006), the approach taken to the data analysis is described as enabling patients' motivations and experiences to be theorised in a straightforward way (p 85).

5.5 How data were analysed

A supervisor (CM) had access to all raw data and coded interviews and carried out in-depth scrutiny of four examples, on which she comprehensively commented, leading to agreed alterations. On several occasions, at each point in the evolution of the framework, CM and the author met to peruse and discuss it together, resulting in its refinement and development. On other occasions, CM provided written feedback, comprehensive comments and suggestions, following evaluation of the framework in its various stages of development, leading to a number of revisions.

I. The process of transcribing and coding was begun while interviews were still underway. To enable familiarisation with the data, transcriptions were read repeatedly by the author before and during coding, and notes relating to interesting issues were taken throughout.

II. The entire data set was coded to ensure its comprehensiveness. Labels (short descriptive "*codes")* were attached to all lines of text, which were relevant and interesting. At this stage the codes were considered issues of (potential) interest to the study.

Only a small amount of raw data was *not* coded: talk about phonemes/words that patients struggled with; stories of their strokes; conversation unrelated to dysarthria or SLT (eg a family argument). Issues of interest which were similar were assigned the same codes as they arose throughout the interviews and case-notes, and in this way it was possible to discern those codes which were of limited interest when compared to others and detect “*themes”* in the data. Relevant data were highlighted and marked in the interviews along with their assigned codes. The transcription line numbers for these extracts were also organised into meaningful groups stored in table form.

An example: One code at this early stage was “*Trust and therapeutic relationship*”. Several quotes were found from a number of interviewees which related, however tenuously (at this stage) to this issue, such as: *“It’s important that you trust me to do what you tell me to do and its important that I trust that what you tell me to do will be benefiting me*” (Des); “*I would say I wouldn’t work as hard for someone I didn’t like*” (Laura). To give the reader an idea of the nature of the coding process, these initial quotes and their codes can be found in rough form, in no order, in appendix 9

III. When all relevant data had been assigned codes and the list was complete the search for themes (categories of ideas gleaned from grouping the codes began). The process of organising all the individual codes into cogent groups was carried out largely on computer, cutting and pasting into tables, and moving codes around to find the best fit. In this way the codes were organised into themes and sub-themes, and a cursory thematic map was produced to represent these.

An example: At this point in the process the code "*Trust and therapeutic relationship*" was designated membership of a group of themes relating to *"The nature of the therapeutic relationship and its impact on therapy*", which at this stage was the title of one of several overarching themes (later changed following a review) (Appendix 10 demonstrates how issues of interest moved through to codes and themes).

IV. Next, on reviewing themes, it became clear several were inadequate, for reasons including: too little content; needing reduction/expansion; repetitious; or belonging elsewhere. This review process led to a reorganisation of themes and a more coherent thematic map. The earlier, un-evolved sub-theme entitled *"Trust and therapeutic relationship"* was given a more descriptive title as subtheme 1.3.a: *"Good relationship helps patients feel comfortable/relaxed*", existing within the theme 1.3 "*The Therapeutic Relationship*". To make for a more coherent write-up, the themes were arranged into two groups ("Overarching Themes") according to whether they were themes that related to personal/interpersonal factors which may have impacted on patient adherence, or therapy-related factors (see Appendices 11 and 12).

The following chapter presents for the reader the results of the quantitative data analysis, from the timelogs and CES, followed by the results of the analysis of the interviews/case-notes data.

Chapter 6. Results

The data presented below allow an exploration of the factors raised in the interview guide. The section uses a number of extracts of data chosen to illustrate pertinent points, and attempts to retain some of the context from which they were taken. Any potential associations with adherence are explored, to be discussed in Chapter 7.

6.1 Quantitative data – from timelogs and CES

The patients are introduced in Table 4 according to their status as adherers (who carried out the recommended amount of practice) and non-adherers (who did not do so) and provides characteristics correct at the time of starting NONSPEX: age; months post-stroke; dysarthria severity (as rated by referring SLTs using the mild, moderate, severe and profound descriptions applied in Mackenzie et al, 2010); cohabiting/has partner. Their group allocation refers to the groups to which patients were randomly assigned in the NONSPEX programme. The number of minutes patients spent practicing each task, as self-reported, is also documented in this table.

Table 5 summarises patient information, including: severity of dysarthria; age; months post-stroke; group allocation (“Speech”/“NSOME”) and the variable “cohabiting/have partner”.

Table 4. Data relating to each patient, organised into “adherers” and “non-adherers” groups

Patient	**Age at start of NONSPEX**	**Months post stroke at start of NONSPEX**	**Dysarthria severity at start of NONSPEX**	**Group allocation**	**Cohabiting / has partner**	**Minutes spent practicing on each task over 7 weeks of therapy.**			
						NSOMEs	**Speech**	**Conversation**	**Total**
Adherers									
Mary	80	7	Severe	Speech	Yes	N/A	2516	1966	**4482**
Laura	66	5	Mild	Speech	Yes	N/A	653	1688	**2341**
Adrian	58	17	Severe	Speech	Yes	N/A	1033	1018	**2051**
Harry	72	3	Mild	Speech	Yes	N/A	873	1001	**1874**
Terry	60	15	Moderate	Speech	No	N/A	1690	80	**1770**
John	71	3	Moderate	Speech	Yes	N/A	620	620	**1240**
Anthony	56	11	Profound	NSOME	Yes	1389	1415	1296	**4100**
Sarah	68	14	Severe	NSOME	No	2539	575	514	**3628**
Arthur	79	7	Moderate	NSOME	Yes	1015	810	420	**2245**
Des	66	4	Mild	NSOME	No	436	625	1120	**2181**
Non-adherers									
Dean	76	7	Moderate	Speech	No	N/A	155	340	**495**
Neil	46	14	Severe	Speech	No	N/A	75	5	**80**
Anna	46	4	Severe	NSOME	Yes	80	93	0	**173**
Paul	72	18	Severe	NSOME	No	105	60	0	**165**
Andy	60	3	Severe	NSOME	No	0	0	0	**0**

Table 5. Summary of patient characteristics

	Total	Adherers	Non-adherers	p-value *
Total	15 (100%)	10 (67%)	5 (33%)	
Gender				1.000
Male	11 (73%)	7 (64%)	4 (36%)	
Female	4 (27%)	3 (75%)	1 (25%)	
Age (years)				0.420
Mean	65	68	60	
Min; max	46; 80	56; 80	46; 76	
Cohabiting/has a partner				0.119
Yes	8 (53%)	7 (88%)	1 (12%)	
No	7 (47%)	3 (43%)	4 (57%)	
Severity of dysarthria #				0.450
Mild	3 (20%)	3 (100%)	0 (0%)	
Moderate	4 (27%)	3 (75%)	1 (25%)	
Severe	7 (47%)	3 (43%)	4 (57%)	
Profound	1 (7%)	1 (100%)	0 (0%)	
Randomly assigned group				0.608
NSOMEs + speech practice	7 (47%)	4 (57%)	3 (43%)	
Speech practice only	8 (53%)	6 (75%)	2 (25%)	
Time since stroke (months)				0.937
Mean	9	9	9	
Min; max	3; 18	3; 17	3; 18	

Data are number (%) unless otherwise specified. Percentages in the two right-most columns are of the row totals, i.e. 64% (7/11) of the males were adherers. * Categorical data were analysed using Fisher's exact test, age and time since stroke were analysed using Wilcoxon rank sum test. All tests were two-sided. # Moderate, severe and profound severity of dysarthria were pooled together into a single category for the purpose of the test for association.

Information from Tables 3 and 4 is examined below with reference to any possible relations with adherence. With data from only fifteen patients it is not possible to draw conclusions about associations or cause and effect, but it is possible to speculate about tentative connections or affiliations.

From a total of 15 patients (11 males and 4 females) with an average age of 65 years, 67% were classed as adherers, and 33% as non-adherers. There is no suggestion of any association between group allocation and adherence. The mean number of minutes spent practicing also varied little between groups (1792 minutes in the SPEECH group versus 1785 minutes in the NSOME group).

From the Severity Rating Scores, four of the five non-adherers fall into the more severe categories whereas under half (4/10) the *adherers* fall into the more severe categories (see Table 5). All three people classified as mild adhered.

Whether a patient had a partner/was cohabiting offers an insight into the amount of support the patients may have had at home where they carried out the practice. Of the total, 8 were cohabiting or with a partner, versus 7 who were not. In the adherer group however, 7 (70%) were cohabiting/had a partner, while only 1 of the 5 non-adherers (20%) was cohabiting/had a partner. Despite this difference, the limited number of patients provides insufficient data for it to be statistically significant (Fisher’s exact test; two-sided; p=0.119 (Appendix 12); it does however suggest a trend.

The CES scores are presented in Table 6, with the mean scores plotted separately for the groups of adherers and non-adherers in Figure 1. All participants completed the CES at each time point, although there were four missing item scores, which were handled using pro-rating.

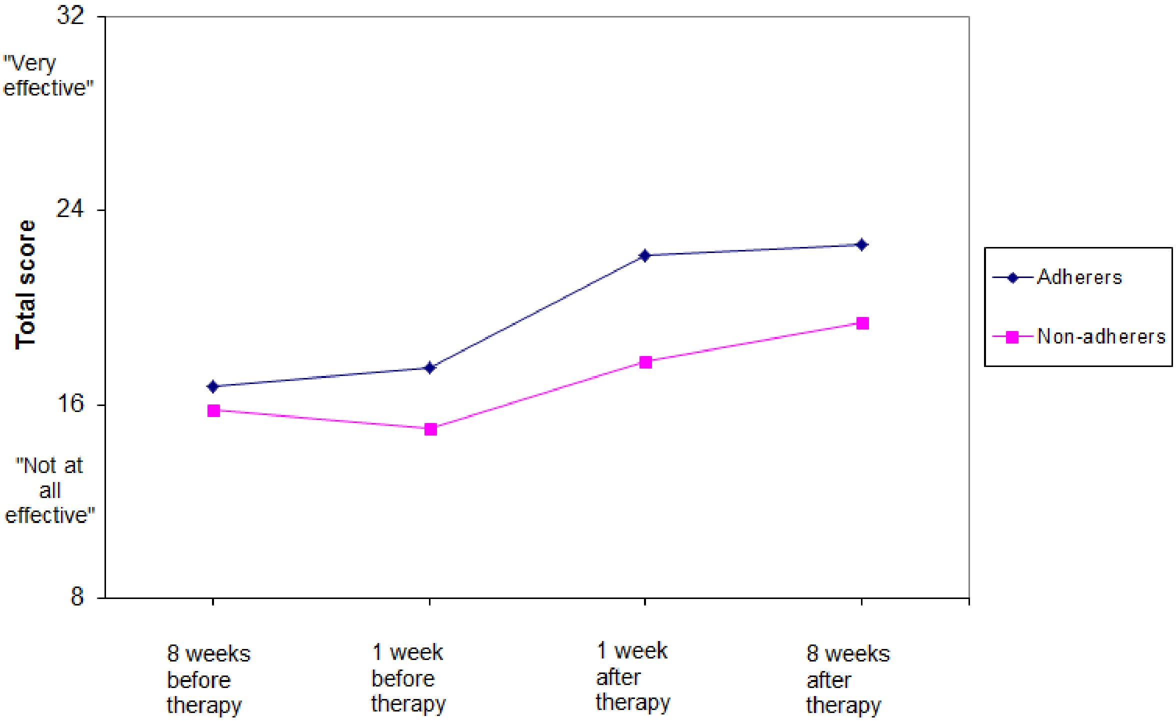

Figure 1. CES scores over the course of the NONSPEX programme in adherers and non-adherers

Table 6. Communicative Effectiveness Survey scores in adherers and non-adherers (higher scores indicate more effectiveness).

	Adherers			Non-adherers		
	N	Mean	Range	N	Mean	Range
8 weeks before therapy	10	16.7	10-27	5	15.8	11-20
1 week before therapy	10	17.5	9-24	5	15.0	10-21
1 week after therapy	10	22.2	10-30	5	17.8	12-23
8 weeks after therapy	10	22.6	10-32	5	19.4	14-23

The average scores depicted in Figure 1 do not convey the variability in individual CES scores over time; this is illustrated in Table 6, which presents the range of scores at each assessment. The patients' perceived communicative effectiveness improved over the course of therapy, and the average scores at one and eight weeks post-therapy increased. The effect is sustained 8 weeks later. Non-adherers (who also tended to have more severe dysarthria) on average started off therapy with lower self-ratings than adherers, and this difference is consistently maintained throughout. This suggests that poor adherers are less likely to rate their CE as highly as those who adhere to therapy regimes.

6.2 Qualitative data – from interviews and case-notes

Some of the myriad factors which can impact on the ability and motivation of patients to engage with the therapeutic process are incorporated in the data, which have been sifted and organised into two overarching themes, represented in diagrams 1 and 2 (for detailed thematic tables refer to Appendices 11 and 12). Those within the “Overarching Theme 1: Personal and Interpersonal Factors” are associated with factors related to the patients’ own reported personal attitudes, motivations, awareness and physical health, any of which may have impacted on their adherence to therapy. Overarching Theme 2 is titled “Therapy Related Factors” and pertains to specific aspects of the therapy and how it was implemented. Both Overarching Themes have further Themes and Sub-Themes, the contents of which are grounded in, and generated from, the data.

6.2.1 Overarching theme 1: personal & interpersonal factors

This first overarching theme (Figure 2) embraces issues discussed by the patients which could arguably be mitigating factors in their adherence to therapy but are not directly related to the therapy process itself. These factors are of a personal and internal nature, relating to: their physical health and wellbeing; their emotional reactions and attitudes to therapy; their perceived level of control over the therapeutic process; aspects of their relationship with the therapist; access to support from family or friends; and the avoidance of some activities of daily living as a result of their communication impairment.

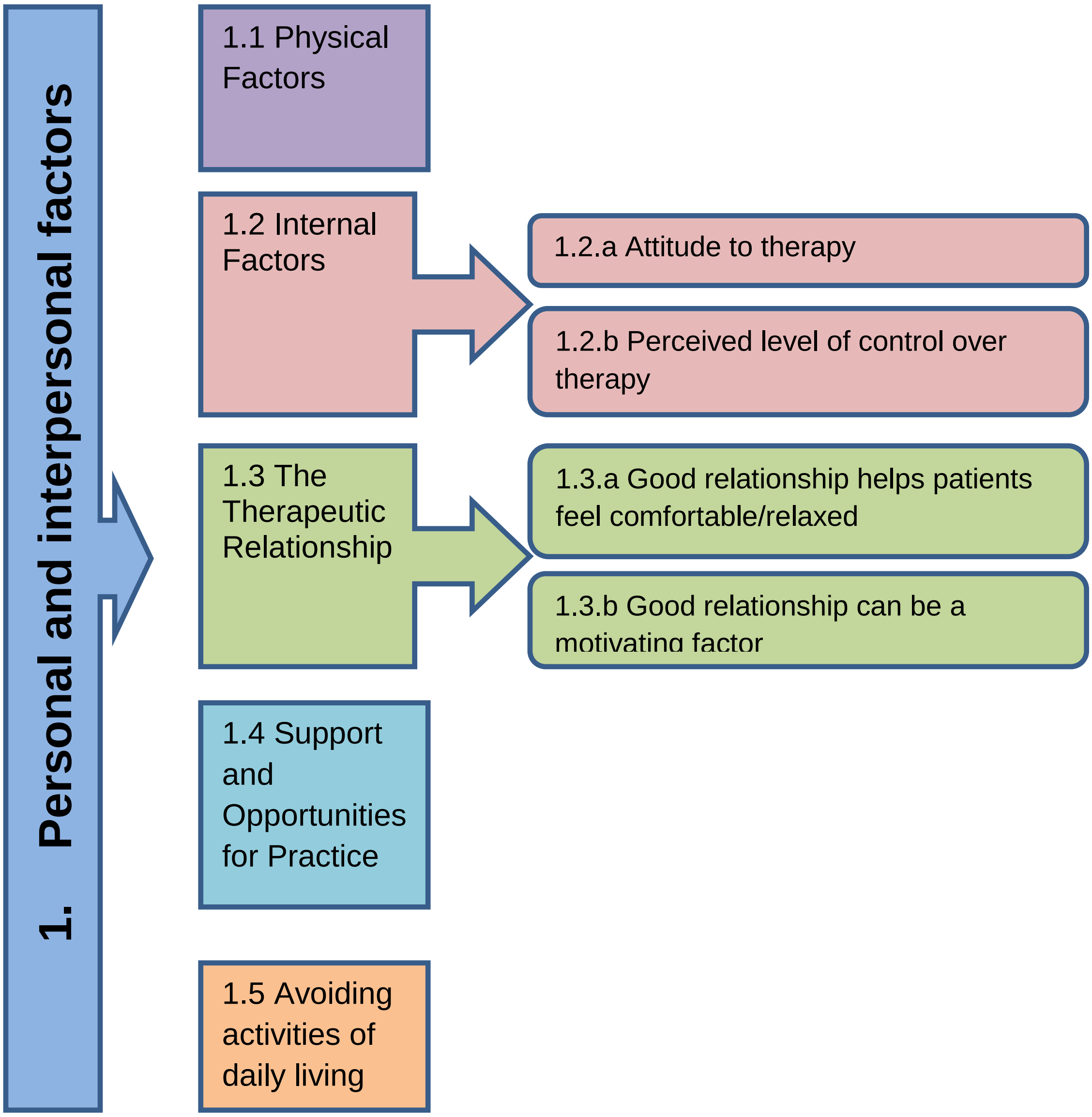

Figure 2. Overarching Theme 1: Personal and Interpersonal Factors

Physical Factors (1.1)

A number of physical factors were reported, including impaired memory, tongue pain, difficulty concentrating for prolonged periods and fatigue. Neil could not recall specific details about the therapy, and Andy appeared to have a significantly impaired memory, being unable to remember either the sessions or the therapy tasks. He acknowledged that his memory difficulties may have impacted on his ability to remember to carry out the practice tasks independently and these cognitive issues were noted in the case-notes.

152-3

AJ: “Do you remember me being here at all…?

Andy: Not really”

52-4

AJ: “Do you think you’d have remembered to do (the practice) every week?

Andy: …em, sometimes I knew there were supposed to be some, other times I didn’t

AJ: You would forget?

Andy: Aye”

John (51-6) admitted that the amount of independent practice he had been able to do was contingent on how tired he felt, and indeed his case-notes recorded that he had fallen asleep twice during his penultimate session, impacting on his ability to participate in the session.

Laura (464) reported that tiredness impacted on her speech, and observed that concentrating ***“on every single word...was tiring*”.** In addition, she had become tuned to the fluctuating nature of the sensation in her face and mouth, and its deleterious effect on her speech, and developed strategies to pre-empt and manage this effect, planning her days accordingly (70; 240; 314-8**)**.

Internal Factors (1.2)

The title of this main theme describes those factors which relate to attitudes and levels of awareness. Examining their reported attitudes to, or motivations for, participating in therapy may offer some insight into their adherence.

Attitude to therapy (1.2a)

This subtheme explores the patients' attitudes to therapy as inferred from the terminology they use to describe the sessions and the practice. As this sub-theme relates to the internalised, emotional reasons for participating and continuing in the therapeutic process it is considered separately from sub-theme 2.5, which details the therapeutic aims and goals of the patients. People's attitudes were quite diverse, and have been crudely categorised below for consideration.

Affect and adherence

Because of his apparent memory impairment, Andy (non-adherer) was unable to discuss his attitude to the therapy specifically. However, in his illustration of his inherent attitude through a description of his typical reaction to being given other tasks to do, he presents as apathetic:

52-9:

AJ: "Do you remember ever sitting and working on trying to say (the practice words/phrases) clearly on your own?"

Andy: "Nah"

AJ: "Do you think you did at all?"

Andy: Nah

AJ: No. Yes that's what you used to tell me- that you hadn't done that…

why..?"

Andy: Just lazy (laughs)"

176:

Andy: "If somebody tells me to do something, I just don't do it"

In the following quote from his case-notes, it is clear that Andy, who had significant physical disabilities in addition to his severe dysarthria, was suffering:

"(Andy) was [displaying] very low mood on my arrival. Said he did not feel like talking to anyone" "He said he sees no future for himself, watches people from his window and feels he will never be 'normal' like them again." (session 5),

This, in addition to his admission that recovering his physical independence is more important to him than working on his speech, Andy (97-108), suggests that he may have had little motivation to work hard at remediating his speech.

Passive attitude to therapy

Neil (non-adherer) compared therapy to hypnosis (415-29), suggesting that for therapy to work, the person has to *believe* it will work, and engage in it completely: *"**If you don't want to they can't do it to you at all, so… You have to let yourself go".*** This also implies an element of passivity relating to therapy – that it's necessary to give in to it and have it *done* to you. The following extract from the case-notes highlights his reported attitude to his ability to effect change in his situation, an outlook which may have influenced his adherence to the therapeutic programme: *"He suggested [he's] feeling fatalistic re speech difficulties. Appears non-motivated to tackle it"* (session 7).

Frustration relating to therapy and adherence

Neil did not practise speaking with others despite this being recommended by the SLT. He gave the reason for this as being frustrated with his lack of intelligibility as he felt he could accurately form the words when internally rehearsing them:

257-71:

AJ: "Was that what stopped you from speaking to people?

Neil: Eh well xxx cos I got frustrated…I speak to myself in my head…I think it's very clear…When I try to speak I try to say it it doesn't come out what it was supposed to say.

AJ: OK so you say it inside your head and it sounds very clear

Neil: Yeah very clear but when you actually speak it's not very clear so"

Sarah (adherer) described being frustrated and upset by her speech during sessions and by some of the tasks (see 2.1.a), for which she blamed herself: **"*My fault…My fault. Ooh I could strangle myself!"*** (197). It appears from her interview and the case-notes from the sessions that she had high expectations, and agreed that she can be hard on herself (792).

Determined attitude impacted on adherence

When asked if she had been frustrated by the slow nature of the progress, as she saw it, Sarah replied "***Well yes but I just got down to it"*** (158), suggesting a determined approach to tasks. This exemplifies the attitude she took to her rehabilitation; she carried out considerably more NSOMEs practice than any other participant interviewed.

Despite the severity of his dysarthria, Anthony (adherer) had high expectations for the level of improvement he would experience as a result of therapy, saying he had expected that ***"I could speak"*** (as he had speech, albeit limited, at the time of the interview, he perhaps meant that he wanted to speak *normally* again – see Goals 2.5). When he realised that these expectations were unrealistic, half way through therapy, he nevertheless continued to participate, suggesting a determination to improve.

After Mary, Terry completed more speech practice than any other patient - more than double the total amount of practice carried out by all the non-adherers. He adopted a fighting attitude to his rehabilitation: ***"I felt that I could beat this"*** *(301)*. Adrian's (adherer) wife said that they also approached therapy as if it were a challenge, stressing it *had* been struggle at times (421).

Enjoyment of therapy influenced adherence

Mary (adherer) expressed a positive attitude to the therapy sessions, saying ***"I enjoyed it!"*** (398), and her husband commented that ***"[therapy day] was the highlight of her week"*** (161-2)***.*** Another adherer, Laura also expressed a positive attitude to therapy, describing it as ***"enjoyable"*** (672). Terry (adherer) displays his positive attitude to the therapy when he admits it was a lot of work for him: ***"Aye, but I enjoyed it"*** (10) "***And I kind of like the work, ken"*** (272). Arthur (adherer) also expressed a positive attitude to the therapy, which may have impacted on his level of adherence: *"**I looked forward to you coming … I did …Just eh enjoyed improving"*** (212-9).

Sensitivity to others' opinions impacted on adherence

Laura's (adherer) attitude to therapy may have been affected by being a teacher; she did not want to be thought by the SLT not to have done any work, and admitted that this motivated her to adhere ***"I didn't want you coming in and thinking "Oh she's done nothing all week! You know?"*** (668). Here she shows empathy with the position of the SLT: *"**That's the teacher in me! I know what it's like!"*** (671).

One motivating factor for Terry was to prove to both his friends and the SLT that he was able to improve his speech (227; 468). As he continued to receive compliments on his improvement, he was further motivated to practise: ***"to me that was a big boost"*** (241).

Pragmatic attitude impacted on adherence

Arthur had intimated during therapy sessions that he wished he had died instead of being resuscitated following a medical incident, and this fact was alluded to in his interview (63-79), and documented in his case-notes: "*[Arthur] continues to talk about wanting to be dead. Family concerned [about his] low mood*" (session 5). With this in mind, it is interesting that Arthur adhered completely to the therapeutic regime and by his own admission worked hard to improve his speech (81). When the subject was broached during the interview he explained his motivation for doing so: ***"Well, I still wanted to explain to people how I felt. And get in a conversation with them"*** (85-6).

Ambivalent attitude to therapy

"… at the beginning when you talked about … speech therapists ... it's just a load of nonsense x what am I needing to get a speech therapist for I can talk fine. But eh…as it's went on and (my wife) has been at me about it and you've come… I felt the benefit of it as well in a way" (409-12). From this quote it seems John (adherer) was initially unconcerned about his speech. Although he admitted that at times he had to make an effort to be understood by his wife (192-4), he seems to have accepted his speech the way it was for everyday purposes (293-5).

From his timelogs it appears that Des fully adhered to the regime, and carried out the exercises as prescribed, however some ambiguity arises in the interview about his adherence to the regime (see 2.4.b). He reports that he felt stupid doing the exercises (36-7) and made it clear that he could see no practical benefit from doing NSOMEs, as he felt they could not impact on his impairment:

98-110

AJ: *"…How would you describe the reasoning behind (the NSOMEs)?*

Des: Well, the reasoning behind them is if you were looking for muscular defects or defects in the facial positions that were used to form words but having determined that once, that's all that had to be done!

AJ: Did you see them as having a rehabilitative effect?

Des: It was almost repetitive and pointless.

AJ: …the idea is…that they strengthen muscles. Would you agree - what do you think of that?

Des: Bullshit!

AJ: Pardon? Bullshit? (laughs) OK! So you don't think they work, do you?!

Des: It's by someone who's a theorist speech therapist."

If it *was* the case that he did not fully adhere to the prescribed regime, it is possible that his attitude to the NSOMEs and his understanding of their purpose and effectiveness impacted on his adherence to one or all of the components of practice and potentially hampered potential gains.

It is difficult to infer people's attitudes to therapy solely from what they said in the interviews, and it is not possible to draw conclusions regarding how attitudes impacted on adherence to therapy. However, it is clear that some who adhered said they enjoyed the experience, and some approached therapy with determination to overcome their difficulties despite the frustration they felt with themselves/their speech. Non-adherers and also Des, whose adherence is questioned, expressed more ambivalent, non-motivated or passive attitudes to therapy.

Perceived level of control over therapy (1.2b)

Some patients seemed to differ in how much control they perceived themselves to have in relation to therapy and how it was carried out – some may have felt they were not able to suggest changes or alternatives. Others differed in their perceived level of control over their own progress, and their ability to effect change.

Three patients, Des, Harry and Adrian (353-62), all adherers, stated they did not feel it was their place to suggest changes if they had not liked an aspect of therapy: ***“you want to kind of bow to the person who’s teaching you or coaching you, ye dinnae start telling them what you're wanting to do”*** (Harry 247-8); ***“I don’t presume to know a great deal about it”*** (Des 121-2). The latter comment is interesting when considered in the light of Des’ attitude to the NSOMEs (1.2.b).

Terry bought a digital recorder (179-83, 414-22) on his own initiative; despite this he relinquished responsibility for his therapy: ***“I was doing what you told me to do, because obviously you’re more experienced than me*”** (269-70)

Laura (Adherer) (427-34), Anna (37-40) and Dean (106) (non-adherers) said they *would* have asked to change something if they had wanted to. Sarah’s (adherer) response was ambiguous; when asked if she felt she had a say she replied ***“half and half*’** (395), and later said she would have felt comfortable asking to change a task she did not like (404-12). However when in fact given tasks she did not like, she did *not* tell the therapist:

649-57

AJ:	*"…Why didn't you say that at the time?*
Sarah:	***It didn't matter***
AJ:	*But you said there that if… you'd not liked something about the therapy, you felt you were comfortable to say so*
Sarah:	***Yes***
AJ:	*But you weren't, were you?*
Sarah:	***No. I thought it was good for me"***

It is not possible from the interviews to distinguish any connection between the amount of say patients may have felt they had over the content and structure of therapy, and the extent of their adherence to the therapeutic regime.

Therapeutic relationship (1.3)

Without exception the patients reported that this was an important factor in therapy. None was ambivalent about the significance to them of therapist and patient getting on well. Several explicitly related the quality of the relationship to their levels of adherence.

Good relationship helps patients feel comfortable/relaxed (1.3a)

Around half the patients specifically attributed a good relationship with the therapist to feeling comfortable and uninhibited, for example ***"I was more relaxed"*** (Paul 183-4) *"**Puts you at ease"*** (Sarah 854), and in the words of Mary's husband: ***"from…what (she)…told me afterwards about your meetings, she was very much at ease with you"*** (316-7). Dean also felt that being comfortable enough to express his sense of humour was an important factor in the relationship: **"*telling jokes and things like that, that makes a difference…I feel more relaxed doing that*"** (322-4).

Adrian suggested that a poor relationship presents an obstacle to therapy: ***"You work better...if you get on...If you don't like [SLTs] there's a barrier"*** *(*368-72). Two patients said that would have made their participation in therapy difficult: ***"I wouldn't like somebody I disliked doing [therapy]…I would always be thinking about and dreading going to a class"*** (Anna 186-8). However, although Sarah felt a poor relationship would have been "***terrible"*** for her, she would have ***"stuck it out"*** *(857; 875).* Sarah became tearful in some sessions (for discussion see 2.1.a) and it is apparent she felt supported enough within the therapeutic relationship to display her distress and have it acknowledged by the therapist before continuing with the therapy programme.

A good relationship was seen as important to avoid feeling self-conscious: ***"got to feel easier…not to be em intimidated by the person"*** (Neil 355), echoed by Dean, who might have felt inhibited with a therapist he did not get on with: ***"…you don't want to speak in case you make mistakes, ken?"*** (308). Dean agreed that having a good relationship ***"got more out of"*** him (311-2) and he described its significance in terms of team-working: ***"If you can work together it makes an awful difference"*** (303). The idea of working as a team was also acknowledged by Des: ***"It's important that you trust me to do what you tell me to do and it's important that I trust that what you tell me to do will be benefiting me…It's two-way traffic"*** (203-5). Here is John agreeing with his wife, who also referred to the reciprocal nature of the therapeutic relationship suggesting that without it, giving and receiving honest feedback would be challenging: "***it would have been a difficult situation if…there hadn't been a good relationship…I think it would have been difficult in communicating…being honest"*** (337-51).

In the following quote, John associates a good relationship with focussing in therapy on a topic he is interested in (explored further in 2.2.e), and which may have motivated him to adhere: ***"we've got on well…it's no very many people that'd sit over and over to talk about bibles...You know in their job…You've come and gone with me and the things I've needed to do and say to you"*** (318-34).

Good relationship can be a motivating factor (1.3b)

Several respondents reported that a good relationship motivated them to adhere to therapy, eg: ***“I would say I wouldn’t work as hard for someone I didn’t like”*** (Laura 659); *“**…if the therapist came to the house and you didn’t get on. You just you wouldn’t be doing what they were saying. You’d tell em to go and get lost!*** (Harry 208); “***If I didn’t like you I wouldn’t have opened the door!...Simple…You’ve got tae have a bond between youse…you’re willing to give me time for to help me, so I’m gonnae do it”*** (Terry 432-40); “***When you first came I was wondering whether I’d stick it or not…But you were so nice, and then I says; “oh, I’ve got to stick it!””*** (Arthur 270-83)

The patients’ responses suggest some were motivated to maintain the quality of the relationship and it was important the therapist recognised and was satisfied by their progress: ***“you want to do it for yourself and for you (the therapist) as well…I didn’t want you coming in and thinking: “Oh she’s done nothing all week!” You know?”*** (Laura 661-75). Similarly, Terry said he worked hard so he could show the therapist: ***“See, I can do this!”*** *(*468), and Arthur acknowledged that in addition to wanting to improve for his own sake, he also ***“worked for good remarks”*** (296).

Support & Opportunities for Practice (1.4)

This theme tentatively examines relationships between high levels of support and opportunities to practise speech (such as through having a supportive family), and the patients' adherence to recommendations.

Among adherers, 7 (70%) were cohabiting/had a partner, while only 1 of the 5 non-adherers (20%) was cohabiting/had a partner (see Table 4). There follows details gathered from the interviews about how patients were supported in their practice by their families or partners.

Support among adherers

Some described spouses encouraging or pushing them to do their practice. Harry says of his wife: ***"…I'd be sitting here and watching the telly or whatever nice and quiet and xx say to myself 'Oh there she's over getting that book' and she'd sit on the couch and 'Right!' And whenever a sentence starts with 'Right!' that's it"*** (144-147). John said his wife ***"was doing my teaching…she pushed me forward"*** (15-17) and, as he put it: ***"She was always in charge."*** (38).

Some describe support of a more collaborative nature: Anthony's partner was a big support to him: ***"I did it with (her)"*** (113), as was Laura's husband ***"…often after you'd gone I'd say to (him) come and hear this!...We'd go over it again"*** (723-6). Her daughter helped too: ***"she was afraid [of assisting physically] at the beginning so speech therapy was good because she says 'Oh this is something I can do'"*** (395-6). Mary's husband supported her (226). He has visual difficulties, and as his support was important to Mary, this was accommodated, as can be seen from this reminder in her case-notes: "*Bigger print diaries [needed] for husband to access"* (session 2).

Adrian did not invite his wife to observe sessions, so she could not interrupt or take focus from him (218-39), however he accepted her support. She explained: ***"I would sit at night and say 'Right come on, we'll do your speech'"*** (79). He believed it would have been more difficult on his own, without feedback from his wife (102-7). Terry worked long shifts (42-3) and his statement: ***"I took the stuff to my work. I done it [at home] and I also done it [at work]"*** (203-5) implies he had support from colleagues.

Arthur lived with a sibling and other family members, but interestingly, the case-notes document that he reported *"reduced interaction opportunities despite large household. Had not completed "conversation practice" in timelog forms"* (session 2). He did in fact carry out considerably less conversation practice than speech or NSOMEs practice. Sarah and Des were the only adherers who lived alone, and neither had any support with their practice

Support among non-adherers

Anna was the only non-adherer who cohabited, and her husband supported her practice: ***"(he) is really serious you know: 'you never said…that right, it's that', whatever. He's really good at my words"*** (97-8). She had a teenage son, and when asked whether her son helped her practise she answered: ***"Nah, you're joking!"*** (146-7). The remaining non-adherers

(Andy, Paul, Neil, Dean) lived alone; although some had occasional visitors, they did not have consistent support to carry out their practice.

Avoiding activities of daily living (1.5)

Avoiding social contact and telephones was frequently referred to in the interviews, and links with the goals that people set for therapy (see 2.5 Goals), as the aim of no longer having to avoid activities that were once commonplace may have motivated people to adhere to therapy. Des (adherer), reported he continues to avoid the phone (not a specific goal of his therapy) (13), and that although he avoided contact with people before therapy, during its course he had been motivated to join two social groups (141-3), in line with his therapeutic goal (see 2.5). Paul (141-47), Laura (445-7) and Terry (304-19) had also avoided speaking on the phone, eg: "***Oh! I was afraid! I was afraid to talk on the phone"*** *(Terry 312).* All three reported that following therapy they no longer avoid this. Paul had a specific goal relating to not avoiding the phone, and reported: ***"I keep phoning different folk…And they hear what I say"*** (149-51).

When it was suggested to Anthony (adherer) that he might be ready to have more conversations with people, he agreed (257), but admitted: ***"I find it hard"*** (265). Neil (non-adherer) continues to avoid speaking to people outside his family; his brother speaks for him when they are out (252-60). Similarly, Anna (non-adherer) continues to avoid social contact**: *"See when I'm out, I'm really quiet. That's not like me. I don't say a word"*** (249-50). She agreed with the suggestion that therapy focussing on increasing her confidence in speaking to people may have reduced her avoidance, but was unable to envisage what form the therapy could have taken (251-67). For Anna, and maybe for others, a therapeutic focus on increasing her participation in activities of daily living, rather than at the impairment or activity level, could have resulted in better adherence and possibly in better outcomes.

6.2.2 Overarching theme 2: therapy related factors

This second overarching theme examines the therapy itself from the patients' perspective, and attempts to make some connections between patients' adherence, and their opinions of therapy. Examined below are their views regarding the tasks and materials; the feedback received; how they followed the recommendations; their goals and the outcomes of therapy.

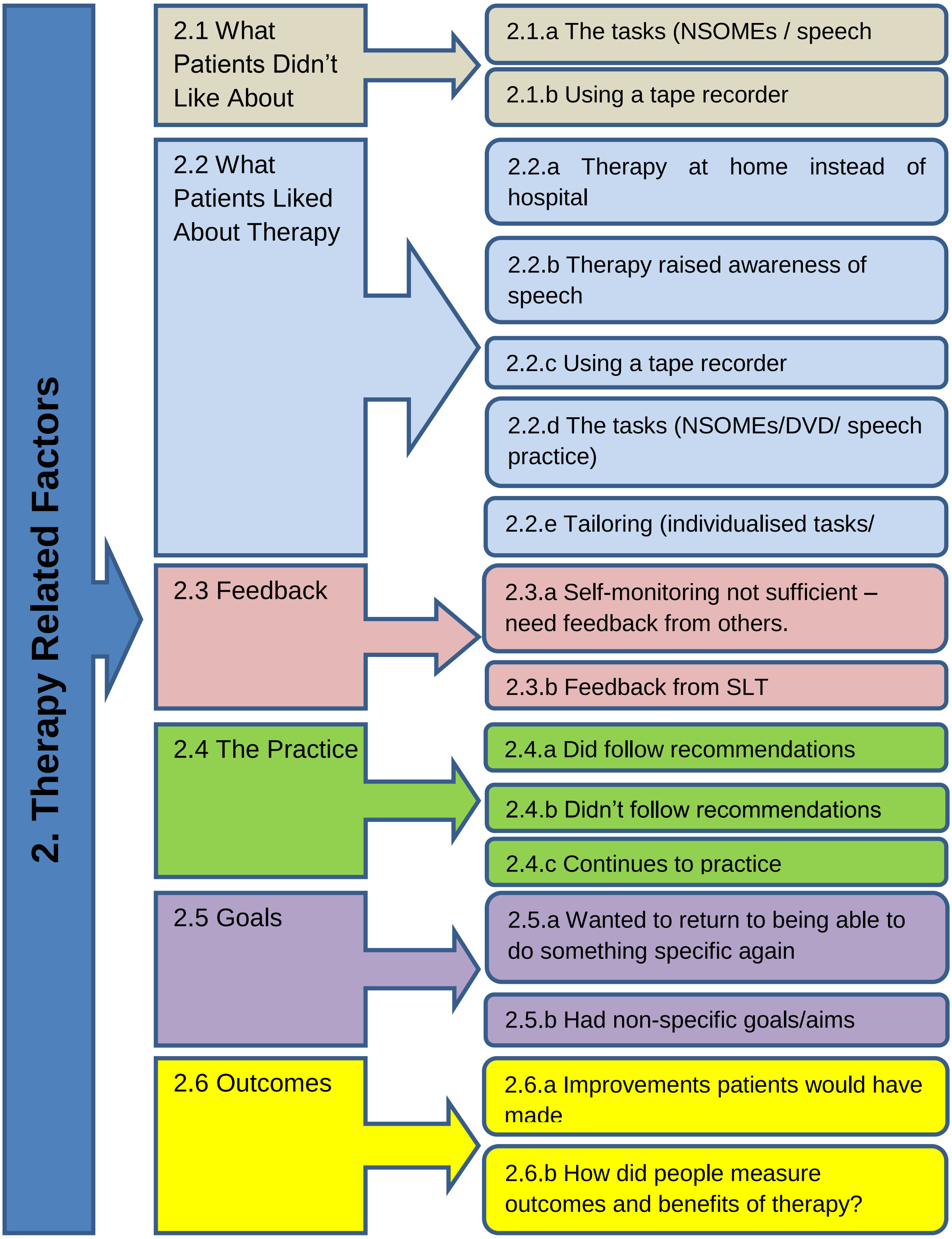

Figure 3. Overarching Theme 2: Therapy related factors

What patients didn’t like about therapy (2.1)

Although this was a difficult area for participants to discuss, possibly because they did not want to offend the interviewer/therapist, aspects of therapy that they reported not to like may offer insights into why some did/did not adhere.

The tasks (NSOMEs / speech practice) (2.1a)

As described in 1.2.b, Des believed NSOMEs have no rehabilitative function other than as an assessment tool: ***“Possibly they were useful to you in determining whether I had a muscular defect”*** (84-5); ***“The mouth exercises themselves? Pphh. Of no point…I thought they were useless”*** (92-5). He felt it was impossible to monitor progress with them: “***There’s nothing tangible to tell you whether you were doing well, whether it was being effective”*** (45). Because he believed muscle weakness not to be the cause of his speech disorder (***“If I had a problem with one side of my face and not being able to shape my mouth I could understand that”*** (48-9)), he doubted his speech could be improved via NSOMEs (193-6).

Although Laura was not in NSOME group, she received similar exercises while an inpatient. She described how she would have felt if required to carry out NSOMEs as part of her therapy: ***“I felt that’s what was needed to be done at that time…whereas if you’d come along, like, nearly a year later and said I want you to do (NSOMEs) I think I would have given up a bit earlier”*** (560-8) ***“well it’s like everything, you want to progress you don’t want to be sitting…a year after your stroke sort of going “ah ooh eeh”….I think that’d be soul destroying”*** (598-602). In the following quote, she compares NSOMEs to reading aloud, the latter being an aspect of her therapy programme, and which she describes as more akin to natural speech, implying it is a more effective therapeutic tool: ***"I suppose it's just repetitive and boring whereas reading out things is…what you're doing naturally in speech"*** (583-8).

In contrast, when asked her opinion on reading tasks, Sarah was unable to express what she did not like about them ***"…no I don't know I just didn't like them very much"*** (603). Referring to another task, she explained she disliked it because: ***"I couldn't get the words…I didn't know any"*** (177-9) and ***"I couldn't think enough"*** (670). This admission suggests Sarah was uncomfortable with some speech tasks, which may have exposed an unacknowledged language difficulty. Although she blamed herself for this (197), she continued with therapy and when asked why she had not asked for changes to be made, she demurred: ***"I thought it was good for me"*** (657)

Using a digital recorder (2.1b)

All those interviewed used a digital recorder to listen to their speech during therapy. Three expressed distaste for recording their speech for therapeutic purposes, eg Neil ***"Basically you knew yourself it wasn't right but the tape recorder only confirmed it"*** (318); ***"Cause it's you and it doesn't tell lies..."*** (340). Anna describes listening to herself on tape as ***"terrible",*** but agreed with the suggestion that it helped her to understand how she sounded when she spoke (431-449).

What patients liked about therapy (2.2)

Certain aspects of therapy disliked by some were liked by others, and there is variety in their responses, as well as some more universally popular aspects of the therapy, discussed below, any of which may have motivated patients to adhere. The tailoring of therapy to fit individuals' needs and interests was frequently cited as a positive factor, with several reporting it increased their motivation to adhere.

Therapy at home instead of hospital (2.2a)

All seven patients - a mixture of adherers and non-adherers - who were directly asked reported a preference for therapy in their home with none saying they would have preferred it in a hospital setting. Four, Harry, Sarah (880-5), Paul (190-8) and Mary said they felt more at ease: ***"…you feel more comfortable… in your own surroundings*"** (Harry 227-8). Mary felt it was no imposition - ***"Not a bit!"*** (402) - and her husband's opinion: ***"It's so much nicer than sitting in a hospital…I'd always had the feeling (hospital) was…a little bit sterile almost"*** (390-3)

Others appreciated the convenience of therapy at home: ***"there's no travelling, and I just could get up and get ready and I knew you was coming and I didnae have to rush"*** (Arthur 303-15); ***"Saves having to go out in bad weather"*** (Adrian 345). Terry found it convenient, and it fitted around work commitments ***"Wouldn't miss my overtime, for to go there, ken?…Sometimes you sit there for half an hour…in the hospital…waiting"*** (59-65); ***"Plus getting parked"*** (73).

Therapy raised awareness of speech (2.2b)

This subtheme refers to some patients' lack of awareness of specific phonemes they did not realise in speech, and the impact of this on their intelligibility. Terry had not known: ***"until you asked me to speak, mind, and you recorded me and I could hear"*** (413-7). Laura "***found it very helpful because it made me think about how, you know, you produce speech"*** (233-4) and said: ***"it was interesting to know that I could form the words all properly and it was just a mechanical thing…With, you know, my face and my tongue and things"*** (247-50). She also liked being aware of the link between tiredness and the worsening of her speech (298-302)**.** Des reported he found t therapy useful for illustrating specific difficulties he had with multisyllabic words: ***"…you were pointing out that I had difficulty to (pronounce) multisyllables and I had to slow down and I had to take care, and these were all…good advice"*** (124-6)

Therapy helped Mary make **"words, especially *words with s more distinct. And I tend to repeat those words if I feel I haven't made a good job of them"*** (144-5), suggesting she is conscious of how her speech sounds as she is talking. Similarly, Harry, Anna, Sarah and Paul reported therapy made them more conscious of their speech. Interestingly, when asked how therapy had helped her, Sarah did not remark on improvements in her speech, but said: ***"I feel as though I know what I'm doing now"*** (947), suggesting that learning how she sounds, and how to manage it, has been a positive outcome for her.

Using a digital recorder (2.2c)

In section 2.1.b., three patients expressed a dislike for listening to their recorded speech but, conversely, five patients described it as beneficial. These included adherers Laura, Anna, Harry, Mary and Terry, the latter two having purchased devices to help them monitor progress and to use in practice sessions: ***"I could actually tell myself what I'm doing wrong"*** (Terry 179-83). Using a digital recorder gave Laura confidence ***"because I sounded better on the tape than I thought I did. You know than gets into my ear! (laughs)…You know it sounded not bad at all"*** (735-46). Similarly, Mary said she finds her speech on tape very clear and yet her husband often cannot understand her. He described how he can understand ***"every word"*** she says when she records her practice material (221-8), instead it is her conversational speech he cannot understand.

The tasks (NSOMEs/DVD/ speech practice) (2.2d)

Of those who received NSOMEs (due to self-reported memory difficulties, Andy was not asked), all but Des were positive about the NSOMEs and DVD. Several described it as useful to have a consistent model, e.g.: ***"Well, the woman (on the DVD) was very good 'cause it made me do exactly what she said. Each time."*** (Arthur 169). Sarah reported she liked having a model, but preferred to use the written instructions, possibly because she could go slower(531-58). Although she described feeling ***"funny"*** at first when carrying out the NSOMEs and acknowledged it is boring to have to carry them out over time, she would have liked more. Anthony liked the DVD because he could keep up, and was able to control when he watched it (161-8).

Tailoring (individualised tasks/ strategies/advice) (2.2e)

Everyone came up with examples of elements they felt had been useful or enjoyable, with the exception of Andy whose memory difficulties prohibited discussion. Most examples given were of tasks/ materials tailored to their individual needs and interests.

Laura described why she found it useful to work on specifically identified targets, rather than working to produce non-words: ***"I got my speech therapy lists out from (hospital) and I thought how much better your approach was, because (the work from the hospital) was saying 'bah pah kah dah'…it's much more useful to see where you're having problems you know? Because I could say 'l – l – l' you know til I'm blue in the face but I still couldn't say "Philip", you know?"*** (329-36).

Working from a generic American book - as he had in hospital - felt alien to Adrian (185-9), whose wife linked his improvement to the tailored nature of the therapy: ***"I do feel that he has come on a lot since you come in to see him...More so than at (hospital). That's just a general - for everybody. I felt (this) was more tailored for his needs"*** (410-3)

Knowing which specific sounds are problematic seems to be useful to help people anticipate difficulties, e.g.: ***"It does help 'cause then you're aware of the sounds that are going to cause problems, you see them coming***

and you can maybe adjust” (Laura 354-60). Mary focussed in therapy on pronouncing pertinent words she consistently had trouble with, and agreed with her husband that although she occasionally has trouble saying them clearly, she can now anticipate difficulty and repair it:

(418-25)

Husband: ***“…she had a job saying ‘hospital’***

AJ: *Yes*

Mary: ***Hospital!***

Husband: ***Now she still…***

Mary: ***And “husband***

Husband: ***…stutters a little bit over saying ‘hospital’, but she knows it immediately and she’ll repeat it properly***

Mary: ***Yes”***

During therapy Terry identified specific sounds as important for him, as a singer, to work on because ***“every song has that in it…Doesn’t matter what kind of song it is, you always hear that letter”*** (405-10), and he attributed his motivation to adhere to the tailored approach: “***Well, there were certain sounds I couldn’t make and all (the) homework you gave me…It had all these sounds in it, all they different ‘p’s and ‘s’ s, all that…that’s why I stuck it”*** (116-21).

Arthur wanted to be able to tell medics not to resuscitate him in the event of another heart attack, and practised this in therapy: ***“Just to be able to say, likes of me not wanting rus… resuscitation…I couldnae***

explain…Difficult words that I could not have done without you… getting me to practise the words" (135-44).

Each patient's therapy was planned to provide materials comprising appropriate items from their individualised inventory of sounds/words/phrases. The materials were relevant to their interests and experiences, and included: news articles; TV reviews; dialogues; role plays; and their own transcribed anecdotes. Several patients placed importance on the personally relevant nature of the tasks; Laura described how this was accomplished: ***"…you asked me questions about what I did and I told you then you made up things to suit me, which I thought was great, you know because it was all interesting and what I liked, and so it wasn't like a chore to do"*** (420-2)**;** ***"the fact that you chose things that I was interested in…made it all the more enjoyable, really"*** (624-5). This is echoed by Mary: "***Well, you did pick up on my interests and you focussed on them…it made it easy – easy to attend"*** (166-75). Below are some examples of tasks which were referred to by patients as being personally relevant and motivating.

Mary'shusband felt travel was a motivating topic for her: ***"…one of the things which did her a great deal of good was your introduction of pictures of places she knew from holiday…so it makes her think*** **and** ***speak*** (Mary's husband 177-81)

Ttherapy focussed on John's involvement in church, using excerpts from the bible, a factor he describes as motivating: ***"For me it was especially what***

we were reading … it wasnae just out of any book, it was out the bible… and that was the difference. It helped me to be encouraged to do it more” (152-6).

As Terry’s goal was to return to singing on stage, musical analogies and song lyrics were used in therapy (356-61). Roleplay helped Laura to revisit her previous role as a tour guide, lost after the stroke, and to which she was thinking about returning: “***Yes it was sort of: “Oh I used to do this!” you know? From another …another era***” (520).

Some found the nature of the work challenging; when asked to elaborate on what she thought was ***“good”*** (157) about the words and homework, Anna said: “***They weren’t easy”*** (160), suggesting she liked tasks designed to challenge her. Sarah suggested that she liked to be challenged by the work (755-61); perhaps she found this motivating.

Laura suggested therapy is demotivating if it does not feel relevant to the individual: ***“when you're like this every day is a struggle and you don’t want to waste a lot of time…everything I do has got to be related, to help me do something else”*** (343-5).

Feedback (2.3)

Feedback was discussed in the interviews, with several patients reporting preference for honest feedback from the therapist, and some finding it challenging to receive feedback on their speech from family members. Others suggested it was difficult to carry out the practice without another listener's honest feedback. This may suggest that *self*-monitoring during practice sessions was not sufficient to enable some of them to modify or improve their speech.

Self-monitoring not sufficient – need feedback from others (2.3a)

Adrian admitted he had trouble monitoring his speech and needed feedback from others to keep him right: ***"I wouldn't know if it did sound right ...No feedback"*** (102-7). Des highlighted the challenges of self-monitoring when carrying out the NSOMEs: ***"Because there's no feedback...If something gets done wrong, if something is not effective in the way it should be, you modify it and you improve things - things get better. With (the DVD) there was nothing...tangible to tell you whether you were doing well, whether it was being effective or anything like that"*** (41-6). ***"It would have been easier doing it with another human being if they were saying 'look, you're not doing this properly'...if you were being told what was wrong you could then try and correct it*"** (52-55). In addition to highlighting the lack of support Des had in carrying out his practice, these comments must also be considered in light of his frequent refusal to carry out the NSOMEs with the therapist (see 2.4b).

Feedback from SLT (2.3b)

Providing feedback/reinforcement is an essential component of therapy, and can be constructively critical of a behaviour/outcome, specific in nature, and can serve to highlight patients' areas for development. Despite this, no respondent reported misgivings about the manner in which feedback was provided, eg: ***“there’s no point you coming just giving me stuff and letting me get on with it and not having any input…That was fine. It was obviously done in such a way that I didn’t get upset or anything…I’m a tough old bird!”*** (Laura 701-15); and Adrian “***It’s how you say it not what you say”*** (399).

Despite this, constructive feedback may still prove a difficult experience for the recipient, no matter how it is delivered. Sarah felt critical feedback is an essential, but challenging, aspect of therapy (769-76). Neil also admitted he found feedback challenging, saying he became frustrated with himself rather than the therapist*:* ***“xxx get annoyed with yourself ‘cause you’re trying to say something and it’s not coming out the way you intended to do”*** (399-400).

John’s wife suggested he does not appreciate feedback from *her,* instead accusing her of not hearing him. He was not irritated by feedback *from the therapist*, suggesting constructive feedback is easier for him to accept when coming from a professional:

(247-68)

Wife: ***"If I say to you…"I can't hear clearly what you're saying, would you say it again?" You don't take that well"***

John: ***Do I no'?***

Wife: ***No. You don't like to repeat it***

John: ***Yeah I know I don't like to repeat it because I've got to shout it out to you, I've told you, you're needing a hearing aid.***

AJ: *…it's interesting though that you didn't get angry with <u>me</u>…So why do you think that is then?...*

John: ***Aye. Well she's she's my wife so she wouldnae do it the same as you would do it.***

Dean accepted feedback about his speech because he was aware it was part of the SLT's role: ***"Well, that's your job is it no?"*** (339), and it was recognised by patients that *honest* feedback is a necessary part of therapy, and can be motivating:

219-28

Arthur: ***"..Just eh enjoyed improving…I liked you to say; "Oh you're a lot better…And that helped me... to keep doing it.***

AJ: *That's great. Well, I wasn't always positive though was I? There'd be times when I'd say: "No that's not clear enough"*

Arthur: ***Oh yeah that's right but that's your job. I was glad you done that…I would rather you tell the truth instead of saying I'm doing alright and perhaps I wasn't"***

When asked if it was OK to get critical feedback from the SLT, his response suggests he took it as a challenge to put more effort into his practice: ***"Aye! Oh definitely aye definitely 'cause I worked and worked and worked harder and harder and harder***!" (458-72)

Sarah found it useful to get specific *written* feedback about what she needed to work on: ***"I worked harder on the things that weren't so good…Words and things underlined …I worked harder on them"*** (892-902).

The practice (2.4)

This theme outlines what methods people *reportedly* used to carry out the practice; it does not reflect adherence in terms of the amount of time spent practising. Most, but not all, of those who adhered (according to timelog totals) also reported carrying out their practice as prescribed. Whether a person carried out the exercises as prescribed may have impacted not only on final outcomes but also on motivation to continue adhering throughout therapy and beyond.

Did follow recommendations (2.4a)

Sarah reported she carried out NSOMEs daily (540-4). For her speech practice she underlined words which in a section of text she struggled to produce clearly, working hard on their articulation, and repeatedly attempting to produce them with precision. She attempted to simulate conversations with herself; there were limited opportunities to converse with others (250-4; 273-7; 310; 893-900). Although this is not a practice that was recommended, it is clear that she tried to follow recommendations, as far as she could.

Terry worked shifts and practised at work and at home. He used his tape-recorder to help him monitor progress (203-5 495-500), and case-notes report he had been *"practising reading aloud from mags etc"* (session 3).

As described above, several people were supported by spouses and partners, who listened and gave feedback. Adrian’s wife described the practice they carried out together: ***“...he was saying the words and I was repeating what I thought if I wasn’t sure what it was...and then he would do it again”*** (82-91). Similarly, Laura’s husband assisted her to practise as prescribed: ***“We’d go over it again. And he said ‘oh no (AJ) said not to do them xxx’ ”*** (723-8) John’s wife took him through the phrases and words: “**I started normally with the small sentences…and did maybe a paragraph at a time of the reading**” He found making time practice difficult in hospital (32-42), and his partner assisted him (113).

Harry concentrated on his breathing and how much he could say on one breath. When reading aloud, he prepared himself for tricky words by slowing down (168-80). In addition to prescribed methods, Laura used roleplay to rehearse strategies (536-47).

Didn’t follow recommendations (2.4b)

Arthur (adherer) used the DVD in preference to practice materials provided: ***“Yes (the manual) was good…but the DVD was much better…But I still practised a bit, but not the way I should have. I didn’t… I don’t know why but it was more the DVD”*** (181-4)**.**

Although Des (adherer) recorded in his timelog that he completed the recommended amount of practice, he admitted: ***“I’ve never played the DVD all the way through”*** (25), suggesting he did *not* in fact carry out the exercises as prescribed. The case-notes show that, possibly because he felt

“stupid” (37) doing NSOMEs, he refused to carry them out in four/eight sessions. Consequently, there is doubt regarding his adherence. Similarly Paul (non-adherer) said he “…***didn’t watch the DVD. It was the book…made me speak”*** (239). He admitted it was difficult to watch the DVD as: ***“I got a new machine…and I don’t know how to work*** **it!”** (245) (on the few occasions when this arose as an issue, AJ tried to instruct patients on how to operate their machines). Five of his case-notes report he carried out no practice in the preceding week.

As discussed in 1.3.b, Anna’s (non-adherer) report that she practised frequently corresponds with neither timelog records nor case-notes, four of which document little/no practice in the preceding week. The case-notes also reflect that Anna required support to enable her to understand recommendations, provided in writing, verbally, and on the DVD.

Andy carried out no practice, according to his timelogs and self-report (see 1.1 and 1.2.a) and Neil’s (non-adherer) explanation of how he practised was insufficiently intelligible to establish whether he had followed recommendations. He acknowledged that he would read the practice material aloud once, rather than several times in several sessions daily, as instructed: ***“I’d say well I just read it once but to do it you have to read it a few times. You know?”*** (102-3).

Continues to practise (2.4c)

Some of those interviewed report they have continued to practise, including Paul, Arthur, Terry, Sarah and Anthony. Mary practises daily for 30-45 minutes: ***"I do it every morning – every every every morning!...But I do too long. I'm sure I'm better doing it in short bursts"***. Although she feels this is excessive, she does it ***"To get it out of the way…for the rest of the day"*** (38-52), and thinks they are effective (66). Laura explained: "***I do take it out sometimes that I feel it's, you know, I'm not doing as well as I should"*** (69).

Goals (2.5)

This theme allows an examination of any relations between goals and adherence. There follow two subthemes; the first describing patients' goals to return to an activity or state, and the second outlining some of the less specific aims that some people worked towards.

Therapy aimed to help patients achieve clearer speech, but many of those interviewed found it challenging to set specific person-centred goals at the commencement of therapy around which the tasks could be built, despite this being a factor considered important to effect good outcomes. Laura articulated the challenge: *"**I don't think I could cite specific goals at that time because you don't know how much…you can do"*** (473-4), suggesting people may require support to identify appropriate goals.

The benefit of setting appropriate goals was also described by Laura: ***"Just by achieving small goals…I mean sometimes in the speech [therapy] I would maybe one day just suddenly say something like 'Lilias' just – right out! .. And that boosts you to try, you know, other things…You've***

got take it slowly. I think if you set unachievable goals…You don't achieve them therefore you get depressed" (821-8)

Wanted to return to being able to do something specific (2.5a)

Some patients *were* able to set goals, including Laura who aimed to stop avoiding speaking situations, including telephone calls and conversations (443-7), as well as to ***"get to a stage where I don't have to concentrate on every single word that I'm saying 'cause it was tiring as well"***(463-4)

Paul's goal also related to the telephone, which he feels he has achieved *"**Well, I thought I'd be able to talk to folk and I can do on the phone now…Make myself understood. And I can do that as well" (***132).

When asked about goals, Des denied having any (139) although a goal *had* been agreed at the beginning of therapy, and was documented and stored with his therapy materials, referred to here: *"…look, that's the goal that I wrote down after our second meeting: "to seek out conversation with unfamiliar people occasionally"* (AJ 158-9). Following discussion of this during the therapy programme with the SLT he had joined two social groups (139-163).

Although Neil's goal was to speak to checkout staff on shopping trips, he avoided doing so: ***"I got frustrated"*** (258). It is apparent from the discussion below that the goal, to which he had agreed initially, had been suggested by the therapist, a factor which could potentially make the goal less motivating to work towards.

231-7

AJ: “I suggested…speaking to the woman at ASDA ‘cause that was the only trip that you were getting outside the house wasn’t it?

Neil: Yeah

AJ: Uhuh what did you think about that when I suggested that to you?

Neil: I thought you were quite right. Speaking to different people who xxx used to me. My family I was speaking to them so they knew how I spoke…”

This was discussed further, and Neil was asked what could have been done to help him to work toward that goal:

284-8

AJ: “If I’d come with you, do you think that would have helped…

Neil: Yeah but I knew what I had to do, anyway so

AJ: So it wasn’t the fact that I wasn’t there, it was the fact that you just didn’t want to

Neil: Yeah it’s down to the individual person, so”

Terry was unequivocal about the goal he worked toward in therapy: ***“I wanted to go back on stage”*** (347). As described in 2.2.e, his therapy was delivered partly through musical analogies and song lyrics, to motivate him to achieve that goal. Additionally, he wanted prove a point to his colleagues ***“I wanted to prove to them that I wasn’t drunk”*** (226-8)

John’s goals were also occupational in nature (to explore returning to his old job, and to deliver bible readings (121-9)), while Mary wanted to be understood by her husband (1-7).

Had non-specific goals/aims (2.5b)

Sarah's aim was ***"to be able to speak clearly"*** (442). When asked if she would have preferred to have worked towards a specific task, such as speaking to someone in a busy shop, her answer; ***"I'd like to manage myself"*** (476), suggested that she preferred to keep the focus of therapy on reducing her impairment rather than lessening the limitations placed upon her participation by her impaired speech.

Anna (non-adherer) did not have a specific goal other than **"Just to speak that's all"** (325). She hadn't expected it to be hard work, and had thought that therapy would result in her talking perfectly (9-21). In her interview she agreed with the suggestion that a goal aimed at increasing her confidence might have helped her to start considering a return to work (328-44).

Arthur stated his aim as: ***"I wanted to make myself clear"*** (90), and Anthony had at the commencement of therapy expected to be able to speak normally again despite having a significant speech impairment (32-52).

Outcomes (2.6)

Outcomes were monitored through assessments administered and scored by an external assessor. In addition, patients completed the CES before and after therapy, to expose changes in their perception of their ability to participate in communicative situations. When asked to discuss outcomes, patients commonly referred to an increase in their ability to participate in certain situations again. It was also clear that there was a tendency to use feedback from others to measure their outcomes and progress.

When asked what changes could have been made (such as to improve outcomes), most people found it very challenging to come up with suggestions for change.

Improvements patients would have made (2.6a)

Des would have improved the therapy programme by removing the DVD of NSOMEs, as he felt it offered neither tangible means of monitoring performance, nor feedback, and was not tailored to address his difficulties (41-55). He felt it may be necessary to prepare people to be confronted with their dysarthria in therapy, such as through listening to themselves on tape, an experience he did not enjoy (275).

A few (Sarah 368-73; Anna 457-8; Anthony 140-4) would have liked more sessions, and both Sarah (379-81) and Mary's husband (282) proposed follow-ups, to update exercises and activities. Other changes endorsed but not suggested by patients included more carryover activities, such as couples taping themselves conversing, enabling them to monitor speech improvements in natural situations (Mary 221-233). Arthur would have liked his target words/sentences on a DVD to help him practise (204).

Terry did not recommend any improvements, because: ***"I think you can only do what you can do and it's up to the individual for to do the rest"*** *(*289-90). It appears he was satisfied that therapy met his needs and he believed it to be the patient's responsibility to put in the work.

How did people measure outcomes and benefits of therapy? (2.6b)

A number of comments demonstrated that patients used their own observational skills and raised awareness to measure improvements; ***"I could feel my words getting clearer"*** (Sarah 152); ***"I'm not (excessively) shouting the same anymore"*** (Anna 78); ***"I can see the difference it's made to me on that basis that what I was like…when I came in"*** (John 429-30); ***"I've got more confidence in myself now…/…Speak a lot better to people (now)"*** (Dean 166/179). Terry kept recordings of his speech, which he compared and contrasted to monitor his progress (179-83). **"*I know it was helping my voice*"** (10-12). Anthony's wife reported ***"I've noticed that recently we've been speaking a lot more"*** (425)

Several patients, such as Laura (119-24), John (112) and Mary (476) gauged their own improvements through the feedback of others. Arthur said: ***"You know I think I'm a bit better because (family members) say I'm a lot better*"** (99-100). This was echoed by Adrian, who responded when asked how he knew his speech had improved: **"*People can understand me more"*** (166). In Terry's case his workmates helped him monitor his outcomes: ***"The more you came out they could understand me more and more and more*"** (92).: ***"…even my work said to me …'That speech therapy has done wonders'"*** (Terry 230-32)

The following chapter discusses the results of the current study, findings which can guide SLTs who treat people with stroke-related dysarthria in devising ways to increase patients' adherence to clinical recommendations.

Chapter 7. Discussion

The following section discusses the study's key findings in relation to its aims, and to current literature, through the lens of adherence. Methodological limitations and strengths are discussed and critically evaluated, and suggestions for further study are offered.

The paper met its aims by investigating 15 patients' personal perspectives of an eight-week course of community-based SLT for stroke-related dysarthria. Adherence to treatment was examined using information provided by the participants, and from therapy case-notes. Patients' reports of their experiences were compared to identify commonalities and differences between those who adhered and those who did not.

7.1 Key findings

The data suggest answers to the following research question: *"What factors, related to patients' perspectives of a therapeutic programme for dysarthria, impact on their adherence to treatment recommendations?"* and the key findings are as follows:

> Key finding 1:
> Inclusion in the treatment programme of bespoke, individualised therapeutic tasks was viewed favourably and several patients explicitly linked these tasks to adherence**.**

The participants recognised and appreciated the bespoke nature of the therapeutic tasks. They specifically valued tasks that were based on their interests and used pertinent names, words and phrases as targets for practice, rather than generic word-lists or tasks, and four of them explicitly linked this aspect of the therapy with their adherence. This was reflected in the anonymous evaluation feedback given by 34/39 NONSPEX (Mackenzie, et al. 2014) patients, of which 15 were also participants in the current study; there was no disagreement with the suggestion that the 'activities were useful for me'.

The finding that patients appreciate therapeutic tasks that are relevant to their lives is in line with those of other studies. Brady et al (2011a) found patients' adherence dwindled when they viewed the therapeutic activities they were given (such as tongue twisters and generic lists) as functionally irrelevant or childish. Participants on the *Living with Dysarthria* programme reported that tailored tasks met their individual needs precisely and flexibly, and the variety kept them engaged (Mackenzie et al, 2012).

People with dysarthria frequently experience disruptions in their social participation, and their identities (Dickson et al, 2008; Brady et al, 2011b; Walshe & Miller 2011). It is easy to see why they would want their therapy to be intrinsically related to their individual lives and the interests that define or express their identities. Additionally it may make the link between their therapy and their daily lives more palpable, and be "perceived…as relevant and worthwhile and… ensure adherence to recommended rehabilitation activities" (Brady et al, 2011a. p16).

> Key finding 2:
>
> A good therapeutic relationship was explicitly linked to adherence by some and was widely considered important for the effectiveness of therapy.

Patients reported that a good therapeutic relationship was important, with four adherers directly attributing what they perceived to be their own positive therapeutic relationship as having motivated them to adhere, stating that they worked hard at their practice because they liked the therapist and appreciated getting affirmative remarks. Explicitly linked with a good therapeutic relationship were the following qualities: trust; honest feedback; being relaxed; reduced inhibitions; enjoyment; and fun. If positive therapeutic relationships are indeed one of the factors that impact on adherence, then the SLT-patient relationship should be seen as a vital part of therapy, with the potential to mediate the effectiveness of therapy.

In psychotherapy, the therapeutic alliance (TA), is a widely researched variable of change; with results supporting the conclusion that TA is a key factor influencing psychotherapy outcome, (e.g. Crits-Christoph, Gibbons, Hamilton, Ring-Kurtz, & Gallop 2011)

The following definition of TA, incorporating both task and affect-oriented features of relationships seems to fit the processes of SLT well: TA is summarised as consisting of “the extent of patient-provider agreement on treatment goals;…collaboration on treatment tasks necessary for goal attainment; and …the affective bond…between patient and provider” (Arnow

& Steidtmand 2014, p238). The following definition additionally emphasises the communicative aspect of the relationship: "A trusting connection and rapport established between therapist and client through collaboration, communication, therapist empathy and mutual understanding and respect" (Cole & McLean 2003, p33).

In psychotherapy, with its approaches overlapping those of SLT (Brumfit & Clarke 1982), there is a growing call for researchers to consider that successful therapeutic outcomes can be explained by the "common-factors model" of therapeutic change (Wampold 2001). This attempts to explain what drives effective behavioural therapies, and is based on the premise that there are components common to therapy approaches which contribute more to a successful therapeutic experience than the specific ingredients *unique* to different approaches. These common factors include the therapist and therapist-mediated factors (such as the TA) which are ignored by the medical model commonly used in outcomes research (Wampold 2001; Ebert &Kohnert 2010). In an address to the American Speech-Language-Hearing Association in 2004, Brown described the common-factors model, and rejected the use of the statistical Analysis of Variance in medical research, saying its use is appropriate only if the individual clinician has little or no impact on the effectiveness of the treatment method. He described the clinician as having seldom been considered as a source of variance in research.

If, as the common-factors model suggests, clinicians *are* primary mediators of change, it is essential that they continually monitor their own effectiveness, including their ability to mediate positive therapeutic relationships. In this way they may be able to increase the prospect of better adherence, and potentially improve outcomes. Measuring TA at regular points throughout therapy may provide clinicians with information regarding how likely a particular patient is to adhere to therapy (Keller, Zoellner & Feeny 2010).

There are many assessments purporting to measure TA in psychotherapy, most of which rely either on subjective (clinician/patient) reports, with the accompanying risks of bias, or external observations of specific behaviours relating to different elements of the TA (see Elvins & Green, 2008, for a review). Although developed for use in psychotherapy and not tested for reliability/validity in other fields, several of these have been used to examine the impact of TA in other therapeutic areas, such as physiotherapy (eg Hall, Ferreira, Maher, Latimer & Ferreira 2010, who found TA to be positively associated with treatment adherence in patients with brain injury) and interdisciplinary brain injury rehabilitation (eg Clea, et al., 2008, who found that at discharge following intervention to increase team/client TA, the treatment group had higher functional status than controls).

The most commonly used measures include the Working Alliance Inventory (Horvath & Greenberg 1989); its shorter version (WAI-S) (Tracey & Kokotovic 1989); and the California Psychotherapy Alliance Scales (Gaston & Marmar 1994). These consist of questions related to how the client perceives aspects of the TA during sessions, accompanied by visual analogue scales for rating. Many such measures are overly long to be used on a daily basis in a clinical setting (Duncan et al, 2003). A TA measure developed for psychotherapy, for clinical rather than research purposes, can be seen in the Session Rating Scale Version 3 (Johnson, Miller, & Duncan 2000). This presents four visual-analogue scales, with instructions to rate the session on a continuum; negative responses depicted on the left and positive responses to the right. The first scale rates the session from “I did not feel heard, understood, and respected” to “I felt heard, understood, and respected.” These are followed by ratings related to goals, methods and the client’s perception of the quality of the session. This “ultra-brief” (Duncan et al., 2003 p. 4) scale could easily be incorporated into a clinician’s toolkit of regularly used instruments.

Clearly the therapeutic relationship is important, and may have facilitated the adherence of some of the patients to their therapeutic programme, but some did not adhere. As discussed earlier, there could be many reasons for this, including the lack of a positive therapeutic relationship (an aspect of the therapy about which participants were not asked directly by NONSPEX researchers in the anonymous evaluation forms). The results from the current study also suggest another potential factor facilitating adherence; support.

> Key finding 3:
>
> Those who adhered were more likely to be cohabiting and have support from a significant other, than their non-adhering peers. Several patients

explicitly linked the support of a partner/family member to adherence, or to increased amounts of practice.

The results suggest that support in carrying out therapy tasks is a factor that can impact on adherence. There were many reported instances of partners/family playing an active supportive role, and six patients explicitly related this to their own adherence. Support was given by encouraging and motivating participants to carry out their practice; rehearsing strategies; acting as a conversation partner and evaluating their progress. Respondents made it clear such feedback also provided a valuable means of measuring their outcomes. It is apparent that family and friends have substantial roles to play as a source of support for the patient and for the SLT, and in the provision and maintenance of therapy.

This reflects the findings of Mackenzie et al. (2013) and Brady et al. (2011a), who found many partners were very supportive of participants' therapy, and sought involvement. Similarly, many of the partners/relations of 48 people with aphasia interviewed by Howe et al (2012) specifically stated they wanted to be included in the therapy process - not just updated on progress - they wanted to be useful, and to help SLTs reinforce therapy goals.

There were some participants in the current study who did not have support, or who were ambivalent about the idea of accessing support. Adrian excluded his wife from therapy sessions, apparently to maintain the focus on himself, and John's difficulty accepting feedback from his wife regarding his speech was a source of friction between the couple. Elements of family dynamics and the home environment are factors that can mediate outcomes (Brady et al., 2011a) and, presumably, adherence.

Supporting people after stroke can be demanding, with evidence suggesting that the greater the severity of communication difficulty, the greater the burden of supporting a family member/partner (Long et al., 2009). Communication difficulties can have huge effects on families, impacting on family members' health, activity limitations and participation restrictions (Grawburg, Howe, Worrall & Scarinci, 2014). Therapists should take care to ensure that enlisting the support of a partner/family member in carrying out therapy is not perceived as another, possibly unwelcome, demand.

A number of the participants may have benefited from frequent support by trained communication partners/volunteers. The use of trained volunteers has been found to be beneficial in aphasia therapy as an adjunct to SLT (Worrall & Yiu 2000), but it would have been a challenge to make volunteers available to help the patients with their practice to the extent required for full adherence by the NONSPEX study. Distance support is another option, such as through videotelephony, as in a programme working with people with aphasia, in which therapists supported patients to carry out therapeutic tasks via Skype (Goldberg, Haley & Jacks 2012).

> Key finding 4:
>
> The inclusion of NSOMEs in their therapeutic programmes made people no more or less likely to adhere.

This is interesting simply because it adds to the growing body of evidence relating to the use of NSOMEs in SLT. One of the reasons that SLTS provide patients with NSOMEs is because they believe patients want or expect them. Mackenzie et al (2010), reported that 51% (n=79) of SLTs surveyed gave patient expectations as a rationale for NSOME use, and 25% (n=37) cited carer expectations. However being given NSOMEs made the current study’s patients no more likely to adhere than those who did not receive NSOMEs. Kamhi (2008) suggests that clinicians, in the face of a lack of guidance from research findings will, despite controversy surrounding their effectiveness, continue to use NSOMEs in the hope of engaging clients in therapy. It seems that the patients in this study did not find NSOMEs engaging enough to increase their adherence in comparison to their peers without NSOMEs.

An interesting finding

With data from only fifteen patients no conclusions can be drawn about associations or cause and effect, but it is possible to speculate about affiliations. From the Severity Rating Scores, four of the five non-adherers (80%) fall into the more severe categories, whereas of the 10 adherers, 4 (40%) were in the more severe categories. All three people who were classified as mild adhered. There is insufficient data to draw any conclusions, but it is interesting to consider the question: are those with more severe dysarthria less likely to adhere?

7.2 Clinical implications of the findings

The clinical implications of the key findings suggest it may be possible for clinicians to increase adherence to the therapy they provide by delivering programmes aimed at increasing patients' participation, in alliance with a family member/friend or volunteer to support, devised in collaboration with patients to meet their individual needs and goals empathically, in an atmosphere of trust and respect.

The key findings from this study fit perfectly within the philosophy of Person-Centred Care (PCC) which, in a paper exploring its role in SLT is defined as: "having a primary focus on the person as opposed to the task, recognizing and valuing personal knowledge and experience as well as the person's autonomy and competence in terms of decision making and problem solving related to both physical and emotional needs" (DiLollo & Favreau 2010, p. 91). Specifically, this approach lends itself to the bespoke tailoring of therapeutic activities patients' individual needs, such as by ensuring they have support to facilitate their adherence. A focus on the person rather than the task may mean avoiding the use of NSOMEs, in line with emerging evidence that they are not effective (Mackenzie et al, 2014), and as the findings of the current study suggest, they may not even increase adherence to therapy programmes as a whole. A good relationship between patient and clinician is necessary to enable the collaborative negotiations necessitated by this person-centred approach, as it is described in the definition. In addition, as positive therapeutic relationships have been found to improve outcomes and adherence, clinicians need to ensure they have the tools and the skills to be able to assess and mediate such relationships effectively. They need to have the clinical confidence to listen to the patient’s voice, and look beyond the task to the person.

7.3 Methodological strengths and limitations

This section discusses and examines the implications of a number of the salient strengths and weaknesses of the study’s methodology, including: the dual SLT-interviewer role; the challenges posed by the interviews; and the potential for self-selection bias.

7.3.1 Data collection

Implications of the dual-role

The person conducting and transcribing the interviews also planned and delivered therapy, and there are advantages and disadvantages to this, discussed in the following section.

It could be argued that this deterred participants from expressing candid opinions or critical comments about the therapy or the therapist. Limited critical comment was elicited, a finding echoed by Wade, Mortley & Enderby (2003) and Mackenzie et al (2013). Richards and Emslie (2000) found research interviewees to be less likely to criticise professional groups represented by the interviewer, and this could surely be the case when, as in this situation, it would mean criticising the individual in question. I took steps to help participants feel more comfortable to express honest opinions, reminding them that the programme was delivered according to a strict protocol devised by other SLTs, and that their honesty was appreciated as it provided useful data. Some examples follow:

Sarah 664-665

AJ: *"…OK try and see how else you can describe it for me because it's great, this is really good, I'm really interested to hear this…"*

Terry 285-287

AJ: *"Are there any suggestions that you would make to change…for me working with people in the future. Anything at all. You may have already told (NONSPEX assessor) these things but you can tell me them again if you want."*

Arthur 117-121

AJ: *"Let me say first of all Arthur that you can say whatever you want. The therapy that we did together was given to me - I was told to do it a certain way…So any negative things that you say, they don't… you know, they don't offend me in any way"*

Mackenzie, et al. (2014) gathered anonymous evaluation (AE) feedback via questionnaires from 34 of the 39 participants who had participated in NONSPEX. These evaluation forms contained the feedback of at least some, although it is not possible to know how many, of the current study's patients. The data indicated high levels of satisfaction with the programme and its outcome. This demonstrates that even when given the platform through which to express critical opinions anonymously, there was a lack of negative feedback. Although it is not possible to make a direct connection between the feedback given anonymously and feedback from the current study participants, there is the suggestion that overall, participants felt positively about the therapy. However, recommendations for gathering candid feedback from this study's participants can be found in section 7.4.1. There were several *advantages* to having the same person conducting both the interviews and the therapy. Both parties were familiar with each other and substantial efforts had been made to establish and maintain therapeutic rapport over the eight weeks of therapy. Establishing rapport is advocated by Paterson and Scott-Findlay, 2002 (who suggest a pre-interview meeting with people who have communication difficulties). I was familiar with the speech of the interviewees and strategies that facilitated their intelligibility, as to an unfamiliar ear, the speech of several of the patients was not easily intelligible The interviewees in Carlsson, Ehrenberg & Ehnfors (2004) feared they would not be understood by the interviewer - not a concern that was raised by any of the interviewees in the current study, possibly because they had confidence that I would make all attempts to understand their speech, as I had done all through therapy. In addition I was familiar with the therapy and progress of each patient, which was advantageous when posing questions, using examples and probing further.

Limitations of the interviews

The interview guide was designed to be a guide to the interviewer and provide a loose enough structure to provide opportunities to discuss topics in more detail with questions asked when it felt appropriate to do so. The wording of questions was not the same for all respondents, and although I had some prompts to use if needed, I did not use these consistently. In retrospect, a more structured schedule, with a list of open, broad questions and some consistent prompts may have made my interviews more rigorous and helped gather richer data.

At the outset of the study, despite a practice session in which I was supported by a skilled colleague who took the part of the interviewee, I was an inexperienced interviewer, apparent particularly in the earlier interviews. I made many errors, including being at times overly directive in my questioning. There follows an example of how I inadvertently led Sarah to describe herself as feeling silly carrying out NSOMEs. I probed by offering her alternatives where it would have been better to ask her to describe further:

Sarah 261-269

AJ: *"Yeah. OK. Em. Thinking about the exercises, you know the lip and tongue ones, how did you find doing them?*

Sarah: ***Funny to begin with***

AJ: *Funny? Uh huh. In what way - embarrassing? Strange?*

Sarah: ***Strange****.*

AJ: *Uh huh…. Tell me more - what do you mean?*

Sarah: ***Em…… (pause 6 secs) just funny.. . just different***

AJ: *Different. Did you think they're a bit silly?*

Sarah: ***Yeah. Silly"***

Occasionally I made the mistake of letting my familiarity with the interviewees get in the way of enabling them to tell the story in their own voice. In the following example, Des had not mentioned the word “silly” in the interview; I was remembering he had used it in the past, and ineptly took the opportunity from him for his words to be recorded in the data set.

Des 92-93

AJ:	*OK. And you said you felt silly doing them as well. Was that because you didn’t feel they were of any use, or was it because it was embarrassing..?*

The most prescient of errors I made was not adequately probing the interviewees for more information or helping them to develop their answers. This impacted on the quality of the data gathered; it was not as rich and nuanced as it could have been. There were several reasons for the lack of probing. Among those with more severe dysarthria it was difficult to get detailed answers, due to the effort required to respond. Additionally, there were instances in which I felt uncomfortable asking searching questions, even though a candid response would have informed my analysis. For example, I was confident that Des had not carried out as much practice as was documented in his timelogs, but I felt unable to probe him about his reported adherence, as to do so meant questioning his honesty or causing him to lose face (Goffman 1959). To obtain verification of his adherence was not possible, as there was no alternative means of measuring adherence built into NONSPEX.

The main reason however for the lack of exploratory questioning was my lack of experience, in particular of interviewing people with communication difficulties (not the same as providing therapy). Additionally, and it is also the reason that interviews were difficult to steer, was the fact that they were at times exhausting for both parties. I would have benefited from more skills and strategies to help me focus simultaneously on developing the interview, gathering rich data and supporting the interviewee with communication difficulties. Listening closely to and interpreting dysarthric speech whilst retaining a focus on the messages and the interview process was mentally challenging. Carlsson et al (2007) explicitly acknowledge this as an unreported phenomenon in carrying out qualitative research with people with communication difficulties.

Communication difficulties

The interviews of those with the most severe dysarthria were the most difficult to execute and some of them gathered only limited amounts of useful data. However, no data would have been gathered had their views and opinions not been sought. Perhaps more information could have been gathered from those with severe dysarthria by selecting questions more economically (Paterson & Scott-Findlay 2002) and carrying out a few short, focussed interviews (Carlsson, et al 2004), but due to time and financial constraints that was not feasible. The interviews which gathered sparse data however were in the minority; most elicited interesting data and all accorded voices to the people often avoided by researchers because of the very challenges faced in interviewing them (Kovarsky 2008; Carlsson et al. 2007; Parr et al.1997).

Lack of member checks

Post-hoc member-checks (in which participants are given a transcript of interviews, or syntheses of the data/findings to allow them to judge their accuracy and make corrections) were not carried out. From a practical perspective, it may have been challenging for participants to remember their stories, or the reality of their lives at the time the interviews had taken place, or at the time of their involvement in therapy. Member-checking can introduce variables capable of influencing the findings of studies; participants may take away or add extra data or revise views that had been valid at the time of the telling (Sandelowski 1993). In addition, the same challenges regarding encouraging participants to find fault with me or the therapy programme would have existed (as discussed in Chapter 1 and the current chapter). Theoretically, the participant's perceived experience as it occurred is the one considered valid and accurate in qualitative inquiry, and to use member-checking would be "squelching the creativity, keeping our results close to the data and preventing abstraction" (Morse 2005, p6).

Measuring adherence

For this study "adherence" was calculated by totalling the amount of minutes spent carrying out the practice tasks and comparing the total to the target amount of minutes recommended by the NONSPEX programme. This measurement provides a one-dimensional view of adherence to recommendations, akin to a proxy measurement of adherence – measuring the "how much" rather than the more descriptive (and more clinically relevant) "how much and how well". It was not possible for the current study to measure how well people adhered, although it was possible to gather qualitative information regarding how well they thought they had adhered.

It is clear from the interviews that people took different approaches to their practice, despite all receiving the same written and verbal instructions. Variously, some adherers and non-adherers described doing much more than recommended, some ignored the speech tasks or DVD, one did not watch the whole DVD, and another apparently read the practice tasks aloud once. None of this was apparent from the timelog totals, raising questions about the utility of "time spent practicing" as a measurement of adherence.

7.4 Recommendations related to study replication

The following section discusses some recommendations relating to how the current study could be improved in the event of being replicated.

7.4.1 Gathering candid feedback

Eliciting patients' frank views on the therapy in which they had participated was an issue in this study. One solution would be to provide participants with a means of giving negative comments anonymously, such as in a questionnaire, forwarded to a third person for processing before being passed on to the researcher.

Another way of gathering views, which may have practical clinical applications would be to have the contemporaneous collection of feedback built into the therapeutic programme. As discussed above, there is a growing interest in the measurement of TA in professions allied to health, and there are measurements for use in psychotherapy which could be adapted for people with communication difficulties to identify issues which may impact on adherence. Having a simple tool to gather patients' views on the techniques used in therapy, its progress and the TA, at regular points during therapy could provide the researcher/clinician with information on adherence (Keller, et al. 2010), and how to tailor therapy responsively, as well as providing valuable research data. Knowing such a tool is an intrinsic part of therapy may acclimatise patients to the process of giving feedback and reduce anxiety about offending the clinician.

7.4.2 A valid measure of adherence

Another limitation of this study pertained to the lack of an effective way to measure adherence, a complete picture of which cannot be gained from simply measuring the time spent practising. A fuller picture can be gained from observing the practice taking place, which seems an impossible feat as recommendations may stipulate that people practice several times daily. However, mobile phones and tablets, which have cameras, large memories, and facilities to prompt people to do a task could be tools to monitor and video patients carrying out recommended tasks on a frequent basis. This would however require an element of technical confidence in the participants, and may be costly. Identifying and training a nominated person (family member/friend/volunteer) to provide support and facilitate adherence would be useful and may be welcomed by some participants. This would add extra costs, in terms of time spent training those providing support, and finding volunteers, but may enable a better measurement of adherence.

7.5 Recommendations for further research in this field

The following recommendations relate to possible future investigations.

7.5.1 More measures to investigate adherence

The current study was bound to only use measures utilised by NONSPEX, as displayed in Table 4. A future study including measurements of depression, apathy, and the impact of dysarthria on the individual (e.g. a measure of its impact on participation), may enable the investigation of any links between psychosocial issues and adherence.

7.5.2 Examine impact of person-centered goals on adherence

This study was unable to draw any conclusions about the impact of goals on adherence, as information about any person-centered goals that patients set for themselves were not documented or measured as part of NONSPEX, as this was not a feature of the programme. Only three were able to articulate long-term goals they had been working towards in therapy, beyond wanting to speak clearer or as they had before, possibly because patients need support to identify realistic, specific and achievable goals. It would be prudent to examine the impact of person-centered goals, relevant to their lives and interests, would increase adherence, and to do so would require the setting of such goals to be inherent in a therapeutic programme.

7.5.3 Explore the role of significant others in adherence

As discussed earlier, the results of this study suggest that support from family/partners can impact on adherence. It would be informative to examine in detail (for example, through the analysis of videoed interactions) the methods used by people supporting their family members/partners with dysarthria to carry out the recommendations of SLTs, and determine those which are effective in helping the patient maintain or improve adherence. These findings could inform the development of training programmes for families/partners of patients (or volunteers), and subsequently it would be possible to test how effective the training is at improving adherence by comparing adherence levels pre- and post-training.

Chapter 8. Conclusion

Gathering patients' views about therapy for dysarthria is instructive. The expressed preferences of those in the current study, and the finding that support possibly impacted on adherence have implications for practitioners, particularly those working with socially isolated patients. SLTs should encourage the involvement of family members and partners as a tool to enhance and support therapy. This, and the findings that both the therapy tailored to meet the individual needs and interests of patients, and the therapeutic relationship all have clinical implications which could impact on adherence. The author recommends providing therapy that fits within the philosophy of person-centred care, with its aim of focussing on the person rather than tasks; for clinicians this involves helping patients set person-centred goals and monitoring the therapeutic relationship in order to maintain it, with the aim of increasing adherence.

The results suggest that, among this group: NSOMEs did not increase adherence; the therapeutic relationship was reported to be of great value to the participants and may have impacted on the adherence of a number of them; they also valued tasks and activities that were tailored to meet their needs and interests; support seemed to be of significance for adherence, those who had support may have adhered better.

The implications of the findings are relevant because they can inform SLT interventions. They may prompt therapists to include family or volunteers as support as a matter of course, or to place clinical emphasis on developing and regularly monitoring the quality of the therapeutic relationships they build with patients. The findings that among this group NSOMEs did not increase adherence to the intervention, coupled with those of Mackenzie et al (2014), which suggest that the NSOMEs as used in their intervention did not affect outcome, may give therapists the confidence to avoid using NSOMEs in the future, if they feel them to be clinically irrelevant.

The study has also been informative in other ways. It has demonstrated that interviewing people with dysarthria can be a challenging undertaking for a researcher, and as described above, requires the use of some facilitative communicative techniques. It necessitates careful consideration of who is best placed to interview people with severe dysarthria, and the potential problems with the dual therapist-interviewer relationship. Most importantly, it has added further evidence to the growing literature which demonstrates that it is possible to gather the views and opinions of people with dysarthria of all severities through interviews, and to use the information gathered to benefit their treatment. There is no need for the voices of people with dysarthria to go unheard.

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Appendix 1. NONSPEX (Mackenzie at al 2014)

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Research Report

Non-speech oro-motor exercises in post-stroke dysarthria intervention: a randomized feasibility trial

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Abstract

Background: There has been little robust evaluation of the outcome of speech and language therapy (SLT) intervention for post-stroke dysarthria. Non-speech oro-motor exercises (NSOMExs) are a common component of dysarthria intervention. A feasibility study was designed and executed, with participants randomized into two groups, in one of which NSOMExs were a component of the intervention programme.
Aims: To examine (1) operational feasibility of the programme; (2) participants' views of the programme; and (3) speech intelligibility, communication effectiveness and tongue and lip movement at four points (A1 and A2 before, and A3 and A4 after intervention).
Methods & Procedures: Thirty-nine participants were randomized into Group A ($n = 20$) and Group B ($n = 19$). Groups were equivalent at enrolment in demographic variables and A1 measures. Intervention was behavioural, delivered in eight home-based SLT sessions, and included practise of individually appropriate words, sentences and conversation, and for Group B also NSOMExs. Between-session practice was recorded in a diary. Data on speech intelligibility, effectiveness of communication in conversation, self-rated situational communication effectiveness, and tongue and lip movement were collected at 8-week intervals, twice before and twice after intervention. Anonymous evaluation (AE) questionnaires were completed.
Outcome & Results: The recruited number was 20% below the target of 50. Thirty-six participants completed the intervention and 32 were followed through to A4. The programme was delivered to protocol and fidelity was verified. Thirty-four AEs were returned. These showed high satisfaction with the programme and its outcome. According to diary records from 32 participants, 59% carried out at least the recommended practice amount. Outcome measure performance across the four assessment points did not indicate any group effect. For the whole sample both externally rated and self-rated communication effectiveness measures showed statistically significant gains across the intervention period (A2/A3), which were maintained for 2 months after intervention (A2/A4). Non-intervention period changes (A1/A2 and A3/A4) were not present. There were no intervention-related gains in tongue and lip movement or speech intelligibility, but the latter is likely to be attributable to a ceiling effect on scores.
Conclusions & Implications: The results indicate positive outcomes associated with a short period of behavioural SLT intervention in the post-stroke dysarthria population. The inclusion of NSOMExs, delivered in accordance with standard clinical practice, did not appear to influence outcomes. The results must be viewed in relation to the nature of feasibility study and provide a foundation for suitably powered trials.

Keywords: dysarthria, stroke, intervention.

What this paper adds?

What is already known on this subject?

The benefits of intervention for post-stroke dysarthria are under-researched. Non-speech oro-motor exercises are commonly included in intervention, despite a lack of evidence of an influence on communication outcomes.

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What this study adds?

The paper documents the successful conduct of a feasibility study in which participants were randomized into groups for which intervention included and did not include non-speech oro-motor exercises. The behavioural intervention programme was very positively received and assessment results show gains in communication effectiveness associated with the intervention period. No added benefit for the exercise group was indicated. The results provide a foundation for further trials.

Introduction

Speech and language therapists (SLTs) use a variety of interventions in their management of acquired dysarthria, including behavioural and compensatory methods, conversation partner training, counselling, and speech supplementation (Royal College of Speech and Language Therapists 2005). The evidence base for improved dysarthria outcomes associated with SLT is limited, especially for stable presentations, such as are associated with stroke. Most studies of post-stroke dysarthria involve fewer than 10 participants and some include stroke with other aetiological groups (see Mackenzie 2011, for a review). Stroke is the most common cause of complex adult disability (Adamson *et al.* 2004), and the presence of dysarthria is frequently documented in both acute and 3-month post-stroke clinical trial data (Ali *et al.* 2013). Even mild dysarthria may have marked social and psychological effects (Dickson *et al.* 2008) and SLT input is highly valued by people with dysarthria (Brady *et al.* 2011, Mackenzie *et al.* 2013). Thus the paucity of robust research that informs on the results of intervention with the dysarthria stroke population is anomalous.

Tongue and lip exercises are often included in dysarthria intervention. There is a long tradition of use of such exercises, known as speech mechanism exercises (Hustad and Weismer 2007) or non-speech oro-motor exercises (NSOMExs) (Mackenzie *et al.* 2010). Publications in English, which promote these exercises in acquired dysarthria, date from around 1940 (Robbins 1940, Froeschels 1943). Advocates believe that NSOMExs increase levels of tension, endurance and power of weak muscles, viewing speech as a multi-component motor skill and maintaining that exercises provide a foundation for and lead to enhancement of speech (Dworkin 1991). An alternative view is that the motor activities of speech are highly specific, so even if improvement through practice occurs for non-speech activities, speech will not be affected (Rosenbek and Jones 2009). The case against NSOMExs is supported by the limited relationship between non-speech oro-motor performance and dysarthria severity (see Weismer 2006, for a review) and the demonstration that physiological capacity in healthy individuals far exceeds speech requirements (Hinton and Arokiasamy 1997).

Recent research in both the United Kingdom and the United States confirms the continuing and widespread inclusion of NSOMExs in SLT (Lof and Watson 2008, Mackenzie *et al.* 2010). From a survey of SLTs in the UK working with acquired dysarthria, Mackenzie *et al.* (2010) reported 76% of respondents used NSOMExs in stroke-related dysarthria. Exercises were used with all dysarthria severities, and at both acute and chronic stages. Their use was much more common in stroke than in any other acquired neurological disorder. This continued practice is not supported by any firm evidence of benefit to speech and is inconsistent with much current expert opinion. Two small studies reported gains following therapy in a dysarthria assessment (Robertson 2001) and in single-word intelligibility (Ray 2002). Both show methodological limitations, including the absence of demonstrated baseline stability. Lass and Pannbacker (2008) concluded, from theoretical and empirical evidence, that NSOMExs 'should be excluded from use as a mainstream treatment' (p. 418). SLTs who include NSOMExs in acquired dysarthria intervention cite reasons for use, such as their own informal evidence of benefit, discussion with and observation of colleagues, patient expectations, educational focus and tradition (Mackenzie *et al.* 2010). There is no association between using or not using NSOMExs and years of SLT experience (Mackenzie *et al.* 2010).

Resolution of the question of the efficacy of NSOMExs is regarded as a dysarthria research priority (Duffy 2007). McCauley *et al.* (2009) called for 'well-designed single-subject and group experimental studies that provide adequate descriptions of participants and interventions, control for the influences of variables outside of treatment, and incorporate reliable and valid outcome measures' (p. 356). We report a feasibility study involving people with chronic post-stroke dysarthria, randomized to receive an SLT programme comprising speech practice alone or speech practice plus NSOMExs, carried out at usual clinical practice intensity. We aimed to examine the following:

- Operational feasibility.
- Participants' views of the intervention programme.

- Speech intelligibility, communication effectiveness and tongue and lip movement at four points (two before and two after intervention), comparing outcomes in the two groups (intervention including and not including NSOMExs).

Method

Participants

Inclusion criteria were: minimum 3 months since the last stroke; no co-existing neurological condition; dysarthria, with articulatory imprecision, diagnosed by a referring SLT; Mini Mental State Examination (Folstein *et al.* 1975) score $\geq$ 24; Boston Diagnostic Aphasia Examination (Goodglass *et al.* 2001) aphasia severity rating of 4–5; community residence at time of intervention; first language English and vision and hearing adequate, with any required augmentation, for reception of spoken stimuli, following instructions, and reading enlarged stimulus material, as informally judged by self-report and by referring SLT.

The target enrolment total for the study was 50 participants within a 1-year period, with 40 completing to final assessment. As a feasibility study this number was not devised from power calculation, but was considered appropriate to address the aims and provide data that could be utilized in a sample size calculation for a larger trial (Lancaster *et al.* 2004).

Participants were identified by SLT managers in six health boards. From 121 identified cases, 39 were enrolled, randomized and allocated to two groups: Group A: 20; and Group B: 19. Reasons for non-enrolment are shown in the participant flow figure (figure 1). An individual external to the research team managed the process of allocation to Group A (intervention without NSOMExs) or Group B (intervention with NSOMExs). Randomization was computer generated in blocks of around eight, in line with referrals, and group allocation was concealed and communicated only to the intervention SLT, via opaque envelopes, which were opened just before the first intervention session.

Participant summary data and group allocation are given in table 1. Age range was 30–91 years. Time post the most recent stroke was 3–32 months. Dysarthria severity was qualitatively rated at point of referral by referring SLTs using the mild, moderate, severe and profound descriptions applied in Mackenzie *et al.* (2010). Stroke aetiology was verified medically by clinical presentation and confirmed by tomography or imaging in all but four cases, for whom scan results were not obtainable. Methods of lesion reporting were inconsistent due to variation across services, and are summarized according to stroke type (infarct, haemorrhage, not known), hemisphere (right, left, bilateral), location (supratentorial, infratentorial, mixed, not known). Aphasia (minimal) was deemed present if Boston Diagnostic Aphasia Examination severity rating scale at referral was 4, rather than 5 (no aphasia). Group A and B profiles were equivalent at enrolment in respect of age ($t(37) = 1.31$, $p = 0.20$), months post-stroke ($t(37) = -0.78$, $p = 0.44$), dysarthria severity (chi-square (1) = 1.29; $p = 0.26$), gender balance (chi-square (1) = 0.21, $p = 0.65$), living situation (chi-square (1) = 0.30; $p = 0.58$), stroke type (chi-square (2) = 0.01; $p = 0.99$), hemisphere (chi-square (2) = 0.36, $p = 0.84$) and location (chi-square (2) = 4.00, $p = 0.14$) and presence of minimal aphasia (chi-square (1) = 0.01, $p = 0.92$).

Intervention

Both groups received eight once weekly SLT-led sessions of around 40 min. This regime was agreed with a consultation group of SLT managers, who deemed it consistent with practice and a dysarthria advisory group, comprising people with stroke-related dysarthria and family members, who considered it suitable for participant compliance.

Sessions were conducted in participants' homes. The intervention was behavioural, and focused on articulatory imprecision, the component of motor speech most clearly linked to tongue and lip activity, and the most commonly reported feature of post-stroke dysarthria (see Mackenzie 2010, for a review). In each session, intervention for both groups included practice of individually relevant speech sounds in words, sentences and conversation, throughout which appropriate clear speech maximization strategies were encouraged. Concurrent impairments such as poor breath support and reduced stress were not directly targeted through specific exercises, but strategies for optimizing participants' speech (e.g. slowed rate; emphasis of key syllables; deliberate articulation) involved manipulation of individually relevant parameters in addition to articulation. In addition Group B carried out NSOMExs. Intervention for the two groups differed only in that where Group A had 20-min practice of words and sentences, for Group B there was 10 min of this and 10 min of NSOMExs (table 2).

A minimum of two research team members, who were also experienced SLT clinicians, carried out detailed listening, review and discussion of the data available from the first assessment. Affected speech sounds and contexts were identified and transcribed with particular attention to loss of phonemic contrasts and phonetic imprecision. From these data, relevant speech targets, contexts and response lengths were individually determined for each participant (see the appendix, for example). All sessions for all participants were carried out by one experienced SLT (AJ), who devised the aims for each session

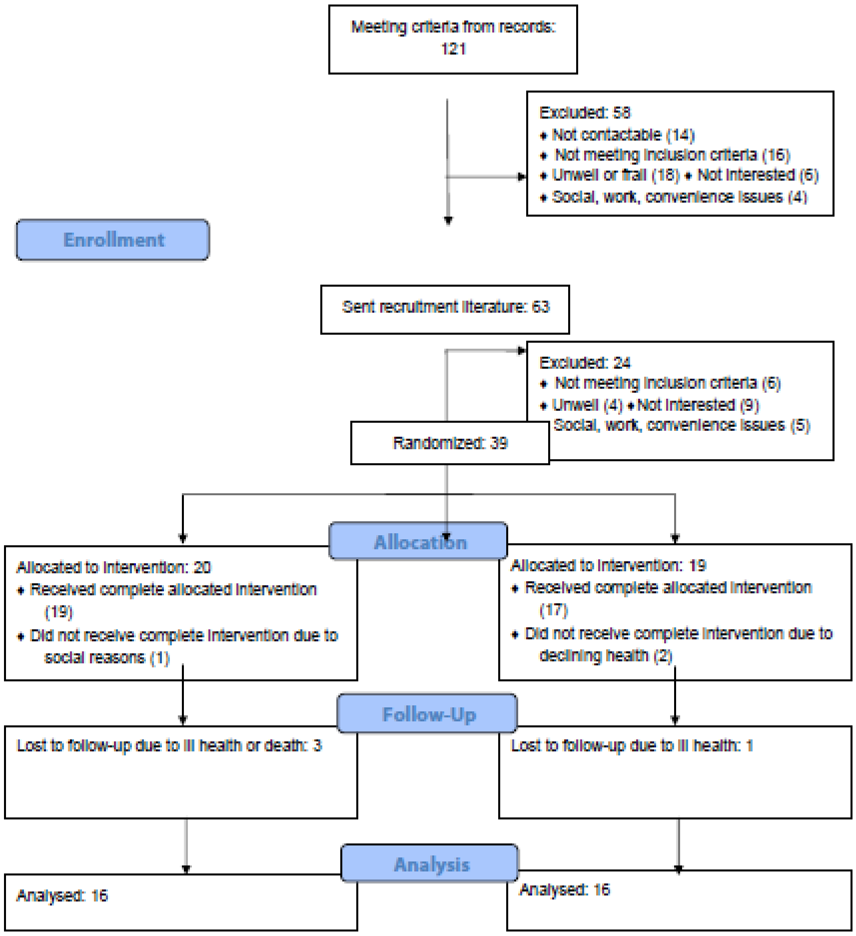

Figure 1. Participant flow.

and individually relevant practice materials, where possible reflecting the interests of the participant. On each visit she introduced the treatment material, with written stimuli, provided modelling, practice opportunities, feedback, reinforcement of desired responses, verbal reward, review, correction of non-desired responses, and encouragement, endeavouring to maximize and maintain motivation. There were at least five attempts at each verbal stimulus at each practice occasion. The criterion level for progress to a new stimulus set was 80% success. Conversation was an integral component of the sessions and was structured to incorporate opportunities to use material practised earlier in the sessions. In each session, before introducing and practising the individually specific speech stimuli, a core set of carefully modelled words and sentences were practised, chosen for variety of articulatory placement and complexity (e.g. paper; which; Scotland; where are you going; in Scotland it often snows in winter). Participants were instructed to make speech 'as good as possible' and 'use clear lip and tongue shapes' and to attempt to maintain clear speech in the succeeding individually tailored practice and in conversation. These stimuli were given in written form and demonstrated on a DVD using a 'practise with me'

Table 1. Participant background data

	Total	Group A	Group B
Total	39 (100%)	20 (51%)	19 (49%)
Gender			
Male	26 (67%)	14 (70%)	12 (63%)
Female	13 (33%)	6 (30%)	7 (37%)
Age, mean (SD)	65.44 (12.42)	67.95 (12.10)	62.80 (12.52)
Lives alone			
Yes	14 (36%)	8 (40%)	6 (32%)
No	25 (64%)	12 (60%)	13 (68%)
Severity of dysarthria			
Mild/moderate	21 (54%)	9 (45%)	12 (63%)
Severe/profound	18 (46%)	11 (55%)	7 (37%)
Time since stroke (months)			
mean (SD)	10.05 (6.13)	9.3 (5.12)	10.84 (7.09)
Stroke type			
Infarct	27 (68%)	14 (70%)	13 (68%)
Haemorrhage	8 (20%)	4 (20%)	4 (21%)
Not known	4 (10%)	2 (10%)	2 (11%)
Stroke hemisphere			
Right	8 (19%)	4 (25%)	4 (21%)
Left	19 (49%)	9 (45%)	10 (53%)
Bilateral	12 (31%)	7 (35%)	5 (26%)
Stroke location			
Supratentorial	21 (53%)	8 (40%)	13 (33%)
Infratentorial	7 (18%)	4 (20%)	3 (16%)
Mixed	6 (15%)	5 (25%)	1 (5%)
Not known	5 (13%)	3 (15%)	2 (11%)
Minimal aphasia			
Yes	12 (31%)	6 (30%)	6 (32%)
No	27 (69%)	14 (70%)	13 68%)

Table 2. Session structure

Group A		Group B	
5 min	Session opening/review of practised material and diary record	5 min	Session opening/review of practised material and diary record
20 min	Speech practise (words and sentences)	10 min	Non speech oro-motor exercises
		10 min	Speech practise (words and sentences)
10 min	Conversational practise	10 min	Conversational practice
5 min	Session closing and discussion about future goals	5 min	Session closing and discussion about future goals

format. For Group B only, NSOMExs were also included on the DVD. These comprised repetitions of tongue and lip movements which had relevance to positions for speech sounds, e.g. mouth opening and closing, and tongue elevation behind the upper teeth. Each exercise was carried out five times with positions held for 5 s, followed by a pause.

In addition to practice within sessions, a practice regime of two to three periods of 10–15 min, 5 days a week, carried out independently or with available support, was promoted. In the absence of guidelines on optimum amounts of practice and how to maximize compliance, the proposed practice amount was influenced by clinicians' typical practice for NONSOMExs (Mackenzie *et al.* 2010), and documented participant adherence (Robertson 2001). The recommended practice included conversation, the core word and sentence set, using speech maximization strategies, the individually relevant stimuli introduced in the sessions; and for Group B the NSOMExs practising along with the DVD model. Where required, a DVD player was provided, with full instructions and demonstration for use. A practice diary was issued for recording amounts of time spent between therapy sessions in practice of words and sentences, conversation, and for Group B, NSOMExs. A total independent practice time of 1050 min was deemed consistent with recommendation (30 min × 5 days × 7 between-session practice weeks). The intervention SLT guided participants on diary completion, collected and reviewed records at each session, and encouraged full compliance in those whose records indicated low amounts of practice.

Table 3. Assessment schedule

Assessment 1 (A1)	8 weeks before Assessment 2
Assessment 2 (A2)	Within a few days of start of the 8-week intervention period
Assessment 3 (A3)	Within a few days of the end of the 8-week intervention period Anonymous evaluation (AE) questionnaire issued
Assessment 4 (A4)	Eight weeks after Assessment 3

Assessment and outcome measures

Data were collected at four points (table 3). All data were collected by a single experienced SLT research assessor (MM), who was blind to group allocation. Average assessment time at each point was 45 min.

- *Speech intelligibility at sentence level* with Speech Intelligibility Test (SIT; Yorkston *et al.* 1996). Eleven sentences, one each of length five to 15 words, are computer-generated from pools of 100 sentences of each length. Sentences were presented individually at font point size 24 for reading aloud. Imitation was used where there were reading difficulties, with the model subsequently deleted. Each listener-identified stimulus word receives a score of 1 (maximum score: 110).
- *Communication effectiveness in conversation* with Communication Effectiveness Measure (CEM; Mackenzie and Lowit 2007). A one- to seven-point equal appearing interval scale (1 = not at all effective, 7 = very effective) provides a single indicator of listener-perceived overall communication effectiveness during conversation. Five to 10 min of conversation with the research assessor (MM) about topics such as a typical day, life since stroke, recent activities, work, family and friends were recorded.
- *Lip and tongue movement tasks* from Frenchay Dysarthria Assessment—2 (FDA-2; Enderby and Palmer 2008). Six items, each scored on a five-point equal appearing interval scale, with the provision for between-point ratings, allowing for ratings from 1 (low) to 9 (high) (maximum = 54). Lip and tongue at rest status and movement in speech are also rated in FDA-2, but these are excluded here as the intended focus was non-speech activity.

  Data were recorded using consistent procedures in as quiet an environment as possible in the participants' homes. SIT responses were recorded on a Roland Edirol digital audio recorder directly onto an SD card, at a sample rate of 48 kHz. For CEM and FDA-2 a Canon Legria FS200 digital camcorder recording directly to an SD memory card was used. This recorded very mildly compressed audio at a 48 kHz sample rate. For all of the above an Audio-Technica ATR35s omni-directional condenser Lavalier tie-clip microphone was positioned approximately 20 cm beneath the speaker's mouth.
- *Self-rating of communication effectiveness* with Communicative Effectiveness Survey (CES; Donovan *et al.* 2007). Eight items, e.g. 'having a conversation with family or friends at home' and 'conversing with a stranger over the telephone', are rated on a 1 (not at all effective) to 4 (very effective) scale (maximum = 32). Participants did not have sight of their previous ratings at any point.

Audio and video data preparation and handling

Audio and video clips for SIT, CEM and FDA-2 (see above) were copied to a hard drive and edited using Sony Vegas Movie Studio 10 Platinum, to cut them into easily identifiable files. For CEM, extracts of around 4 min were taken from each sample. These included both assessor and participant contributions and excluded opening and closing elements and clues to assessment point.

Audio was normalized to prevent differences in volume across clips. Some gentle noise reduction was done using Izotope RX (on the highest quality setting) to remove hiss and background noise without affecting the dialogue.

To facilitate management of the high volume of data, participant samples were divided into two participant sets (SET 1 and SET 2), with samples for all assessment points included in the same set. Data samples were then randomized for transcription (SIT) and rating (CEM and FDA-2), which was carried out by groups of graduating SLT students, blind to assessment point and group, over a single week. For SET 1 and SET 2 students, group sizes were respectively: SIT: 3, 4; CEM: 7, 7; and FDA-2: 3, 3. All transcribers and raters had normal hearing by self-report were native English speakers and familiar with the relevant Scottish accents. They had no previous contact with the participants or their data.

- *Intelligibility:* SIT data were distributed as files and transcribed orthographically. Each sentence was heard twice, with 5-s gaps, using headphones. Following practice data, listeners proceeded at their own rate, pausing the recordings as required. They were able to select and adjust playback volume. Breaks were taken each hour. The transcriptions were divided between two researchers for calculations of correctly identified words. A total of 21% of the transcribed data were scored independently by both researchers. Point-to-point agreement was 99.79%. Word identification variation across the three listeners was anticipated and present, and is likely to be influenced by factors such as extent of previous exposure to speech disorders, level of attention and individual discrimination ability. Individual words omitted in participants' reading of the stimuli were deducted from the possible scores. Scores are therefore presented as percentages of words correctly identified, using the listeners' mean.

- *Communication effectiveness.* Data were distributed as a DVD-Video disc, viewed together by raters on a video projector and sound system. Training included discussion of 'communication effectiveness' as it relates to dysarthria, using Hustad's (1999) concept of an effective communicator as 'active and efficient in getting the message across [. . .] in real-world social contexts' (p. 483). Raters were instructed to attend to intelligibility, speech naturalness, efficiency and non-verbal aspects of communication which might contribute to overall comprehensibility and to be aware of any dependence on the communication partner's contribution for understanding the message. They were directed not to evaluate language. Three samples representing CEM levels 2, 4 and 6 were used in training. Data samples were then rated in sets of five, with each sample viewed twice, and each set followed by a short break. The level 4 example was played before each set of five samples. Intra-class correlations across the data for SETs 1 and 2 respectively were 0.99, $F = 73.80$, $p < 0.001$; and 0.98, $F = 49.74$, $p < 0.001$. Mean rater scores were utilized for data reporting and analysis.
- *Lip and tongue movements:* Data were distributed as a DVD-Video disc, viewed together by raters on a video projector and sound system. Each response was viewed twice, with 5-s gaps. The relevant FDA-2 scoring descriptors were used to rate performance. Training included full consideration of these descriptors, and practice followed by discussion, using three samples representing varied severities. Consistent with the direction given in the test manual, raters were instructed to apply the 'best fit' rating. Breaks were taken after each set of five or six samples. Items from the practice samples were reviewed at several points during the rating process. Intra-class correlations across the data for SETs 1 and 2 respectively were 0.88, $F = 8.01$, $p < 0.001$; and 0.92, $F = 11.74$, $p < 0.001$. Mean rater scores were utilized for data reporting and analysis.
- *Self-rated communicative effectiveness:* Participants' totals on CES were tallied by one researcher. A second researcher independently tallied 40% of the data. Agreement was 100%.

Participants' views of the programme

A post-intervention anonymous evaluation (AE) questionnaire was issued to participants following the final intervention session. The intervention therapist was not involved in this nor did she see the returns. No validated measure was available that would provide informative study-specific anonymous feedback, so a questionnaire was modelled on that used in a previous stroke dysarthria intervention study (Mackenzie *et al.* 2013). It comprised (1) 15 statements on therapy sessions and results, for response on a one to five scale (1 = strongly disagree; 2 = disagree; 3 = neither agree nor disagree; 4 = agree; 5 = strongly agree); (2) 12 suggested programme improvements, using a 'tick all that apply' response, covering session difficulty, pace, length, number, amount of content and of home practice; (3) a question on preferred therapy location; and (4) two open questions requesting further suggestions for programme improvement and 'anything else you would like to tell us'.

Statistical analysis

Group equivalence at A1 ($n = 39$) was measured by t-tests and for categorical data by chi-square. Assessment point and group effects were examined by analysis of variance (ANOVA) ($n = 32$). Where across assessment variance was established, assessment point pairwise comparisons were used, with Bonferroni adjustments applied. Analysis was also carried out with results imputed for the seven additional cases with incomplete intervention and/or post-intervention assessments, by last observation carried forward and multiple imputation. Association between amount of practice and A2/A3 performance change was examined by Pearson tests.

Results

Operational feasibility

The target number of 50 participants had been agreed with collaborating SLT managers as a realistic aim within a 1-year period. Identification and recruitment strategy was active: a research assistant at the university base liaised with the local collaborators and followed up all leads. Initially four health boards were involved, and two more distant locations were later added, alongside a 4-month extension of the recruitment period. As participants were seen at home, some travelling distances for assessor and intervention therapist were more than anticipated, the furthest being 87 miles from base. From 121 individuals, whose clinical records suggested suitability for the project, 58 were excluded because they were not contactable, unwell or frail, did not meet criteria, were not interested or for whom social or work

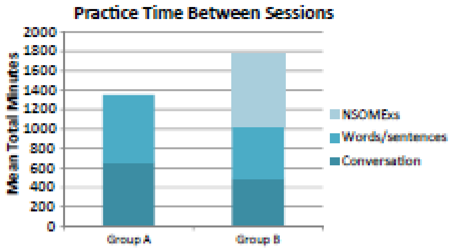

Figure 2. Total practice between sessions.

circumstances or inconvenience precluded participation. Similar reasons, with the exception of contact failure, applied to a further 24 who were excluded after the sending of recruitment literature. There were 39 enrolments. Thirty-six people completed the intervention programme and 32 (Group A: 16; Group B: 16) completed to final assessment, 8 weeks after intervention (figure 1). There was no movement from one group to another. Two participants from each group missed one session each. Attrition was within the 20% projection and was mainly due to ill-health.

Fidelity to intervention protocol was monitored by a member of the research team during two sessions with each of six participants representing four health boards. Intervention consistent with protocol was verified, in relation to time distribution within sessions, therapy materials, and appropriate inclusion of modelling, practice opportunities, feedback, reinforcement, verbal reward, review, response correction, encouragement, communication maximization strategies, and achievement of 80% threshold success on stimulus sets before progression.

Records of practice were obtained from the 32 participants who completed through to A4. The total amount of time recorded for practice varied greatly (range = 0–4482 min, mean (SD) = 1559 (1300.58). A total of 19/32 (59%) completed at least the recommended practice total of 1050 min (30 min × 5 days a week × 7 between-session weeks). Four participants recorded less than 1 h in total throughout the programme, whereas five people exceeded 3000 min. Although Group B, with three practice conditions rather than the two conditions for Group A, had a higher mean total practice minute score (figure 2), the difference did not approach significance. Groups A and B did not differ in practice totals across all conditions ($t(30) = -0.90$, $p = 0.38$), nor in totals for word and sentences stimuli ($t(30) = 0.70$, $p = 0.49$), nor conversation ($t(30) = 0.80$, $p = 0.43$). Correlations of total practice and A2/A3 score changes on the four outcome measures were not significant, with the exception of FDA-2 (SIT: $r = 0.02$, $p = 0.92$; CES: $r = 0.17$, $p = 0.35$; CEM: $r = 0.25$, $p = 0.16$; FDA-2: $r = 0.38$, $p = 0.03$). For the Group B who carried out NSOMExs, correlation of A2/A3 score change on FDA-2 (tongue and lip status) and total time recorded for NSOMExs practice did not reach significance ($r = 0.39$, $p = 0.14$).

Participants' views of the programme

Thirty-four participants returned the AE. Responses to the 15 statements indicated high satisfaction with the programme and its outcome. Few responses were not 'strongly agree' or 'agree'. A total of 82% thought their speech had improved and 88% felt they were more confident in communication. A total of 82% had been able to carry out the home practice. The usefulness of the DVD was confirmed in that 82% found it helpful and 76% found it easy to use. A total of 73% found the practice diary easy to complete. In relation to the content of sessions, only one participant reported that the sessions had not met expectations. Over 85% respondents thought the activities useful, at an appropriate level of difficulty and pace. Excepting one non-respondent, all thought they had been given enough feedback by a helpful and well prepared SLT. A total of 76% thought the sessions included enough practice. Further details are given in figure 3.

For the 12 suggested improvements to the programme, the largest responses were 'have more sessions' (56%), 'give more home practice' (44%), 'make sessions more difficult' (32%) and 'make sessions longer' (32%). All other responses were from few individuals. No one thought there should be fewer sessions or less home practice. No suggestions for improvement additional to those provided were offered. The domestic situation was preferred over hospital-based therapy by 73% and 15% had no preference. The final open question of 'anything else you would like to tell us' produced only positive remarks about the sessions, their enjoyment and usefulness, the SLT and belief that improvements had occurred e.g. 'Friends and family have commented on how my speech has improved as I now take my time and any difficult words I break them down which I have learned through this programme.' One respondent endorsed the individualization of practice stimuli and another indicated that he/she continued to practise: 'We felt the sessions were more useful when the sentences, words and phrases were interesting to the participant'; and 'I thought the idea was good and has helped my speech. I am looking forward to improving each week as I practise more and more.' Two respondents conveyed a need for SLT feedback: 'Speech practice alone is no good without an SLT's feedback—this is one of the main benefits of SLT'; and 'There is no benefit in tongue exercises if you don'*t* get any feedback.' One respondent referred to

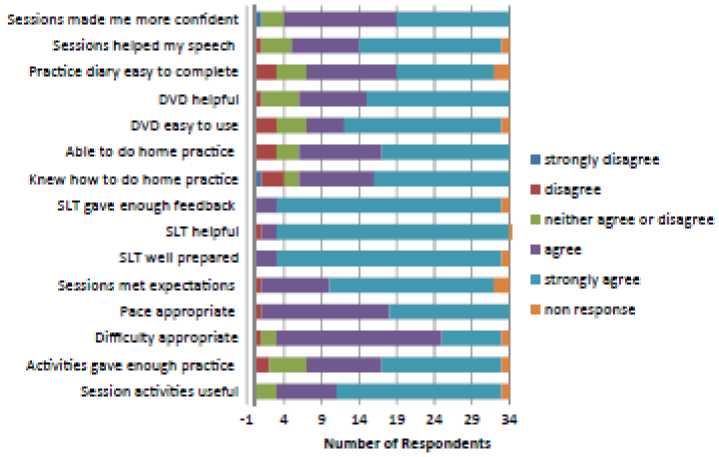

Figure 3. Anonymous evaluations (AEs): responses to statements.

the usefulness of the DVD: 'I found it helpful to practise along with the DVD, imitating the speech models presented on it.'

Participants status on outcome measures

Group A ($n = 20$) and Group B ($n = 19$) performance was equivalent at A1 on all outcome measures: SIT $t(37) = -0.69$, $p = 0.49$, CEM $t(37) = -1.18$, $p = 0.25$, CES $t(37) = 0.55$, $p = 0.59$, FDA-2 $t(37) = -1.05$, $p = 0\ .30$.

Figure 4 shows performance of Group A ($n = 16$) and Group B ($n = 16$), and the combined groups on the four measures ($n = 32$) at the four assessment points.

Group A versus Group B difference was not indicated on any of the four measures, based on data for 32 completing participants: SIT $F(1, 30) = 1.46$, $p = 0.24$; CEM $F(1, 30) = 2.39$, $p = 0.13$, CES $F(1, 30) = 0.58$, $p = 0.45$; FDA-2 $F(1, 30) = 2.61$, $p = 0.12$. There was no significant interaction between group allocation and assessment point on any of the four measures for these participants: SIT $F(3, 90) = 0.88$, $p = 0.97$; CEM $F(3, 90) = 0.34$, $p = 0.80$; CES $F(3, 90) = 0.16$, $p = 0.92$; FDA $F(3, 90) = 0.12$, $p = 0.95$.

In view of the scale nature of the CEM measure, non-parametric analysis was also undertaken and provided similar results. Imputation of results for seven additional cases with incomplete intervention and/or post-intervention assessments, by last observation carried forward and multiple imputation provided similar results for all measures.

Whole sample ($n = 32$) variance across assessment points was demonstrated for all measures, except SIT. SIT $F(3,90) = 1.02$, $p = 0.39$, CEM $F(3,90) = 8.87$, $p < 0.001$, CES $F(3, 90) = 21.70$, $p < 0.001$, FDA-2 $F(3, 90) = 10.34$, $p < 0.001$. Pairwise comparison of assessment points for CEM, CES and FDA-2 were justified. Table 4 shows significance levels, with Bonferroni correction, effect sizes and 95% confidence intervals. For all three measures, performance did not change significantly across non-intervention periods (A1/A2 and A3/A4). CEM and CES showed significant gains across the intervention period (A2/A3), between A2 and A4 and also between A1 and A4. The intervention period effect size was small for the CEM and at the high end of medium for CES. For FDA-2 performance across the intervention period (A2/A3) did not change, but significant gains were present between A2 and A4 and A1 and A4, the latter with a medium effect size.

Because of the close relationship between the FDA-2 tasks and the NSOMExs in the Group B intervention, Groups A and B were examined separately on this measure. This confirmed significant A1/A4 change for both groups (Group A $t(15) = -3.947$, $p < 0.01$; Group B, $t(15) = -3.551$ $p < 0.05$). No other pairwise comparisons were significant.

To examine further the results for the two measures (SIT and FDA-2) for which an intervention effect was not indicated, A2/A3 results were inspected for high and low scorers. For SIT at A2 21 participants scored above and 11 below the sample mean (76%). The A2 and A3 means (SD) respectively were 93.52(4.43) and 92.86 (6.61) for high scorers and 43.55 (24.18) and 52.91

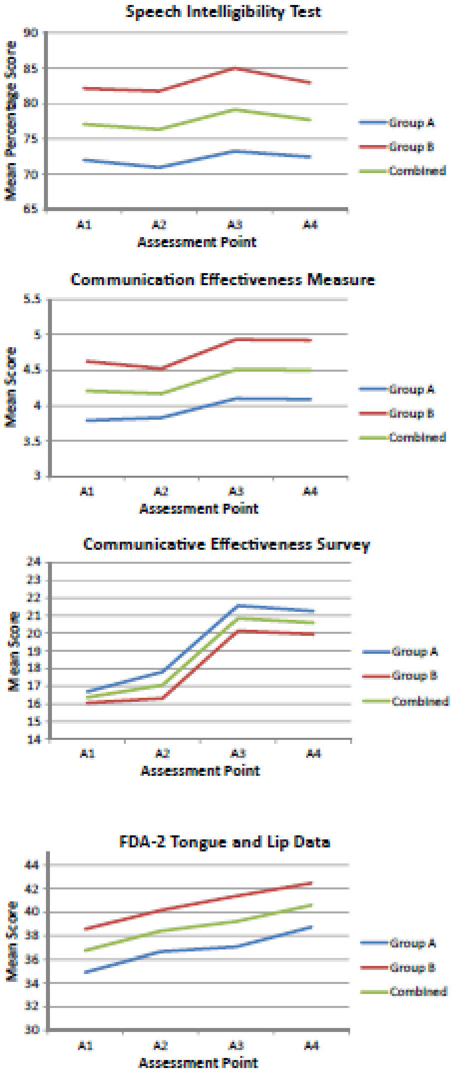

Figure 4. Mean scores at assessments 1–4.

(29.45) for low scorers. For the high scoring subgroup there was no A2/A3 gain: ($t(20) = 0.46$, $p = 0.65$, CI $= -2.39$ to 3.72). For the lower subgroup change was significant ($t(10) = -3.12$, $p = 0.01$, CI $= -16.05$, -2.68). The data and results suggest that a ceiling effect may contribute to the non-variance of SIT scores across assessment points. This subgroup comprised seven Group A and four Group B members. For FDA-2 at A2 20 participants scored above and 12 below the sample mean (38.22/54). The A2 and A3 means (SD) respectively were 43.43 (3.16) and 43.00 (3.60) for high scorers and 29.53 (4.91) and 32.89 (6.00) for low scorers. For the high scoring subgroup there was no A2/A3 gain; ($t(19) = 0.61$, $p = 0.55$, CI $= -1.06$, 1.92). For the lower subgroup change was significant ($t(11) = -2.36$, $p = 0.04$, CI $= -6.50$, -0.22). This subgroup comprised seven Group A and five Group B members.

Discussion

The behavioural management provided was positively received by the dysarthric stroke population and the evidence of benefit includes both external measures and participant evaluation (Sackett *et al.* 2000, Kovarsky 2008). The inclusion of NSOMExs in the intervention programme did not appear to provide additional benefit. The results presented contribute to the limited literature on outcome of SLT intervention for post-stroke dysarthria and should be viewed in the context of the sample size, the content and amount of intervention and the outcome measures used.

A feasibility study design, rather than a fully powered trial, was appropriate to the current state of progress of intervention research for chronic post-stroke dysarthria. Participants were randomized into groups that differed only in respect of the inclusion of NSOMExs. The same amount of therapy time was provided to both groups by a single SLT. There was not a non-intervention control group. The inclusion of non-intervention periods, equal in length to the intervention period, allowed evaluation of participant status on the outcome measures with and without intervention.

Feasibility and participant feedback

Feasibility is considered in relation to recruitment, retention and engagement, delivery of and adherence to the intervention protocol, and suitability of outcome measures.

Recruitment, retention and engagement

Recruitment was lower and slower than projected. Even with extension of the recruitment period and inclusion of two further, more distant, health boards, the enrolled number was 20% below target. From the original 121 identifications 32% were enrolled to the study and allocated to an intervention group. There were then two stages of exclusion: 48% of those whose records indicated suitability were not sent recruitment literature and 38% of those who were sent literature were not

Table 4. Assessment point pairwise comparisons: CEM, CES and FDA-2

	A1/A2	A3/A4	A2/A3	A2/A4	A1/A4
CEM	$t(31) = 0.30$ $p = 1.00$ $d = -0.02$ $[-0.26 \text{ to } 0.32]$	$t(31) = 0.16$ $p = 1.00$ $d = 0.01$ $[-0.20 \text{ to } 0.22]$	$t(31) = -3.90$ $^{**}p < 0.01$ $d = 0.22$ $[-0.59 \text{ to } -0.09]$	$t(31) = -4.25$ $^{**}p < 0.01$ $d = 0.21$ $[-0.55 \text{ to } -0.11]$	$t(31) = -3.34$ $^{*}p < 0.05$ $d = 0.20$ $[-0.55 \text{ to } -0.04]$
CES	$t(31) = -1.24$ $p = 1.00$ $d = -0.16$ $[-2.26 \text{ to } 0.89]$	$t(31) = 0.40$ $p = 1.00$ $d = -0.04$ $[-1.55 \text{ to } 2.05]$	$t(31) = -5.77$ $^{***}p < 0.001$ $d = 0.72$, $[-5.66 \text{ to } -1.90]$	$t(31) = -5.60$ $^{***}p < 0.001$ $d = 0.67$, $[-5.34 \text{ to } -1.72]$	$t(31) = -5.85$ $^{***}p < 0.001$ $d = 0.87$, $[-6.28 \text{ to } -2.16]$
FDA-2 tongue and lip movement	$t(31) = -1.89$ $p = 0.44$ $d = 0.21$ $[-4.15 \text{ to } 0.85]$	$t(31) = -2.43$ $p = 0.14$ $d = 0.21$, $[-3.02 \text{ to } 0.24]$	$t(31) = -1.36$ $p = 1.00$ $d = 0.11$ $[-2.25 \text{ to } 0.89]$	$t(31) = -3.33$ $^{*}p < 0.05$ $\mathrm{d} = 0.30$ $[-4.09 \text{ to } -0.31]$	$t(31) = -5.36$ $^{**}p < 0.01$ $d = 0.54$, $[-5.91 \text{ to } -1.79]$

Notes: CEM = Communication Effectiveness Measure (Mackenzie and Lowit 2007), CES = Communicative Effectiveness Survey (Donovan *et al.* 2007), FDA-2 = Frenchay Dysarthria Assessment—2 (Enderby and Palmer 2008).
$^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

enrolled. Taking these two stages together, a high number of exclusions related to poor health and this is not unexpected in a stroke population. An equally high proportion of exclusions were due to non-fulfilment of inclusion criteria, such as speech standard now being good, diagnosis of additional neurological disease or cognitive deficit, hospital residence or markedly poor vision or hearing. A relatively small number of people on initial contact indicated that they were not interested in participating and further people declined after receiving the participant information sheet. This conformed to NHS ethical guidelines, and was formatted and worded appropriately for the population. In many cases we did not determine the reason for not wishing to join the study, but there were instances where speech was not a priority for the individual or he/she did not want to commit to the schedule of assessment and intervention. Consideration should be given in future research to seeking this information systematically from individuals who decline to participate, via anonymous questionnaires. For some people non-participation was linked to personal and domestic situations, including work commitments and family member health or support factors. The recruitment experience showed that for a stroke dysarthria intervention study, even with a tenacious approach, it is likely that many apparently eligible people will not be enrolled, and for very varied reasons. Conducting further, larger scale research in this field would require a wider geographical radius. Consistency of approach, with one assessor and one intervention therapist carrying out all sessions, was a strength of the current study. Further training and monitoring steps are required to maintain such consistency across researchers in future, larger studies. Attrition on health grounds is inevitable with stroke populations and the 18% attrition (three people during the intervention phase and four others before follow-up) was as expected. Participant sustained engagement was indicated by there being no withdrawals or loss to follow-up through reduction in interest, and very few missed sessions. Further evidence of interest and engagement is provided from participant feedback (see below). It is likely that the domestic location, about which participants were almost unanimously positive, supported attendance. The project does not inform on aspects of efficiency and economics of home versus hospital models and that is a topic for future research. Also the participant sample represented broad spectra of age and time post-stroke. Evaluation of programme response with reference to these two potentially important variables was not appropriate in a study of this size.

Intervention protocol delivery and adherence

Currently post-stroke dysarthria research and practice guidelines do not inform on optimum dosage and duration of intervention, or amounts of independent practice. A regime of eight once-weekly sessions was consistent with previous behavioural intervention in post-stroke dysarthria which reported positive outcomes (Mackenzie and Lowit 2007). The people with dysarthria, family members and clinicians consulted when planning the project thought this appropriate and that recruitment and attrition may be affected by a longer programme length. Via AE over half of the participants recommended having more sessions. No one thought there should be fewer sessions. This feedback, and attrition being mainly related to health issues, indicates the course length was appropriate for many. The effects of a longer and/or more intense programme are unknown. Outcomes associated with different dosage and duration of intervention, which is a current topic in aphasia research (Leff and Howard 2012), requires to be viewed in conjunction with what is acceptable to and sustainable by the dysarthric stroke population.

The programme of assessment and intervention was delivered to plan and we monitored and confirmed fidelity to protocol in relation to time management, session content and a broad range of behavioural intervention features. Participant satisfaction with the sessions was demonstrated by the level of sustained attendance and also by AE responses. Session content was individualized to take account of not only dysarthria severity and the profile of affected speech sounds and contexts, but also to incorporate material of interest to participants, e.g. song lyrics and scripture excerpts. Endorsement of this approach is indicated by there being no disagreement in the AE that the 'activities were useful for me'. Much pre-session preparation was involved and in the AE there was unanimous agreement that 'the therapist was well prepared', 'helpful' and gave 'enough feedback'. Response agreement was high as regards the difficulty level of materials and the pacing of sessions. A strong majority thought there was enough practice in the sessions, though some participants felt they could have tackled more, and this was evident also in 26% agreement with the suggestion to 'include more in each session'. Clinicians should discuss the amount of practice in sessions, at an early stage, and make relevant adjustments to optimize this for individuals.

Behavioural dysarthria therapy is practice based and between-session practice typically is a component of management programmes (Rosenbek and Jones 2009). Structured practice, to supplement the SLT led sessions was recommended for two to three short periods (10–15 min) for each of 5 days each week. There was much variation in amounts of practice recorded, and its distribution across word and sentence stimuli, conversation, and NSOMExs (Group B). The data do not indicate any quantifiable relationship between group membership, practice and improved outcome. According to the AE only a few people had been unable to carry out the home practice but the diary records indicate that over 40% did not complete the recommended amount, although the importance of adhering to the home practice schedule was regularly emphasized by the intervention SLT and the participants appeared well motivated. No one agreed with the AE suggestion that there should be less home practice and over 40% agreed that more home practice should be provided. As with amount of session content, clinicians should gauge the extent of practice appropriate for individuals and be flexible in their approach to this. Mackenzie *et al.* (2013) similarly reported variation in attitude to home practice in the Living with Dysarthria group programme. The availability of a practice partner appeared to be influential, leading Mackenzie *et al.* (2013) to suggest volunteer assistance to maximize home practice. A total of 36% of the participants in the current study lived alone and involving volunteers in between-session practice should be considered. Some people find it difficult to maintain records of practice and there may be reason to question the reliability of the records, although according to the AEs a strong majority found the practice diary easy to complete. The intervention SLT reported that some participants were vague about independent practice amounts and some needed assistance to complete records retrospectively. We learned the importance of full engagement of available family. Volunteers might assist in maintaining records as well as in carrying out practice. The practice records inform only on the amount of time individuals reported that they spent practising, and not on how they approached this and with what success. The gathering of such valuable information would be facilitated by the full involvement of a practice partner.

To aid home practice a DVD was given, and used also in the sessions. This demonstrated clear, careful articulation and for Group B included the NSOMExs. As we anticipated, the DVD format was difficult to use for some less fit people who lived alone, and some were unable to use it consistently. Nevertheless three-quarters of respondents agreed this material 'was easy to use', and an even higher proportion thought it was helpful. We conclude that for many people this is a useful adjunct to written format materials.

Suitability of outcome measures

We aimed to obtain outcome information that was relevant to everyday communication. The SIT, CEM and CES are concerned with intelligibility and effectiveness of connected speech and the CES provides the perspective of the person with dysarthria. In contrast to these three measures that have face validity as regards how much of speech is understood and how effective communication is, the lip and tongue tasks from FDA-2 inform on movements and their rate and were included because lip and tongue movements were practised by one participant group. Informal feedback from the assessor indicates that these measures, including the use of audio and video, which were necessary for data analysis, were acceptable to the participants and the time involved, at an average of 45 min on each occasion, was not excessive. The FDA-2, SIT and CES are widely used in dysarthria and are validated and standardized measures. The CEM is an informal measure, used in the absence of a reputable single external rating of communication effectiveness, applicable to the stroke dysarthria population. Standardization and validation testing are required. We detected a possible ceiling effect for SIT scores for this population. Scores may have been inflated by the volume normalization applied in the data editing process and by listeners being graduating speech SLTs, who were permitted to select and adjust playback volume. These decisions were made because all data were collected in participants' homes and we wished to avoid ratings being negatively affected by issues which were reflective of recording rather than patient status. Although every effort was made to keep conditions constant there were inevitably occasions where individual circumstances and conditions, such as posture and background noise affected recordings. Collecting data under laboratory conditions would allow more objective measurement. Further consideration should also be given to the most appropriate indexes of intelligibility. Miller (2013) points out that sensitivity may be increased by supplementary listener confidence or ease of listening ratings. Also future research might add a measure that captures the impact of dysarthria. Several tools are in development, including Communicative Participation Item Bank (Yorkston and Baylor 2011), Dysarthria Impact Profile (Walshe *et al.* 2009), and Living With Dysarthria questionnaire (Hartelius *et al.* 2008).

Outcomes

There was no apparent advantage on any of the four outcome measures for the participants whose intervention included NSOMExs. Thus this study provides no support for the inclusion of these exercises, as used in this programme, in SLT management of people with post-stroke dysarthria. To date no robust study has demonstrated speech gains attributable to NSOMExs.

The results for the combined groups data indicate intervention related improvements in communication effectiveness, based on external rating of conversational samples and participants' self-ratings. The effect size for the self-ratings, at just below large, shows that participants viewed themselves as more effective communicators following the programme and maintained this increased confidence with their communication two months after the end of the programme, suggesting a lasting effect. The effect size for the externally rated effectiveness measure, CEM, was lower, but here too the significant gain was maintained, indicating that this improved communication was not dependent on ongoing SLT input. SLT behavioural interventions comprise several interacting components, linked to participant, therapy and therapist (Mackenzie and Lowit 2012). Variables relevant to this study included practice of individually selected word and sentence stimuli and conversation, both incorporating speech maximization strategies, a therapist with whom participants had favourable rapport, and also for Group B, NSOMExs. It is impossible to tease out the relative contributions of these factors in a feasibility study of this nature, but controls built into future research might include comparisons of outcomes associated with conversational practice only versus the specific stimuli plus conversational model used here. Relevant also is input from a non-SLT versus planning and provision by an experienced SLT. Bowen *et al.*'s (2012) results for the acute stroke population indicated no added benefit of SLT over social contact from an employed visitor.

Significant variance across assessment points was also evident for the FDA-2 tasks. However the absence of A2/A3 gain suggests no intervention effect but gradual changes over the assessment time period. Assessment may be identifying slight ongoing improvements in tongue and lip activity. Also it is possible that there is some familiarity effect with this motor task, with participants feeling more comfortable with what initially may be perceived as strange demands. These changes did not appear to be related to group allocation in that across assessment profiles of Group A and Group B were similar. Furthermore the low scoring group, for whom significant A2/A3 change was present, comprised members of both groups in almost equal numbers. It would seem that the NSOMExs regime used in this study has no specific effect on the tongue and lip movement tasks of the FDA-2. This challenges even the sceptical position on the use of NSOMExs in dysarthria that, while speech is not likely to improve, ability to do the exercises should improve (Rosenbek and Jones 2009). The exercises were practised at an intensity that was consistent with clinical practice (Mackenzie *et al.* 2010). The results do not inform on outcome that may be associated with high intensity repetitive practice, an approach which is thought to show promise for limb activity (Langhorne *et al.* 2009). Future research might examine the outcome of high-intensity practice with selected motivated participants who have the required stamina. Intervention was not structured to adhere to motor learning principles concerning practice and feedback conditions (Schmidt 1988). With the exception of one small randomized study of dysarthria in Parkinson's disease (Adams *et al.* 2002), which showed that skill retention is aided by low rather than high-frequency feedback, the effects of the implementation of motor-learning principles have not been explored in acquired dysarthria. Nevertheless, taken together with evidence from studies of healthy adults and apraxia of speech a motor learning approach is considered promising and worthy of further investigation (Bislick *et al.* 2012). We considered whether intervention for the exercise group should comprise solely exercises, which might permit a purer comparison with speech treatment. This was not acceptable to our clinical collaborators because of its inconsistency with usual practice. Furthermore it would be difficult to achieve group parity of session length where intervention was limited to exercises.

Given the significant improvements in effectiveness of communication and the intervention emphasis on clarity of articulation, the absence of parallel gains in the intelligibility measure was anomalous. Dysarthria affects not only intelligibility but also dimensions such as naturalness and rate (Yorkston *et al.* 2010) and while all had articulatory imprecision many participants entered the study with relatively good intelligibility. A prevailing mild–moderate impairment level is documented in the literature on dysarthria in stroke (see Mackenzie 2011, for a review). The additional analysis of A2/A3 SIT results suggested a ceiling effect for this test in that change was significant in low-scoring participants.

Participants' positive views of outcome were further demonstrated via the AE. Only one participant disagreed with the statement 'I feel the sessions and practice helped my speech' and four responded neutrally. One strongly disagreed that 'I feel the sessions and practice have made me more confident in communication' and three responded neutrally. Thus from the CES and AE results, it may be concluded that the majority of participants thought the programme beneficial, rating themselves as having improved speech, being more confident in speech, and being more effective communicators in everyday functional situations. This 'participant voice' (Kovarsky 2008) strengthens the relevance of SLT to the management of post-stroke dysarthria demonstrated in outcome measurement. SLT practice currently lacks the tested and validated patient experience tools which are widely used in primary healthcare, such as the Scottish Health and Care Experience Survey (Scottish Government 2014) and the development of appropriate instruments is an important area for future research. Methods of collecting data to evaluate patient satisfaction such as focus groups, interviews and questionnaires, each have advantages and disadvantages. Questionnaires of the type used in this study have the benefits of convenience, anonymity and ease of completion and obviate the possibilities of fatigue and perceived confrontation which interviews may present (Flick 2007), but do not permit detailed exploration of responses. For example it would be informative to probe as to why the recommended amount of practice was not carried out and the perceived usefulness of the DVD. The use of more than one method may increase the richness, completeness and robustness of information (Cohen and Crabtree 2006). We will be separately reporting on a subgroup of participants who took part in individual interviews, the data from which may provide further insights into the therapeutic experience and the perceived value of the programme.

As a disorder of the integrated motor speech system, dysarthria in stroke variably affects articulatory accuracy, but also respiration, phonation, resonance and prosody (see Mackenzie 2011, for a review). Behavioural SLT intervention may therefore incorporate several areas in addition to articulatory accuracy, which were not directly targeted in this study, and which may impact on articulatory accuracy and evaluations of intelligibility and communicative effectiveness. Future stroke intervention research may attend to a broader profile of impairment and incorporate outcome measures relevant to these.

Conclusion

This research confirms the feasibility of delivering and evaluating a randomized SLT trial in post-stroke chronic dysarthria to examine and compare outcomes in groups where intervention includes and does not include NSOMExs. Although recruitment was below target, the study involved a higher number of participants than has previously been reported in post-stroke dysarthria intervention research, and contributes to a limited evidence base for the relevance of behavioural intervention. The recruitment experience, with a strategy that was appropriately active and focused, indicates a future requirement for an approach that is not only multicentre but also widely based geographically. The wide age span of the participant sample was representative of SLT caseloads and time post-stroke was also diverse. These variables would be controllable in a larger study. Careful attention would be required to maintain and monitor consistency of approach across an increased number of assessors and intervention therapists.

The study informs on outcomes associated with a small number of SLT sessions targeting articulatory precision, supplemented by a home practice regime. The significant post-intervention gains in the effectiveness of communication during conversation, and in self-ratings of situational effectiveness, maintained 2 months after the conclusion of the programme, were demonstrated on a background of pre-intervention stability. The inclusion of NSOMExs, delivered in accordance with standard clinical practice, did not appear to influence outcomes. There is a need to incorporate additional steps to maximize practice compliance in order to facilitate completion of the recommended amount of between-session practise. For able and motivated participants future research might examine the acceptability and effects of higher intensity and prolonged practice and an increased number of sessions.

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Appendix: Example of participant individual therapy targets

Beginning at single-word level, and across all word positions, improve articulatory precision of approximants /l/, /ɹ/, /w/, /j/, /ʍ/.

Beginning at single-word level, improve clarity of distinctions between vowels, e.g. /e/ and /ɛ/ (Jane versus Jen); and /ʌ / and /ɪ/ (but versus bit).

Achieve syllable closure in functional disyllabic words (e.g. worry, living, housework, working).

Promote clarity of word boundaries in connected speech.

Promote optimum (reduced) phrase length for maximum intelligibility.

Appendix 2. Case-notes template

Date: ________________ **Session no:** _______________

Success level		**Comments** (specific to targets)
NSOMEx		
Single words	/10	
Sentences	/10	
Convers-ation	/10	
Specific targets for next week		
Other comments		

Appendix 3. Timelog – first page (NSOME group)

Practice Diary

Try to practice your speech activities most days of the week, twice, or 3 times if you can. To keep a record of the speech practice that you do, tick each box once you have done the practice. There is space for you to add in any comments you want to about the practice e.g "*speech is getting clearer*" or "*it's hard work*" or "*I'm enjoying the practice*"

Name: _______________
Week beginning: ____/_____/_____

Monday

Practice 1	Lip & tongue exercises ☐ How long? ____ mins	Words / sentences ☐ How long? _____ mins	Conversation practice ☐ How long? ____ mins
Practice 2	Lip & tongue exercises ☐ How long? ____ mins	Words / sentences ☐ How long? _____ mins	Conversation practice ☐ How long? ____ mins
Practice 3	Lip & tongue exercises ☐ How long? ____ mins	Words / sentences ☐ How long? _____ mins	Conversation practice ☐ How long? ____ mins

Comments:

Tuesday

Practice 1	Lip & tongue exercises ☐ How long? ____ mins	Words / sentences ☐ How long? _____ mins	Conversation practice ☐ How long? ____ mins
Practice 2	Lip & tongue exercises ☐ How long? ____ mins	Words / sentences ☐ How long? _____ mins	Conversation practice ☐ How long? ____ mins
Practice 3	Lip & tongue exercises ☐ How long? ____ mins	Words / sentences ☐ How long? _____ mins	Conversation practice ☐ How long? ____ mins

Comments:

Appendix 4. Timelog – first page (SPEECH group)

Practice Diary

Try to practice your speech activities most days of the week, twice, or 3 times if you can. To keep a record of the speech practice that you do, tick each box once you have done the practice. There is space for you to add in any comments you want to about the practice e.g "*speech is getting clearer*" or "*it's hard work*" or "*I'm enjoying the practice*"

Name: _______________
Week beginning: ____/_____/_____

Monday

Practice 1	Words and/or sentences ☐ How long? _____ mins	Conversation practice ☐ How long? _____ mins
Practice 2	Words and/or sentences ☐ How long? _____ mins	Conversation practice ☐ How long? _____ mins
Practice 3	Words and/or sentences ☐ How long? _____ mins	Conversation practice ☐ How long? _____ mins

Comments:

Tuesday

Practice 1	Words and/or sentences ☐ How long? _____ mins	Conversation practice ☐ How long? _____ mins
Practice 2	Words and/or sentences ☐ How long? _____ mins	Conversation practice ☐ How long? _____ mins
Practice 3	Words and/or sentences ☐ How long? _____ mins	Conversation practice ☐ How long? _____ mins

Comments:

Appendix 5. Communicative Effectiveness Survey

Communicative Effectiveness Survey

Name: ____________________ Date: ______________________

In this survey we ask you to rate how effective your speech is in different communication situations. Please read each statement. Then rate how effectively you communicate in that situation. If you feel your speech is very effective, mark the 4. If your speech does not allow you to communicate at all in a situation, mark the 1. Feel free to use any number on the scale.

1. Having a conversation with a family member or friends at home.

Not at all effective Very effective

1	2	3	4

2. Participating in conversation with strangers in a quiet place.

Not at all effective Very effective

1	2	3	4

3. Conversing with a familiar person over the telephone.

Not at all effective Very effective

1	2	3	4

4. Conversing with a stranger over the telephone.

Not at all effective Very effective

1	2	3	4

5. Being part of a conversation in a noisy environment (social gathering).

Not at all effective Very effective

1	2	3	4

6. Speaking to a friend when you are emotionally upset or you are angry.

Not at all effective Very effective

1	2	3	4

7. Having a conversation while traveling in a car.

Not at all effective Very effective

1	2	3	4

8. Having a conversation with someone at a distance (across a room).

Not at all effective Very effective

1	2	3	4

Donovan, N.J., Velozo, C.A., & Rosenbek, J.C. (2007). The communicative effectiveness survey: Investigating its item-level psychometric properties. *Journal of Medical Speech-Language Pathology,* 15, 447.

Appendix 6. Laura’s interview

Hello! Hopefully it works! So... yeah I feel personally that it's quite a lot, you know, that we ask of people. Its its, i know that we're providing therapy, but we're also expecting people to take quite a lot on board
Hmm
Eh, practice and then recording the practice, and the type of practice they have to do. So my thinking is that it would be interesting to find out what makes, what *enables* people to do the practice - what they don't like about it, what they do like about it, em and see if there's anything we can unpick that can help us in the future.
Yeah yep.
yeah to make it more accessible to people .
hmm hmm
and you know I've had .. and I say to be people, you know, when im interviewing them to be as honest as they can
yes
because the stuff that I do with people is all according to a very strict protocol, so its not even anything that I have much control over, you know?
No
So in other words it's not something that I can get offended about!
(Laughs)
So if somebody says they don't like it, I go: "well, that's fine! I'll abdicate that responsibility over to...
Somebody else
...my boss!" Exactly!
Thats right
So that's why im really trying to impress upon people that they can be as honest as they want. You know.
Yes yes.
So ....that's great. Thank you very much.
You asked for it (laughs)
"You asked for it you're going to get it!" Oh but first of all, cause I always forget this bit. I need your consent again.. is that ok? and it's - well you can read it yourself. I won't bother reading it to you!

OK (Pause while she reads) **Good.**
Is that alright with you?
Yes that's fine
Do you want..? A pen. And you don't need to make it nice and neat a scribble is fine!
Thanks
How's your writing coming on?
It s not too bad I don't get time to practice it was getting good at Christmas cause eh I did most of my cards.
Did you? That's great. Practice helps doesn't it?
And quite a few folk actually phoned and said "Did you do my card?" (Laughs)
Oh..
So they appreciated it ...
Yeah. Course they did. So did you actually write messages in the cards as well as just your name?
Short messages! (Laughs)
That's great.

My... I've got sort of three old aunts and an uncle and I always write a letter so I just typed it
Uh huh
And wrote why I wasn't writing
They'd understand wouldn't they?
Oh! ha ha! I've done that the wrong way round!
Oh don't worry that's fine it doesn't matter. You don't need to do it again. It's OK I'll just change the headings
Oh good!
Don't worry about it, I'll just forge your signature! (Laughs) Only joking.
(Laughs). That's what I get for talking and not reading the question!
That's my fault I interrupted you
(Laughs)
Thank you. So what I've done is I've brought along the stuff that we did together, cause it was ages ago! Wasn't it?
Yes. I've got it there
Oh you've got it there as well. I'm sure you have it by your side *all* the time!
Well it slips in there quite neatly!
(both laugh)
As long as it doesn't slip in the bin! haha!

2.4.a Did follow recommendations

Actually I must admit I do take it out sometimes that I feel it's you know - I'm not doing as well as I should. But I've discovered it's really when I'm tired

1.1 Physical Factors

Yeah
You know? And its not em... its not the actual eh... *making* the sounds, its the - still this lip is you know, (gestures to mouth) sometimes it's pulled. So that you know this lip is not letting me make the sounds properly
Uh huh. It doesn't have the manoeuvrability?
That's the word.
Uh huh
I can't say that! (Laughs)
Does stress as well - does stress impact on it? When you're stressed? (Briefly checks sound monitor on recorder) Just checking that's recording...
Sorry
No it's OK, I'm just looking at it.
Yes, when I go to the (names charity she's involved with) I have to get myself from the car and into the restaurant, and then we have a meal and then into the meeting room and there's lots of people milling about chatting. So the first time was (mimes exhausted) oh! (Laughs) I was kind of... ah. Fortunately they all came up and spoke to me, you know I said – "sit down, sit down" They all came up one at a time more or less and gave me a hug and all that. So really nice and now they just treat me as if ...
Yeah
...there's nothing wrong
That's good
It's quite nice
So you got a bit of attention at the beginning and then they just left you to it
Yes, yes
That's lovely. So, Stress, yeah I can understand how that would be difficult. Well, this is what we did (referring to treatment manual)
Yes right
Here you can have a look at it though you've obviously seen it again since then but
Yes
We started off kind of talking about what we would be doing. That's the notes that I took - not much – about what you told me about things that you thought you were having trouble with.
Yes. Xxx
You said that to make your speech clearer you slowed down.
Yes
And I've written – don't know what that means – can speed up a bit but I think that meant...
yeah
...you were able, you said you were able to
yes I *can* speak quicker. But... I find that if it's people that don't know me I really

have to slow down

Do you?

And em raise you know speak a bit more

Raise your game

Yes. Speak a bit more loudly. But with my friends and everything I don't… I .. when I've got two or three friends in I don't feel as if I'm making any effort

That's great

They're understanding me

Uh huh

You know it's quite good

That's fantastic

2.6.b How did people measure outcomes and benefits of therapy?

Cos I said to them, you know, if you're not understanding what I say, tell me (mimics her friends, raises hands) "No no!" And they're good at saying "What was that?" You know, they don't mind now that I've said.

That's great. Good for you. Well done. Em. And ok you can just have a look just to remind yourself if you want.

Right yeah

If you feel you need to

Yes

We identified em some sounds.

Yes

Both together. I think you know you told me some of the ones you had difficulty with.

Yes

And then also from watching the video that Margaret did of you Margaret em I don't know if I was I can't remember if it was me there, but there's always two or three people we sit down and work out what oh shes having a bit of trouble getting that "s" sound…

Yes

…or "t"or something like that.

It's "l" s!

I remember

It's still – sometimes I say s-p-l-int and sometimes (laughs), I don't know what comes out!

(Both laugh)

I think your speech is sounding better, I have to say

There was something the other day, t was eh it was somebody's name I think it was Philip something and there was an "l" – was it Philip Larkin that's right. And I've got it now…

Yes

…but I went oh! I cant say that! (laughs)

Oh no! We didn't cover that one did we? Philip Larkin!

And again that'll be at night you known when Im tired. It was on television last night and "oh theres that phfflu..!! ha ha ha!

Phuhluhluhluh!

(Both laugh)

Oh! Yes so that just shows you it's the tiredness.

Fortunately I just laugh. Because I used to get "oh! can't say that bit" you know?

Yeah

Now I think that just makes it worse you know?

Yes

It's the same with this hand (coughs) its coming on but its eh somedays it''s very stiff and the day after I've been exercising my legs

Mmhmm

The arm seems to stiffen up so I just wait til it goes! (laughs)

Do you? And that usually helps does it?
Uhuh yes...stretch it
That's great
So, OK dokey.
So what we did with those kind of targets that we identified together all of us, we made up some – I thought about or *compiled* some lists of words to learn and sentences usually.
We also… this is just me recapping
Its alright, yes!
We also had, you know conversations, often about set topics or which hopefully would kind of target the sounds that we were aiming for
Yes
And we kind of tried to take a continuum from the easiest words or the easiest thing to say which is usually single words which are one syllable or so, all the way up, we tried more difficult challenging…
Absolutely!
…multi-syllabic words, yes! And then sentences
mmm
and then talking around a particular topic I think we might have done as well.
Yes
Didn't we maybe where I would maybe say talk for a minute
That's right yes
And then a more conversation-ey thing
Yes
And then there was one time I got you to stand up do you remember?
Yes! [laughs]
And yes be the guide!
Be the guide in the house!
Uh uh. Have you got back to doing that at all? (Referring to voluntary work as tour guide of stately home)
No I haven't because the house is shut from October to April
That's right
So em I don't know. Maybe.
Just see. See how you feel. See how you feel. Oh well that's good
So!
So that what we did.
Right
The rest is all there but you've obviously looked at again since.
Yes. Uh huh
Em. There that reminds you doesn't it of all the things we did? There was p and b, sh and ch
Uh huh
And because you were a teacher, the level – I tried to make the levels kind of hopefully appropriate to you, but that's the kind of thing I want to find out – if you thought it was or not.
That's right
You know?
That's right.
Let me just get some notes out then I'll be able to ask you some questions. So. There's about five kind of areas that I'm going to ask about. I won't spend too long I promise! I won't take up too much time.
No! It's all right, it's all right. Uhuh.
Thank you. Em I'll ask about
Heh! Quite glad of the seat!
(both laugh)
Are you?! After your
Oh! The gym! (Laughs)
I think that's great! I'd be asleep if I were you!
That's right

Em its just asking about the therapy tasks and your maybe your involvement in therapy, how involved you felt in it

Mmm

Em goals, Ive got here – these are just the headings – materials – the kind of relationship between the therapist and the person, or patient or whatever you want to call … you! Heh!

Uhuh

Em and again im going to keep checking (the digital recorder). Im so scared it's going to run out of batteries oh it happened to a friend of mine

Oh itd be awful if you had to re-do it all

I know. So em what's – first of all whats your experience of the therapy how did you find it?

Well I found it very helpful because it made me think about how, you know, you produce speech

2.2.b Therapy raised awareness of speech

Mmhm

And eh I began to get very aware of my saliva problem and eh as I say this neuralgia sort of feeling in my face and some days if my speech was bad I could link it to either the saliva problem or if it was a day when my face felt bad then my speech was bad as well.i don't mean "bad" but, you know, it was an effort. But em now that, you know, I thnk im coping alright em I'm aware of this and at night time like later on, like when the news comes on or something, and I turn to [husband's name] and say "Can I have a cup of coffee please?" but I just sort of go "gubbuh gubbuh guh" you know?!

1.1 Physical Factors

Oh right. uhuh.

Im so tired that I waken up the next morning and I'm you know fine

It's better again?

Uh uh. So it was interesting to know that I could form the words all properly and it was just a mechanical thing

2.2.b Therapy raised awareness of speech

Mhmm

With, you know, my face and my tongue and things, so

OK

I think! [laughs]

Yeah! Xx make you more aware of your saliva particularly?

Well, when you're… when you're talking you would end up with this mouth full.

Yeah

In fact I went to the dentist yesterday… the other day…sometime this week, and lying back and, you know, saliva trickling down my throat, I had to stop a couple of times – cos it felt really bad so I told her and she said "oh you should have said earlier, that's fine"

Hmm

She's got a …. [gestures with hand]

Suction

Ah a suction thing. She got the girl in and says: "Go and get the big suction" (laughs) she says: "Now, if you r tongue disappears down xxxx!" (laughs)

Ooh! Oh goodness!

I said "aye right!" you know?! But em I hadn't been bothered with it particularly just whatever xx was going on in my mouth

Hm

But eh she's very good. She said I can come every three months

Uhuh

And just get a polish. I don't have to see the dentist

Good

Um and she said to me: "If its too much for you to pay" - em its about a tenner I think – em you know, you can get a grant and all this sort of thing. So,

Yeah

I said: "Oh, right!"

That's good.

I'll just do it. I just feel as if I'm you know, cleaning with my left hand, and I'm maybe not getting this [gestures brushing teeth], you know, getting round it as I should.

Yeah I know what you mean

So there we are.

So you made

Xx there was, like, two months where I hardly cleaned my teeth at all because you know, it was just so…!

You had a lot of other stuff on your plate

Xxx concentrate xx yes

Yeah exactly

So

So it, so the therapy itself then, raised your awareness of

Yeah

Of your … of your movement of your mouth, is that what you mean?

I would say that, yes

And did it raise your awareness of the movement of your mouth during *speech* as well?

Yes

And

Yes, that's what I mean

Yeah

I sort of it's as if I em I realise that your mouth actually is *part* of the speech, do you know what I mean? You sort of, you realise when you're speaking its coming from your larynx and things and your teeth and your tongue but actually having an overhanging lip [referring to decreased mobility in lip] does restrict you somewhat! [laughs]

2.2.b Therapy raised awareness of speech

Yes

You know, and eh I just I thought it was just part of everything but em but that's sort of comforting in a way because you know there's a reason for it you know? Um if somedays I couldn't speak too well [husband's name] says: "Ah well you've been down at the gym and you're tired and that, so"

Mhmm

But as I say it's got better, it's got better. I feel it's not quite as good as it can be just now because I've been to the gym for an hour, you know?

That makes sense.

But em. Mhmm.

Mhmm

Eh as I say mornings, you know up til about oh well say about four o'clock are my best times and then as it gets towards the evening I feel more tired but then the nights I go out to the [charity organisation] it's only once a month right enough, but I pace myself and have a sort of relaxing afternoon and then I can keep going, you know, well enough to be understood.

1.1 Physical Factors

Uhuh

Em so that's

That's good that's really good

Just dealing with it as it comes you know

Uhuh. And em in terms of the actual tasks that we did, the kind of activities, remember I mentioned – saying words

Yes

Repeating them until you've got it right and so on

Hmhmm

How did that – how did you feel about that?

Well I got my speech therapy lists out from [names hospital] and I thought how much better your approach was because that was saying "bah pah kah dah" you know, it was – which in you know in its way at that time when my speech was really bad it (the tasks) was good but then that to me is a progression that you don't have making sense you don't really mean anything, to actually practice, you know, speaking. You know it's much more useful to see where you're having problems you know? Because I could say "I - I - I" you know til im blue in the face but I still couldn't say "Philip", you know?

Vermillion!

Yes! (laughs)

2.2.e Tailoring (individualised tasks/ strategies/advice)

That's good, so the stuff then, cos I always make a conscious effort to try and at least make it as relevant as I can for people

Yes. That's that's good

Do you agree that it's, I mean

Absolutely because when you're like this every day is a struggle and you don't want to waste a lot of time on things that you feel are not, you know, everything I do has got to be related, to, to help me do something else if you know what I mean.

Yes I do

Em. So sitting saying "kah lah mah dah" you know I mean to me that was – not a waste of time – it probably was helpful, but I didn't you know I couldn't connect it with anything, you know, *relative* to what I was doing.

Yes. Whereas trying to say the word Lilian that you were having trouble with or

Trying to say… which, cos I've got a friend called Lilias, and I

Lilias that's right

You know I was telling her about the thing and she says "Oh! I'll have to come up and see that! She says: "I'm famous!" you know! But it does help cos then you're aware of the sounds that are going to cause problems, you see them coming and you can maybe adjust or

2.2.e Tailoring (individualised tasks/ strategies/advice)

So it help you to anticipate difficulties

Yeah.Yeah

As well as deal with them.

Absolutely.

That's good to know that's great. Em and em you know when you were doing your practice.

Hmmhm

I don't know if you ever did it on your own, if you tended to, or with a partner or

Well I did it with a partner and my children suffered! (laughs)

Did they! And what was that like?

1.4 Support and Opportunities for Practice.

Well, they were wanting to hear me, you know, to hear the improvement and eh my son said: "you know mum that's great when you were in the hospital it felt as if you were talking with your teeth clenched or something". And he said you know we could hardly make you out. He said now you know it's a lot better. So.

That's great.

It's good. And he's, I'm seeing him, I mean he was in hospital every day. And since I've come home he's here twice a week and he said "because I see you regularly I don't particularly notice"

Hmm

But eh he said: "when I think back to you know the way you were" em he says its great. Its super. So.

And did it feel em when you did it front of your family, how did that actually feel? You know some people have said that they feel a bit silly… other people don't mind…

I don't mind. No I don't mind.

Uhuh and were they, was it useful to have family around?

Yes they were I mean they want to be involved and help you know, it's the same, eh my daughter takes me out some days you know and takes the disabled badge and off we go up to Braehead for a run round the shops, you know

Yeah

And that sort of thing's great. And at first she wasn't keen on doing it "Oh what if you fall…" and eh but eh we used to go "Oh put the wheelchair in the back just as, you know, standby"

Yeah

And touch wood I've never had to use it, yet, but it's a back up you know

Uhuh

So.

So she likes being a kind of helper in some ways

Uhuh shes not a youngster she's thirty odd

Yes I know. Yeah

But she was afraid at the beginning so speech therapy was good because she says: "Oh this is something I can do" you know she says: "Oh let me hear that bit"

And she'd feedback to you, would she?

Yes. So it was good

1.4 Support and Opportunities for Practice.

That's great that you've got a very supportive family

Oh yes!

Em OK so that was a bit about the tasks, em and you talked about how the words were quite relevant to you and that's

Yes.

And that's quite interesting to know because that's definitely, that was part of the protocol of the study, that they had to be - as far as you can – have them relevant to someone's interests and

2.2.e Tailoring (individualised tasks/ strategies/advice)

Well that's right and there were interesting bits to read you know it wasn't just a,

you know, a series of words, well, I know the practice was but it came to a nice wee story … I mean when I read the bit about em (Charles Rennie) Macintosh to eh …was it that, or? Oh, some bit I read and I realised [son's name] was listening to what I was saying you know. It wasn't… you know -

He was listening to the content

- cos I said you know listen tell me if you can make out every word or if I'm, you know, and he said "I was that busy listening to what you were saying that I *think* I understood every word" (laughs)

Think it was OK, uh uh! That's good

That was good, so there you are.

2.2.e Tailoring (individualised tasks/ strategies/advice)

Glad to hear that. OK. Thanks. So in terms of the therapy that we did then, did you feel em what kind of influence do you think you had over what we did together, if any?

Well I think, because you asked me questions about what I did and I told you then you made up things to suit me, which I thought was great, you know because it was all interesting and what I liked and so it wasn't like a chore to do you know and em

You don't have to be polite you know, don't worry!

No!

OK good that's nice to know that it was positive

Yes uh uh!

That's great. Em so would you have felt if there was anything that you had – or *was* there anything that you'd have liked to have done and didn't get a chance to cover?

Don't think so…no. Don't think so.

If there had been would you have felt comfortable asking me to change tack or add something in.

1.2.c Internal locus of control

Yes, uh uh.

That's good to know

I would tell you.

Em well that's great that kind of covers some of those, about how involved you felt.

Yes

So Im glad to see that you did, that's good news. Em and then about *goals* that's what I mean by that is the kind of the *aims* of therapy [checks digital recorder] so that's yeah what you were working toward

Yes

2.5.a Wanted to return to being able to do something specific again

And I think I always want to know if somebody felt that whether or not they did feel that they had a goal that they were working towards.

Well I just had a general goal of, you know, I think at the beginning to, I was still at the: "Oh that's a phonecall I'll just let [husband] pick it up" you know whereas now I don't think about it I just go to the phone. And em I was at that stage avoiding instances where I was going to have to speak and you know just going maybe wth friends and letting [husband] do all the talking, you know?

Yeah

So I think now I feel much more comfortable and quite often [husband] comes in to the gym with me to help me on and off the machines but eh I go on a Friday and it's a what do you call it a… supervised gym

Hmm hmm

And so the helpers are there to help you on and off and you know I chat away with them and you know I don't feel – in fact sometimes I forget, Im so busy trying to make this bike go a bit faster [laughs]

That you actually forget about your speech

I forget about my speech. And then I see somebody kind of looking you know and I say "oh sorry!"… so that's great. That's great.

Yeah it is good

Mm hmm

2.5.a Wanted to return to being able to do something specific again

It is. So is that the kind of general goal that was not really formed in your head would you say?

Yes I think so I think it really was: get to a stage where I don't have to concentrate on every single word that I'm saying cos it was tiring as well

Yeah, sure.

Em but as I say its nice when you can concentrate on your legs and your arm and it just comes out your mouth naturally.

Uh uh. That's good. Yeah because sometimes well I try to talk about goals with people usually at the beginning

Yes
and say is there anything in particular that you want to do. I don't know if we had that discussion, do you remember back?
I remember but I don't think I could cite specific goals at that time because you don't know how much you can you can do.
Uh uh

2.5.a Wanted to return to being able to do something specific again

But as I say I think that's it. I mean this morning at the gym we were in a dance studio actually and there's about five of us and the chap who takes it he's really nice, but anyway, he talks well it's across a gym which is quite... so the first two or three times I was just sort of nodding
Hmm
But em this morning there were only three or four of us and he was chatting away so he talked really fast and I was beginning to chat back, you know
Uh uh
He says anybody seen War Horse [a film] I said: "Oh yes, I've seen it it's good"
Oh yeah
"Don't tell me if the horse dies or not". No, No he said: "don't tell me about it, but does the horse die?" I said: "no", he said: "Right I'll go and see it!" (Both laugh)
Well now you've told me I won't go and see the film!
You think it's going to die! But anyway!
Ah! Right just spoil it for me!
It's a marvellous picture
Everybody says that, yeah
So I, we're having this conversation you know over the gym noise and em the gym next door there's all sorts of bangs and crashes going so I thought...
Uh huh. That's really good
MMhm
You're really improving your
And I think I thought about it this morning cause I knew you were coming you know, I though Oh I better think about my speech!
It made you increase your awareness, uh huh.
So there you are.
If you can speak without worrying about it that's fantastic!
Yes. Yes.
What more could you want you know!
Ive enough to worry about! [laughs]
Yeah exactly
Xx anyway

2.5.a Wanted to return to being able to do something specific again

Em... so that kind of addresses the next question which was actually, you know was there anything you wanted to be able to do by the end of therapy?
Well that was it more natural speaking, just speaking more naturally to people and not being afraid to have a go you know?
Yeah And we kind of did talk about potentially you going back to that – not work, but the voluntary work that you did and we kind of addressed - well we didn't address it *ful* extent that you were 100% ready
No no
But we tried to kind of talk about (special interest) didn't we? [referring to a role-play
Yes
Uh huh. I don't know, did you find that exercise, how did you find that standing up and doing the – pretending to be a (special interest activity)
Yes it was sort of: "Oh I used to do this!" you know? From another ....another era.
Uh huh
But it was fun. I think I'll be alright (referring to returning to voluntary work). I think the main problem is standing for two hours but if I can start with an hour and just be a room, a room guide then you stay in the one room and if anyone asks you questions you answer them.
Mhmm
So I could manage that. I'm quite sure
Mhmm. So would you recommend that if somebody has a particular goal that they want to work towards, say going back to a particular job like... Oh gosh, I can't think of anything now! Being a telephone answer eh operator
Yes I know what you mean

2.2.e Tailoring (individualised tasks/ strategies

2.4.a Did follow recommendations

Would you recommend that that is something that a speech therapist does with a patient actually *practice* doing something like that?

Well I think that's em … hmm. I don't know if my actual speech was that bad as I say I think it was the mechanics of you know my teeth and my gum and everything and all this that was preventing me from speaking properly. Em and with as you say thinking about Macintosh and thinking about going back into that situation I think it's good because you know you can work toward it and yeah I don't know what im trying to say... em.

Do you think it would be a useful thing, so say this telephone operator

Yes

Is there such a job anymore, I don't know!

Tele sales!

2.2.e Tailoring (individualised tasks/ strategies/advice)

Tele sales right. Would it be something that you think would be useful for somebody to do using the kind of words that they would - going over the words that they would use? Actually sitting on a phone?

Yes that's what I mean yeah. Yeah I think that's good. Far better than, I mean the exercises I used to do were excellent because they were stretching my mouth and

Is that at [hospital]?

Yes. And it was eh Ive got my wee book here [containing NSOMEs from hospital]

That's OK I know the ones you mean yeah.

You know sort of ah ooh eeh you know that sort of thing

To try and increase the muscle strength

So at that time that was just sort of five six weeks into my stroke that was helpful because that was the problem, you know, I just... as if my mouth had closed. So em that was good getting everything working

Yeah

So.

So there's a time and a place for different types of tasks and activities

Yeah so I think earlier in your stroke the actual mechanics of speaking is different you know so exercising we had you know tongue exercises and lips and cheek and all that sort of thing I think that was great because em I felt that's what was needed to be done at that time.

Uh huh

2.1.a The tasks (NSOMEs/DVD /speech practice)

Whereas if you'd come along, like, nearly a year later and said I want you to do these (NSOMEs) I think I would have given up a bit earlier.

Would you?

Yes.

That's quite interesting cause that's actually what we're doing with the other group of patients, so

Right

We're doing, some people are in the group that just gets the speech – like we did – and then other people are in the group that gets the speech practice plus these exact exercises.

Oh right

So tell me – you think that you, how do you think you would feel, cause you said that you would not fancy that..?

Well, I what I do I used to do the speech exercises and at night if I was tired I would maybe do a few of those you know. Just to you know when I felt as if I was all tightened up, I would do that sort of thing (demonstrates).

Right

SO I had those behind me if I needed them

But you don't feel that that would be something that you'd like to do

No I don't feel no I think its em… I suppose its just repetitive and boring whereas reading out things is…

When it's doing movements like that?

2.1.a The tasks (NSOMEs/DVD /speech practice)

And I think em yes, I think em when you're reading a passage then you try to put some inflections into it as if you were speaking so its what you're doing naturally in speech. Reading, you know - bits.

OK

I think

That's interesting. These kind of oral or… oral exercises are repetitive and boring

Yes
Is that what you're saying
Yes
And you don't think that if you were given them at the moment now
Now?
You wouldn't
They were fine at the beginning of the stroke but em I think as you go on, well its like everything, you want to progress you don't want to be sitting an hour after eh a year after your stroke sort of going "ah ooh eeh" (demonstrates, laughs).

2.2.e Tailoring (individualised tasks/ strategies/advice)

Oh no no that's right
I think that'd be soul destroying (laughs)

2.1.a The tasks (NSOMEs/DVD /speech practice)

Do you? Right. That's interesting
But em. Some of the stretching exercises and that I still do even like in the morning when I'm going to brush my teeth then I just do (demonstrates)
Do you?
Yeah
Well. It's certainly not done you any *harm* has it? So that's a good thing
(laughs) (checks digital recorder)
Still going – good!
Em. OK well, that's really interesting. Em so the next thing that we'll move onto is the materials so that's the em kind of worksheets, the – well there was a DVD included as well,
Yes got that. Do you want that back?
No you can keep it if you want, whatever
Right
Put it on your wall!
(Both laugh)
Em and anything written or printed out really and the instructions as well I think, id quite like to ask about?
Yes

2.2.e Tailoring (individualised tasks/ strategies/advice)

OK so. Bit of a general question really, but how did you find them? What did you think about all that stuff?
I thought it was excellent. I thought it really was and I mean I don't know how much em, well obviously you had a big input but the fact that you chose things that I was interested in has x made it all the more enjoyable, really.
OK
And as I say, I mean as you know we got involved in one of the stories and [husband] found out xx (laughs)

1.2.b Attitude to therapy

That's good
So it was quite you know it was interesting.
That's really good. And what about things like the - did you feel that you were properly prepared for what you would, by the instructions that I gave you ether verbally or written about what you had to do on your own?
Yes, uh huh. I think so
Right
I followed it anyway, no problem uh huh yeah
I know yeah you did. So that's an outcome in itself isn't it? Heh. And em what about the DVD did you watch that much?
I watched it yeah
Did you?
But I watched it a few times at the beginning and then a few times was enough really
Yes cause it was really just some
Just the "eeh mm" that sort of thing
That's right, it was examples of clear speech really wasn't it? Uh huh and it maybe only has a certain limited usefulness
That's right yes. Well as I got on through the programme xx the passages were getting longer and longer so I was taking time to read the xx so I didn't bother putting that on.
That's good that's kind of the way we were hoping it would go.
Good

1.3.b Good relationship can be a motivating factor

OK. That's great that's brilliant. Em and then the last kind of area that I want to really explore relates to the therapeutic relationship xx its called xx cause I think its interesting to find out how people get on you know?
Yes
people that say, cause there are some that say it doesn't really matter if a patient, for want of a better word, gets on with their therapist. Or has any kind of, a relationship with the

therapist.

I would say I wouldn't work as hard for someone I didn't like.

Really?

Yeah. I think em I think I would do it but I think I would you know if it was somebody you really didn't like theres that "I" again - *didn't like* em I think you would think Oh God here she comes again, you know? And eh so I think it was good that you know we got on quite well.

1.3.b Good relationship can be a motivating factor

Uh huh right

And eh you want to do it for yourself and for *you* as well

OK

You didn't em I didn't want you coming in and thinking "Oh she's done nothing all week! You know? (laughs)

Oh really? In case I would tell you off!

1.2.b Attitude to therapy

That's the teacher in me! I know what its like

Yeah well its obviously stood you in good stead! So you think that that's actually a *motivating* factor?

Oh yes

Having a good relationship

1.3.b Good relationship can be a motivating factor

Uh huh yes. Its the same in the hospital you know there were some nurses and you

whatever and eh and other ones they always you know brought a smile to your face you know so obviously you would react better with them you know.

So you had another speech therapist and I think you

She was great too yes.

So you had a good...

Yeah

...rapport, if you like?

Yeah and (name of SLT) at the (hospital) she came in the first or was it the second day I was at the (hospital) and eh she sat and just chatted to me for a wee while and she said I don't think I can eally ehlp you! laughs

Did she?

I said oh right ok so em but eh you know I m free any time just to phone her if ive got a problem

1.3.b Good relationship can be a motivating factor

Great

She was lovely

Uh huh that's good so having that kind of good rapport or relationship can kind of help you to actually buck up and do stuff?

That's right that's right

Cause you know the persons coming along xxx

Xx

OK that's interesting. Em and let me see. Em what about things like feedback then. What I mean by feedback is cause I don't know if you agree but maybe I had to tell you what wasn't working what was working. How did you feel about that? Me coming in and

That's fine! That's fine! I mean theres no point you coming just giving me stuff and letting me get on with it and not having any input you know you have to say. That was fine. It was obviously done in such a way that I didn't get upset or anything xx told

You didn't

2.3.b Feedback from SLT

No no

Not offended or

No

(Both laugh)

Because I think that its quite a specific job isn't it

Yes

Sitting and telling somebody that

That's right

And I just wonder how people actually just feel about that

Uh huh well I'm a tough old bird!

(both laugh)

good! And of course you know theres no offence ever meant

no no not at all

you knew there was a reason for it. Did it ever get to the stage where you were just you know “stop telling me I'm doing it wrong!”

no no! no no.

[laughs]

in fact quite often after you'd gone I'd say to (husband) come and hear this! You know?

Uh huh

2.4.a Did follow recommendations

We'd go over it again. and he said on no she said not to do them xxx Oh yeah!

Right

Xx while it was fresh

Fresh in your mind

1.4 Support and Opportunities for Practice.

And then the next day I could do it again and(husband) said now remember Amy said xx (laughs)

Oh gosh! “Amy said!” “I'll phone her and tell her!”

Xx OK!

And you had to listen to yourself on tape quite a bit what was that like

It was strange (laughs) but it was alright

Uh huh How... Did you think it was useful or not?

Yes it was because I sounded better on the tape than I thought I did. You know than... gets into my ear! (laughs)

Uh huh

2.2.c Using a tape recorder

You know it sounded not bad at all

Mhmm. Did it help you to identify sounds that were troublesome?

Uh huh, the l and the m and s

Ok right so that helped you

Mh mm

...to increase you awareness did it?

Xx Uh huh the s-h as well “sh”

xxUh huh

xx xxxx

certainly has. It has.

Mmm

Well that's great! Thank you very much

Is that you?

That's me that was all I was going to ask.

[following a brief discussion off-record, the tape is switched on again] I've had some patients I'm talking about speech now

Yes

But I have other patients who might have more severe difficulties but they don't do any practice really. Do you have any insights into that? Have you met anybody that...?

Every child I've ever taught! [laughs]

Right, OK

Och theres always, you know...

No accounting is there?

There's usually about – with any class there's 10% who xxxll do everything you say perfectly, behave well and everything and tehre's a big bulk of say 60 % that do eh the minimum and sometimes xx the homework and sometimes xx do it and xx sometimes don't and then you have the bottom you know the small percentage although getting bigger percent I believe em who just never do anything. Em and I think that goes right through life.

Yeah OK

There's I mean there's folk at the gym where I go and xxx theres another chap he's lost the lower half of his leg em and he's there with me, you know walking and so on so we've said we'll go for the comic relief xx mile

Really?

Yes!

Good for you!

We're going to do it on the treadmill.

Uh huh

And that'll its 1.6 Km

Gosh that's great

So ive done, ive done up to 1.2

That's brilliant! Oh you should be so proud of yourself. And I've got rid of my big splint

Oh good! Oh you hated that splint, didn't you you hated it!
So im down to just my ankle splint
Uh huh
And ive got xx splint as well
So you're very motivated xx with your physical activity and the same exactly as you were with your speech
Xx speech you have to take it in small bits you know em there's no point in saying I'll do the marathon in a year and a half you know you've just got to take it small bits at a time
Uh uh do you mean have short goals to work towards?
Yes
Is that what you mean?
Yes
Yeah
Achievable goals to work for xx

2.5.a Wanted to return to being able to do something specific again

Uh huh
I mean because I em walked, nearly waked a kilometre now that's sort of half as much again to get to a mile but I know I can do it because im increasing xx goingt othe gym im increasing by maybe .2 of a kilometre
That's great
You know, so
So measurable
Xxx
Yeah
Yesterday I did a Km on the bike
M hm?
In I think it was a minute – oh [husband] 'll tell you a xxx minute quicker than I did the week before!
God! A whole minute that's great.
Xxx as well!
Oh good for you
So you know I mean that boosts you
Yeah
So you keep going lke that
That's great you're obviously very motivated…
(new recording after short break)
well you mentioned just there after I turned off the, the recorder that you feel more confident and what do you think it was that's made…how do you improve confidence that's such an elusive factor.

2.5.a Wanted to return to being able to do something

Just by achieving small goals small steps however small they are I mean sometimes in the speech (therapy) I would maybe one day just suddently say something like Lilias just – right out! [laughs]
Uh huh
And that boosts you to try you know other things and the same with eh my leg I'll maybe only going .1 of a Km faster than the day before but that's .1 and it ll be .2 next week – you've got take it slowly I think if you set unachievable goals you know just ridiculous things
Uh huh
You don't achieve them therefore you get depressed xxx
Yeah.
So…
Do you think that em doing things like your speaking in public and – I don't mean public speaking
Yes
but speaking in front of a group
Yes
Like you do, does that help?
Well they've asked me at the (charity organisation) if next year probably if I felt like talking abut the stroke to other folk
Oh that'd be great
And I thought, well, now I probably will whereas 3 or 4 months ago I might not have

been so sure!

No

You know? But em och I think… I don't know

Mmm

I think eh

Because you've put yourself out if you like, if you know what I mean.

Yes

You know put yourself out there

Yes

Havent you? And that's obviously worked its obviously helped,

Yes yes

Rather than sitting at home

Absolutely

Like you said and sitting really quietly xxx

I mean this morning I woke up and I saw the weather and it was so dull and I thought och Ive to go to this class you know anxxxx I thought come on get out of bed and do it

Do it. And you feel better don't you?

Yeah I do!

Appendix 7. Interview guide

Interview guide

The themes listed below are to be used within a semi-structured interview session. They will be used as a guide for the interview to facilitate the topics covered within the session in a flexible way, through as natural a conversation with the carer as possible.

Introduction:

“Thanks very much for agreeing to take part in this interview today. I’d like to talk to you about the therapy programme you participated in recently- I’m interested in discussing your personal experience of the therapy. The five aspects of the therapy programme we’ll discuss will be: the activities you carried out- like any “homework” or exercises, for example; your involvement in therapy- such as how much of a say you had in what you did in therapy; whether or not you felt you were aiming toward any clear goals; the materials used in therapy, like the DVD and the handouts and so on; and finally, what it was like doing all this with a therapist- in other words, your view of the support you received”

Themes:

1. **Therapy tasks**
   Eg: experience of therapy, opinions of tasks etc

2. **Involvement/engagement in therapy**
   Eg: relevance of therapy, ownership etc

3. **Goals**
   Eg: aims of therapy, personal relevance of goals etc

4. **Materials**
   Eg: accessibility of DVD, written worksheets etc

5. **Therapeutic relationship**
   Eg: motivation, feedback, support

6. **Any additional issues raised by participant**

Appendix 8. Preliminary data analysis: Coded data from case-notes

Case notes data, coded as appropriate

These are data taken from the comments section of the case notes systematically. Included are any references to adherence and practice. All that are relevant have been coded (in capitals, with their reference number), and those that did not fit into a code have been left uncoded.

Adrian

Session 2:

- “obvious fatigue toward end of session” - 1.1 PHYSICAL FACTORS

Andy

Session 1:

- “DVD – missing a lead” – TECH BARRIER
- “Pt became fatigued” - 1.1 PHYSICAL FACTORS

Session 2:

- “Needs plug adaptor to enable DVD watching” - NO CODE
- Ask sister to prompt pt to practice and help with DVD set up” –1.4 SUPPORT

Session 3:

- Had done no practice. Do not foresee him doing a great deal of individual work [missing some text here]” – 2.4b DIDN’T FOLLOW RECS

Session 4

- “Had to stop due to pt fatigue” – 1.1 PHYSICAL FACTORS
- No practice carried out” - 2.4b DIDN’T FOLLOW RECS
- “Pt has very negative self image and avoiding going out. Also sees no hope of any change physically” - 1.2a ATTITUDE / 1.5 AVOIDING ACTIVITIES

Session 5:

- “pt was very low mood on my arrival. Said did not feel like talking to anyone” 1.2a ATTITUDE / 1.5 AVOIDING ACTIVITIES
- He said he sees no future for himself, watches people from his window and feels he will never be ‘normal’ like them again. Also said he wanted to ask how long he’d ‘been like this’ ie since stroke. Needs info, as [he] has memory difficulties and this appeared to upset him (that he didn’t know what had happened to him/when) - 1.2a ATTITUDE / 1.1 PHYSICAL FACTORS

Session 6:

- “Has not been practicing” 2.4b DIDN’T FOLLOW RECS
- “Does not carry out independent work” 2.4b DIDN’T FOLLOW RECS

Session 7:

- “Pt refused [to do NSOMEs] – said was too much work.” 2.4b DIDN’T FOLLOW RECS / 1.2a ATTITUDE
- “Has not been practicing” 2.4b DIDN’T FOLLOW RECS

Anna

Session 1:

- “DVD player not available” - TECH BARRIER
- “unable to identify any strategies she uses for clearer speech, although was breaking longer words down into syllables/shorter words when reading at SWL” - 2.2b WHAT PTS LIKED RE TX – RAISED AWARENESS OF SPEECH

Session 2:

- “Had not carried out practice of words and phrases – gave more instructions” - 2.4b DIDN’T FOLLOW RECS

Session 3:

- “Had not used DVD since last session – said she did not realise this was homework, despite having this explained to her last week, in detail” - 2.4b DIDN’T FOLLOW RECS

Session 5:

- “Not done [lip and tongue] practice through holiday period and 1 x episode of words and phrases practice only. Discussed reasons for this: unable to give reason – sometimes too busy. Discussed need to practice as SLT alone cannot effect change; needs hard graft” - 2.4b DIDN’T FOLLOW RECS

Session 7:

- “Not keen to listen to recording” - 2.1b USING A TAPE RECORDER
- “Little practice carried out (max 20 mins)” - 2.4b DIDN’T FOLLOW RECS

Anthony

Session 1:

- “DVD poor quality - kept sticking” - TECH BARRIER
- ”New DVD needed!!” - NO CODE

Session 4:

- “The [DVD] player cut out part way. Therefore abandoned this” - TECH BARRIER Session 5:
- “DVD began sticking at end – new DVD!!” - TECH BARRIER
- “Another new DVD needed” – TECH BARRIER

Session 6

- “..They’re practicing +++” - 2.4a DID FOLLOW RECS

Session 7:

- “Again DVD sticking – although able to watch exercises, but distracting.” - TECH BARRIER
- “get another DVD!!” - TECH BARRIER

Arthur

Session 1:

- “No DVD set up – will be set up next week” - TECH BARRIER

Session 2:

- “reports reduced interaction opportunities despite large household. Had not completed “conversation practice” 2.4b DIDN’T FOLLOW RECS / 1.4 SUPPORT

Session 3:

- “Has been doing a lot of exercises, frequently” - 2.4A DID FOLLOW RECS
- “Really keen to work on speech”- 1.2a ATTITUDE

Session 4:

- “Reports little opportunity for practice conversation” – 1.4 SUPPORT / 2.4b DIDN’T FOLLOW RECS

Session 5:

- “NB pt continues to talk about wanting to be dead. Family concerned re low mood.” – 1.2a ATTITUDE
- “He is also concerned re his memory – feels he’s forgetting things and is upset by this. Forgets to fill in diary therefore possibly not all practice sessions not recorded” - 1.1 PHYSICAL FACTORS

Session 6:

- “Has been practicing ++” 2.4a DID FOLLOW RECS

Session 7:

- “Reports that family understand him better on the telephone [now]” - 2.6b OUTCOMES

Des

Session 1:

- “DVD player not working” - TECH BARRIER
- “[reduced] conversation practice opportunities” – 1.4 SUPPORT

Session 2:

- “Reports going well, has carried out lots of exercise sessions and completed diary. However, feels they are not useful or effective so far” - 1.2a ATTITUDE

Session 3:

- “Reports they [the exercises] are not working” – 1.2a ATTITUDE

Session 4:

- “Reports doing OK [with the NSOMEs] and has been occasionally doing exercises, despite feeling they are not effective. Not keen to carry out exercises with me, therefore did not go through DVD” - 1.2a ATTITUDE

Session 5:

- “[Pt] did not want to go through exercises today – we just discussed them and how to make them more effortful (patient embarrassed)”- 1.2a ATTITUDE
- “Reported that his Daughter said his speech had improved and was clearer. This has given him some confidence in his speech.”- 1.4 SUPPORT
- “Not keen to be recorded” - 2.1b USING A TAPE RECORDER

Session 6:

- “Went through exercises with pt today – needed ++ persuasion. Some difficulty carrying these out – not achieving targets consistently. Reported he felt silly (?embarassed), therefore did not carry out final exercise”. - 1.2a ATTITUDE

Session 7:

- “Pt will not go through exercises with me, but reports is carrying them out” - 1.2a ATTITUDE

Session 8:

- “Continues to report ‘embarassment’ doing the exercises, even when alone. Therefore would not od the exercises with me and apparently not doing them as practice” 1.2a ATTITUDE
- “[name] had some difficulty identifying specific trouble areas and reported he felt uncomfortable listening to recordings therefore we stopped. – 2.1b USING TAPE RECORDER

John

Session 1:

- “Pt’s goal is to return to bible readings at bible meetings at his church therefore [we] will use biblical material. - 2.5a WANTED TO RETURN TO SOMETHING SPECIFIC

Session 4

- “”[he] reported he’s unwell and seemed unable to concentrate.. stopped early” - 1.1 PHYSICAL FACTORS

Session 5:

- “Wife keen to help. Supports his return to some reduced amount of work with [company] so feels .. [telephone work] would be appropriate to concentrate on” 2.5a WANTED TO RETURN TO SOMETHING SPECIFICGOALS / 1.4 SUPPORT

Session 7:

- “Wife reports now on sleeping tablets and she feels this has impacted on speech. He fell asleep x2 during session and increased drooling evident (new). Not been practicing” - 1.1 PHYSICAL FACTORS

Session 8:

- “No independent practice carried out” - 2.4b DIDN’T FOLLOW RECS

Laura

Session 1:

- She identified repeated l as a priority. 2.2e TAILORING

Session 2:

- “?Beginning to fatigue at end of session” 1.1 PHYSICAL FACTORS

- “Reports she’s becoming more confident even since starting sessions” - 1.2a ATTITUDE
- “Has been practicing +++” 2.4a DID FOLLOW RECS

Session 5:
- Has been practicing +++” - 2.4a DID FOLLOW RECS

Session 8:
- “PT seems pleased with progress and will continue with practice, she reports” – 1.2a ATTITUDE / 1.2b LEVEL OF CONTROL

Mary

Session 2:
- “Bigger print diaries [needed] for husband to access” - 1.4 SUPPORT

Session 7:
- “Pt ?developing UTI. Speech became fatigued with reduced saliva management and reduced voice” - 1.1 PHYSICAL FACTORS

Session 8:
- “Speech ?deteriorated today – has has UTI [resulting in] affected movement and mobility. She feels speech [is] affected” - 1.1 PHYSICAL FACTORS

Paul

Session 1:
- “Pt has little or no opportunity for conversation practice during the week – v isolated” – 1.4 SOCIAL SUPPORT / 2.4b DIDN’T FOLLOW RECS

Session 2:
- “Pt had difficulty using DVD player – needed assistance” – NO CODE
- “Had not practiced since last week” 2.4b DIDN’T FOLLOW RECS

Session 3:
- “Trouble setting up DVD again, and pt had difficulty using remotes” - 2.4b DIDN’T FOLLOW RECS
- “Had not carried out any practice since last session. Advised he is the only person who can effect any change”. - 2.4b DIDN’T FOLLOW RECS

Session 4
- “Carried out after some difficulty negotiating the DVD machine” - TECH BARRIER • “Not carrying out independent practice” 2.4b DIDN’T FOLLOW RECS

Session 5:
- “Complaining of pain and discomfort continually (back) – impacting on session” 1.1 PHYSICAL FACTORS
- “Pt not practicing outside [of] sessions” 2.4b DIDN’T FOLLOW RECS

Session 7:
- “…not completed due to pt’s c/o pain in neck and back and dizziness. Also c/o tiredness” - 1.1 PHYSICAL FACTORS

Sarah

Session 1:
- “DVD could not attach to TV” - TECH BARRIER

Session 3:
- “Became tearful in session. c/o feeling tired by the work” - 1.1 PHYS FACTORS / 1.2a ATTITUDE

Session 6:
- “Pt became very upset when discussing speech progress – crying and unable to speak. Attempted to reassure her that she was working very hard and doing everything possible. Reassured her that the next session will concentrate on strategies and conversation and not specific phonemes. This is to minimise her feelings of failure which it is apparent she’s experiencing” - 1.2a ATTITUDE

Appendix 9. Preliminary data analysis: Codes → Themes

CODES →THEMES

Key to original anonymising codes for each patient

1D=Des; 2A=Andy; 3P=Paul; 4H=Harry; 5J=John; 6N=Neil; 7L=Laura; 8A=Arthur; 9T=Terry; 10D=Dean; 11A=Anthony; 12S=Sarah; 3A=Anna; 14M=Mary; 15A=Adrian

1. THE NATURE OF THE THERAPEUTIC RELATIONSHIP AND ITS IMPACT ON THERAPY

Code	Data	Notes
Trust and therapeutic relationship	**1D** 203	
	3P 183-4	**3P** us getting on made him more relaxed
	4H 207-228	**4H** would tell SLT to get lost if didn't like them– more comfortable at home
	5J 312-34 337-51 372	**5J** Doing bible stuff gained his trust/cooperation. Wife said it wd have been uncomfortable and honesty would've been hard. Appreciated that we were there to help. Important to get on well or else could be intimidating. Needs to be a motivating relationship.
	6N 346-57 369-72	
	7L 659-64, 674-6, 681-95	**7L** Wouldn't work as hard for someone she didn't like. Was a motivation to get on well with slt. Her previous slt in hosp was a big support
	8A 270-83	**8A** Changed his mind about giving up when he met me
	9T 432-40	**9T** Need a bond between you; wouldn't have opened the door to me if he hadnt got on with me
	10D 297-328	**10D** Said he was lucky we got on I got more out of him because we got on – he might have been afraid to make mistakes with someone he didn't get on well with. Said we "clicked right away". And we laughed a lot –"telling jokes makes a difference" Humour in the relationship was important –he felt it relaxed him.
	11A 306-311	**11A** they see a lot of each other.
	12S 846 – 857, 875	**12S** would be terrible if they didn't get on, puts you at ease. But would have stuck it out if we hadn't got on anyway.
	13A 174-90,	**13A** liked the therapists and would have dreaded someone tx if didn't like them. Maybe not be

	316- **14M** 306-25 **15A** 368-87	motivated **14M** needed someone who would listen as she talks a lot (approach to building a relationship has to be individually tailored and SLT has to be sensitive to the communication style of the individual); husband says she was at ease with me and MM. “had a nice morning together” so the its important to her that we get on as it had a positive impact on the work she did. **15A** Work better together if you like the SLT, otherwise there’s a barrier.its motivating if you like the slt and made it a more pleasant experience.
Not wanting to let therapist down, work hard for SLT	**6N** 460-63 **7L** 666-75 **8A** 288-298	 “Worked for good remarks from you”
Took feedback from therapist better than from partner	**5J 258-62**	

2. AVOIDANCE

Code	**Data**	**Notes**
Avoiding the phone	**1D** 13 **3P** 141-47 **7L** 445-7 **9T** 304-319	**1D** still avoids the phone **3P** was avoiding the phone before tx not now **7L** was letting husband do the talking on the phone- feels more comfortable now **9T** Was scared to spk on the phone. Now feels confident enough to do so and be understood apart from by foreign call centre workers
Avoiding communication with others	**1D** 5, 152	**1D** reported avoiding people in his initial conversation with me**.** Also his goal although he said he had no goal, was to NOT avoid people so much and he did actually join two groups during our therapy

	 7L 447 **11A** 208-9, 257-60 **13A** 249-62	time. **7L** Before therapy avoided instances where she had to speak and now doesn't, esp when she is in a situation where she forgets about her speech eg gym. **11A** Avoids communicating with people. A bit more open to trying though, now. **13A** very quiet when she goes out not like her

3. **FEEDBACK**

Code	**Data**	**Notes**
No feedback from the exercises	**1D 31 41 52 81 88 173 176**	
Feedback helps	**1D** 52 81 204 208 252 **7L** 701 **8A** 227 **9T** 458-472 **10D** 333-49 **11A** 317, 333, 343 **15A** 105-07; 388-99, 600	 **7L** No point in not feeding back. Did it in a way that didnt upset her 8AHe liked the honesty and preferred atht to someone making it up and good to keep him in line **9T** He tried harder cos of my feedback; he was glad of it ?saw it as a challenge **10D** Pushed him to make it better. Didn't mind that it was coming from a younger person. Good relationship made it easier to take the feedback. **11A** helpful – made him slow down. Prefers honest feedback instead of people pretendeing to understand **15A** He couldn't hear n his own how he sounded, needed feedback from someone else – wife. Was a teacher so understands that feedback is needed. Recognises that its how you say it not what you say. Wouldn't have known if it had sounded right or not without feedback from wife. Its how you say it not what you say. Wanted more hope in his initial feedback about prognosis.
Feedback can be challenging	**6N** 394-400 **12S** 772-774,	**6N** Can be annoying- get annoyed with self when it comes out wrong **12S** it was just too bad if I uspet people with negative feedback

4. GOALS

Code	Data	Notes
Goals	**1D** 139-1563 **5J** 121-29 **6N** 231-7 **7L** 443-47, 453-57, 463-64, 473-4, 510-1, 821-8 **9T** 348-78 **12S** 442-468 **13A** 324-333 **14M** 1-7	Didn’t have any explicit goals, but had wanted not to avoid people as much because of his dr, and he has now joined 2 groups. **6N** didn’t work towards his goal- too frustrating **7L** had a goal of not avoiding speaking situations eg telephone; couldn’t set goals at beginning cos she didn’t know how much she was capable of doing or where she could aim. Needed support to do that? ; achieving small goals motivates her **9T** wanted to go back on stage (singing and entertaining) but this was hampered by new health issues. Activities carried out fro practice were relevant to this – songs “to be able to speak clearly” no specific goal. Didn’t like the idea of a smart goal. ? felt that a goal like that was reducing her independence “I’d like to manage myself.” Happier with more traditional impmnt based work **13A** did not have a specific goal. Maybe a more functional goal esp around increasing her confidence might have been better. If she could no longer be avoiding people and be looking at going back to work she would have felt she’d have achieved more. **14M** her goal is to speak as she was speaking before. And for husband to understand her

5. TAILORING TO FIT

Code	Data	Notes
Particular troublesome	**1D** 14	

words	**14M** 417-35	**14M** Specific words that she found difficult – handy to have them highlighted and for her to practice. She knows which ones to look out for: Husband I suppose so etc
Tailored Activities relevant to the pt	**1D 47-49, 194-197** **5J 134-56 179 319-33** **7L 343-51, 407-15, 420-22, 624-5** **8A 240-9** **9T 356-361** **11A 288-296** **14M 166-181, 254-62, 417-430** **15A 185-195; 410-3**	1D did not like the exercises for the reason that they were not tailored to his needs. He felt they were too generic; He didn't feel that he had muscle weakness so didn't need exercises 5J Bible and work 7L she found it interesting and enjoyable as it was more targeted and relevant 8A Liked talking about places and history relevant to him 9T used songs in therapy to make it relevant to his goal to sing on stage again; specific phonemes targeted were also those heard in songs frequently, he pointed out. 11A he could see himself saying them (they were relevant to him and he would actually use them) 14M made it easier to attend, having stuff relevant to her interests. Her husband describes how it motivated her to keep carrying out the activities..helped her with spontaneous speech- making up sentences around eg venice. Feels that because they were specifically done for her they help more and ?this motivates her more. Hated doing generic quotations. Specific words that she found difficult – handy to have them highlighted and for her to practice. She knows which ones to look out for.(Do an inventory before planning therapy). 15A Working from a generic book not tailored to his specific needs felt alien; wife says tailored to his needs was better than generic like at hospital
Targeted speech work concentrating on specific tricky sounds was useful	**7L 329-36, 354-57**	
Use of role play help pt to revisit old roles or prepare for new ones	**7L 520, 536-47**	7L Talks about it as if it were another era. May have helped her get started thinking about returning to previous lost role.
NSOMEs no use later post stroke	**7L 560-8, 598-600**	7L Says would be soul destroying one yr down the line
Speaking more useful than NSOMES as more natural	**7L 586-8** **9T 325-34**	9T to improve your speaking and confidence you need to speak

The usefulness of targeting challenging words was appreciated	**7L** **8A 135-46** **12S 755-61** **13A 157-160**	12S She said she needed it 13A she thought the fact that they were hard was a good thing.

6. THE ACTIVITIES/SESSIONS/MATERIALS

Code	**Data**	**Notes**
Felt stupid doing the NSOMEs	**1D** 37 **12S** 215-221	**12S** Thought they felt funny and silly at first.
Didn’t feel practice helped	**1D** 79 88 92	
Exercises were useless	**1D** 104 110 112 **14M** 121	14M she didn’t get NSOMEs but remarked that they might not have been useful as her mouth is quite mobile.
Exercises were repetitive	**1D** 104 **7L** 583	**7L** she had NSOMEs in hospital
Sessions – boring?	**6N 59-69** **10D 61** **12S 804-9** **13A 211-21** **14M 250**	6N Good that sessions were different each week 10D Not boring 12S a wee bit boring, but she wanted more 13A not boring 14M frequent daily repetition makes it boring
Materials	**1D 179**	
Tape recorder	**1D 259-66** **4H 187** **6N 318 341** **7L 735-46** **9T 179-83,**	1D Saw the tape recorder as an aid to my memory rather than for his therapy but this is in hindsight. Didn’t like it. 4H Liked it thought was useful 6N hated it! Could upset people – depends 7L strange at first but liked it- sounded better on tape than in her ear. Helped her hear tricky sounds 9T He liked that he could listen back to himself again, and hear where he was going wrong. Also used

	414-422 **13A 431-449** **14M 199-209** **221-232**	it to sing his songs into for practice. Difficult to hear it in his own head before the tape recorder was introduced. 13A hated tape recorder didn't like listening ot her speech. It raised her awareness though 14M bought her own TR. Used it a lot. She doesn't u understand why she sounds so clear on tape but her husband cant understand her.
Some activities made pt feel uncomfortable	**12S 589-646; 670; 719-746**	12S Didn't enjoy "spontaneous" speech practice, in which pt is to generates speech she felt those tasks put her on the spot and she couldn't think of stuff ot say, made her uncomfortable "couldn't think enough". The task in which she had to listen to herself on tape and identify tricky sounds may have exposed her weaknesses to her too much.
Use of role play help pt to revisit old roles or prepare for new ones	**7L 520, 536-47**	7L Talks about it as if it were another era. May have helped her get started thinking about returning to previous lost role.
NSOMEs no use later post stroke	**7L 560-8, 598-600**	7L Says would be soul destroying one yr down the line
Speaking more useful than NSOMES as more natural	**7L 586-8** **9T 325-34**	 9T to improve your speaking and confidence you need to speak
DVD was good	**8A 155-169, 329-338** **12S 514-23; 531-42** **13A 167-172**	8A Preferred to have the DVD rather than just instructions; provided good model; felt good afterwards 12S She liked it – very clear, provided a good model. However she preferred the written instructions as she could go at her own pace, which she admitted was slower than with DVD 13A preferred to have a DVD to having written or pictorial instructions- easier to copy

7. LOCUS OF CONTROL

Code	**Data**	**Notes**
Having a say over what happens in therapy	**1D** 122 **12S** 395-412	 12S "half and half"

	13A377-400	13A felt she could have said if shed wanted to change anything
The expert – therapist knows best	**1D** 118, 122, 252 **4H** 91 215 247 **9T** 269-70 **15A** 353-62	**4H** would “bow to the greater knowledge” of SLT **15A** Wouldn’t have said anything as it’s not up to him to do so
Some activities made pt feel uncomfortable	**12S 589-646; 670; 719-746**	12S Didn’t enjoy “spontaneous” speech practice, in which pt is to generates speech she felt those tasks put her on the spot and she couldn’t think of stuff ot say, made her uncomfortable “couldn’t think enough”. The task in which she had to listen to herself on tape and identify tricky sounds may have exposed her weaknesses to her too much.
Would have felt comfortable to ask to change tack	**7L430-34** **10D 106 117** **12S 412**	12S she said she would initially

8. SUPPORT FROM OTHERS/THE ROLES OF OTHERS IN CARRYING OUT PRACTICE

Code	**Data**	**Notes**
Partner motivated patient and/or provided therapy	**3P** **4H** 144-160 **5J** 15-43 77-91 **7L** 395-8, 723-30 **13A** 93-105 **15A** 76-91, 100-16	**3P** carer would help **4H** wife motivated him and pushed him on **7L** daughter keen to be of use and not phased by helping as she was with more physical activities **13A** one of the reasons she liked the ex’s was because she could do them with her husband. Her husband motivated her and worked with her. Gave her feedback. She wouldn’t have done the same amount of work without him. **15A** Wife filled in diaries for him, jogged him along and prompted him to do the work. A team; he couldn’t have done it as well without her as he couldn’t as easily heard how he sounded. Feedback important.

Took feedback from therapist better than from partner	**5J** 258-62	

9. HOW DID THE PATIENT DO THE HOMEWORK?

Code	**Data**	**Notes**
Use of role play help pt to revisit old roles or prepare for new ones	**7L** 520, 536-47	**7L** Talks about it as if it were another era. May have helped her get started thinking about returning to previous lost role.
How people did the practice	**1D** 25; 49 **4H** 168-80 **5J** 32-42 **6N** 79-112 **9T 203-5** **10D 37, 72-80** **11A 170-77** **12S 250-4, 273-77** **13A 93-105** **14M 38-52** **15A 82-91; 421**	1D never played the DVD to the end. Felt stupid doing them. Felt he should have been using a mirror. 4H Concentrated on his breathing and how much he could say on one breath. Read thru passage and prepare himself for tricky words by slowing down 5J wife took him thru the phrases and words "I started normally with the small sentences and that and did maybe a paragraph at a time of the reading" 6N explanation not clear re how he did it and in sessions had described how he read through the practice work once in his head, not aloud. Said in interview that he read it once but had to read it through a few times before that to it properly. Ie did the practice incorrectly. 9T Carried out practice in the work place as well as at home; with a tape recorder 10D Did a bit every day, not routine 11A did it with partner, in spite of tongue pain 12S if it wasn't clear she would repeat it, could hear herself; had conversations with herself as she couldn't practice with people much 13A Used to practice with her husband and then me. He was a big support adnshe wouldn't have done as much without him. 14M still does the practice – every day for 30-45 mins. She feels that this is too much and its better in short bursts. She thinks they are working 15A Lots of repetition-she would listen and repeat back to him what she heard and he would repeat. Treated it as a challenge

10. WHAT CHANGES COULD HAVE BEEN MADE TO IMPROVE THERAPY/OUTCOMES?

Code	Data	Notes
? any improvements or alternatives	**5J** 174 **6N** 222 **8A** 259-60 **12S** 337-9; 828	none none 8A Because he felt it worked 12S initially said she wouldn't change anything. Despite activities being boring, there should have been more work.
Participation based approach rather than impairment based might have been more effective	**13A 262**	13A could have worked on her confidence in different situations
Would have liked more sessions/follow up	**11A 140** **12S 368-73; 379-81** **13A 457-8** **14M 282-**	11A Would have liked twice weekly – would help him remember 12S not enough and as a result, she does it on her own now; would have liked follow up. 13A more 14M why is there no follow up husband asked – to update exercises and activites
Would've liked DVD with SLT on it saying target words for practice	**8A 204**	
Carryover an issue	**5J 106** **14M 221-233**	14M she sounds OK on tape but her husband doesn't understand her when she speaks to him. Need to be taught how to tape themselves having a conversation – is tape recorded speech a true depiction of her speech?
Technical problems	**3P 241-248** **11A 276-280** **12S 482-93**	3P couldn't access DVD easily cos of tech probs 12S DVD player didn't work, was a barrier
Prepare pts better	**1D 275**	1D may be necessary to prepare people for the fact that they will have to listen to themselves on tape and be confronted with their dysarthria in therapy.

11. WHAT THE PATIENTS SPECIFICALLY LIKED ABOUT THE THERAPY

Code	**Data**	**Notes**
Practical advice	**1D** 133	
Doing the therapy raised awareness of speech and ways of speaking	**3P** 71, 79 **4H** 17-25 **7L** 233, 236**,** 247, 298-302 **9T** 414-420 **12S** 925-950 **13A** 42-451	3P helped him to concentrate on what he was doing 4H make you pay attention to yourself 7L Could link reduced speech to neuralgia playing up as well 9T Had not been aware of specific phonemes he couldn't realise before therapy 12S when just speaking to people it comes out more naturally (ie than when she thinks about it). ?It possibly raised her awareness of her difficulties to a level whe was not comfortable with??? But she says she would do it again. 13A was not aware before therapy but tx helped her so now she is always conscious of how she's speaking
Prefer therapy at home rather than hospital	**3P** 190-207 **4H** 222-230 **8A** 303-315 **9T** 37-45, 59-67 **12S** 880-6 **14M** 387-98 **15A** 338-346	3P prefers because he is more comfortable and relaxed. 8A Gave reasons- travel 9T works shifts and long hrs so its better; wouldn't have gone to as OP to hospital – listed travel, the time spent waiting, the parking and the need to work. 12S prefers therapy at home, puts u at ease. 14M husband found doing in in hospital sterile and she preferred it at home –not an imposition 15A Easier physically – for access eg in bad weather
Not producing the sound in isolation but instead in words	**7L3**35-6,	
Use of role play help pt to revisit old roles or prepare for new ones	**7L** 520, 536-47	7L Talks about it as if it were another era. May have helped her get started thinking about returning to previous lost role.

The usefulness of targeting challenging words was appreciated	**7L** **8A** 135-46 **12S** 755-61 **13A** 157-160 **14 M** 417-35	12S She said she needed it 13A she thought the fact that they were hard was a good thing. 14M Specific words that she found difficult – handy to have them highlighted and for her to practice. She knows which ones to look out for. (Do an inventory before planning therapy). Husband I suppose so etc
DVD was good	**8A** 155-169**,** 329-338 **12S** 514-23**;** 531-42 **13A** 167-172	8A Preferred to have the DVD rather than just instructions; provided good model; felt good afterwards 12S She liked it – very clear, provided a good model. However she preferred the written instructions as she could go at her own pace, which she admitted was slower than with DVD 13A preferred to have a DVD to having written or pictorial instructions- easier to copy
Comments on the NSOMEs	**8A** 183-88 **10D**	8A Preferred the NSOMEs to speech practice 10D Liked doing them
Enjoyed the work	**9T** 10 **10D** 67	
Tailored nature of it	**7L** 343-51, 407-15, 420-22, 624-5	7L she found it interesting and enjoyable as it was more targeted and relevant

12. EFFECT ON THERAPY OF PATIENT/PERSONALITY/ATTITUDE/INTERNAL FACTORS

Code	**Data**	**Notes**
Concentrating on every word is tiring	**7L** 464	

Doing the therapy raised awareness of speech and ways of speaking	**3P** 71, 79 **4H** 17-25 **7L** 233, 236, 247, 298-302 **9T** 414-420 **12S** 925-950 **13A** 42-451	3P helped him to concentrate on what he was doing 4H make you pay attention to yourself 7L Could link reduced speech to neuralgia playing up as well 9T Had not been aware of specific phonemes he couldn't realise before therapy 12S when just speaking to people it comes out more naturally (ie than when she thinks about it). ?It possibly raised her awareness of her difficulties to a level whe was not comfortable with??? But she says she would do it again. 13A was not aware before therapy but tx helped her so now she is always conscious of how she's speaking
More informed - Liked being informed about dysarthria as a condition	**4H** 58-77	Had never heard of it before
Tiredness impacted on amount undertaken and on speech	**5J** 55 **7L**70 240, 316-8 **11A** 152-5	**7L** tiredness impacts on her speech a lot. She was reassured to find out that was normal and be able to predict it/deal with it. (316-8) Plans her day to reduce tiredness if necessary **11A** he got tired with practice
Pain on practicing	**11A** 170-4	**11A** in tongue but he continued to practice
Physical limb impairment more of an issue than speech - reduces motivation	**2A 103**	
Reasons given for why some people didn't work at the practice	**2A** 180 **9T** 226; 289-291	2A SLT can only help people if they want to be helped 9T Theyre lazy; up to the individual to do the work
Not too concerned re speech	**5J** 119-20 291-92	5J Wife and he not v bothered altho admitted at times it was bad
Frame of mind and attitude to therapy	**6N** 425 **12S** 158-66; 791-803 **15A** 421	6N made analogy with hypnotism-have to be in right frame of mind 12S She just got down to it, she was the only one who could do it; she is always hard on herself, pushes herself, and did so to the extent that she got upset in therapy – high expectations for herself 15A treated it as a challenge
Practicing is down to	7L 763-8	

individual people, some will some wont		
Motivations for doing practice	**8A** 76-100, 102-6, 219-22 **9T** 226-43, 246-53, 460-69 **11A** 120, 345-352 **12S** 241-242 **14M** 379-386 **15A** 113; 382-7	8A Despite wishing he was dead he still practiced a lot; wanted to speak to distant family on phone; SLT motivated him 9T got fed up of people saying he was drunk. His colleagues motived him when they said they could understand him more; felt would have practiced more if they couldn't understand him. My (critical) feedback motivated him,so he could show me he could do it 11A Wanted to improve his voice (ie speech)! Slt, partner and himself were motivations. 12S Wanted to speak properly 14M was a teacher and she likes to be organised and do her work. 15A When he goes out he needs to be able to speak; felt there was improvement –maybe this motivated him to continue with practice? Getting on with SLT was a motivating factor
Emotional impact of SLT on patient	**12S** 156-83, 195-7	12S frustrated and angry with herself. slow progress frustrating

13. SPECIFIC STRATEGIES THAT THE PATIENTS USE TO INCREASE INTELLIGIBILITY

Code	**Data**	**Notes**
Strategies either suggested by slt or devised by pt	**1D** 126 **3P 14** **4H** 104 **6N** 38 **7L** 105, 354-7 **11A** 58, 64, 321	**1D** Liked getting practical advice **3P** slow down and speak clearly **4H** slow down stop get a breath **6N** take your time slow down **7L** slow down and speak up; anticipate sounds before they come up **9T** 208-217 carried out practice standing up to aid breathing **11A** Keep shoulders down. Breathing; Slow down **12S** 310, 893-900 when she gets stuck on a word she spells it. Underlined words that were not good

	 13A 291-308 **14M** 142	and worked harder on them for h/wk **13A** works out £ before going into shop to stop herself getting in a tizz about change. **14M** slowed her down and made her say each word distinctly.concentrate more os words with an s in them

14. PTS' EXPECTATIONS OF THERAPY

Code	Data	Notes
Expectations	**1D 275** **9T** 26-30 **10D** 2-15 **11A** 32-52 **12S** 76-102, 129, 144-5, 791-801 **13A** 9-21 **14M** **15A** 20-22, 30-33, 68	**1D** may be necessary to prepare people for the fact that they will have to listen to themselves on tape and be confronted with their dysarthria in therapy. **9T** Didn't know what to expect at all **10D** Expected that it would be similar to SLT he'd had before **11A** he expected to be able to speak again despite having a significant speech impairment. Realised halfway thru that that would nt be the case. **12S** didn't know what to expect. Her first stroke had left her with little/no dysarthria dn so SLT been easier. Didn't expect it be such hard work. Had high expectations of her own ability in therapy **13A** hadn't thought about it but didn't expect it to be hard work. Thought she'd be talking perfectly at the end **14M** expected it to be like what she got before.. didn't get NSOMEs before. They gave her poetry and words **15A** Didn't know what to expect didn't really think about it; wife had no idea as had never been allowed in!; Hoped for some improvement
Took a while to get the concept of the therapy over to him	**9T** 150-161	

15. STILL TO BE ORGANISED INTO THE THEMATIC FRAMEWORK

Code	**Data**	**Notes**
Social activities	**1D** 142 **3P** 158-175 **7L** 839-55	**3P** makes him feel better and increased his opps for communication **7L** being involved in a charity has increased her confidence
The story of their stroke	**1D** 234-246 Tam	Didn’t know he’d had a stroke. He didn’t know either
Opportunities to speak to people	**2A** 47 **3P** 159-175 **6N** 228-30 255 **10D** 87-99 **12S** 266-7	**3P** joining a social grp has provided him with more opps. Has opportunities to converse with people frequently despite living alone **12S** found practice a bit tricky as limited social sphere.
Impact of dysarthria on relationships	**3P** 1-8 **4H** 27-37, 120 **5J** 278-84 **14M** 6-10 **15A** 30-31; 218-239	**3P** his sister does not listen to him now and he stopped talking to her on the phone- they fall out. **4H** comes from a talkative family and dr makes it hard for him to get his platform and have his say when family are around. **5J** stressful **14M** frustrating **15A** Pt did not want wife included in his therapy, did not want her involved or to observe ?why. as a result she did not know what to expect when I came to house. She didn’t know anything about what we did in the sessions. He suggested that he didn’t want her to jump in/take away some of the focus from him. **11A** 182-9, 233-8, 250-4 Awkward, puts people off and has to shout. Misses out on conversation; people need to give him time. Isolation . Doesn’t get out enough
Description of physical/emotional/social sequelae of dysarthria	**7L** 73	Talks about lip being pulled
Specific sounds mentioned as difficult	**7L** 140 **9T** 119, 407, 414-6, 501	**7L** /l/ **9T** /p,s, t/ this opened his eyes to the target sounds he was not achieving. He had not known that before therapy. Also pointed out that they are hi-freq sounds in song

	14M	**14M** /s/
Saliva management an issue – impacted on speech	**7L** 254	
How people measured their own outcomes	**3P** 130-139, 146 **9T** 88-94 304-18 **12S** 948 **13A** 23-28 **14M** 24-29, 192-6 **15A** 166; 273-321, 425-35	**3P** he speaks to people more on the phone now **9T** He phoned his colleagues every day with a report and they could understand him more and more; can phone people and they understand him now **12S** knows it worked cos she knows what she is doing now. **13A** worked “a wee bit” shes talking slower now. **14M** friends telling her they can understand her better now.still. speaking more slowly now. **15A** People can understand him more. Wife feels he si more confident - because he has picked up on previous activites he avoided (special interest club) (altho he says that hadn’t put him off and it was more the physical access that had stopped him) wife says he is in his “comfort zone” there. Has been speaking more.
Specific sounds identified as tricky for the pt were targeted	**4H** 198	**4H** Talks about breath support as main concern **9T** 116-125 this made him stick at it, he liked the fact that it was specific to him not generic
Working on pt’s confidence is important	**9T** 315-334 **10D** 160-77, 255 **12S** 952-966 **15A** 327-30	**9T** his has improved, and he feels to improve your speaking you need to speak and confidence helps that Words were slurred initially but not bothered by it now- “more confidence in myself now” from SLT **12S** did not increase or diminish her confidence **15A** His confidence has improved as his speech improved and he took up more activities and gets more opps to practice.
Practiced despite pain	**11A** 170-6	**11A** Tongue pain
Pt overestimated amount of work done, according to what they actually recorded.	**13A** 121-138	

Previous early acute therapy	**3P** 106-27 **15A** 40-58; 176-95; 410-3; 442-59	**3P** had no SLT after first stroke, wished he had **15A** Concentrated mostly on swallowing, was told wouldn't get back to normal (he felt they were too negative, he needed more positive but honest predictions of outcome **570-603**); worked from a generic book – American. Felt alien. Wife felt tailored to his needs was better than generic and he did better because of it. Dysphagia was too much of a focus initially (ie maybe not enough speech focus?), and they were too cautious. Important for him to know why they were doing things - information.
AAC	**15A** 473-522	**15A**Talks about the challenges of this, and changes he would have made, eg QWERTY layout, space bar, full stop, etc

Appendix 10. Preliminary data analysis: Themes

THE NATURE OF THE THERAPEUTIC RELATIONSHIP AND ITS IMPACT ON THERAPY

Key to original anonymising codes for each patient
1D=Des; 2A=Andy; 3P=Paul; 4H=Harry; 5J=John; 6N=Neil; 7L=Laura; 8A=Arthur; 9T=Terry; 10D=Dean; 11A=Anthony; 12S=Sarah; 3A=Anna; 14M=Mary; 15A=Adrian

Themes				
	Being comfortable / relaxed	**Motivation**	**Good relationship makes it easier to give and take negative feedback**	**Good relationship => want to please the therapist**
1		**1D** 203 Trust is important and should be both ways. **“Its important that you trust me to do what you tell me to do and its important that I trust that what you tell me to do will be benefiting me.”** Tells anecdote about MRI– he is alluding to the communication between professional and patient and how good communication engenders trust/respect. He felt Cardiologist was dismissive of his opinion, and as a result thought doc was a “dickhead” and ?this		

		impacted on relationship with him.		
2		**2A 160 “Well if I didn’t like you coming that’d be a waste of time.”** (?suggests that he wouldn’t have done any work)		
3	**3P** 183-4 us getting on made him more relaxed			
4	**4H** 207-228 would tell SLT to get lost if didn’t like them– more comfortable at home	4H 208 You wouldn’t do what someone said if you didn’t like them		**4H 213** He acknowledges that the SLT is there to help and therefore does what is asked of him
5	**5J** 312-34 337-51 372 Doing bible stuff gained his trust/cooperation. Wife said it wd have been uncomfortable and honesty would’ve been hard. Appreciated that we were there to help.	**5J 96 156** Both felt he was more motivated because the activities were tailored to his interests.	**5J** 312-34 337-51 372 honesty would’ve been hard. **5J 258-62** Took feedback from therapist better than from partner **–** working relationship	
6	**6N** 346-57 369-72 Important to get on well to motivate the patient. Should not be intimidated.	**6N** 346-57 369-72 Needs to be a motivating relationship		**6N** 460-63Didn’t want to let either himself or me down by not doing the work “**Yeah the only person you let down if you don’t do it is yourself and yourself”**.
7		**7L** 659-64, 674-6, 681-95		**7L** 666-75 Wanted to do it for

		Wouldn’t work as hard for someone she didn’t like. Was a motivation to get on well with slt. Her previous slt in hosp was a big support. **7L 668** Motivated by wanting to not let SLT down**: “I didn’t want you coming in and thinking “Oh she’s done nothing all week! You know?”** she puts this down to having been a teacher.		herself and for SLT **“you want to do it for yourself and for *you* as well.. I didn’t want you coming in and thinking: Oh she’s done nothing all week! You know?”**
8		He was motivated by my comments on his improvement. **8A 217:** *“**Well, (I) just eh enjoyed improving and… I liked you to say; “Oh you’re a lot better (name) …And that helped me... to keep doing it”*** **8A 270-83** Had initially thought he would not stick the therapy – but we got on and I was ***“so nice”*** that he changed his mind – ie our good relationship and his enjoyment of the therapy was a motivation to		**8A 288-298** He wanted to do himself justice and please me- **“Worked for good remarks from you”**

		continue.		
9		**9T** 432-40 Need a bond between you; **“wouldn’t have opened the door**” to me if he hadn’t got on with me		
10	**10D 297-328** ***“If you can work together it makes an awful difference*”** Said he was lucky we got on I got more out of him because we got on – he might have been afraid to make mistakes with someone he didn’t get on well with (might have inhibited him). Said we “clicked right away”. And we laughed a lot **– “*telling jokes makes a difference.. Well I feel more relaxed doing that***” Humour in the relationship was important –he felt it relaxed him.		**10D 297-328** **333-49** Good relationship made it easier to take the feedback. Said he was lucky we got on - I got more out of him because we got on – he might have been afraid to make mistakes with someone he didn’t get on well with. Took feedback from a “snotty girl” (My quote) because it was my job and he ?felt confident in my knowledge and ability.	
11	**11A 306-311** They see a lot of each other. (ie they have to be comfortable with each other and gave a good relationship			
12	**12S 846 – 857, 875** would be terrible if they didn’t get on, puts you at ease. But she would have stuck it out if we hadn’t got on anyway. **12S 589-646; 670; 719-746** Some of the activities made her uncomfortable. Didn’t enjoy			

	"spontaneous" speech practice, in which pt is to generate speech she felt those tasks put her on the spot and she couldn't think of stuff to say, made her uncomfortable ***"couldn't think enough"*** *"**I couldn't get the words"*** She was comfortable enough with me to show me her frustration and to cry. The task in which she had to listen to herself on tape and identify tricky sounds may have exposed her weaknesses to her too much. Maybe good TR was useful in helping her get past that?			
13	**13A** 174-90, 316- liked the therapists and would have dreaded someone tx if didn't like them.	**13A** 174-90, 316- She liked the therapists and would have dreaded someone tx if didn't like them. Maybe not be motivated 13A 180 ***"youse are nice at approaching me so I think it's nice***"		
14	**14M** 306-25 needed someone who would listen as she talks a lot (approach to building a relationship has to be individually tailored and SLT has to be sensitive to the communication style of the individual); husband says she was at ease with me and MM. "***had a nice***			

	morning together" "Wednesday was the highlight of her week!" so its important to her that we get on as it had a positive impact on the work she did.			
15	**15A** 368-87 Work better together if you like the SLT, otherwise there's a barrier. if you like the slt it made it a more pleasant experience.		**15A** 368-87 Work better together if you like the SLT, otherwise there's a barrier.its motivating if you like the slt and made it a more pleasant experience. Its about your manner and approach.	

Appendix 11. Overarching themes 1 and 2.

Key to reading the tables:

- Patients’ names are in the left-hand columns.
- The bolded sets of numbers relate to the line numbers in the interviews at which the quote can be found. Eg:
  464 - 72 = The quote can be found at line numbers 464 through to 472 in the named patient’s interview.
- Italicised text represents quoted speech. In quotes from the interviews, the speech of participants is bolded. Eg:
  - “Did you see them as having a rehabilitative effect?
  - It was almost repetitive and pointless.”
- Information taken from the therapy casenotes is in italics. These quotes are preceded with the session numbers to which they refer, in capitals. Eg:
  SESSION 3: *“Became tearful in session. c/o feeling tired by the work*”

	1.1 Physical Factors
Andy	Significant memory problems impacted on his remembering to carry out practice. The following three quotes suggest he has persisting memory problems: **10-14** *-“…the other thing you did was a DVD… Do you remember that at all? No* ***-no*** *-OK. Em. What you had to do was sit and watch a DVD and move your mouth and your tongue and your lips. Do you remember that bit?* ***-No”*** **139-142** *-“…Do you remember when you first got home?* ***-… I can’t remember”*** **152-3** *-“Do you remember me being here at all…?* ***-Not really”*** The next quote suggests that he believes his memory problems resulted in him forgetting to do practice independently: **52-4** *-“Do you think you’d have remembered to do them every week?* ***-…em, sometimes I knew there were supposed to be some, other times I didn’t.*** *-You would forget?* ***-Aye”***

	1.1 Physical Factors
	SESSION 5: "*Needs info, as [he] has memory difficulties and this appeared to upset him (that he didn't know what had happened to him/when)"*
John	Tiredness impacted on amount undertaken and on speech. **51-6** -*(wife speaking)"It em some days depending on how he felt it was better than others. But em he did he did em he did well* ***-Oh aye*** *-(wife speaking) But that very just much depended on how (he) felt on the day* ***-Aye cos sometimes if I was tired I couldnae do too much if I was tired. Yeah"*** **186-8** -*(wife speaking)"The thing is his speech maybe when he's talking in general can be pretty slurred at times, still.* ***Im just tired that's all it is just tired"*** SESSION 4 *""[he] reported he's unwell and seemed unable to concentrate.. therefore stopped early"* SESSION 7:"*Wife reports now on sleeping tablets and she feels this has impacted on speech. He fell asleep x2 during session and increased drooling evident (new). Not been practicing"*
Neil	Some evidence of memory difficulties: **84-88** -(re the independent practice) "What did you actually do - can you remember back that far? **-Um…..** -It's OK if you can't **-No I cant, don't remember, no"** **223-5** -*"..there must have been some things (about therapy) that you'd have changed?* ***-No not XXX I can't remember"*** SESSION 1 *"Cognitive issues and literal thinking"*
Laura	***464*** Concentrating on every word is tiring. **236-48** Could link her "neuralgia" playing up to a decrease in speech. **70 240, 314-8.** Tiredness impacts on her speech a lot. She was reassured to find out that was normal and be able to predict it/deal with it **(314-8)** Plans her day to reduce tiredness if necessary. *SESSION 2 "?Beginning to fatigue at end of session"*
Anth.	**152-5**, **170-4** he got tired with practice and despite pain in tongue he continued to practice

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
Des	**98-104** *“-What did you think was the purpose of those exercises? How would you describe the reasoning behind them?* ***-Well, the reasoning behind them is if you were looking for muscular defects or defects in the facial positions that were used to form words but having determined that once, that’s all that had to be done!*** *-Did you see them as having a rehabilitative effect?* ***-It was almost repetitive and pointless.”*** (ie: Saw no point to exercises therefore didn’t do them) His attitude could have been a self-fulfilling prophecy – didn’t think they were working therefore didn’t do them after a few sessions, therefore didn’t give himself a chance to improve!:His attitude seemed to be that the exercises were useless therefore he wouldn’t really bother with them. See therapy case-notes written just after the sessions: *SESSION 2: “Reports going well – has carried out lots of exercise sessions and completed timelog. However, feels they are not useful or effective so far”* *SESSION 3: “Reports they [the exercises] are not working”* *SESSION 4: “Reports doing OK … and has been occasionally doing exercises, despite feeling they are not effective. Not keen to carry out exercises with me, therefore did not go through DVD”* *SESSION 5: “[He] did not want to go through exercises today – we just discussed them and how to make them more effortful (patient embarrassed)”* *SESSION* 6: “*Went through exercises with [him] today – needed ++ persuasion. Some difficulty carrying these out – not achieving targets consistently. Reported he felt silly (?embarrassed), therefore did not carry out final exercise”.* *SESSION* 7: “*[He] will not go through exercises with me, but reports is*	**117-123, 252 “I’d accept anything that’s designed to improve my situation, or will help others. So to answer your question im in no position to make a judgement”.** He said he thought he might have said if he didn’t like something I was doing and that he wouldn’t presume to know much about it. However he chose to refuse to carry out the NSOMEs!

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
	carrying them out" He tells me he has been doing the exercises but what he says at other times contradicts this. Eg: *SESSION* 8: *"Continues to report 'embarrassment' doing the exercises, even when alone. Therefore would not do the exercises with me and apparently not doing them as practice"*	
Andy	He is aware of how he usually reacts to being given work to do- his own inherent attitude- and describes his own attitude to certain tasks below (**52),** suggesting he had little motivation to work hard on improving his speech**:** *-"Do you remember ever sitting and working on trying to say them clearly on your own?* ***-Nah*** *-Do you think you did at all?* ***-Nah*** *-No. Yes that's what you used to tell me- that you hadn't done that(…) why(..)?* ***-Just lazy (laughs)"*** Similarly, he describes his attitude to physiotherapy (**126-31)** *-"Would you have liked to have done that?* ***-Nah*** *-Cos - that would have been working on your movement wouldn't it?* ***-Aye. I should have wanted to.*** *But you didn't, did you?* ***-Nah"*** **176:** here he describes his usual reaction to being told what to do: ***-"If somebody tells me to do something, I just don't do it"***	

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
	180 He said that the SLT can only help people if they want to be helped – he was one person who did no practice. Maybe he didn’t want to help, or had other priorities. **103** Physical limb impairment is identified by him as more of an issue than speech - ?reduced motivation He may have felt unable to effect any change re his situation, which would impact on his adherence. As in the case notes: *SESSION* 4: “*[Andy] has very negative self- image and avoiding going out. Also sees no hope of any change physically”* *SESSION* 5: “*[He] was very low mood on my arrival. Said did not feel like talking to anyone”* *“He said he sees no future for himself, watches people from his window and feels he will never be ‘normal’ like them again”.* He presented in those sessions as lacking in motivation to work to change or improve his situation.	
Harry		**91 215 247** would “bow to the greater knowledge” of SLT. May not have felt able / willing to say anything ***-“you want to kind of bow to the person who’s teaching you or coaching you, ye dinnae start telling them what you're wanting to do”***
John	**137, 156** He and wife felt he was encouraged to do practice because the activities were centred around bible readings, which interests him. **106-12, 119-20 291-95** Wife and he are not too concerned re his speech, although he admitted that at times it was bad. He accepted his speech the way it was for everyday purposes: -**“*What am I wanting a speech therapist for?*… *I mean I could talk just the way I would normally talk*…*if you’re going to be standing in the***	

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
	public reading aye that's a different matter. I'll need my speech to be right then" **192-8** He needs to make an effort so that his wife can hear him and without him feeling he is shouting. **407-18** ***-"..its just a load of nonsense x what am I needing to get a speech therapist for I can talk fine"*** He appears to have a reduced awareness of his impairment. Would this make him less likely to adhere to recommendations?	
Neil	**425** Made analogy in which he compared participating in therapy with being hypnotised-have to be in right frame of mind. His reduced confidence and his frustration with himself and his speech stopped him from practicing conversation with unfamiliar people. Mentions being frustrated several times (eg **399**) He may have felt unable to effect any change re his situation, which would impact on his adherence. See case notes: *SESSION 7: "He suggested [he's] feeling fatalistic re speech difficulties. Appears non-motivated to tackle it. Has very limited opportunity to speak and has not attempted his goal of speaking to staff when shopping at ASDA. Possibly because the goal was suggested by SLT and in the absence of a self-identified goal?"*	
Laura	**343-5** ***-"when you're like this every day is a struggle and you don't want to waste a lot of time on things that you feel are not, you know, everything I do has got to be related, to, to help me do something else"*** Therapy is de-motivating if doesn't feel effective or relevant	**427-34** said she would feel comfortable asking to change something if she didn't feel it was working. From the SLT notes, below, it seems possible that

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
	Laura 672 She found it **"enjoyable"** **668-71** does not want to be seen to be lazy or not having worked: ***-"I didn't want you coming in and thinking "Oh she's done nothing all week! You know?"*** she puts this down to having been a teacher. SESSION 8 *"(she) seems pleased with progress and will continue with practice, she reports"* Apparent success in therapy leads to her being motivated to carry on working at it. **157-*"Fortunately I just laugh"*** This suggests that a sense of humour is important in coping. Makes it worse to stress about it. **763-8.** She talks about her experience in the classroom which showed her that only some people are willing to practice – its down to individual people, some will some won't SESSION 2 "*Reports she's becoming more confident even since starting sessions"*	because she felt her confidence was improving and she was obviously seeing the benefit of her practice – she had some control over her continued progress, which may have encouraged her to continue practicing: SESSION 2 "*Reports she's becoming more confident even since starting sessions"* Session *8 "(She) seems pleased with progress and will continue with practice, she reports"*
Arthur	He had made it clear in therapy sessions that he wished he had died during a recent operation and this was touched on in the interview**.** **64:**-*"…one of the things... that I'm quite interested in…is what you were saying just a wee bit earlier was about… you've told me - that you would - you're not feeling particularly happy with your life - that you'll be satisfied that it'll be coming to an end soon"***.** **76-100, 102-6, 219-22** Despite wishing he was dead, he still practiced a lot; wanted to be able to speak to distant family on phone; -***"Well, I still wanted to explain to people how I felt. And get in a conversation with them."*** SLT motivated him: *SESSION 3 Really keen to work on speech"*	

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
	SESSION 5:“NB [Arthur] continues to talk about wanting to be dead. Family concerned re low mood.” However, he still wanted to work to improve his speech Family saying they could understand him more motivated him to continue working. *“**I looked forward to you coming*** *Did you?* ***Yes*** *Uh uh that’s nice!* ***I did.*** *So what was it then that you enjoyed about the… if you can put it into words? About what you enjoyed about what we did?* ***Well, Just eh enjoyed improving and I had to start and say to you… I liked you to say; “Oh you’re a lot better…”*** *Mhm hmm* ***And that helped me... to keep doing it.”***	
Terry	**24-35** He was motivated by a desire to improve his speech and was keen to access the options open to him. Similarly to Sarah (line 76) he did not know what to expect. **120** Part of the reason he ***“stuck it”*** was because the tailored nature of the tasks felt relevant to him and motivated him. **226-43, 246-53, 460-9** Terry got fed up of people saying he was drunk and wanted to prove to them he wasn’t. His colleagues motivated him when they said they could understand him more; he felt he would have practiced even more if they couldn’t understand him. My (critical) feedback motivated him, so	**179-83, 414-22** He liked that he could listen back to himself again on the tape recorder, and hear where he was going wrong. He bought his own tape recorder, and appears to have been taking initiative and responsibility for his own therapy. **269-70** Here he relinquishes responsibility for his progress: -*“**I was doing what you told me to do, because obviously you’re more experienced than me**”*

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
	he could show me he could do it. *Feedback made him work harder* ***466**-“**I worked and worked and worked harder and harder and harder”*** **226, 289-291** He said the reason people didn’t do the practice is because they’re lazy; he believes it’s up to the individual to do the work **10** When it is suggested that it was a lot of work he agrees but says: ***“Aye but I enjoyed it”*** **Terry 272** -“***And I kind of like the work, ken”*** He seems to relish the challenge of the work he was given. **260-301**He has an optimistic outlook: ***“I felt that I could beat this”***	
Dean		**106 117** He feels that he would have had the confidence to tell me to change therapy if it hadn’t been to his liking**.** **-*“if I didn’t like something I’d have told you”***
Anth.	**120, 345-352** Wanted to improve his speech. SLT, partner and himself were motivations. **124-30** Despite realising halfway through therapy that he would not get back to normal again, he continued to do the therapy and persevere.	
Sarah	**241-242** Wanted to speak properly **158-66; 791-803** She just got down to it, she was the only one who could do it; she is always hard on herself, pushes herself, and did so to the extent that she got upset in therapy – She had high expectations for herself. **461-76** She wants to feel in charge of her own progress - ***“I’d like to manage myself”***. It’s not clear exactly what she means by this but it may be that she feels that working toward goals that aim to increase her participation would be unpalatable and perhaps intrusive.	**395-412; 589-646;** Initially she said she would have felt comfortable asking to change tack. When asked if she had a say she said - ***“half and half*’.** But she didn’t say anything when she was given tasks she did not enjoy

	1.2 Internal Factors	
	1.2.a **Attitude to therapy**	**1.2.b** **Perceived level of control over therapy**
	156-83, 195-7 frustrated and angry with herself. slow progress was frustrating: SESSION 3: *"Became tearful in session. c/o feeling tired by the work* SESSION 6:*"[Sarah] became very upset when discussing speech progress – crying and unable to speak. Attempted to reassure her that she was working very hard and doing everything possible. Reassured her that the next session will concentrate on strategies and conversation and not specific phonemes. This is to minimise her feelings of failure which it is apparent she's experiencing"*	
Anna		**377-400** felt she could have said if she'd wanted to change anything
Mary	**379-386** was a teacher and she likes to be organised and do her work. ***156-63*** ***-"I didn't complain, did I?*** *-Did she? Did she not complain?* *- (husband) No no. No no.* *-No? OK!* ***-No I didn't*** *- (husband) Oh no now that was one thing, the whole series, it was a question of: Wednesday was the highlight of her week!* ***-(laughing) I enjoyed that"*** ***-"I enjoyed it!"***	
Adrian	**113; 382-7** When he goes out he needs to be able to speak; felt there was improvement –maybe this motivated him to continue with practice? Getting on with SLT was a motivating factor. **Adrian 421** they treated therapy as a challenge, his wife reported.	**353-62** Wouldn't have said anything as it's not up to him to do so. He felt it wasn't his place.

	1.3 The Therapeutic Relationship	
	1.3.a **Good relationship helps patients feel comfortable / relaxed**	**1.3.b** **Good relationship can be a motivating factor**
Des		From the therapy casenotes, it is clear he is not keen on the NSOMEs and often won't even do them with me, however he occasionally assures me he has been doing them on his own only to contradict himself the next week. Could it be that the relationship between us made him want to exaggerate the amount of exercise he had been doing? **203** Trust is important and should be both ways: -***"It's important that you trust me to do what you tell me to do and its important that I trust that what you tell me to do will be benefiting me."*** Tells anecdote about MRI– he is alluding to the communication between professional and patient and how good communication engenders trust/respect. So, he believes a good relationship engenders trust, and is a motivating factor, He should be able to trust what I say and then he will do the work.
Andy		**160** ***"Well if I didn't like you coming that'd be a waste of time."*** (suggests that he wouldn't have done any work if he hadn't liked me)
Paul	**183-4** us getting on made him more relaxed	
Harry	**207-228** would tell SLT to get lost if didn't like them–	**208** He believes that you wouldn't do what someone said if you didn't

	1.3 The Therapeutic Relationship	
	1.3.a **Good relationship helps patients feel comfortable / relaxed**	**1.3.b** **Good relationship can be a motivating factor**
	more comfortable at home	like them
John	**312-34 337-51 365-75** Building the sessions around the bible gained his trust/cooperation. Wife said it would have been uncomfortable and honesty would’ve been hard (ie giving and receiving honest feedback).	
Neil	**346-57 369-72** Person should not feel intimidated.	**460-63** Didn’t want to let either himself or me down by not doing the work **-**“***Yeah the only person you let down if you don’t do it is yourself and yourself”*** **346-57 369-72** Important to get on well to motivate the patient Needs to be a motivating relationship
Laura		**661-75** Wanted to do it for herself and for SLT ***-“you want to do it for yourself and for you as well.. I didn’t want you coming in and thinking: Oh she’s done nothing all week! You know?”*** **659-64, 672-6,** Was a motivation to get on well with slt. Her previous slt in hospital was a big support and she felt that was a motivating factor too. **(681-95)** ***“I would say I wouldn’t work as hard for someone I didn’t like. (659)*** She agreed with this: -*“So you think that that’s actually a motivating factor?*

	1.3 The Therapeutic Relationship	
	1.3.a **Good relationship helps patients feel comfortable / relaxed**	**1.3.b** **Good relationship can be a motivating factor**
		-Oh yes *-Having a good relationship* ***-Uh huh yes.”*** ***(672-4)*** **Laura 668** She was motivated by wanting to not let SLT down**:** ***“I didn’t want you coming in and thinking “Oh she’s done nothing all week! You know?”*** she puts this down to having been a teacher
Arthur		**288-298** He wanted to do himself justice, and please me- ***“Worked for good remarks from you”*** He was motivated by my comments on his improvement. **217:** *“****Well, (I) just eh enjoyed improving and… I liked you to say; “Oh you’re a lot better (name) …And that helped me... to keep doing it”*** **270-83.** He had initially thought he would not stick the therapy – but we got on and I was ***“so nice”*** that he changed his mind – ie our good relationship and his enjoyment of the therapy was a motivation to continue.
Terry		He worked harder and harder so he could prove to SLT that he could do it **465-71** ***“I worked and worked and worked harder and harder and harder!...And then, see, you’d come back and; “See I can do this!” No no, I was glad”*** **432-40.** You need a bond between you; he **“wouldn’t have opened the door**” to me if he hadn’t got on with me

	1.3 The Therapeutic Relationship	
	1.3.a **Good relationship helps patients feel comfortable / relaxed**	**1.3.b** **Good relationship can be a motivating factor**
Dean	**297-328** ***“If you can work together it makes an awful difference”*** He said he was lucky we got on He felt the SLT got more out of him because there was a good therapeutic relationship – he might have been afraid to make mistakes with someone he didn’t get on well with (might have inhibited him). Said we “clicked right away” and laughed a lot **–“*telling jokes makes a difference.. Well I feel more relaxed doing that*”** Humour in the relationship was important –he felt it relaxed him.	
Anth.	**306-311** Very important that they get on with each other as they see a lot of each other. (ie they have to be comfortable with each other and have a good relationship)	
Sarah	**846 – 857, 875** would be terrible if they didn’t get on, puts you at ease. But she would have stuck it out if we hadn’t got on anyway. **167-173** Some of the activities made her uncomfortable (see **589-646; 670; 719-746.** She didn’t enjoy “spontaneous” speech practice, in which pt is to generate speech. She felt those tasks put her on the spot and she couldn’t think of stuff to say, which made her uncomfortable ***“couldn’t think enough”*** “***I couldn’t get the words”)***, however she was comfortable enough	

	1.3 The Therapeutic Relationship	
	1.3.a **Good relationship helps patients feel comfortable / relaxed**	**1.3.b** **Good relationship can be a motivating factor**
	with the therapeutic relationship to show the therapist her frustration and to cry. The task in which she had to listen to herself on tape and identify tricky sounds may have exposed her weaknesses to her too much. Maybe the good TR was useful in helping her get past that?	
Anna	**174-90, 316 -** liked the therapists and would have dreaded tx wiith someone she didn't like.	Despite not carrying out much practice at all according to her weekly timelogs, she presented herself as if she had worked hard. This could have been in part to present a good image, or perhaps not to let down the therapist?
Mary	**306-25-** She needed someone who would listen as she talks a lot; husband says she was at ease with me and MM. **-** "***had a nice morning together" - -"Wednesday was the highlight of her week!"*** So it's important to her that we get on as it had a positive impact on the work she did.	
Adrian	**368-87** Work better together and it is a more pleasant experience if you like the SLT, otherwise there's a barrier.	

	1.4Support and Opportunities for Practice.
Des	Lived alone – no access to support other than dx in occasional phonecalls

	1.4Support and Opportunities for Practice.
	SESSION 1 “[reduced] conversation practice opportunities”
Andy	**47** very socially isolated- feels that “just talking” would help his speech but has ltd options to do this - never leaves house- no access to support SESSION 2: Ask sister to prompt [him] to practice and help with DVD set up”
Paul	**63** Lived alone but carer would help occasionally **158-175** Increased social contact recently. Makes him feel better and increased his opportunities for communication. See this quote from the notes on the first session, below: SESSION 1 “[He] has little or no opportunity for conversation practice during the week – v isolated” Maybe some connection between increase in his social life and his perceptions of improvement in speech?
Harry	**144-160** Lives with wife: wife motivated him and pushed him on
John	**15-43 64-67, 77-91, 258-62 278-84** Lives with wife. The practice sessions weren’t too stressful but impact of dysarthria on relationship can bring stress SESSION *5: “Wife keen to help. Supports his return to some reduced amount of work with [company]..”*
Neil	**228-30 255** Lives alone, very socially isolated, rarely leaves house. Rarely speaks to people other than family. SESSION 8 *“Would probably not go to a group. Refuses to consider going out unless to ASDA with his brother” (Reliant on his brother for social contact with outside world). This impacted on his goals (he could not achieve his goal of speaking to more people).* SESSION *1:“Few opportunities for conversation”*
Laura	**395-8, 723-30** Lives with husband- supportive family who visit frequently. Daughter keen to be of use and not as phased by helping in speech activities as she was with more physical activities. **363-9** She suggests that family and friends comments re speech offer updates on progress (like an outcome measure), as they can compare current presentation with that of speech immediately post stroke.
Arthur	Limited conversation opportunitiess. Our sessions offered him chances for conversation that he might not have often in everyday life: **240 *“Well… we talked about different things, and it’s good to get into a conversation”*** SESSION *2: “reports reduced interaction opportunities despite large household. Had not completed “conversation practice” in timelog forms”*
Dean	**87-99** Has opportunities to converse with people frequently despite living alone **101**: “***No handicap that way”***
Anth.	Lives alone, but partner round a lot and helped with practice. **182-9, 233-8, 250-4** Talking to people is awkward, it puts people off and he has to shout. He misses out on conversation; people need to give him time, this results in isolation . Doesn’t get out enough – very socially isolated. As a result he could not do much conversation practice.

	1.4Support and Opportunities for Practice.
Sarah	**266-7** found practice a bit tricky as limited social sphere
Anna	**93-105** Lives with husband and son. Husband supportive, son not. One of the reasons she liked the exercises was because she could do them with her husband. Her husband motivated her, worked with her and gave her feedback. She said she wouldn't have done the same amount of work without him
Mary	Lives with husband- very involved and joined in sessions and supported her practice. Although could be frustrating **(6-10)** as she has to repeat herself for her husband and gets annoyed. Also grandchildren helped occasionally. SESSION 2 "*Bigger print diaries [needed] for husband to access"* He wrote her timelogs for her. Must consider the needs of those supporting the pt, too.
Adrian	**76-91, 100-16** Lives with wife no other family. Wife filled in timelogs for him, jogged him along and prompted him to do the work. A team; he said he couldn't have done it as well without her as he couldn't as easily heard how he sounded. Her feedback and support was therefore important. **105-07; 388-99** He couldn't hear on his own how he sounded, needed feedback from wife.. Wouldn't have known if it had sounded right or not without feedback from wife. **30-31; 218-239** He did not want his wife involved in his therapy previously, as a result she did not know what to expect when NONSPEX therapy started at their house. She wasn't invited by him to observe any of our sessions, either. He suggested that he didn't want her to jump in/take away some of the focus from him. But he was happy for her support outwith sessions.

	1.5 Avoiding activities of daily living This was a commonly mentioned theme, and links with the goals that people set for therapy, and the aim of no longer avoiding once commonplace activities may have motivated people to adhere.
Des	**13 42 152-6**.Had been avoiding the phone, and avoiding contact with people. Joined 2 groups as a result of discussions about goals in therapy
Andy	SESSION 4: "[He] has very negative self image and avoiding going out. Also sees no hope of any change physically"
Paul	**141-47** was avoiding the phone
Neil	**252** avoided speaking to people eg at supermarket even though his goal in therapy was to speak to checkout girl at ASDA. Instead his brother spoke for him and he got frustrated with himself SESSION 8: *"Would probably not go to a group. Refuses to consider going out unless to ASDA with his brother"*
Laura	**445-7** Avoiding the phone and speaking to people -*"**Oh that's a phonecall I'll just let [husband] pick it up" you know whereas now I don't think about it I just go to the phone.***

	And em I was at that stage avoiding instances where I was going to have to speak and you know just going maybe with friends and letting [husband] do all the talking"
Terry	**304-19** Was scared to speak on the phone. Now feels confident enough to do so and be understood apart from by foreign call centre workers
Anth.	**208-9, 257-60** Still avoids people. It is hard, but he agreed with the suggestion that perhaps he feels more ready to have conversations with more people now.
Sarah	**317-319** she does not avoid phonecalls with friends or strangers. She mentions a strategy she uses – she spells words out on the phone.
Anna	**244 249-62** she's "**starting to go away on holiday again"** (suggesting she'd been avoiding this). Continues to avoid communication with others. Very quiet when she goes out -not like her. When it is put to her that a different focus in therapy might have helped her to get more confidence in speaking to people she agrees, but is unable to say how that could have been effected.

	2.1 What Patients Didn't Like About Therapy	
	2.1.a The tasks (NSOMEs/DVD /speech practice)	**2.1.b Using a tape recorder**
Des	**47-49, 194-197** did not like the exercises for the reason that they were not tailored to his needs. He felt they were too generic; He didn't feel that he had muscle weakness so didn't need exercises **37 104 110 112 79 88 92** He felt stupid doing the NSOMEs, and in his opinion they were useless, repetitive and practice did not help.	**259-66** He saw the tape recorder as an aid to the therapist's memory rather than as a therapy tool but this is in hindsight. He reports that he didn't like it. **275** He feels that it may be necessary to prepare people for the fact that they will have to listen to themselves on tape and be confronted with their dysarthria in therapy. SESSION 8 *".. had some difficulty identifying specific trouble areas and reported he felt uncomfortable listening to recordings therefore we stopped"* *SESSION 5 "Not keen to be recorded"*
Andy	**44** Didn't think exercises would have helped: -"What *would* have helped, do you think? **-Just talking"**	
Neil		**318 341** He says he always hated tape recorders - it never

	2.1 What Patients Didn't Like About Therapy	
	2.1.a The tasks (NSOMEs/DVD /speech practice)	**2.1.b Using a tape recorder**
		sounded as it did in he thought he'd said it. *"**Basically you knew yourself it wasn't right but the tape recorder only confirmed it"*** *SESSION 1 "Didn't want to listen to tape" SESSION 8 "Refused to listen to tape, although it clearly showed improvement. ?maintenance post therapy."*
Laura	**Laura** had NSOMEs in hospital, and the following quote refers to her experience of the NSOMEs given to her there: **583** -"***I suppose it's just repetitive and boring"***. **560-8, 598-602** in her opinion NSOMEs would be no use in chronic stroke and would be soul destroying to have to do them one yr down the line **586-8** She feels that speaking is more useful than NSOMES, as it's more natural.	
Sarah	**589-657; 670-705; 719-746** She didn't enjoy "spontaneous" speech practice tasks - in which patient generates speech (eg speaking around a given topic). ***-"…Well, I couldn't … I ran out of words.*** *-You ran out of words. So it was quite taxing to think* ***-Yes*** *-about the words* ***-that I want*** *-you wanted to say?* ***-Yes*** *-Do you feel it put you on the spot?* ***-It did."*** She couldn't think of what to say; it made her uncomfortable and it seems she didn't like coming up with her own material. She mentions at another point that she didn't know any words	

	2.1 What Patients Didn’t Like About Therapy	
	2.1.a The tasks (NSOMEs/DVD /speech practice)	**2.1.b Using a tape recorder**
	and that was why she got upset **178-9** **670**:“***couldn’t think enough***”. Perhaps this exposed her weaknesses to her too much.	
Anna		**431-449** She hated tape recorder didn’t like listening to her speech. It raised her awareness though, she said. SESSION *7:“Not keen to listen to recording”*

	2.2 What Patients Liked About Therapy				
	2.2.a Therapy at home instead of hospital	**2.2.b Therapy raised awareness of speech**	**2.2.c Using a tape recorder**	**2.2.d The tasks (NSOMEs/DVD/ sp practice)**	**2.2.e Tailoring (individualised tasks/ strategies/advice)**
Des		**133** ***-“They were useful because you were pointing out that I had difficulty to (pronounce) multisyllables and I had to slow down and I had to take care, and these were all very good. Good advice.”*** (He learnt something he had not been aware of prior to therapy)		**173-76** Thought the DVD was good (quality) albeit impractical ***“ If I’d had a problem with some facial muscles that would have been necessary. Vital in fact.”***	**244-6** He knew nothing about stroke so welcomed all information/advice **192-4** Below he describes how he didn’t want NSOMEs, but would have preferred activities that in his opinion were more relevant to his speech impairment: -*“So am I right in thinking then that you’d have liked a more personalised- instead of a DVD which is one size fits all- would you have preferred a personalised exercise regime?* ***-No I’d prefer something more akin to the problems I had”*** **286 -“ *I’ve met enough people who’ve had strokes to know that there are as many strokes as there are different people…And no one size fits all. Its got to be tailored towards the individual*”** **ID 125-34** He liked getting practical

	2.2 What Patients Liked About Therapy				
	2.2.a Therapy at home instead of hospital	**2.2.b Therapy raised awareness of speech**	**2.2.c Using a tape recorder**	**2.2.d The tasks (NSOMEs/DVD/ sp practice)**	**2.2.e Tailoring (individualised tasks/ strategies/advice)**
					individualised advice: ***-“They were useful because you were pointing out that I had difficulty to (pronounce) multisyllables and I had to slow down and I had to take care, and these were all very good. Good advice.*** *-You liked it when things seemed to have a purpose...* ***-Yes.*** *-..and were practical and not theoretically based.* ***-Yes”***
Paul	**190-207** Prefers therapy at home because he is more comfortable and relaxed. He feels one works better when relaxed.	**71, 79** Therapy helped him to concentrate on what he was doing			
Harry	**222-230** Prefers therapy at home	**17-25** Feels that therapy makes you pay attention to yourself and how you speak	**187** He liked the tape recorder as it was useful for self -monitoring purposes and memory		**58-77** More informed - Liked being informed about dysarthria as a condition Had never heard of it before. Likes to be able to tell people the nature of his speech imp. Maybe this reduces the stigma?
John		**228** Although he started off thinking			**134-56 176-9 319-33.** Wife said doing stuff he was interested in

	2.2 What Patients Liked About Therapy				
	2.2.a Therapy at home instead of hospital	2.2.b Therapy raised awareness of speech	2.2.c Using a tape recorder	2.2.d The tasks (NSOMEs/DVD/ sp practice)	2.2.e Tailoring (individualised tasks/ strategies/advice)
		his speech was fine, he started to realise that ***"when I was doing that (reading aloud from bible) .. I was shaky, you know?"***			encouraged him, made him make more of an effort and kept him interested. He appreciated that the therapist made the effort to talk about the bible with him. -***"You've come and gone with me and the things I've needed to do and say to you"*** (ie Bible and work related topics) *"**For me it was – especially what we were reading … it wasnae just out of any book, it was out the bible … and that was the difference. It helped me to be encouraged to do it more."***
Neil					**59-69** Good that sessions were different each week. He liked variety. **38** He thought specific advice re speech strategies was helpful. Slow down.
Laura		**233** ***"I found it very helpful because it made me think about how, you know, you produce speech"*** **236-48, 298-302** Liked being able to understand the link between tiredness and worsening of speech. Could link	**735-46** Tape recorder strange at first but liked it- sounded better on tape than in her ear. Helped her hear tricky sounds	**586-8** She liked the reading passages, enjoyed it. She felt reading aloud and putting inflections in was akin to speaking.	**329-36, 347-60** Targeted speech work concentrating on specific sounds that challenged her was useful. More useful than her previous therapy had been which was just lists of words and non-words that she felt weren't necessarily targeting the specific sounds she was having trouble with. **-*"It does help cos then you're aware of the sounds that are going to cause problems, you see them coming and you can maybe adjust or*** *-So it help you to anticipate difficulties*

	2.2 What Patients Liked About Therapy				
	2.2.a Therapy at home instead of hospital	**2.2.b Therapy raised awareness of speech**	**2.2.c Using a tape recorder**	**2.2.d The tasks (NSOMEs/DVD/ sp practice)**	**2.2.e Tailoring (individualised tasks/ strategies/advice)**
		reduced speech to “neuralgia” playing up as well.			***-Yeah.Yeah”*** SESSION 1: *She identified repeated l as a priority*. **335-6,** She thought it was useful to not work on producing the sound in isolation but instead work on producing it in words **343-51, 407-15, 420-22, 624-5** Places and people of interest, friends names, role plays. she found it interesting and enjoyable as it was more targeted and relevant ***407:*** ***-“and there were interesting bits to read you know it wasn’t just a, you know, a series of words, well, I know the practice was but it came to a nice wee story”*** **420:** ***-“Because you asked me questions about what I did and I told you then you made up things to suit me, which I thought was great, you know because it was all interesting and what I liked and so it wasn’t like a chore to do you know”*** **343-5** ***-“when you're like this every day is a struggle and you don’t want to waste a lot of time on things that you feel are not, you know, everything I do has got to be related, to, to help me do something else”*** Therapy is

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					de-motivating if doesn’t feel effective or relevant **520, 536-47** Re use of role play help the person to revisit old roles or prepare for new ones: She talks about her role as a volunteer as if it were another era. -“***Yes it was sort of: “Oh I used to do this!” you know? From another …another era*”** As if stroke had removed her from that situation and she was considering it again. May have helped her get started thinking about returning to previous lost role. Also, **522 “*It was fun”*** **560-8, 586-8 598-600** She feels therapy should be tailored to the individual’s needs as she feels NSOMEs no use some time post stroke**.** She says would be soul destroying one year down the line. Speaking more useful than NSOMES as more natural. NB She didn’t receive NSOMEs as part of the therapy discussed, she is talking hypothetically.
Arthur	Preferred therapy at home: **303-315 *“Well, there’s no travelling, and I just could get up and get ready and I knew you was coming and I didnae***			**155-169,** Preferred to have the DVD rather than just instructions; provided good model; **8A169** *“***Well, the woman was very good***	**240-9** He liked talking about places and history relevant to him. **135-46** He wanted to work on a particular word – *resuscitation* **–** in case he was ever in a position in which he would have to tell people he did not want to be resuscitated. He was grateful for me helping him practice that word, and other Multisyllabic words**.**

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	have to rush (about)"			***'cause it made me do exactly what she said. Each time."*** **329-338** It/he felt good afterwards as he felt it was helping.	**143:** ***"Difficult words that I could not have done without you … getting me to practice the words"*** I wondered if he might have found it useful to have me on a DVD providing model for specifc words/phrases to practise in my absence– **202:** ***"****How would you have felt if there'd been a DVD with me on it, saying the words I wanted you to say and you copy them?...* ***I think it'd have been lovely!"***
Terry	**37-45, 59-77** He works shifts and long hours so it's better; he wouldn't have gone as an OP to hospital – listed travel, the time spent waiting, the parking and the need to work as reasons.	**414-420** He had not been aware of the specific phonemes he couldn't realise before therapy	**179-83, 414-422** Tape recorder: he liked that he could listen back to himself again, and hear where he was going wrong. -***"I could actually tell myself what I'm doing wrong"*** He was taking initiative and responsibility for his own therapy. He also used it		**208-17** Took on advice to practice sanding up to increase breath support: -*"you had your own special way of doing it, you … used to stand up didn't you?* ***-That's right aye*** *-Which would help..* ***-aye*** *-And what did that help.. with ..?* ***-It helped my breathing I think…"*** **414-20** He had not been aware of the specific phonemes he couldn't realise before therapy. He had needed to work on bilabials and /s/ as they occur frequently in the songs (esp *baby*). -*"did you know that those were the sounds you couldn't really pronounce before, or was it not that clear in your head before I came along to*

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			to sing his songs into for practice. Difficult to hear it in his own head before the tape recorder was introduced. **185-6** he recorded himself singing, working toward his goal. SESSION *2:* *“Keen to find a tape recorder to tape himself”* SESSION *8:* *“He listened to his first recording and compared it to his last one: marked difference improvement in intelligibility and even voice quality. He said he was happy*		*help you pinpoint the sounds?* ***-Not before you came*** *-Not before I came* ***-Until - until you asked me to speak, mind, and you recorded me and I could hear”*** **116-25** The individualised targeting of the tasks made him stick at it, he liked the fact that it was specific to him and not generic **356-61** Songs were used in therapy to make it relevant to his goal to sing on stage again; specific phonemes targeted were also those heard in songs frequently, he pointed out. *SESSION 1: “use musical analogies”* (this was a note to myself re how I could best explain speech and dysarthria to him and how to tailor therapy to his interests.)

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			with this and feels more confident. Plans to go back to singing in a few weeks with his band!"		
Dean				He didn't get the NSOMEs, but he remembered that he had liked getting them at the hospital: **28 *"Well its exercise too you know?"*** (He maybe enjoyed feeling like he was actively doing something positive, ie exercise). **61** speech practice was not boring	**228:** He liked targeting specific sounds and the work we did on altering his tongue placement for certain sounds: **-*"With the "z" and the "s" too and things like that..There's a different way you pronounce x, ken?"*** An example of tailoring the delivery of therapy to fit the client: He appreciated humour and humour was used in therapy with him, as a medium through which to give him feedback, make him comfortable, and get him to engage. ***319:*** -*"So is that part of it as well, being* ***-Yeah I think so yeah able to laugh and.. Telling jokes and things like that that makes a difference"*** **271** With prompting, he remembered the main strategy to improve his speech: **-*"..for god's sake slow down!"***

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Anth.				**163:** He liked the DVD because he could use it outwith sessions – he could choose when to do exercises (NB he had little else in his environment that he could control)	**288-296** He could see himself saying them (they were relevant to him and he would actually use them) He liked getting specific practical advice eg reminding him to slow down
Sarah	**880-6** She prefers therapy at home, puts u at ease.	**925-50** when just speaking to people it comes out more naturally (ie than when she thinks about it). Maybe it raised her awareness of her difficulties to a level she was not comfortable with? But she says she would do it again. **947 -** "How do you think it's helped? **-I feel as though I know what I'm**		**570-5** She liked the word lists. **215-221 804-9** Thought they felt funny at first (she agreed with the term "silly" when fed it by the SLT) . They were a bit boring, but she wanted more **514-23; 531-58** She liked DVD – very clear. She liked having a model. However she preferred the	**755-61** She states that she wanted tasks which were a challenge to her, perhaps because she finds this motivating. She admits that the tasks *were* often difficult, as she wanted - ***"I needed that."*** This suggests that she wanted her to tasks to be tailored to her specific needs, which were that she be challenged by the work she carried out. **325-30** She thought it was useful to include words that are relevant to the individual in the therapy tasks: **-*"you're more familiar with (the words)"***

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		doing now”		written instructions as she could go at her own pace, which she admitted was slower than with DVD	
Anna		**42-51** She was not aware before therapy but tx helped her so now she is always conscious of how she’s speaking -“***Im speaking, thinking all the time what Im doing.*** **-**And do you think you weren’t so aware before therapy then of how your speech sounded? **-No** -and how to make it a bit clearer?		**167-172** referred to have a DVD to having written or pictorial instructions- easier to copy **211-21** NSOMEs not boring	**155-160** The words were challenging. She thought the fact that they were hard was a good thing. -*“The words and the homework were good?* ***-Aye. They were good.*** *-What do you mean? Tell me more about the words and the homework. What was good about them?* ***-They weren’t easy”.*** This suggests that she liked tasks to be tailored in such a way as to provide her with a challenge

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		-No" SESSION 1: *"unable to identify any strategies she uses for clearer speech, although was breaking longer words down into syllables/shorter words when reading at SWL".*			
Mary	**387-98** Husband found doing therapy in hospital sterile, and she preferred it at home –it wasn't an imposition	**148** It raised her awareness of the words /sounds that were tricky for her.	**199-209, 221-232** She bought her own tape recorder, and used it a lot. She doesn't understand why she sounds so clear on tape but her husband can't understand her.		**417-35** Specific words that she found difficult – handy to have them highlighted and for her to practice. She knows which ones to look out for. Eg: Husband I suppose so etc **166-181, 254-62, 417-430** Having stuff relevant to her interests made it easier to attend to the work. Her husband describes how it motivated her to keep carrying out the activities and helped her with spontaneous speech- making up sentences around eg venice. She feels that because they were specifically done for her they help more and ?this motivates her more. Hated doing generic quotations.

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Adrian	**338-346** Easier physically – for access eg in bad weather		**215** ***- ”It makes me hear ...what I’m saying and how it sounds.*** *-So it kind of gives you an extra ear?* ***-(nods)”***		**185-195; 410-3** Working from a generic book, as he had in hospital before the NONSPEX programme, which was not tailored to his specific needs felt alien; wife says having therapy tailored to his needs was better than the generic therapy he got at hospital

	2.3 Feedback	
	2.3.a Self-monitoring not sufficient – need feedback from others.	**2.3.b Feedback from SLT**
Des	**31 41 52 81 88 173 176** No feedback from the NSOMEs. Mirror would have provided an element of feedback. ***45 There’s nothing tangible to tell you whether you were doing well whether it was being effective or anything like that*** **52 81 204 208 252** lived alone and felt that practice was not useful without “another human involved” and giving him feedback.	**252** Took feedback from therapist because he felt I knew what I was talking about.
Paul		**322** He did not feel challenged by critical feedback
John		**252** **-** (to his wife)***“…I don’t like to repeat it because I’ve got to shout it out to you – I’ve told you – you’re needing a hearing aid”*** He is irritated by having to repeat himself to his wife- puts blame on

	2.3 Feedback	
	2.3.a Self-monitoring not sufficient – need feedback from others.	**2.3.b Feedback from SLT**
		her. **258-68** Next he explains why feedback from the SLT did not make him angry: -*“…So why do you think that is then?...* - ***Aye. Well she’s she’s my wife so she wouldnae do it the same as you would do it.*** -*…So I would do it differently because it’s my job?* ***-Aye and you - not only that; you’d be out the door, x you know*** -*[laughs]* ***-You’d be running away and [wife] wouldnae, she’s just got to sit here with me”*** He took feedback from SLT better than from wife, because SLT would do it differently and also because of the differing relationships between the parties. Maybe more of a working/professional relationship between therapist and patient **312-34 337-51** If there hadn’t been a good relationship it would have been difficult to be honest and feed back candidly. **278-86** He finds it hardest to take feedback from his wife when it happens outside of te htherapeutic context (ie when she tells him to speak more clearly on everyday situations) **247-51** His wife asserts that he did not take feedback or requests for repetition well from her, eg: -*“.. You don’t take that well”*
Neil		**394-400** Can be annoying- although he said he didn’t get annoyed with *me* but himself it came out wrong
Laura		She did not feel it was too challenging to receive feedback from SLT: **701** She points out that there’s no point in *not* feeding back. Did it in a way that didn’t upset her

	2.3 Feedback	
	2.3.a Self-monitoring not sufficient – need feedback from others.	**2.3.b Feedback from SLT**
Arthur		**227** He liked that SLT was honest with him and preferred that to someone making it up. It helped to keep him on track. He was motivated by comments on his improvement. **217:***“**Well, (I) just eh enjoyed improving and… I liked you to say; “Oh you’re a lot better (name) …And that helped me... to keep doing it”***
Terry		**458-72** He tried harder because of SLT feedback; he was glad of it and maybe saw it as a challenge
Dean		**297-328 333-49** Good relationship between SLT and client made it easier to take the feedback. He said he was lucky SLT and he got on - SLT got more out of him because of that – he might have been afraid to make mistakes with someone he didn’t get on well with. SLT pushed him to make it better . He didn’t mind that it was coming from a younger person. Because it was SLT’s job and he ?felt confident in the knowledge and ability of the therapist.
Anth.		**317, 333, 343** Helpful – made him slow down. Prefers honest feedback instead of people pretending to understand. Suggested people pretend to understand sometimes. ***“I prefer it (to)…people pretending to understand”*** (341-3)
Sarah		**892-902** She found that it was useful to get specific feedback on what she needed to work on, and it helped to have it written down, or words underlined-easier to remember **769-72:** -“*I wondered if that would be upsetting to you to hear … “no you’re doing that wrong this is wrong, that’s wrong this is wrong” Was that not quite tough to hear from me?* ***-It was really.”*** **772-774,** She admitted getting upset. But it was just “***too bad*** “ if SLT upset people with negative feedback.

	2.3 Feedback	
	2.3.a Self-monitoring not sufficient – need feedback from others.	**2.3.b Feedback from SLT**
		936 Therapy may have highlighted the extent of speech impairment that she was not even really aware of. May have had a negative effect on her confidence.
Adrian	**105-07; 388-99, 600** He couldn't hear on his own how he sounded, needed feedback from someone else – wife. He used to be a teacher so understands that feedback is needed. Recognises that how you say it is important. He wouldn't have known if it had sounded right or not without feedback from wife.	**368-87** He thinks a good relationship is important. It's easier to work better together if you like the SLT, otherwise there's a barrier. Its motivating if you like the slt and makes it a more pleasant experience. ***388-99*** *He accepted critical feedback from the SLT because he felt it was delivered in an appropriate manner. He recognised that this is an educational/therapeutic tool, as he was a teacher before his stroke.* *-"...there'd be a lot of times I think, a lot of times when i would have to say to you: "no that was no good, no do it again" how did that* ***-That's fine.*** *-That sat OK with you, did it?* ***-Well, it was similar to me teaching (a skill)*** *-Teaching, it was similar to you teaching? Ah except the other way round? OK. And is there anything in the way that that is delivered that helps to kind of sweeten it a wee bit? Or not?* ***-Its ... how you say it .. not what you say*** *-...So its about your manner and approach.* ***Yes"*** He and his wife describe how they feel that he was given poor or negative feedback at the beginning of his rehab (as an inpatient) and that he felt demotivated by this. **447-59** Regarding his dysphagia management as an inpatient he felt the SLTs didn't explain well to him their caution at introducing oral feeding. **549-93** He felt the AHPs on the ward were negative and ?too honest re his prognosis and that this did not motivate him.

	2.3 Feedback	
	2.3.a Self-monitoring not sufficient – need feedback from others.	**2.3.b Feedback from SLT**
		600-3 His wife said the staff at hospital should have given him more hope in his initial feedback about prognosis -***“What they probably should have said was ”well, your speech ll probably not come back to what it was but we don’t know for sure” There could be a glimmer of hope there, you know if you practice hard it may but you cant guarantee, but to turn round and say no you can’t do that ..”***

	2.4 The Practice		
	2.4.a Did follow recommendations	**2.4.b Didn’t follow recommendations**	**2.4.c Continues to practice**
Des		**25; 49** Never played the DVD to the end. Felt stupid doing them. Did not use a mirror.	
Andy		Didn’t do any practice **52-6** -*“…Do you remember ever sitting and working on trying to say them clearly on your own?* ***-Nah*** *-Do you think you did at all?* ***-Nah”*** *SESSION 3: “Had done no practice”.* see also SESSIONS 4,6,7	
Paul		**239** He admitted he did not use the DVD for practice outwith sessions. He felt the book of activities and practice tasks was more useful because it made him speak. SESSIONS 2 3 4 5: *“Had not practiced since last week”* SESSION 1: *“PT has little or no opportunity for*	**63** Carer occasionally gets out materials and encourages him to practice.

	2.4 The Practice		
	2.4.a Did follow recommendations	**2.4.b Didn't follow recommendations**	**2.4.c Continues to practice**
		conversation practice during the week – v isolated" **245** Also he didn't know how to work his DVD player.	
Harry	**168-80** Concentrated on his breathing and how much he could say on one breath. Read through passage and prepare himself for tricky words by slowing down, with his wife supporting and encouraging.		
John	**32-42** His wife took him through the phrases and words -"**I started normally with the small sentences and that and did maybe a paragraph at a time of the reading".** Making time to do the practice was difficult in hospital.	Whether he did the practice or not depended on his mood/levels of fatigue. **31** -"… how did you do (the practice)? What did you do? -(wife speaking")…*But that very just much depended on how (he) felt on the day* ***-Aye cos sometimes if I was tired I couldnae do too much if I was tired. Yeah..I just said no no' today"*** *SESSIONs 7 & 8 "No independent practice carried out"*	
Neil		**79-112** This explanation he gave re how he did the practice was not clear and in sessions he had described how he read through the practice work once in his head, not aloud. Said in interview that he read it once but had to read it through a few times before that to it properly. ie did the practice incorrectly.	

	2.4 The Practice		
	2.4.a Did follow recommendations	**2.4.b Didn’t follow recommendations**	**2.4.c Continues to practice**
		SESSION 1:“Few opportunities for conversation” (therefore, he must have struggled to fully adhere to practice recommendations) Below he alludes to the fact that he used the practice material to read aloud once, not several times, in several sessions daily, as instructed. **102-3** *-“OK. and would you do that a few times or just the once, or… how did you carry that out?* ***I’d say well I just read it once but to do it you have to read it a few times. You know?”***	
Laura	**520, 536-47** Role play helped her to envisage herself in previous role and practice using strategies in more real context. She had her husband help with the practice, and he assisted her to carry out the practice as prescribed: **723 -*“in fact quite often after you’d gone I’d say to (husband) come and hear this!... We’d go over it again. And he said oh no she said not to do them xxx ..”*** SESSION 2 & 5: *“Has been practicing +++”*		She continues to practice **769** ***-“Actually I must admit I do take it out sometimes that I feel it’s you know - I’m not doing as well as I should”***
8		He concentrated more on the DVD. This suggests he may not have fully complied with	**162** He continue to practice ***“I still use it sometimes”***

	2.4 The Practice		
	2.4.a Did follow recommendations	**2.4.b Didn’t follow recommendations**	**2.4.c Continues to practice**
		the prescribed regime, which was to carry out speech practice activities and conversation practice in addition to the NSOMEs. **181-90** ***-“Yes, it was good that (the speech practice materials), but the DVD was much better…But I still practiced a bit*** (ie with the speech practice materials)***, but not the way I should have. I didn’t… I don’t know why but it was more the DVD.*** *-You prefer to use the DVD…* ***-Yes*** *-Uh huh, than to use the written stuff.* ***-That’s right. I’ve still got the written stuff here…But to be honest I don’t use it very often”*** *SESSION 2: “reports reduced interaction opportunities despite large household. Had not completed “conversation practice” in timelog forms”* SESSION 3: *“Has been doing a lot of exercises, frequently* (ie the NSOMEs)”	
Terry	**203-5 495-500** He carried out practice in the work place as well as at home; with a tape recorder. **403 “*Whatever you gave me I worked hard*”** *SESSION 3: “Has been practicing reading aloud from mags etc”*		**488-500** continues to carry out practice when he feels his speech is unclear or needs work

	2.4 The Practice		
	2.4.a Did follow recommendations	**2.4.b Didn’t follow recommendations**	**2.4.c Continues to practice**
Dean	**37, 72-80** Did a bit every day, not routine		
Anth.	**170-77** did it with partner, in spite of tongue pain *SESSION7 “..They’re practicing +++”*		**1-19** has done some practice since last session
Sarah	**250-4, 273-7 310, 893-900** If it wasn’t clear she would repeat it, could hear herself; had conversations with herself as she couldn’t practice with people much She would underline words that were not good and worked harder on them for h/wk **12S 540-4** She did the NSOMEs every day. **12S 100, 145**. She worked harder on her therapy than she had had to after her first stroke.	**268-78** She had conversations with herself as she couldn’t practice with people much. This is not what was recommended, and surely its very difficult to simulate a real conversation in this way. However it is clear that she tried to follow recs, as far as she could within her abilities.	**60,** She continues to practice “***I do them all***”
Anna	**93-105** She used to practice with her husband and then me. He was a big support and she said she wouldn’t have done as much without him. According to her timelogs, she did not carry out as much NSOME practice as was recommended (ie she was a non-adherer), however she asserted in her interview that	She did not adhere to recs, according to timelogs and casenotes: *SESSION 2: “Had not carried out practice of words and phrases – gave more instructions”* *SESSION 3: “Had not used DVD since last session – said she did not realise this was homework, despite having this explained to her last week, in detail”* *SESSION 5: “Not done [lip and tongue] practice through holiday period and 1 x*	

	2.4 The Practice		
	2.4.a Did follow recommendations	**2.4.b Didn't follow recommendations**	**2.4.c Continues to practice**
	she did lots. **115: -** "***I was always in the kitchen, book opened***" *See next column →*	*episode of words and phrases practice only. Discussed reasons for this: unable to give reason – sometimes too busy. Discussed need to practice as SLT alone can not effect change; needs hard graft"* *SESSION 7: "Little practice carried out (max 20 mins)"*	
Mary	**38-52** She still practices – but for longer than recommended - every day for 30-45 mins. She feels that this is too much and its better in short bursts. She thinks they are working		**38-46** **"I do it every morning – every every every morning!"**
Adrian	**82-91, 421** His wife helped him do lots of repetition-she would listen and repeat back to him what she heard and he would repeat. Treated it as a challenge		

	2.5 Goals	
	2.5.a Wanted to return to being able to do something specific again	**2.5.b Had non-specific goals/aims**
Des	**139-163** Said he didn't have any goals (**139**) but… *"…look, that's the goal that I wrote down after our second meeting: "to seek out conversation with unfamiliar people occasionally"* (**SLT 158-9**). Following discussion with SLT he joined 3 groups. He didn't feel he could have worked toward something more concrete (too tired).	
Paul	**141-3** He had wanted to speak on the phone-not avoid phone. Feels he has achieved that (although his sister doesn't understand him - ?hearing impairment) **132**: -*"**Well, I thought I'd be able to talk to folk and I can do on the phone now…Make myself understood. And I can do that as well. … And eh I would feel better*** *-Right ..and do you feel that's what's happened?* -***Yes"***	
Harry		**113** he didn't expect it to be perfect after therapy: ***-"I've got enough common sense to ken that itll not be the way it was before"***
John	**121-29** He had wanted to go back to selling and speaking in church *SESSION 1 "Pt's goal is to return to bible readings at bible meetings at his church therefore [we] will use biblical material.* *SESSION 5:* *"Wife keen to help. Supports his return to some reduced amount of work with [company] so feels .. [telephone work] would be appropriate to concentrate on"*	

	2.5 Goals	
	2.5.a Wanted to return to being able to do something specific again	**2.5.b Had non-specific goals/aims**
Neil	**231-7** He didn’t work towards his goal- which was to speak to ASDA staff – it was too frustrating *“It might have changed now but then I suggested why don’t we try to practice speaking to the woman at ASDA cos that was the only trip that you were getting outside the house wasn’t it?* ***Yeah*** *Uhuh what did you think about that when I suggested that to you?* ***I thought you were quite right. Speaking to different people who XXX used to me. My family I was speaking to them so they knew how I spoke, so…*** *It’s not exactly the way you wanted it to sound or not what you wanted to say. Em is there anything I could have done to have increased your confidence around speaking to other people?* ***No.*** *Why not?* ***At the end of the day it’s down to yourself. So…*** *You think that’s down to you?* ***Yeah*** *You don’t think its part of my job to help you?* ***No.*** *As a speech therapist, do you not* ***Speaking yeah, XXX but when you're actually doing it its down to yourself. So…*** *True, that’s true, its down to you. If id come with you, do you think that would have helped, if I’d have, instead of your brother, Id have come with you, and tried to…* ***Yeah but I knew what I had to do, anyway so…*** *So it wasn’t the fact that I wasn’t there, it was the fact that you just didn’t want to*	

	2.5 Goals	
	2.5.a Wanted to return to being able to do something specific again	**2.5.b Had non-specific goals/aims**
	Yeah its down to the individual person, so…" *SESSION 2: "Goal = speak to staff member at ASDA checkout"* *SESSION 7 "He suggested [he's] feeling fatalistic re speech difficulties appears non-motivated to tackle it. Has very limited opportunity to speak and has not attempted his goal of speaking to staff when shopping at ASDA. Possibly because the goal was suggested by SLT and in the absence of a self-identified goal?"*	
Laura	**443-64, 473-4, 510-1, 821-8** She had a goal of not avoiding speaking situations eg telephone; couldn't set goals at beginning because she didn't know how much she was capable of doing or where she could aim. -*"**I don't think I could cite specific goals at that time because you don't know how much you can you can do"*** It seems from what she says that people need support to do that. **788-796** ***"Xx speech you have to take it in small bits you know em there's no point in saying I'll do the marathon in a year and a half you know you've just got to take it small bits at a time*** *Uh uh do you mean have short goals to work towards?* ***Yes*** *Is that what you mean?* ***Yes*** *Yeah* ***Achievable goals to work for xx"*** Achieving small goals motivates her. Her goal was to: ***"get to a stage where I don't have to concentrate on every single word that I'm saying cos it was tiring as well"***	

	2.5 Goals	
	2.5.a Wanted to return to being able to do something specific again	**2.5.b Had non-specific goals/aims**
	821 She describes how achieving one goal motivates you to aim for more and they must be achievable: **-“*Just by achieving small goals small steps however small they are I mean sometimes in the speech (therapy) I would maybe one day just suddenly say something like ‘Lilias’ just – right out! .. And that boosts you to try you know other things … you’ve got take it slowly I think if you set unachievable goals you know just ridiculous things…You don’t achieve them therefore you get depressed”***	
Arthur		**90-100** he wanted to be able to tell people how he felt and speak clearly
Terry	**348-78** He had wanted to go back on stage (singing and entertaining) but this was hampered by new health issues. Activities carried out for practice were relevant to this – songs **226-8 “*I wanted to prove to them that I wasn’t drunk”*** Ie wanted to sound sober. *SESSION 8: “He listened to his first recording and compared it to his last one: marked difference improvement in intelligibility and even voice quality. He said he was happy with this and feels more confident. Plans to go back to singing in a few weeks with his band!”*	**14 “*I want to help my voice*”**
Anth.		**32-52** He had expected to be able to speak normally again despite having a significant speech impairment. Realised halfway through that that wouldn’t be the case, and admits that he didn’t achieve that.
Sarah		**442-468** **-“to be able to speak clearly”** No specific goal. **242 “*I wanted to be able to speak properly”*** She didn’t like the idea of a SMART goal. It seemed that

	2.5 Goals	
	2.5.a Wanted to return to being able to do something specific again	**2.5.b Had non-specific goals/aims**
		she felt a goal like that was reducing her independence or encroaching on her personal life: -“***I’d like to manage myself.”***
Anna		**241 324-333** She did not have a specific goal. Maybe a more functional goal esp around increasing her confidence might have been better. If she could no longer be avoiding people and be looking at going back to work she would have felt she’d have achieved more. **9-21** She hadn’t thought about it but didn’t expect it to be hard work. She had thought she’d be talking perfectly at the end
Mary	**1-7** Her goal is to speak as she was speaking before. And for husband to understand her.	
Adrian		**20-22, 30-33, 68** Didn’t know what to expect – hadn’t really thought about it. His wife had had no idea as had never been allowed in to therapy. Hoped for some improvement

	2.6 Outcomes	
	2.6.a Improvements patients would have made	**2.6.b How did people measure outcomes and benefits of therapy?**
Des	**41-55** He would have got rid of DVD as it did not offer a tangible means of seeing monitoring performance. Exercises should have been specific to his difficulties. Needed human feedback. **185 -*“Instructions to use a mirror would have been useful- and to watch out for what was wrong. I think that would have initially come from you and would have been translated into practice”.*** **275** He felt it may be necessary to prepare people for the fact that they will have to listen to themselves on tape and be confronted with their dysarthria in therapy.	Although not part of the design of the therapeutic programme, he was referred to a stroke group (primarily to enable him to access opportunities for conversation). He saw a benefit of this being that he was able to meet others in similar or worse situations and also to increase his understanding that there were others worse off than him, which he saw as a benefit **:** ***148-9 “So I know im not so badly affected. Im one of the lucky ones”.*** *SESSION 5 “Reported that his daughter said his speech had improved and was clearer. This has given him some confidence in his speech.”*
Andy	He was not asked about changes he would have made, because of his memory difficulties.	
Paul		**132-6** He measured his outcomes thus: ***-“Well, I thought I’d be able to talk to folk and I can do on the phone now…Make myself understood. And I can do that as well. ..And eh I would feel better”*** (he didn’t specify what he meant re feeling better, but later says that he feels better now that he is “***out and about***” So maybe he was able to get out because his speech had improved thus making him feel better **165-**7). He was no longer avoiding the phone, either (**149**) He saw a benefit of therapy as being that it (**3P 39)** made him ***“start thinking of what to do what to say.”*** **106 “*I wish I’d got it sooner*”**
Harry	No changes recommended	**17, 25, 104-5** Therapy helped him pay more attention to his

	2.6 Outcomes	
	2.6.a Improvements patients would have made	**2.6.b How did people measure outcomes and benefits of therapy?**
		speech, and slow down. **76-7** He also found it useful to learn more about dysarthria so he can explain his problem to others when he encounters difficulties. **238** he thought therapy “***was quite good”***
John	No changes recommended	**106-20** Initially he didn’t feel he needed therapy as his speech was fine. He likes it when the carers tell him his speech is improved. **429 487** he can see a difference, when compared to how he was initially.
Neil	No changes recommended	
Laura	No changes recommended	**119** She measures her outcomes by what her friends tell her and how much they can understand her. She also alludes to the fact that her progress is variable and that gains she has made can be lost briefly when she’s tired. She also has to speak slower to strangers.
Arthur	**259-60** None because he felt it worked **8A 204** He would’ve liked DVD with SLT on it saying target words for practice	**99-104** He measures outcomes by what family tell him about how much they can understand him. It is highly motivating for him to work toward them understanding him on phone. Family feedback helps him to monitor his progress. **99:** **-“*You know I think I’m a bit better because (family members’ names) they say I’m a lot better*”.** *SESSION 7:“Reports that family understand him better on the telephone [now]”* **137** He also measured his outcomes by his ability to say specific words**.**
Terry	**289-90** couldn’t recommend any improvements, because : ***I think you can only do what you can do and its up to the individual for to do the rest.”*** He appears, from what he has said, to be	**10-12 “*I enjoyed it… I know it was helping my voice*”** He believed there was benefit to the therapy because he could see a change, it was working.

	2.6 Outcomes	
	2.6.a Improvements patients would have made	**2.6.b How did people measure outcomes and benefits of therapy?**
	satisfied that his therapy had met his needs and that if others weren't progressing, there was little else that the therapist could do – its down to the patient to put in the work.	**321** He feels that both his speech and his confidence have improved equally **304** Now he feels he can use the phone in all situations except with foreign call centre workers**.** No longer avoids the phone. **179** He listened back to old tape recorded segments of speech to compare and contrast his performance and monitor progress. **230-9, 92** He also measured his outcomes by noting what colleagues told him re his intelligibility and how much they could understand him. ***"The more you came out they could understand me more and more and more*"**
Dean	No changes recommended	**D 166:** He feels he has more confidence now and his speech doesn't bother him any more. **179:** -"***Speak a lot better to people (now)***"
Anth.	**140-144** He would have liked twice weekly sessions – would help him remember, he said.	
Sarah	**337-9; 828-32** Initially said she wouldn't change anything. Despite activities being boring, she felt there should have been more work. **368-73; 379-81.** Would have liked more sessions/follow up - not enough and as a result, she does it on her own now; would have liked follow up.	**152** **-*"I could feel my words getting clearer"*** She felt it was working and was beneficial because she could hear an Improvement in clarity
Anna	**262** Participation based approach rather than impairment based might have been more effective. She agreed it could have worked on her confidence in different situations **457-8** more sessions	**31** She feels she has improved a bit because she can talk slower and because she's more aware: **45:** -"***Im speaking, thinking all the time what Im doing."*** **78 *"Im not shouting the same anymore"***
Mary	**282-**why is there no follow up, husband asked, to update	**476** Friends say she's better. She gauges her improvement

	2.6 Outcomes	
	2.6.a Improvements patients would have made	**2.6.b How did people measure outcomes and benefits of therapy?**
	exercises and activities **221-233** She says she sounds OK on tape but her husband doesn’t understand her when she speaks to him. This suggests that more carryover activities might have been useful. Maybe she could have been taught how to tape themselves having a conversation, and listening for whether tape recorded speech is a true depiction of her natural speech?	through others’ feedback.
Adrian	No changes recommended	***166*** *-”How do you know theres been improvement how can you say that so confidently?* ***-People can understand me more.”*** Wife said: ***-”And Ive noticed that recently we have been speaking a lot more”***

Appendix 12. Fisher’s Test

Cell(1,1)	Table prob
0	0.0056
1	0.0783
2	0.2937
3	0.3916
4	0.1958
5	0.0336
6	0.0014

Table	No support	Support	
Non-adherer	5	1	6
Adherer	2	7	9
	7	8	15

Fisher's exact test	5 or more (one-sided)	0.035
Fisher's exact test	4 or more extreme (two-sided)	0.0406