Increasing opportunities for functional communication learning in post-stroke aphasia: an exploratory study of Early Supported Discharge rehabilitation



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For Dad

The inspiration and support for this thesis

### Am I Alive

Film just starting, Whiskey glass full, Fire warm, Cold outside.

Why am I here? I'm shouting With no sound, My arms won't move.

White coats, Stethoscopes hanging, Writing, Walking Away.

Why am I here? I'm shouting With no sound, My legs won't move.

Pretty smile, Gentle voice, Relax and rest As she wired my chest.

Wheelchair waiting, Out for tests, Back to the ward, That sign on the door.

STROKE RECOVERY UNIT

Film just starting, Can't even remember What I want to forget. Am I alive?

Pretty smile, Gentle voice, Sleep now.

P. St 16 (m) Peter Shiggins

### Abstract

Aphasia is a communication disorder affecting all language modalities to varying degrees of severity, and impacting on the person's overall quality of life, place in society and interpersonal relationships. Early post-stroke, healthcare professionals (HCPs) are often the main communication partners of people with aphasia (PWA), yet there are apparently few opportunities for communication practice in the course of rehabilitation. Practice is key to (re)learning, with other processes such as intensity, context, and the therapeutic alliance also shown to impact on outcomes of (re)learning. Currently, PWA in the UK receive stroke rehabilitation in a variety of care settings. Rehabilitation in the home through Early Supported Discharge (ESD) is the focus of this study.

A systematic review using adapted Cochrane methodology examined how learning processes are reported in speech and language therapies for post-stroke aphasia with a functional outcome. The 34 included studies were reported with variable degrees of adherence to the Template for Intervention Description and Replication (TIDieR) checklist. More specific and comprehensive articulation of the learning processes entailed in rehabilitation and (re)learning is needed in such aphasia therapies.

An exploratory study was conducted to understand how conditions for (re)learning are produced during routine rehabilitation for PWA in the ESD context. Observational and interview methods were used to collect data on perceptions and practices of routine rehabilitation with 10 PWA and 22 HCPs (observation study) and 9 PWA and 8 HCPs (interview study). Interview data were analysed using thematic analysis; observational data explored the structure and ecology of the rehabilitation session and how the interview themes were enacted in interactions. Interview and observation data were analysed and combined within an Activity-based Communication Analysis (ACA) approach.

Opportunities to enhance (re)learning of functional communication during routine rehabilitation were identified, but not consistently realised. The home environment, rapport, emotions, the structure of sessions and HCP training all influence PWA's (re)learning. These findings have clinical implications and warrant further research.

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### Gó raibh míle maith agaibh!

## Acronyms

Acronym	Description
ACA	Activity-based Communication Analysis
ANELT	Amsterdam-Nijmegen Everyday Language Test
AP	Assistant Practitioner
вох	Lexical Semantic Therapy Program (Translated from Dutch)
BP	Blood Pressure
СА	Conversational Analysis
CADL	Communication Activities of Daily Living
CASP	Critical Appraisal Skills Programme
CETI	Communicative Effectiveness Index
CIAT	Constraint-Induced Aphasia Therapy
CILT	Constraint-Induced Language Therapy
CIMT	Constraint-Induced Movement Therapy
FSD	Farly Supported Discharge
FCP	European Communication Profile
FIKs	Phonological Therapy Program (Translated from Dutch)
GCP	Good Clinical Practice
НСР	Healthcare Professional
	International Classification of Functioning Disability and Health
	Language Enrichment Therany
	Language Impairment and Euroctional Therapy
MCA	Mental Canacity Act
MDT	Multidisciplinary Team
MIT	Melodic Intonation Therapy
	National Health Service
NIE	No Longer Eligible
	No Longer Lingible
	Instructional research Ethics Service
UASIS	rehabilitation for people with aphasia in Early Supported Discharge
OT	Occupational Therapiet
DACE	Decupational meraphs
	Promoting Aphasics Communicative Enectiveness
	Participant Information Sheets
	Patient and Public Involvement
	Priysioliterapist
	Person/People with Aphasia
	Research and Development
RA	Renabilitation Assistant
RUSLI	Royal College of Speech and Language Therapists
RUI	Randomised Controlled Trial
REC	Research Ethics Committee
REST	Reduced Syntax Therapy
SLI	Speech and Language Therapy/Therapist
SIPARI	Singen Intonation Prosodie Atmung Rhythmusubungen
	Improvisationen (trans. Singing Intonation Prosody Rhythmic
	exercise Improvisation)
SKT	Speech Repetition Therapy
TBI	Iraumatic Brain Injury
tDCS	Iranscranial direct-current stimulation
TIDIER	Template for Intervention Description and Replication
TMS	Iranscranial Magnetic Stimulation
TOMs	Therapy Outcome Measures
UK	United Kingdom

UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VAS	Visual Analogue Scale
VNeST	Verb Network Strengthening Treatment for Aphasia
USA	United States of America
WAB	Western Aphasia Battery
WHO	World Health Organization
VAS VNeST USA WAB WHO	Visual Analogue Scale Verb Network Strengthening Treatment for Aphasia United States of America Western Aphasia Battery World Health Organization

### Chapter 1: Introduction to the thesis

### Increasing opportunities for functional communication learning in post-stroke aphasia: an exploratory study of Early Supported Discharge rehabilitation

### 1.0 Introduction

The introductory chapter will provide the background to the thesis, outlining the field of study, aphasia after stroke, its impact on the person with aphasia (PWA) and rehabilitation options for aphasia. Rehabilitative interventions for aphasia and how these have developed in recent years will be discussed. The thesis will also focus on learning and how this has been studied and reported in aphasia research. Gaps in the knowledge base will be identified and the purpose of this thesis outlined.

### 1.1 Stroke

Stroke is one of the most common neurological conditions worldwide (Sousa et al., 2009) with figures set to rise with ageing populations along with the increase of noncommunicable diseases (Strong, Mathers, Stephen, & Beeaglehole, 2005). About 150,000 people have a stroke in the UK each year (Stroke Association, 2016) and stroke is a leading cause of disability (Ances & D'Esposito, 2000).

### 1.2 Aphasia

Aphasia is the name given to the acquired communication disorder caused by damage to specific language areas of the brain (Koenig-Bruhin, Kolonko & Annoni, 2013; McNeil & Pratt, 2001). Aphasia may impair speaking, understanding, reading and/or writing in one modality or in a combination of modalities. It can occur as a result of a variety of aetiologies such as trauma, infection, tumour or vascular reasons, the latter being the most common aetiology (Koenig-Bruhin, Kolonko & Annoni, 2013). It is reported to affect one in three stroke survivors after first-in-a-lifetime stroke (Code & Petheram, 2011).

### 1.3 International Classification of Functioning Disability and Health (ICF)

The personal experience, impact and resultant disability of aphasia is highly individual and arises from an interaction between the impairment itself and the person's environment, activities, psychological and social factors (World Health Organization, 2001). This was conceptualised in the International Classification of Functioning Disability and Health (ICF) (World Health Organization, 2001)(Figure 1). The ICF helped to shift the view of illness and health from a medical model, where the focus is on the impairment alone, to a functioning, disability and health perspective (World Health Organization, 2011), in which health is

viewed from a biological, social and individual perspective (Stucki, Ewert, & Cieza, 2002). Aphasia can impact the different areas of the ICF and to different degrees, making it a highly individual experience.



Figure 1. International Classification of Functioning Disability and Health (ICF)

### 1.4 Impact of aphasia

Aphasia can affect the different modalities of language to different levels of severity. Impairments in language, such as word-finding difficulties or problems with processing auditory and/or orthographic information, can have a significant effect on how a person communicates. The resultant impairment can have a substantial impact on all aspects of an individual's life, with immediate and long-term implications for communicative effectiveness (Long, Hesketh, Paszek, Booth, & Bowen, 2008). This in turn can impact a person's social competence (Simmons-Mackie & Damico, 2007) and willingness to communicate. A person's identity can be profoundly affected (Cruice, Worrall, Hickson, & Murison, 2005; Hilari & Byng, 2009) by the resultant social isolation and exclusion, changes in interactions with others, roles and identity (LaPointe, 1999). People with aphasia report an overall poorer quality of life than individuals who have had a stroke without aphasia (Hilari & Byng, 2009; Kim, Warren, Madill, & Hadley, 1999; Ross & Wertz, 2003). Therefore, it is important to listen to PWA to fully understand how aphasia impacts their life and their psycho-social wellbeing (Long et al., 2008). Speech and language therapists (SLTs) have a key role in the management of rehabilitation for PWA. The Royal College of Speech and

<sup>(</sup>World Health Organization, 2001)

Language Therapists (RCSLT) guidelines advocate that assessment and intervention target all the areas of the ICF (RCSLT, 2005).

### 1.5 Distinction between language and communication

There is a distinction between the terms language and communication. Language is the mode used to transfer information; an example is the French language. It has certain properties such as syntax and morphology, and can be used in spoken or written forms. Language can have interactional functions, used to negotiate peer relationships, offer turns and save face for both parties in the conversation (Brown & Levinson, 1987; Labov, 1972; Sacks, Schegloff, & Jefferson, 2012), as well as 'transactional' functions for getting a message across (Brown & Yule, 1983); the former being the most frequent use of language. Language also incorporates other purposes such as establishing identity, creating interpersonal meanings and establishing relationships (Armstrong & Ferguson, 2010). Communication, however, is the transfer of information from one person to another using a variety of different modes, for example verbal linguistic modes and non-verbal modes, such as facial expression and gestures. Language is therefore a subset of communication. A person can have impairment in their linguistic accuracy but retain communicative skills.

### 1.6 Impairment-based approaches to aphasia management

There are a number of approaches to the management of an individual with aphasia, including impairment-based and functional approaches. An impairment-based approach to rehabilitation involves assessing PWA to identify the nature of their impairment, for example identifying expressive language difficulties with marked phonemic (word sound) difficulties. After a needs-based assessment, interventions focus on methods for improving the impairment in linguistic abilities, for example, addressing word-finding impairments using semantics (word meanings) or word sounds (phonemes) (e.g. Best & Nickels, 2000; Davis & Pring, 1991; Hickin, Best, Herbert, Howard, & Osborne, 2002; Howard & Orchard-lisle, 1984; Kay, Lesser, & Coltheart, 1996; Nickles & Howard, 1994).

### 1.7 Functional communication approach to aphasia management

Functional communication approaches, by contrast, take the focus beyond language to communication. The observation that people with aphasia can 'communicate' better than they can 'talk' (Holland, 1980) heralded a move away from focusing on therapies for linguistic accuracy ('impairment-based' therapies) to therapies that focused on communicative ability ('functional communication' therapies). In the early 1970s, Martha Taylor Sarno was revolutionary in developing an alternative to impairment-based therapies

for people with aphasia. She developed functional approaches to assessment and intervention using what she termed the 'Functional Communication Profile' (Sarno, 1969). The functional communication approach places emphasis on the activity and participationlevels of the ICF (World Health Organization, 2001) and views aphasia as a disorder of 'masked competence' (Simmons-Mackie & Damico, 1995) which can be unveiled through rehabilitation. This approach addresses the person's actions, the ways in which they convey messages, and the activities that they engage in and that are meaningful to them (Davis, 1986; Simmons-Mackie & Damico, 1995). A functional communication assessment can involve identifying the PWA's communication strengths, such as maintained gesticulation abilities. It can also include identifying the activities the person wants to engage in, such as writing emails, and the environments and social settings they prefer to communicate in, such as the workplace or with family and friends in places such as pubs or restaurants. Functional communication interventions aim to restore the individual's capacity to engage in activities, in their everyday environments, despite residual language and communicative impairments (Brookshire, 2007; Byng, Pound, & Parr, 2000; Cruice, Worrall, Hickson, & Murison, 2003). People are encouraged to adapt/compensate for impairments by getting their message across using spared abilities such as intonation, gesture or facial expression, tailored to individual needs, roles and relationships (Elman & Bernstein-Ellis, 1995).

There have been calls for more functional communication approaches in clinical management and research (Holland, 1980; Sarno, 1969; Worrall & Fratelli, 2000). Increasing a person's communicative ability through speech and language therapy with a functional goal may have a positive effect on the person's social participation and thereby their quality of life (QOL) (Cruice et al., 2003).

### 1.8 Definition of functional communication

The term 'functional communication' was originally coined based on a need for a definition for third-party insurance in the US. It originated exclusively as 'information exchange or message transfer' (Roth, 2011), nearly becoming synonymous with transferring basic needs (Elman & Bernstein-Ellis, 1995). At that time, the term came into vogue and was used inconsistently on grant applications and in articles (Elman & Bernstein-Ellis, 1995). This caused confusion regarding the meaning of the term. In the aphasia literature and clinical practice, the term 'functional communication' has been ambiguous and used inconsistently; definitions changed according to purpose and context. With more focus on the area of functional communication in research, the definition needs to be succinct. Due to this inconsistency, the researcher has outlined an all-encompassing definition for the purpose of this research. This was influenced by the work of leading aphasia researchers Worrall and Frattali (2000) and Sarno (1969). A 'functional communication' outcome as defined for this thesis is:

For the person engaging in therapy to be able to function communicatively with autonomy and participate actively in their communicative environments. This goal can be addressed through restorative (addressing the impairment) or compensatory (adapting to the impairment) interventions. Communicative competence is targeted, whereby the person can use the best modality – such as gesture or facial expression – or combination of modalities to achieve their chosen communicative goal, such as telling a joke, buying a cup of coffee or Skyping grandchildren.

### 1.9 Learning in rehabilitation

### 1.9.1 Definition of learning, skills and performance

In neurorehabilitation, adaptation after a stroke is thought to occur as a result of (re)learning (Krakauer, 2015), placing learning in a central role for restorative therapies (Winstein, Lewthwaite, Blanton, Wolf, & Wishart, 2014). For the purpose of this research, learning is defined as a sustainable or long-term change in a capability or skill acquisition (Winstein et al., 2014). A skill is thought to be developed when the person has the ability to attain the same goal with maximum certainty and minimum time and energy (Guthrie, 1952; Schmidt, R & Lee, 2013). This should be distinguished from short-term temporary change, known as performance (Schmidt & Lee, 2013; Winstein et al., 2014). In rehabilitation, performance is exemplified in the patient's ability to have success with a particular skill immediately after training, whereas learning is their ability to carry out the rehabilitation goal in the long term. Learning, rather than performance, is the focus of this study.

### 1.9.2 (Re) learning and learning processes

(Re)learning is a complex process that involves neuroplasticity, including spontaneous recovery and learning-dependent cognitive processes associated with practice, training or experience, that lead to long-term change in behaviour (Langhorne, Bernhardt, & Kwakkel, 2011; Schmidt, 1988).

Neuroplasticity is the underlying mechanism of (re)learning (Cramer et al., 2011). The literature on motor learning has set out learning processes that can affect neuroplasticity after a stroke (Shumway-Cook & Woollacott, 2007; Weinstein, Lewthwaite, Blanton, Wolf

& Wishart, 2014). Practice is one of the most important learning processes for skill acquisition (Dayan & Cohen, 2011; Schmidt & Lee, 2013) with feedback (Van Vilet & Wulf, 2006), intensity, context and saliency all shown to be influential (Shumway-Cook & Woollacott, 2007). These learning processes have been adapted in research to discover how to optimise (re)learning after a stroke (Kleim, 2011).

### 1.9.3 Learning processes and aphasia rehabilitation

Advances in the understanding of neuroplasticity and learning processes in stroke rehabilitation generally have been influential in informing and energising research in aphasia therapies. As the motor-learning literature has also shown, more practice brings about increased rehabilitative success for aphasia (Krakauer, 2006). Donovan and Radosevich (1999) and Pulvermuller et al., (2001) have investigated the optimum configuration of practice for aphasia rehabilitation, but it is still unknown. Levels of saliency (personal relevance and importance) (Kleim & Jones, 2008), engagement in rehabilitation (Horton, Howell, Humby, & Ross, 2011), the context of rehabilitation (Beckley et al., 2013), intensity (Bhogal, Teasell, & Speechley, 2003; Pulvermüller et al., 2001), feedback (Shumway-Cook & Woollacott, 2007) and the therapeutic alliance (Bordin, 1979) have all been shown to have an impact on (re)learning in aphasia rehabilitation. However, the ways in which (re)learning and generalisation of learning occur has been underexplored and underexplained in aphasia research (Vallila-Rohter & Kirana, 2013). More explanation is needed of the process by which individuals with aphasia actually learn targeted behaviours (Ferguson, 1999).

Other variables also contribute to (re)learning and thus adaption in aphasia rehabilitation. For example, there is strong evidence that the site and size of the lesion is associated with prognosis (Pataraia et al., 2004; Price, Seghier, & Leff, 2010) as well as the person's health status, age, education level and the timing after the stroke related to so-called spontaneous recovery (Kleim, 2011).

### 1.10 Rehabilitation care pathways: Early Supported Discharge

There is currently a variety of rehabilitation contexts in the UK, including in- or out-patientbased rehabilitation in hospitals or clinics (acute and post-acute). Early Supported Discharge (ESD) has been added as part of the National Health Service (NHS) stroke pathway (Langhorne et al., 2005). In ESD, the person who has experienced a stroke is discharged from hospital when they are medically fit to undertake rehabilitation services at home. ESD enables people to return to their home earlier, with reduced need for institutional care and increased success in regaining functional independence (Fearon, Langhorne, Early Supported Discharge Trialists, 2000). A systematic review of RCTs reviewing ESD services found a reduced risk of death or dependency (Langhorne & Widen-Holmqvist, 2007). ESD also showed positive results in terms of the length of hospital stays and satisfaction with care services (Langhorne et al., 2005). A case study of an ESD service in Sweden showed benefits for patient motivation, more focus on self-directed activities, greater partnership between patient and therapist, greater saliency and a more realistic understanding of the prospects of future recovery (Langhorne & Widen-Holmqvist, 2007).

ESD is currently included in 66% of stroke rehabilitation services in the UK (Intercollegiate Stroke Working Party, 2012). The NHS hopes to increase this service as it would be costeffective for the NHS over a ten-year timeframe (Department of Health National Audit Office, 2010). ESD is an economically viable addition to in-patient stroke care (Langhorne et al., 2005), saving the NHS money and providing a solution for limited bed space in hospitals (McNamee, Christensen, Souter, Rodgers, & Craig, 1998). However, ESD is a complex system of care and success depends on a Multi-Disciplinary Team (MDT) approach with regular coordinating meetings (Langhorne, Berhardt & Kwakkel, 2011).

### 1.11 Justification for thesis

(Re)learning is key to the success of aphasia rehabilitation (Hopper & Holland, 2005). Processes entailed in (re)learning, such as intensity, context, saliency, feedback and the therapeutic alliance, are thought to influence the success or otherwise of (re)learning. Practice is key to skill acquisition and (re)learning and is an important factor in rehabilitative success for aphasia (Krakauer, 2006). However, there are a number of key areas that warrant clarification and further study regarding (re)learning in aphasia rehabilitation. Salonen (2013) outlined that clearer definitions of learning are needed in aphasia research, and this may help us to understand why rehabilitation works for some people but not others (Best & Nickels, 2000; Kelly & Armstrong, 2009).

Currently the number of direct contact hours between PWA and SLTs in the NHS is decreasing. NHS stroke guidelines place SLTs' priority on swallowing disorders over communication management. This means that there are fewer opportunities for functional communicative practice for PWA, thus reducing opportunities to practise the key component of (re)learning. However, PWA have contact with a variety of healthcare professionals (HCPs) as part of the MDT stroke team. It may be possible to optimise these contacts to increase opportunities for communication practice.

ESD could reduce the cost of stroke care by 9-20% (Beech, Rudd, Tilling, & Wolfe, 1999), and on average 40% of acute stroke patients are suitable candidates for ESD services (Fearon, Langhorne & Early Supported Discharge Trialists, 2000). Therefore, the NHS and UK Department of Health, which aim to improve the quality and equity of care and outcomes for priority service areas in the UK (Agrawal & Mitchell, 2005; Department of Health National Audit Office, 2010), advocate increased ESD services.

Research has been conducted on the effectiveness of ESD compared to conventional stroke services. However, it appears from a comprehensive literature search that no studies have examined speech and language therapy rehabilitation specifically in this context. No studies have researched how the context of domicile-based ESD rehabilitation may influence (re)learning of functional communication skills. There may be opportunities in routine rehabilitation which can be exploited to increase speech, language and functional communication practice and, consequently, rehabilitation success. Increased rehabilitative success may affect the quality of life of a person with aphasia and help with their reintegration post-stroke. Considering the importance of learning processes on (re)learning in aphasia rehabilitation and the potential increase in ESD stroke services, more research needs to be conducted in this area.

The overall aim of this study is to explore opportunities for functional communication (re)learning in the context of routine ESD reahabilitation (rehabilitation conducted in day-to-day practice) between healthcare professionals and people with aphasia.

### 1.12 Purpose statement

The purpose of this study is to develop a deeper understanding of the potential for enhancing functional communication rehabilitation for people with aphasia by increasing opportunities for learning in the context of post-stroke Early Supported Discharge (ESD).

### 1.13 Research objectives

- To examine the learning processes that underpin speech and language therapies with a functional goal and how these have been examined and discussed in speech and language literature.
- To explore and understand the nature of the interactions between people with aphasia, healthcare professionals and the rehabilitation activity in the context of Early Supported Discharge (ESD).

- 3. To identify opportunities for increased interactional/transactional activity practice and functional communication learning during routine ESD rehabilitation.
- 4. To identify barriers to and facilitators of functional communication learning in ESD rehabilitation.

### 1.14 Research questions

1. How have the learning processes that underpin rehabilitation been reported in speech and language therapies for aphasia with a functional outcome?

In the context of post-stroke Early Supported Discharge:

- 2. What conditions exist during routine rehabilitation sessions for enhancing functional communication learning for aphasia?
- 3. What is the nature of these conditions, how do they arise and how can they be produced?
- 4. What are the barriers to and facilitators of the uptake of opportunities to enhance functional communication learning for aphasia during day-to-day clinical practice?

### 1.15 Thesis guide

In order to address these research aims, two methodological approaches were taken: a systematic review and an empirical study.

### 1.15.1 Systematic review

### **Research question**

1) How have the learning processes that underpin rehabilitation been reported in speech and language therapies for aphasia with a functional outcome?

**Chapter 2:** To gain a greater understanding of how learning processes are reported in speech and language therapies with a functional outcome, a systematic review on the topic was conducted. The processes of learning, such as dosage, intensity, context and saliency, are thought to have an effect on the rehabilitation outcomes. A systematic review allowed the researcher to develop an understanding of the topic by synthesising previous research in the study field. Five key databases – AMED, PsycInfo, Embase, Medline (Ovid) and CINAHL – were searched to identify previous research that fit the predefined inclusion/exclusion criteria. This research was collected systematically, analysed and synthesised. It was a thorough, objective and exhaustive method and therefore a valid and reliable method for collecting data. The background, methods and results of the systematic review will be discussed in this chapter. In addition, the findings of the systematic review

will be discussed in detail in relation to the research questions and the contribution that this novel research makes to the field of speech and language therapy will be outlined.

### 1.15.2 Empirical study

The remainder of the research questions and objectives will be addressed using qualitative methods with an inductive-constructivist approach, within an empirical study.

- 2) What conditions exist during routine rehabilitation sessions for enhancing functional communication learning for aphasia?
- 3) What is the nature of these conditions, how do they arise and how can they be produced?
- 4) What are the barriers to and facilitators of the uptake of opportunities to enhance functional communication learning for aphasia during day-to-day clinical practice?

**Chapter 3:** The title of this empirical study is 'Increasing opportunities for functional communication learning in rehabilitation for people with aphasia in Early Supported Discharge (ESD)-(OASIS)'. Chapter three outlines the background of the empirical study.

**Chapter 4:** The design of the research is discussed, including methodological choices made in designing the study, the decision-making behind the chosen methods, data collection, sampling, demographic information for healthcare professional participants and participants with aphasia, and analytical methods.

**Chapter 6 and 7:** Research questions 2, 3 and 4 (above) were addressed using video observation and interview methods. Interviews were conducted with the PWA and a sample of HCPs who took part in the observational study. Interview methods were used as an adjunct to the video observation with the aim of adding further depth and knowledge to questions 2 and 4. A semi-structured interview was conducted using a topic guide, which was personalised using vignettes from the observational data. The interview data were analysed using thematic analysis (Braun & Clarke, 2006). The analysis and interpretation of the HCP interviews are discussed and summarised in Chapter 5. The analysis and interpretation of the interviews with PWA are discussed and summarised in Chapter 6.

**Chapter 7:** Observational data were used as an adjunct to the interview data to provide an in-depth analysis of how opportunities for functional communication learning arise and are produced in routine rehabilitation. Interactions between HCPs, varying in roles and experience, and PWA, of varying types and severities, during routine rehabilitations in the context of ESD, were analysed. Observational data allowed the researcher to investigate

how themes that emerged from the interview data were enacted in routine rehabilitation. These data were collected through video observations of routine rehabilitation. They were analysed within an Activity-based Communication Analysis approach (Ahlsén, 1995; Allwood, 1976), noting the ecology of the interaction, the structure of the session, how discourse and conversational structures were impacted by the influencing factors identified. In this chapter the results of the observation study will be outlined. In addition, the results from the three sets of data (interview and observation) will be synthesised within an ACA approach and summarised.

**Chapter 8:** In this chapter the principal findings will be synthesised to provide an answer to the research questions. The principal findings are contextualised within the current literature, outlining the contribution of these findings to the field of study. Limitations and strengths of the research will be discussed. Finally, the implications of this research, for clinical practice and future research are outlined.

### Chapter 2: Systematic review

# Learning processes in speech and language therapies for stroke-related aphasia with a functional communication outcome: a descriptive systematic review

### 2.0 Introduction

(Re)learning is a key aspect of language adaptation and attainment of goals in aphasia rehabilitation. Key concepts derived from motor learning such as intensity, context, saliency, feedback, the therapeutic alliance and practice have all been applied to (re)learning in aphasia rehabilitation. There is growing interest in how people with aphasia (PWA) learn in rehabilitation and how this can be optimised. In this chapter the background, methodology, and results of a descriptive systematic review of how learning processes are reported in speech and language therapies with a functional outcome will be presented and discussed.

### 2.1 Background

### 2.1.1 Learning theories and aphasia rehabilitation

Early studies of aphasia rehabilitation and learning emphasised behavioural rather than neurophysiological theories. Behavioural learning theories such as operant conditioning (Skinner, 1969) were applied (Goodkin, 1969), for example, providing verbal, token- and self-reinforcement and punishment to the person with aphasia to reinforce the correct response. Social learning theory (Bandura, 1971) emphasises that a person can learn through experience or by observing the target behaviour used by others. This learning can occur without reinforcement. This theory was applied in Promoting Aphasics' Communicative Effectiveness (PACE) intervention, which is usually conducted in a group setting (Davis & Wilcox, 1985).

### 2.1.2 Developments in learning theories and aphasia rehabilitation

In recent years investigations of learning have increased focus on neurophysiological models and theories of learning and their application. Research has investigated how prompts should be delivered by the HCPs to the PWA and whether focus should be on avoiding errors, i.e. errorless learning (Fillingham, Sage& Lambon Ralph, 2006). The optimum intensity of rehabilitation has been investigated (Cherney, Patterson, & Raymer, 2011). The principles of Constraint-Induced Movement Therapy (CIMT) (Taub, Uswatte, & Pidikiti, 1999) have been applied to Language Therapies (CILT) (Pulvermüller et al., 2001), as well as the processes involved in patient engagement and participation (e.g. Beckley et al., 2013; Horton et al., 2011; Horton, 2008; Vallila-Rohter & Kiran, 2013).

#### 2.1.3 Neuroplasticity

Neuroplasticity is the underlying mechanism of learning. The nervous system can change its structure, function and connectivity in response to stimuli and experience (Cramer et al., 2011). Hebbian learning theory suggests that particular neural pathways are activated during new skill acquisition (Hebb, 1949). There is a link between skill acquisition and neuronal reorganisation (Dayan & Cohen, 2011; Hebb, 1949). Neuroplasticity can be manifested during the acquisition, consolidation and retention of motor skills (Dayan & Cohen, 2011) and continues throughout the life course (Cohen, Brasil-Neto, Pascual-Leone & Hallett, 1993). These neural changes are illustrated in the cases of braille readers whose sensorimotor cortex adapted when they learned braille (Pascual-Leone & Torres, 1993), and the enlargement of the hippocampi of London taxi drivers after learning the numerous routes in London (Maguire et al., 2000).

### 2.1.4 Neuroplasticity and rehabilitation

(Re)learning, recovery and compensation after brain injury occurs through neural plasticity (Raymer et al., 2008), particularly in the early stages after injury, when the brain is most capable of change (Raymer et al., 2008; Robertson & Fitzpatrick, 2008). However, functional improvements have been shown in the chronic stages post-stroke, especially with intensive rehabilitation (Raymer et al., 2008). The brain can adapt and reorganise itself after lost function by using existing but dormant pathways, identifying 'silent synapses', identifying alternative networks, making synapses more efficient or through axonal sprouting (Kleim, 2011; Krakauer, 2006). It is this observed capability of the brain to change that has influenced modern rehabilitation initiatives (Weinstein et al., 2014), to promote neuropastic changes and to prevent maladaptive neuroplasticity, such as phantom limb pain for amputees (Flor et al., 1995).

#### 2.1.5 Neuroplasticity and aphasia rehabilitation

Neuroplasticity post-stroke has been extensively studied within the field of motor learning (Pascual-Leone & Torres, 1993; Shumway-Cook & Woollacott, 2007) and interest in its role in post-stroke aphasia has increased (Raymer et al., 2008; Thompson, 2000). For example, Hamilton, Chrysikou and Coslett (2011) found that treatment for aphasia can influence the reorganisation process and promote neuroplastic changes. Reorganisation of language for people with aphasia can occur through inter- and intra-hemispheric interactions (Hamilton et al., 2011).

#### 2.1.6 Learning processes

Learning processes are variables that can be adjusted to influence neuroplasticity (Shumway-Cook & Woollacott, 2007) and these have been adapted in research to discover how to best optimise neuroplasticity post-stroke (Kleim, 2011). These were originally set out in the motor learning literature (Weinstein et al., 2014). Practice is one of the most important variables for the acquisition of skills or (re)learning (Dayan & Cohen, 2011; Schmidt& Lee, 2013), with feedback (Van Vliet & Wulf, 2006), intensity, context and saliency all shown to be influential (Shumway-Cook & Woollacott, 2007).

### 2.1.7 Practice

The most important factor in (re)learning or the acquisition of a new skill is practice (Schmidt & Lee, 2013). Practice is the act of engaging in a behaviour or activity repetitively (Ericsson, 2006; Schmidt & Lee, 2013). This can be deliberate, when practice is highly structured with immediate feedback (Ericsson, Krampe, & Teschromer, 1993), or the person may engage in an activity or behaviour in a non-structured way (Ericsson, 2006). The aim of practice for most people is to learn a skill to a level that allows them to use it in everyday life, for example, driving a car (Ericsson, 2006). Some people will increase the levels of practice to achieve mastery, the two most researched areas being music and chess (Ericsson et al., 1993; Hambrick et al., 2014). Increased practice has been shown to bring about increased rehabilitative success in speech and language therapies for aphasia (Bhogal et al., 2003; Krakauer, 2006). Donovan and Radosevich (1999) found that distributed practice (spaced, short sessions over a longer time) rather than massed practice (short intervals between successive bouts of practice) resulted in better maintenance of learning, whereas Pulvermüller et al.(2001) found the converse to be true.

### 2.1.8 Intensity of therapy

There is still uncertainty about the optimum intensity of practice for speech and language therapy. Speech and language therapies applying the same procedures in the same context or setting can yield different results. Therapy intensity is thought to account for some of these differences in outcome (Bhogal et al., 2003). Intensity can be defined as the amount of treatment provided over a certain time interval (Hinckley & Craig, 1998), for example, three to four hours of treatment per day for two weeks (Cherney, Patterson, Raymer, Frymark& Schooling, 2008), compared with, for example, one hour a week over six weeks. The optimum intensity of rehabilitation for aphasia has yet to be established. However, success has been shown for therapies administered intensively with both impairment- and functional-focused interventions (Basso & Caporali, 2001; Robey, 1998). In a review,

Bhogal, Teasell and Speechley (2003) attributed the increases in outcome measures to intensity, with an average of 8.8 hours of therapy per week for 11 weeks. These results were supported by a systematic review which provided positive effects for CILT and modest evidence for more intense treatment (Cherney, Patterson, Raymer, Frymark & Schooling, 2008).

### 2.1.9 Context of rehabilitation

The context of rehabilitation has an effect on how people learn (Beckley et al., 2013). PWA have been shown to be better able to learn to use strategies when the rehabilitation conditions in which they learn are similar to the environment of expected use (Purdy & Koch, 2006; Simmons-mackie & Damico, 1997), with home-based rehabilitation shown to be beneficial as a result (Beckley et al., 2013). The context of learning is important in relation to generalisation and transfer of target behaviours (Kagan, Black, Felson-Duchan, Simmons-Mackie & Square, 2001; Simmons-mackie & Damico, 1997).

### 2.1.10 Saliency

Increased saliency (personal relevance) of tasks has been shown to bring about greater efficiency of learning through experience-dependent plasticity (Brown, Gonzalez, & Kolb, 2000; Kleim & Jones, 2008). Saliency is likely to be an important variable, with people more likely to engage in therapy that is relevant to their lives (Worrall, 2005). More effective rehabilitation is likely to arise from greater commitment of the PWA in the rehabilitation processes (Horton et al., 2011; Lequerica, Donnell, & Tate, 2009).

### 2.1.11 Therapeutic alliance

There is a link between the therapist-patient relationship and communication and health outcomes across a variety of healthcare areas, including rehabilitation; cardiovascular diseases (Schoenthaler, Kalet, Nicholson, & Lipkin, 2014); general medical treatment (Neumann et al., 2010; Smajdor, Stöckl, & Salter, 2011) and chronic lower back pain (Farin, Gramm, & Schmidt, 2013; Hall, Ferreira, Maher, Latimer, & Ferreira, 2010). Jesus and Lopes Silva (2015) outline four key influencing factors that bring about better rehabilitative outcomes: 1) knowing the person and building a supportive relationship; 2) effective information exchange and education; 3) shared goal-setting and action planning; and 4) fostering a positive, yet realistic, cognitions in the PWA to be more adaptive in therapeutic engagement and re-framing to aid adjustment to disability. This is supported in the aphasia literature, with Safran and Muran (1996) arguing that the quality of the relationship

predicting positive therapeutic outcomes. The PWA, as an adult learner, should become a 'mutual partner' in the learning process (Merriam & Caffarella, 1999). A strong 'therapeutic alliance' is founded on both participants being mutual partners (Bordin, 1979; Horvath, & Greenberg, 1994; Martin, Garske, & Davis, 2000), with therapy tasks and goals agreed by both therapist and client (Bordin, 1979). Indeed, the attitudes and feelings of the SLT have long been considered important factors in bringing about therapeutic success (Van Riper, 1975). When HCPs value what is being targeted in rehabilitation and they respect patients' choices, the therapeutic process has the potential to increase patient motivation and impact positively on outcomes (Bordin, 1979; Intercollegiate Stroke Working Party, 2012; Jesus & Silva, 2015; Meyer et al., 2011).

Personalities and personal attributes also have an impact on learning (Hambrick et al., 2014). The therapist's understanding, attentiveness and interpersonal skills such as warmth, confidence, calmness and gentleness, as perceived by the client, can bring about greater therapeutic success (Fourie, 2009; Littauer, Sexton, & Wynn, 2005; Palmadottir, 2006; Williams & Irurita, 2004). Client factors such as a lack of motivation, compliance, independence or negative emotions can also inhibit learning in the rehabilitative process (Oratio, 1980). Engagement and motivation can be enhanced through a collaborative relationship between the therapist and the PWA (Bordin, 1979).

#### 2.1.12 Feedback

Some form of feedback is important to learning (Shumway-Cook & Woollacoot, 2007). Feedback can be intrinsic, arising from the person's sensory system; or extrinsic, coming from an external source, for example, given by the therapist to the patient who provides information about their performance (Shumway-Cook & Woollacott, 2007). Extrinsic feedback broadly falls into 'knowledge of performance' and 'knowledge of outcome' or results (Shumway-Cook & Woollacott, 2007). Knowledge of performance involves information given on the process of achieving the goal, for example, information on the shape of the patient's mouth when they attempt to say a word. Knowledge of results, in contrast, is information provided on the outcome, for example, correct or incorrect. Feedback can be used to shape the patient's learning, provides motivation (Simmons-Mackie, Damico, & Damico, 1999) and has a role in establishing the discourse structure of the rehabilitation session (Simmons-Mackie, Damico, & Damico, 1999; Horton, 2006). These findings are useful but more investigation of feedback in aphasia rehabilitation is needed (Fink et al., 2002; Fillingham, Sage & Lambon Ralph, 2005).

### 2.2 Justification for systematic review

(Re)learning is key to the success of aphasia rehabilitation (Hooper and Holland, 2005). In order to optimise functional communication outcomes in rehabilitation for PWA, more work needs to be conducted into how neuroscience-informed principles of learning and learning processes can be related or applied to aphasia rehabilitation. How these are then specified and reported in the speech and language therapy literature may be important to how research is translated into clinical practice, synthesis and comparative research (Brady et al., 2014). Greater specification in speech and language therapies with functional outcomes may help us to better understand the 'active ingredients' that contribute to successful therapy outcomes, as rehabilitation therapies, unlike pharmacological treatments, are difficult to define operationally. There has been a call for better reporting in the field of aphasia (Brady et al., 2014) and in other complex non-pharmacological interventions (Hoffmann et al., 2014). Brady and colleagues (2012) completed a Cochrane review of Randomised Controlled Trials (RCTs) of speech and language therapy and found that descriptions of the speech and language interventions were limited. Having completed a comprehensive search of the aphasia literature, no systematic review to date has addressed how learning processes are reported in speech and language therapies with a functional outcome.

### 2.3 Aim of systematic review

The aim of the systematic review is to determine how learning processes are reported in speech and language therapies for post-stroke aphasia with a functional outcome, using the Template for Intervention Description and Replication (TIDieR) checklist (Hoffman et al., 2014).

### 2.4 Objective of systematic review

- 1. To examine how learning processes are reported in speech and language therapies for post-stroke aphasia with a functional outcome.
- To determine whether included studies adhere to the items of the Template for Intervention Description and Replication (TIDieR) checklist (Hoffman et al., 2014).

### 2.5 Methodology

This systematic review was conducted following a modified version of the Cochrane systematic review guidance (Higgins & Green, 2011). The focus of this systematic review is on the mechanisms rather than the outcomes of the intervention.

### 2.5.1 Scoping exercise

A scoping exercise was undertaken to ensure that a systematic review of this nature had not been conducted and that there were studies for potential inclusion. Speech and language therapy studies for aphasia with a functional outcome were identified in this scoping exercise. These were used to inform development of the search terms and search strategy.

### 2.5.2 Systematic review question

Detailed specification of the research question was needed to guide and focus the systematic review, with the Population, Intervention, Comparator, Outcome and Study designs (PICOS) that would be the focus of the systematic review clearly outlined (Cochrane: Higgins & Green, 2011). This guided the inclusion and exclusion criteria for the reviewed studies. As the aim of the systematic review was not to compare interventions, the 'Comparator' was removed. The PIOS is outlined in Table 1 below.

### Table 1. PIOS of systematic review

Population	Adults (18+) with aphasia post-stroke
Intervention	Speech and language therapies
<b>O</b> utcome	Functional communication outcome
<b>S</b> tudy design	Case studies, RCTs, control trials, intervention studies, published/unpublished work (to avoid publication bias), theses, small- group studies

### 2.5.3 Search strings

Search strings were developed by the lead author using the keywords; Aphasia, Stroke, Learning, relevant MeSH terms, and initially functional communication. These search strings were piloted to ensure that key papers from the scoping exercise were identified. Key papers were not always identified when the keyword 'functional communication' was included. As discussed in Chapter 1, this term is not used consistently in studies and often not included in keywords of articles. For this reason, 'functional communication' was removed as a keyword.

The search strings were revised by the researcher using keywords *stroke, aphasia, learning* and relevant MeSH terms, and approved by the research supervisors SH and VP. The search syntax was modified according to the electronic databases. Search terms used can be found Appendix I.

### 2.5.4 Data sources

The five electronic databases used most frequently in the disciplines of health, medicine, nursing and allied health professions were chosen. Search terms were applied to AMED, PsycInfo, Embase, Medline (Ovid) and CINAHL. The search was restricted to humans, and within this, a cohort of adults only (18+ years). In addition, reference lists of included articles, grey literature and clinical trials registers, namely the Cochrane Stroke group trials register, www.strokecenter.org/trials and clinicaltrials.org were reviewed. The search was completed in May 2015.

### 2.5.5 Study Selection

Inclusion criteria for study selection were developed by CS and her academic supervisor (SH). These are further detailed in the Table 2 below. These inclusion/exclusion criteria were considered throughout the screening process.

	Inclusion Criteria	Exclusion Criteria
Population	Adults (18+) post-stroke in any care location e.g. acute care, rehabilitation, nursing home, own home	Diseases or conditions other than stroke e.g. Traumatic Brain Injury (TBI), dementia, and progressive and degenerative diseases
	Must present with aphasia post-stroke in any modality including alexia and agraphia and at any level of severity	Healthcare professionals or the person with aphasia's family or communication partner only
Intervention	Any speech and language-based intervention for people with aphasia post-stroke that has a specified functional outcome, according to the the researcher's definition of functional communication, or which uses functional outcome measures Intervention delivered by a speech and language therapist or volunteer,	Speech and language therapy interventions that do not have a functional outcome, or which do not use functional outcome measures e.g. impairment-based outcome measures Only Transcranial Magnetic Stimulation (TMS) Psychotherapy/counselling
	care assistant or spouse who is trained and assisted by a speech and language therapist	Only pharmaceutical interventions/treatments
	Computer based interventions in combination with speech and language therapy	Only computer based interventions or assistive technologies

### Table 2. Inclusion/Exclusion criteria

Intervention focused on the individual with aphasia and/or the person with aphasia and their communication partner	Where the focus of the intervention is on the healthcare professional or the person's family or communication partner only
Any – except those in the exclusion criteria Qualitative, quantitative and mixed- methods data	Discussion/viewpoint paper Policy statement Guidelines News items Opinion pieces
Functional communication-based outcome, e.g. standardised functional assessment, Therapy Outcome Measures (TOMs), discourse or conversation analysis Functional reading or writing Self-reported communicative outcomes	Quality of life measures Self-reported health status measures Patient satisfaction measures Psychological outcomes Impairment-based assessments e.g. Comprehensive Aphasia Test (CAT), Psycholinguistic Assessments of Language Processing in Aphasia (PALPA), Prescribed passage of reading 'Standardised' or narrative passage, e.g. Cinderella story Word or sentence repetition
	Intervention focused on the individual with aphasia and/or the person with aphasia and their communication partner Any – except those in the exclusion criteria Qualitative, quantitative and mixed- methods data Functional communication-based outcome, e.g. standardised functional assessment, Therapy Outcome Measures (TOMs), discourse or conversation analysis Functional reading or writing Self-reported communicative outcomes

### 2.5.6 Screening for relevant studies

After searching the databases, all titles identified were exported from the electronic databases to the referencing software EndNote and duplicates removed. Titles were reviewed by CS and titles that were clearly irrelevant, or ones that the filters had missed, e.g. those including children and animals, were removed.

Abstracts were reviewed by CS using a screening checklist developed by CS and SH (Appendix II). One third of the abstracts were reviewed by the second reviewer (JP), a speech and language therapy PhD candidate, who was familiar with systematic review methodology and the topic of research, using the same screening checklist.
During screening of abstracts it was noted that the abstract often lacked information regarding the outcome of the intervention. Consequently, it was difficult to ascertain if the interventions had a 'functional communication' outcome as per the inclusion/exclusion criteria above and the definition outlined in Chapter 1. Consequently, CS decided to review the methodologies after abstract screening and before moving to full texts to focus on the outcomes of the studies.

Full texts were reviewed by CS according to the inclusion/exclusion criteria. The second reviewer (JP) reviewed one third of articles. If there was disagreement about relevance to this review, then the third reviewer (SH) considered the article. The reference lists of included studies and systematic reviews were searched to identify relevant studies within these. If information was missing in potential studies, lead authors were contacted, given two weeks to respond and then excluded if there was no response. To further ensure rigour, 10% of the excluded studies were reviewed by JP to ensure that they had been excluded correctly.

#### 2.5.7 Data extraction

A data extraction form was developed by CS and SH which was informed by items from the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014); relating to learning processes (Appendix III). Using this form the researcher extracted and identified learning processes that were reported (in the speech and language interventions with a functional outcome) such as: instructions provided for the intervention; materials used; feedback given; the setting of the intervention; any adaptations made to the intervention to make it salient (meaningful to the PWA); the mode and provider of the intervention (face-to-face or computer-based intervention); the dosage and intensity of the intervention. These data were then applied to items from the TIDieR checklist which related to learning processes (Hoffman et al, 2014), (see Hoffman et al., 2014 for a complete description of the checklist). This form also extracted information on study design, the country where the research was conducted and the participants. This was piloted on identified full texts and refined accordingly. Data extraction was completed by the lead author and 10% of data extraction was reviewed by SH to ensure reliability.

#### 2.5.8 Methodological quality and risk of bias

Investigating the methodological quality of the studies involves reviewing how rigorously the authors conducted their research to ascertain if it was to the highest possible standards

(Higgins & Green, 2011). Investigating the risk of bias involves reviewing the procedures taken by the authors to minimise bias when conducting their research, such as randomisation, exposure and presentation of results. As discussed, this systematic review adapted the Cochrane methodology for systematic reviews (Higgins & Green, 2011). The aim of the systematic review was to examine how learning processes are reported in speech and language therapies for post-stroke aphasia with a functional outcome and to determine whether included studies adhere to the categories from the Template for Intervention Description and Replication (TIDieR) checklist (Hoffman et al., 2014). Therefore, it was decided not to synthesise the study outcomes, and that the quality of reporting, rather than methodological quality would be reviewed in order to answer the research question.

#### 2.5.9 Quality of reporting

The extracted data was applied to the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014), which was developed as a quality of reporting tool. Hoffman and colleagues (2014) noted that the quality of reporting of interventions in publications was remarkably poor: they lacked complete and thorough descriptions of interventions, making it difficult for clinicians and researchers to replicate. Data relating to learning processes were extracted, and applied to each item with the exception of item 10 (Modifications: if the intervention was modified during the course of the study, describe the changes (what, why, when, and how)) and item 11 (How well planned: if intervention adherence or fidelity was assessed, describe how and by whom, and *if strategies were used to maintain or improve fidelity),* as these items did not apply to the aim of this study. Any reference to the reporting items by the author was noted on the data extraction tool by the researcher (marked with a tick). If the author of the study did not refer to an item on the TIDieR checklist this was noted (marked with an X). Hoffman et al. (2014) recommend that protocols of interventions should be made available. If the protocol was published or information was provided on where supplementary information could be found, this was noted on the data extraction sheet (Appendix III).

#### 2.5.10 Data synthesis

As meta-analysis synthesises outcomes of independent studies, a meta-analysis was not appropriate for the purpose of this research, as the focus is on interpreting how the processes of learning are reported. It was decided that a narrative synthesis would be appropriate, with results discussed under the different items of the TIDieR (Hoffman et al., 2014) checklist and then synthesised.

# 2.6 Results

The PRISMA flow diagram (figure 2) displays the results of the database search, screening at title, abstract, methodology and full-text level, and the final number of included studies. Four articles written in Japanese were also reviewed until the stage where methodologies were reviewed. The researcher contacted the authors to obtain additional information regarding the outcome measures used. These articles were excluded at this stage as they did not meet the inclusion criteria. One Persian article was excluded as the author did not reply with the additional information needed to review the article's suitability.





#### 2.6.1 Included studies

Data from the included studies were extracted using a comprehensive data extraction sheet (Appendix III), including information on, study design, year of publication, country where the study was conducted, aim of the study, participants, outcome measures used and learning processes. These data, in combination, provided the systematic review with an in-depth insight into how learning process were reported across study designs, in relation to the study aims and year of publication. It also allowed analysis of changes in reporting of learning processes. Details of the included studies can be found in Table 3 (study aim and design) and Table 4 (country of research, participant information and functional communication outcome used). These studies were conducted across eleven countries: Australia, USA, The Netherlands, Germany, United Kingdom, Republic of Ireland, New Zealand, Sweden, Italy, France and Austria, published between 1974 and 2014. The study designs of the included studies include: pre-post study designs (24%; 8/34); case studies (single and longitudinal) (41%; 14/34) and randomised and non-randomised control trials (35%; 12/34). Data relating to learning processes, which were examined using the TIDieR checklist (Hoffman, 2014), are outlined in Table 5. Table 3, 4 and 5 should be read in combination to provide a complete picture of results.

Included studies	Study aim (as outlined by the authors)	Study design
Beeson, Rising, Kim, & Rapcsak (2010)	To explore the application of interactive treatment as a complement to phonological treatment <sup>1</sup> targeting phonological alexia/agraphia <sup>2</sup>	Multiple single-case studies
Blom Johansson, Carlsson, Ostberg, & Sonnander (2013)	To evaluate an early family-orientated intervention	Multiple single-case studies
Cherney, Halper, Holland, & Cole (2008)	To assess the use of AphasiaScripts <sup>3</sup> training	Pre-post study design
Cherney et al. (2012)	To compare epidural cortical stimulation plus language treatment to language treatment alone	Randomised controlled trial
David, Enderby, & Bainton (1982)	To compare 'conventional speech therapy' and 'stimulation and support from untrained volunteers'	Randomised controlled trial
Doesborgh et al.(2004)(a)	To investigate clinically relevant effects of Multicue <sup>4</sup>	Randomised controlled trial
Doesborgh et al.(2004)(b)	To compare semantic treatment (BOX) to phonological treatment (FIKS)	Randomised controlled trial
Edmonds, Mammino, & Ojeda (2014)	To conduct a group analysis evaluating the effect of Verb Network Strengthening Treatment for Aphasia (VNeST) <sup>5</sup>	Pre-post study design

Table 3. Study aims (as outlined by the authors) and designs of included studies

Fridriksson et al.(2012)	Testing whether training with speech	Pre-post study design
	entrainement <sup>6</sup> improves speech	
	production (experiment 3)	
Galling, Goorah, Berthier.	To describe the effect of a 30mg dose of	Single case study
& Sage (2014)	bromocriptine and SLT in the treatment	
	of a PWA	
Godecke Hird Lalor Bai	To compare daily aphasia therapy (min	Bandomised controlled
& Phillins (2012)	5 days a week (no less) for max 4	trial
Q 1 mmp3 (2012)	weeks) and usual care (not more than 1	
	session per week)	
Hopper Holland &	To investigate the effects of	Pre-post study design
Rowaga (2002)	conversational coaching <sup>7</sup> and to	Fie-post study design
Newega (2002)	determine variables of the treatment	
Huntlov & Conzoloz Pothi	To investigate the amonability of verbal	Single case study
	To investigate the amenability of verbal	Single case study
(1988)	The investigate the treatment	
Jonannsen-Horbach,	To investigate the treatment of chronic	Multiple single-case
Cegia, Mager, Schempp,	global aphasia with nonverbal	studies
& Wallesch (1985)	communication system	
Jungblut, Suchanek, &	To describe the use of directed music-	Longitudinal single-case
Gerhard (2009)	supported training approach (SIPARI)	study
Laska, Kahan, Hellblom,	To compare very early SLT using	Randomised controlled
Murray, & von Arbin	Language Enrichment Therapy (LET)	trial
(2011))	compared to no formal SLT	
Leader (1983)	To describe the SLT progress of a PWA	Longitudinal single-case
	over the course of 1 year	study
Lincoln et al. (1984)	To compare speech therapy to natural	Randomised controlled
	recovery alone	trial
Lyon et al. (2007)	recovery alone To examine the effectiveness of	trial Pre-post study design
Lyon et al. (2007)	recovery alone To examine the effectiveness of communication partner training	trial Pre-post study design
Lyon et al. (2007) Marangolo et al.(2013)	To examine the effectiveness of communication partner training To determine the efficacy of	Trial Pre-post study design Controlled trial
Lyon et al. (2007) Marangolo et al.(2013)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation	trial Pre-post study design Controlled trial
Lyon et al. (2007) Marangolo et al.(2013)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational	Trial Pre-post study design Controlled trial
Lyon et al. (2007) Marangolo et al.(2013)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA	Trial Pre-post study design Controlled trial
Lyon et al. (2007) Marangolo et al.(2013)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls	trial Pre-post study design Controlled trial
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a	Trial Pre-post study design Controlled trial Single case study
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign	trial         Pre-post study design         Controlled trial         Single case study
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech	Trial Pre-post study design Controlled trial Single case study
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, &	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with	trial         Pre-post study design         Controlled trial         Single case study         Single-case study
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia	trial         Pre-post study design         Controlled trial         Single case study         Single-case study
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia To explore whether therapy could	trial         Pre-post study design         Controlled trial         Single case study         Single-case study
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia To explore whether therapy could improve note-taking for a PWA	trial   Pre-post study design   Controlled trial   Single case study   Single-case study   Single-case study
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia To explore whether therapy could improve note-taking for a PWA To investigate the treatment effect of	trial         Pre-post study design         Controlled trial         Single case study         Single-case study         Single-case study         Pre-post study design
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013)	recovery aloneTo examine the effectiveness of communication partner trainingTo determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controlsTo utilise 'total communication' – a system combining standardised sign language and speechTo explore returning to work with aphasiaTo explore whether therapy could improve note-taking for a PWATo investigate the treatment effect of Aphasia Language lmpairment and	trial         Pre-post study design         Controlled trial         Single case study         Single-case study         Single-case study         Pre-post study design
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia To explore whether therapy could improve note-taking for a PWA To investigate the treatment effect of Aphasia Language Impairment and Eunctional Therapy (UET) across	trial         Pre-post study design         Controlled trial         Single case study         Single-case study         Single-case study         Pre-post study design
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013)	recovery aloneTo examine the effectiveness of communication partner trainingTo determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controlsTo utilise 'total communication' – a system combining standardised sign language and speechTo explore returning to work with aphasiaTo explore whether therapy could improve note-taking for a PWATo investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICE domains	trial Pre-post study design Controlled trial Single case study Single-case study Pre-post study design
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia To explore whether therapy could improve note-taking for a PWA To investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domains	trial Pre-post study design Controlled trial Single case study Single-case study Pre-post study design Multiple single case
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013) Ruiter, Kolk, & Rietveld	recovery aloneTo examine the effectiveness of communication partner trainingTo determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controlsTo utilise 'total communication' – a system combining standardised sign language and speechTo explore returning to work with aphasiaTo explore whether therapy could improve note-taking for a PWATo investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domainsTo evaluate a Dutch and adapted ucessing a fibre domated Summary and Summer of Partner of Summer of Partner o	trial         Pre-post study design         Controlled trial         Single case study         Single-case study         Single-case study         Pre-post study design         Multiple single-case
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Moorris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013) Ruiter, Kolk, & Rietveld (2010)	recovery aloneTo examine the effectiveness of communication partner trainingTo determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controlsTo utilise 'total communication' – a system combining standardised sign language and speechTo explore returning to work with aphasiaTo explore whether therapy could improve note-taking for a PWATo investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domainsTo evaluate a Dutch and adapted version of Reduced Syntax Therapy 9	trial   Pre-post study design   Controlled trial   Single case study   Single-case study   Single-case study   Pre-post study design   Multiple single-case studies
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013) Ruiter, Kolk, & Rietveld (2010)	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia To explore whether therapy could improve note-taking for a PWA To investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domains To evaluate a Dutch and adapted version of Reduced Syntax Therapy <sup>9</sup> (REST)	trial         Pre-post study design         Controlled trial         Single case study         Single-case study         Single-case study         Pre-post study design         Multiple single-case studies
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013) Ruiter, Kolk, & Rietveld (2010) Schlaug, Marchina, &	recovery alone To examine the effectiveness of communication partner training To determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controls To utilise 'total communication' – a system combining standardised sign language and speech To explore returning to work with aphasia To explore whether therapy could improve note-taking for a PWA To investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domains To evaluate a Dutch and adapted version of Reduced Syntax Therapy <sup>9</sup> (REST) To compare treatment effects of Multiple ICF domains	trial   Pre-post study design   Controlled trial   Single case study   Single-case study   Single-case study   Pre-post study design   Multiple single-case studies   Controlled trial
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013) Ruiter, Kolk, & Rietveld (2010) Schlaug, Marchina, & Norton (2008)	recovery aloneTo examine the effectiveness of communication partner trainingTo determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controlsTo utilise 'total communication' – a system combining standardised sign language and speechTo explore returning to work with aphasiaTo explore whether therapy could improve note-taking for a PWATo investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domainsTo evaluate a Dutch and adapted version of Reduced Syntax Therapy 9 (REST)To compare treatment effects of Melodic Intonation Therapy (MIT) 10 and Compare treatment effects of Melodic Intonation Therapy (MIT) 10 and	trial   Pre-post study design   Controlled trial   Single case study   Single-case study   Single-case study   Pre-post study design   Multiple single-case studies   Controlled trial
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Moorris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013) Ruiter, Kolk, & Rietveld (2010) Schlaug, Marchina, & Norton (2008)	recovery aloneTo examine the effectiveness of communication partner trainingTo determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controlsTo utilise 'total communication' – a system combining standardised sign language and speechTo explore returning to work with aphasiaTo explore returning to work with aphasiaTo investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domainsTo evaluate a Dutch and adapted version of Reduced Syntax Therapy 9 (REST)To compare treatment effects of Melodic Intonation Therapy (SRT) 11	trial Pre-post study design Controlled trial Single case study Single-case study Pre-post study design Multiple single-case studies Controlled trial
Lyon et al. (2007) Marangolo et al.(2013) Moody (1982) Morris, Franklin, & Menger (2011) Panton & Marshall (2008) Rodriguez et al.(2013) Ruiter, Kolk, & Rietveld (2010) Schlaug, Marchina, & Norton (2008)	recovery aloneTo examine the effectiveness of communication partner trainingTo determine the efficacy of Transcranial Direct Current Stimulation (tDCS) coupled with conversational therapy for People With Aphasia PWA compared to healthy controlsTo utilise 'total communication' – a system combining standardised sign language and speechTo explore returning to work with aphasiaTo explore whether therapy could improve note-taking for a PWATo investigate the treatment effect of Aphasia Language Impairment and Functional Therapy (LIFT) across multiple ICF domainsTo evaluate a Dutch and adapted version of Reduced Syntax Therapy 9 (REST)To compare treatment effects of Melodic Intonation Therapy (SRT) 11 To compare the efficacy of Constraint	trial   Pre-post study design   Controlled trial   Single case study   Single-case study   Single-case study   Pre-post study design   Multiple single-case   studies   Controlled trial   Randomised controlled

	standard treatment at the same	
	intensity	
Sparks, Helm, & Albert	To investigate the efficacy of Melodic	Pre-post study design
(1974)	Intonation Therapy (MIT)	
Stahl, Henseler, Turner,	To compare the therapeutic advantage	Controlled trial
Geyer, & Kotz (2013)	of singing, rhythmic speech and	
	standard therapy	
Stark (2010)	To explain the value of long-term	Longitudinal single-case
	treatment for clients with chronic	study
	aphasia	
Szaflarski et al. (2008)	To test a modified version of a	Pre-post study design
	Constraint Induced Aphasia Therapy	
	(CIAT) protocol in patients with chronic	
	aphasia	
Tessier, Weill-	To determine the efficacy of a specific	Single case study
Chounlamountry,	auditory analysis rehabilitation	
Michelot, & Pradat-Diehl		
(2007)		
Weill-Chounlamountry,	To determine whether phonological	Single case study
Capelle, Tessier, &	multimodal therapy can improve	
Pradat-Diehl (2013)	naming and communication	
Wertz, et al. (1981)	To compare individual and group	Randomised controlled
	treatment	trial

<sup>1</sup>Intervention targeting speech sounds

<sup>2</sup> Reading and writing

<sup>3</sup> 'AphasiaScripts is a software program using an animated agent that serves as a virtual therapist for script training for individuals with aphasia.....AphasiaScripts provides repeated opportunities for the client to practice individualized conversations that have been prerecorded' (Cherney, Halper, Holland, & Cole, 2008 p.2 1)

<sup>4</sup> 'Multicue's approach to tailoring treatment to the individual is to supply persons with aphasia with a range of different cues and to encourage them to discover for themselves which cues they find most suitable' (Doesborgh et al., 2004 p.215)(a)

<sup>5</sup> The VNeST protocol requires 'participants to produce diverse scenarios related to trained verbs (e.g., a nurse weighs a patient, a cashier weighs produce, a jeweler weighs gold, a veterinarian weighs a puppy), which potentially promotes spreading activation to untrained neurological networks, thereby facilitating generalized word retrieval in sentences and discourse' (Edmonds, Mammino, & Ojeda, 2014 p.79)

<sup>6</sup> Patient's ability to 'mimic audio-visual speech stimuli enabling them to produce fluent speech in real time' (Fridriksson et al.2012, p.3815)

<sup>7</sup> Conversational coaching involves teaching communication strategies to individuals with aphasia and their spouses. Strategies are chosen by the couple and are taught and practised in the context of a conversation' (Hopper, Holland, & Rewega, 2002 p.745)

<sup>8</sup> Verbal akinesia is 'decreased word fluency, reduced syntactic complexity, and diminished speech initiative' (Huntley & Gonzalez Rothi, 1988 p.55).

<sup>9</sup> Reduced syntax therapy is a 'therapy that teaches German and English agrammatic speakers to produce reduced utterances' (Ruiter, Kolk, & Rietveld, 2010 p.426)

<sup>10</sup> Melodic Intonation Therapy a 'treatment that uses the musical elements of speech (melody and rhythm) to improve expressive language by capitalizing on preserved function (singing) and engaging language-capable regions in the undamaged right hemisphere' (Schlaug, Marchina, & Norton, 2008 p.431)

<sup>11</sup> In Speech Reptition Therapy 'phrases are spoken rather than intoned (sung), syllables are not sustained, and there was no hand tapping associated with the production of speech' (Schlaug, Marchina, & Norton, 2008 p.318)

<sup>12</sup> CIAT 'includes an intensive, massed practice' and 'compensatory mechanisms are constrained' (Sickert, Anders, Münte, & Sailer, 2014 p.51)

Author	Year	Country of research	Sample size	Age of participants in years (mean if applicable)	Gender	Functional outcome measure used	Time post-stroke onset
Beeson et al.	2010	USA	2	43 and 76	F (n=2)	Writing for school and pleasure	5 and 9 years post-stroke
Blom Johansson et al.	2013	Sweden	3 Dyads	(73) (PWA)	F (n=2) M (n=1) (PWA)	Measure of skills in Supported communication (adapted into Swedish)	Maximum 2 months post- stroke
Cherney et al.	2012	USA	8	42-61 (52)	F (n=2) M (n=6)	Communicative Effectiveness Index (CETI) $^{1}$	12 months + post-stroke
Cherney et al.	2008	USA	3	65;65;78 (69)	F (n=2) M (n=1)	<ol> <li>Spontaneous speech</li> <li>Communication Activities of Daily Living (CADL)<sup>2</sup></li> </ol>	6 + months post-stroke
David et. al.	1982	UK	96	(68)	F (n=40) M (n=56)	Functional communication profile (FCP) <sup>3</sup>	3 weeks + post-stroke
Doesborgh et al.(a)	2004	The Netherlands	18	53-77 (64)	F (n= 9) M (n=9)	Amsterdam-Nijmegen Everyday Language Test (ANELT) <sup>4</sup>	11-17 months post-stroke
Doesborgh et al. (b)	2004	The Netherlands	58	20-85 (53)	F (n=25) M (n=33)	ANELT	3 months + post-stroke
Edmonds et al.	2014	USA	11	35-71 (53)	F (n=4) M (n=7)	CETI	14-144 months post-stroke
Fridriksson et al.	2012	USA	13	45-75 (57)	F (n=4) M (n=9)	Conversations on topic	6 months + post-stroke
Galling et. al	2013	UK	1	58	Female	1. Spontaneous speech subtest of the Western Aphasia Battery (WAB) <sup>5</sup>	2months + post-stroke
Godecke et. al	2012	Australia	59	55-83 (69)	F (n=30) M (n=29)	Functional communication profile	Acute median 3 days post- stroke
Hooper et al.	2002	USA	4 (2x2 dyads)	39-76 (57)	F (n=2) M (n=2)	1. Exchanging meaningful information 2. CADL	2 years + post-stroke
Huntley & Gonsalez-Rothi	1988	USA	1	40	Male	Spontaneous answering of questions	2 years + post-stroke

# Table 4. Characteristics of included studies

Author	Year	Country of research	Sample size	Age of participants in years (mean if applicable)	Gender	Functional outcome measure used	Time post-stroke onset
Johannsen-Horbach et.al	1985	Germany	4	41-57	F (n=1) M (n=3)	Use of Bliss symbols in communication at home <sup>6</sup>	6 months + post-stroke
Jungblut et al.	2009	Germany	1	57	Male	Increase in spontaneous speech in everyday life	3 years post-stroke
Laska et.al	2011	Sweden	123	38-94 (66)	F (n=67) M (n=56)	ANELT	2 days + post-stroke
Leader, B.J.	1983	USA	1	49	Male	Increased conversational exchange	14 weeks post-stroke
Lincoln et.al	1984	UK	191	38-92 (68)	F (n=82) M (n=109)	FCP	Acute 4 weeks post-stroke
Lyon et al.	2007	USA	10 triads	(68) (PWA)	F (n=2) M (n=8) (PWA)	1. CADL 2. Informal measure of communication	13 months + post-stroke
Marangolo et al.	2013	Italy	32	40-75 (58)	F (n=12) M (n=18))	Language sample of video clips of conversation (x3)	1 year + post-stroke
Moody E.J.	1982	New Zealand	1	55	Male	Increase of communication through sign	2 years post-stroke
Morris et al.	2011	UK&Ireland	1	45	Male	Self-reporting from participant (GD)	5 months post-stroke
Panton & Marshall	2008	UK	1	56	Male	Note-taking tasks	1 year post-stroke
Rodriquez et al	2013	Australia	11	18-79 (49)	F (n=4) M (n=7)	1. CETI 2. A proxy rated assessment carer's perception of functional	6 months + post-stroke
Ruiter et. al	2010	The Netherlands	12	36-67 (52)	F(n=5) M(n=7)	Semi-structured interview	8 months + post-stroke
Schlaug et al.	2008	USA	2	47 and 58	M (n=2)	Conversational interviews	1 year + post-stroke
Sickert et al.	2014	Germany	100	48-72 (60)	F (n=40) M (n=60)	Communicative activity log	1-4 months post-stroke

Author	Year	Country of research	Sample size	Age of participants in	Gender	Functional outcome measure used	Time post-stroke onset
				years			
				(mean if applicable)			
Sparks et al.	1974	USA	9	Not reported	Not reported	Semi-structured interview for eliciting meaningful conversation which was transcribed	Not reported
Stahl et. al.	2013	Germany	15	40-72 (56)	F (n=7) M (n=8)	Informants' rating of how sentences were used in the context of home	6 months + post-stroke
Stark, J.	2010	Austria	1	47	Male	1.Reported increase in verbal communication in everyday life 2.ANELT	14.5 month post-stroke
Szaflarski et al.	2008	USA	3	58-64 (61)	M (n=3)	Communication activity logs	2-20 years post-stroke
Tessier et al.	2007	France	1	65	Female	Aphasic patients communication scale	10 months post-stroke
Weill-Chounlamountry et al.	2013	France	1	52	Female	Bordeaux verbal communication scale <sup>7</sup>	10 months post-stroke
Wertz et al.	1981	USA	67	40 -79 (60)	M (n=67)	<ol> <li>Conversational rating to determine conversational ability</li> <li>An informant's rating of functional language use</li> </ol>	4-48 weeks post-stroke

<sup>1</sup> Communicative Effectiveness Index (CETI)-Measure of change in functional communication ability assessed through rating the person with apahsia's ability in series of communication situations (Lomas et al., 1989)

<sup>2</sup> Communication Activities of Daily Living (CADL)-To determine the functional communication skills of adults in the following categories: Reading, Writing, or Using Numbers; Social Interactions; Divergent Communication; Contextual Communication; Nonverbal Communication; Sequential Relationships; Humor/Metaphor/Absurdity (Holland, 1980)

<sup>3</sup> Functional communication profile (FCP)-The *FCP-R* yields an overall inventory of the individual's communication abilities, mode of communication (e.g., verbal, sign, nonverbal, augmentative), and degree of independence (Sarno, 1969)

<sup>4</sup> Amsterdam-Nijmegen Everyday Language Test (ANELT)-is designed to measure, first, the level of verbal communicative abilities of aphasic patients and, second, changes in these abilities over time. The level of communicative effectiveness is determined by the adequacy of bringing a message across. Test items are constructed as scenarios of familiar daily life situations. (Blomert, Kean, Koster & Schokker, 1994)

<sup>5</sup> Western Aphasia Battery (WAB)-The WAB assesses the linguistic and main nonlinguistic skills of adults with aphasia. This provides information regarding the type and severity of aphasia and lesion location (Kertesz, 1982)

<sup>6</sup> Bliss symbols-Blissymbols form a system of meaning-based symbols which can be used by people with severe difficulties in speaking to communicate without speech. The system has a large and flexible vocabulary and contains logical rules for expanding vocabulary and grammar. (Bliss symbol communication UK, 2017) http://www.blissymbols.co.uk/

<sup>7</sup> Bordeaux verbal communication scale- a French questionnaire including 34 questions about current communication behaviours in daily living (ICF categories d2 to d9). (Darrigrand & Mazaux, 2000)

Author	1. Name	2. Why	3. What (materials)	4. What (procedures)	5. Who provided	6. How (the modes of delivery)	7. Where	8. When and how much	9. Tailoring/ specificity of intervention
Beeson et al. (2010)	$\checkmark$	1	1	$\checkmark$	$\checkmark$	1	X	1	X
Blom Johansson et al. (2013)	$\checkmark$	1	$\checkmark$	$\checkmark$	$\checkmark$	<b>√</b>	$\checkmark$	$\checkmark$	1
Cherney et al. (2008)	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	1	$\checkmark$	$\checkmark$	$\checkmark$	1
Cherney et al. (2012)	$\checkmark$	1	1	$\checkmark$	$\checkmark$	1	X	$\checkmark$	X
David et. al. (1982)	X	1	X	X	$\checkmark$	X	1	$\checkmark$	X
Doesborgh et al. (2004)	$\checkmark$	1	$\checkmark$	$\checkmark$	$\checkmark$	1	X	$\checkmark$	X
Edmonds et al. (2014)	$\checkmark$	1	$\checkmark$	$\checkmark$	$\checkmark$	1	1	$\checkmark$	X
Fridriksson et al. (2012)	$\checkmark$	$\checkmark$	1	$\checkmark$	$\checkmark$	<ul> <li>Image: A start of the start of</li></ul>	X	X	X

# Table 5. Assessment according to the TIDieR checklist

Author	1. Name	2. Why	3. What (materials)	4. What (procedures)	5. Who provided	6. How (the modes of delivery)	7. Where	8. When and how much	9. Tailoring/ specificity of intervention
Galling et. al (2014)	$\checkmark$	1	$\checkmark$	1	$\checkmark$	1	X	$\checkmark$	1
Godecke et. al. (2012)	X	$\checkmark$	X	X	$\checkmark$	<b>√</b>	1	1	X
Hooper et al. (2002)	<b>√</b>	$\checkmark$		$\checkmark$	$\checkmark$	1	X		$\checkmark$
Huntley & Gonsalez-Rothi (1988)	X	1	1	1	$\checkmark$	<b>√</b>	$\checkmark$	X	x
Johannsen- Horbach et al. (1985)	$\checkmark$	1	$\checkmark$	1	X	1	X	$\checkmark$	X
Jungblut et al. (2009)	1	1	$\checkmark$	1	X	1	X	$\checkmark$	1
Laska et al. (2011)	X	1	X	X	$\checkmark$	X	X	$\checkmark$	X
Leader, B.J. (1983)	X	1	X	$\checkmark$	X	1	1	1	X

Author	1. Name	2. Why	3. What (materials)	4. What (procedures)	5. Who provided	6. How (the modes of delivery)	7. Where	8. When and how much	9. Tailoring/ specificity of intervention
Lyon et al. (2007)	$\checkmark$	1	$\checkmark$	1	$\checkmark$	$\checkmark$	1	1	1
Marangolo et al. (2013)	$\checkmark$	1	$\checkmark$	1	$\checkmark$	$\checkmark$	X	1	X
Moody E.J. (1982)	1	$\checkmark$	$\checkmark$	1	$\checkmark$	$\checkmark$	X	<b>√</b>	X
Morris et al. (2011)	$\checkmark$	$\checkmark$	1	1	1	$\checkmark$	<b>√</b>	$\checkmark$	<b>√</b>
Panton & Marshall (2008)	1	1	$\checkmark$	1	$\checkmark$	$\checkmark$	<b>√</b>	<b>√</b>	1
Rodriquez et al. (2013)	$\checkmark$	1	1	1	1	$\checkmark$	X	$\checkmark$	1
Ruiter et al. (2010)	1	1	$\checkmark$	1	1	$\checkmark$	X	$\checkmark$	X
Schlaug et al. (2008)	$\checkmark$	1	1	X	$\checkmark$	1	X	1	X

Author	1. Name	2. Why	3. What (materials)	4. What (procedures)	5. Who provided	6. How (the modes of delivery)	7. Where	8. When and how much	9. Tailoring/speci ficity of intervention
Sparks et al. (1974)	X	$\checkmark$	$\checkmark$	<b>√</b>	1	$\checkmark$	X	$\checkmark$	X
Stahl et al. (2013)	$\checkmark$	$\checkmark$	✓	$\checkmark$	X	$\checkmark$	1	$\checkmark$	X
Stark, J. (2010)	X	$\checkmark$	$\checkmark$	<b>√</b>	$\checkmark$	$\checkmark$	X	1	$\checkmark$
Szaflarski et al. (2008)	1	<b>√</b>	$\checkmark$	<b>√</b>	$\checkmark$	$\checkmark$	X	1	X
Tessier et al. (2007)	✓	✓	$\checkmark$	1	✓	1	X	1	<ul> <li>Image: A second s</li></ul>
Weill- Chounlamountry et al. (2013)	1	1	<b>√</b>	<b>√</b>	1	<b>√</b>	<b>√</b>	<b>√</b>	1
Wertz et al. (1981)	X	$\checkmark$	X	X	$\checkmark$	1	$\checkmark$	$\checkmark$	X
Sparks et al. (1974)	X	✓	$\checkmark$	1	$\checkmark$	1	X	$\checkmark$	X

#### 1. Brief name: Provide the name or phrase that describes the intervention

This item was assessed as addressed in the study if the author outlined a name or phrase in a succinct sentence or title where the category of intervention was clearly outlined. A brief name allows readers of the study to identify and link topics efficiently. This item was reported in 74% of included studies.

Speech and language therapies for aphasia with a functional outcome fell into the following categories: music-based (Sparks et al., 1974; Schlaug, 2008; Jungblut et al., 2009; Stahl et al., 2013); conversational coaching and communication partner training (Hopper et al., 2002; Lyon, 2007; Cherney, 2008; Szaflarski, 2008; Fridriksson, 2012; Marangolo, 2013; Blom-Johansson, 2013; Ruiter, 2010), verb strengthening (Edmonds et al., 2014); constraint-induced therapies (Szaflarski, 2008; Sickert et al, 2014); computer-based rehabilitation (Doesborgh, 2004; Tessier et al., 2007; Weill-Chounlamountry, 2013); sign language or symbol exchange (Moody, 1982; Johnannsen-Horbach et al., 1985); writing therapies (Beeson et al., 2010; Panton & Marshall, 2008) and combination interventions (Rodriquez et al., 2013; Cherney, 2012; Morris, 2011). A brief name or phrase also outlined whether priming was involved in the intervention, such as transcranial Direct Current Stimulation (tDCS) (Marangolo, 2013), epidural cortical stimulation (Cherney, 2012) and pharmacological (Galling, 2014).

# 2. Why: Describe any rationale, theory or goal of the elements essential to the intervention

The goal and theory behind the intervention was made explicit in all of the included studies. The articles provided clear rationales for the interventions that were implemented. The goals differed from those that aimed to assess whether a certain intervention worked, e.g. tested using an outcome measure (e.g. Sparks et al, 1974; Moody, 1982, Hopper et al 2002; Lyon, 2007; Cherney et. al 2008; Szaflarski et al, 2008; Edmonds et al., 2014). Studies also compared group and individual therapy (Wertz et al., 1981), comparing the influence of who implemented intervention on outcome (David et al., 1982), speech and language therapy treatment compared to no treatment (Lincoln et al., 1984; Doesborgh et al., 2004), timing of intervention (Laska et al., 2011; Sickert et al., 2014) and intensity of treatment (Godecke et al., 2012; Rodriquez et al. 2013).

3. What (materials): Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training intervention providers.

Studies were assessed as adhering to this item if the author made reference to, or provided a description of, the intervention materials. For controlled studies, adherence was assessed as present if the materials were described for either the case or control arm. Information on the therapy materials used was provided in 79% of studies. Descriptions of materials varied from broad categories, such as 'low and high frequency words' (Beeson et al., 2010) and 'concrete objects' (Moody, 1982) to more specific lists of words which were provided in appendices (Edmonds et al., 2014). Studies also used computers and computer programs (Doesborgh, 2004; Fridriksson, 2012; Cherney et al, 2012). Materials could be prescribed, such as 'twenty items from the Pyscholinguistic Assessment of Language Processing in Aphasia' (PALPA), (Galling et al, 2014), or tailored to the client, such as 'sixty words chosen that were related to the client's work' (Panton & Marshall, 2008).

# 4. What (procedures): Describe each of the procedures, activities and/or processes used in the intervention, including any enabling or support activities

This item was assessed as present if the procedures of the intervention were outlined explicitly or if the reader was directed to an article where full information on the procedures could be obtained. The procedures needed to be replicable to be counted and these were made explicit in 85% of the included articles. Procedures were outlined in step or tabular format. Edmonds et al. (2014) and Stark et al. (2010) included protocols in the appendices of the articles, with supplementary information. Terms such as 'standard therapy' (Sickert et al., 2014) and 'usual care' (Lincoln et al, 1984) were used to describe the procedure of some interventions.

Feedback was provided either on the outcome of the intervention activity or on the performance in half of included studies, with the other half not specifying feedback.

# 5. Who provided: For each category of intervention provider (for example psychologist or nursing assistant), describe their expertise, background and any specific training given

This item was assessed as present if authors made any reference to who delivered the intervention, for example a Speech and Language Pathologist ('SLP'), clinician, therapist or volunteer. Authors made reference to an intervention provider in 88% of the included

studies. However, details regarding their years of experience, background, role in the study or training were made explicit in only 18% of articles (Edmonds et al., 2014; Lyon et al, 2007; Stahl et al., 2013; Ruiter et al, 2010; Blom-Johansson, 2013; Laska et al, 2011). The most detailed description was found in Edmonds et al. (2014 p.320), where it is stated that 'three speech and language pathologists with extensive clinical (8-30 years) and research experience with aphasia conducted the research'.

# 6. How: Describe the modes of delivery (e.g. face-to-face, internet or telephone) of the intervention and whether it was provided individually or in a group

The modes of intervention were face-to-face (patient and therapist), face-to-face (patient, communication partner or family member and therapist), computer-based with an avatar or via Skype and individual and group intervention (including choirs). These modes were discussed in 90% of the included studies. Studies had one mode such as individual, face-to-face intervention, for example (Edmonds et al., 2014), a combination of modes such as computer-based and with a therapist, for example (e.g. Galling et al, 2014), or individual and group intervention, for example (Morris et. al, 2011).

# 7. Where: Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features

Therapy was provided in a variety of settings such as: rehabilitation centres; sub-acute hospital setting or outpatient; at home or a combination. The setting of the intervention was made explicit in 49% of included studies.

# 8. When and how much: Describe the number of times the intervention was delivered and over what period of time, including the number of sessions, their schedule and their duration, intensity or dose

All articles outlined the amount of time per session, the number of sessions per week and the duration of the intervention block. For example, in Cherney (2008), the amount of practice differed between patients with averages reported. From the information provided, the reader would be able to obtain the dosage and intensity of the intervention.

# 9. Tailoring: If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when and how

This item was counted if the author reported whether the intervention or goal was tailored in order for these to be salient and meaningful for the patient. Of the included articles, 36% made this explicit using terms such as 'collaborative goal setting' (Morris et al, 2011), choosing meaningful targets for the patient (Galling et al, 2014; Panton & Marshall, 2008) or whether individualised communication training was provided (Lyon, 2007).

#### 2.6.3 Data synthesis

The learning processes involved in (re)learning in aphasia rehabilitation were extracted and applied to the the items from the TIDieR checklist (Hoffmann et al, 2014); relating to learning processes. The most frequently reported items were: the rationale underlying the intervention (item 2), located in the background and introduction of the article; and the dosage and intensity of the intervention (item 8). Both item two and eight were made explicit in all of the included articles. Information on feedback provided (item 4), the setting of intervention (item 7) and how the intervention was tailored (saliency of intervention) (item 9) were the least reported learning processes, with 50%, 49% and 36% respectively of studies reporting these items.

Seven articles reported all items of the TIDieR checklist: (Lyon et al, 2007; Cherney et al., 2008; Panton & Marshall, 2008; Morris et al., 2011; Sickert et al., 2014; Blom Johansson et al., 2013; Weill-Chounlamountry et al., 2013). These articles include intervention studies, case studies and a controlled trial. The controlled trial, however, did not outline all the items of the TIDieR checklist for both arms of the trial, with the 'standard therapy' being described as 'guided by standard aphasia treatment focusing on training specific deficits examples' (Sickert et al., 2014 p.52).

Some studies directed the reader to relevant articles where additional information on the interventions could be obtained, such as: Laska (2011), Stark (2010), Rodriquez et al. (2013), Jungblut et al. (2009), Ruitier, (2010), Stahl et al. (2013) and Godecke (2012). Edmonds et al. (2014) and Beeson et al. (2010), who provided additional intervention information, such as the protocol and/or word lists in the appendices of the article.

# 2.7 Discussion and interpretation

Thirty-four studies were included in this systematic review. Data were extracted from these studies, relating to learning processes and applied to the TIDieR checklist (Hoffman et al, 2014) to ascertain how learning processes are reported for speech and language therapies with a functional outcome. In addition, the number of learning process reported ranged from three (Laska et al., 2011) to nine (Lyon et al, 2007; Cherney et al., 2008; Panton & Marshall, 2008; Morris et al., 2011; Sickert et al., 2014; Blom Johansson et al., 2013; Weill-Chounlamountry et al., 2013). Additional information and direction was occasionally provided in appendices and online supplements.

Learning processes were reported variably irrespective of study design. However, controlled trials showed the greatest lack of adherence to reporting items, with four studies reporting five or fewer learning processes (Godecke et al, 2012 (RCT); Laska et al, 2011 (RCT); Wertz et al, 1981 (CT); David et al, 1982 (CT). It is acknowledged that in a controlled trial the author has two interventions to describe, one for each control arm. However, terms such as 'usual care' (Godecke et al., 2012) and 'such treatment as she thought to be appropriate' (David et al, 1982) provide little information on what was provided as a comparator. Additional information could be reported in the appendices or in a published protocol. If terms like 'usual care' are used, a sample of the intervention provided should be outlined.

The seven articles that reported all the items assessed from the TIDieR checklist were all published in the last decade, with more focus placed on tailoring of interventions from the early 2000s on.

The three least-reported learning processes were: (i) feedback; (ii) the setting or context of the intervention; and (iii) how and if the intervention was tailored to the client, either for intervention goals or for materials. This is important because the context of rehabilitation affects how people learn (Beckley et al., 2013). It is also important in relation to generalisation and transfer of target behaviours (Kagan et al., 2001; Simmons-Mackie & Damico, 1997). Despite the importance of context for learning in rehabilitation, a number of studies do not specify where the intervention took place. Given the variety of possible intervention contexts and the importance of context to learning, this should be explicitly stated in studies.

Some form of feedback is essential to learning (Shumway-Cook & Woollacoot, 2007), whether it is knowledge of outcome or of performance. The findings of this systematic review support the finding that few investigations focus on feedback in aphasia rehabilitation (Horton, 2006; Simmons-Mackie et al., 1999).

Increased saliency (whether or not the intervention is meaningful for the patient) has been shown to bring about greater efficiency of learning by helping the person to engage in the rehabilitation (Brown et al., 2000; Kleim & Jones, 2008). Despite this, the learning process that was least reported was tailoring of intervention. There was an increase in this item being adhered to in the last decade. This item was described least within controlled trials, with ten studies not adhering to this item (Cherney et al., 2012; David et al., 1982; Doesborgh et al., 2004; Fridriksson et al. 2012; Godecke et al., 2012; Laska et al., 2011; Marangolo et al. 2012; Schlaug et al., 2008; Stahl et al. 2013; Wertz et al., 1981). It is acknowledged that the aim of controlled trials may be to compare two different interventions with only one variable changed between the two. As a result, the researchers may need to keep the interventions consistent in both arms of the study. This may have made it difficult for the researcher to use salient intervention in these studies. Similar adherence to tailoring of intervention was found for case and intervention studies.

The variation in the term 'functional communication' and its use as a 'catch-all' term for meaningful intervention posed a difficulty in this review. The term is used by authors in spite of a lack of functional goals or outcome measures. Furthermore, it is not used in study keywords. Consequently, the term functional communication could not be used as a search term. The author also needed to explicitly outline what this term would mean for this research by developing a definition for the purpose of this research, including this in the inclusion/exclusion criteria and adding a screening of methods as part of the screening process in this systematic review.

The way in which learning processes are reported in speech and language therapies for aphasia with a functional outcome has never been investigated through synthesis of published literature. Hoffmann and Walker (2015 p.657) state that 'evidence-based interventions cannot be provided unless there is a clearer understanding of what the intervention is'. This novel piece of research has shown that reporting of learning processes is variable. This makes replication of some if not all studies difficult for researchers, and interpretation or implementation of findings difficult for clinicians. Complex interventions, including speech and language therapy for aphasia, need to make these processes explicit if we are to increase the evidence base of this subject area.

In line with Hoffman and colleagues (2014), the researcher acknowledges that formats and word limits set out by journals can make it difficult for authors to report interventions in detail. However, these could be made available by publishing the intervention protocol online or putting it in appendices. Authors can also direct the reader to supplementary information, or to relevant articles where further information can be obtained.

#### 2.7.1 Strengths of the review

The novel nature of this research is a strength of the systematic review reported here. The TIDieR checklist (Hoffman et al., 2014) has not been applied in the discipline of speech and language therapy or aphasia prior to the present review. Hoffman and Walker (2015) advocate for its use in understanding *how* rehabilitation works, which is often described as the components of the 'black box' in rehabilitation studies. From a search of current published literature, the TIDieR checklist (Hoffman et al., 2014) has been applied successfully in approximately 250 health-related published articles.

The data extraction sheet (Appendix III) and the integration of data from Tables 3, 4 and 5 provided an in-depth analysis of how (re)learning and learning processes are made explicit in speech and language interventions with a functional outcome. This systematic review revealed that the number of items from the TiDieR checklist, relating to learning processes, did not increase consistently with the year of publication or study design. The in-depth analysis also revealed the diversity and comprehensive range of aims and types of intervention, functional communication outcomes and study design used for speech and language therapy interventions with a functional outcome. The rationale or mechanisms underlying elements essential to successful interventions, such as learning were not made explicit. The data extraction sheet (Appendix III) allowed the researcher to reveal explicitly what learning processes could be elucidated and which learning processes could not.

Another strength of the present systematic review is that CS comprehensively searched for all published articles which adhered to her inclusion criteria. CS adapted the keywords, deciding not to include *functional communication* as a keyword, knowing that this caused articles to not be identified in electronic searches. To reduce this risk, 15,996 titles were reviewed by CS, making this a thorough piece of research. CS also decided to include articles from all languages to reduce a language bias. Japanese, Persian and Chinese articles were identified and CS contacted the authors for information about methods used so that these could be reviewed to inform a decision about inclusion or otherwise.

#### 2.7.2 Limitations of the review

The main limitation of this review was that, due to resource constraints, there was a lack of one independent second reviewer to review and extract all of the data. However, in this systematic review 15%-30% of articles were reviewed by a second reviewer and SH and JP were consulted throughout this process.

Although all precautions were taken to ensure all eligible articles were included, the researcher recognises that published articles may have been missed. This is a potential limitation.

# 2.8 Conclusion

This systematic review is the first to synthesize how learning processes are reported in speech and language therapy interventions with a functional outcome. Greater articulation of the learning processes of rehabilitation is needed in speech and language therapies for aphasia with a functional outcome. Consistent with Brady and colleagues (2012), the researcher found that the included speech and language therapy interventions were reported variably. Brady and colleagues (2014) call for clearer reporting of complex interventions. All learning processes need to be reported explicitly if clinicians and researchers are to be able to replicate studies, or apply them in clinical practice. Outlining the learning processes gives the reader insight into *how* the rehabilitation might have worked rather than just *if* it did. Greater specification of these processes allows the researchers and clinicians to better understand the mechanisms by which people with aphasia may learn in rehabilitation. Clarity in reporting will allow researchers to synthesize these data to better understand how successful outcomes in interventions are achieved. This could allow researchers and clinicians to develop better knowledge and evidence that could further optimise interventions.

## 2.8.1 Implications for practice

Further information on learning processes is needed in reports of research studies to enable implementation of evidence-based interventions by clinicians.

## 2.8.2 Implications for research

The TIDieR checklist (Hoffman et al., 2014) was a useful tool to investigate how learning processes were reported speech and language studies for aphasia that had a functional

outcome. The items in this checklist could be used by authors when writing articles to ensure that all items are reported.

More explicit outlining of learning processes might allow researchers to extract data relating to the different learning processes that could be used in future systematic reviews or data analysis.

# Chapter 3: Exploratory study: Background

# Increasing opportunities for functional communication learning in rehabilitation for people with aphasia in Early Supported Discharge (ESD)-(OASIS)

### 3.0 Introduction

The overall aim of this thesis is to investigate how functional communication learning can be optimised for people with aphasia post-stroke during routine rehabilitation. The systematic review (chapter 2) explored and elucidated how learning processes are reported in speech and language therapy interventions with a functional outcome. Reports from published research studies have a bearing on how and whether research is translated in to clinical practice (Brady et al., 2014) and how rehabitation is conducted by healthcare professionals. As is clear from the Systematic Review, detailed reporting of interventions relevant to functional communication learning and outcomes is variable, with rationales and processes often implicit in reports. The exploratory study was developed to investigate in detail the nuaces and complexities of routine rehabilitation and to investigate and make apparent how learning may be optimised in the day-to-day practice of routine rehabilitation. This chapter provides a background to the exploratory study, outlining the literature that underpins this study and setting out the aims and research questions.

#### 3.1 Conversation partners of people with aphasia

People's social networks change with age, with some people experiencing significant reductions in the opportunities for communication and conversation (Davidson, Worrall, & Hickson, 2003; Northcott & Hilari, 2011). PWA are at greater risk of a reduction in the number of communication partners than people post-stroke without aphasia, because they particpate in a smaller range of communication activities (Davidson et al., 2003). This reduction may be due to the PWA experiencing: unsuccessful communication and consequent reduced social competence (Simmons-Mackie & Damico, 2007); receiving hurtful comments from those close to them (Northcott & Hilari, 2011); restrictions in physical mobility and environmental barriers such as lack of public transport (Northcott & Hilari, 2011) and; changes in identity and social roles (Cruice et al., 2005; Hilari & Byng, 2009). All of these factors can make PWA reluctant to engage in communication, which raises their risk of losing their friendship groups (Cruice, Worrall, & Hickson, 2006). Approximently a third (30%) of PWA reported that they have no friends at all (Hilari & Northcott, 2006).

PWA also experience changes in their communication partners after onset of aphasia. The communication partners of PWA may be different from healthy adults without aphasia. For example, Davidson, Worrall and Hickson (2003) found that PWA communicated more with Healthcare Professionals (HCPs) and with a smaller number of acquaintances, strangers and neighbours. However, the number of significant others that people with aphasia and healthy adults communicated with were similar (Davidson, Worrall & Hickson, 2003). These findings are supported by Godecke, Armstrong, Hersh, and Bernhardt (2013) who found that nurses were the key communication partner for PWA, whereas for people without aphasia it was family and friends.

# 3.2 Opportunities for functional communication practice

Despite HCPs being reported as key communication partners for PWA, there are few opportunities for communication in healthcare settings (Byng, Farrelly, Fitzgerald, Parr, & Ross, 2003). PWA communicate with HCPs in this setting for less than 50% of their time (Knight, Worrall, & Rose, 2006). Indeed, early after their stroke, people have been reported to spend 60% of their time alone (Berhardt et al., 2004). Furthermore, people without aphasia spent nearly three times more of their day communicatively engaged than people with aphasia (Godecke et al., 2013). When PWA did engage in conversation with HCPs it was during therapy and at direct contact time. However, the time spent actively communicating in therapy in the first month post-stroke was variable. Godecke et al. (2012) found that a PWA received on average 14 minutes per week, whereas Bowen et al. (2012) found that it was 1.3 hours per week.

## 3.3 Communication and contextual factors

Communication and language use is shaped by social purpose and context; people often adapt their discourse depending on the purpose and their conversation partners (Fairclough, 2003). For example, when a researcher lectures to students, the discourse will be tailored to this topic and the tone will be professional, but the tone will change when they converse over dinner with close friends. Conversation is also influenced by the communication partner, as meaning is co-constructed by the two (or more) parties involved (Clark & Wilkes-Gibbs, 1986; Goodwin, 1981). The responsibility for successful interactions therefore lies with both communication partners.

Environmental factors such as attitudes and accessibility can potentially act in ways either enabling or disabling to communication, as highlighted in the ICF (Stucki et al., 2002; World Health Organization, 2001). Barriers to successful communication can include conversation partners who can act in disabling ways if they do not see conversation as a collaborative process, holding the PWA responsible for communicative breakdown. In the acute hospital setting, further barriers have been identified. These include: healthcare providers' knowledge of and skills in communicating with PWA (Cottrell & Davies, 2004; Parr, Byng, Gilpin & Ireland, 1997); attitudes of healthcare professionals (Parr, Byng, Gilpin & Ireland, 1997; Sundin, Jansson, & Norberg, 2000); the physical environment (Cottrell & Davies, 2004); and services and policies (Horton, Lane, & Shiggins, 2015; Kagan & LeBlanc, 2002).

#### 3.4 Impact of missed opportunities for communication in healthcare settings

PWA may have difficulties communicating views, needs and desires to their HCPs, leading to sub-optimal care (O'Halloran, Hickson, & Worrall, 2008), which may impact on their immediate health (Stewart, 1995) and medical recovery (Gordon, Ellis-Hill, & Ashburn, 2009). Article 3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) emphasises the importance of: 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'. In addition, the WHO (World Health Organization, 2007) highlights that all patients should have access to information that is easy to understand and suitable for their needs. Consequently, to uphold the human rights of a PWA and to be fully effective, communication between PWA and HCPs in healthcare settings should go beyond the transactional role of addressing basic needs, such as need for the toilet or identifying pain. HCPs need to collaborate in a conversation with a PWA to negotiate care needs, rehabilitation goals and expression of views and attitudes. Despite the key importance of this communication, HCPs often focus on physical care alone (Gordon et al., 2009; Pound & Ebrahim, 2000). As well as essential information exchange, positive interactions between HCPs and PWA can foster positive therapeutic relationships and increase motivation (Mold, McKevitt, & Wolfe, 2003).

Lack of communication and opportunities for conversation can have further detrimental effects due to learned non-use (Pulvermüller et al., 2001). Experiences of failure when using an impaired communication skill can lead to 'absence of reward' for the PWA (Pulvermüller & Berthier, 2008). This means that the person can be less likely to use their impaired skills, instead relying on their retained skills (Pulvermüller & Berthier, 2008). When neural reorganisation does occur later post-stroke, if learned non-use has become established, a functional impairment will remain (Taub, Uswette, Mark, & Morris, 2006). Practice is the most important variable that can prevent learned non-use from becoming permanent and

allow functional reorganisation to occur (Hamzei, Liepert, Dettmers, Weiller, & Rijntjes, 2006). Therefore, optimising opportunities for communication practice could prevent further impairments due to learned non-use. HCPs have a responsibility to foster an environment where meaningful communication can occur (Gordon et al., 2009).

## 3.5 Rationale for exploratory study

Studies of interpersonal communication/conversation in aphasia have generally focused on interactions between PWA and their caregivers (Beeke et al., 2013; Cunningham &Ward, 2003; Lock et al., 1999; Wilkinson & Wielaert, 2012). Research is growing on the interaction between PWA and their HCPs and has been carried out in the context of elderly care facilities (Hickson, Worrall, Wilson, Tilse, & Setterlund, 2005), on a specialist stroke ward (Gordon et al., 2009) and in acute hospital setting (Hersh, Godecke, Armstrong, Ciccone, & Bernhardt, 2016; Knight et al., 2006; O'Halloran et al., 2008). HCPs are one of the key communication partners for PWA in the early stages (first weeks and months) during hospital stays and rehabilitation and PWA have numerous interactions with HCPs. PWA and HCPs also need to engage in conversations regarding healthcare decisions, instructions to improve or maintain health, such as medication, and expressing views and healthcare needs during this time. Successful interactions are thus essential to ensure that PWA are getting the best care possible while exercising their autonomy.

Having completed an extensive literature search, no studies have explored interactions between PWA and their HCPs in the context of ESD. ESD provides a seven-day service for a minimum of 45 minutes a day, for two to twelve weeks depending on rehabilitation potential and goals (RCP Stroke Guidelines 2008 3.13.1 page 3.9). The most important factor in (re)learning is practice (Schmidt& Lee, 2013), and this also prevents the negative effects of learned non-use (Pulvermüller et al., 2001). PWA are disadvantaged by their communication difficulties, with fewer opportunities to practice communication in everyday conversations. Such rehabilitation occasions have the potential to function as task-specific practice opportunities (Godecke et al., 2013). PWA therefore need functional communication practice in their communicative contexts and meaningful interactions with their HCPs. Increasing the participation of PWA in their rehabilitation, which is key to success, is receiving growing attention (Horton et al., 2015). There are opportunities in the healthcare setting for active participation and communication from the PWA that are inconsistently realised, with caseload pressures, time constraints and environmental factors being cited as barriers to communication (Horton et al., 2015). There may be

opportunities in healthcare professional interactions that are not being optimised and that could enhance (re)learning for a PWA.

The focus of this research is interaction between HCPs and PWA. No studies to date have examined the learning process in aphasia rehabilitation taking account of the relationships between aphasic impairment, activity, HCP-PWA personal factors and context, and how these relate to the success or otherwise of interventions. ESD is a relatively new stroke pathway, and research into processes and outcomes is in its infancy in this field. Novel research such as this has the potential to add to and develop the field of aphasia, providing information on how (re)learning in the context of ESD can be enhanced for PWA.

The systematic review discussed in Chapter 2 was developed to answer the first research question. The exploratory study was developed to answer research questions 2, 3 and 4:

- 1) What conditions exist during routine rehabilitation sessions for enhancing functional communication learning for aphasia?
- 2) What is the nature of these conditions, how do they arise and how can they be produced?
- *3)* What are the barriers to and facilitators of the uptake of opportunities to enhance functional communication learning for aphasia during day-to-day clinical practice?

# Chapter 4: Exploratory study: Methodology

# 4.0 Introduction

This chapter sets out and discusses the methods used to address the aims of the exploratory study. Ethical approval, patient and public involvement, recruitment and sampling of study participants, and methods used for data collection and analysis will be outlined.

# 4.1 Ethical approval

This study received full ethical approval from the National Research Ethics Service (NRES) Committee East of England, Cambridge South (REC reference: 13/EE/0322) on 10 October, 2013 (Appendix IV); Research and Development (R&D) approval was granted on 18 December 2013 (Reference: 2013GC12) (Appendix V). A copy of the participant information sheets (PIS) submitted to the Research and Ethics Committee (REC) can be found in Appendices VI to XIV. The researcher completed Good Clinical Practice (GCP) training on 16 November 2012; a GCP refresher on 24 February 2015; and obtained a research passport (November 2012) and clearance following a Criminal Records Bureau check (CRB) (October 2012 and October 2013).

# 4.2 Patient and Public Involvement (PPI)

Patient and public involvement (PPI) is held to improve the way that research is undertaken, from design to dissemination (Hayes, Buckland, & Tarpey, 2012). Active participation by patients and members of the public provides researchers with an 'expertise by experience' perspective, leading to more relevant and applicable research (Chalmers, 1992; Hayes et al., 2012).

An advisory group was therefore brought together by the research team, consisting of two PWA, two SLTs and the administration assistant from the ESD team. They contributed to the development of the study protocol, the participant information sheets and consent forms. The researcher liaised with them throughout the life of the project.

All information and consent forms were assessed by the advisory group, who advised on adaptations and approved final versions, to ensure that they were accessible for PWA, HCPs and would be understood by families and/or carers. On advice from the two people with aphasia a 'permission to contact' form was developed (Appendix XII) so the SLTs could ask the PWA the best mode of communication for them to be first contacted by the researcher, such as email or phone. The advisory group also suggested that forms be sent to potential participants prior to the consent meeting to allow them to digest the information. All forms were also sent electronically, where appropriate, to allow people to make use of speech outputting (text-to-speech) devices if reading written text was difficult for them.

One of the PWA attended the ethics meeting with the researcher (CS) and her PhD supervisor (SH) on 10 October, 2013. This was the first time many panel members had met a PWA, and they found this valuable. This gentleman presented with severe expressive aphasia; CS and the gentleman with aphasia showed how supported communication could be used to help convey and obtain information.

In the meetings with two SLTs and the ESD administrative assistant, the researcher developed an understanding of the ESD referral system, into and out of the team, timescales for PWA in the service and how HCPs were allocated to certain patients. The SLTs also outlined when they would be able to approach PWA and how they would contact the researcher if PWA expressed an interest in the study. The recruitment and data collection procedures were developed using information obtained in these meetings. This process was then scrutinised by the stakeholders from the ESD team to ensure that it was as efficient and streamlined as possible.

## 4.3 Participants

PWA and HCPs from the Norfolk ESD team were recruited to this study. The inclusion and exclusion criteria for both groups of participants are outlined below.

#### 4.3.1 Participants: people with aphasia

PWA were approached from the ESD Service if they fulfilled the inclusion/exclusion criteria below (Table 6). Stroke survivors with any level of severity or type of aphasia were recruited. The aim was to recruit PWA with a range and variety of aphasia severity within the sample of participants. The Mental Capacity Act (MCA) (Department of Health, 2005) states that it is unethical to involve people in research who are unable to provide informed consent, therefore the participants needed to have the capacity to consent and be cognitively aware in order to be included in this study. Only adults (18+) were included to provide self-consent. The researcher also wanted to look at the effect of aphasia on communication with HCPs, and did not want any communication difficulties arising in these interactions to be caused by shortcomings in English language proficiency. Therefore, those who did not have English as a first language were excluded. Finally, the focus of this study was stroke rehabilitation; therefore the researcher excluded people who had aphasia as a result of any other aetiology.

## Table 6. Inclusion/Exclusion criteria for participants: People with aphasia

Inclusion criteria	Exclusion criteria
Able to give informed consent	Unable to give consent
Aged 18+ years	Under 18 years of age
Have had a stroke (first or recurrent) and have any level or type of aphasia, established by a speech and language therapist (SLT)	Have a presentation of aphasia due to a disorder that is not stroke e.g. traumatic brain injury (TBI) People whose first language is not English or who have limited command of spoken/written English as established by members of the clinical team People with severe cognitive impairments

## 4.3.2 Participants: healthcare professionals

HCPs from the Norwich ESD team were approached if they fulfilled the inclusion/exclusion criteria below (Table 7). The HCPs had to be members of the Norwich ESD team, as this was the team for which R&D approval had been granted. SLTs from the ESD team were not recruited to the study, as they acted as gatekeepers to recruitment of PWA, and this could have given the study an internal bias. HCPs of grade bands 3-7 were included, as these were the grade bands of staff providing face-to-face rehabilitation with patients in that ESD service. In contrast to the participants with aphasia, HCPs who had English as a second language were included as they had passed an English language proficiency test to work in the NHS.

## Table 7. Inclusion/exclusion criteria for participants: Healthcare professionals

Inclusion criteria	Exclusion criteria
Work as a member of the Norwich ESD team	Do not work for the Norwich ESD team
Any healthcare professional working with people with aphasia except those stated in the exclusion criteria	Speech and language therapists on the ESD team
Aged 18+ years	Under 18 years of age
Grade band 3-7	Are below band 3 or above band 7

## 4.4 Recruitment of participants

This section outlines how HCPs and PWA were recruited to the study, and includes demographic information for the participants recruited. The researcher decided that HCPs would be recruited prior to approaching PWA. This decision was based on information

collected at the stakeholder meetings with the ESD team. Due to the short time period between recruiting PWA to the study and the first observational data collection session, it was essential to have recruited the HCPs with whom PWA would be working in order for observations to begin without delay.

## 4.4.1 Recruitment of healthcare professionals participants

The study rationale and process of recruitment were introduced to staff in December 2013, at an ESD MDT meeting. The researcher outlined the project, providing information sheets and consent forms. At the meeting, the HCPs had time to read and digest the information, ask questions and discuss the research. If HCPs felt comfortable signing consent forms at the meeting they did so, and then provided demographic information. If not, the researcher returned 24 hours later (as stated in the ethics application) to collect signed and dated consent forms. Demographic information was then collected. Due to staff turnover and rotational posts, recruitment was an ongoing process. When a new HCP began on the team, the researcher was informed, and she discussed the research with them. The process of recruitment was then the same as for those earlier in the life of the project. The recruitment process for HCPs is illustrated below (Figure 3).



#### 4.4.2 Sampling: Healthcare professionals

The Norwich ESD service is divided into three teams according to geographical location. Referrals are made to the ESD team from the stroke rehabilitation ward based in the same community hospital, or from the local acute care hospital. The person is then allocated to a team depending on where they live. Each team consists of a mix of HCPs: Occupational Therapists (OT), Physiotherapists (PT), Assistant Practitioners (AP), Rehabilitation Assistants (RA) and nurses. Each team had one OT, PT and SLT, and included a variable number of APs and RAs. RAs and APs occasionally changed team according to demands on the team working in any of the geographical areas.

Purposive sampling was used in order to obtain a diverse data-rich sample (Patton, 2002). The researcher aimed to obtain a sample of HCPs that included a variety of possible professions working with PWA in the ESD team, thus allowing the researcher to observe a variety of rehabilitation activities, topics and materials, and use of different spaces within the home setting.

As the researcher did not know which geographical areas the PWA would live in or who would be working in that team at the time of observation, the aim was to recruit a diverse sample of HCPs from all three ESD teams.

#### 4.4.3 Recruitment of people with aphasia participants

SLTs in the ESD team acted as gatekeepers for the recruitment of PWA. SLTs met the researcher and the project was discussed; they were given opportunities to ask questions about the study and to ask for clarification of the recruitment process (Figure 4). Due to staff turnover of SLTs in the ESD team, the researcher had to train new SLTs on the recruitment process when they began on the team.

The SLTs identified people who they diagnosed as having aphasia, and who met the other inclusion criteria. If people with aphasia met the inclusion criteria, they were approached and the research was discussed with them by the SLT. Those who expressed an interest in the research completed a permission to contact form, which included contact details and how they would like to be contacted by the researcher e.g. by email, phone or through the person's next of kin. The SLT then provided the PWA with the information sheets, the aphasia-accessible information sheets, a cover page with information on the research and the research team, and a consent form (Appendices VI to XIV).

The SLT then rang or met with the researcher to provide them with the PWA's contact details and their preferred medium of communication. For security and confidentiality reasons, this information could not be sent by email.

On advice from the stakeholder group, the researcher met with potential participants with aphasia in a separate meeting to go through the full information sheet and to discuss the study. The researcher contacted the PWA through their preferred medium and arranged a time that best suited them and their family/significant others to go to their home or a location of their choice and discuss the research. Aware that the PWA was receiving intensive input from the ESD team, the researcher was flexible with the timing of these meetings and included evenings and weekend visits.

The researcher met with the PWA, and with their family, if so wished, using supported communication as appropriate to ensure that the potential participant fully understood

what the study entailed. An accessible version of the information sheet was left with the person, and they were given up to 24 hours to consider participation in the study. Where the person had difficulty writing, their carer or family member was able to witness oral consent and sign the form. Once consent was obtained, the researcher collected demographic information from the PWA.

Figure 4. Flowchart of participant recruitment for people with aphasia



#### 4.4.4 Sampling: people with aphasia

Decisions regarding sample size in qualitative research are made depending on the research question, the amount of data needed for analysis, and resources, such as time (Patton, 2002). The sampling frame for participants with aphasia included the main variables that the researcher and team thought would impact on experience of aphasia and ESD rehabilitation; these were: sex; severity and type of aphasia; co-morbid difficulties such as mobility; and whether the person lived alone. The researcher aimed to recruit between 8 and 10 PWA until a variety of participants were recruited, in order to ensure maximum variation in the sample (Fassinger, 2005). This took into account recruitment time for therapy process studies (Horton, 2008) and was within the bounds of feasibility for an exploratory study relative to the complexity, size and dimensions of the data set generated through the study research methods (Miles, Humberman & Saldana, 2013).

#### 4.5 Participants

Recruitment took place over a 15-month period, beginning with the recruitment of HCPs in December 2013 and ending in February 2015, when the recruitment target for participants with aphasia was reached.

#### 4.5.1 Participants: Healthcare professionals

Twenty-one HCPs were recruited to the study between December 2013 and December 2014. The total number of ESD team members changed throughout the study due to staff turnover and rotational posts. On average the team, excluding SLTs, consisted of 25 HCPs. In order to retain participant anonymity each staff participant was assigned a unique identifying number according to the order in which they were recruited to the study. A range of professions were represented, including: OT (24% of HCP participants); PT (19%); RA (29%); AP (14%); and nurses (14%), with 57% of the participants holding a professional qualification. The years of experience of recruited participants working in healthcare ranged from 2 months to 20 years. Only two men worked on the ESD team, both of whom were recruited, making the sex split 90% female and 10% male. Two HCPs were recruited who spoke English as a second language and Tagalog as their first language. Demographic information for HCP participants is set out in Table 8.
Study Identifier	Sex	Profession	Years of Experience Ban	d grade	Hours	First Language
1	Female	ОТ	5 years	6	Part time	English
2	Female	ОТ	2 months	5	Full time	English
3	Female	РТ	1 year	5	Full time	English
4	Female	РТ	4 years 6months	6	Full time	English
5	Female	ОТ	10 years	7	Part time	English
6	Female	RA	3 years	3	Full time	English
7	Female	Nurse	4 years	5	Part time	English
8	Female	Nurse	5 years	7	Full time	English
9	Female	RA	6 years 6 months	4	Full time	English
10	Female	ОТ	1 year 2 months	5	Full time	English
11	Female	RA	3 years 4 months	3	Full time	English
12	Female	AP	4 years 6 months	4	Full time	English
13	Male	RA	4 years	3	Full time	Tagalog
14	Female	РТ	6 months	5	Full time	English
15	Female	AP	15 years	4	Full time	English
16	Female	RA	4 years	3	Part time	English
17	Female	AP	6 months	4	Full time	Tagalog
18	Male	RA	2 years	3	Full time	English
19	Female	ОТ	1 year	5	Full time	English
20	Female	РТ	9 years 6 months	6	Full time	English
21	Female	Nurse	20 years	7	Full time	English

## Table 8. Demographic information: Healthcare professionals

## 4.5.2 Screening and recruitment: people with aphasia

Figure 5 below sets out the recruitment flow for participants with aphasia: those who were approached by the SLT gatekeepers, screened and those that were recruited to the study. The researcher met with SLT gatekeepers and kept in phone contact regularly to collect these figures.



## 4.5.3 Participants: people with aphasia

Ten PWA were recruited to the study between January 2014 and February 2015. In order to retain participant anonymity, each PWA participant was assigned a unique identifying number according to the order in which they were recruited to the study. The sex split was 40% female and 60% male with a mean age of 72 (range 52–92 years). The severities of aphasia varied, including: severe aphasia (40%); moderate aphasia (20%); and mild aphasia (40%). All PWA self identified as white British and of varied socioeconomic class (based on occupation). All PWA lived at home except for PWA 7, who lived full-time in a care home. Living arrangements were varied, including: living alone (3); with a significant other (5); with care home residents (1): and with a home-based 24-hour carer (1). The participants with aphasia presented with a variety of co-morbid difficulties, including: hemiparesis; hearing impairments; memory difficulties; cognitive difficulties; difficulties with movement; and arthritis. Demographic information for PWA participants is set out in Table 9.

Study	Age	Sex	Aphasia	Marital	Ethnicity	Previous	Co-morbid
Identifier			Severity	Status		Occupation	difficulties
PWA 1	67	Male	Severe	Separated (living alone)	White British	Farmer	Right side hemiparesis
PWA 2	77	Male	Mild	Married	White British	Farmer	None
PWA 3	52	Female	Severe	Partner	White British	Telephone operator	Right side hemiparesis
PWA 4	72	Male	Moderate	Divorced (living alone)	White British	Truck driver	Right side hemiparesis
PWA 5	79	Male	Mild	Married	White British	Broadcaster	Hearing Impairment
PWA 6	75	Male	Moderate	Married	White British	Postman	Mild memory difficulties
PWA 7	89	Female	Severe	Widow (care home)	White British	Unknown	Cognitive difficulties
PWA 8	77	Male	Mild	Married	White British	Dentist	None
PWA 9	65	Female	Severe	Single (living alone)	White British	Secondary school teacher	Right side hemiparesis
PWA 10	92	Female	Mild	Widow (24 home care)	White British	Factory worker	Arthritis; difficulties with movement; mild memory difficulties

## Table 9. Demographic Information: People with aphasia

## 4.6 Methodology

## 4.6.1 Methodological underpinnings

Research questions in the exploratory study were addressed using an inductive constructivist approach. Constructivism is based on the underlying assumption that phenomena cannot be reduced down into parts (Crotty, 1998), where 'truth' is not objective but is constructed by people and through interactions in a social context (Lincoln

& Guba, 2013), which affects people and their behaviours. Rather than forming a hypothesis which is supported or refuted through research, in a constructivist approach, the hypothesis or theory is developed through the data. As a research philosophy it is equipped to account for contextual, personal and societal variables, which are key factors in the research questions of this study.

## 4.6.2 Methodological choices – qualitative methodologies

A range of methods were needed to address the study's aims and research questions, which assumed a number of interacting factors: aphasia type and severity; the PWA; the HCP; the physical context (place and space); the activity; learning processes; and the knowledge base, attitudes and beliefs of participants. Qualitative methods seek to elucidate subjective experiences and the influences of context, emphasising the importance of novel or unanticipated findings and acknowledging the need for flexible research plans (Bryman, 1984). It is important to emphasise that this is, as far as is possible, a naturalistic study of routine day-to-day clinical practice as experienced by PWA and HCPs alike, using an exploratory, open-ended approach designed to produce in-depth, detailed data.

To ensure that the research has not been limited 'arbitrarily or inappropriately' (Mason, 2002 p.26), the researcher considered a number of methods: focus groups, journaling, photography, interviews and observations. Taking into consideration the research aims and the communicative abilities of the participants, video observations and interviews were the qualitative methods chosen as most appropriate to answer the specific research questions of the exploratory study. Justifications for and limitations of these choices are set out in Table 10 below.

Research questions	Data sources and methods	Justification
What conditions exist during routine rehabilitation sessions for enhancing functional communication learning for aphasia?	Observation: Of routine rehabilitation between people with aphasia and healthcare professionals Interviews: Semi-structured interviews following a topic guide, but informed by analysis of video observations	<b>Observations:</b> Observational methods will allow rehabilitation practices to be recorded
What is the nature of these conditions, how do they arise and how can they be produced?	<b>Observation:</b> Video recordings of interaction	Video recordings enable repeated study and analysis of HCP–PWA interaction (e.g. supporting, enhancing or restricting patient communication)
		Video recordings capture aspects of non-verbal communication
		Limitations: Observer effect; selective recording
What are the barriers to and the facilitators of the uptake of opportunities to enhance functional communication	<b>Observation:</b> Of routine rehabilitation between people with aphasia and healthcare professionals	Interviews: Enable the research to capture the subjective experience of the participant
day-to-day clinical practice?	Interviews: Semi-structured interviews following a topic	The researcher has the flexibility to follow the participant's lead
	guide, but informed by analysis of video observations explore and ga all the topics t covered	Allows the researcher to explore and gain information on all the topics that need to be covered
		<b>Limitations:</b> Information from interviews can be subject to bias introduced through the questions asked or through social desirability, i.e. the

# Table 10. Justifications for and limitations of methodological choices

participant says what they think the interviewer wants to hear

#### 4.6.3 Interviews

Semi-structured, topic-guided interviews were conducted with a purposive sample of the HCP participants (Appendix XIII) and all PWA who completed the study (Appendix XIV). The semi-structured topic guide was informed by the literature, individual perspectives the researcher hoped to capture and information gained from the advisory group. The topic guide was personalised using information gained through the observation data. Vignettes from the observation data were used as appropriate to gain the PWA's and HCPs' perspectives on observed data. The sample frame for HCPs was constructed from the following variables: those who were observed; those who were also willing to be interviewed; and a range of professionals to ensure that at least one representative from each healthcare profession was included, to include a variety of perspectives.

Interviews are an effective method for exploring and understanding the subjective experience of the participant and how they perceive an event or experience (Ritchie & Lewis, 2014). The interviews were used to explore and account for factors that could not be observed, such as emotions felt by PWA and HCPs, attitudes towards rehabilitation or aphasia and what they felt enhanced learning in rehabilitation.

All participants who were interviewed were given the option to see vignettes from the observational data, which the researcher particularly wished to explore further to seek clarification of actions, such as aspects of rehabilitation activity, or to gain an understanding of a particular event from the participant's perspective. If the PWA or HCP did not wish to see the vignettes, the researcher described the situation based on the vignette and asked the participant to discuss the described observation. Participants' views on the use of video recording as a method were also sought.

#### 4.6.4 Limitations

There are limitations to interviews as a method: interviews can be time-consuming in terms of data collection and analysis; participants' responses in the interview could have been affected by the fact that the same researcher collecting the observational data also conducted the interviews; participants' responses could be influenced by trying to 'save face', trying to mirror the researcher's views in their answers, or being reluctant to speak badly of others, thus limiting the depth of the answers. In order to minimise these limitations, the researcher spent time building a rapport with the participants to ensure that they were comfortable during the interviews. She also paraphrased responses to ensure that participants were satisfied with her interpretation of their expressed views.

#### 4.6.5 Video observations of routine rehabilitation

Video-based observations provide insight into interactions, processes and behaviours, and allow the researcher to understand how the participants interact with space and materials used (Ritchie & Lewis, 2014). This method was used to capture routine rehabilitative activities between PWA and HCPs in the context of home-based practice. The video camera was directed towards the HCP and the PWA, but the observations were kept unfocused by using a wide-angle lens to incorporate as much of the environment as possible. Video recordings have a number of advantages: data can be viewed and reviewed; they are equipped to capture interaction-in-action and non-verbal communication used by PWA; and in contrast to field notes they help to alleviate the 'inherent subjectivity' and incomplete data sets that can occur when the data relies on the researcher's memory, efficiency and accuracy. Video observation has been shown to be an effective data collection method when working with PWA post-stroke, yielding rigorous results (Godecke et al., 2013; Hersh et al., 2016; Horton et al., 2011) and enabling the researcher to observe the nuanced complexities of interaction (Davidson et al., 2003).

#### 4.6.6 Limitations of observations

Limitations of this methodology, such as observer effects and camera reactivity, are acknowledged. The issue of participants' 'camera reactivity' is still debated (Monahan & Fisher, 2014; Speer & Hutchby, 2003), with some studies treating this also as an object of investigation itself (e.g. Horton, 2002; Lomax & Casey, 1998; Speer & Hutchby, 2003). The presence of the camera (and the researcher) inevitably affect the phenomena being studied. Steps were taken, however, to minimise the effects that these would have: the researcher spent time with the HCP participants to create trust and to learn about the culture and environment of the ESD team; multiple videos were recorded with each participant, providing them with repeated exposure to the camera, thus reducing the effects of camera reactivity (Latvaia et al 2000); and a hand-held camera was used to minimise possible distraction by bulky equipment, such as a tripod. Hand-held camera use allowed the researcher to move quickly and quietly to follow interactions as the participants moved around spaces within the home environment. The researcher remained silent throughout the session and positioned herself discreetly.

## 4.6.7 Integration of observation and interview data: rationale

Incorporating interview and observational data was key to providing a complete and indepth examination of the research questions. Data from interviews and observations were intended to augment, rather than confirming or refuting, each other. Thus interviews allowed the researcher to generate a particular perspective on the rehabilitation practices that had been observed, to discuss routine rehabilitation and the experience of life after stroke or the stroke pathway and to gain an in-depth understanding of participants' opinions and experiences within and beyond this context. The interviews allowed the researcher to understand PWA's and HCPs' personal factors that may influence routine rehabilitation. The observational data helped to extrapolate the practices in routine rehabilitation that produce conditions for learning and to see how the topics that were discussed in the interviews were enacted in routine rehabilitation. By combining these qualitative methods, it was hoped that the researcher would have a variety of perspectives that would make any recommendations from this research more practical, relevant and applicable in clinical practice. Video observations and interviews have both been demonstrated to provide thorough descriptions and accounts of communication in naturalistic settings in aphasia research (Davidson et al., 2003; Gordon et al., 2009; Knight et al., 2006; Simmon-Mackie & Damico, 1995).

#### 4.6.8 Reflexivity

Reflexivity is key to the development and implementation of qualitative research strategies. Reflexivity entails the researcher thinking critically about the thought processes behind research decisions and actions. It forces researchers to confront and often challenge their own assumptions, recognising that prejudice and past experience can alter the way data are perceived, analysed and interpreted (Mason, 2002). Reflexivity was practised throughout the research process in order to ensure the credibility of the research, interpretation of data and production of findings. A reflexive log was kept throughout the development of the study protocol and data collection process. In this log the researcher reflected on the decision-making process, logged key decisions and how these may have been altered and why: for example, use of a hand-held camera rather than use of a tripod because the researcher found that using a tripod interrupted and disturbed participants. The researcher also reviewed and critiqued her interview technique in order to improve it for the subsequent interviews, for example by using more follow-up, exploratory questions. The researcher also reflected in order to identify preconceptions on the topic and prejudices that may give internal bias to the interpretation of the data, such as her background as a speech and language therapist or her own experience, both personal and professional, of stroke. The researcher noted when a point made by a HCP and/or PWA provoked a particular reaction in her. She reflected on why this was the case, so that these feelings did not impede the data collection or analytical process.

## 4.7 Process of data collection

For each participant with aphasia the aim was to collect observational data in a maximum of six healthcare intervention contexts, approximately equivalent to three therapy sessions at or near the beginning of the rehabilitation block, and three at or near the end. The number of sessions observed for each participant varied according to when they were discharged (e.g. earlier than expected); the type or nature of sessions and whether they were appropriate for the researcher to attend (e.g. washing and dressing or mood screening); 'timetable' clashes (e.g. between two participant sessions); or HCP and PWA illness on a scheduled observation session. The researcher aimed to observe the PWA with the greatest possible variation of HCPs. The researcher choose which sessions to observe based on the purposive sampling frame (Patton, 2002), which encompassed a range of dimensions directly relevant to the research questions: 1) observable routine rehabilitation activities (i.e. face-to-face therapies and therapist- or nurse-patient planning or goalsetting discussions); 2) healthcare staff intervention types (e.g. physiotherapy [PT], occupational therapy [OT], speech and language therapy [SLT]); and 3) healthcare staff (therapists, rehabilitation assistants, assistant practitioners, nurses). This was subject to HCP involvement for individual participants with aphasia – for example, some participants did not have OT involvement and some did not have PT involvement.

The data collection process was facilitated by a single point of contact in the ESD team (the ESD administrative assistant), from whom ESD timetables were obtained for each of the three teams. MDT meetings were held every Tuesday and Wednesday, where new referrals and discharge planning were discussed. The timetables were drawn up by the administrative assistant on Thursday and Friday each week. When a new referral was made to the ESD team the person would begin involvement with the team the following week. If the person was deemed to no longer need or want intensive rehabilitation, they were discharge date. The researcher contacted the ESD single point of contact once a week after the multidisciplinary meetings to be updated on the PWA's expected discharge date. According to this date the researcher would choose when to complete the second set of videos and carry out the same data collection process as she did for the first set of videos.

A sample of the data collection process is shown in Table 11. This sample is based on a sixweek block of intervention, which is the average intervention period for a PWA in the ESD service. The timings may vary where the person was engaged in a shorter or longer intervention block. Once the last video-observation was completed with a participant with aphasia, the researcher arranged a time to complete the one-to-one topic guided interview.

Rehabilitation block in weeks	Example of data collection
Week 0–1	Speech and language therapists invite patients who meet the
	inclusion/exclusion criteria to consider taking part
	Person expresses interest in participating in the study. SLT asks
	the potential participant how they would like to be contacted
	by PI. A permission to contact form is filled in accordingly
	Researcher collects the permission to contact form from the gatekeepers
Week 1–2	Researcher contacts the potential participant through their
	preferred medium and arranges a meeting to discuss the
	information sheets and sign consent forms
	Meeting held and consent obtained in up to 24 hours
	Single point of contact in the ESD team contacted and
	timetable obtained. Time arranged for first video recording.
	Permission sought from all participants to observe particular sessions
Week 1–3	Three therapy sessions observed and video-recorded (onset of
	rehabilitation block)
Week 4–6	Three therapy sessions observed and video-recorded (pre-
	discharge from the ESD team)
Week 7	One-to-one semi-structured interviews with the person with
	aphasia (at discharge) and a sample of the ESD staff (when all video observations are completed)
	Debriefing with the person with aphasia if requested/needed

Table 11. Data collection process for PWA with indicative examples

# 4.7.1 Process of data collection for individual participants: video observations

When a PWA was recruited to the study, the researcher would make a phone call to the ESD administrative assistant to obtain information on: the ESD team members working with him/her; and their timetable for the following week. The researcher then contacted the HCPs involved to ensure that they were happy for the researcher to observe the proposed sessions. If the HCPs were happy to have the proposed sessions observed, the researcher then contacted the nontacted the PWA and advised them on the days that she would be attending the

session and making a video recording. The researcher, recognising that consent is fluid (Mental Capacity Act: Department of Health, 2005), always sought consent from all participants at the beginning of the session before the video recording began.

## 4.7.2 Details of video observations

Fourty-two routine rehabilitation sessions were observed and video-recorded by the researcher (CS), including 33.5 hours of data (ranging per participant between 56 and 314 minutes). The observations included a range of HCPs including: OT; PT; RA; AP and nursing staff. Further details are outlined below in Table 12.

Study identifier: PWA	Total number of sessions observed	Total duration of observations (minutes)	Number of observations set 1 (HCP)	Number of observations set 2 (HCP)
1	4	173	3 (RA, PT, OT)	1 (AP)
2	2	56	1 (RA)	1 (RA)
3	6	279	3 (AP, RA, RA)	3 (RA, RA, AP)
4	4	196	2 (RA, AP)	2 (AP, RA)
5	5	254	3 (RA, AP, OT)	2 (AP, AP)
6	5	247	3 (OT, AP, RA)	2 (AP, nurse)
7	2	113	2 (RA, RA)	No Longer Eligible (NLE)*
8	2	105	1 (AP)	1 (AP)
9	6	314	3 (AP,PT, RA)	3 (PT, RA, AP)
10	6	282	3 (AP, RA, PT)	3 (OT, AP, PT)

## Table 12. Sessions observed for each participant

\*NLE = no longer eligible to participate in study due to ill-health

## 4.7.3 Interviews with people with aphasia

One-to-one semi-structured interviews were carried out with each participant with aphasia after the final set of video data had been collected. These interviews were conducted in the PWA's own home by the researcher (CS) and guided by a topic-guide (Appendix XIV). In addition, the researcher followed up on topics initiated by the person with aphasia.

Interviews were video-recorded, lasted between 15 and 70 minutes. Adjustments were made to the interview process as appropriate for the needs of PWA with limited communication, as used by Luck and Rose (2007). Additional time or individualised resources, such as use of pen and paper; Visual Analogue Scales (VAS) and Likert scales were used to support the person with aphasia's communication and participation in the interview, to allow the PWA to make a full contribution. For all interviews, the researcher paraphrased the PWA's answers to ensure she had interpreted them correctly and paid close attention to non-verbal communication, being careful to respond to all non-verbal initiations. As discussed above, the researcher offered to show the PWA vignettes from the video observations. The researcher also discussed video observation as a methodology with the participants. Individual participants' interview details are set out in Table 13.

Study identifier	Aphasia severity (as established by SLT)	Duration of interview (minutes)	Adjustments made	Vignettes used (yes/no)
1	Severe	32	Pen and paper, closed questions	Yes
2	Mild	15	None	No
3	Severe	57	Pen and paper, Likert scales, VAS, closed questions	Yes
4	Moderate	48	None	No
5	Mild	71	Paper and pen	No
6	Moderate	19	None	No
7	Severe	NLE*	N/A	N/A
8	Mild	42	None	No
9	Severe	35	Closed questions	No
10	Mild	44	None	Yes

#### Table 13. Details of interviews with participants with aphasia

\*NLE = no longer eligible to participate in study due to ill-health

## 4.7.4 Interviews with healthcare professionals

From the cohort of HCPs recruited to the study, eight HCPs were interviewed using a semistructured topic guide (Appendix XV). The eight HCPs were: still working on the ESD team; had been observed conducting routine rehabilitation; and consented to be interviewed. The interviews with HCPs were conducted after the final set of video data had been collected. Interviews lasted between 30 and 60 minutes and were conducted in the ESD rehabilitation office, in the rehabilitation hospital, at the staff's convenience. Individual HCP participants' interview details are set out in Table 14.

Study identifier	Profession	Duration	Vignettes used (Yes/No)
6	RA	33 minutes	No
10	ОТ	35 minutes	No
12	AP	60 minutes	Yes
13	RA	50 minutes	No
15	AP	37 minutes	No
17	AP	46 minutes	No
20	РТ	42 minutes	No
21	Nurse	44 minutes	No

#### Table 14. Details of interviews with healthcare professionals

## 4.8 Data analysis: theoretical background

The goal of qualitative data analysis is to uncover patterns and develop understandings from often extensive and contrasting data sets (Patton, 2002). All data from this study were organised and analysed under principles drawn from Activity-based Communication Analysis (ACA) (Allwood, 1976; 2007). ACA is an approach open to all methods of data collection, which is concerned with authentic linguistic interaction. The aim of an ACA approach is to develop theory and a greater understanding of the use of language, including multimodal communication, in different social activities (Allwood, 2007). It is based on the assumption that language used in all social interactions is governed by the nature of the social activity, which has certain inherent characteristics.

ACA is influenced by many different schools of thought including those from philosophy, psychology, sociology and linguistics. These influences are reported and discussed thoroughly in Allwood (2000). Wittgenstein (1953) described how language is used and integrated into actions. All interactions are situated within a context and there are circumstances which influence interactions, but the converse is also true (Johansson, 2007). Meaning is determined by use and people take part in 'language games' as a result, using the language that is typical for that social activity (Wittgenstein, 1953). Therefore, contexts can change how a person acts and use language in any particular interaction. For example, a person's communication, including discourse, tone and turn-taking, differs greatly between institutionally contextualised occasions, such as business meetings, and informal settings, such as dinner with close friends. Through past experience of similar social situations and general situational rules, people can decide how to make their next communicative move (Bateson, 1973) and which move would be most appropriate to the situation. In addition, how people present themselves in an interaction is influenced by the interplay between interactional meanings and social structures (Johansson, 2007). Erving Goffman (1974), from the school of interactional sociolinguists, first described this theory as 'framing' and 'footing'. In an interaction a person can 'frame' themselves in a particular way and perform appropriately based on past experience, understanding of the context or how they want to be perceived by others. Therefore, the person's behaviours can change depending on the role they hold in the interaction, for example a position of authority. People may also be influenced in their interactions by a desire to engage in 'cooperative' interactions, described by Grice (1975). A 'cooperative' interaction included four underpinnings: quantity – the person must be as informative as possible; quality – a desire to be truthful; relation – discussing topics relevant to the discussion; and clarity – brevity when conveying information (Grice, 1975). Brown and Levinson, (1987) suggests that people are also influenced in interactions by a desire to maintain politeness strategies, where both parties in the interaction 'save face', i.e. the people involved in the interaction feel affirmed and not embarrassed. Finally, the complexity of interaction is enacted in what is actually said by the people in the interaction and how it is said. This is the focus of the school of linguistics. Conversation and its structure may be analysed through Conversational Analysis (CA) (Sacks, 1992; Sacks et al., 2012). CA focuses on sequences of talk-in-interaction, turn-taking, and repair mechanisms. In contrast to other schools of thought discussed above, CA does not focus on the context of interactions or take into consideration background information which may influence the interaction, focusing

exclusively on analysis of transcribed sequences of interaction and how meaning is created through language use. ACA as an approach allows the incorporation of these interdisciplinary ideas to provide a comprehensive means to analyse the complexity of communication and interaction in context. It takes into account the different characteristics associated with social activities. It allows the researcher to analyse how language and communication can be the goal or the instruments for an activity (Allwood, 2007) while incorporating the identity of the participants; their thoughts, feelings and emotions.

Taking the combination of different theorectical underpinnings into consideration, an ACA approach acknowledges that in interactions there are influencing and influenced factors (Allwood & Ahlsén, 2012). Influencing factors can be: 'global', affecting interaction as a whole at a macro level, such as culture; 'local', which can have a collective influence on all the participants in the interaction at the meso-level, such as the purpose of the activity, the environment or the materials used; or individual influencing factors, which are at the micro level and are different for each person in the interaction. e.g. the individual's goals in that interaction (Allwood & Ahlsén, 2012). People in interactions can hold a particular role, thus impacting on the individual influencing factors. These roles include: human beings, who are motivated and rational; members of a community, with cultural beliefs who speak a particular language; members of social institutions and organisations, for example doctors or teachers; role holders in an activity, for example instructors and conversation partners; and individuals as communicators, for example speakers and listeners (Allwood, 2007).

The influencing factors discussed above combine and influence how an interaction is enacted. The influenced characteristics of interactions can be collective, such as communication patterns and conversation management, e.g. turn-taking; or individual to the participants, e.g. grammar or vocabulary (Allwood & Ahlsén, 2012). These influenced factors, at the macro, meso and micro levels of interactions, can have enabling or constraining effects on communication and interaction as part of a social activity (Allwood, 2007).

This study aims to explore the conditions that exist in naturalistic interactions in routine rehabilitation to enhance functional communication learning; how these conditions have been produced; and what barriers to and facilitators of the uptake of opportunities for learning exist. ACA as a set of guiding principles allows the researcher to investigate the factors that could influence and be influenced in the rehabilitation activities between PWA

and HCPs. An ACA-informed approach allows the researcher to investigate the influence of the environment and activities, which are likely to be important variables in home-based rehabilitation. It can also be used to examine how interactions may be influenced by aphasia, and the resultant impact this can have on communication and interactions. ACA, therefore, provides a comprehensive approach to analysing ecologically valid interactional data. As ACA does not dictate the methods used to collect data, and therefore provides a suitable vehicle for integrating, fieldnotes, observations of routine rehabilitation and interview data to help address the study's research questions. The analysis assumes that the interactions taking place in this study came under the influence of a number of key macro, meso and micro factors: for instance, ideas and views governed by the National Health Service (NHS) as an established organisation; and healthcare professionals cast in the role of 'expert' and people with aphasia as 'patients'.

# 4.9 Phases of data analysis

Using an ACA-informed approach data were analysed at the macro, meso and micro levels, using in-depth exploration of the individual and collective influencing and influenced factors. Analysis of interview and observation data were carried out iteratively and supplemented with information from the researcher's field notes and reflexive diary. The phases and processes of analysis involved six recursive phases. These are outlined in Table 15 and set out graphically in Figure 6.

	Phase	Desciption of the process
1	Reviewing fieldnotes and reflexive data	Researcher's reflexive diary and fieldnotes are reviewed noting influencing factors-collective and individual. Topics to be discussed futher at interview are noted.
2	Ecology of the rehabilitation session	Video observations are reviewed after each rehabilitation session noting: the timing of the rehabilitation session; the rehabilition ecology (the participants, the setting of the rehabilitation, the artefacts in the rehabilitation setting, the rehabilitation tasks, activities and materials); the timing and structure of the rehabilitation session. Illustrative examples of how conversation and discourse were influenced were analysed using techniques derived from Conversation Analysis (Sacks et al., 2012) and Discourse Analysis (Gee, 2005).
3	Identifying interview	The researcher reviewed all collected video observations an individual participant was involved in, prior to conducting

interviews with that person, to identify vingettes to be discussed

#### Table 15. Phases of data analysis

vingettes

in the interviews and to further individualise and populate the semi-structured topic guide.

- 4 Thematic Interview data were analysed using thematic analysis. analysis of interview data
- 5 Enactment of Video observation data were re-viewed in their entirety noting interview themes how and when the themes from the interview data were enacted in video in the rehabilitation sessions.
- **6** Combining data The data were combined under the ACA framework.

#### 4. 9.1 Phase 1: Reflexivity and fieldnotes

The researcher read her fieldnotes and reflexive diary after every interaction with a participant and/or observed rehabilitation session. The researcher noted any items from these which she wanted to discuss with the participants at the interview. Influencing and influenced factors were also highlighted, both collective and individual, for example if there was traffic on a particular day that caused the HCP to be late for a rehabilitation session.

#### 4.9.2 Phase 2: Ecology of the rehabilitation session

When all observation data were collected, the researcher re-viewed the video data, which allowed full immersion in the data. The aim of this phase was to obtain a fine-grained analysis of interaction taking into consideration the different variables that can influence a social interaction, such as the participants in an interaction, their role and identities, the setting, and the organisational framework (Heath and Hindmarsh, 2002). Therefore, initial notes were made regarding the communicative ecology of the interaction, including: the setting of the interaction; the participants; their positioning; the materials involved; and how these were used. The structure of an interaction can distinguish the genre of the interaction (Halliday & Hasan, 1985; Halliday, 1994), for example clinical or classroom. A rehabilitation session is a context for learning and therefore has similarities to a classroom interaction (Ferguson & Elliott, 2001). Brookshire (1986:131-132) suggests that a session is differentiated from other interactions, such as a dinner with friends, by the following components: 1) the 'hello' segment which includes the greeting, rapport-building and a discussion of changes; 2) an 'accommodation', where the client is orientated to the tasks; 3) a 'treatment' section which can include various tasks; 4) the 'cool down' which includes successful and familiar materials; and 5) the 'goodbye' which includes planning and leaving. Ferguson and Elliot (2001) outlined the structure of a session for people with communication impairments, stuttering and aphasia. These studies were largely in agreement with Brookshire (1986), with sessions comprising: greeting, review, procedural orientation, therapeutic activity, planning and leave-taking. The structure of the observed sessions and how they were organised into phases according to the goal of the particular section, for example introduction, transition, closure, and the activities involved, was noted along with how much time, in minutes, was spent on each section. The structure of the session allowed the researcher to see how the macrostructure of the context of learning had been influenced by the influencing factors, collective and individual. The researcher also noted if these phases and timings were consistent for PWA of different types and severities of aphasia and how this structure was shaped by the influencing factors. This provided the researcher noted how transitions occurred between these component tasks and who controlled these transitions, PWA or HCPs. Influenced factors such as aspects of interactional behaviour in turn-taking, initiation and response practices and language used were analysed using techniques derived from Conversation Analysis (Sacks et al., 2012) and Discourse Analysis (Gee, 2005).

#### 4.9.3 Phase 3: Identifying interview vingettes

When a PWA's last video observation was collected all the observations involving that participant were viewed in their entirety. The researcher reviewed all collected video observations prior to interviewing a participant. The researcher noted the PWA the HCP worked with and their presentation of aphasia. For HCP participants the researcher viewed all routine rehabilitation sessions that they were involved in. The researcher noted any points in the observations where the researcher's interpretations of the observation needed to be checked by discussing them with the participant and moments from the observation data the researcher wanted to discuss further. The researcher noted the timings of these sections of video, to be either shown as a video vignette to the participant, or to be discussed with the participant without watching the video. These questions further populated and individualised the interview topic guide.

#### 4.9.4 Phase 4: Thematic analysis of interview data

A number of analytical methods could have been adopted to make sense of the vast amount of interview data: grounded theory (Charmaz, 2014; Glaser & Strauss, 1967), interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009), discourse analysis (Gee, 2005) or thematic analysis (Braun & Clarke, 2006). The researcher reviewed these methods in light of the research questions, acknowledging the different benefits and limitations of each. Discourse analysis places the emphasis on an exploration of the language used in the data and establishing patterns in language to see how this conveys the social construction of reality (Coyle, 2007). As the aim of the interviews was to gain subjective insights from the participants rather than analyse the language used in the interviews, this was not an appropriate method of analysis. Grounded theory, IPA and thematic analysis generate ideas from the data and categorise these ideas together in themes. In grounded theory the researcher aims to generate theory from the data, with an understanding of the social processes that surround the topic (Charmaz, 2014; Glaser & Strauss, 1967). The researcher stops analysing data when saturation of theme generation is achieved (Glaser & Strauss, 1967). Most similar to thematic analysis is IPA, in which themes are generated from the data, and the participant's lived experiences are investigated (Guest, Namey & Mitchell, 2013). However, IPA places more emphasis on the individual participant's account and their individual experience, where a narrative account is usually formed. In IPA the participant and their context are 'mutually constitutive' (Larkin, Eatough, & Osborn, 2011) so it can be seen as the investigation of a person's experience in that particular context. In thematic analysis, however, similarities and differences can be drawn across data (Braun & Clarke, 2006). Thematic analysis allows the researcher to identify and interpret themes across a data set in relation to the research question (Braun & Clarke, 2006) and is appropriate for small samples (Joffe & Yardley, 2004). Therefore, it was decided that inductive thematic analysis (Braun & Clarke, 2006) would be the method used analyse the interview data as it was the most appropriate method to adderss the aims of this research. Although the researcher acknowledges that it is difficult to obtain a tabula rasa on a topic area and theory, the aim was to generate interpretation from the data (bottom-up).

The data were analysed using the procedure outlined for thematic analysis by Braun and Clarke (2006; 2013). Firstly, all recorded interviews were watched in full by the researcher (CS) to become familiar and immersed in the data. This allowed the researcher to obtain an overall impression of the data (Braun & Clarke, 2013). The interview data were transcribed verbatim using Jefferson transcription conventions (Atkinson & Heritage, 1984) (Appendix XV) (by CS) and rechecked. The transcripts were uploaded to the data management software QSR NVivo 11 (2015) where complete coding was organised. The researcher reviewed all transcripts, labelling each extract with a single word or phrase that described the explicit meaning of that extract. An extract was considered as one semantic block, which was one answer to a question, one part of the answer, or sometimes the question and answer were inextricably linked, relying on each other to bring semantic

meaning and therefore had to be coded as a block. These labels were the initial codes from the data that related to the research question. NVivo 11 allowed the researcher to collate extracts with the same codes together for further analysis. If a relevant code already existed the extract would be coded to it; if not, a new code was developed. This was an evolving process, with codes being reviewed to make sure that they were most applicable to the extract. At times one extract could be coded in multiple ways; it was decided that an extract would be coded in the one way which most described the essence of the extract, to streamline the analytical process and avoid repetition. These initial codes were specific to retain nuanced differences.

When coding was complete the initial codes were reviewed and categorised by the researcher into overarching 'candidate themes and sub-themes' (Braun & Clarke, 2013) across the data set. These themes were broader ideas around the meaning of the codes that were important to the research question (Braun & Clarke, 2013). These themes allowed the researcher to collate how the codes were being discussed in relation to the research question. These data were managed using Microsoft Excel (2013). Each theme became a tab in Microsoft Excel (2013) with sub-themes and illustrative extracts within the tab. These themes were subsequently reviewed and merged if they were similar under a further 'organising concept' (Braun & Clarke, 2013). The initial codes and the extracts were reviewed to make sure that each candidate theme was relevant to these and remained true to the original data. The themes that remained were reviewed in relation to the research question and it was decided which themes were most appropriate to interpret further for the purpose of this thesis.

The analytical process was discussed with the primary supervisor (SH). Codes and interpretations were reviewed and checked by him to increase the rigour of the data.

#### 4.9.5 Phase 5: Enactment of interview themes in video observations

The video observation data were re-viewed by the researcher in its entirety, noting how and when the themes from the interview data were enacted in the rehabilitation sessions. The researcher noted how these themes arose and were produced to create conditions for learning, the nature of these conditions and the barriers of or facilitators to learning. The researcher examined how talk and action were influenced by the activity in hand, the patient's level or type of impairment, and the physical context. Although this viewing was oriented by the interview themes, the researcher noted factors that may have had an influencing role or were being influenced at the macro, meso- and micro-levels, that had not been discussed in the interviews. Illustrative examples were noted of where and how successful or unsuccessful interactions became salient and where and how opportunities for naturalistic conversation practice were optimised or not.

## 4.9.6 Phase 6: Combining data under the ACA framework

These data were combined within the ACA framework. The influencing and influenced factors, both collective and individual, were collated from the analysis across data sets.

# 4.10 Participant anonymity

In the transcription of both the interviews and observations the names, addresses or any other identifiable information of the participants were anonymised. The PWA and HCP's study numbers were used to identify turns and CS was used to identify the researcher. No identifying information is used in the thesis, or will be in subsequent publications or dissemination events.

Figure 6. Phases of data ar	Act	ivity-based Communicati (ACA) Combine all data unders Influencing factors: collective and Influenced factors: collective and	ion Analysis : individual individual	
Reflexivity and fieldnotes	2 Ecology of the rehabilitation session	3 Identifying interview vingettes	4 Thematic analysis of interview data	5 Enactment of interview themes in video observations
<ul> <li>Review</li> <li>fieldnotes and</li> <li>reflexive diary</li> <li>after interaction</li> <li>with a participant</li> <li>or observed</li> <li>rehabilitation</li> <li>session</li> <li>Note influencing</li> <li>or influenced</li> <li>factors to be</li> <li>discussed at</li> <li>interview</li> </ul>	Note details of observed rehabilitation session: -Participants -Setting -Activity/task -Rehabilitation materials -Structure and timing of the rehabilitation session -Conversation and discourse analysis	<ul> <li>-Re-view video observations to identify moments that need to be discussed with the individual participant at interview</li> <li>-Use vingettes to populate and individualise the semi-structured interview topic guide</li> </ul>	-Use inductive thematic analysis to analyse interview data (Braun & Clarke, 2006)	-View all video observations noting if, when and how the themes from the interview data are enacted

# Chapter 5: Findings of HCP interviews

# 5.0 Introduction

This chapter outlines the findings of interviews between the researcher (CS) and a sample of HCPs (n=8) who took part in the observational study. Thematic analysis (Braun & Clarke, 2013) was used to interpret the data, as outlined in the methodology. The themes that were developed from the data will be outlined in relation to research questions 2 and 4.

# 5.1 Research questions

- 2) What conditions exist during routine rehabilitation sessions for enhancing functional communication for aphasia learning?
- 4) What are the barriers to and facilitators of uptake of opportunities to enhance functional communication learning for people with aphasia?

# 5.2 Themes

The eight interviews produced 52 codes (Appendix XVI). These codes were organised into seven key themes relating to the research questions: (1) emotions; (2) rapport; (3) collaboration; (4) rehabilitation materials; (5) rehabilitation procedures; (6) staff training; and (7) environment. These themes and their subthemes are set out in Table 15. The themes that were produced from the data were interlinked; occasionally influencing and being influenced by the other themes. Themes are discussed in detail below; quotations from the interviews are used for illustrative purposes and connections between each theme are illustrated at the end of each subsection.

Theme	Sub-theme	Commentary
Emotions	<ul> <li>Desire to increase positive rather than negative emotions experienced by PWA</li> <li>Emotions experienced by HCPs working with PWA</li> </ul>	HCPs discussed the emotions they thought that PWA felt during rehabilitation. In their opinion many of these emotions were negative and they sought to create more positive emotions for PWA. HCPs also reported the variety of emotions they experienced working with PWA. These emotions had an impact on how rehabilitation was enacted. The HCPs' emotions

		changed throughout the episode of rehabilitation. They were impacted by the level of HCP–PWA rapport developed. The physical environment of the rehabilitation also had an impact.
Rapport	<ul> <li>Benefits for PWA</li> <li>Benefits for HCPs</li> <li>Impact on learning processes</li> <li>Conditions that help develop rapport</li> </ul>	Rapport was a central theme and was discussed by all HCPs. When a rapport was developed it helped the HCP to make the rehabilitation more salient, provide more appropriate and tailored feedback, engage the PWA more actively in their rehabilitation and motivate the PWA. Rapport was also beneficial for the HCP, reducing their negative emotions. Rapport development was influenced by the intensity of the sessions and the
Collaboration	<ul> <li>Power dynamics</li> <li>Control of the rehabilitation session</li> </ul>	Rehabilitation sessions could be collaborative, with PWA being empowered by making decisions about how their rehabilitation progressed. Collaboration ensured the patient and their family felt valued and listened to. Collaboration increased PWA's motivation and engagement in the rehabilitation. HCPs did report a struggle with the power dynamics and the shift in perception required to pass control to the PWA. The environment – the PWA's home – did impact on power dynamics. Control and collaboration influenced HCPs' and PWA's emotions and how rapport was developed.

Rehabilitation materials	<ul> <li>Facilitators of learning</li> <li>Barriers to learning</li> </ul>	Rehabilitation materials were both items in the PWA's own home, such as the space in the home and family pictures, and formal materials brought by the HCP, such as formal assessments and laptops. Rehabilitation materials also included rehabilitation programmes, which might entail a number of activities or tasks and which were developed by HCPs with a professional qualification, for RAs and APs to follow. In these programmes the HCPs also had to write notes from the rehabilitation session. Rehabilitation materials could act as barriers to or facilitators of learning.
Rehabilitation procedures	<ul> <li>Structure of the rehabilitation session</li> <li>Adaptations to communication</li> <li>External pressures that impact on the rehabilitation</li> </ul>	HCPs discussed the structures of rehabilitation sessions and the processes of rehabilitation that influenced how the session proceeded. HCPs made adaptations to the rehabilitation as a result of aphasia. HCPs needed to adapt both the structure of the session and their own communication. Their ability to make these adaptations to maximise learning for PWA was influenced by external pressures, including NHS pressures. HCPs may have been under time pressure and pressure to multitask in order to fulfil their obligations expected of them for that session. The HCPs who had experience working in different healthcare settings discussed how these

		pressures differed between contexts.
Staff training	<ul> <li>Current training available</li> <li>Desire for more training provision</li> <li>Lack of training provision</li> </ul>	HCP training became a prevalent theme discussed by many of the HCPs. This included the training they had or had not received on aphasia and supported communication. APs and RAs felt that more information and training was needed to help them better understand the professions – OT, SLT and PT. They felt that better understanding would help them to make rehabilitation more salient and facilitate learning. The HCPs discussed their desire for more training in a variety of areas. They also discussed how external pressures influenced access to training.
Environment	<ul> <li>Benefits for PWA &amp; HCPs</li> <li>Benefits for rehabilitation</li> </ul>	The rehabilitation environment, the PWA's home, was the most influential theme impacting on all other themes. The environment influenced how the HCPs worked with the PWA and how the session was carried out.

# 5.3 Emotions

All HCPs discussed emotions: how they felt working with PWA and the emotions and feelings they thought that PWA experienced during rehabilitation. Emotions impacted on how the HCPs engaged in the rehabilitative process. Negative emotions could act as barriers to the uptake of opportunities to enhance functional communication learning. In contrast, positive emotions could create conditions for increased functional communication learning and could be optimised by the HCPs.

## 5.3.1 Emotions of HCPs working with PWA

HCPs emphasised the centrality and importance of communication between the PWA and HCP. Successful communication, as a collaborative process, could enhance the PWA's and

HCPs' engagement in the rehabilitation, the activities and could increase the PWA's positive wellbeing. The key role of communication for all stakeholders involved in rehabilitation – the PWA, their families and the HCPs – did place pressure on the HCPs as they found communication with PWA a difficult and daunting experience. The HCPs were aware of the impact of unsuccessful communication and how this could act as a barrier to learning when working with PWA.

'And it is what families and carers and all of us in the team find the most difficult part of stroke rehab is communication with people who have aphasia because it is such a vital part of everyone's interaction, vital to interaction whether you are doing a nursing task, physio, going out, whatever you are doing with the patient, if you haven't got that communication bit right you are not going to have a successful therapy session of any discipline So that is the most difficult bit I think and it is hard to know if you are doing the right thing sometimes' (HCP 21)

HCPs reported that they experienced 'anxiety', 'fear', 'stress' and 'doubt in themselves and their abilities' when working with PWA. Many HCPs felt that their communication skills in general were a strength. These skills were challenged when working with PWA. Negative experiences due to communication breakdown and failed communication had a negative impact on their emotions. As a result, HCPs generally did not look forward to working with PWAs.

# 'Em and I don't relish working with people with aphasia for that reason I think I'm always kinda anxious about having conversation with somebody with aphasia' (HCP 21)

The HCPs focused on fixing problems and making things better. As a HCP 'you always want to do the best for patients'. These identities –the 'fixer', the 'caregiver' and the 'successful service provider' were challenged when working with PWA as the HCPs did experience more feelings of failure when working with PWA. They felt that it was more challenging as communication difficulties were not as 'curable' compared to other impairments they work with, such as movement. These 'failures' knocked their confidence and exacerbated their anxiety and stress.

'I think maybe to make sure that I've got it right Umm and it's my anxiety, definitely, em because it is upsetting if you can't understand somebody and you want to be able to help them and you can't understand what it is they need or asking for then as a nurse, that's what we do, we make people feel better But if we can't understand that then it's hard as a nurse I think' (HCP 21)

## 'Em so yea it can make you feel a bit

It can be a bit anxiety provoking if you know you are going to a patient that is difficult to communicate with, just because you want to give them a good service and you don't want them to miss out on something because of you not being able to communicate with them properly' (HCP 20)

Some HCPs also felt that their fear and anxiety stemmed from a lack of confidence due to limited training and experience. Many HCPs reported that they had little training in the areas of aphasia and supported communication. Some HCPs said that they were unsure if engaging in a conversation would benefit the PWA or would make it worse for both parties.

All HCPs did say that fear, anxiety and discomfort were greater when they first started working with PWA. However, more experience working with PWA did not necessarily prevent HCPs from having negative emotions about communicating with PWA; some HCPs with many years of experience still felt negative emotions. HCP 21, who has 20 years experience, reported that she still did not 'relish' working with PWA. As a result of negative emotions HCPs spoke of avoiding conversations with PWA and PWA initiations, particularly when working on wards, where there was more time pressure.

# 'Like thinking back to when I was newly qualified and things and I would work with people on the stroke unit I'm thinking (pull's face) 000000

I don't think if I am going to make things better or worse trying to communicate with this person or if you are worried that they are getting more and more frustrated by trying I think sometimes then you can kind of I'll just stop and leave them cos they are getting frustrated ......So they just sort of give up' (HCP 20)

#### 5.3.2 Emotions of PWA

The HCPs noted that PWA were often 'upset' and 'frustrated'. They discussed the importance of empathy in trying to gain insight into the PWA's difficulties. They emphasised the importance of showing understanding and compassion to the PWA.

'It's just getting across You know what they want to say and sometimes They don't always They can't always tell you exactly what they want So then they get frustrated so maybe they don't get as much out of it' (HCP 6)

HCPs reported that they did not want to exacerbate any negative feelings and/or cause any additional stress and worry to PWA by engaging in a conversation about emotions and feelings for fear of communication breakdown. Although HCPs discussed their role in

alleviating the PWA's negative emotions, they did find this role more difficult due to the communication difficulties. PWA's episodes of upset or frustration therefore may not be discussed. These negative emotions could act as a barrier to full participation in their rehabilitation and to functional communication learning.

'Em but I think it has started to become a bit more natural I don't feel quite so nervous now When I first started in stroke I did used to it did kind of fill you with a little bit of fear going in, just thinking how am I going to do this, what am I going to do, and the idea of I don't want the patient to feel kind of frustrated at not being able to get what they wanted across so, yea It is good the more I've come to see people and got used to assessing people with language problems it has helped with my confidence' (HCP 10)

Overall, HCPs did feel very positive about their roles in healthcare, stating that they 'loved' their jobs and had good levels of job satisfaction. The variety in the presentation of PWA and the role, the rewarding nature of the job and the close working relationship between the MDT were cited as reasons for loving their job. The importance of rapport, the rehabilitation processes and training in alleviating the barriers that negative emotions created in rehabilitation was clear in all interviews.

'Difficult at times. Sometimes it is a bit daunting to start off with I think when you first go out and visit a patient. Definitely I think after that first visit you know where they live, where they are, how they might communicate with you, the family situation, everything like that. So then it makes you feel a bit more comfortable going in a second time' (HCP 12)

#### Figure 7. Connections between themes: HCP Emotions



# 5.4 Rapport

Rapport was described by HCPs as the professional relationship that is developed between the HCPs and the PWA during the lifespan of the rehabilitation. HCPs emphasised the central role of rapport to rehabilitation: it is 'all about getting a good rapport with them' (HCP 6). HCPs felt that rapport is established through valuing the person with aphasia and treating them as they would like to be treated. Good rapport involved getting to know the PWA – their interests, their rehabilitation and life goals and their values.

'Yea cos you don't want them to feel they're different If I was in that situation I wouldn't want somebody to treat me different And I think that that is important to try and keep things normal isn't it If it helps them just having a single word said fine But if that isn't the case why exclude them from a normal conversation' (HCP 15)

## 5.4.1 Benefits of and barriers to good rapport for PWA

Good rapport was discussed by all HCPs as a facilitator of the uptake of learning opportunities in rehabilitation. HCPs emphasised the importance of listening to the client and 'trying to get out exactly what they are wanting to say' (HCP 6), in spite of severity of aphasia. To not do this was seen as 'patronising'. 'I think so, yea yea, you should really. Shouldn't you be the same. You should give everyone that same opportunity whether they are more severe or less severe really. You should really just be the same and try and have that same conversations and you know build the same rapport with everyone' (HCP 12)

HCPs emphasised the importance of developing trust between the PWA and the HCPs. HCPs felt that the development of trust was challenged by the assessment process which was described as 'automatically a barrier that comes down cos people think that you are going to label them' (HCP 10) and it being a 'scary thing' to PWA. Assessments can reveal impairments and reductions in competencies that can be difficult for the PWA to come to terms with. Getting to know the person with aphasia can help put them at 'ease' and remove anxieties surrounding rehabilitation.

# 'I don't like coming in and assessing someone straight away I just think that you need to build up a rapport with someone and they need to trust you' (HCP 10)

# 5.4.2 Benefits of good rapport for HCPs

As discussed, HCPs described feelings of anxiety, fear and discomfort working with PWA. Establishing rapport helped to alleviate some of these negative emotions and when a good rapport was established, it made rehabilitation more enjoyable for the HCP.

'Em I think it's nice to have that more informal relationship Yea just to chat on a more informal basis and make it more enjoyable for people as well More natural' (HCP 15)

Rapport also made it easier for HCPs to assess and provide rehabilitation to PWA, as they knew more about them as people, their limits and their co-morbid difficulties such as fatigue and attention difficulties.

## 5.4.3 Influence on learning processes

HCPs felt that a good rapport helped the PWA and the HCPs to collaborate in rehabilitation and to centralise the person and their views.

'Yea in terms of gaining people's trust to let you in and keep people motivated em and for them to know that em you understand what they want to get out of the therapy' (HCP 17)

HCPs acknowledged that people could decline to take part in rehabilitation and therefore maintaining motivation was very important, particularly as many people they worked with fatigued easily and/or experienced depression.

'And you can stimulate or you can motivate someone Or they are just tired and don't want to do it' (HCP 13) By knowing more about the PWA's interests, their personal and family lives, the HCP was able to engage more in naturalistic conversations, thus helping the PWA to practise conversation skills. HCPs were thus also able to tailor the sessions and make them more salient to the PWA. Saliency helped to engage the PWA in the rehabilitation process and to motivate them.

'Yes definitely that it's something that interests them and we have had a lot of that just recently. Patients have said well that does not interest me I don't really I am not too keen on working on that. It is not something I would do in my day-to-day life. They cannot see the relevance of doing something as related bringing it back to their day-to-day life and act as they do normally so it's finding that balance I think between sometimes you can't I am not sure I think often you can find something that interests that person and work on that at the same time. I think that is a priority really to find out that patient's interests because then I think it would really help with therapy and how they get on in their session because I think if it is something that interests them rather something they cannot really understand why it might help. I think that would tend to benefit people' (HCP 12)

HCPs also reported that it was easier for them to provide honest and tailored feedback to a PWA when they had developed a good rapport as they knew more about their individual impairments. It helped the HCPs to provide feedback on outcomes and more tailored feedback on performance by knowing what prompts or cues worked best for that particular PWA.

'I don't know really, it depends on the person really You know until you get to know them a little bit you might say do you want me to give you the first letter or, prompt or, or the sound Talking through prompts with a person initially Do you want me to see if that will help Getting to know other people's communication Sometimes it will, just the sound and then they can get that word out Or they can start the word and then you can give them the next bit And then they can follow on and actually produce that word and then they can repeat it' (HCP 15)

It also helped them to know the PWA's personality and how they were dealing with aphasia. Providing feedback to a PWA could be difficult for HCPs, particularly if the person was struggling to come to terms with their aphasia, were upset by their new identity or frustrated.

'Yea I find em you have to be very tactful very cautious with how you approach it because Em being cautious with people with aphasia not to frustrate them with making mistakes there are only a sort of number of times you want to say go back you didn't say that word right to the point where he could get frustrated with that so I tried to sort of word it to him to be aware of his mistakes without him getting too frustrated' (HCP 17)

# 5.4.4 Factors influencing rapport development

ESD rehabilitation is intensive, with HCPs working with PWA daily or even twice daily up to seven days a week. The intensity of ESD rehabilitation was cited as being a key factor in developing rapport. As the HCPs were divided into three teams depending on geographical area, the same HCPs from the team working with the PWA would visit the PWA regularly. The HCPs discussed and emphasised the importance of the continuity of the HCPs. This helped to put the PWA at ease, as HCP 15 noted how 'unnerving' it was for PWA to have different 'strangers' coming to their house every day.

'Often we do try to stick to the same few people going in so I think that really helps because it just keeps that continuity same faces you then get to know what people do in their day-to-day life, you get to know what their hobbies are, what they enjoy doing what they have been up to at the weekend, you know things like that. Then that helps with conversation, how they communicate with you' (HCP 12)

All HCPs discussed the importance of naturalistic conversation in developing rapport and that they spent time having these conversations, particularly at the start of a period of rehabilitation.

'I like the challenge of finding something depending on how severe they are it's finding something that you can communicate with them over but once I found out that he was plumbing and he loved sport and the Olympics was on It was fine cos you could say did you watch the running or whatever events were on and you just sort of have that connection and something to work with' (HCP 15)

HCPs also felt that personalities played a role in developing rapport. For example, HCP 13

used humour as a tool: 'I always start my session with a laugh'; HCP 20 and 12 described

themselves as 'chatty'; HCP15 felt that being 'slightly older' helped PWA open up to her.

When rapport was established it was marked by terms of endearment and more informal language.

'When the rapport is already there and its more of a like not just a patient and therapist you have a relationship being friends somehow and yea because on the first two visits maybe it's more formal like sir' (HCP 13)

#### Figure 8. Connections between themes: rapport



# 5.5 Collaboration

The theme of collaboration included the subthemes 'control of the session and the environment', 'managing inputs from different stakeholders' and 'power dynamics'. These sub-themes were influenced by the environment and the level of rapport developed. Collaboration between the therapist and the PWA could establish conditions which enhanced functional communication learning. Collaboration helped to develop more positive emotions and establish rapport, which empowered and motivated PWA.

## 5.5.1 Power dynamics

HCPs pointed out how power dynamics between PWA and HCPs differed between wardand home-based contexts. For example, HCP 21 discussed how HCPs put themselves in a position of power in hospital settings. She shared how disempowered she felt while in hospital as a patient and how much worse she imagined this experience would be without a medical background. HCPs felt that being in the PWA's home shifted this power balance, with PWA more empowered in the home context.

'I think patients often particularly maybe more elderly patients on a hospital ward look at the staff as the authority figures They will kind of meekly go along with what people say and staff aren't always very good at asking the patient what they really want to do Once they are in the home environment they are a lot more comfortable and a lot more vocal about what is important to them or not What they want to do and what they don't want to do

# They are making more decisions about their care which is different to when you are in hospital which is nice' (HCP 20)

The HCPs acknowledged the presence of a different dynamic in home-based rehabilitation. This change in power dynamics could sometimes be difficult for the HCP as they needed to be flexible with their rehabilitation sessions. The HCPs felt it was important for them to be open-minded in rehabilitation and to be willing to adapt to the client's wishes and views. Despite it sometimes meaning that the HCPs needed to adapt, they felt it was important as it helped to centralise the PWA and their views.

'A different dynamic to working in the hospital environment because obviously you are kind of in their environment and you have to adapt to their life in a way and how they work in their own home' (HCP 20)

## 5.5.2 Control of the session and the environment

PWA were empowered to control the rehabilitation sessions more in their own home environment and the HCPs felt that it was very important that this shift occurred. This change in control from HCP to PWA sometimes did occur organically through the shift in power dynamics and 'ownership' of the environment.

'Em because my experience working in the ward Em patient can be more em frustrated More frustration, helpless on wards Em not being able to go out, not being able to going to the toilet by themselves Can feel a bit helpless but Eh in the home setting they feel they are more in control' (PWA 13)

Joint control was also established through establishing rapport and a conscious choice on the part of the HCP to capitalise on a person's environment in assessments and rehabilitation activities. Collaborative goal setting through listening to and valuing the PWA's opinion also helped to shift the balance of control.

## 'It's their therapy session and if they want to

Try to communicate that they have had problems logging I don't know onto their own computer or they have had problems trying to identify something in their fridge then that is just as important as it is important to them and it's practical to their everyday life so You can eradicate that and sort it out and give them some strategies and help them with that you are helping them with their stress aren't you and Trying to smooth it out again for them so it is not a massive problem' (HCP 15)

There were times when HCPs found it difficult that they could not exert more control over the session; for example, when they felt that changes to the environment could have been beneficial to the rehabilitation activity, such as the removal of distractions in the home like noisy pets and family; difficulties manoeuvring in tight spaces; or not being able to change the positioning of furniture.

# 5.5.3 Managing inputs from a range of stakeholders

HCPs' involvement and management of families in the ESD context could be a barrier to or a facilitator of learning. Families were important to the PWA, making them more comfortable in their home and acting as an important resource and support in the rehabilitation process.

'Em but I also think that it is nicer in terms of their rehab because you have got their families or carers or friends or important people in their life are around who you can involve in their treatment' (HCP 20)

However, managing families could also pose a challenge to HCPs in the home environment as HCPs did not want to appear rude, but also wanted to ensure that they were listening to the PWA and their wishes and not the families'. Due to the rebalancing of power in the home environment, where the PWA and their family held more power, it could sometimes be difficult for the HCPs to manage the families' input in the sessions. The HCPs also wanted to respect the family and not be insensitive to them either.

'Em but I think it's difficult when you've got a family member who is probably jumping in all the time and you are trying to communicate with the patient rather than those that are involved with them and that can be tricky depending on how severe it is' (HCP 10)



Figure 9. Connections between themes: collaboration
## 5.6 Rehabilitation materials

All HCPs spoke about the materials used in rehabilitation in the ESD context. 'Rehabilitation materials' discussed incorporated the physical space used, the bodily position, and eye contact between the PWA and HCP. HCPs also contrasted the use of materials that they brought with them and those that they enrolled as therapy materials in the home, such as the PWA's kitchen, pictures or the PWA's objects and ornaments. Rehabilitation materials are discussed under the subthemes facilitators of and barriers to learning.

#### 5.6.1 Rehabilitation materials as facilitators

The way that rehabilitation materials are deployed can help to put a person at ease and make them more comfortable. They can help a person to understand the process of rehabilitation, for instance through timetables; provide information on stroke and aphasia; and adapt the environment to reduce disability, for example through a grab rail fitted in a bathroom, or changing the PWA's bed for one that is height-adjustable.

'I have a gentleman at the moment and em they're putting the programme together for him and he has a lot of people coming in because he has the carers as well So we are putting together some photos of regular staff that are going to go in and see him cos he was getting frustrated cos he didn't know who was walking in the door And now when you come in he says ahh (points finger) cos he recognises after three or four times, but we thought if we have the photos for him and for his wife then at least he can say (HCP's name) or whoever, it's all about the visual as well which will help' (HCP 15)

The HCPs argued that materials can act as prompts to a person and help their communication and conversation. For example, scenario communication cards could be used to help a person tell a story, and prompt sheets with the alphabet on provided the person with a phonological (sound) cue. One HCP thought that the PWA's result on an assessment which was carried out in the home was a better representation of their abilities as the outcome is not influenced by an unfamiliar space. For example, in an assessment of sequencing and processing using the PWA's own kitchen in a 'making a cup of tea' task, the outcome will be a result of the person's sequencing and processing abilities and not unfamiliarity with the kitchen.

'And some of what you are asking and difficulties with understanding is being taken away Because you can go into the kitchen show them the kettle They are more likely to understand then if you take them to a completely alien kitchen you know, it's easier for me to assess in that environment It puts me at ease automatically' (HCP 10)

The HCPs reported that using materials from the person's home environment tended to be more salient to the person. They also provided the HCP with clues about who the PWA was, thus helping the HCP to engage the PWA in conversation and develop rapport. HCPs spoke of using pictures and maps in the home to help them get a sense of the person and to start naturalistic conversations.

The home environment also meant that intervention materials could be more 'functional', 'specific', 'practical' and 'tailored'. HCPs felt that rehabilitation was more meaningful and motivating using the person's own physical items as word targets, such as items surrounding them in the sitting room. Using their space where they would be using the skills acquired in rehabilitation was beneficial to the PWA when practicing rehabilitation goals, such as making a sandwich in the kitchen and safely bringing it back to the sitting room to eat.

## 'It is more task-orientated doing the real life things, more specific and functional It is more practical practising the real things they need to do and it can be a lot more tailored to what they need to do which is good' (HCP 10)

The HCPs recognised the benefits of using the items in the person's own home as therapy materials, but also acknowledged that it was difficult sometimes trying to incorporate these items into therapy, as it meant that they had to 'improvise more'.

'Em and its more difficult physio-wise because you haven't got the kind of standardised equipment and the things that you might need around you You have to improvise a lot more' (HCP 20)

#### 5.6.2 Materials as barriers

The HCPs reported that using formalised assessments and therapy materials could be intimidating for PWA. This might be due to the size, content and how alien and unfamiliar the materials were to people. Formal materials can evoke negative emotions in the PWA and reduce their motivation to take part in the rehabilitation session.

'Yea the last thing you want to do is walk in and take out a load of paperwork or a computer, especially with some people cos they look at a computer and you can just see (breathes in) them like a rabbit in headlights' (HCP 15)

Rehabilitation materials and the physical environment could also break down conversation and reduce opportunities for naturalistic conversation. Many HCPs discussed the barrier to communication and learning produced by the laptops used in ESD rehabilitation: 'laptops kill a conversation' (HCP 15). One HCP said that laptops made her feel 'devalued' and that she was using them because she was an assistant. She did not feel like they filled the PWA with much trust in their abilities as HCPs. Some HCPs felt that computer programmes bored PWA and the tasks were not personally relevant enough to engage them in therapy.

'And we have had a patient with severe aphasia with a lot of programmes on REACT and she wasn't responding well to them, she was just guessing and I felt like I was doing less and less or that because it just didn't feel like she was getting much from it' (HCP 17)

HCPs also noted that the bodily position needed to work with the laptop made it difficult for the HCP to attend to non-verbal initiations made by PWA, for example pointing or changing direction of eyegaze. This was particularly important for those with more severe aphasia, who relied more on non-verbal communication methods. The bodily position needed for the PWA and the HCP to look at the laptop screen and manoeuvre the mouse also meant that it was difficult for the HCP and the PWA to maintain eye contact with the eachother. This could also serve to close down communication.

'I personally don't like using any computer programs, I feel like they impact on communication because rather than talking to each other you are sitting there side by side and you've got this screen in front of you and I feel like a lot of things on the screen a lot of programmes on the computer could be done in person especially when it is just pointing, on the screen you have got a mouth that says the word and then the person repeats it and I don't know understand why we couldn't just say the word I noticed with PWA 3 if you get her to look at your mouth she finds it a lot easier to say the words, it seems like there is no reason for that to be on the computer because I could have a list of words in my head or on a piece of paper I could say the word and the patient could look at my mouth and do it that way and I think it is a definite boundary having that screen there' (HCP 17)

Bodily position could also act as a further barrier in some physiotherapy and occupational therapy tasks where the HCP 'might be doing something down by their feet' and it might be difficult to see the PWA's face. HCPs recognised the importance of looking up at the PWA on a regular basis as PWA often conveyed pain through their facial expressions.

#### Figure 10. Connections between themes: rehabilitation materials



#### 5.7 Procedures of rehabilitation

Rehabilitation procedures refer to processes such as 'the structure of the session', which might influence what can be achieved in a rehabilitation session. External NHS pressures, such as targets, caseload pressures and time restrictions per session, were noted by HCPs to have an overarching effect on rehabilitation. The HCPs discussed how these NHS pressures differed between rehabilitation contexts. In addition, HCPs spoke of having to adapt their practice, communication and structure of the session to best suit the needs of the PWA. These adaptations could act as a facilitator of learning.

#### 5.7.1 Structures

The structure of rehabilitation sessions was seen as a condition that could enhance functional communication learning. According to HCPs there was a difference between the structure of an AP or RA session and an OT or PT session. The APs and RAs reported that there was a 'natural' structure to their sessions, consisting of: opening and conversation; task; time transitioning between tasks or a break; task; feedback and closing of session. They pointed out that opportunities for naturalistic conversation occurred when they first entered the home, the main topic being 'how the PWA had been since their last session'; there might also be naturalistic conversation while transitioning between tasks; and again at the end of the session before leaving the house. The OTs and PTs said that their sessions were less structured and they attributed this to the functional nature of their tasks. They reported that they tried to incorporate naturalistic conversation throughout the session. 'And then I'd do the exercises then I'll get them to stop and then have that chat Add natural conversation throughout unless it is difficult for the patient I guess I do try and put in spaces for that conversation, for natural conversation Throughout the session but I wouldn't always do it during the exercises It depends on the patient and how well they cope doing exercises and chatting at the same time (laugh), cos some people don't cope well with that..... there are some patients that we have that really struggle with dual tasking Who can't do more than one thing at a time So for those patients I would tend to say OK we're gonna do this exercise ten reps Then we'll have a chat about bla' (HCP 20)

#### 5.7.2 External pressures

The HCPs spoke about external pressures and systems that had an impact on how they carried out their rehabilitation sessions. The two main difficulties discussed by APs and RAs were the time it takes to writeup notes and seeing the rehabilitation programmes prior to their sessions. In the context of ESD, notes were left in the PWA's home; the OT, PT and SLT developed and adapted the PWA's programmes once a week and left them in the PWA's folder in their home, while also putting a copy on the computer system when they returned to the office at the end of the day. Occasionally, if the HCPs were under time pressure, they might not get the opportunity to read programmes on the computer system prior to arriving at the PWA's home, although they said that they 'always try'. This might be due to HCPs leaving the office in the morning and not returning until the afternoon. In addition, a PWA might have input from two HCPs in a day so programmes might change while the second HCP is out of the office. HCPs described reading the notes in the session as 'awkward' and 'embarrassing', especially as programmes are not always 'clear'.

#### 'Sometimes I can find them a bit awkward especially em

There's occasions where we may not have seen the OT or the speech programmes before going out and we do need time ourselves to look at notes in the house and with some patients they can be very comfortable with that and they'll feel very comfortable and with another patient and their family members you could feel them watching you so you feel under pressure to go straight into the next thing eh whereas I do need a few seconds to myself just to think what am I doing next and get prepared for it ......I need some time to just get my head around what I will do next Em and it is because it is quite a big job as well to be doing the speech programme it's a very difficult thing to do' (HCP 17)

The HCPs also needed to write in the notes at the PWA's home so that the next HCP could be updated on progress or any difficulties the person may be having. HCPs reported that writing up these notes in session tended to shut down conversation, as it was hard for the HCP to pay attention to writing notes and to the PWA at the same time. While looking at the notes they were unable to pay attention to PWA's non-verbal methods of communication. HCPs also felt that writing notes might 'distract the patient, just make them feel that you are not listening as much'. Some HCPs said that they would explain to the PWA that 'your notes are really important...with their progress'; one HCP reported that she did not write the notes in the session and sometimes opted to write them in her car.

'Yea yea I do because I am not listening or looking at what they are trying to say and I feel like they think that I am not listening to them as well cos I am just jotting down But I do explain to some patients that you know I have to write these notes down just you know for my reference' (HCP 6)

Many HCPs discussed time pressures that were experienced in every NHS setting. However, the HCPs felt that time pressure was not as bad in the ESD setting as on an acute and rehabilitation ward. This was discussed more thoroughly by the HCPs who had formerly worked in the hospital setting.

13 'Of course you have a bit of time pressure
I mean it depends on the booking really
But em you still get plenty of time even with the booking is just 45 minutes
CS Do you have a bit more leeway
13 Yea yea cos you are able to work it out anyway
Unlike on the ward when you are with a patient and then the bell would ring
What are you going to do
You can't carry on chatting when you have got to go
So even if the patient still wanted to talk to you or enjoying your company and you are having a conversation with them
You have got to go' (HCP 13)

#### 5.7.3 Adaptations

The HCPs spoke of adaptations they made to practice when working with PWA in the ESD context. These adaptations produced conditions for and facilitated learning for PWA. As discussed, HCPs did not feel as much time pressure in the home-based context, but the rehabilitation sessions were still 'time-limited'. When working with PWA they were able to adapt the timings of sessions a little, as long as they could make it to their next patient on time. HCP 12 felt that this 'really does help because we have got more time as well I think a lot of the time patients say they don't feel as rushed, however, the trade-off is that 'it can take longer so you have to plan you are not necessarily going to get everything done' (HCP 20). They reported that the MDT in their ESD team were understanding and supportive of the adaptations that sometimes needed to be made to programmes. They felt they could explain if that they did not get everything completed.

'So that they can do a bit of both or they've got that extra flexibility to have a bit more time to do the discussion or if it takes a bit longer to explain the exercises or whatever they've got that flexibility there, so I think we can work around it But it definitely does have an impact, so you know I think that's really important Cos if you don't get it right at the beginning then you are not going to' (HCP 20)

Some HCPs also noted that they could adapt tasks and programmes if PWA were not responding to them and if they felt that they were not beneficial. Rapport helped HCPs to understand how best to accommodate the PWAs needs and to circumvent any co-morbid difficulties. HCPs tried to structure sessions to reduce the impact of other variables that would affect learning, such as fatigue or attention difficulties. This could involve rescheduling the time of sessions, such as having only morning sessions or splitting sessions into two shorter sessions in a day.

'Yea I mean normally we get allowed an hour for speech Em sometimes that can be just right Sometimes it can be too long cos then they get fatigued and they get frustrated and it's very individual isn't it really I think you know after the first two or three times you've been in you can kind of pretty much gauge how much they can tolerate and then just adjust it to what they need really And be sort of guided by them' (HCP 15)

'And some people like the rest in between And some people want to get on with it It's trying to gauge from different people how they respond' (HCP 17)

#### 5.7.4 Adapting communication

HCPs also noted that they needed to adapt their communication to best suit the patient's needs and remove barriers to their participation in rehabilitation. It might mean that they needed to adapt the topics of conversations to make them more meaningful to the PWA. Establishing topics that interested the PWA was facilitated by being in the person's own environment and developing a rapport with that person.

'You might get someone who really really struggles with word finding but if you get them on a topic that they feel comfortable with then it flows a lot better, it's easier They don't struggle for the words so much, it's just natural Where you are asking them specific things The conversation can stop or they can't get their words out you know' (HCP 15)

The HCP might also need to adapt the method through which they communicated to best

suit the patient's needs. HCPs said that they communicated through pen and paper,

gesticulations and/or adapting the sentence length or amount of information content.

The OT also noted that she was more conscious of PWA eye contact, as it was a good way

to 'assess and maintain attention' and 'show you're listening to them'.

'So if they can gesticulate and it is quite challenging if they have quite severe communication difficulties and then they have a difficulty trying to talk it out I'm not adverse to miming pads (laugh) or equipment or stuff like that Or where you put it on but those sorts of things I am quite happy to act out and mime We have a communication folder but I very rarely use it actually' (HCP 21)

HCPs noted that it was extremely important to adapt communication to receive the message that the person wanted to say, not what the HCP thought they wanted to say. This was important for goal setting, understanding patients' wishes, emotional support and developing rapport. They acknowledged that as it was difficult for a PWA to initiate a topic so they paid close attention to respond when the PWA did so.

'If they are initiating something and it's so difficult for them to speak even if they are trying to initiate something it is obviously something really important that they need to tell you, so I would always try to use strategies So if they've got any communication aids or if I Or I will start by trying to narrow the topic down If they have got reliable 'yes/no' or something I would always try and get to roughly where they need to be Or try and support them to tell me what it is they are trying to initiate the conversation about' (HCP 20)

#### Figure 11. Connections between themes: procedures of rehabilitation



#### 5.8 Staff training

Another key theme discussed by HCPs was their need and desire for more training about aphasia and supported communication techniques. RAs and APs talked about how they would like more information on the disciplines OT, PT and SLT. One RA emphasised that, 'I need to learn need to improve' (HCP 13). All the HCPs had a desire to improve their skills in order to provide the best service for PWA.

They also felt that the lack of information and understanding of aphasia in the general population could act as a barrier to rehabilitation, including managing expectations of PWA and their family members. The fact that the general public could not see the resultant impairment associated with aphasia could also make rehabilitation and adaptation more difficult.

'Definitely. Yea I think we definitely need to increase the awareness of aphasia and what it is and how everything else impacts on it as well' (HCP 12)

'Um ehh and I think it is one of the things I've noticed anecdotally that is quite possibly one of the most distressing em symptoms of stroke I think I have noticed for patients and their loved ones I think if you've got a physical disability I think it is easier for people to be kinder to you because it is an obvious thing Um and I think maybe there are easier ways around it There's lots of things and lots of aids that you can get to support you with a physical disability I think, not saying that it's not hard for people But I think with a communication difficulty, I think it's phenomenally Frustration is obviously the word that most people come out with Yea and it's the invisible disabilities and people aren't as understanding and they probably put it down as them being drunk or it's very difficult for people' (HCP 21)

The levels of training that HCPs had received varied among the group interviewed. Many HCPs reported that they had never received any formal training on supported communication or communication impairments when at university or when beginning the job. Some reported that they had attended a course run by the local university on supported communication techniques, which they had found very beneficial. They found it helped them know how to adapt practice, how to engage in conversations using different communication methods and overall increased confidence and reinforced ideas for adapting communication to a PWA's needs.

'It was the mixture of people they had there
Getting to communicate with people with aphasia who use different communication strategies, those that were communicating with lightwriters
Other people had their iPads
You know other people were verbally communicating but obviously had problems
And then you would have a mixture of the verbal communication and the pen and paper
It was just a good mixture of people really
CS And did it make you change your communication when you went to work with people
with aphasia again
15 I think it just kind of reinforced things really
Sort of actually I am not that bad really
At trying to understand different things and what they are trying to say
It's a sort of reminder of everything I suppose' (HCP 15)

Other HCPs reported that they had received some informal training from the SLTs on their team and discussed communication techniques regularly with them. One HCP also mentioned that s/he had had opportunities to shadow SLTs and other team members of the MDT. They reported that 'it is just learning from colleagues that type of thing' (HCP 21) and that this was very helpful. They cited their supportive team as a great resource and felt 'lucky' to have it.

'Emm but I think as long as you have other people you can come back and tap into you can usually find a way around And the more you do it the more confident I think you become Things that you can try or strategies that can work Strategies that don't work Because there are common things that a lot of patients do find help so it's knowing what to use for what patients sometimes

#### But em yea' (HCP 20)

Some reported that NHS financial pressures were a barrier to this informal means of training because there had been a reduction in staff numbers and teams were busier; so this resource was not as easily accessed. 'Since I started XXX there has been such a shortage of staff' (HCP17). All HCPs said that more training was needed for HCPs working with PWA.

#### 'So it would be useful I think

If we had had some formal training at the beginning Particularly for people who haven't worked with stroke patients before Mmm I guess if you've worked with people for a long time and worked alongside good speech therapists for a while in other jobs and such, which I kind of have You do pick stuff up but it's still not the same as having some proper training and feedback on what you are doing cos I do think that's probably the best way to know if you are doing something right or wrong is to actually do it and have some feedback and have that training So no I haven't really done anything formal' (HCP 20)

Some HCPs expanded on this, saying that this type of training was needed for HCPs in all healthcare settings. One HCP reported that unless you can 'shout loudest' on a ward you may not get as much attention you need. Another reported that 'it is something that people do need training with because it is hard at times that working with people with aphasia' and it was 'overwhelming' in all settings. This was exacerbated by the complexity of aphasia and the fact that 'everyone relies on their verbal communication' (HCP 10).

'People on all wards or on all teams will come across people with aphasia even if they are not working on a stroke team so in some ways it would be useful to have some formal communication training for everyone really Em because everyone is going to come across it Everyone is going to need to know how to deal with somebody with aphasia at some point in their career, whatever team they work in Yea so that would be useful I think but it's one of those things that's not high on the priority for the people above so It's not kind of a mandatory training requirement And not something that everybody does but Em it would be good, it would be good to do' (HCP 20)

One AP identified an additional training need. They reported that they would like more general information on OT, PT and SLT. They discussed that he/she had never received any training on these disciplines and as a result did not feel fully comfortable completing the programmes made by the qualified HCPs. They felt that more information on these aspects of rehabilitation would help to gain a better understanding of the underlying mechanisms that were helping to bring about change for the PWA. They spoke of occasions where they could have capitalised on opportunities to adapt tasks and sessions to make them more salient but they were too afraid to do so. At present, they felt that SLT was 'complex' and they did not want to change anything that could have a

detrimental effect on the PWA.

'My understanding of speech and language isn't enough to know if I improvise will it benefit the patient I feel much more that I have to go back to the speech therapist and say I hope that it is OK that we did this ......So I feel like there are more grey areas in terms of what I can improvise and I have to really check that if I change something in the session that it was OK to do that Em so I feel like then I would have to speak to the therapist to know if it was OK that I had adapted to something else and that I wasn't doing something else on the programme' (HCP 17)





## 5.9 Environment

The rehabilitation environment and discussions contrasting different possible contexts of rehabilitation permeated all the other themes. The environment impacted on the rapport developed between the HCPs and the PWA, with much of this attributed to both HCPs and PWA having more positive feelings in the context of home-based rehabilitation.

21 'Em I probably am more relaxed I think in their homes aswell
I probably do feel
Not quite as relaxed as a friend of mine who is a health visitor who ended up putting her feet up on the sofa (laugh)
CS (laugh)
21 I wouldn't get that relaxed' (HCP 21)

The positive emotions were also attributed to them having their own things around them and being able to sit in a 'comfy armchair'. These materials made it easier for HCPs to get a sense of who the person was and to begin naturalistic conversations.

'Again it's often from what patients have told me that they feel much more confident and comfortable in their own environment and they feel able to tell you more and say exactly how they feel and obviously to remember what they used to do before things like that help and they have everything around them that they would normally use – computers or reading the newspaper or things like that. You can find out a lot about someone from being in their environment I think more so than on the ward' (HCP 12)

The physical space was also a useful rehabilitation tool for HCPs and for PWAs. The PWA's

own space, such as their kitchen or bedroom, provided an ideal location for functionally

based assessments and intervention. One HCP used the physical environment as a method

of allowing the PWA to take a break and calm down when frustration levels increased.

'But I mean that was challenging and he would get so frustrated and em I used to open up the patio door and tell him to go for a walk up the garden and he would come back and he was fine and we would carry on again' (HCP 15)

All the HCPs who were interviewed preferred working in home-based rather than ward-

based settings; in addition, they thought that the benefits were greater for the PWA they

worked with than those PWA who received their rehabilitation in hospitals.

'Emmmm but em in my observation The improvement is better when they are at home Cos maybe down to the mood or em they are more inspired to get better Home more inspiring to get better' (HCP 13)

#### Figure 13. Connections between themes: environment



#### 5.10 Summary

Seven key themes were produced from these data: (1) emotions; (2) rapport; (3) collaboration; (4) rehabilitation materials; (5) processes of rehabilitation; (6) staff training; and (7) environment. These seven themes were interrelated (as illustrated), conveying the perceptions and experiences of HCPs and the conditions that exist in routine rehabilitation sessions for enhancing functional communication learning for PWA. The HCPs identified barriers to learning, such as rehabilitation materials, negative emotions, rehabilitation procedures, and lack of awareness of aphasia and training needs for HCPs. The HCPs also identified facilitators to learning which could be optimised further, such as changes in collaboration and control that occur naturally in the home environment, using the environment to aid naturalistic conversations and develop rapport, making rehabilitation more salient by using materials in the home, and alleviating negative emotions by making both the HCP and PWA more comfortable.

# Chapter 6: Findings of PWA interviews

## 6.0 Introduction

This chapter outlines the findings of interviews between the researcher (CS) and all the participants with aphasia who completed the research study (n=9). Thematic analysis (Braun & Clarke, 2013) was used to interpret the data, as outlined in the methodology. The themes that were developed from analysis of these interviews will be outlined in relation to research questions 2 and 4.

## 6.1 Research questions

- 2) What conditions exist during routine rehabilitation sessions for enhancing functional communication learning for people with aphasia?
- 4) What are the barriers to and the facilitators of uptake of opportunities to enhance functional communication for aphasia learning?

## 6.2 Themes

The nine interviews were coded; 113 codes were produced (Appendix XVII). These codes were synthesised to produce the following six key themes relating to the research questions: (1) journey of stroke and aphasia; (2) PWA emotions; (3) attitudes; (4) rapport; (5) rehabilitation materials; and (6) environment. These themes and their subthemes (Table 16) will be set out in detail and quotes from the interviews will be used for illustrative purposes. The themes that were produced from the data were interlinked; occasionally influencing and being influenced by the other themes and these are illustrated at the end of each subsection.

Theme	Sub-theme	Commentary
Journey of stroke & aphasia	<ul> <li>Communication difficulties</li> <li>Co-morbid difficulties</li> <li>Adaptations &amp; changes as a result of aphasia</li> <li>Lack of memory of stroke event</li> <li>The general public's unawareness of aphasia</li> </ul>	All PWA spoke extensively about their personal journey of aphasia. This theme impacted on every area of their lives and therefore permeates and contextualises all the other themes in this research.
PWA emotions	<ul><li>Negative emotions</li><li>Positive emotions</li></ul>	PWA reported feeling frustrated, anxious and

Table 16.	Themes and	subthemes f	rom i	interviews	with	peopl	e with a	aphasia
	Themes and	Justificilies			WVILII	pcopr		apriasia

	•	Influencing factors	embarrassed after their stroke. Some PWA reported low mood which was exacerbated by guilt. The one positive emotion discussed was hope. PWA hoped that their abilities would be restored and they could get back to activities they enjoyed. PWA's families, the general public's lack of knowledge about aphasia, and their progress influenced their emotions.
Attitudes	•	PWA's own attitudes HCP attitudes	The PWA spoke of their inherent attitudes to life, aphasia and their own rehabilitation. These influenced how the PWA engaged in their rehabilitation and could be harnessed by the HCP to facilitate learning. The PWA also appreciated if their HCP had a positive attitude to their rehabilitation. This also helped them to develop a rapport.
Rapport	•	Personalities of HCPs Naturalistic conversation Adapting communication Focus & clarity of rehabilitation Feedback	PWA appreciated having a rapport with their HCP, and this facilitated the PWA's learning in rehabilitation. The personality of the HCP, their willingness to engage in naturalistic conversation, the focus and clarity of the rehabilitation, feedback and supported communication acted as facilitators, creating conditions for learning in rehabilitation.
Rehabilitation materials	•	Facilitators to learning Barriers to learning	Rehabilitation materials acted as barriers or facilitators to learning. Rehabilitation materials could put the PWA at ease

		and keep them engaged in rehabilitation by being fun, flexible, varied and meaningful. Materials could act as a barrier to learning if they were repetitive or if the PWA could not make choices about materials used in rehabilitation activities.
Environment	<ul> <li>PWA's emotions</li> <li>Environment- enhancing sessions</li> <li>Environment creating barriers to learning</li> </ul>	All PWA preferred having their rehabilitation in their own home compared to a hospital setting. It helped them adjust to life after stroke, made them feel more comfortable and helped with their progress. Distractions in the home environment could act as a barrier to their learning by affecting their concentration.

## 6.3 Journey of stroke and aphasia

Descriptions of the PWA's journeys of stroke and aphasia, from the incidence of stroke to becoming a stroke survivor, living with aphasia and making progress, were dominant throughout these interviews. This was a central theme as it contextualised all other data, the rehabilitation experience and involvement in this research study. Therefore, although this theme does not directly answer the research questions, the importance of the journey of stroke and aphasia means that it permeates all other themes.

#### 6.3.1 Communication difficulties

All the PWA spoke about the impairments they had in their language as result of aphasia. In this sample of nine PWA the language difficulties experienced were varied; they described difficulties in all language modalities, verbal expression, comprehension, reading and writing. PWA reported that they got their 'words muddled....it just comes out wrongly' (PWA 10), getting words 'the wrong way round' (PWA 5), 'getting stuck' (PWA 8), and PWA 9 said that it comes out 'Or dilala dilala dilala'. PWA 2 found his main difficulty was 'replying to someone' and that his difficulties were 'no good'. Many PWA had difficulty reading and/or writing as they 'jumbled' up letters and numbers. All PWA expressed confusion surrounding the recent changes to their communication and the mistakes that they made as a result:'Why did you do that, but that's what me brain was telling me' (PWA 10). 'Em I don't know I feel like I've got very kind of (blablablabla) Can't say anything (puts hand up to her throat) Try to think what I'm thinking It's not anything [ahhhhh] [(pulls face)] I dunno' (PWA 9)

#### 6.3.2 Co-morbid difficulties

All PWA interviewed also described the co-morbid difficulties they experienced. PWA reported that they had reduced concentration, increased fatigue, reduced motivation, increased memory difficulties and difficulties with their vision. Some of the PWA also had hemiparesis and severe pain.

CS	'So your main issue is your arm and your leg
PWA 1	Yea and then
	[ahhhhhh]
	[(throws down hand)]
CS	And then after that your speech
PWA 1	[Yes]
	[(points at CS)]
	Yea
CS	So your main priority is your arm and your leg
PWA 1	And then
CS	And then your speech
PWA 1	Cos
	[0000000000]
	[(screws up face and throws down arm)]
CS	Cos it's really painful is it
PWA 1	Yea
	(raises hemiparetic arm slowly and then has to lift
	it with the other hand)
CS	It's getting much better PWA 1
PWA 1	O yea
CS	But it's still very painful is it
PWA 1	Cos [ugh (grunt)] [ugh (grunt)]
	[(Points at leg)] [(points at arm]
CS	It's driving you mad
PWA 1	(Shakes fist)
	But
	(raises hemiparetic hand)' (PWA 1)

All PWA spoke about how these co-morbid difficulties impacted on them and their rehabilitation. They spoke about how these difficulties exacerbated the problems they had with their language, their willingness to communicate and how they engaged in rehabilitation.

'Not as much as I should be For instance I have got an email There as a draft for two if not three days And I say I've got quarter of an hour I can do that, go upstairs (Pantomimes sitting down at a computer) O I look at this first and then O I can't do it now So I haven't motivated to somethings sometimes I'm not motivated to but I would love to get back to doing DIY I would like to be again motivated more' (PWA 5)

#### 6.3.3 Adaptations & changes

Having a stroke and aphasia impacted on how the PWA lived their lives on a daily basis. All

PWA had adapted the way they communicate. HCPs had taught them self-cueing techniques, which facilitated their communication.

'Em they teach me, they taught me em tricks In other words if I cannot think of something like em (bangs table with a clenched fist) something I couldn't think what a [table] is [(taps kitchen table with his finger)] Em I would think chair I want a chair It's not chair Bed No no no no I want table So I can either draw something on a bit of paper for me And that will help me bring it back or emmm think around it Think of other ways Think of me laying a table with a knife A fork and a spoon Chairs (touches the table with both hands) Ah [the table] that's the word I want you see [(hits the table with his hands)] It is very clever' (PWA 5)

Most PWA discussed changes they had made to the activities they took part in as a result of stroke and aphasia. For example, PWA 4 said that he no longer read the whole newspaper cover to cover, instead prioritising the most important pieces or those that interested him most. He also reported that he changed the distances he would travel to engage in an activity, to conserve energy for other things he wanted to do.

'I wouldn't go halfway around the city I'd perhaps just go up the market' (PWA 4)

Many PWA spoke of how the stroke and aphasia had changed their lifestyle and identity. PWA 1 no longer worked on the land as a farmer, instead spending much more time watching television. PWA 5's role and identity in his family had changed. He felt that he was 'more likely to make a mistake' so left 'officialdom' to his wife, something that annoyed him. PWA 2 also experienced changes in his family role and did not like that he was dependent on his family for transport. He felt that it took away his freedom to 'get in the car and just go somewhere'.

PWA 1	'[But em]
	[continues to wave hand and point in front of him
	to where the telly is]
CS	The telly
PWA 1	Yes and
	(continues to point forward at the TV)
CS	You spend a lot of time watching [TV] now
	[points at the TV]
PWA 1	[Yea]
	[raises hand palm to the ceiling]
CS	And that is different to life out on the farm
PWA 1	[OOO YEA]
	[eyes widen]
CS	[yea]
	[nods head]' (PWA 1)

One PWA (PWA 3) presented with a mild right-sided facial palsy (droop) and was concerned with how she looked after her stroke. She felt that her appearance had changed and this impacted on her confidence.

CS	'It's the whole difference
3	(rubs the paretic side of her face)
3	[(taps paretic side of her face)]
	[here]
CS	The change in your face is it
3	[mmm]
	[(nods head)]
3	[cos no]
	[(points to corner of her mouth)]
CS	[just at the mouth]
	[(points to the corner of her mouth)]
3	Yea (laugh)
	(smiles and nods)' (PWA 3)

#### 6.3.4 No memory of stroke event and lack of knowledge of aphasia

All PWA discussed having no memory that they had experienced a stroke and this became a prominent theme. They reported not 'recognising it', 'not registering what was in my head', knowing that 'something weren't right' but they didn't know what it was. PWA 8 reported that in the hospital 'there is so much babbling that you didn't really know what to actually describe the stroke'.

*'Well I, I don't remember anything about it From the beginning to the end All I know is what I have been told happened .....* 

#### ......You know I don't remember ever arriving at the hospital' (PWA 10)

They also discussed how neither they, nor their families, were aware of the term aphasia or what it was prior to their stroke. Only one PWA's daughter, who was a medical professional, knew the term; PWA 3 reported that her daughter had been very helpful in her journey by educating others. Four PWA mentioned that they do not remember the term ever being discussed with them, and were not aware that that was the name for their communication difficulties.

The journey of stroke and aphasia was an important theme for all PWA interviewed. The language and co-morbid difficulties, changes in identity, activities and lack of awareness of aphasia could all act as barriers to learning if not taken into consideration by the HCP. This lived experience provides background to the other themes that were discussed in the interviews.





#### 6.4 Emotions

All PWA described the emotions they felt as a result of their stroke and aphasia. All PWA described negative emotions such as frustration, embarrassment, annoyance, anxiety and low mood. These negative emotions could act as a barrier to learning in rehabilitation. Some PWA reported that they were hopeful and this facilitated them in engaging in rehabilitation. They also spoke of factors that exacerbated their emotions, such as certain activities, their communication partners, the fact that aphasia is an 'invisible' disability, and

the general public's lack of knowledge about aphasia. This meant that people were not as understanding of the PWA's experience and were not as sensitive to their impairments compared to somebody with a visible movement disorder.

#### 6.4.1 Frustration and annoyance

All PWA described the frustration they felt as a result of their aphasia. PWA felt frustrated at their communication difficulties, frustrated that they could not speak when they wanted to or get the words out. PWA 5 talked of being frustrated when he would read an article in the newspaper and he would not be able to remember it the next day. He was annoyed that 'this thing doesn't work as fast as it should', pointing to his head. Overall he described the experience as 'extraordinary and damn annoying'. Three people with severe aphasia conveyed this frustration through audible exhaling, shaking fists, slapping their leg or a table, or clenching their jaw.

CS	'But do you still feel quite frustrated
3	[yea]
	[(nods head)]
	(laugh)
	[yea yea yea]
	[(moves hand to and from his mouth repeatedly)]
	(moves her hand to her ear)
	000000
CS	<i>Is it because the words don't come out when you want them to</i>
3	O God em OOOO (pauses, open mouth and leans
	forward) no (closes mouth and leans forward)
	(laugh)
	Yea' (PWA 3)

PWA 9 felt that this frustration was exacerbated by the slowness of progress and not being able to fulfil her desire to get better.

## 6.4.2 Anxiety

Some PWA felt greater generalised anxiety and anxiety around communication since acquiring aphasia. PWA 4 described this anxiety by saying that 'I'll just clam up you know'.

PWA 3 said that she would be scared to participate in a local peer-support group. Other PWA reported that they generally felt more worried now, 'sort of worry unnecessary' (PWA 10).

#### 6.4.3 Embarrassment

Aphasia and the different impairments experienced by PWA after their stroke made many PWA feel embarrassed. PWA 10 reported that the aphasia made her feel like an 'idiot' and PWA 5 said that when he was talking 'nonsense' it was all 'embarrassing very embarrassing'. PWA 4 reported that embarrassment would cause him to avoid some interactions and activities.

## 'Well I do but I try to avoid anything if I can you know

If I thought I can't explain a word or anything about it then I'd rather leave it you know I don't want to look at me as if I am being stupid or there is something wrong with me you know Cos I know it is something in the brain but you not explain it But people will think you are drunk or something like that So it is better to stay in the way of them you know' (PWA 4)

## 6.4.4 Low mood and guilt

Some PWA discussed having feelings of low mood after their stroke. PWA 9 spoke of this feeling being variable, with extreme lows and then some highs. Some PWA reported that their low mood was exacerbated by guilt. PWA 5 spoke of the guilt he felt about having a stroke and the implications this had had for his family; another PWA said that sometimes she felt that if she had died in 'some respects' it would have been easier. PWA 4 felt guilty, as he 'personally didn't look after my health enough'.

9	'Bet best better but not [don't know]
	[(shrugs shoulders and moves hand from side to side)]
CS	[Middle]
	[(moves hand from side to side)]
9	Yea yea
	I feel not kept alright
	But sometimes I feel
	[O I'm fine]
	[(puts one finger up in the air)]
CS	Yea
9	And other days I feel UGH outted
CS	So some days you feel a bit higher
9	And sometimes lowed
CS	Low
	Yea
9	Yea' (PWA 9)

#### 6.4.5 Hope

The one positive emotion that was discussed in the interviews was hope. Many PWA were hopeful that the abilities they had lost through their stroke would be restored. PWA 9 reported that this hope had increased as things were starting to 'pop back'. PWA also had hope that they could start returning to activities that they enjoyed.

'Er em eh just hope to keep going Just starting to think about holidays Not just immediately but later on' (PWA 8)

#### 6.4.6 Influencing factors

The emotions experienced by PWA were variable and were influenced by factors such as the communication partner, the rehabilitation activity, the general public's lack of knowledge about aphasia and the fact that people could not see aphasia and therefore may not be as sensitive to the PWA's impairments.

'It depends a bit on how you are on who you are with (laugh) how you' (PWA 8)

Some PWA found that their negative emotions were exacerbated by speaking on the telephone or to large groups, while others struggled to speak with those they did not know well and some found it most difficult when people asked them specific questions.

'I wouldn't have dared gone up the city because I'd have been trying to explain to them I wouldn't have been able to speak to them you know Cos I went to the bank and they wanted a cheque and I couldn't even the word cheque I couldn't even write it down' (PWA 4)

Family acted as a great support to some PWA and helped lift their mood. One PWA spoke about her sister making her get out of bed when she had very low mood. Another PWA said that he would often seek help from his wife and that she helped him by prompting him or completing tasks if he was not able to. However, another PWA said that his family could make matters worse and increase his annoyance and frustration by speaking for him and finishing his sentences.

The general public's lack of knowledge about aphasia and the fact that they did not have a visible impairment also influenced the PWA's emotions. These factors increased the PWA's anxiety and caused them to avoid situations in which they may have to speak with members of the general public or people they did not know. One PWA commented that he was afraid that people would think he was drunk.

PWA felt more comfortable engaging in their everyday activities if people were aware they had had a stroke. For example, PWA 5 felt more comfortable getting his daily paper without the company of his wife because the girl in the shop was aware that he had had a stroke.

## 'Everything else I look quite normal you know But I am not right at the moment' (PWA 4)

Seeing improvement in their own abilities and discussing this progress with their HCPs lifted the PWA's mood. Many of the PWA interviewed mentioned progress as an influencing factor. They spoke of 'getting better', being 'clearer now' and 'slowly getting new'. Some PWA spoke about good moments in their communication when 'I can and do occasionally have decent conversations with somebody' (PWA 5)

- CS 'So you feel that last week it got a stage better
- 9 Yea yea
  - So O gonna
- CS Brilliant
- 9 So I am hoping that it will get [cona and cona and cona]

[(moves hand up and down three times)]

- So O
- CS So you are hoping that it will do the same progress
- 9 [yes] [(nods head and raises up her hand)]' (PWA 9)

Progress had an impact on the PWA's confidence and how they felt about engaging in conversation with people or participating in activities.

- CS 'Have you felt more confident about communicating with your aphasia Do you feel a bit happier about communicating with your aphasia
- 3 [mmm hmm] [(nods head)]
  CS Cos you said earlier on that that's something that does really affect you
  3 [um]

[(nods head and looks sad)] Yea cos (points to face and runs finger down cheek to pantomime crying) Yea

- CS Are you feeling any more confident about communicating with your aphasia
- 3 [ummm] [(nods head)]
- CS Yea
- 3 Yea
- CS And was that
- 3 (opens mouth)
- CS Sorry go ahead
- 3 (starts searching through paper) Ahh umm (picks up piece of paper and gives it to CS)
- CS This says aphasia café
- 3 Ahh yeaa 000
- CS So you feel that you are looking forward to this
- 3 [ummm] [(nods head)] Yea
- CS Yea' (PWA 3)

PWA reported experiencing a wide range of emotions since their stroke. These did have a significant impact on the person, the activities they were willing to undertake, and their motivation to engage with others. People's emotions could become more positive through support from others, or seeing and discussing progress. Therefore, emotions could act as a barrier to or facilitator of learning in rehabilitation.





## 6.5 Attitudes

PWA's inherent attitudes had an influence on how they engaged in rehabilitation. These attitudes referred to the PWA's personal mind-set and the type of character they were. Unlike emotions, these attitudes did not vary, and were not contingent on external factors. Attitudes could act as a facilitator of or a barrier to learning in rehabilitation. The attitude of the HCPs and their mind-set with respect to aphasia and rehabilitation could also influence learning and create conditions for learning.

#### 6.5.1 Attitudes of PWA

The PWA interviewed had a variety of attitudes to life, their stroke and aphasia. Some of these attitudes, such as being determined, accepting and having an overall positive attitude, facilitated the PWA's engagement in their rehabilitation. PWA 10 was accepting that it was 'still gonna be like this' and that that was OK as she was 92 years old. PWA 8 also felt that it was something that he personally needed to accept and that it was his responsibility to 'deal with it'.

'Yes I think so I mean most of it as far as I was concerned anyway Em you just had to deal with it em There wasn't great responsibilities to other people Just you to deal with it yourself And get on with it And eh just what makes you get on and do it Eh which I am going to (sigh) (laugh)' (PWA 8)

Many PWA reported that they were determined and had great resilience. PWA 9 shared how her tenacious attitude was vital to her getting out of bed when she was experiencing extremely low mood.

CS	'Em and when you said that you came back here first and you were in bed
	Were you in bed when you got back to the house first
9	Yea yea that's cos
	xxx (points down to the bedroom)
	I was (closes her eyes and slumps)
CS	You were very sort of sick at that time still
9	Not sinus just you know
CS	Just everything was at its worst then
9	Yea (audibly exhales)
	I didn't even (waves hand) stay there
	I said no eh eh (waves hand)
	That I had to deal with the same'(PWA 9)

This determination was reflected in how she engaged in rehabilitation. When asked about the intensity of rehabilitation she replied that she wanted 'more, more, more' and 'I

wanted to do I really wanted to do it loads'. Another, PWA 10 had found ways to increase the amount of practice she got by playing scrabble on her TV, while another lady wanted to attend a local peer-support group as a way to communicate more. PWA 5 saw it as an 'unfinished job' that needed to be worked on for a 'long time yet'.

A positive attitude also influenced how the PWA engaged in their rehabilitation. Two PWA felt lucky that they were 'still here to tell the tale'. They felt lucky that somebody found them the day they had their stroke and that they were still alive. PWA 10 said that she realised that on a 'different day it would probably have been a different story'.

Some PWA were positive about their spared abilities. They compared themselves to others, who they felt were 'worse off' and as a result they 'counted their blessings'. These four PWA all pointed out a spared ability that they were grateful to still have, such as being able to feed themselves or having retained physical abilities. One PWA described himself as 'getting away with it'.

'Quite a lot of other people must do much more Have been affected more physically than I was I was never really sort of I was always able to walk more or less' (PWA 8)

PWA 4 added that he realised how lucky he was to have the support of his family and people who care for him. He noted that others do not have this support and felt that they must be very 'lumbered'.

# 'I know what I've had but I also realise that a lot of people are a lot worse than what I am so I am quite happy....With all my family helping me' (PWA 4)

The positive attitudes discussed influenced how the PWA viewed their stroke, aphasia and their rehabilitation. They spoke of being appreciative of their HCPs and everything they did for them. PWA 8, who was a retired dentist, said that working as a dentist meant that he had to be 'adaptable' and this meant that he was happy to be flexible in rehabilitation. PWA 9 reported that being determined and having a desire to do things quickly was part of her personality in general.

Two people with severe aphasia made it clear however that they had a negative attitude towards their stroke and aphasia. PWA 1 described it as a very bad experience, making a tutting sound and shaking his head to convey this. PWA 3 became visibly upset and frustrated in sessions. This was discussed in the interview, using a vignette taken from the video-recorded observation.

CS	'But do you still feel quite frustrated
3	[yea]
	[(nods head)]
	(laugh)
	[yea yea yea]
	[(moves hand to and from her mouth repeatedly)]
	(moves her hand to her ear)
	000000
CS	<i>Is it because the words don't come out when you want them to</i>
3	O God em OOOO (pause open mouth and leans
	forward) no (closes mouth and leans forward)
	(laugh)
	Yea' (PWA 3)

PWA 3 found that her negative attitude did influence how she engaged in her rehabilitation. She found it more difficult to engage in SLT activities, as she was aware that she was not succeeding.

Another PWA had a negative attitude towards HCPs and healthcare practices which was influenced by a negative experience she had while in hospital. PWA 10 recounted how this bad experience had influenced her attitude to rehabilitation and initially made the experience very difficult for her. As a result of this she would be reluctant to go back to hospital again.

10 'And see that's where I first experienced my bed moving And I screamed out, and she was so nasty to me You know what I mean, she wasn't a bit pleasant
CS Was this the nurse
10 Yea and this put me right off hospitals' (PWA 10)

## 6.5.2 Attitude of HCP

All PWA appreciated HCPs who had a positive attitude towards them, their aphasia and the rehabilitation session. The attitude of the HCP was closely linked to the PWA's ability to build a good rapport with their HCP. All the PWA interviewed felt that the HCPs had a good attitude, with PWA 3 awarding the HCPs' attitudes a score of 5 out of 5 on a 0–5 point Likert scale.

**CS** 'And their attitudes to your aphasia was that [bad or good]

[(leans forward and points to the scale)]

- **CS** Do you think that they had a good attitude to the aphasia
- 3 Yea (leans forward and points to the scale)
  CS 5 again
- 3 Mmm hmm

3

Yea' (PWA 3)

#### Figure 16. Connection between PWA interviews: attitudes



#### 6.6 Rapport

PWA emphasised the importance of getting to know their HCPs and building a rapport with them. This helped the PWA feel comfortable and happy to have the HCP in their home. Rapport also made the session more enjoyable for the PWA. The PWA thought it was 'nice' to have them in their home every day, and the intensity of rehabilitation was not an issue. Five PWA added that they were going to miss the HCPs on completion of the rehabilitation block: 'I'm going to miss them all so very much' (PWA 10). Speaking about the HCPs, PWA 6 added that 'they sort of made the day up for me'. The PWA appreciated the HCPs and the work they did with them, which was enhanced by getting to know them.

#### 'Yes well

Can't tell you how pleasantly they are Em from the moment they come to the door to the time we meet them Em or I will shake hands By the time we have finished we are practically hugging each other We get along I understand She obviously she is very professional em ...... ......But em they arrived They made us friends straight away' (PWA 5)

Rapport was developed between the PWA and the HCPs through a combination of factors, such as: the personality of the HCP; the HCP taking time for conversation to get to know them; the intensity of the rehabilitation; adapting communication and being empathic; reassurance; and celebrating their achievements and progress.

CS	<i>'When people did come in and it was a good experience</i>
PWA 1	Yea
CS	What made it good for you
	Was it their personalities
PWA 1	(Looks away)
	[Yea]
CS	[was] it how they acted with you
PWA 1	No
	(moves hands back in arcs)
CS	Was it that they came in and had a chat with
	you
PWA 1	Yea [yea]
	[(nods head)]
	Yea
CS	And that they were nice to you aswell
PWA 1	OO yea
CS	Yea
PWA 1	Yea
CS	And you felt that they were good to you
PWA 1	Yea' (PWA 1)

## 6.6.1 Personality of the HCPs

PWA felt that the HCP's personality was an important factor for building a rapport. The PWA felt that the HCPs generally had 'good' personalities. PWA 6 appreciated if the HCP was 'nice' and 'easy to talk to', and elaborated by saying that he liked working with them because they were 'just ordinary sort of people' and was happy that 'they just came and that was it'. PWA 5 appreciated that they were pleasant and friendly and PWA 3 preferred if the HCP was 'chatty'. PWA 1 appreciated that his HCP was calm as this helped him to feel calmer himself.

	*watch video*
PWA 1	'(makes a waving gesture)
	[yea but]
	[(makes a waving gesture)]
CS	She was very calm was she
PWA 1	(Points finger)
	YEA
CS	So you liked that she was very calm
PWA 1	Yea
	(repeats wave motion)
	Yea
CS	Let me turn this off while we talk about that
	*turns off video*
	So you found that she was very calm when she did
	her therapy

PWA 1	Yea yea
	(wave motion)
CS	And did that make you feel more calm
PWA 1	Yea
CS	So what made her such a good
	Was she [good]
	[(thumbs up)]
PWA 1	Yea
CS	Because she was nice and calm

## **PWA 1** Yea' (PWA 1)

#### 6.6.2 Naturalistic conversation

Most PWA felt that engaging in naturalistic conversation with their HCP during their rehabilitation sessions enhanced their overall rehabilitation experience. PWA found that engaging in naturalistic conversation helped them to get to know their HCP and helped them to develop a PWA–HCP rapport. PWA 8 felt that developing a rapport was a cyclical process – the better he knew his HCP, the more topics he had to begin and continue naturalistic conversations with the HCP, during which he would find out more about the HCP. PWA 3 felt that the intensity of sessions and the rapport that was developed helped her to be able to converse with her HCP.

'(name of HCP) em eh she was the one that we most saw and em Quite got to know her (laugh) So yes usually as we got to know her more and and we sorta get it You would be more more communication And more just on the normal business' (PWA 8)

Some PWA reported that they would have liked more time to discuss their chosen topics in a naturalistic conversation. The PWA did feel that the sessions could become too taskfocused with little room for 'chit chat', and that too many tasks could make the session feel a 'bit hectic'. PWA 4 commented that he felt his communication was better when communicating naturally.

'I think actually when I am talking naturally to them that I am sometimes talking a lot longer and talking more But as soon as I try on concentrate on myself then I learn to O I'm writing O I'm talking to words that I can't quite get' (PWA 4)

Some PWA did mention that they understood why this time for naturalistic conversation may not be possible. They mentioned that they knew that the HCPs were under time pressures, and that there were issues with staffing shortages.

#### 6.6.3 Adapting Communication

Supported communication and the HCPs' willingness to adapt their communication to facilitate a two-way conversation with the PWA helped develop rapport. Most PWA felt that the HCPs did adapt their communication when necessary and 'seemed to do everything anything' they could to communicate (PWA 9). The PWA appreciated being given more time to respond to questions and instructions. They also appreciated when HCPs spoke slowly, repeated themselves and 'put it another way' (PWA 2). Gestures and writing words down were useful for some PWA but not for all. Two PWA outlined the importance of bodily contact and eyegaze; as PWA 5 explained, it 'makes it much easier for me to understand them'. Being able to see the HCP's mouth aided PWA 1's comprehension. PWA 5 appreciated being taught how to prompt himself to aid his communication. Being able to communicate effectively with their HCP helped to create the conditions for learning and was therefore a great facilitator. PWA 3, a woman with severe aphasia, appreciated the HCP's checking on her wellbeing throughout the session to make sure that she was still engaging in rehabilitation.

## 'Em by looking at me, looking at my eyes Eyes and teeth, eyes and mouth, sorry, not teeth' (PWA 5)

#### 6.6.4 Individualisation: flexibility and openness

Salient activities helped the PWA develop a rapport with their HCP. The PWA appreciated if the HCP tailored the session to them and their 'needs' ('concentrating on my problem', PWA 4). They appreciated if the HCP was aware of their emotions and sensitive to their needs and emotions. PWA 5 was grateful that the HCPs made friends with him straight away; this helped him to not feel embarrassed by his difficulties. The PWA appreciated if their HCPs reassured them and were empathetic.

## 'They made us friends straight away And em I wasn't at all em ashamed of my problems On the contrary' (PWA 5)

PWA wanted procedures and programmes to be clearly explained to them to increase their understanding. Clarity in rehabilitation procedures and processes, such as explaining when HCPs would next come to their home and what they would focus on in that session was remarked on in positive ways. PWA mentioned that they could become confused by the different people coming into their homes. Two PWA pointed out that the programme timetables were a particularly helpful reference point. 'Go'ay they've been brilliant They've been absolutely brilliant And they've turned up They've left me a little note saying what time they would be here And they've been here on time Very good' (PWA 2)

Confusion surrounding rehabilitation sessions could affect the running of the session and how the PWA engaged in it. PWA 8 felt that the HCPs were sometimes not on the same page and he would get 'a whole lot of different signals'. He appreciated knowing the reasoning behind the rehabilitation activities and having this explained to him was useful.

'Well I think you pictured me once (laugh) eh trying something they want me to do (pantomimes writing) Do different things I really couldn't see why they wanted me to do it (laugh)' (PWA 8)

Finally, all PWA outlined the important role of feedback to their rehabilitation. Honest, tailored and appropriate feedback helped PWA to develop a good rapport with their HCP and helped them to engage and be motivated in rehabilitation. Feedback on their outcome and performance in a task helped them to understand how they could improve in rehabilitation, with prompts tailored to them appreciated by all PWA. PWA also noted that when HCPs celebrated their progress and rehabilitative achievements it helped with engagement and motivation in their rehabilitation sessions.

'They were all charming They really are Like the one that came this morning I said you are the one who was so pleased She was sitting on the other side of the bed and I got my legs up off the floor I said I did that all by myself didn't I (laugh) She said yes you did' (PWA 10)

#### Figure 17. Connection between PWA themes: rapport



## 6.7 Rehabilitation materials

All PWA spoke about the materials that were used in their rehabilitation. The PWA focused on the physical materials used. They spoke mainly about the materials that were brought to the home by the HCPs for aphasia-related tasks, such as picture cards and laptops. Similarly to the HCPs, the PWA discussed materials under the subthemes facilitators of and barriers to learning.

#### 6.7.1 Materials as facilitators

The different rehabilitation materials used had the ability to put the PWA at ease and make them feel comfortable in their rehabilitation. The PWA discussed that materials could be fun and bring humour to the session. For example, a game called Connect Four was used in an OT activity. PWA liked when the activity was livelier and this was interlinked with developing a good rapport with their HCPs.

CS	'So did you feel in this session you felt very
	comfortable
PWA 1	Yea yea
CS	And was that down to the therapist
PWA 1	Yea and no
CS	Yes and no
PWA 1	Yea
CS	So somewhat to do with the therapist
PWA 1	Ahhhh
	(lifts hand and points it at the screen)
	Yea
	(waves pointed finger side to side)

CS	Do you think it was more to do with the house
PWA 1	No
	There's
	(rotates finger in a circle)
CS	Was it more to do with the activity
PWA 1	Yea
CS	So it was more to do with the game
	So what made you feel most comfortable was the
	materials you were using
PWA 1	Yea
	(thumbs up)
	Yea' (PWA 1)

PWA liked if the materials were varied and the HCPs were flexible with the materials they used. PWA 2 thought it was 'superb' that the HCPs 'would look in their diary or the newspaper and they would find something in there'. PWA preferred working with materials that were more salient/meaningful and familiar to them. PWA 3 said that she enjoyed when she was working on naming her family members; PWA 1 appreciated when the HCPs included words associated with Liverpool Football Club in his rehabilitation.

#### 6.7.2 Materials as barriers

PWA felt that some materials used in rehabilitation were repetitive, particularly the picture cards. PWA 8 noted that 'some of the times towards the end they had cards, em and I had already seen all of them (laugh)'. Many PWA did not enjoy working with laptops on rehabilitation programmes such as REACT during their rehabilitation. One PWA felt that the activities were not explained to him when they were working with the laptop.

4	'Most of them brought these little bloody candles,
	about, comp
CS	Computer yea
4	They were just pressing them
	They weren't explaining the words you know
	Or doing therapy and that
	I didn't really do much of that at all' (PWA 4)

Another PWA said that she was not keen using laptops as 'em it's the attitude they use it because' (PWA 9). She felt that laptops were used more for the benefit of the HCP than the PWA.

Finally, PWA 8 noted that he would have liked to have had more control over the tasks and materials in rehabilitation. He felt that these were decided by the HCP and were sometimes boring, repetitive or he did not understand why he was doing them.
'It is a lot easier and I think a lot more effective to try and actually have something you are supposed to be doing rather of several things that are you know either see or it or we or whatever, we are just allowed to just em (audibly exhale) to decide how we do it' (PWA 8)



## Figure 18. Connection between PWA themes: rehabilitation materials

## 6.8 Environment

The environment where rehabilitation took place, the person's own home, became a central theme. The environment had an impact on the PWA's emotions, the rapport they developed with their HCPs and the materials that were used in rehabilitation. It also acted as a facilitator of learning for PWA, prompting them in communication and aiding their memory of the rehabilitation activities. It also enabled them to continue to practise the rehabilitation activities, in the same environment, after the session finished.

CS	'I see I see So you found it a very positive experience having the healthcare professionals in your house
3	Yea
CS	Brilliant
	[and would you rate the]
	(picks up a pen)
	lf I gave you a scale [1, 2, 3, 4, 5]
	[(draws scale on a piece of paper)]
	If 1 is bad and 5 is [good]
	[(thumbs up)]
	Would you say that your experience of having
	your rehabilitation in your home is 1 to 5
3	(leans forward and points to the scale)
CS	It's 5
	It's the best
3	Yea' (PWA 3)

## 6.8.1 Environment and emotions

All the PWA preferred having their rehabilitation in their own home compared to a hospital environment. The PWA felt that being at home helped with their adjustment post-stroke. PWA 8 felt that he could use the time in between sessions to 'deal with' having a stroke. The HCPs coming to his home helped to motivate him when 'you might have been a bit less enthusiastic yourself'.

'It's because the rest of your time you can deal with As much as you can Em deal with things and you can breathe and everything and it is all there ready' (PWA 8)

Some PWA liked that they could continue with their usual daily routines in-between their rehabilitation sessions.

'Well I can sit here, I can read the paper, and I can wait for people to come' (PWA 2)

All PWA felt that rehabilitation in general was more relaxed in their own home. PWA 9 felt more comfortable as she was in her own chair; PWA 3 liked that she could relax with a cup

of tea during rehabilitation. PWA 10 could look around and all her memories were there, and these reminded her of happy times, which helped with her mood and the adjustment to life after stroke. They felt that it was easier and less disruptive than travelling to a hospital. Some of the PWA did not enjoy their experience in hospital and were eager to get home. PWA 3 pantomimed marching to depict the atmosphere in the hospital.

- *3 (points forward towards a cup of tea on the table)*
- **CS** You can have a cup of tea
- 3 Yea yea
- **CS** Like we are now
- **3** Yes (smile)' (PWA 3)

## 6.8.2 Environment-enhancing sessions

Most PWA felt that having rehabilitation in their home environment helped with their progress. PWA reported that the environment facilitated conversation with their HCPs. PWA could show the HCPs their belongings or point to a room to provide context to a conversation. PWA 1 used photos stored on his iPad to discuss his family; PWA 3 liked that they could look out and discuss her garden or her cat; PWA 2 mentioned that he had conversations with HCPs about the 'ducks out on the pond'. The environment also helped PWA 1 initiate an important medication query. In the interview, CS showed PWA 1 a vignette and he discussed a session where he initiated a query by getting his weekly pill organiser, using it as a support for conversation.

The environment also acted as a prompt to PWA in-between sessions. Looking around their own environment reminded them what they did in sessions and helped them to remember what they needed to practice. Working on functional tasks such as making a cup of tea in their own home helped the PWA and HCP to identify issues that could arise. This made the PWA feel more comfortable as issues could be identified and dealt with while the HCPs were with them, thus reducing their anxiety. PWA 10 reported that it helped her anxiety that she had a rail in her bathroom that she could grab if she needed to or was at risk of a fall; PWA 9 was able to show her HCP that after she had made a cup of tea she was unable to transfer it to the sitting room with the stick she had.

9 'Yes Because when I come out I can go but he couldn't cup of tea But I haven't got one
CS You haven't made one since
9 No

	She taught me to put it (leans forward and puts her hand on the
	stick)
	To get that
	But she's got me a (points at her sling and then around her body)
CS	They are going to get something to kind of so you can carry everything
9	And then I can put the [key in]
	[(pantomimes putting a key in here pocket)]
CS	Ahhhhh
	Cos obviously you can't carry a cup of tea and [use this]
	[(points at the stick)]
9	No
CS	No
9	(makes face and throws her hand up)' (PWA 9)

## 6.8.3 Environment as a barrier

Two PWA identified distractions in their home environment as a barrier to their learning. PWA 3 and PWA 5 found it difficult to concentrate on their rehabilitation activities when there was noise from appliances or other people, including family members. PWA 3 felt that she became frustrated when this happened.

### Figure 19. Connection between PWA themes: environment



## 6.9 Summary

These data produced six central themes relating to the research questions: (1) journey of aphasia; (2) emotions; (3) attitudes; (4) rapport; (5) materials; and (6) environment. The PWA's rehabilitation was influenced by the person's individual stroke journey and this contextualised the rest of the themes. The person's emotions and attitudes could be fostered to enhance conditions for learning in rehabilitation. Developing a rapport with their HCPs facilitated learning, providing the PWA with topics for naturalistic conversations and making them feel more comfortable. Materials could act as barriers or facilitators to rehabilitation learning. Materials could be fun and engaging, motivating and salient. Materials however could also be prescriptive and repetitive, leaving the PWA with little choice in their rehabilitation. The environment of rehabilitation, the PWA's own home, helped the PWA to adjust to their stroke as they could continue with their lives in-between their rehabilitation sessions. The environment was linked to the PWA's emotions as it made the person feel more comfortable and relaxed. Distractions in the environment could act as barriers to learning by dividing the PWA's attention. Analysis of these data identified themes that could be optimised and barriers that could be minimised to facilitate learning for PWA in routine rehabilitation.

## Chapter 7: Observational study: Findings

## 7.0 Introduction

This chapter sets out the results of the observational study. Thirty-four hours of interactions between PWA and their HCPs were observed and recorded during routine rehabilitation. These data were analysed following the methods outlined in Chapter 4 and Table 6. The findings will be set out within an ACA framework, including the collective and personal influencing and influenced factors, in relation to the research objectives below. The contingent nature of these interactions meant that the influencing and influenced factors were very complex. Descriptions and transcriptions from the observations will be used to provide illustrative examples to support findings. These will demonstrate how practices arose and were produced that might tend to facilitate or act as a barrier to learning.

## 7.1 Research objectives

- To explore and understand the nature of the interactions between people with aphasia, healthcare professionals and the rehabilitation activity in the context of Early Supported Discharge (ESD).
- 3) To identify opportunities for increased interactional/transactional activity practice and functional communication learning during routine ESD rehabilitation.
- 4) To identify barriers and facilitators to functional communication learning in ESD rehabilitation.

## 7.2 Ecology of the rehabilitation session

The researcher viewed and re-viewed all videos, making notes on the communicative ecology of the interactions, including: the participants involved in the interaction; the activities the participants were engaged in over the course of the session; the rehabilitation materials used; and the environment of the interactions. The researcher also noted the places and spaces within the environment where rehabilitation activities took place and the artefacts or materials within these contexts. Details of these focused viewings for each rehabilitation session observed are outlined in Table 17.

	Participants	Obs set	Video	Location of rehabilitation *	Activities	Materials; therapy items; focus of therapy	Time
PWA 1	PWA 1; HCP 2 (OT) & SLT	1	1	Kitchen & dining room	OT (making tea; discussion re. pain & medication; fine motor movement; and cognition)	Items needed to make a cup of tea (kitchen); medication box & list; Connect Four game	47 mins
	PWA 1 & HCP 14 (PT)	1	2	Sitting room; kitchen & stairs	PT (arm and leg)	PWA's hand; gesture & non-verbal communication to convey pain; pointing to parts of his body and answering Qs re. sensation; programme; moving in kitchen & stepping on stairs	49 mins
	PWA 1 & HCP 13 (RA)	1	3	Dining room table	PT (arm) SLT (comprehension)	PWA 1's arm; laptop & SLT programme sheets	30 mins
	PWA 1 & HCP 15 (AP)	2	1	Sitting room	Discharge plan; Discussion; SLT (picture naming)	Pre-discharge checklist; research information sheets; SLT picture sheets; programme	12 mins, 35 mins
Total							173 mins
PWA 2	PWA 2 & HCP 13 (RA)	1	1	Kitchen table	SLT (matching opposites; picture description)	SLT word sheets; Picture cards	10 mins 8 mins
	PWA 2 & HCP 13 (RA)	2	1	Kitchen table	Making a cup of tea; SLT (matching opposites; matching synonyms; semantic links)	Items to make tea	38 mins
Total							56 mins
PWA 3	PWA 3 & HCP 13 (RA)	1	1	Dining room table	SLT (writing task; speech sound repetition; comprehension – laptop)	Programme; Pen & paper; SLT sound lists;Laptop & SLT computer programme;	63 mins
					PT (arm movement) Discussion	PWA 3's arm	10 mins 2 mins
	PWA 3 & HCP 15 (AP)	1	2	Dining room table	PT (hand stretching)	Programme; PWA 3's hand	20 mins

## Table 17. Ecology of rehabilitation sessions and rehabilitation materials for each observed rehabilitation session

Participants	Obs set	Video	Location of rehabilitation *	Activities	Materials; therapy items; focus of therapy	Time
PWA 3 & HCP 16 (RA)	1	3	Sofa in the sitting room	SLT (speech sounds & comprehension on the laptop)	SLT sound list & mirror; programme; laptop & SLT programme	46 mins
PWA 3 & HCP 13 (RA)	2	1	Dining room; kitchen; hall & stairs	PT (limb movement; cleaning the table; walking & stepping)	Water & basin; tea towel; exercise ball; walking in PWA 3's house; stairs	55 mins
PWA 3 & HCP 16 (RA)	2	2	Dining room table	SLT (reading & repeating words; yes/no task)	Word list – families' names; word lists – nouns; questions	45 mins
PWA 3 & HCP 17 (AP)	2	3	Dining room table	SLT (word repetition – laptop; writing task; days of the week)	Laptop & SLT programme; word lists & mirror; days of the week; using the internet	38 mins
						279 mins
PWA 4 & HCP 4 (RA)	1	1	Dining room table	SLT (reading comprehension; naming; story elicitation)	Laptop & SLT programme; questions to elicit a conversation (from programme)	42 mins
PWA 4 & HCP 18 (RA)	1	2	Dining room table	SLT (reading comprehension; sentence reading)	Laptop & SLT programme; worksheets	47 mins
PWA 4 & HCP 12 (AP)	1	3	Dining room table	SLT (semantic categories; writing; reading aloud)	Programme; picture cards; paper to write; work sheet; word lists	55 mins
PWA 4 & HCP 12 (AP)	2	1	Dining room table	SLT (reading comprehension; writing to dictation; reading words)	Laptop & word list; categories (in programme); paper to write; naturalistic conversation	52 mins
						196 mins
PWA 5 & HCP 13 (RA)	1	1	Kitchen table	SLT (listening comprehension; reading passages)	Laptop & SLT programme; prescribed passage on sheet	53 mins
PWA 5 & HCP 12 (AP)	1	2	Kitchen table	SLT (naturalistic conversation; semantics and spelling)	Naturalistic conversation; programme; paper & pen; categories (from programme)	11 mins
						42 mins
PWA 5 & HCP 22 (OT)	1	3	Kitchen table	OT (functional assessment – rating scale; discussion on progress)	Naturalistic conversation; pen & paper & rating scale	59 mins
PWA 5 & HCP 12 (AP)	2	1	Kitchen table	SLT (categories & synonyms)	Naturalistic conversation; programme; paper & pen; worksheet with categories	49 mins
PWA 5 & HCP 12 (AP)	2	2	Kitchen table	SLT & OT (listening & memory task; categories)	Pen & paper; programme; prescribed paragraph; work sheet & categories	40 mins
	Participants         PWA 3 & HCP 16         (RA)         PWA 3 & HCP 13         (RA)         PWA 3 & HCP 16         (RA)         PWA 3 & HCP 17         (A)         PWA 3 & HCP 17         (RA)         PWA 4 & HCP 17         (AP)         PWA 4 & HCP 18         (RA)         PWA 4 & HCP 12         (AP)         PWA 4 & HCP 12         (AP)         PWA 5 & HCP 12         (AP)	Participants         Obs set           PWA 3 & HCP 16         1           (RA)         2           PWA 3 & HCP 13         2           (RA)         2           PWA 3 & HCP 16         2           (RA)         2           PWA 3 & HCP 16         2           (RA)         2           PWA 3 & HCP 17         2           (RA)         2           PWA 4 & HCP 17         2           (RA)         1           PWA 4 & HCP 18         1           (RA)         2           PWA 4 & HCP 12         1           (AP)         2           (AP)         2           PWA 4 & HCP 12         1           (AP)         2           (AP)         2           (AP)         1           PWA 5 & HCP 12         1           (AP)         1           PWA 5 & HCP 12         1           (OT)         2           (AP)         2           (AP)         2           PWA 5 & HCP 12         2           (AP)         2           (AP)         2	Participants         Obs set         Video           PWA 3 & HCP 16         1         3           (RA)         2         1           PWA 3 & HCP 13         2         1           (RA)         2         2           PWA 3 & HCP 16         2         2           (RA)         2         3           PWA 3 & HCP 17         2         3           (RA)         1         1           PWA 3 & HCP 17         2         3           (RA)         1         1           PWA 4 & HCP 17         2         3           (RA)         1         1           PWA 4 & HCP 18         1         2           (RA)         1         3           PWA 4 & HCP 12         1         3           (AP)         1         1           PWA 5 & HCP 12         2         1           (AP)         1         2           PWA 5 & HCP 12         1         3           (OT)         1         3           PWA 5 & HCP 12         2         1           (AP)         1         3           PWA 5 & HCP 12         2         1	ParticipantsObs setVideoLocation of rehabilitation *PWA 3 & HCP 1613Sofa in the sitting roomPWA 3 & HCP 1321Dining room; kitchen; hall & stairsPWA 3 & HCP 1622Dining room table (RA)PWA 3 & HCP 1723Dining room table (RA)PWA 3 & HCP 1723Dining room table (RA)PWA 4 & HCP 1711Dining room table (RA)PWA 4 & HCP 1812Dining room table (RA)PWA 4 & HCP 1213Dining room table (RA)PWA 4 & HCP 1213Dining room table (RA)PWA 5 & HCP 1213Dining room table (AP)PWA 5 & HCP 1212Kitchen table (AP)PWA 5 & HCP 1213Kitchen table (AP)PWA 5 & HCP 1221Kitchen table (AP)PWA 5 & HCP 1222Kitchen table (AP)	Participants       Obs set       Video       Location of rehabilitation *       Activities         PWA 3 & HCP 16       1       3       Sofa in the sitting room       SLT (speech sounds & comprehension on the laptop)         PWA 3 & HCP 13       2       1       Dining room; wither laptop)       PT (limb movement; cleaning the table; walking & stepping)         PWA 3 & HCP 16       2       2       Dining room table stars       SLT (reading & repeating words; yes/no task; days of the week)         PWA 3 & HCP 17       2       3       Dining room table       SLT (word repetition – laptop; writing task; days of the week)         PWA 3 & HCP 17       2       3       Dining room table       SLT (reading comprehension; naming; story elicitation)         PWA 4 & HCP 17       2       3       Dining room table       SLT (reading comprehension; sentence reading)         PWA 4 & HCP 18       1       2       Dining room table       SLT (reading comprehension; reading aloud)         PWA 4 & HCP 12       1       3       Dining room table       SLT (reading comprehension; writing to dication; reading words)         (RA)	Participants         Obs set         Video         Location of rehabilitation *         Activities         Materials; therapy items; focus of therapy           PWA 3 & HCP 16         1         3         Sofa in the sitting room         SLT (speech sounds & comprehension on the laptop)         SLT sound list & mirror; programme; laptop & SLT programme           PWA 3 & HCP 13         2         1         Dining room; stairs         PT (Inm browement; cleaning the table; walking & stepping)         Water & basin; tea towel; exercise ball; walking in PWA 3's house; stairs           PWA 3 & HCP 16         2         2         Dining room table stairs         SLT (reading & repeating words; yes/no task; days of the week)         Word list – families' names; word lists – nouns; questions           PWA 3 & HCP 17         2         3         Dining room table         SLT (reading comprehension; naming; task; days of the week)         Laptop & SLT programme; questions to elicit a conversation (from programme)           PWA 4 & HCP 4         1         1         Dining room table         SLT (reading comprehension; sentence reading)         Laptop & SLT programme; worksheets conversation (from programme)           PWA 4 & HCP 12         1         3         Dining room table         SLT (reading comprehension; writing to aloud)         Laptop & SLT programme; prescribed passage on sheet           PWA 5 & HCP 12         2         1         Dining room table         SLT (reading co

	Participants	Obs set	Video	Location of rehabilitation *	Activities	Materials; therapy items; focus of therapy	Time
PWA 6	PWA 6 & HCP 10 (OT)	1	1	Kitchen table	OT (memory activities – cards; picture; scanning activity)	Programme; playing cards; OT worksheets- scanning for letters & maze; picture (increasing level of the tasks by asking questions as a distractor)	35 mins
	PWA 6 & HCP 13 (RA)	1	2	Kitchen table	SLT (picture naming picture description; conversation); OT (solitaire)	Picture cards; laptop & solitaire	50 mins
	PWA 6 & HCP 17 (AP)	2	1	Kitchen table	Pre-discharge checklist; explanation of discharge plan; discussing trail. SLT (naming from picture description; writing)	Programme; pre-discharge checklist; information for research; Picture cards; objects from the environment; pen & paper	55 mins
	PWA 6 & HCP 17 (AP)	2	2	Kitchen table	OT (sequencing task – setting up a laptop & sequencing cards; solitaire). SLT (categories; picture naming; writing)	Laptop – solitaire; Sequencing cards; Picture cards; Pen & paper; Naturalistic conversation	51 mins
	PWA 6 & HCP 21 (nurse)	2	3	Kitchen table	6 month follow-up appointment (checking on wellbeing; need for community team; checking blood pressure (BP) & weight; discusses medication)	6 month follow-up checklist; weighing scales; BP monitor; leaflets	56 mins
Total							247 mins
PWA 7	PWA 7 & HCP 13 (RA)	1	1	Care home	SLT (reading comprehension) OT (scanning exercise; memory task)	Laptop & SLT programme; playing cards; OT worksheet – numbers & picture	71 mins
				Care home	OT (memory task and scanning task) SLT (picture naming and writing tasks)	Naturalistic conversation – using a calendar; OT (worksheets – numbers; picture cards; pen & paper	42 mins
Total							113 mins
PWA 8	PWA 8 & HCP 17 (AP)	1	1	Conservatory	PT (arm strengthening; fine motor practice; sensation) SLT (sequencing; writing task and numbers)	Programme; Theraband; jigsaw; items with different textures e.g. shell, soft cloth; pen & paper; numbers; sequence cards	56 mins

	Participants	Obs set	Video	Location of rehabilitation *	Activities	Materials; therapy items; focus of therapy	Time
	PWA 8 & HCP 17 (AP)	2	1	Conservatory	SLT (categories; writing sentences; reading out loud & numbers); PT (arm & hand strengthening; sensation)	Programme; naturalistic conversation; notepad; newspaper; Theraband; putty; programme list	49 mins
Total							105 mins
PWA 9	PWA 9 & HCP 12 (AP)	1	1	Dining room table & chair in sitting room	SLT (categories; auditory processing; writing)	Laptop & SLT programme; picture cards; pen & paper	42 mins
	PWA 9 & HCP 15 (AP)	1	2	Chair in sitting room	SLT (auditory processing; word associations; picture naming)	Laptop & SLT programme; picture cards	54 mins
	PWA 9 & HCP 20 (PT)	1	3	Chair in sitting room & kitchen	PT (stretching leg & foot; balance; walking; moving around the kitchen)	Splint; programme; leg stretching; walking in home environment with stick; arm stretching; balancing & moving in the kitchen	54 mins
	PWA 9 & HCP 20 (PT)	2	1	Chair, walking around the house & kitchen	PT (walking to the bathroom; discussion re. progress & falls; balance; leg & arm movement; shoulder taping removal; stretching)	Walking in the environment with stick; balance & movement in the kitchen; photos of exercise; arm & leg stretching	60 mins
	PWA 9 & HCP 12 (AP)	2	2	Kitchen, chair in sitting room	PT/OT (making a sandwich & tea) SLT (comprehension of paragraphs; reading paragraphs; word descriptions & writing; discussing programme)	Kitchen – items to make a sandwich & cup of tea	51 mins
	PWA 9 & HCP 18 (RA)	2	3	Sitting room, bedroom W/C & Kitchen	PT (walking bedroom to sitting room; getting into bed; leg stretching & strengthening; making a cup of tea; standing exercises)	Walking in the environment with stick; her bed; leg stretching; movement in bathroom; kitchen – balancing; items needed to make a cup of tea	53 mins
Total							314 mins
PWA 10	PWA 10 & HCP 12 (AP) (carer in the next room)	1	1	Sitting room, kitchen & bathroom	PT/OT (making a cup of tea; movement in the bathroom; walking) SLT (writing – name & address)	Walking in her environment with her frame; movement in bathroom; pad & pen	37 mins
	PWA 10 & HCP 18 (RA) (carer in the next room)	1	2	Sitting room, walks in hall of house	SLT (writing – name & address; alphabet; shopping list) PT (walking task)	Pad & pen; Walking with her frame	44 mins

	Participants	Obs set	Video	Location of rehabilitation *	Activities	Materials; therapy items; focus of therapy	Time
	PWA 10 & HCP 20 (PT)	1	3	Sitting room, bathroom & bedroom	PT (walking practice; transfer to & from the commode; discussion of movement difficulties & progress; revising programme)	Walking in her environment; commode; programme	46 mins
	PWA 10 & HCP 10 (OT)	2	1	Sitting room	OT (discussion about current difficulties using the commode; environmental adjustments needed & progress; memory assessment)	Discussion Formal memory assessment	53 mins
	PWA 10 & HCP 12 (AP)	2	2	Sitting room	OT/PT (discusses difficulties with ADLs; walking to the kitchen; making a cup of tea) SLT (picture description). Discusses rehabilitation plan	Walking in her environment; items needed to make a cup of tea Picture cards	51 mins
	PWA 10 & HCP 20 (PT)	2	3	Sitting room, bedroom, hall & kitchen	PT (discusses walking to the bathroom at night; getting in & out of bed practice; walking & turning in the hall; practising with new trolley on kitchen floor; revising goals	Discussion; walking in her environment with frame & trolley; her bed; programme	51 mins
Total					~		282 mins

\*Location=the PWA's own home unless otherwise stated

## 7.3 Collective influencing factors

The researcher kept a reflexive diary and field notes, in which she noted the collective influencing factors which may influence how interactions occur in the observed rehabilitation session. Further information on collective influencing factors, such as pressures and procedures of rehabilitation, was obtained through interviews with the HCPs and PWA. At the macro level all HCP–PWA interactions should be understood in the context of the NHS healthcare system in which they were produced. For example, time constraints and patient targets influenced how interactions could occur. The HCPs in the ESD team have a full daily timetable of visits, which could be in different parts of the county. HCP actions and practices were therefore inevitably influenced by the time needed to get to their next session, including driving time. These constraints could be further exacerbated by external influencing factors such as traffic or if sessions overran. Every session the HCPs had a certain number of activities or tasks from the programme that they needed to complete in a specific timeframe. This ESD team was also under human resourcing pressure, further influencing the time constraints and caseload pressures. Caseload numbers were unpredictable, fluctuating according to the number of people post-stroke discharged from inpatient rehabilitation and acute hospitals. Caseload numbers are further influenced by: the number of stroke cases in this particular NHS trust; recovery rates for individuals; and the address of the person being discharged from hospital, as the ESD teams work according to geographical area. As discussed in Chapter Four, this meant that one of the three ESD teams could be busier than the others at any one time; meaning that HCPs sometimes had to change teams. APs and RAs interviewed also reported that occasionally they would not have access to programmes prior to arriving at the PWA's house, which meant that they would have to read the programme when they arrived. This reduced the time the HCP and PWA could spend discussing or conversing.

The other collective influencing factor was the roles of the participants. The HCPs held the role of provider of rehabilitation, whereas the PWA's role was recipient of rehabilitation. These roles were expressed through: 1) the clothes worn: HCPs wore an NHS uniform and a lanyard, whereas PWA wore their own clothes; 2) the HCPs arrived to the person's house at a prescribed time, decided by the ESD administrator; and 3) the HCP's plan for the session and the materials they brought with them to use during the routine rehabilitation. Although the PWA was given an opportunity to contribute to goal setting and session planning, generally it was the HCP who would arrive at the session with a plan for the

session, rather than the PWA. The priorities of the two groups of participants were occasionally in stark contrast, with the goal of the HCP to complete tasks, whereas, the PWA were observed to want to speak about familial issues, difficulties they had been having with their aphasia, or engage in general naturalistic conversation. The HCPs and PWA did have a 'joint activity', to engage in stroke rehabilitation, towards a common goal of progress in rehabilitation. This goal influenced all interactions, which were observed and recorded.

The environment of the interaction was a collective influencing factor. All observed interactions took place in the person's own home, except for one which took place at a primary healthcare setting (six-month follow-up with PWA 6 and HCP 21 (nurse)). The homes differed in structure, size and geographical area, including both urban and rural settings. PWA 7 currently lived in a care home and all observations took place in her individual room. The materials also differed between and within sessions and included standard materials, for example checklists, technology (e.g. laptops), and the person's own environment, for example their kitchen. Further information on these details is set out in Table 17.

Finally, the presence of the researcher and the video camera had an influence on all the interactions and on the participants. The researcher therefore must be included as part of the ecology of the setting. As discussed in Chapter 4, the researcher took all reasonable measures to reduce the influence of both the researcher and the camera. From the interviews all participants reported that the rehabilitation sessions observed were representative of a regular session and that they did not notice the camera after the initial few moments in the first observation. Some HCPs discussed how they had been nervous at the beginning of the first session but these nerves subsided quickly.

- **15** *'Em I hate having my picture taken so, but you just have to block it out and just get on with it, you just relax after a while and just carry on as if it is not there. I didn't find it a problem'*
- **CS** 'Do you feel it impacted on how you did rehabilitation'
- 15 'No, not at all'

## 7.4 Individual influencing factors

Information on individual influencing factors was obtained from the interviews with both HCPs and PWA. The presence of aphasia was the most prominent factor influencing the interactions and was discussed by all participants. PWA presented with a range of types and severities of aphasia. As a result, the interactions were adapted to facilitate successful contributions from both communication partners, including the use of gestures, pen and paper for writing or drawing, closed questions or changing bodily position to aid lip reading. By adapting their communication to best suit the needs of the PWA, HCPs could remove barriers to full participation in rehabilitation. As discussed in findings from the interview data (Chapters 5 and 6), the extent to which the presence of aphasia influenced the interaction was different for each individual, depending on: individual personalities; attitudes; their individual emotions at the time of the interaction; the person's individual difficulties and co-morbid difficulties; the rehabilitation activity; rehabilitation materials; and their perspective on the rapport that had been established. The rehabilitation materials, collaboration, the environment and the amount of training the individual HCP received had an influence on the individual's emotions.

## 7.5 Influenced factors

The researcher viewed and re-viewed the video data, noting the overall structure of the rehabilitation session, including the purpose of tasks and the time spent on these tasks. The researcher also analysed how the themes that were produced through analysis of the qualitative interviews were enacted in the observations of routine rehabilitation. Although this viewing was oriented by the themes from the interviews, the researcher also noted conditions for learning or opportunities or barriers to learning that had not been discussed by participants.

### 7.5.1 Structure of the sessions

The structure of the session allowed the researcher to see how the macrostructure of the context of learning, the rehabilitation session, had been shaped by the influencing factors, collective and individual. The structures of the observed rehabilitation sessions were largely consistent across the observations, with a similar pattern and including similar components despite the range of different activities, professions and aphasia severities: greeting; naturalistic conversation or discussion, during which HCPs checked on the wellbeing of the PWA and discussed the plan for the session; instruction and orientation, where the HCP described to the PWA what was required of them in an activity or task; task, which included the rehabilitation tasks across the disciplines of OT, PT, SLT, and nursing; break and transition, which included the PWA taking a break between tasks or the HCP discussed the session, provided feedback, wrote notes and discussed the programme, i.e.

who would be visiting next; and goodbye. The components of instruction and orientation, task, and break and transition, repeated depending on the number of tasks or activities completed in a session. APs and RAs spent more time than the qualified professionals reviewing the programme and writing in their notes. In OT and PT sessions more time was devoted to discussing the difficulties the PWA was experiencing, checking and revising goals. This difference could be attributed to the OTs' and PTs' roles in personally developing and being responsible for the rehabilitation programmes. Levels of discussion or naturalistic conversation within sessions were more dependent on the particular HCP than the activity or the profession. In the interviews, HCPs 10 and 20 noted that conversation and discussion was not always appropriate when working with PWA who had co-morbid difficulties with attention, as conversation could be a distractor.

The structure and components of observed rehabilitation sessions with two PWA are set out below in Tables 18 and 19. Table 18 outlines the structure of the observed sessions for PWA 1, a gentleman who presented with severe aphasia, and Table 19 outlines the structure of sessions for PWA 5, a gentleman with mild aphasia. Table 18 and 19 also show the amount of time spent of each of these components. Severity of aphasia did not impact on the structure of a session; however, less time was spent with the gentleman with severe aphasia (PWA 1) in discussion or naturalistic conversation and there were more breaks where both the HCPs and PWA 1 remained in silence compared to the sessions with the gentleman with mild aphasia (PWA 5).

# Table 17. Structure of sessions from beginning to end: PWA 1

	Session 1 (OT)	Session 2 (PT)	Session 3 (RA)	Session 4 (AP)
Total time allocated to each activity per session	Discussion= (15 mins 40 secs) Task= (21 mins 25 secs) Naturalistic conversation= (1 min 30 secs)	Discussion= (9 mins 40 secs) Task= (34 mins) Programme= (2 mins 30 secs)	Discussion= (3 mins 30 secs) Task= (42 mins) Breaks (silence)= (45 secs) Programme= (30 secs) Setting up laptop= (30 secs)	Discussion= (11 mins 30 secs) Task= (28 mins 30 secs) Naturalistic Conversation= (4 mins 30 secs) Breaks (silence)= (2 mins 30 secs)
Beginning of session	<b>Discussion</b> re. carers (1 min)	<b>Discussion</b> re. pain & programme (1 min 30 secs)	Begins session –turns on laptop (30 secs)	<b>Discussion</b> – discuss materials (30 secs)
	Instruction(30 secs)	Task – hand movement & stretching – instructions HCP & PWA 1 hand movements (7 mins)	Begins task – arm exercises (4 mins 30 secs)	Introduces checklist (30 secs)
	<b>Begin task</b> (feedback on performance throughout) (2mins)	<b>Break</b> –discussion re. difficulties & progress (1 min)	<b>Discussion</b> – checks on wellbeing (30 secs)	Task – pre-discharge checklist (11 mins) Includes naturalistic conversation (3 mins)
	Break – as kettle boils – introduces new task	Introduction of new task– shoulder exercise (30 secs)	<b>Task</b> – shoulder blades (2mins)	<b>Discussion</b> re. research trial (3 mins)
	<b>Task</b> – discussion re. hemiparetic hand & arm lifting (2 mins 45 secs)	<b>Task</b> – shoulder movement (3 mins)	Break (15 secs)	<b>Discussion</b> – re. pain & programme – incl. 15 rings office to find out programme at PWA 1's request (7 min 30 secs)
	<b>Task</b> – PWA 1 initiates a return to the initial task by pointing to the kettle; <b>discussion</b> re. carers (3 mins 30 secs)	<b>Break – discussion</b> -re. pain (30 secs)	<b>Task</b> – arm movement (4 mins 15 secs)	Introduces new task (30 secs)

Session 1 (OT)	Session 2 (PT)	Session 3 (RA)	Session 4 (AP)
<b>Move location</b> from kit sitting room (1 mins 30	tchen to <b>Demonstration &amp; ne</b> ) secs) mins)	w task (2 Break – discussion re. wellb (30 secs)	eing Task – SLT worksheet (7 mins)
<b>Discussion</b> – re. pain & (10 mins)	medication <b>Demonstration &amp; ne</b> min)	ew task (1 Task – hand to mouth (3 mi secs)	ns 30 <b>Break</b> – PWA 1 looking for something, HCP 15 looking through programme (1 min)
Introduction– new tasl (1 min)	k Break – discussion re (30 secs)	e. next activity <b>Break</b> (15 secs)	Task – SLT worksheets (9mins 30 secs),incl. naturalistic conversation (1 min 30 secs)
<b>Task</b> – following a pen & <b>discussion</b> – re. field o (1 min 30 secs)	Looking for & lookin of vision programme (1 min 3	<b>g through Task</b> – arm movement (1 m 0 secs)	in) Closing session – 'right I think we'll call it a day for today'
<b>Discussion</b> – pain patch	h (30 secs) <b>Demonstrate &amp; new</b> (9 mins)	task-sensory Discussion re. difficulties & progress (1 min)	Packing up & writing up notes – no conversation (2 mins 30 secs)
Set up new task & disc impairments& progress Connect Four (1 mins 3	<b>cussion</b> re. <b>Discussion</b> re. practions re. practions of the set up difficulties (1min) 30 secs)	ce & <b>Task</b> – hand strengthening (	6 mins) Naturalistic conversation – re. grandchildren (1 min 30 secs)
Instructions for task(1	min) <b>Discussion</b> – re. what to do (30 secs)	he would like <b>Break</b> (15 secs)	<b>Discussion</b> – programme & next sessions (30 secs)
<b>Task</b> – game of Connec mins 30 secs)	ct Four (6 <b>Programme</b> – lookin programme sheets (2	g for <b>Task</b> – hand movement (3 n 1 min 30 secs)	nins)
PWA 1 gets cushion (3	0 secs) Putting on collar & co	uff (1 min) <b>Discussion</b> re. pain & progresses)	ess (30
Initiates new game(30	secs) <b>Programme</b> – lookin programme sheets (2	g for <b>Discussion</b> – re. next activity 1 min) 30 secs)	/ (1 min
<b>Task</b> – new game of Cor (4 mins 30 secs)	nnect Four Movement to kitche seconds)	en (30 Programme (30 secs)	
Naturalistic conversati win (30 secs)	ion about Discussion – re. prog secs)	ramme (20 Task – SLT (3mins)	

Session 1 (OT)	Session 2 (PT)	Session 3 (RA)	Session 4 (AP)
<b>Task</b> – new game of Connect Four (4 mins)	Task – standing exercises (10 mins)		
<b>Discussion</b> – re. progress, feedback on performance (30 secs)	<b>Discussion</b> – check re. wellbeing & difficulties (1 min)		
<b>Closing the session</b> –'we'll have to leave it there'	<b>Task</b> – stepping activities (1 min 30 secs)		
<b>Discussion</b> – re. activities & packing up material (1 min)	<b>Transfer</b> back to sitting room (30 secs)		
<b>Naturalistic conversation</b> – re. grandchildren (1 min)	<b>Discussion</b> re. difficulties, progress & placing PWA 1 in a good position (4 mins)		
<b>Discussion</b> – re. programme & sessions (30 secs)	<b>Closing the session</b> – 'I'll leave you to have a rest now'		
<b>Discussion</b> – re. medication & hand movement (2 mins 30secs)	<b>Discussion</b> programme & next session(1min)		
Discussion to practice (20 sees)			

**Discussion** re. practice (20 secs)

	Session 1 (AP)	Session 2 (RA)	Session 3 (OT)	Session 4 (AP)	Session 5 (AP)
Total time allocated to each activity per session	Discussion= (8 mins 45 secs) Task= (44 mins 45 secs) Naturalistic conversation= (4 mins) Programme= (2mins) Feedback= (30 secs)	Discussion= (4 mins 30 secs) Task= (51 mins30 secs) Naturalistic conversation= (0 min) Programme= (1 min)	Discussion= (28 mins) Task= (23 mins) Naturalistic conversation= (30 secs) Programme= (1 min) Feedback= (6mins) Explaining processes= (1 min)	Discussion= (3 mins) Task= (40 mins) Naturalistic conversation= (6 mins) Programme= (0 min) Feedback= (1 min)	Discussion= (2 mins 30 secs) Task= (30 mins 30 secs) Naturalistic conversation= (5 mins 30 secs) Programme= (0 min) Feedback= (1 min 30 secs)
Beginning of the session	<b>Naturalistic conversation</b> (1 min 30secs)	<b>Task</b> – SLT laptop (39 mins)	<b>Discussion</b> – re. difficulties & activities (6 mins)	Naturalistic conversation – news story (5 mins 30 secs)	Naturalistic conversation & discussion re. difficulties (5mins)
	<b>Discussion</b> – re. difficulties (7mins)	Discussion– re. progress (1 min)	<b>Task &amp;discussion</b> – PWA 5 retells news stories (4mins 30 secs)	<b>Discussion</b> – re. wellbeing & difficulties (2 mins)	Introduces task – listening task (1 min)
	Naturalistic conversation- with prompting from HCP 12 (2 mins)	<b>Programme</b> – discussing programme sheet (1 min)	Feedback – knowledge of performance & discussion on difficulties (2 min 30 secs)	Begins tasks –'what should we do today?'& looks through programme (2 mins)	<b>Task</b> – listening to paragraphs & answering Qs (7 mins)

# Table 18. Structure of sessions from beginning to end: PWA 5

Session 1 (AP)	Session 2 (RA)	Session 3 (OT)	Session 4 (AP)	Session 5 (AP)
Introduces task (30 secs)	Introduces task – instruction (30 secs)	Task &discussion- PWA 5 retells news stories (4 mins)	<b>Task</b> – writing words in a category (26 mins 30secs)	<b>Task</b> – same task new paragraph (5 mins)
<b>Task</b> – SLT writing categories with prompting from HCP 12 (38 mins)	<b>Task</b> – reading paragraphs & answering questions (12 mins)	Feedback – knowledge of performance & discussion on difficulties (2mins 40 secs)	Introduces new task – synonyms (1 min)	Feedback – knowledge of performance (1 min)
<b>Feedback</b> – on performance (30 secs)	Closing session – HCP 13 looks at phone to see time PWA 5 'Ding ding bell'	Introduces new task – rating scale (1 min 30secs)	<b>Task</b> – synonyms (10 mins 30 secs)	<b>Task</b> – same task new paragraph (10 mins 30 secs)
<b>Discussion</b> – re. wellbeing (15 secs)	<b>Discussion</b> – re. difficulties & packing up materials (3 mins 30 secs)	<b>Task</b> –completing rating scale (21 mins 30 secs)	Feedback – knowledge of performance (1 min)	Feedback – knowledge of performance (30 secs)
Introduces new task (15 secs)		<b>Discussion</b> re. programme (2 mins)	<b>Discussion</b> re. difficulties (30 secs)	<b>Discussion</b> re. difficulties (1 min)
<b>Task</b> – SLT synonyms incl. prompts from HCP 12 (6 mins)		Discussion re. difficulties &feedback & progress (6 mins)	<b>Closing task</b> –'brilliant shall we leave it there for today?'	Introduces new task & looking through programme (1 min)
Naturalistic conversation- re. gardeners (30 secs)		<b>Programme</b> – revising programme (1 min)	<b>Discussion</b> re. session (30 secs)	<b>Task –</b> writing categories (6 mins)

Session 1 (AP)	Session 2 (RA)	Session 3 (OT)	Session 4 (AP)	Session 5 (AP)
Closing session –'well I		Discussion re. difficulties	Naturalistic conversation	Closing –'I think then
think probably that will be		(5 mins 30 secs)	(30 secs)	we'll probably have to
enough for today'				leave it there'
		Foodbook Incontation of		Discussion un difficultion
<b>Discussion</b> re. sessions &		Feedback – knowledge of		Discussion re. difficulties
feedback on performance		performance & progress		
(1 min 30secs)		(1 mins)		(1 min 30 secs)
 Programme – discuss next		Explaining practice to		Naturalistic conversation
sessions (2 mins)		PWA 5's wife (1 min)		(30 secs)
		Closing session –		
		feedback (30 secs)		
		Naturalistic conversation		_
		(30 secs)		

## 7.6 Influenced factors – Enactment of interview themes

### 7.6.1 The physical environment

Analysis of the observational data showed how the home environment produced conditions for learning. The environment acted more as a facilitator than a barrier to learning with only one barrier identified, distractions from family members or domestic appliances, for example the washing machine. The environment consistently created opportunities for personally meaningful practice with PWA 1, PWA 6, PWA 9 and PWA 10 all completing functional movement tasks using the spaces within their own environment, such as their kitchens, bedrooms and bathrooms, in the majority of their sessions. For example, the HCPs used the home environment to practise walking, in one instance asking the PWA to walk from their chair in the sitting room to the bathroom and back and in other session PWA 1 and PWA 3 used the steps in their home to practise stepping independently. By practising these tasks in the PWA's own environment, HCPs and PWA were able to identify issues that could arise for the PWA and could cause problems for them if they were alone. For example, during a PT session the PT (HCP 20) asked PWA 9 to walk to her bathroom and go through the movements that she needed to master using the toilet in the bathroom. This was one of PWA 9's main rehabilitation goals. During this task HCP 20 noticed that PWA 9 found it difficult to turn to get the toilet paper. As a result, the toilet paper was moved to an easier position and the turning movement needed for that task and to flush the toilet became a rehabilitation goal.

The PWA, rather than the HCP, appeared to be more in control of the rehabilitation session in their own environment. PWA 1 stopped the rehabilitation activity to turn down his television; PWA 3 showed the HCP where the plug was to plug in the laptop; and PWA 6 made the HCP aware that she had not turned the switch on at the wall to power the plug. Despite mobility issues PWA 1 got out of his chair to help HCPs 14 and 15 look through sheets and programmes and find what they were looking for. PWA 1 was observed to take control during a 'making tea activity' in his kitchen, by offering everybody in the room a cup of tea (including the researcher) when asked to make one by HCP 2 as part of his rehabilitation.

### Excerpt 1: HCP 2 and PWA 1 making tea activity (0.00-0.25)

- 1 HCP 2 Have a think about what you are doing here
- 2 PWA 1 ((takes one cup down from the cup stand))
- 3 PWA 1 [((opens the tea caddy))] [Oi]
- 3 PWA 1 ((turns and points to HCP 2))
- 4 HCP 2 [((points at PWA 1))]
  - [just one for yourself]
- 5 PWA 1 ((points over his shoulder at the researcher))
- 6 HCP 2 No just for you

The environment acted as a springboard and a scaffold for conversation. The PWA's personal and physical environment was a rich source of information about the PWA. This information was used by HCPs visiting the PWA's home to begin conversations with the PWA. For example, PWA 3 had a canvas picture of her family hanging on the wall, which HCP 15 used as a scaffold to discuss PWA 3's family. Having a visual prompt meant that HCP 15 could point to the people in the picture, and this also supported PWA 3 to respond to this initiation, removing communication barriers. PWA 10 often looked from her chair towards her garden, which was filled with flowers, bird feeders and different birds. Throughout PWA 10's rehabilitation sessions, HCPs were observed discussing the different elements in her garden, leading to naturalistic conversation and discussion. On seeing an incomplete jigsaw on a table HCP 17 asked PWA 8 how he was succeeding with it. This led to a conversation about his rehabilitation and the progress he was making with his fine motor skills. The environment could act as an icebreaker to begin more conversation on wider topics and continue a naturalistic conversation. For example, at the end of a rehabilitation session during the 'closing' phase, HCP 13 and PWA 2 were sitting side by side at the kitchen table, looking out on PWA 2's pond. HCP 13 had tidied the rehabilitation materials and both HCP 13 and PWA 2 started drinking their cups of tea, which had been prepared at the start of the session. PWA 2 initiated and began to tell a story about living in the country and hunting. This conversation was continued by PWA 2 when he asked about HCP 13's birth country, which HCP 13 responded to.

## Excerpt 2: HCP 13 and PWA 2 – talking about the ducks on the pond (1.16)

1	PWA 2	We had four little ducklings out there about a month ago probably
2		O no there were 6 of them and now there are only 3 left
3		And yesterday morning three more little ones hatched
4		And this morning there's none there
5		I don't know what's eating them up
6	HCP 13	Yea
7		They might have gone for a wander
8	PWA 2	No they wouldn't go too far
9	HCP 13	They'll come back
10	PWA 2	No I don't think they will
11		They are only little baby ones so I think they will have had it
12	HCP 13	Is there any foxes around here
13	PWA 2	What any cats and things
14	HCP 13	Fox foxes
15	PWA 2	O well could be? Could be
16		I haven't seen any
17	HCP 13	Do you like hunting
18	PWA 2	Me? No no
19	HCP 13	No? why have you got the horn there

The home environment enabled PWA 1 to respond to the question 'what age are your grandchildren' as he was able to move into his sitting room and find a picture of them. He brought the picture back to the HCPs, who commented 'O very young'. This allowed the matter of his grandchildren to be topicalised and the conversation to continue. This was instrumental in facilitating the continuation of a naturalistic conversation.

The environment also acted as a prompt to PWA 5 and PWA 10 in a therapy task, where they were required to name items in a category (as many types of flowers as they could). PWA 5 could be observed to look around his home, and PWA 10 out to the garden, for prompts to help them in their naming task. This strategy benefited both PWA and they completed the task successfully.

Both PWA and HCPs appeared relaxed during rehabilitation in the home environment. For example, PWA could sit back comfortably in furniture that they preferred, such as their armchair; PWA and HCPs were often observed drinking tea, which framed the interactions in a relaxed, non-clinical way.

### 7.6.2 Materials

Consistent with the results from the interviews, materials were observed as both a facilitator and a barrier to learning. Physical objects were often used by PWA to provide context to and 'scaffold' conversations. For example, PWA 1 was observed to stand up and find his pill organiser. He picked it up and brought it back to where HCP 2 was sitting and used this to provide context to a question he wanted to ask her. This initiation was successfully responded to by HCP 2 and this led to a 10-minute discussion focused on pain and medication, something which was both important for PWA 1 to understand in order to put him at ease, but also medically very important to ensure that he took the correct medication at the correct times.

Standardised materials such as picture cards could also act as a facilitator for naturalistic conversation, providing the PWA and HCP with a topic to begin a naturalistic conversation. For example, in response to a picture card of a car which was being used in a naming task, PWA 7 told HCP 13 a story about going for drives with her late husband in their old car, subsequently sharing that she never drove. Materials such as pen and paper also acted as a scaffold to support communication for some PWA, although these were not appropriate for all PWA.

Materials also signified a change from one component of the rehabilitation session to another within the structure of the rehabilitation sessions. In all observations materials were used by HCPs to show that a task was beginning, changing or ending. For example, the HCPs would open the rehabilitation programme to change from the greeting and discussion components at the beginning of the session to begin the task-based components. Materials were observed to make the distinction between 'chat' time and 'work' time. When a rehabilitation activity was coming to an end or the HCP wanted to change task, they were observed to put the sheets that were being used in the current activity in a pile or tidy them away. They were then observed to take new materials out into view and begin to organise them, which conveyed that a new task would soon begin. When materials were removed from the PWA, it could even indicate that the session was over. This method of 'material movement' could also exert the HCPs' control of the rehabilitation session. For example, on one occasion the HCP removed the worksheet which had been the focus of the task from PWA 5's view, even though he was still thinking through the answers to the questions. This indicated to PWA 5 that the session was over and that HCP 13 wanted to close the session.

Programme reviewing and note taking by HCPs acted as a barrier to communication between the HCPs and PWA. These activities were usually conducted by HCPs in the planning and orientation phase of the session, at the start; while transitioning between tasks; and/or at the tidying up and closing down of the session, at the end. During the phases of the session, where the PWA was not engaged in a task, they were more likely to initiate a discussion or naturalistic conversation. As a result, the desires of the two participants were in conflict and a barrier was created to conversation. This was observed through moments of silence, no response being made by HCP to initiations by PWA, or oneworded replies from HCPs to initiations but no further follow-up. For example, in a session with HCP 15 and PWA 1, HCP 15 is kneeling beside PWA 1 while conducting a naming task with the worksheet held in joint view. On completion of the rehabilitation task, HCP 15 moves to the sofa opposite PWA 1 and tidies up the worksheets. This signifies the transition from the 'task' phase to the 'closing the session and tidying up' phase. During this time HCP 15 shifts her gaze towards the programme and begins writing in the notes. PWA 1 initiates and these initiations are not responded to, resulting in a period of extended silence and an opportunity for conversation missed.

## Excerpt 3: HCP 15 and PWA 1: closing the session (30.27–32.25)

1	HCP 15	Right I think we'll call it a day for today shall we?
2	PWA 1	((shrugs shoulder))
3	HCP 15	You'll have to put up with me again next week
4	PWA 1	Yea
5	HCP 15	[((laugh))}
		[((Tidies up worksheets and stands up))]
6	PWA 1	[000]
		[((scrunches up face))]
7	HCP 15	It's tiring isn't it
8		((stands up and moves to sofa to sit down))
9		((takes out rehabilitation notes))
10	PWA 1	((raises index finger in the air))
11		((looks down the side of his chair ))
12	HCP 15	Just making a note of what we've been doing
13	PWA 1	((lifts up his iPad and opens the cover))
14		((presses button on iPad and nothing happens))
15		000000
16		((presses button on iPad and the iPad makes a peculiar noise))
17		N000000
18	HCP 15	(0.20) [((HCP15 is writing notes in the programme))]
	PWA 1	[((PWA 1 is swiping the iPad and pressing the button))]

19	PWA 1	[000000]
		[((swiping at IPad))}
20	PWA 1	[there]
		[((opens the locked screen and begins scrolling))]
21	PWA 1	[yea]
		[((points at the iPad screen))]
22	HCP 15	((continues writing notes))

In other sessions HCPs did attempt to respond to the PWA's initiations in these breaks, but it was observed that HCPs would use one-word answers or 'fillers' such as 'mmmm' and 'o yea' to respond to the PWA while their gaze remained on the sheet. Due to the dual attention needed by the HCPs at these times, i.e. trying to respond to an initiation while writing in notes or looking at the programme, it made it difficult for them to continue conversations with the PWA. At other times it meant that the PWA would remain in silence looking around the room, waiting for the HCP to complete their task. In one instance, while HCP 15 completed a checklist, PWA 1 was observed shifting his gaze to the television and watching a programme in-between checklist questions, when the HCP made note of his answers to the checklist. The gaze needed by the HCPs to view the programme and write notes also meant that non-verbal initiations, particularly those made by people with severe aphasia, were occasionally not seen or responded to. For example, PWA 9 shook her fist while completing an SLT activity on the laptop, an action which was missed by HCP 12, who was writing in her notes at the time. Although writing in the notes is an integral part of the role of the HCP, they rarely explained to the PWA why they were doing this and there were times where the HCP would disengage from a conversation to begin writing with no accompanying explanation.

Laptops and computer programmes acted as barriers to learning opportunities. Two PWA spoke in the video-recorded sessions of not liking the laptops, with one PWA commenting on how long they took to set up. The laptops were observed to be slow to set up and in all sessions where a laptop was used, up to 6 minutes was spent setting it up. PWA often spent this time sitting in silence, while the HCP turned the laptop on, plugged it in to charge, inserted the multiple passwords needed, opened the computer programme and set it to the level needed. Laptops were observed to be prone to technical difficulties, 'freezing', beginning to configure and/or running out of battery power. PWA 6 was provided with a laptop to use for home practice. At the beginning of his next session with HCP 17, when she asked how laptop practice had gone, he reported that his laptop had gone 'up the

creek'. This meant that the HCP spent extra time at the beginning of this session fixing the computer.

Computer programmes were observed in sessions to provide feedback on knowledge of outcome, with just two sounds played; one for a correct and one for an incorrect answer. The noise made for an incorrect response was disheartening for PWA, with PWA 7 repeatedly saying, 'o crumbs', and PWA 9 responding to the noise with 'God o dear'. PWA would be visibly upset when they heard this negative noise, screwing up their faces and on one occasion crying. This feedback was not productive as the PWA was not informed where, how and why they were wrong. At the end of a computer programme level the computer would say 'brilliant'. PWA were observed to respond badly to this when they knew that they had found a level difficult, with PWA 4 responding on one occasion, 'I don't blooming think so'. PWA and HCPs also found the pictures on the computer programmes confusing and sometimes misleading. Across the observed sessions 17 instances were noted by the researcher where either the PWA or HCP reported that pictures on computer programme; or the programme used American terms, which were not understood.

PWA and HCP also described materials, such as computer programmes and picture cards, as repetitive. On a number of occasions, in the observed sessions, the HCP or PWA would comment on the number of times they had completed the same task or had used the same materials. For example, PWA 5 was observed telling HCP 13 that he was doing the same computer programmes and levels as he had done in his previous sessions; PWA 8 told HCP 17 that he had seen all the picture cards for naming tasks and sequencing cards before. In fact, HCP 17 was aware that PWA 8 had already used the sequence cards and said in one session, 'you probably know these all by heart'. PWA 8 responds 'it's just things, it's nothing', clearly conveying that the task was no longer engaging or motivating for him. PWA 4 said in one session that he was doing well on tasks only because he had already completed them.

### Excerpt 4: HCP 6 and PWA 4: repetitive materials (5.20–5.54)

1	Computer	Ding (noise made in response to a correct answer)
2	HCP 6	You are doing very well at these
3		Very good
4	PWA 4	Well I've done it before ((laugh))
5	HCP 6	Have you done this one before
6	PWA 4	Yea

Materials could also act as a barrier when they perpetuated a PWA's co-morbid difficulties. PWA 7 noted that the font was too small on paper-based worksheets, as her vision was poor, for example worksheets used for scanning (circling a particular number or letter from a paragraph of many numbers and letters) and word lists used for naming. Line drawings were also observed to be difficult to interpret for some PWA, who reported that they achieved more success with real objects. For PWA 9, actual photographs of her doing her exercises aided her memory and were easier for her to follow than line drawings. The photographs had been developed by the SLT and introduced to PWA 9 by the PT. PWA 9 reported in one observation that she remembered to practise her physiotherapy exercises more between sessions now that she had the photographs.

The personal meaning and relevance of activities involving OTs and PTs was more apparent than those involving SLT activities. This was evidenced in the observational data through use of the physical environment and use of materials that were already available in the home, for example the person's kitchen. As discussed in more detail in the 'environment' section, OT and PT rehabilitation materials included: the PWA's bed; the bathroom; walking in their home; stepping on the stairs; and making a sandwich and/or cup of tea in the kitchen. In contrast, the researcher observed that for SLT activities standardised and formal materials were often brought with the HCPs to the person's home, such as laptops and picture cards. Fewer materials readily available in the home were used compared to OT and PT activities. On the few occasions the HCPs did use materials from the home that were more personally meaningful, in SLT activities, the PWA responded well by smiling and laughing. On these occasions the PWA also made attempts to initiate conversation, telling the HCP more about the personalised item. For example, when 'Liverpool' was included as a target word in a naming task for PWA 1, PWA 1 turned towards a signed Steven Gerrard jersey and began to point at it, and when family names were used as naming targets for PWA 3, she began to tell a story about one of her family members. These initiations were responded to by HCPs but were not followed up further to begin a conversation on the topic. Task completion was prioritised over following up on these initiations. This occurred in one instance, and later in the same session PWA 4 tried to initiate a naturalistic conversation. He had begun to talk during the task about not being able to go as far into the town as he would have prior to his stroke. HCP 6 replied 'OK' and continued with the naming task. Later in the same session, she tried to elicit a naturalistic conversation using the question 'can you tell me the most embarrassing moment you've ever had?' This abstract unfamiliar question was confusing for PWA 4. Due to confusion, HCP 6 had to ask a second question: 'tell me about a time you were on holiday?' to elicit conversation.

#### Excerpt 5: HCP 6 and PWA 4 eliciting naturalistic conversation

1	HCP 6	So we are just going to finish with one more activity if that is OK with
		you
2	PWA 4	Hmm ahh
3	HCP 6	OK can you tell me the most embarrassing moment you've ever had
4		(.) In your lifetime
5		Can you think of something
6	PWA 4	Oooooo (xxxx) as a kid ((laugh))
7		(0.3) I don't know (0.5) I don't really know (0.06)
8		Emmmmm (0.3) o God (0.4)
9		I'd like to bleeding tell you but I am not going to
10	HCP 6	((laugh)) So there is nothing
11		What about emm holidays
12		Can you remember one of your first holidays
13		Can you

These prescribed stimuli questions were observed to be used by the HCPs to elicit a naturalistic conversation and were often met with confusion as they were not personalised or individualised and were not questions you would be asked regularly in daily life. In contrast, when PWA 5, who had a keen interest in current affairs and who had lived in many countries, was asked by the OT to discuss topical news stories from the newspaper as part of his rehabilitation session, he spoke for over 15 minutes about the case of an unarmed black teenager being shot by police in Ferguson, USA, terrorism in Kenya, and a cricketer being hit by the ball under his helmet (stories which were in the news at the time the session was observed). PWA 5 said after this conversation that, 'It seems to be if I've got something that's already experienced by me ahhh in the same sort of subject or interest, that interests me already it gets easier'.

It was observed that HCPs stuck strictly to the programme despite there being opportunities to make activities more salient. HCP 17 asked PWA 6 to name as many sports as he could in one minute, despite him telling her immediately prior that he did not like sport.

### Excerpt 6: HCP 17 and PWA 6 tailoring sessions to PWA's interests

- 1 HCP 17 Are you a sports fan?
- 2 PWA 6 No
- 3 HCP 17 Can you name some sports please

PWA 6 was observed to have great difficulty with this task, naming only three sports in a minute, and he needed prompting from HCP 17 to provide the three answers. In the middle of this activity he repeated again that he did not like sport during the next task. HCP 17 then changed the topic of the task and asked PWA 6 if he watched TV. PWA 6 responded that he watched TV nightly. When asked to name as many TV programmes as he could in a minute, he had much better outcomes than with the topic of sport. In another session, this time involving HCP 17 and PWA 8, the same task (naming as many items in a category as you can in one minute) was observed. On this occasion, however, the topic was tailored to PWA 8's interests (whose previous occupation was a dentist), with HCP 17 asking PWA 8 to 'name as many things as you can that you would find in a dentistry surgery'. This activity was clearly more meaningful for the PWA, as he engaged fully in the activity by naming over 15 items in the minute and laughing throughout.

## 7.6.3 Control and collaboration

Although HCPs reported in the interview data that they felt that the PWA had more control of the rehabilitation session in their home environment, it was observed that session structure was largely in the control of HCPs. The HCP was the main contributor to the session, holding the floor with more communicative turns per session. The HCPs were observed to introduce each of the phases of rehabilitation session: the HCPs would ask how the PWA had been since their last session; introduce and explain tasks; ask questions in tasks and activities; provide guidance for tasks; give feedback on outcome and performance; explain the procedures and plan for the next session; and close the session according to their timeframe and plan. HCPs did topicalise PWA initiations by responding and following up appropriately but this mainly occurred during the 'opening up' or 'closing down' sections of the session, before or after 'task'-based activities. Once the first task of the session began, HCPs would respond and follow up inconsistently to the PWA's 'off-task' initiations. This could act as a barrier to learning, reducing the PWA's opportunities for communicative practice and was occasionally observed to increase negative emotions for PWA, as they became frustrated and upset. However, when these initiations were responded to and the communicative floor was given to the PWA, the HCPs often uncovered useful information for the rehabilitation session. For example, when HCP 12 responded to a non-verbal initiation made by PWA 9 by following up with another question, she discovered that due to a miscommunication PWA 9's new carers had not come at lunchtime and therefore PWA 9 had not eaten since early morning. HCP 12 responded to this by saying that she would ring them and make sure it would not happen again.

Genuine collaboration, however, was a facilitator of learning, engaging and motivating the PWA. Genuine collaboration was developed by asking the PWA their preference for activities in a meaningful way. This was observed through HCPs changing programmes, adapting and being flexible in sessions in response to PWA's wishes and their goals for rehabilitation. For example, the PT (HCP 20) had planned in the rehabilitation programme to work on transferring from bed to commode. In response to PWA 10 telling her how much she disliked using the commode and how she had found a use for it as a 'place to put her coffee', PWA 10 and HCP 20 had an active discussion about rehabilitation goals. The rehabilitation goals were revised from moving from bed to the commode to moving from the chair to the bathroom and getting in and out of the bed. HCP 20 also followed this up with a referral to the continence team. On four occasions in the observed sessions, HCPs were not prepared for occasions when the PWA said 'no' to an activity. For example, when PWA 10 told HCP 18 that she did not want to practise her bed exercises, he had to return to the programme to replan the session.

### Excerpt 7: HCP 18 and PWA 10 declining an activity

1	HCP 18	Are you happy to do your bed exercises
2	PWA 10	No (laugh)
3	HCP 18	(laugh)
4	PWA 10	I've done all those
5	HCP 18	OK fine
6	PWA 10	You see what I mean you do them
7		I don't not carry on after you've been
8		I still carry on with them
9	HCP 18	[yea]
10		[((begins looking through rehabilitation programme))]
11	PWA 10	It isn't as if you come today and I don't do them anymore

		I do
12	HCP 18	Mmm hmm
13	PWA 10	That's why you can see the muscles in my legs
14	HCP 18	((looks through programme and moves sheets))
15	PWA 10	But likewise=
16	HCP 18	=it's OK if you are not happy to do them it's OK
17		[you can finish your cup of tea]
18		[((looks at programme))]

HCPs were observed being inflexible with rehabilitation activities and programmes and shutting down opportunities for collaboration. On another occasion, PWA 8 told HCP 17 that his problems are 'with verbal not writing' but the HCP continued with the writing task. HCPs also could be persistent to obtain a perceived 'right answer' in a task. For example, when PWA 4 was asked to name 'types of wood', PWA 4 began to self-prompt for the word 'maple' by saying 'In Canada, red, on the Canada flag'. At the same time, HCP 6 starting prompting him for the word on her task sheet, saying, 'it's quite an expensive wood, begins with a C, it's red in colour', eventually telling him, 'it's cedar wood'. This 'holding of control' through prior knowledge was observed for another HCP who corrected PWA 6 when he was telling a story about his past occupation. PWA 6's wife had previously told HCP 13 the story, resulting in HCP 13 telling PWA 6 the story of his past occupation, which meant that PWA 6 stopped talking and engaging in the activity.

HCPs exerted control over the rehabilitation session and activities through their discourse. For example: they would signify the end of activities with statements such as 'shall we take a little break'or 'take a break and relax'. Discourse markers such as 'OK' and 'Okie dokie' were used at the end of informal conversations and discussions to bring the PWA back to the task; at the end of sessions they would initiate closure with a statement, such as: 'I think we'll leave it there for today'. Once, in a joint session, the HCPs discussed PWA 1's progress between them rather than including him in the conversation, referring to PWA 1 in the third person: 'he is doing well though'.

HCPs also demonstrated control of the session through their positioning of materials. As discussed, rehabilitation tools were observed as a key way of showing transitions between phases of the rehabilitation sessions and these materials were often kept under HCP control. HCPs would often keep the materials in front of them in a position that was not visible to the PWA, therefore not sharing the information or enabling it to be discussed collaboratively. For example, HCPs were often observed to position the rehabilitation

programme directly in front of them and flick through it, while the PWA sat at a different angle at the table, meaning they would have to move position to see it. In contrast, there were instances when the HCP collaborated with the PWA by placing the programme or instructions where both participants could see it, or by giving the programme to the PWA for them to choose the activity. Occasionally the HCP was observed to share the control of the session with the PWA through joint decision making regarding the rehabilitation session. Incidences were observed where the HCP would choose the task but asked the PWA what activity they wanted to complete first. This was evident on an occasion when HCP 12 provided PWA 5 with a list of categories and asked him to choose which one he wanted to do first. Joint collaboration, through sharing decision making, was not always exercised meaningfully. The HCPs could ask the PWA what activity they wanted to do, but already had the materials out on the table, set up and ready for an activity they had chosen to do, which exerted the HCP's control. On all occasions, the PWA agreed with the activity the HCP had chosen.

Inviting the PWA to discuss the plan for the session, possible activities and explaining why the HCP wanted to complete certain activities were observed to facilitate collaboration. For example, HCP 12 asked the PWA if they were happy to start the session and offered to change the activity when she noticed negative non-verbal reactions from the PWA that showed that the PWA was not enjoying the activity. This particular HCP also started each activity by telling the PWA to tell her if they wanted to stop an activity. The use of 'we' was observed to be used by many HCPs, which enabled collaboration, for example 'what are we going to do next' and 'shall we begin' as it gave a sense of joint ownership of the session.

Occasionally in the observed sessions, the PWA took control of the session by providing the HCP with an instruction, for example to get their glasses or to close a door. On three occasions only, PWA challenged the HCP's decision to close the session by communicating that they wanted to keep the session going: PWA 9 replied 'one more' when HCP 15 asked her 'do you want to do finish'. PWA 5 initiated by taking control of the materials by asking HCP 22 to 'hang on' when a sheet was being removed from the joint line of sight. He took the sheet back so he could read it himself. In another instance, PWA 5 took control of the activity by asking HCP 13 if he (PWA 5) could click the mouse, when HCP 13 was doing this for him.

### 7.6.4 Clarity, feedback, processes

As has been outlined in the background of the systematic review (chapter 2) there are essentially two forms of feedback: knowledge of outcome and knowledge of performance. HCPs were observed to regularly use feedback to provide knowledge of outcome in response to the PWA's answer, for example 'good', 'brilliant' and 'well done'. This was also used to motivate the PWA through use of praise. This form of feedback was mainly used in a question, answer, feedback sequence, as part of a rehabilitation activity, such as asking the PWA to lift their leg; when the PWA lifted their leg, the HCP would say 'well done' and repeat this sequence throughout the activity.

Detailed, accurate and explicit feedback, providing the PWA with knowledge of their performance, was observed to function as a facilitator of learning. This form of feedback visibly enhanced PWA's emotions, causing them to smile or look more relaxed. HCP 12 would end most sessions by providing the PWA with information on their performance, areas where they had difficulties and how these difficulties could be improved, ending with areas in which they progressed. This was observed to be appreciated by the PWA, as they smiled and thanked her repeatedly at the end of sessions. In contrast, untailored feedback increased PWA's negative emotions. As discussed in the rehabilitation materials section, instances were observed when the computer program said 'excellent' at the end of an activity, when the PWA had been unsuccessful and this frustrated PWA who responded, 'I don't blooming think so'. PWA 7 was also aware when a HCP was providing her with untailored feedback, when at the end of a session she began to tut and screw up her face in response to HCP 13 telling her that she had 'done good', when in fact she had little success in the session and was aware of this.

Prompts and feedback on performance became more specific as the rehabilitation block went on, when the HCP had developed a rapport with the PWA and was more aware of the PWA's difficulties and particular needs. For example, HCPs frequently empathised with the PWA when they knew that they were completing a task they found difficult. At the end of and activity HCP 17 told PWA 3, 'that was good, I know you find these difficult'. HCPs would also gesture, use pen and paper to write or provide speech sound cues (phonemic cues), for example 'b' to prompt the word 'ball', depending on what the HCP had found was useful in a previous session. In another instance HCP 6 encouraged PWA 4 in a reading task that he found difficult by saying, 'It's just having that time to read through them, isn't it?' Rarely, instances were observed where the HCP interrupted the PWA, did not provide them with enough time to say what they wanted to say and repeated target words in naming tasks louder each time the PWA was unsuccessful with the target rather than prompting. For example, in a reading task, a task which PWA 4 found most difficult, he was unsuccessful at reading the target word. After the first unsuccessful attempt, HCP 18 says the target word, PWA 4 attempts the word again and HCP 18 interrupts his attempt to say the word again but louder. PWA 4 says the target word and the task continues. PWA 4 later says 'boy' instead of 'man' (a semantic error) to which HCP 18 replies 'look at the picture properly'. This continues until PWA 4 became frustrated conveyed through discussing how bad the pictures are describing them as 'dam things' and saying 'bloody' repeatedly; HCP 18 begins to laugh nervously.

### Excerpt 8. HCP 18 and PWA 4: prompting

PWA 4	The boy is wa?
	The boy is wash? Eh ehh ehh
	I've got the boy is bawsh ba ba b b
HCP 18	Washing
	WASHING
PWA 4	The boy is bosh ba=
HCP 18	=washing ((points at the word with his pen))
PWA 4	Washing the boke
	The boy is boshing
HCP 18	[WASHING]
	[((points at word with his pen))]
	WASHING
	WASHING
PWA 4	The boy is washing boy washing and a bike
HCP 18	That's good
	PWA 4 HCP 18 PWA 4 HCP 18 PWA 4 HCP 18

Explanations of upcoming tasks could act as a facilitator or barrier to learning depending on the clarity of the explanation. Some HCPs were observed to consistently explain the purpose of an activity before it began and this was part of the structure of the sessions. For example, HCP 12 would begin most sessions by explaining the full session and checking that the PWA was happy with this plan. Other HCPs, however, did not always explain to PWA the reasoning for the rehabilitation activities before beginning them. For example, on one occasion the HCP explained to PWA 1 what the task was and its purpose five minutes into the activity. There were instances, particularly with physiotherapy movement exercises, where activities moved quickly and where instructions for each task were not delivered
clearly. This often occurred in tasks with only ten repetitions of a movement before moving to the next exercise. On these occasions PWA were observed to look confused. For example, while completing a physiotherapy leg movement exercise, lying on the bed, PWA 9 stopped HCP 18 to ask him what they were doing during the activity. In the same session she was later observed sitting on the edge of the bed and throwing her eyes towards the ceiling as she was being rushed through activities.

#### Except 9. HCP 18 & PWA 9: unclear instructions

1	HCP 18	And rest		
2	PWA 9	((Lies back in her bed))		
3	HCP 18	((picks up programme))		
4	HCP 18	We are going to do the next one		
5	PWA9	What is the next one		
6	HCP 18	[Are you ready]		
7		[((puts programme back on the bed))]		
8	PWA 9	[what is the next one like]		
9		[((points at the programme))]		
10	HCP 18	Right the next one		
11		[you need to bend this one]		
12		[((lifts PWA 9's knees))]		
13		Put your hands to the side		
14		And try to move your bottom up		
15	PWA 9	O right OK		

HCPs were occasionally observed to provide information without leaving time or a pause for queries or questions from the PWA. For example, during the 'closing' stage of the session HCP 17 needed to provide a list of information to PWA 6, as he was coming to the end of his rehabilitation block. She outlined his programme and sessions for the following week with him. Without providing a pause or checking that PWA 6 understood this information, she began to discuss his changeover from the ESD to the community team, which visibly confused the PWA. Such confusion might be exacerbated if a PWA also presented with impaired cognitive or linguistic processing.

HCP's adaptation of their communication and their use of prompting (phonological or semantic, verbal or written or gesture) also needed to be clear and tailored to be a facilitator of the PWA's learning. When HCPs spoke slowly, rephrased questions and provided tailored prompts the PWA appeared more engaged in the session. This was evidenced by initiations by PWA to continue conversations about their impairments and rehabilitation.

#### Excerpt 10.HCP 15 & PWA 4: clear explanations

1	HCP 15	And we are going to relax it back again
2		((lower PWA 3's hand to the table))
3		You alright
4	PWA 3	Yea
5	HCP 15	If you think when we started it was just [like that]
6		[((gestures hand position at the beginning of
		rehabilitation))]
7		[so by doing it we are just trying to loosen off}
8		[((gestures exercise moves wrist up and down))]
9		[to get that range back]
10		[((rubs PWA 3's arm))]
11		We are not really just being mean
12	PWA 3	((laugh)) goo goo ((lifts wrist))

#### 7.6.5 Rapport

Consistent with results from the interview data, rapport was observed as a facilitator of learning. Rapport was observed to be established through expressions of empathy and reassurance; understanding of difficulties and challenges; engaging in naturalistic conversation, for example about their interests or family; honest and constructive feedback; and celebrating the PWA's achievements and progress. When a rapport was established the PWA would look visibly more relaxed, by smiling or adopting a relaxed position in their chair.

Many HCPs would begin the session by enquiring about the PWA's general wellbeing. PWA were observed to respond to this initiation by openly discussing their difficulties with their HCP. This often led to a discussion about the PWA's worries. The HCPs would respond with answers to their questions before the task-based activities began. All HCPs were observed checking on the PWA's wellbeing throughout the sessions. This occurred most frequently at the transitions between two stages of the session, for example at the transition between two rehabilitation tasks. HCPs were often seen to ask the PWA, 'are you OK to do one more?' PWA responded well to these enquires about their wellbeing and were often seen

thanking HCPs if the HCP showed an understanding of aphasia and their co-morbid difficulties, or showed a willingness to adapt their communication or complete shorter activities to help with the PWA's fatigue. For example, HCP 17 told PWA 6, 'I understand that this is hard work'; HCP 15 responded to PWA 9's loud audible exhale by saying 'take your time, you've got this'; on one occasion, PWA 3 said 'why?' when she was finding an exercise difficult, HCP 16 consequently stopped the task to explain why she would find the particular task difficult and that that would be normal after a stroke. Here PWA 3 responded by tapping her chest, on the position of her heart, and HCP 16 reassured her further.

Rapport was also observed to be established through celebration of the PWA's progress and encouragement. PWA were seen to be happy and excited when HCPs encouraged them and celebrated their achievements, emphasising their abilities. For example, HCP 15 told PWA 9 when she did well in a task, 'you've got this, I didn't give it to you'. PWA 9 began to smile in response to this comment. PWA 10 spoke to HCPs, in two observed sessions, about HCP 12 celebrating with her when she got her legs onto her bed without assistance. When HCP 12 entered her home PWA 10 was observed to say, 'you are the one that cheered when I got my legs up'.

Naturalistic conversation was a key method used to develop rapport. When either HCPs or PWA remembered a conversation from a different session and followed up on it, it was topicalised by the other person and resulted in a discussion about the topic. For example, HCP 13 asked if PWA 3 had enjoyed going swimming again. This had been one of PWA 3's key goals and she became excited when he mentioned it, smiling and making swimming stroke gestures. In another instance, PWA 6 asked how HCP 17 was feeling, as she had missed a session due to illness. She thanked him for asking and this led to a discussion about being sick. On another occasion PWA 6 and HCP 17 bonded over a mutual dislike of football, which led to great laughter and joking.

Although rapport was observed as being key to rehabilitation by both HCPs and PWA, instances were observed when opportunities to develop rapport were missed. For example, when PWA 9's initiation, 'I don't think I'm gonna to do it', was not responded to by her HCP, PWA 9 appeared to look sad throughout the following activity. Occasionally PWA's attempts to say that they were finding a task difficult or needed clarification on a task or instruction were ignored or missed, particularly if these attempts to express these difficulties or requests for clarification were non-verbal. For example, PWA 9 came close to

tears when she was repeatedly unsuccessful with a task. She opened her mouth to initiate but as the HCP was looking at the computer screen PWA 9's initiation was not responded to.

#### 7.6.6 Emotions

PWA's emotions were the topic most discussed in the observational data. This usually occurred at the beginning of the session, when the PWA would initiate or respond to the HCP's question regarding their wellbeing and they would discuss the difficulties or successes they had experienced since their last session. Discussions regarding these difficulties appeared to put the PWA at ease and help them to engage with the session. For example, in PWA 5's observed sessions, he was observed at the beginning of the session to initiate about a word or a topic that he had had difficulty with since the last session. When the HCP discussed and responded to this difficulty he would be happy to begin the tasks for that session. However, on some occasions it was observed that his worries were not responded to and he would initiate about his difficulty during the task. For example, PWA 5 initiated at the beginning of the session that he had been having difficulty remembering the name of 'the top lad in the hospital'. He repeated 'con, con'. HCP 12 initiated a different topic but PWA 5 responded by putting his hands in his head and repeating 'con con'. HCP 12 subsequently prompted PWA 5 using pen and paper and writing down a phonemic (speech sound) cue. PWA 5 exclaimed 'consultant, that's it, thank you thank you'. He smiled and they continued with the session. PWA 5 then appeared more relaxed and responded to HCP 12's earlier 'on-task' initiation.

PWA and HCPs did show their emotions in sessions. PWA were observed shaking their fists, hitting their legs, hitting the table, putting their head in their hands, cursing and crying. These emotions were often observed to coincide with a PWA finding a task difficult, being unsuccessful with the targets of the rehabilitation activities, or at moments when they were aware of their own communication difficulties. For example, PWA 3 presented with an impairment in her auditory feedback loop (i.e. she found it difficult to hear what she had said) and therefore was unsure whether her expressive language was correct or not. While completing a speech and language therapy activity in which she had to name items on picture cards, she was unsuccessful with target words numerous times in a row. As a result, she had received negative feedback on the outcome of her performance from her HCP many times in quick succession. She began to tap her ear to convey she couldn't hear what she was saying. She shook her head, tapped her ear again and then began to cry. HCP 13

responded to this emotion with a discussion around the task, reassurance and then introduced humour. PWA 3 was then observed to laugh. Humour was often introduced by HCPs to counter the effects of negative emotions. Jokes were made by both PWA and HCPs about materials or activities. For example, PWA 3 was practising cleaning the table with a tea towel, moving it in circular movements, as part of a PT activity. HCP 13 commented with the well-known movie reference 'wax on, wax off' and both PWA 3 and HCP 13 began to laugh.

Occasionally HCPs were seen to be focused on the task or activities they needed to complete and missed opportunities to discuss PWA's emotions. For example, during a picture-naming task a picture of a car provoked PWA 4 to discuss that he could no longer drive and that this upset him. HCP 6 replied with the discourse marker, 'OK' and asked the next question in the task. In another session, PWA 4 became very frustrated when he was unable to achieve the target word. HCP 18 became nervous and responded by laughing. PWA 4 followed up with, 'I'm losing it now', which was not responded to.

HCPs also showed emotion during sessions. They were observed to smile and enjoy engaging in humour, making jokes and laughing and discussing common interests. Once PWA 5 told HCP 12 that she was, 'very clever' and she 'boost[s] my morale' which made her smile. HCPs looked relaxed in the home environment and were observed drinking cups of tea with the PWA during the rehabilitation session.

#### 7.6.7 Gaze and bodily alignment

Gaze and bodily alignment were observed to produce the conditions for learning, by allowing the HCP to observe initiations, to indicate to the PWA that they can take a turn in the conversation, and to keep the PWA's attention. HCP 20 was observed throughout sessions to move her bodily position to an angle where she had best view of the PWA's face. She knelt on the floor in front of PWA 9 rather than beside her so she could notice non-verbal communication during the task. She was also observed to repeatedly lift her head if she was working with the PWA's limbs, such as stretching the foot. Keeping eye contact with the PWA or moving their gaze toward the PWA was observed to facilitate HCPs picking up on PWA's non-verbal initiations and cues. For example, HCP 16 moved her gaze towards PWA 3 throughout the physiotherapy task. As a result, she observed PWA 3 pulling a face and she responded by providing her with positive feedback. In contrast, when HCPs did not keep their gaze on PWA, initiations could be missed. For example, HCP 13's gaze was fixed on the rehabilitation materials. PWA 3 opened her mouth to initiate and began

to make a groping movement with her mouth, but this was not noticed and PWA 3 gave up on her initiation.

As discussed in the materials section, gaze and bodily alignment was seen to be important during tasks and when using materials such as worksheets. HCPs often moved their bodily position to ensure that both parties could both see the material. HCP 20 moved and sat beside PWA 10 so that both parties could read the rehabilitation programme together. This also helped provide a sense of collaboration and shared control. HCP 12 also moved her body position and moved closer to PWA 5 so that he would have the worksheet in front of him as he completed a writing task, but she was able to see the material to provide tailored, timely prompts if needed. When the worksheet was too far from the HCP it was difficult for a HCP to provide feedback. HCP 22 had to stand up and look over PWA 5's shoulders each time he wrote an answer due to poor bodily alignment at the beginning of the activity. In addition, when HCPs split their attention to write in notes while a PWA was doing an activity, this meant that initiations and opportunities to provide feedback could be missed. For example, HCP 13 missed an opportunity to provide feedback to PWA 5 when he was asking for it as he was focused on his notes. On another occasion HCP 12 missed PWA 9 shaking her fist, as she was also looking at the notes.

For some PWA it was essential for them to see the HCP's face to facilitate their understanding. Body alignment facilitated communication for PWA 3, as she looked at people's mouths to prompt herself.

Maintaining eye-gaze was also used to manage different stakeholders in a rehabilitation session. It was used to direct attention towards the PWA and show that the HCP was still directing the conversation towards them. For example, HCP 20 maintained her gaze to continue directing conversation towards PWA 6 when his wife was answering for him. She maintained this gaze until PWA 6 provided an answer to the question.

#### 7.7 Summary

Data from the observation study provided detailed analysis of interactions between PWA and HCPs in routine rehabilitation. Collective influencing factors such as NHS caseload and time pressures did have an impact on how the rehabilitation sessions could take place. The structure of the sessions was for the most part consistent, irrespective of activity type or HCP. Discussion and naturalistic conversation occurred at the beginning of the activity, at the transition between activities and after the HCP closed the session. The time spent on discussions and naturalistic conversations did vary. More time was spent engaged in discussions or naturalistic conversations with people with mild rather than severe aphasia. There were also sessions in which there was no naturalistic conversation between the PWA and the HCP. Those HCPs with a professional qualification spent more time in discussion or naturalistic conversation than APs or RAs.

The observational data allowed the researcher to see how the interview themes were enacted in rehabilitation. The environment was a facilitator for learning, providing the PWA with opportunities for salient practice and providing scaffolds for naturalistic conversation. It also allowed the HCP and PWA to identify difficulties the PWA may have had with a particular task. The only barrier to learning observed in the home environment was distractions, which had more impact on those PWA with reduced attention. Materials acted as both a barrier and a facilitator of learning. Materials could prompt a PWA and scaffold their learning. PWA were more engaged in activities where the materials were salient. Materials could also act as a barrier to learning if they were perceived as boring and repetitive, or they could shut down opportunities for conversation by distracting the HCP. Materials could signify change in activities and closing of sessions.

Although PWAs were observed taking control of the environment in some instants, control of the session was maintained for the most part by the HCPs. HCPs choose the activities for the session and maintained control of the structure of the session, deciding when activities would begin and finish. Collaboration was enhanced by placing materials where both parties could see them, explaining processes fully, being clear with directions and instruction and giving the PWA opportunities for direct rehabilitation.

Emotions were prevalent in sessions, with PWA becoming frustrated and upset. Humour, reassurance and explaining difficulties helped to negate the effects of negative emotions. Building a rapport was central to the rehabilitation activity and had a direct impact on both the HCP's and PWA's emotions. Rapport was built through naturalistic conversation, honest feedback and celebrating the PWA's achievements and progress.

Finally, the importance of gaze and bodily alignment was observed in these sessions. Gaze and bodily alignment helped the HCP to provide honest feedback, to aid the PWA's understanding and notice PWA's initiations and respond to them appropriately. Gaze also helped to keep the PWA's attention and to show them that the conversation was continuing.

#### 7.8 Exploratory study findings: Summary

The impact of aphasic language impairments on different aspects of a person, their emotional wellbeing, the activities they are willing to participate in, and the communication partners they have opportunities to communicate with permeates the PWA's lived experience of stroke and aphasia. These changes in the PWA's communication and the resultant adaptations to their participation in their environments can mean that the PWA experiences reduced opportunities to practise communication. HCPs can often be the key communication partners for PWA in the early stages post-stroke. Learning processes including: feedback; practice; intensity of rehabilitation; saliency; the context of rehabilitation; and the therapeutic alliance have been shown to impact on the success of rehabilitation outcomes for the PWA post-stroke. The exploratory study aimed to better understand opportunities that exist in routine rehabilitation to optimise these learning processes, using interview and observation data. This section synthesises and summarises the findings of the exploratory study.

#### 7.8.1 Exploratory study: Synthesis of exploratory study findings

#### 7.8.2 Journey of stroke and aphasia

Data from interviews with HCPs and PWA and observations of rehabilitation sessions were contextualised by the PWA's aphasia and stroke journey. The communication difficulties and the co-morbid difficulties they experienced, the adaptations they made to their lifestyle, their appearance and the activities they were willing to undertake were varied in type and severity. Aphasia impacted all areas of the ICF (World Health Organization, 2001), emphasising a general understanding that aphasia has a much broader impact than the impairment itself. PWA discussed how aphasia impacted their emotions, changed their communication partners and activities they had opportunities to partake in, challenging their own personal identity. As a result, aphasia impacted on how they communicated, their motivation and their active participation in their rehabilitation session. The HCPs, all of whom worked with PWA on a daily basis, discussed the impact aphasia had on the rehabilitation sessions they implemented. The observational data showed how the interactions involved in rehabilitation sessions were permeated by the lived experience of stroke and aphasia, both for people living with aphasia and for HCPs working and interacting with them. HCPs were observed adapting communication, rehabilitation sessions, and experiencing communication breakdown as a result of aphasia.

HCPs and PWA discussed the emotions they felt as a result of aphasia and working with PWA. These were predominantly negative emotions, with both PWA and HCPs

experiencing increased levels of anxiety, fear and doubt in their own abilities as a result of aphasia. These emotions were evidenced in the observational data through shaking fists, banging tables and nervous laughter. PWA recounted that their communication partners; the rehabilitation activities they were engaged in; the general public's lack of awareness of aphasia; and the fact that aphasia is invisible, which led to insensitivity from others, all influenced their emotions. HCPs and PWA discussed the positive influence that building a good rapport and the home environment had on their emotions, and both HCPs and PWA emphasised how comfortable they felt in the home environment. This was apparent in the observational data, with HCPs and PWA observed drinking tea and sitting relaxed in the PWA's sitting room. In addition, PWA reported that seeing progress in their rehabilitation alleviated negative emotions. HCPs cited the strong support they received from their colleagues and the interdisciplinary nature of ESD as factors that increased their positive emotions. However, HCPs felt that they did not receive adequate training about aphasia or supported communication, and this negatively impacted their emotions and the care that they gave to PWA. In addition, APs and RAs implemented programmes devised by OTs, PTs and SLTs as part of their role and they noted that they did not fully understand these disciplines. This made it difficult for them to know how to recognise opportunities to make activities more salient to the PWA, and they did not feel confident enough to make these adaptations. APs and RAs reported that the majority of their training about aphasia was informal, such as observing colleagues or discussing issues that arose in a session with the MDT when they returned to the hospital. In the current economic climate, human resourcing and caseload issues made it difficult for HCPs to access these informal channels of training. Overall, RAs and APs reported having the least amount of training and knowledge in the discussed areas, despite spending the most amount of time with PWA. Years of experience had an inconsistent influence on the HCPs' emotions, with some HCPs reporting that they felt more anxious working with PWA when they were newly qualified, whereas other HCPs still did not relish working with PWA, even after many years of clinical experience (up to 20 years).

The HCPs spoke about the negative emotions they thought that PWA experienced, such as frustration and annoyance. They had observed these emotions during rehabilitation sessions and emphasised the need to be compassionate, understanding and to show reassurance to the PWA. However, HCPs did not always feel comfortable engaging in conversations with PWA about their emotions, for fear of communication breakdown or 'making things worse'.

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#### 7.8.3 Therapeutic relationship

Both PWA and HCPs emphasised the importance of rapport development, the benefits of a good rapport and factors that influenced its development. HCPs and PWA appreciated getting to know each other professionally over the course of the rehabilitation period. Good rapport made rehabilitation more enjoyable for both parties and was developed by HCPs being empathetic; reassuring; listening to the PWA; valuing their opinions; developing trust; and taking the time for conversation. HCPs described how when a rapport was developed it made it easier for them to initiate naturalistic conversation with PWA, understand their individual communication difficulties, how best to support their communication, including the prompts that were useful for them, and to tailor feedback. PWA felt that 'supported communication' facilitated two-way communication. They appreciated being given enough time to respond, having words or sentences rephrased by HCPs, used gesture, maintained eye contact and bodily orientation. Rehabilitation procedures and programmes could be confusing for PWA; they appreciated when this information was delivered clearly, and both they and the HCP were 'on the same page'. PWA appreciated HCPs taking the time to communicate with them, but some PWA would have appreciated more opportunities for naturalistic conversation. PWA felt that good rapport made them feel more comfortable having the HCPs in their own homes; HCPs agreed that it must be strange for PWA having 'strangers' in their home.

The intensity of rehabilitation and continuity of HCPs helped PWA and HCPs to get to know each other. The personalities of HCPs, for example 'chatty' or 'funny', were cited by both HCPs and PWA as facilitating the development of good rapport. HCPs reported that they used humour as a tool to develop rapport, and that humour and terms of endearment increased when rapport was established. PWA appreciated that all HCPs were 'ordinary' people, who were nice and easy to talk to.

HCPs discussed how the home environment offered them insights into the PWA's life and their interests. These insights provided the HCPs with topics to initiate and continue naturalistic conversation. PWA were observed using artefacts from the home environment to provide context to initiations and conversations, for example using photos of them or their families to support conversations.

HCPs discussed collaboration and control in the interviews. They felt that there was a shift in power dynamics in the home environment, with PWA having more control in their own environment compared to a ward environment. They felt that it was important to have joint goal setting and to collaborate in rehabilitation to increase the PWA's motivation and engagement. This increase in control was evidenced in the observations, as PWA got up and moved around their house during the sessions and hosted the HCP, for example offering them a cup of tea or some cake. The OTs and PTs were observed collaborating with the PWA to revise goals, and HCPs always asked if a PWA was happy to complete a task. However, the HCPs were observed to exert control over the running of the rehabilitation session through the session structure and control of rehabilitation materials. In addition, HCPs were observed to be surprised when PWA asked for an activity to continue when the HCP had ended it, or when they chose not to complete a planned activity, for example using the discourse marker 'O'. APs and RAs were observed having to return to and re-read the programme when this did occur.

#### 7.8.4 Personally meaningful rehabilitation

It was apparent from examination of all data that there were opportunities to make rehabilitation personally meaningful for PWA. These opportunities arose from the context of rehabilitation, the home environment, and rehabilitation materials drawn from the home environment. HCPs' discussions of materials incorporated the physical space used in rehabilitation, bodily position, eye contact, formalised therapy materials and therapy materials they enrolled in the home, for example the person's kitchen. The PWA focused only on physical rehabilitation materials that were brought by the HCPs, such as picture cards. HCPs with professional qualifications discussed how rehabilitation materials derived from features of the home environment were more salient to the PWA than those brought with them to the rehabilitation session. This was evident in PT and OT sessions where HCPs were observed using the person's kitchen to complete a 'making tea activity', or the PWA's home environment to practise walking or stepping on their stairs. The adoption of artefacts in the home environment as rehabilitation materials was rarely observed in SLT activities. In SLT activities materials were made salient using, on one occasion, family names, and on another occasion, the PWA's favourite football team as target words in a naming task. The computer programmes, picture and sequence cards that were often used in SLT activities were described by PWA as being repetitive, and PWA were observed to comment on this during the session. In addition, laptops were often used in SLT activities by RAs and APs, which were observed to take up to six minutes to set up. The computer programmes were also described by HCPs and PWA in sessions as confusing. The topics or feedback embedded in the software were not salient to the PWA. HCPs discussed how developing a rapport and knowing the PWA's language and communication difficulties, as well as the prompts that supported their communication, helped to tailor feedback of performance and prompts to make rehabilitation more meaningful for the PWA.

#### 7.8.5 Factors influencing opportunities for naturalistic conversation

Finally, rehabilitation procedures including: the structure of the session; external NHS pressures, such as targets, caseload pressure and time restrictions, were described by HCPs as having an overarching influence on what could be achieved in the rehabilitation session. HCPs reported that the amount of time they had for rehabilitation in the home environment, compared to working on a ward in a hospital setting, was a facilitator to learning as they could spend more time with the PWA. Their supportive MDT was understanding if they did not complete all items on the programme. The phase structure of rehabilitation sessions was largely consistent across all observed sessions, with comparable patterns and similar components, despite the range of different activities, professions and severities of aphasic impairments. The structure generally followed a series of phases, including: greeting; naturalistic conversation or discussion; instruction and orientation; task; break and transition, closing the session and tidying up, and goodbye. The time spent on these different components did vary between the different professions, with HCPs who held a professional qualification spending more time on the discussion phase. The structure of rehabilitation sessions created the conditions for functional communication learning but the opportunities for naturalistic conversation that did arise were infrequently realised. Finally, the observational data highlighted the importance of gaze and bodily orientation to facilitating learning and creating conditions for learning.

### **Chapter 8: Discussion**

#### 8.0 Introduction

The purpose of this study was to develop a deeper understanding of the potential for enhancing functional communication learning for people with aphasia post-stroke in the context of ESD rehabilitation. Therefore, this thesis examined: 1) how learning processes that underpin rehabilitation have been reported in speech and language therapies for aphasia with a functional outcome; and 2) explored experiences and practices of ESD-based rehabilitation, in order to understand the conditions that exist during routine rehabilitation to enhance functional communication learning, the nature of these conditions and the facilitators of and barriers to the uptake of these opportunities to enhance (re)learning. This thesis investigated how the learning processes crucial to (re)learning, which were investigated through the systematic review, may be enacted and integrated into the management of PWA after stroke in order to enhance learning.

This chapter contextualises the principal findings within the current literature, outlining the contribution of these findings to the field of study. Limitations and strengths of the research will be discussed. Finally, the implications of this research for clinical practice and future research are outlined.

#### 8.1 Summary of principal findings

The systematic review investigated the reporting of learning processes in speech and language therapies with a functional outcome. In the 34 included studies, these learning processes were inconsistently reported. This was irrespective of study design, although controlled trials reported the fewest learning processes. Feedback, the setting or context of the intervention, and how and if the intervention was tailored to the client, i.e. how salient the intervention was to the PWA, were the least reported learning processes. Inadequate information was presented in studies for the interventions to be fully replicable by clinicians and researchers. More detailed specification of speech and language interventions with a functional outcome for PWA post-stroke could allow clinicians to better replicate interventions that are shown to be effective and increase positive outcomes. For researchers, this would allow the learning processes to be unpicked to guide future research. The results of the systematic review highlighted the need for much closer inspection of these elements, which are thought to be important to the outcome of rehabilitation. It was therefore necessary to examine how these learning processes influence and are influenced in routine rehabilitation and this became the focus of the exploratory study.

Using interview and observation methods, the exploratory study addressed the conditions for enhancing functional communication learning, how these conditions could be identified and optimised, and the barriers to or facilitators of the uptake of these opportunities. This research found that there are opportunities to enhance functional communication learning and provided a deeper understanding of the complexities in routine rehabilitation which can act as barriers to or facilitators of the uptake of these opportunities.

Firstly, negative emotions experienced by PWA can reduce their engagement and motivation in their rehabilitation, acting as a barrier to learning. Harnessing the PWA's positive emotions and inherent positive attitudes and determination, while addressing negative emotions they are experiencing, early post-stroke could remove barriers to functional communication learning. In addition, HCPs reported that they experienced negative emotions working with PWA. As a result, they discussed avoiding conversations with PWA and a reluctance to engage in conversations with PWA about their emotions, for fear of communication failure or increasing the PWA's negative emotions. Increasing HCP training on aphasia and supported communication has the potential to reduce the negative emotions HCPs experience working with PWA. This could increase opportunities for functional communication practice for PWA through naturalistic conversation. Increasing APs' and RAs' knowledge of the disciplines in which they work, OT, PT and SLT, could increase their confidence to tailor rehabilitation activities and materials to make them more salient for PWA.

Secondly, this research emphasised the importance of the home environment to creating conditions for functional communication (re)learning. The home environment was rich in opportunities to increase functional communication learning and/or increase conversational practice. It provided scaffolds and springboards to enhance rapport building, to increase positive emotions, to aid the PWA's adaption to life with stroke and aphasia, and to increase the saliency of rehabilitation. OT and PT rehabilitation activities used more of the PWA's space in their own home and their own artefacts as rehabilitation materials than in SLT intervention. There are opportunities for artefacts in the person's own home to be used as rehabilitation materials in SLT activities to increase the saliency of routine rehabilitation for PWA. This study also found that there are opportunities for

genuine collaboration between PWA and HCPs in routine rehabilitation which are inconsistently realised.

Finally, these data showed that breaks and transitions between rehabilitation activities provide opportunities for functional communication practice that are inconsistently realised, with PWA observed sitting in silence during these breaks. These could be opportunities for functional communication practice or client-directed discussion.

# 8.2 The context of the principal findings and their implications for increasing functional communication learning in ESD routine rehabilitation

#### 8.2.1 Negative emotions

It is known that aphasia can have a profound impact on a PWA's quality of life (Cruice et al., 2005), with significant impact on the person's emotional state (Code, Hemsley, & Herrmann, 1999). Negative emotions are common post-stroke – a quarter of people in the acute stages present with depression, with the figure rising to nearly one third more than three months post-stroke (Astrom, Adolfsson, & Asplund, 1993). In this study, PWA reported a range of negative emotions, experiencing more now than before their stroke. These included: anxiety; fear; embarrassment; annoyance; and low mood. The experience of aphasia was the key cause of these negative emotions. As in Northcott & Hilari's (2011) study, PWA cited communication partners as factors that influenced their emotions. Furthermore, the PWA cited the environment of the rehabilitation and rapport as influencing factors.

In addition to impacting on the PWA's quality of life, these emotional states can have an impact on motivation, physical performance, cognitive and language processing (Power & Dalgleish, 2015). PWA who have more positive mood respond better in therapy (Code et al., 1999), while PWA with low mood show slower rates of recovery (Starkstein & Robinson, 1988). Negative emotions therefore can act as a barrier to learning during routine rehabilitation. Despite the unfavourable impact such negative emotions can have on the rehabilitation process and the influence of positivity on living successfully post-stroke (Grohn, Worrall, Simmons-Mackie & Hudson, 2014), the personal experience of PWA is often neglected during the course of rehabilitation (Code et al., 1999). People post-stroke have reported feeling that HCPs focused on the physical rather than psychological results of stroke (Perry, Hsu, Brooks & Cherry, 1999), a phenomenon that was observed throughout the rehabilitation sessions in this study. The HCPs were observed to consistently check on the PWA's wellbeing and query about difficulties they were

experiencing. These 'checking behaviours' focused predominantly on the PWA's physical health, their stamina, their ability to continue with rehabilitation activities and do so safely, rather than their emotional wellbeing. Listening to PWA to understand the impact aphasia has on their life and psychosocial wellbeing (Long et al., 2008) has an important role for HCPs in addressing PWA directed goals and focusing rehabilitation efforts.

In the areas of mental health, counselling and life coaching there is a focus on harnessing positive emotions to enhance coping and health (Fredrickson, 2000; Tugade, Fredrickson, & Barrett, 2004), including the power of humour (Mahony, Burroughs & Lippman, 2002). People who are able to regain positive emotional states in response to stressful life experiences present with improved health functioning (Martin, 2001), and have less chance of readmission to hospital (Middleton & Byrd, 1996). In this study, HCPs were observed to use humour as a tool for negating the effects of negative emotions, as well as facilitating a good rapport with the PWA. Simmons-Mackie and Schultz (2003) found that humour is used to build rapport, to facilitate the rehabilitation session and interaction, and to mitigate embarrassment. In this study, HCPs were observed using humour to negate the full range of negative emotions experienced by PWA, such as upset and low mood. Humour was used as part of a 'cheering up process'. However, as in Simmons-Mackie and Schultz (2003), there was an apparent asymmetry to the occurrence of humour, with the HCPs initiating most of the humour. There were some occasions where PWA initiated jokes, predominantly about the materials or tasks they had to undertake, which the HCPs responded to by continuing the joke or through laughter.

In the recent aphasia literature there has been growing interest in how positive outcomes for PWA can be enhanced for them to 'live successfully with aphasia' (Brown, Worrall, Davidson, & Howe, 2011; Grohn, Worrall, Simmons-Mackie & Hudson, 2014). The PWA interviewed displayed positive attitudes to life, their stroke and aphasia and rehabilitation (such as determination and positivity), which they utilised to help them through their stroke and aphasia journey. These attitudes provided them with the strength to focus on their rehabilitation and adapt to their life post-stroke. Harnessing these positive attitudes during rehabilitation sessions has the potential to enhance rehabilitation outcomes. Considering the barriers that negative emotions create to motivation and engagement (Code et al., 1999), there is a need for more discussion on the PWA's emotional state to enhance functional communication learning post-stroke. Research in the aphasia literature has predominantly focused on the emotions of PWA (Code et al., 1999; Mc Menamin, Tierney, & Mac Farlane, 2015) or carers of PWA (Grawburg, Howe, Worrall, & Scarinci, 2014; Michallet, Tétreault, & Le Dorze, 2003; Nätterlund, 2010). However, the negative emotions experienced and reported by HCPs in this study suggest that they may play an important role in influencing how comfortable the HCPs felt engaging in conversations about wellbeing with PWA. These HCPs felt anxious, stressed and ill-equipped to communicate with PWA, suggesting a need to address their negative emotions in order to increase their confidence and positive emotions working with PWA. The HCPs in this study identified access to training on aphasia, supported communication and knowledge of the disciplines in which they work as a key method of mitigating the effects of their negative emotions. Training can increase HCP confidence to engage in conversations regarding PWA wellbeing without fear and increase their supported communication skills (Horton et al., 2015).

#### 8.2.2. Training of HCPs

The HCPs interviewed expressed a desire for more training on aphasia and supported communication. They reported a lack of training and a reduction in informal training due to caseload and human-resourcing pressures. The observational data suggested a need for increased training, with some HCPs displaying behaviours, such as interrupting or saying words louder, which created unsuccessful communication. These behaviours act as a barrier to learning as rehabilitation is mediated through communication and language.

A number of studies have shown that supported communication training for HCPs is effective in increasing staff knowledge, confidence and skills in communicating with PWA (Eriksson, Hartelius, & Saldert, 2016; Horton, Clark, Barton, Lane, & Pomeroy, 2016; Horton et al., 2015; Jensen et al., 2015; McGilton et al., 2011; Simmons-Mackie & Damico, 2007). Communication partner training focuses on revealing the PWA's communication competence and acknowledging it (Kagan et al., 2001), and identifying and removing problem behaviours, such as interruptions (Simmons-Mackie & Damico, 1995). Such training has the potential to counteract the negative emotions experienced by HCPs in this study, which were found to impact on their experience of working with PWA and consequently their ability to build rapport. Although communication partner training has been shown to be effective, there are barriers to the transfer of supported communication skills to day-to-day clinical practice in a ward-based setting, including: the PWA's emotions; spaces and events on the ward; and time constraints (Horton et al., 2015). However, a

supportive MDT was cited as a facilitator (Horton et al., 2015), which the HCPs interviewed reported having access to.

The UK Department of Health (2000) advocated that healthcare assistants, including RAs and APs, should work across different professions rather than be linked to one profession, for example physiotherapy assistant. The latter model was criticised as it is not as flexible or sensitive to the patient's specific needs (Waters, 2003). Despite the diverse range of activities the APs and RAs are expected to undertake in a patient-centred way, the RAs and APs in this study had received variable amounts of training, most of which was informal. Consequently, they lacked the confidence to make the programmes more salient for the PWA, despite them spending the most time with PWA. Shield and colleagues (2006) found that inter-professional practitioners needed a broad range of knowledge to carry out their roles, in the areas of both health and social care. They advocated for training and education to be standardised and accredited across the UK. This study showed that there is a need for standardised training for all RAs and APs on aphasia. Supported communication and background information on the different professions could help increase the APs' and RAs' confidence, increase their abilities to make programmes more salient to the PWA, and reduce communication breakdown.

#### 8.2.3 Home-based rehabilitation

The home environment has been described as a 'better arena for rehabilitation' (Cobley, Fisher, Chouliara, Kerr, & Walker, 2013, p.753) with emphasis on the more private and individualised nature of rehabilitation available in the home setting compared with hospital. In addition, Koch, Wottrich and Holmqvist (1998) concluded that the setting of stroke rehabilitation is a key component in empowering the person post-stroke. This study of home-based rehabilitation was observed to provide the PWA and HCPs with scaffolds and springboards for naturalistic conversation. It created optimal conditions for functional communication learning, facilitated rapport building, increased the saliency of rehabilitation, and consequently increased the PWA's active participation in rehabilitation.

Saliency in the form of more meaningful targets for rehabilitation has been shown to bring about greater experience dependent plasticity (Brown et al., 2000; Kleim & Jones, 2008) and to help with engagement in rehabilitation (Worrall, 2005). The home environment was rich with opportunities to increase saliency of rehabilitation materials and activities in the stroke rehabilitation. HCPs implementing OT and PT activities were observed using the PWA's space in their home to practice rehabilitation goals. PWA reported that using their home during rehabilitation activities helped them to remember what they did in their rehabilitation and to practise in-between sessions. Although SLT work included activities such as reading from the newspaper, many of the SLT activities included formal materials brought by HCPs, such as laptops, computer programmes and picture cards. The observational data showed that conditions exist in the home environment to increase the saliency of rehabilitation and to increase the number of functional tasks for speech and language therapy. For example, the SLT could use the PWA's items in their home for naming tasks or to initiate naturalistic conversation, rather than using prescribed questions or picture cards.

Studies of healthcare staff perspectives of working in the community have focused on the HCPs' perception of their role (Gibbon, 1994; Kneafsey et al., 2003). This study investigated the HCPs' perception of working with PWA in ESD services and therefore provides a unique perspective on the rehabilitation. HCPs preferred working with PWA in their home as they had more time with the PWA without the risk of being called away. Time constraints were cited as a barrier to communicating with PWA in the ward (Horton, Lane & Shiggins, 2015). Therefore, time could act as a facilitator to functional communication learning.

Koch, Wottrich and Holmqvist (1998) found that HCPs and patients changed roles, for example from patient to host, during home-based rehabilitation sessions. In this study, both PWA and HCPs were observed to change roles throughout the rehabilitation session. For the majority of rehabilitation sessions, PWA were observed to be both patient and host and HCPs were observed to act as experts and guests. The host and guest role was traded between the HCP and PWA with, on occasion, HCPs offering the PWA a seat or a drink. The PWA did, although rarely, take on the role of expert, for example knowing where things were in their home. The environment facilitated the PWA adopting the expert role. Both participants were at times a friend to the other. This may have been attributed to the way that people frame themselves in their own home, for example as a host, and want to ensure that their guest would feel welcome.

#### 8.2.4 Rapport, collaboration and feedback

The professional relationship between the therapist and the patient has been shown to have an impact on health outcomes in a variety of healthcare areas (Farin et al., 2013; Neumann et al., 2010; Schoenthaler et al., 2014). Jesus and Lopes Silva (2015) suggest that knowing the person and building a supportive relationship is one of the key influencing factors that bring about better rehabilitation outcomes. The HCPs interviewed echoed this

sentiment, emphasising the importance and integral role of rapport to the rehabilitation process. Jesus and Lopes Silva (2015) outline the importance of getting to know the person, listening to them and valuing their opinion as key influencing factors of rehabilitation outcomes. Consistently, both HCPs and PWAs reported that they enjoyed rehabilitation more when they knew each other well, as they had things to discuss, trust was developed and humour was then introduced naturally in sessions. The HCPs felt that this led to collaborative goal setting and management of the rehabilitation session. The emphasis on patient-centred goals in rehabilitation mirrors the shift in rehabilitation from an impairment-focused, medical model of rehabilitation to a model placing the person at the centre of rehabilitation and focusing on the activities they participate in and the social and emotional factors (World Health Organization, 2001). The WHO has proposed that personcentred care is a core component of quality healthcare (World Health Organization, 2011). HCPs who held a professional qualification (OTs and PTs) engaged in discussions throughout their sessions about the patient's goals and how the PWA would like these to be revised. This joint goal setting established a sense of collaboration between the HCP and the PWA. In addition, the HCPs always asked the PWA whether they were happy to engage in an activity or continue working on one. Despite these moments of joint control, the majority of power in the session remained with the HCP. Similarly to the findings of Horton (2006), this was enacted through the structure of the session and controlled by the HCPs through discourse markers (Shiffrin, 1987), such as 'okie dokie' and 'OK'. These discourse markers brought the PWA back to task or marked a transition from one task to another. This tactic is common across healthcare interactions (Simmons-Mackie & Damico, 1995). In addition to discourse markers, deployment of materials was used by HCPs to control the phase structure of the rehabilitation session and to signify transitions between tasks. Materials were introduced into the view of both the HCP and PWA, removed from view or tidied up when the HCP wanted to change task. Similarly to the findings of Wikman and Falthom (2006), the PWA in this study had little influence over the overall structure of the rehabilitation session.

Although the importance of collaboration has been emphasised, Wallin and colleagues (2008; 2009), outlined that contributions from 'patients' are dependent on how the HCP structures the rehabilitation activities initiated by PWA throughout the observed sessions, by asking questions or beginning a conversation. These provided opportunities for collaboration between the HCP and the PWA; however, they were inconsistently responded to. These were occasionally missed due to HCP's desire to stick strictly to the

task, bodily alignment and direction of gaze, sometimes causing the HCP to miss the nonverbal initiations. HCPs interviewed were influenced by external pressures such as time constraints, caseload pressures and session goals, which may have influenced how collaboration and control were enacted in these sessions. Social roles and how clinicians present themselves influence how control is enacted (Ferguson & Elliott, 2001; Goffman, 1974; Horton, 2006) The communication impairment experienced by the PWA also acts as barrier to the PWA taking control of their rehabilitation, instead remaining a passive recipient (Horton, 2006). When these initiations were missed or not responded to, an opportunity was missed for the PWA to provide their opinion or influence the rehabilitation session. The importance of active participation on the part of patients engaging in rehabilitation has been consistently emphasised (Intercollegiate Stroke Working Party, 2012; Jesus & Silva, 2015; Meyer et al., 2011). Collaboration and active involvement in the rehabilitation session can enable self-determination and increase motivation (Maclean & Pound, 2000), which could create conditions to increase functional communication learning. These data suggest that there are opportunities in routine rehabilitation to enhance functional communication relearning by increasing PWA's active participation and control, which could increase PWA motivation and engagement.

Some form of feedback is essential to learning (Shumway-Cook & Wollacoot, 2007). Feedback can shape the person's learning (Simmons-Mackie et al., 1999) by providing the PWA with information on their performance. HCPs also use phrases, for example 'well done' or 'you are doing great', to provide the PWA with knowledge on their outcome and encouragement, which can further motivate the PWA (Simmons-Mackie et al., 1999). Both forms of feedback were observed throughout the rehabilitation sessions. The PWA in this study, however, appreciated when the HCP provided them with honest, tailored feedback to enhance their performance (knowledge of performance) as the PWA were motivated by seeing progress in their rehabilitation and achieving their personal goals. Rapport facilitated the HCPs' ability to provide this form of feedback. Consistent with the literature (Simmons-Mackie et al., 1999), feedback in this study also had a role in establishing the discourse structure of the session, with HCPs often observed engaging in initiation, response, and feedback structures typical of clinical interactions (Simmons-Mackie et al., 1999); Horton, 2006).

#### 8.2.5 Opportunities for communication practice

The phases and general structure of the observed rehabilitation sessions were largely consistent across the data, including: greeting; naturalistic conversation or discussion; instruction and orientation; task; break and transition; closing the session and tidying up; and goodbye. This generally aligns with Ferguson and Elliot's (2001) outlined structure of sessions (greeting, review, procedural orientation, therapeutic activity, plan and leave taking). This study, however, showed that the rehabilitation session structure has one other key component, transitions and breaks, which provide an opportunity for functional communication practice, which was inconsistently realised in the observed sessions. In these breaks both naturalistic conversation and silence were observed. Silence was observed more often with people with severe aphasia than with people with mild aphasia. The interview data suggests that this can be attributed to the HCPs' negative emotions or perhaps lack of training and fear of communication failure.

The HCPs interviewed suggested that an AP and RA session structure differed from an OT and PT session. These data showed that the structure remained the same across the professions; however, the timings spent on each component of the session differed; with OTs and PTs spending more time on the discussion and planning components. The time spent on naturalistic conversation did not differ between professions or between qualified and unqualified staff, with the interview data suggesting that this could be attributed to personality. PWA do experience reduced opportunities for conversation and communication in community settings (Worrall & Hickson, 2003; Northcott & Hilari, 2011). Naturalistic conversation provides opportunities for communication practice, which is essential to enhance relearning (Shumway-Cook & Wollacoot, 2007) and which provides opportunities for the PWA to increase communicative success and reveal competence (Simmons-Mackie & Damico, 1995). Analysis of two PWA sessions in this study suggests that an equal amount of time is spent in silence as on naturalistic conversation in the course of routine rehabilitation for PWA.

#### 8.3 Opportunities to increase functional communication learning

Evidence is positive for ESD as it provides better rehabilitation outcomes for people poststroke than ward-based rehabilitation (Langhorne et al., 2005). This novel research has added to the current literature and knowledge base by providing some insight into the factors that can bring about these outcomes. The research identified opportunities to increase and enhance functional communication learning for PWA post-stroke. It explored how the learning processes that have been shown to have an impact on rehabilitation outcomes could best be optimised. This thesis has outlined the facilitators of and barriers to the uptake of these opportunities. Furthermore, it has provided a nuanced view of the factors influencing how these opportunities arise and are produced, and how rehabilitation is influenced as a result.

#### 8.4 Limitations

There are a number of limitations to this study. There were no observations or interviews with qualified speech and language therapists. Such sessions may have presented different insights into speech and language therapy rehabilitation; however, 58% (23/40) of observed rehabilitation sessions did include speech and language therapy activities which were produced and programmed by the speech and language therapist.

All participants in this study self-identified as white British, except for two participants, both of whom were from The Philippines. These participants were both HCPs. This research was conducted in Norfolk, UK, which has a largely white British population. In the systematic review, the participants in the included studies were from high-income countries with little ethnic diversity. This research therefore did not include ethnic and cultural diversity, and may not be representative of the population of PWA globally.

Finally, the same researcher (CS) collected the interview and observational data. This may have influenced how the participants answered the interview questions. The researcher discussed the methodology of the study with both groups of participants and they felt that getting to know CS made it easier to discuss their opinion's honestly in the interviews. CS also analysed the data, which may have introduced some internal bias. CS kept a reflective diary throughout this process for her to reflect on her own opinions that could influence how the data would be analysed. Analysis of the both interview and video data was peerreviewed by the supervision team to improve the credibility of the results.

#### 8.5 Strengths

The research reported in this thesis demonstrate a number of key strengths. Firstly, new knowledge has been contributed to how (re)learning can be optimised. The systematic review provides evidence that learning processes are reported inconsistently in speech and language therapies with a functional outcome. The exploratory study provides evidence on the nature of routine rehabilitation for PWA post-stroke, the opportunities that exist to increase learning for PWA post-stroke, and the facilitators of and barriers to the uptake of these opportunities. This thesis provides evidence on how (re)learning could be enhanced in routine rehabilitation for people with aphasia post-stroke.

This is a novel piece of research which has added to the current evidence base. It is the first study to: 1) investigate speech and language therapy for aphasia in an ESD context; 2) to specifically focus on the PWA's experience of stroke rehabilitation in the context of ESD, including the perspective of PWA presenting with a variety of severities; and 3) to investigate HCPs' perception of working with PWA in ESD services.

The main strength of this research is the diverse sample of PWA and HCP participants involved, which increases the transferability of the results. The researcher recruited PWA who presented with a variety of severities and types of aphasia. In addition, HCPs were recruited who represented the professions that work with PWA in routine stroke rehabilitation in the context of ESD: OT; PT; nurses; RAs and APs. These HCPs had a range of experience working in this context (from 2 months to 20 years). This provided the researcher with a diverse range of perspectives and interactions.

In addition, the exploratory study was an in-depth and thorough analysis of how learning could be enhanced in routine rehabilitation. The researcher included three components and two qualitative methods in the design of the exploratory study: PWA interviews; HCP interviews; and observational data. These mixed-qualitative methods were used to gain the perspectives of both PWA and HCP on the conditions for learning in routine rehabilitation and the barriers to and facilitators of learning opportunities. The video observation was used to ascertain how these conditions, facilitators and barriers were enacted in routine rehabilitation. Therefore, this research provides an in-depth insight into the opportunities to increase functional communication learning that exist in routine rehabilitation.

Finally, this work has been demonstrated to be of publishable quality, with abstracts and poster presentations accepted and presented at national and international conferences, e.g. the University of East Anglia Postgraduate Conference (poster presentation, 2013); University of East Anglia Public Engagement Conference (poster presentation, 2013); British Aphasiology Society (poster presentations in 2013 and 2015); and International Aphasia Rehabilitation Conference (oral and poster presentation, 2014).

#### 8.6 Implications of the study findings

This thesis provides evidence on how (re)learning could be enhanced for PWA post-stroke during routine rehabilitation, describing opportunities that exist and the facilitators of and barriers to the uptake of these opportunities. Having considered the results of the thesis in light of the limitations and strengths of this study, the following clinical and research implications have been identified.

#### 8.6.1 Clinical implications

This research produced findings that have important clinical implications:

- Increase focus on harnessing PWA's positive emotions and work with PWA's negative emotions in the early stages post-stroke. This could enhance the PWA's motivation and engagement in the rehabilitation process and has the potential to improve rehabilitation outcomes.
- 2) Increase the saliency of the materials used in speech and language therapy rehabilitation in the ESD context by using the PWA's own space and belongings as rehabilitation materials. Compared with the use of standardised materials, this would make the rehabilitation more meaningful to the PWA, which could increase functional communication practice and PWA motivation.
- 3) Provide focused training for HCPs working with PWA, addressing stroke, aphasia and the disciplines that RAs and APs work in, OT, PT and SLT. This would decrease the negative emotions experienced by HCPs working with PWA. It would increase their confidence to engage in naturalistic conversation and discussions regarding wellbeing with PWA, which would increase naturalistic practice, rapport and the PWA's positive emotions.
- Increase naturalistic conversation and communication practice in routine rehabilitation by capitalising on the opportunities that arise during the phase structure of rehabilitation, such as breaks and transitions.
- 5) Increase active control and collaboration in routine rehabilitation by providing more choices regarding rehabilitation activities and materials to the PWA, and increase discussions regarding rehabilitation in all sessions by actively listening to and valuing the PWA's opinions.

#### 8.6.2 Research Implications

- Reporting of learning processes in speech and language therapies with a functional outcome should be consistently and clearly specified. The TIDieR checklist (Hoffman et al., 2014) was a valuable tool for assessing the reporting of complex interventions such as speech and language therapy rehabilitation.
- 2) ACA provides a valuable approach to analysis to better understand naturalistic interactions, such as clinical interactions. It provides a logical framework which

allows fine-grained and in-depth analysis of data and is open to incorporating different qualitative methods.

#### 8.7 Areas for Future Research

This thesis has contributed to the knowledge of how (re)learning could be optimised in routine rehabilitation, and suggests a number of avenues for future research:

- Firstly, further explore the opportunities to use salient materials from the PWA's home environment in routine speech and language therapy rehabilitation in the ESD context. In addition, the researcher would like to investigate the impact of PWA choosing the materials from their home to use in rehabilitation, to increase this saliency further. It would be hoped that this could increase PWA motivation and genuine control in their rehabilitation. It could also increase functional communication learning for the PWA. This could be investigated through a pilot study, using observation and interview methods.
- Secondly, the researcher would like to further investigate the impact of increased HCP training on interactions and naturalistic conversation in routine rehabilitation in the ESD context which has not yet been investigated. The hypothesis is that increased training would lead to a more competent, satisfied workforce. This could be investigated using a cross-over controlled trial, initially providing training to one group of HCPs and then to the control group of participants.
- Finally, the researcher would like to research the impact of reducing negative emotions and harnessing positive emotions to enhance rehabilitation learning and success early after stroke. This could be conducted in a pilot study, implementing an asset-based approach to rehabilitation early post-stroke. This could be a collaborative study, working with PWA to investigate what keeps them healthy rather than what makes them ill.

#### 8.8 Concluding statement

There are opportunities to enhance functional communication learning in routine rehabilitation in the ESD context. This thesis has identified the conditions that exist to enhance functional communication learning and the barriers to and facilitators of the uptake of these opportunities. How these opportunities can be enhanced to improve the efficacy of rehabilitation for people with aphasia post-stroke warrants future research. As well as adding to the literature and providing a basis for future research, it is hoped that this thesis and the publications that arise from it have demonstrated the potential to have

wide-ranging benefits clinically – for healthcare professionals, including speech and language therapists – and for stroke rehabilitation research. It is hoped that this research will increase the efficacy of rehabilitation for people with aphasia.

## Appendix I

Systematic review documentation: search strings

#### 1. stroke.mp.

2. (stroke\* or cerebrovasc\* or cerebral vascular or post-stroke or post-stroke).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

3. 1 or 2

4. (infarct\* or ischaemic\* or ischemi\* or thrombo\* or embolis\*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

5. exp cerebral vascular disorder/

6. CVA.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

7. cerebralvascualr accidents/or cerebral vascular accidents.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

8.5 or 6 or 7

9. (haemorrhage or hematoma or bleed\* or aneurysm\*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

10. (cerebral or cerebellar or brain\* or vertebrobasillar or subarachnoid or intracranial or intracerebral).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

11. 3 and 10

12. 4 and 10

13. 8 and 10

14. 9 and 10

15. 11 or 12 or 13 or 14

#### 16. exp Aphasia/

17. aphasi\*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

18. language disorders.mp.

19. communication disorders.mp. orexp Communication Disorders/

20. communicat\*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

21. anomia.mp.

22. anomi\*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

23. dysphasia.mp. orexp Dysphasia/

24. dysphasi\*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

25. ((language or linguistic) adj5 (disorder\* or impair\* or problem\* or dysfunction)).tw.

26. 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25

#### 27. learning.mp. orexp Learning/

28. therap\*.mp.

29. Intervention.mp. or exp Intervention/

30. education.mp.

31. teaching.mp.

32. ('rehabilitation of speech and language disorders').mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

33. expRehabilitation/or rehabilitation.mp.

34. 32 or 33

35. (speech and language therapy).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

36. (Therap\* or train\* or rehabilita\* or management or assist\* or measure\* or assess\* or remediat\* or augment\* or recover\*).tw.

37. 27 or 28 or 29 or 30 or 31 or 34 or 36

38. 15 and 26 and 37

## Appendix II

Systematic review documentation: Inclusion criteria for full text review

## Learning processes in speech and language therapies for stroke-related aphasia with a functional communication outcome: a descriptive systematic review

Study title:		
Authors:		
Journal:		
Year:	Vol:	Pages:

Study type:

The article needs to answer yes to the questions below to be included for review at full text level.

Inclusion criteria	Yes	No	Maybe	Reason for exclusion/notes
<ol> <li>Are the participants adults (18+)</li> </ol>				
<ol> <li>Do the participants present with a diagnosis of aphasia (any severity/type) post-stroke</li> </ol>				
3. Is this a speech and language based intervention for people with aphasia post- stroke that has a specified functional outcome as outlined by the authors or by using functional outcome measures				

## Appendix III

Systematic review documentation: Data extraction sheet

## Learning processes in speech and language therapies for stroke-related aphasia with a functional communication outcome: a descriptive systematic review

Authors:

Journal:

Year:

Vol:

Pages:

Study type:

Participants	
Sample size	
Age (mean/range)	
Gender (M/F)	
Aphasia severity (as stated)	
Site of lesion (as stated)	
Length of time post-stroke	
Co-morbid difficulties	
Socio-economic class	
Native language	
Country of origin	
Aim of study:	
Other notes	

Method of participant	
selection	
Method of participant	
selection	
Method of data collection	
Who collected data	
Timing of data collection	
Conflicts of interests	

**Instructions:** Please extract the processes of learning outlined below. If the article outlines the process of learning state same with notes. Further instructions for each process can be found below. If the authors do not specify the process please insert "not specified".

Learning Processes	
Intervention summary (Brief conceptual description e.g. CIAT, writing intervention, semantic feature analysis)	
Instructions (Instruction given for task and by whom)	
Therapist/patient relationship (Is there any mention of the patient/therapist relationship)	
Materials used	
Feedback (Knowledge of performance/Knowledge of task/not specified)	
Setting	
<b>Specificity of task</b> (Was this task tailored to be meaningful for the client)	
Time of face to face practice (In session time)	
Homework/practice (Out of session)	
Length of time in intervention	
Adherence to intervention	
Support for production or performance (Priming e.g. TMS, Cuing)	
Response delay (Was a delay specified before the PWA could respond)	
Functional outcome used	
Additional information provided (e.g. In research protocol or appencies)	
Notes:	

## Appendix IV

Research governance, study information and consent: Ethical approval



NRES Committee East of England - Cambridge South

The Old Chapel

**Royal Standard Place** 

Nottingham

NG1 6FS

Telephone: 0115 8839437 (Direct Line)

19 November 2013

Ms Ciara MF Shiggins

School of Rehabilitation Sciences, Queen's building

University of East Anglia

Norwich

Norfolk

NR4 7TJ

Dear Ms Shiggins

Study title:	Increasing opportunities for functional communication learning
	in rehabilitation for people with aphasia in Early Supported
	Discharge (ESD) teams: developing an intervention protocol (OASIS)
REC reference:	13/EE/0322
IRAS project ID:	132353

Thank you for your letter of 22 October 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 10 October 2013

#### **Documents received**

The documents received were as follows:

Document	Version	Date
Covering Letter		22 October 2013
Participant Consent Form: Patient	2	21 October 2013
Participant Consent Form: Healthcare Professionals	2	21 October 2013
Participant Information Sheet: Patient	2	21 October 2013
Participant Information Sheet: Patient - Summary	2	21 October 2013
Participant Information Sheet: Healthcare Professionals	2	21 October 2013

#### **Approved documents**

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter		
Covering Letter		22 October 2013
Evidence of insurance or indemnity		22 May 2013
Interview Schedules/Topic Guides	Person with Aphasia version 1	22 August 2013
Interview Schedules/Topic Guides	Healthcare Professionals version 1	22 August 2013
Investigator CV	Allan Clark	
Investigator CV	Ciara Shiggins	
Investigator CV	Simon Horton	
Investigator CV	Valerie Pomeroy	
Letter from Sponsor		16 August 2013
Letter of invitation to participant	1	22 August 2013
Other: Permission to Contact Form	1	23 August 2013
Other: UEA Studentship Project Proposal Form		
Participant Consent Form: Patient	2	21 October 2013
Participant Consent Form: Healthcare Professionals	2	21 October 2013

Participant Information Sheet: Patient	2	21 October 2013
Participant Information Sheet: Patient - Summary	2	21 October 2013
Participant Information Sheet: Healthcare Professionals	2	21 October 2013
Protocol	1	22 August 2013
REC application	132353/492544/1 /489	16 August 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Yours sincerely

13/EE/0322	Please quote this number on all correspondence
•	

P. Wheal

#### Ms Trish WheatREC Manager

E-mail: nrescommittee.eastofengland-cambridgesouth@nhs.net

Copy to: Ms Yvonne Kirkham – University of East Anglia

Ms Clare Symms, NHS South Norfolk Clinical Commissioning Group

### Appendix V

Research governance, study information and consent: R &D approval

#### Norfolk Community MIS Health and Care

NHS Trust

Tel: 01603 257283 Fax: 01603 257292 E-mail: paul.mills1@nhs.net

Ref:2013GC12

**Ciara Shiggins** 

Norwich NR4 7TJ

Norfolk & Suffolk Primary & Community Care Research Office Hosted by NHS South Norfolk Clinical Commissioning Group Lakeside 400 Old Chapel Way Broadland Business Park Thorpe St Andrew Norwich NR7 0WG

18 December 2013

**Dear Ciara Shiggins** 

#### Letter of access for research

School of Rehabilitation Sciences,

University of East Anglia,

This letter confirms your right of access to conduct research through **Norfolk Community Health & Care NHS Trust** for the purpose and on the terms and conditions set out below. This right of access commences on 18<sup>th</sup> December 2013 and ends on 31<sup>st</sup> October 2015 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at **Norfolk Community Health & Care NHS Trust** has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to **Norfolk Community Health & Care NHS Trust** premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Norfolk Community Health & Care NHS Trust, you will remain accountable to your employer, University of East Anglia, but you are required to follow the reasonable instructions of the head of each relevant Department in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Chief Executive: Michael Scott

Norfolk Community Health and Care NHS Trust Head Office: Elliot House, 130 Ber Street, Norvich, Norfolk NR1 3FR

The Norfolk & Suffolk Primary & Community Care Research Office, hosted by South Norfolk CCG, undertakes research management, design and delivery services for primary and community care across Norfolk & Suffolk.

Chairman: Ken Applegate
You must act in accordance with Norfolk Community Health & Care NHS Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **Norfolk Community Health & Care NHS Trust** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **Norfolk Community Health & Care NHS Trust** premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust (please inform your nominated manager as named above) prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<u>http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf</u>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

**Norfolk Community Health & Care NHS Trust** will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerel

Elizabeth Cooke Head of Human Resources, Norfolk Community Health & Care NHS Trust

cc:

HR department, University of East Anglia

## Appendix VI

Research governance, study information and consent: Participant Information Letter



School of Rehabilitation Sciences, Queen's Building, University of East Anglia Norwich NR4 7TJ

Phone: 01603 59 3320

C.shiggins@uea.ac.uk

Dear colleague,

I am a PhD student in the School of Rehabilitation Sciences at the University of East Anglia (UEA). I am researching communication between people with aphasia after stroke and healthcare professionals.

The members of the stroke rehabilitation team have contacted you as a possible participant in a research study.

We want to understand how we can improve stroke rehabilitation for people with aphasia. We want to do this by observing and recording your therapy sessions with members of the Early Supported Discharge team.

Please take time to read the enclosed **Participant Information Sheet** carefully. If, after reading the Participant Information Sheet, you decide that you would like to take part, I will arrange a meeting with you to go through this. I will support any communication needs you may have. You will then have to sign the enclosed **Consent Form**.

If you have any questions about taking part, please ring me on 01603593320 or by email at <u>c.shiggins@uea.ac.uk</u> and I will be happy to answer your questions and/or arrange a meeting. By expressing interest in the study it does not mean that you have made a commitment to take part.

Yours sincerely,

Ciara Shiggins

Post Graduate Research student

# Appendix VII

Research governance, study information and consent: Participant Information Sheet



School of Rehabilitation Sciences, Queen's Building, University of East Anglia Norwich NR4 7TJ

Phone: 01603 59 3320

C.shiggins@uea.ac.uk

# **Patient Participant Information Sheet**

**Title:** Increasing opportunities for functional communication learning in rehabilitation for people with aphasia in Early Supported Discharge (ESD): developing an intervention protocol (OASIS)

You are being invited to take part in our research. We want to make sure that you understand the study before you agree to take part so please read this sheet; it provides answers to some of the questions that you may have about the study.

## Why have I been invited to take part?

You have been invited to take part in this research as you have had a stroke, have aphasia and are having rehabilitation with the ESD team. Aphasia is the name given to a communication disorder after having a stroke. It makes it difficult for the person to either speak, understand, read and/or write.

# What is the purpose of the study?

The aim of this research is to look at the communication between members of the Early Supported Discharge (ESD) stroke rehabilitation team and people with aphasia, during therapy sessions at home.

We also want to know what it was like for you to have your stroke rehabilitation carried out in your home.

# Do I have to take part?

No. It is entirely up to you whether you decide to take part or not. You can also change your mind and contact me later by emailing me at <u>c.shiggins@uea.ac.uk</u> or ringing 01603593320. If you decide not to take part, it will not affect your treatment in any way.

# What happens if I decide to take part?

You will be asked to sign a consent form. If you cannot write at the moment someone can sign on your behalf having witnessed you giving consent. I will observe up to six of your therapy sessions, up to three at the beginning and up to three at the end of your rehabilitation. I will record them using a video camera. Your therapy sessions will take place as normal.

You will also be asked to take part in an interview and I will ask you about your experience of having your stroke rehabilitation take place in your home. This will also be video recorded.

The research team will also need to have access to your medical notes and therapy records. This is so we can see the number of therapy sessions you have had and what staff have been involved in your care. We will not take any of your personal information out of the hospital and will keep anything that I read confidential.

# What are the possible risks and disadvantages of taking part?

Talking about your stroke and how it has affected your communication **may be upsetting.** You can ask to **stop at any time** and you can ask to talk to a member of the **clinical team** (nurse or therapist). You **may get tired** answering questions during the interview - you can ask to **stop at any time.** 

**Video** – **recording** your therapy may bother you or be inconvenient. You can ask to **stop at any time**.

# Will I benefit in participation in this study?

You will have an opportunity to discuss your therapy and how you feel about it.

Your participation is of value and will increase our knowledge about stroke rehabilitation. It may help develop better rehabilitation for people with aphasia in the future.

# How much time will I need to spend on this study?

The observation will take place during your scheduled rehabilitation sessions. Therefore participation in this research will not take any extra time.

If you take part in the interview this will take 30 to 45 minutes. If you need the interview to take place in two shorter sessions I can arrange this.

# **Confidentiality: Will the information be kept confidential?**

**Yes, all information about you and your participation** in the study will be kept **strictly confidential.** We will follow ethical and legal practice and all information about you will be handled in confidence.

The video recordings will be transferred from the video camera to a secure laptop in your home. The videos will then be deleted from the camera. Only the PI will bring the laptop to UEA and she will

keep it in her possession on this journey. The videos will then be transferred from the laptop to external hard-drives. These will be stored in a secure locker.

The videos will be kept until they have been transcribed or until the end of the PhD to ensure that all data is correct and then destroyed, unless you give consent for your video to be presented at conferences.

# What if there is a problem?

In the unlikely event of a problem occurring, indemnity (a form of insurance cover) will be provided by the UEA.

If you have any **concerns** about the research, you should contact the researcher who will try and **answer your question** or **resolve the problem.** 

Any concerns I may have about participants being at risk of potential harm will be raised with a senior member of staff.

# Who has reviewed this study?

The NHS has a Research Ethics Committee which reviews all studies involving people who are in NHS services. It ensures that the interests of the participants are protected. This study was approved by the East of England-Cambridge South ethics committee: (REC ref: 13/EE/0322).

My supervisory team have also approved this study.

# What will happen to the results of this study?

As this research is part of post graduate research the results may be published in my PhD thesis. They may also be published in scientific peer reviewed journals or presented at meetings or conferences. Videos may be shown at conferences or to members of the rehabilitation team. These conferences may be facilitated over the internet. If you are happy for your video to be used you can give your consent on the consent form. We are intending to send a summary copy of the research findings after the study is completed (in 2015) to all those who have taken part. If you would like further information about the results this can be obtained from me by emailing, <u>c.shiggins@uea.ac.uk</u> or ringing me at 01603593320.

# How to comment or complain?

If you have any concerns about any aspect of this research or wish to complain please contact my PhD supervisor Dr.Simon Horton at <u>s.horton@uea.ac.uk</u> or 01603 593060.

# What happens if I no longer wish to continue with the study?

**You many withdraw** from the study **at any time** without giving a reason. If you withdraw from the study, we will use the data up to the time when you withdrew.

# Withdrawing from the study will not affect your treatment now or at any time in the future by any healthcare team.

Thank you for taking the time to read this information sheet.

# Appendix VIII

Research governance, study information and consent: Patient Participant Information Sheet-Summary



School of Rehabilitation Sciences, Queen's Building, University of East Anglia Norwich NR4 7TJ

Phone: 01603 59 3320

C.shiggins@uea.ac.uk

# Patient Participant Information Sheet: Summary

## 1 Aim of the study

The aim of this research is to gain a greater understanding of the **communication** between members of the Early Supported Discharge

(ESD) stroke rehabilitation team and people with aphasia, when

implementing therapy in your home. We also want to understand your experience of having your rehabilitation in your home.



# 2 What do you have to do?

Six (6) therapy sessions will be video recorded - three (3) of your therapy sessions at the beginning and three (3) sessions at the end.

You will be asked to take part in an **interview** about your **experiences of having therapy in your home** 





No extra time needed Interviews will take **35 – 40 minutes** 

## 4 Do you have to take part?

**NO** and your therapy will not be affected in any way if you do not take part.

#### 5 Confidentiality

All recordings will be kept in a **locked locker** and all computers will have a password

Your **name and address** will **not** be used. I will only use your **initials** when writing up my results.

#### 6 What happens to the data?

PhD thesis

Published in scientific journals

Conferences

#### 7 Advantages of taking part?

The results may help make therapy better for people with aphasia

#### 8 I want to take part – What do I do?

Contact Ciara Shiggins at 01603593320 or <u>c.shiggins@uea.ac.uk</u>

Sign the Consent form

#### **9** I want to complain – I am not happy with this research Contact Simon Horton at <u>s.horton@uea.ac.uk</u>



# Appendix IX

Research governance, study information and consent: Participant Information



School of Rehabilitation Sciences, Queen's Building, University of East Anglia Norwich NR4 7TJ

Phone: 01603 59 3320

C.shiggins@uea.ac.uk

#### **Participant Information Sheet:**

#### **Healthcare Professionals**

**Title:** Increasing opportunities for functional communication learning in rehabilitation for people with aphasia in Early Supported Discharge (ESD): developing an intervention protocol (OASIS)

You are being invited to take part in our research. Before you decide whether you would like to take part we want to make sure that you understand the study and what it involves. Please read this information sheet; it provides answers to some of the questions that you may have.

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

The aim of this research is to look at the interaction between members of the Early Supported Discharge (ESD) stroke rehabilitation team and people with aphasia, when implementing therapy in the person's home. We are looking at the interaction between the impairment, the activity and the context.

We also want to know what it was like for you to provide stroke rehabilitation in a person's home.

#### Why have I been invited to take part?

You have been invited to take part in this research as you are a member of the Norwich Early Supported Discharge Team (ESD).

You are about to begin an intervention block with a person with aphasia who is being recruited to the study.

We are looking for members of the multi-disciplinary team who:

- Are from nursing, therapy or therapy/healthcare assistant staff groups
- Are graded band 3 7

## Do I have to take part?

No. It is entirely up to you whether you decide to take part or not. Taking part in the study is completely voluntary. You are welcome to speak to me before deciding to take part. You can also change your mind and contact me later by emailing me at <u>c.shiggins@uea.ac.uk</u> or ringing 01603593320.

You are also free to withdraw from the study at any time and you do not have to give a reason. It will not affect your appraisal or career progression in any way.

## What do I have to do?

I want you to implement therapy as normal. I do not need you to change anything or do anything differently. I will need to video- record you providing rehabilitation.

You will also be asked to take part in an interview and I will ask you about your experience of providing stroke rehabilitation in the person with aphasia's home. This will also be video recorded.

#### How much time will I need to spend on this study?

The research will take place during scheduled rehabilitation sessions so it will take no extra time.

If you take part in the interview it is estimated that this will take 30 to 45 minutes.

#### What are the possible risks and disadvantages of taking part?

If you take part in the interview you will be talking about your experience and possible difficulties may be distressing. You can stop the interviews at any time.

Being recorded may cause you some discomfort. You can stop recording at any time.

#### Will I benefit in participation in this study?

You will not benefit directly. However, your participation is of value and will increase our knowledge. It may help develop better rehabilitation for people with aphasia.

#### Confidentiality: Will the information be kept confidential?

All information will be kept confidential. The video recordings will be transferred from the video camera to a secure laptop at the location of recording i.e. the person's home or rehabilitation ward and encrypted. The videos will then be deleted from the camera. The PI will take the laptop back to UEA and it will be kept in her possession on this journey. The videos will then be transferred from the laptop to external hard-drives. These will be stored in a secure locker.

The videos will be kept until they have been transcribed or until the end of the PhD to ensure that all data is correct and then destroyed, unless you give consent for your video to be presented at conferences.

In the transcriptions, thesis or any publications that may come from this research your initials will be used and no information regarding your name or address will be disclosed. We will make sure that you are not identifiable in any way.

#### Who has reviewed this study?

The NHS has a Research Ethics Committee which reviews all studies involving people who are in NHS services. It ensures that the interests of the participants are protected. This study was approved by the East of England-Cambridge South ethics committee: (REC ref: 13/EE/0322).

This study has also been approved by the researcher's supervisory team.

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

As this research is part of post graduate research the results may be published in my PhD thesis. They may also be published in scientific peer reviewed journals or presented at meetings or conferences. These conferences may be facilitated over the internet. If you are happy for your video to be used you can give your consent on the consent form. We are intending to send a summary copy of the research findings after the study is completed (in 2015) to all those who have taken part. If you would like further information about the results this can be obtained from me by emailing, <u>c.shiggins@uea.ac.uk</u> or ringing me at 01603593320.

#### What if there is a problem?

In the unlikely event of a problem occurring, indemnity (a form of insurance cover) will be provided by the UEA.

If you have any concerns about this study, you should first contact the researcher, who will do her best to answer any questions you may have or resolve any questions.

Any concerns I may have about participants being at risk of potential harm will be raised with a senior member of staff.

#### How to comment or complain?

If you wish to complain or have any concerns about any aspect of this research then please contact Dr. Simon Horton at <u>s.horton@uea.ac.uk</u> or 01603593060.

#### What happens if I no longer wish to continue with the study?

You many withdraw from the study at any time without giving a reason. If you withdraw from the study, we will use the data up to the time when you withdrew.

Thank you for taking the time to read this information sheet.

# Appendix X

Research governance, study information and consent: Consent form for PWA



School of Rehabilitation Sciences, Queen's Building, University of East Anglia Norwich NR4 7TJ

Phone: 01603 59 3320

C.shiggins@uea.ac.uk

#### **Consent Form**

**Title:** Increasing opportunities for functional communication learning in rehabilitation for people with aphasia in Early Supported Discharge (ESD): developing an intervention protocol (OASIS)

1. I confirm that I have **read and understood** the information sheet (Version 3:22/11/2013) for the above study. I have **had the opportunity to consider the information, ask questions answered** to my satisfaction.

#### I have read and understood the information sheet





2. I understand that my **participation is voluntary** and that I am **free to withdraw** at **any time**, without giving any reason, without any future medical care or legal rights being affected.

## I understand that I can stop at any time

Please initial/tick the box below (with the thumbs up and thumbs down)



3. I understand that members of the research team may need to **look at my hospital notes** 

#### The research team can look at my hospital notes



Yes	
-----	--



No
----

3. I understand that **some information about my stroke may be held by** individuals from the **University of East Anglia**.

#### The research team can know about my stroke

Please initial/tick the box below (with the thumbs up and thumbs down)



4. I understand that the researcher will make video recordings of my rehabilitation therapy in my home.

# I am willing to take part in video recordings of my therapy and care





5. I am happy for my rehabilitation session to be shown at **conferences** or to the **rehabilitation team** 

### I am happy for the video recordings to be shown at conferences or to the rehabilitation team

Please initial/tick the box below (with the thumbs up and thumbs down)



#### 6. I agree to take part in the study

#### I agree



Name of participant	Date	Signature	
Name of witness (In cases of oral consent)	– – – – – – – – – – – – – – – – – – –	Signature	
Researcher D	 Date	Signature	
Please tick the box if study	you would	d like to receive details of the results of	of the

One copy for participant. One copy for researcher One copy for medical notes.

## Appendix XI

Research governance, study information and consent: Consent form – HCP

University of East Anglia

School of Rehabilitation Sciences, Queen's Building, University of East Anglia Norwich NR4 7TJ

Phone: 01603 59 3320

C.shiggins@uea.ac.uk

## Consent Form Healthcare Professionals

**Title:** Increasing opportunities for functional communication learning in rehabilitation for people with aphasia in Early Supported Discharge (ESD): developing an intervention protocol (OASIS)

1. I confirm that I have read and understand the information sheet (Version 3:22/11/2013) for the above study.

No	
	No

2. I have had the opportunity to consider the information, ask questions and have these questions answered satisfactorily.

Yes No

3. I understand that I can withdraw from the research at any time and without reason.

Yes	No
-----	----

4. I agree to my videos being presented at conferences

	Yes	No		
5.	I agree to tal Yes	te part in the above	study.	
Name	of participant	Date Si	gnature	
Resear	rcher I	 Date Signatu	 re	
Please study	tick the box if	you would like to r	receive details of the results	of the

# Appendix XII

Research governance, study information and consent: Permission to contact form

University of East Anglia School of Rehabilitation Sciences, Queen's Building, University of East Anglia Norwich NR4 7TJ

Date:

# **Permission to Contact Form**

Phone: 01603 59 3320

C.shiggins@uea.ac.uk

Name:
Address:
Contact number:
Email address:
Next of kin (name):
Next of kin contact number:
Next of kin email address:
How would you like to be contacted (please tick):
Email By post Via your next of kin
Signature of SLT:

## Appendix XIII

Research governance, study information and consent: Topic guide for interviews – HCPs



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#### Semi-structured interviews Topic guides for healthcare professionals

(Exact questions have not been developed as the researcher wishes to see what topics come from the observations)

- 1. Your understanding of aphasia and communication
- 2. Experience communicating with a person with aphasia
- 3. Training to work with a person with aphasia
- 4. Impact of aphasia on rehabilitation practice
- 5. Rehabilitation in a person's home

# Appendix XIV

Research governance, study information and consent: Topic guide for interviews – PWA



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#### Semi-structured interviews Topic guide for the person with aphasia

(Exact questions have not been developed as the researcher wishes to see what topics come from the observations)

- 1. Your experience of stroke and aphasia
- 2. Communication with rehabilitation team members
- 3. Goals and hopes for rehabilitation.
- 4. Setting of intervention
- 5. Opportunities to practice speech or talking

# Appendix XV

# Jeffersonian transcription conventions

Symbol	Name	Use
[ text ]	Brackets	Indicates the start and end points of overlapping speech.
=	Equal Sign	Indicates the break and subsequent continuation of a single interrupted utterance.
(# of seconds)	Timed Pause	A number in parentheses indicates the time, in seconds, of a pause in speech.
(.)	Micropause	A brief pause, usually less than 0.2 seconds.
. or ↓	Period or Down Arrow	Indicates falling pitch.
? or ↑	Question Mark or Up Arrow	Indicates rising pitch.
,	Comma	Indicates a temporary rise or fall in intonation.
-	Hyphen	Indicates an abrupt halt or interruption in utterance.
>text<	Greater than /Less than symbols	Indicates that the enclosed speech was delivered more rapidly than usual for the speaker.
<text></text>	Less than /Greater than symbols	Indicates that the enclosed speech was delivered more slowly than usual for the speaker.
0	Degree symbol	Indicates whisper or reduced volume speech.
ALL CAPS	Capitalised text	Indicates shouted or increased volume speech.
underline	Underlined text	Indicates the speaker is emphasising or stressing the speech.
:::	Colon(s)	Indicates prolongation of an utterance.
(hhh)		Audible exhalation
? or (.hhh)	High Dot	Audible inhalation
( text )	Parentheses	Speech which is unclear or in doubt in the transcript.
(( italic text ))	Double Parentheses	Annotation of non-verbal activity.

# Appendix XVI

### Initial Codes: HCP interviews

Adapting communication	Interesting work	
Adapting sessions and rehabilitation procedures	Impact of aphasia on the PWA	
Anxiety working with PWA	Job satisfaction	
Avoidance of communication	Listening to the client	
Bodily position of PWA & HCPs in rehabilitation session	Learning	
Challenging working with PWA	Opportunities for independent practice in home environment	
Communication in the home environment	Pressures in different contexts	
Comparison between different patients	PWA being with their family	
Constraint induced learning	PWA emotions in the home environment	
Control	Rapport development	
Conversation partners	Rehabilitation practice in their environment	
Distractions/lack of distractions	Rehabilitation results	
Encouraging independence	Rewarding work	
Emotions towards aphasia and PWA	Structure of rehabilitation session	
Experience of HCPs	Supported communication training	
General public's understanding of aphasia	Therapy materials	
Going into the person's home environment	The HCPs characteristics	
HCP emotions in the home environment	The methodology of the research	
HCP-English as a second language	The influence of different severities of aphasia	
Importance of body language	Time spent with PWA	
Importance of communication in rehabilitation	Training about aphasia	
Information about aphasia for PWA and their families'	Training and information on speech and language therapy	
Improvising with rehabilitation materials in the home environment	Travel	
Inter-disciplinary work	Use of space in the home environment	
Intensity of practice	Working with people including PWA	
Intensity of visits	Variety of work	

# Appendix XVII

# Initial Codes: PWA interviews

Accent	Embarrassing	Missing HCPs
Acceptance of stroke/aphasia	Ending rehabilitation block	Mood
Adapting their communication	Enjoyable rehabilitation	Motivation
Adapting their lifestyle	Explaining rehabilitation procedures	Movement in sessions
Anxiety	Family goals	Naturalistic conversation
Aphasia-invisible disability	Family involvement	Nerves
Attitudes of HCPs towards aphasia	Feedback	NHS pressures
Avoidence of communication	Feeling silly	Non-verbal communication
Avoidence of activities	Feeling stuck	Opportunities for conversation
Awareness of aphasia	Feeling lucky	Optimism
Bad experience of aphasia	Feeling valued	Pain
Being dependent	Flexible communication	Patient goals
Benefit of home environment	Frustration	Patient led
Blame	Functional tasks	Peer support groups
Bodily position of HCPs in rehabilitation	Further to go with progress	Personality factors
Building rapport	'Get on with it'	Practice
Change in appearance	Getting back to normal	Progress
Change in identity	Getting out of the house	Prompts
Change in lifestyle	Giving the PWA time	Reassurance
HCPs checking on wellbeing PWA during rehabilitation	Grateful	Relaxed
Closing the session	Guilt	Rehabilitation environment
Comfortable	Нарру	Reluctance to communicate
Communicating with HCPs	HCP adapting communication	Saliency of materials
Communication difficulties	HCP personalities/characteristics	Salieny of rehabilitation
Communication practice	Home based rehabilitation	Saliency of the environment
Community	Норе	Satisfaction with care
Co-morbid difficulties	Impairments-limbs	Stressful wards
Making comparisons to others	Importance of humour	Success
Confidence	Importance of eye contact	Supported communication
Control of conversation	Importance of having others in their life	Task driven conversation
Control of environment	Talking for them	Technology
Control of rehabilitation	Intensity of rehabilitation	Time
activities		
Conversation as a distraction	Involving the family in rehabilitation	Unable to do things they wish to
Conversation partner	Listening to the client	Unawareness of having a stroke
Distractions in the environment	Living alone	Understanding of aphasia
'Don't know what you've got until you're gone'	Loss of their voice	Vingettes
Determination	Materials	Worst impairment
Deisre to help others	Methodology	

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