

# The development, feasibility, and acceptability of a Breakfast Group Intervention for Stroke Rehabilitation

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# Abstract

**Background:** There are 1.2 million stroke survivors in the UK and the number is projected to increase significantly over the next decade. Research suggests that between 50% and 80% of hospitalised stroke survivors experience difficulties with eating and drinking. Presently, rehabilitation approaches to address these difficulties involve individual rehabilitation sessions led by uni-professionals. Recent national stroke guidance recommends that stroke survivors receive three hours of daily rehabilitation and emphasises the importance of addressing the psychosocial aspects of recovery. Implementing these recommendations presents a challenge to healthcare professionals, who must explore innovative methods to provide the necessary rehabilitation intensity. This study aimed to address these challenges by codesigning a multi-disciplinary breakfast group intervention and implementation toolkit to improve psychosocial outcomes.

**Methods:** The Hawkins 3-step framework for intervention design was used to develop a multidisciplinary breakfast group intervention and to understand if it was acceptable and feasible for patients and healthcare professionals in an acute stroke ward. The Hawkins 3-steps were 1) evidence review and consultations 2) coproduction 3) prototyping. In collaboration with fifteen stakeholders, a prototype breakfast group intervention and implementation toolkit were codesigned over four months. Experience-based Codesign was used to engage stakeholders.

**Results:** The literature review is the first to investigate the psychosocial impact of eating and drinking difficulties post stroke. The key finding was the presence of psychological and social impacts which included, the experience of loss, fear, embarrassment shame and humiliation as well as social isolation. Stroke survivors were striving to get back to normality and this included the desire to socially dine with others. Two prototype iterations of the intervention were tested with 16 stroke survivors across three hospital sites. The multidisciplinary breakfast group intervention was designed to offer intensive rehabilitation in a social group context. The codesigned implementation toolkit guided a personalised and tailored approach. A perceived benefit of the intervention was the opportunity to address the psychosocial aspects of eating and drinking rehabilitation as well as providing physical rehabilitation. Stroke survivors highly value the opportunity to socialise and receive support from their peers. The intervention was acceptable to both patients and healthcare professionals, and the workforce model proved practical and feasible to deliver using a collaborative approach in the context of resource-limited healthcare.

**Conclusions:** The breakfast group interventions, developed through codesign, were positively received by patients and staff and feasible to deliver. They introduce an innovative and novel approach to stroke rehabilitation, personalised to each individual's needs, and offer a comprehensive intervention which addresses both physical and psychosocial aspects which target challenges related to eating and drinking. Unique contributions of this study include a theoretical model for breakfast group interventions, a programme theory and practical tool kit for clinicians to support the translation of research findings and implement breakfast groups in clinical practice.

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# Declaration

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

All images in this presentation have been taken by myself. The use of images and audio recorded during this project has been approved by the North West Ethics Committee and all those in the photos have provided informed consent for their image to be used in this thesis and for dissemination purposes.

## A Stroke Survivor's Sketch

### Breakfast Group

'Coor! Meals we loved.'



*Reproduced with permission of the artist 2023*



# The Main body of the Thesis

## Chapter One: Introduction

### Chapter Summary

This Chapter provides the focus of the PhD research, which aims to develop and investigate the feasibility and acceptability of a codesigned breakfast group intervention in acute stroke rehabilitation. It sets the context for the study by introducing the aims and objectives, research design and methods. It describes the clinical presentation of stroke, the stages of recovery and the consequences of eating and drinking difficulties. Within this Chapter, the concept of breakfast groups in stroke rehabilitation is introduced, alongside an explanation of why this topic was chosen. It describes how the selected methods align with personal and professional values. This Chapter concludes with an outline of the thesis structure.

### 1.1 Focus of the PhD

The primary clinical focus of the PhD revolves around addressing the eating and drinking challenges encountered by stroke survivors after a stroke. Manifestations of eating and drinking difficulties vary considerably but commonly they interfere with the ability to consume enough food and drink and they also affect the enjoyment of eating experiences (Klinke et al., 2013). In the UK stroke population as many as 50 –80% of hospitalised patients have eating and or drinking difficulties putting them at greater risk of malnutrition and dehydration (Jacobsson et al., 2000; Westergren et al., 2001; Poels et al., 2006).

### 1.2 Stroke

#### 1.2.1 What is a stroke?

The World Health Organisation (WSO) defines stroke as:

*“A clinical syndrome consisting of rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin”.* (NICE, 2008)

The pathology of a stroke is classified by reduced blood flow to areas of the brain cutting off the oxygen supply and subsequently damaging or killing brain cells (Intercollegiate Stroke Working Party, 2016). The first signs of a stroke can include a facial droop, impaired movement, slurred speech, mental disorientation, or confusion.

It is estimated that there are 12.2 million new strokes per year, one every three seconds with 101 million stroke survivors worldwide. Stroke is the leading cause of death and the third leading cause of disability globally (Langhorne and Ramachandra, 2020). The estimated cost of stroke to the global economy is 891 billion US dollars (Feigin et al., 2022).

Most people will survive a stroke but live with the long-term consequences (Langhorne, et al., 2011). Stroke impacts are multifactorial affecting cognition, vision, motor function,

sensation, emotions, and communication, which can result in life-changing disabilities. The most common and widely recognised impairment caused by stroke is motor impairment, which can be regarded as a loss or limitation of function in muscle control or movement or a limitation in mobility. Post-stroke motor impairment typically affects approximately 80% of patients in the acute phase, affecting the control of facial, arm and leg movements on one side of the body. In the chronic phase, this impairment persists in about 40% of stroke patients (Hattem et al., 2016). Approximately 70% of stroke survivors experience loss of arm function and 40% go on to have continued problems (Royal College of Physicians, 2023). Swallowing difficulties are also a common consequence of stroke with 37-78% of stroke survivors experiencing swallowing difficulties (Martino et al., 2005).

### 1.2.2 Prevalence and economic impact of stroke

There are 100,000 new individuals having strokes each year (Stroke Association, 2018). It is one of the top five causes of early death in the UK (NHS England, 2019) with a stroke occurring every five minutes (Stroke Association, 2018). Stroke is a preventable disease and one of the leading causes of acquired disability in the world (Langhorne and Legg, 2003).

Considering the ageing population and increased survival rates, the global burden of stroke is set to rise in the future (Legg et al., 2017a; Ranford et al., 2019). In the UK, the number of stroke survivors living with a disability is predicted to increase by a third in 2035 (NHS England, 2019). In Europe, the associated costs of stroke are projected to increase by 44% between 2017-2040 (Stroke Alliance for Europe, 2017).

### 1.2.3 What is stroke rehabilitation?

Individuals who have had a stroke need access to effective specialist services which include healthcare professionals skilled and experienced in stroke-specific knowledge and a specialist team of different disciplines who work together regularly (Royal College of Physicians, 2023). The National Institute for Health and Care Excellence define stroke rehabilitation as:

*“A multi-dimensional process, designed to facilitate restorative adaptation to the loss of physiological or psychological function when reversal of the underlying pathological process is complete.”* (Nyong and Playford, 2017).

Stroke rehabilitation encompasses several key aspects, including the assessment, and identification of difficulties with activities of daily living, the formulation of treatment strategies and personalised goal setting (Nyong and Playford, 2017). Specialist neurological interventions are delivered to support stroke survivors to regain their function or support adaptation to the consequences of stroke impairment. Stroke services are required to provide evidence of adherence to the optimal practices outlined in the National Clinical Guidelines for Stroke in the UK and Ireland (Royal College of Physicians, 2023).

#### 1.2.3.1 The principles of neurorehabilitation

Neurological rehabilitation is characterised as a multifaceted intervention due to its numerous interconnected elements and the presence of varying levels of complexity (Redfern et al., 2006; Moore et al., 2015). In the stroke research literature, Ballinger and colleagues (1999) were the first to introduce the term ‘black box’ in relation to stroke rehabilitation intricacy. Subsequently, a multitude of stroke studies have sought to unpack

the complexity of stroke rehabilitation and understand the contexts, mechanisms, and outcomes that influence changes in stroke rehabilitation and dispel the notion of a mysterious 'black box' (Bode et al., 2004; DeJong et al., 2004; Conroy, Hatfield, and Nichols, 2005; Arienti et al., 2022).

Maier, Ballester and Verschure, (2019) conducted a conceptual analysis of neurological rehabilitation principles based on a meta-analysis of 17 experimental studies. Their objective was to understand the specific components of neurological rehabilitation interventions. They identified 15 principles grounded in scientific knowledge and theory, which clinicians and researchers can employ to structure new and current intervention protocols. Amongst these principles, the three most pertinent to this study were practice, feedback, and goal setting, which will be elaborated on in the following sections.

#### 1.2.3.2 Practice

Six of the neurorehabilitation principles relate to the practice of a task such as an activity of daily living or the practice of a movement (repetitive practice, distributed practice, dosage, task-specific practice, variable practice, grading/increasing difficulty). According to Maier, and colleagues (2019) practice can be consistent and prolonged, distributed over several days and weeks, and varied according to a specific sequence or have no order to the tasks which are described as random. Practice can also be a cognitive exercise such as visualising a particular movement or task and observing actions to replicate them (motor imagery, action observation (Maier, Ballester and Verschure, 2019).

Schmidt and colleagues (2018), found that repetition and learning are important components that induce changes in brain function, thereby enhancing performance. Stroke recovery is thought to include a phenomenon known as neuroplasticity which is defined as *'the brain's ability to reorganise and change in response to experience or after brain damage'* (Kennedy, 2021). Neuroplasticity is thought to manifest at the molecular and cellular levels during stroke recovery. It entails the formation of new connections amongst neurons, or the brain compensating by activating previously unused neural pathways (Kennedy, 2021). A growing number of studies suggest that task-specific training can contribute to this reorganisation of the brain reorganisation, ultimately influencing longer-term outcomes (Hubbard et al., 2009; Schmidt et al., 2018; Kennedy, 2021).

#### 1.2.3.3 Feedback

Five neurorehabilitation principles were associated with auditory, sensory, vestibular & motor feedback (multisensory stimulation, rhythmic cueing, explicit feedback/knowledge of results, implicit feedback/knowledge of performance, and modulate effector selection). These concepts can be categorised into two overarching terms. The first is referred to as 'intrinsic feedback' which is the stroke survivor's sensory and proprioceptive functions operating unconsciously during the performance of a task. The second is 'extrinsic feedback' which involves conscious information which is provided to the stroke survivor from an external source. Also known as 'knowledge of results' and 'knowledge of performance'.

Intrinsic feedback plays a fundamental role in the process of motor relearning (Schmidt et al., 2018; Rajda et al., 2023). During the intervention, all human senses were actively

engaged in the tasks. Patients utilised their sensory abilities for activities such as walking, balancing, sitting, and food and drink preparation, as well as eating and drinking. Additionally, it is believed that providing verbal feedback during task execution can positively influence performance (Vliet, et al., 2006; Stanton et al., 2015; Levin and Demers, 2021).

#### 1.2.3.4 Goal Setting Theory

Maier and coauthors (2019) describe goal-oriented practice as a principle of neurorehabilitation. Scobbie, and colleagues (2011) describe three theories that influence goal-setting interventions in rehabilitation 1) social cognitive theory specifically Bandura's work on self-efficacy (Bandura, 1978) 2) Lock and Latham's goal-setting theory (Locke and Latham, 2002) 3) health action process approach (Schwarzer and Hamilton, 2020). They articulate a gap in evidence for a theory-based goal-setting framework to guide clinicians (Scobbie, et al., 2011).

Despite the extensive research conducted by Scobbie and colleagues in the field of goal setting within stroke rehabilitation (Scobbie, et al., 2009; Scobbie, Dixon and Wyke, 2011; Scobbie et al., 2013, 2015, 2020; Brown et al., 2021), research has largely been focused on the value of goal setting as an outcome measure rather than on developing theoretical frameworks to underpin goal setting processes (Scobbie, et al., 2011).

Goal setting in stroke rehabilitation is fundamental to therapeutic programmes as goals play a significant role in motivating and directing human behaviour (Wade, 2009). However, there are some uncertainties about the mechanisms for goal setting that are most effective (Wade, 2009; Scobbie et al., 2015). A twenty-year systematic review of goal-setting literature found multiple barriers for stroke survivors to contribute and participate in goal-setting despite most clinicians believing the process was patient-centred (Rosewilliam, et al., 2011). The review also reported that stroke survivors preferred goals related to mobility, participation, and social integration. Whereas healthcare professionals tend to prioritise goals related to impairment (Scobbie, et al., 2009). This suggests that there are fundamental differences in the viewpoints and experience of goal setting, particularly in terms of the goals that hold significance for patients. In addition, this current practice is at odds with the definition of goal setting as a collaborative process to enact change through a person-focused rehabilitation intervention (Scobbie, et al., 2009; Connor, et al., 2023).

### 1.3 The complexity of eating and drinking difficulties

Research shows that eating and drinking difficulties can cause serious disruptions to health, well-being, and quality of life (Westergren et al., 2001, Perry and McLaren, 2004). The complexity of eating and drinking challenges are widely reported in the literature (Perry and McLaren, 2003; Medin, Larson, von Arbin, et al., 2010). Early interventions to address the complexities are recommended to improve long-term outcomes (Royal College of Physicians, 2023).

Problems arising include a high prevalence of malnutrition (Poels et al., 2006) and dehydration (Westergren, 2006), reduced muscle strength (Veerbeek et al., 2014), low mood (Torrise et al., 2018), pneumonia (Bath, Lee, and Everton, 2019) and pressure ulcers (Westergren et al., 2001). These complications are thought to lead to higher mortality rates and longer stays in hospital (Westergren et al., 2001; Poels et al., 2006; Johansson and

Johansson, 2009; Medin, Larson, Von Arbin, *et al.*, 2010; Attrill *et al.*, 2018; Eltringham *et al.*, 2018).

### 1.3.1 The psychological impact of eating and drinking problems

The psychological impact of eating and drinking difficulties are less well-known (Moloney and Walshe, 2018). Stroke survivors report feelings of shame and humiliation, (Jacobsson *et al.*, 2000) bewilderment, dismay, and despair (Perry and McLaren, 2003b) and a loss of pleasure from reduced engagement in social eating (Jones and Nasr, 2018).

Klinke and colleagues (2013) found that stroke survivors who were incapable of maintaining acceptable table manners and etiquette experienced psychological distress. Dependency on others for support with eating and drinking (Jacobsson *et al.*, 2000) and a lack of control of eating habits were thought to impact negatively on mood (Medin, Larson, Von Arbin, *et al.*, 2010). Stroke survivors describe how the change in eating habits results in feeling 'child-like' and this can result in avoidance of social dining situations (Klinke *et al.*, 2013; Jones and Nasr, 2018). This could be one explanation for why individuals post-stroke experience feelings of social isolation related to regaining and integrating back into life after stroke (Haun, *et al.*, 2008; Salter *et al.*, 2008).

### 1.3.2 The social impact of eating and drinking difficulties

Social dining carries symbolic meaning in virtually all cultures and therefore it is a matter of considerable social importance (Mennell, *et al.*, 1992). There are long-held traditions in society connecting eating and drinking with religious and cultural events (Fischler, 2011; *et al.*, 2021). Therefore the social impact of eating and drinking difficulties is of paramount importance regarding integration back into daily life (Jacobsson *et al.*, 2000; Carlsson, *et al.*, 2004; Medin *et al.*, 2010; Klinke *et al.*, 2014).

In earlier studies, individuals who had experienced stroke expressed a strong desire to regain their eating and drinking abilities, irrespective of any disabilities they may have had. They considered this recovery essential for their overall health and sense of well-being (Jones and Nasr, 2018). This perspective supports the findings of Perry and McLaren (2003b) who found that stroke survivors have a strong inclination to regain their normal appearances and to conceal any signs of disability, particularly when in social dining situations. Other studies also highlight the significance of individuals' well-being and enjoyment when dining in social settings (Jacobsson *et al.*, 1996; Westergren, Ohlsson and Hallberg, 2001; Westergren, 2008). Consequently, when formulating rehabilitation programmes, it is important to consider the obstacles that may impede social engagement in eating and drinking activities (Jacobsson *et al.*, 1996; Westergren, *et al.*, 2001; Perry and McLaren, 2003; Westergren, 2008).

## 1.4 Evidence relating to eating and drinking interventions

Stroke survivors need to re-learn the ability to eat and drink or build up their skills to adapt to life-changing impairments (Jacobsson *et al.*, 2000). Traditionally rehabilitation for eating and drinking difficulties would be delivered through individual face-to-face therapy sessions. Alternatively, health professionals might engage in collaborative work with individuals to combine approaches and interventions.

Rehabilitation for eating and drinking difficulties might encompass interventions such as using assistive devices for compensation, task-specific training, and modifications. Individuals experiencing swallowing difficulties might be considered for dysphagia rehabilitation which could include muscle-strengthening exercises and neuromuscular electrical stimulation. A recent Cochrane review on swallowing therapy found that interventions such as acupuncture, behaviour interventions, medication, physical stimulation, and electrical stimulation, lead to improvements in swallowing ability, reducing the risk of chest infections and stays in hospital (Bath, Lee, and Everton, 2018).

If stroke survivors have difficulties with upper limb function, there is good quality evidence for interventions such as electrical stimulation, intensive repetitive task-specific training, mental practice, and constraint-induced therapy (Royal College of Physicians, 2023 p91). National Clinical Stroke Guidelines recommended a mixture of one-to-one interventions and group work enhanced by self-directed or semi-supervised practice (Royal College of Physicians, 2023 p.65).

Although group work is suggested for motor impairment (Royal College of Physicians, 2023 p.85), communication therapy (Royal College of Physicians, 2023 p.129) peer support (Royal College of Physicians, 2023 p.171) and psychosocial education (Royal College of Physicians, 2023 p.68) there are no references to group interventions specifically for eating and drinking difficulties and relatively little is understood about using breakfast group interventions in the stroke rehabilitation literature.

### 1.5 The importance of breakfast

Breakfast is widely regarded as the most important meal of the day (O'Neil, Nicklas and Fulgoni, 2014; Gaal et al., 2018; Fayet-Moore et al., 2019). Fayet-Moore and colleagues (2019) define breakfast as a meal composed of items belonging to the sub-major food groups, typically enjoyed during the mornings.

Scholars seem to agree that the consumption of breakfast is associated with a higher intake of fibre (Gaal et al., 2018; Fayet-Moore et al., 2019), essential nutrients and a higher calorie intake that can positively influence metabolism (St-Onge et al., 2017; Fayet-Moore et al., 2019). Researchers suggest that breakfast should contribute to 20%-25% of the total daily intake of nutrients required (Gaal, Maeve A. Kerr, et al., 2018). Having a regular breakfast meal is also positively associated with a lower body mass index and lower prevalence of obesity (O'Neil, Nicklas and Fulgoni, 2014; St-Onge et al., 2017; Fayet-Moore et al., 2019) as well as enhanced cognitive function (Gaal, Maeve Kerr, et al., 2018; Pritlove et al., 2020).

People who do not take breakfast are referred to in the literature as 'breakfast skippers' (St-Onge et al., 2017; Gaal, Maeve A. Kerr, et al., 2018). Breakfast skipping has been associated with a higher prevalence of cardiovascular disease (St-Onge et al., 2017; Fayet-Moore et al., 2019) and obesity (O'Neil, Nicklas and Fulgoni, 2014; St-Onge et al., 2017; Fayet-Moore et al., 2019). Adequacy of nutrition and hydration plays an important part in stroke recovery (Westergren, Ohlsson and Hallberg, 2001; Westergren, 2006, 2008). This collection of research indicated that rehabilitation interventions associated with improving nutrition and



hydration, particularly during the breakfast period could have the potential to optimise stroke care and have other associated health benefits.

#### 1.5.1 Clinical practice and breakfast interventions

As outlined in Chapter 5's stakeholder consultations, health care professionals have been experimenting with the implementation of breakfast groups for the delivery of eating and drinking rehabilitation. In clinical practice, there is a growing trend towards group-based rehabilitation as it proves to be an effective way to increase the number and dose of interventions aligning with the Royal College of Physicians guidance (2023). Based on the insights gained from the consultations in Chapter 5, healthcare professionals regarded breakfast group interventions as a means of intensifying treatment and providing strategies for addressing issues related to eating and drinking difficulties.

A typical breakfast group intervention starts with stroke survivors preparing their breakfast. They mobilise or have assistance to mobilise to a designated workstation equipped with the necessary equipment, food, and drink products. Assistance is given to make and consume the breakfast. Physical support is offered for both the preparation and consumption of the breakfast which includes hands-on facilitation of limb movements, postural support, and assistance with tasks. Whilst participating patients receive specific interventions from members of the multidisciplinary team. This intervention could be swallowing exercises with Speech and Language Therapy or facilitation of the upper limb with Occupational Therapy.

Whilst the participants are consuming breakfast they are encouraged to engage in social conversation, a natural conversation sparked spontaneously or a more contrived conversation e.g., using newspapers to discuss current affairs. The social aspects of a mealtime intervention are referred to in the literature as 'communal dining' (Baptiste, Egan and Dubouloz-Wilner, 2014) or 'social dining' (McLaren-Hedwards et al., 2021). The preferred term for this study is 'social dining'. Although the benefits of social dining have been explored in other clinical specialities such as dementia care (Bunn et al., 2016), geriatrics (Wright, Hickson and Frost, 2006; McLaren-Hedwards et al., 2021) and mental health (Absolom and Roberts, 2011) there is very little written about the concept of social dining in stroke rehabilitation.

#### 1.6 The importance of coordinated multidisciplinary stroke care

A recent Cochrane Review on organised and structured inpatient stroke care found moderate quality evidence to support the view that specialised and coordinated stroke care was likely to result in improved patient outcomes (Langhorne and Ramachandra, 2020). This is supported by Chiu and colleagues (2021) who conducted a large-scale prospective study to establish the effectiveness of post-acute multidisciplinary stroke care.

Langhorne and colleagues (2002) report that characteristics of effective stroke care include co-ordinated practice which they define as '*the same tasks carried out by different staff*'. National Stroke Guidance (2023) regards an intensive coordinated multidisciplinary approach as good practice for supporting stroke recovery. The literature lacks a clear consensus on the definition of multidisciplinary coordinated practice in stroke rehabilitation (Langhorne,

Coupar and Pollock, 2009) although several key features are described as illustrated below in Figure 1.

The core ingredients are a holistic collaborative effort to optimise rehabilitation and potential recovery (Miller et al., 2010; Aries and Hunter, 2014), individualised programmes of care (Miller et al., 2010) and a twenty-four-hour approach (Aries and Hunter, 2014). Aries and colleagues (2014) highlighted the importance of shared knowledge and skills with all disciplines working to a similar level of knowledge (Figure 1). Miller and coauthors (2010) describe each discipline as contributing distinct value to the process with a shared commitment to the delivery of evidence-based approaches. They also propose the integration of repetitive practice of movement and activities of daily living are incorporated as well as collaborative teamwork (Miller et al., 2010). This suggests that a coordinated multidisciplinary approach to stroke care is an important characteristic for improved outcomes (De Villiers, Kalula and Burch, 2009; Aries and Hunter, 2014; Chiu et al., 2021)

Figure 1: Key features of co-ordinated multidisciplinary stroke care gathered from the literature.



### 1.7 The research gap

The National Clinical Stroke Guidelines (Royal College of Physicians, 2023) do not offer any recommendations on group eating and drinking interventions. In the literature, the evidence for breakfast group interventions is largely anecdotal reports and limited in its scope. It could be argued that there have been instances of success with breakfast groups in other specialised areas but the applicability to a broader context remains uncertain, given the limited scale of studies and lack of methodological robustness.



There are a limited number of stroke studies exploring social dining and enriched environments to improve nutritional intake, but these have failed to show clinically significant results (Janssen et al., 2014; Robertson et al., 2020). A study by Rosbergen and colleagues (2019) explored the impact of enriched environments on the uptake of eating and drinking activities but the results were not statistically significant. Enriched environments feature additional equipment and support, and the environment is conducive to patients helping themselves. Although there is evidence to suggest that enriching the environment could impact nutrition and hydration and encourage stroke survivors to do more for themselves, the evidence is not strong enough to be recommended in National Clinical Guidance.

Breakfast groups are being used in UK clinical practice, however, there have been no stroke research studies to determine whether they are acceptable, feasible or effective. A small Irish study focuses on optimising physical assistance with feeding in a mixed geriatric and stroke ward (Teeling et al., 2019). Researchers measured food waste for seven patients over three mealtimes and used an improvement methodology to explore ward processes. Findings suggest that by aiding with functions of eating and drinking there was a reduction in food waste of 0.43kg per person per day and there were no new incidences of aspiration pneumonia (Teeling, et al., 2019). The study leaves unanswered questions and relatively little can be drawn from it other than the possibility of physical assistance improving nutritional and fluid intake.

Clinical practice has not yet reached a consensus on the optimal approach for delivering breakfast group interventions, making this a crucial area for exploration. National guidance emphasises the advantages of group interventions in stroke rehabilitation (NICE, 2023) and social dining interventions in other clinical specialities have demonstrated some positive outcomes (Clendenen et al., 1994; Baptiste et al., 2014; Hung, et al., 2016). There is a call for more research into psychosocial interventions in stroke rehabilitation (NICE, 2023). The recently published National Stroke Service Model advocates for stroke services that involve stroke survivors in stroke care developments and value the voices of patients and the public (Lowe and Powell, 2021). They also recommend addressing the psychosocial impacts that hinder stroke recovery as part of the rehabilitation process. This is outlined below:

*“The entire MDT must address the psychological, emotional, cognitive and neuropsychological effects commonly experienced by stroke survivors; these can greatly impact a person’s engagement with rehabilitation, function, ability to return to work and ultimately the quality of life”. (Lowe and Powell, 2021).*

A study that provides clarity on breakfast group interventions that meets the needs of patients, and staff and adheres to national clinical guidelines is needed. In this research, a multidisciplinary team intervention is created to address psychological and social aspects related to eating and drinking difficulties, with the intention of preventing longer-term consequences of stroke impairment. This study has the potential to influence the management of stroke in acute inpatient wards and to shape the formulation of new models of care for the rehabilitation of eating and drinking abilities.

## 1.8 Aims and Objectives

### Aim:

To codesign a breakfast group intervention and implementation toolkit to improve the way eating and drinking rehabilitation is delivered in an acute stroke unit.

### Objectives:

- I. Review research evidence and theories relevant to rehabilitation of eating and drinking difficulties, to inform intervention development and design.
- II. Codesign with relevant stakeholders a breakfast group intervention and supporting implementation toolkit.
- III. Iteratively develop and test the feasibility and acceptability of the prototype intervention and accompanying toolkit in three stroke services.

## 1.9 Design and Methods

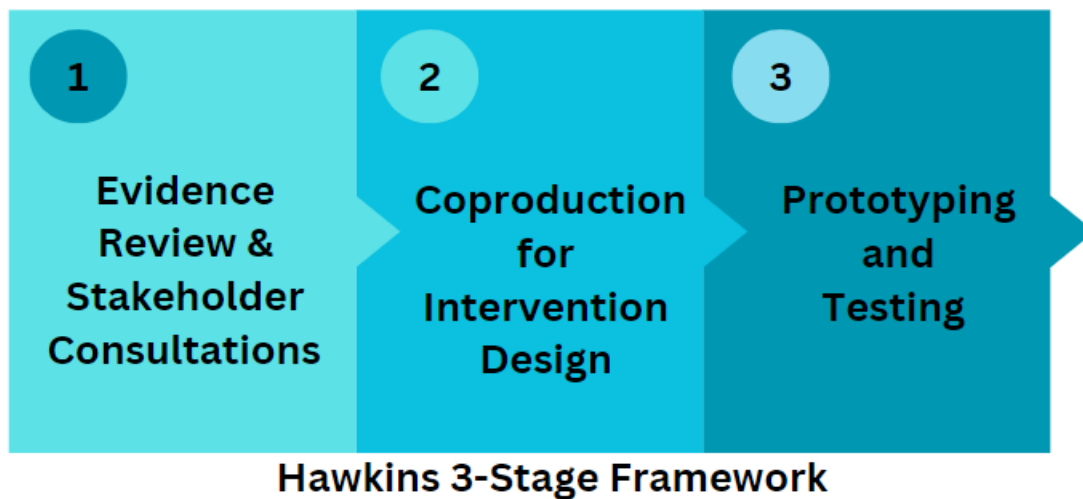
This Study titled '**B**reakfast group **i**nterventions in **s**troke **r**ehabilitation'- shortened to the acronym BISTRo was a mixed methods intervention development study, using participatory action research. Mixed methods research was used to investigate needs, attitudes, beliefs, experiences, and context to identify what intervention components are necessary, feasible and acceptable (O'Cathain, Murphy and Nicholl, 2007; Schoonenboom and Johnson, 2017).

### 1.9.1 Hawkins's three-stage framework for coproduction and prototyping

No single intervention development approach has been definitively demonstrated to be better than another. However, experts suggest that various approaches are used flexibly to suit different contexts, strengthen findings, and enhance intervention development (O'Cathain, et al., 2019). In this study, the 3-stage intervention development framework work devised by Hawkins and colleagues (2017) was deployed (Figure 2). Using a published approach to intervention development provides a structured and systematic process for the researcher to follow.

Hawkins and colleagues (2017) provide a step-by-step guide for the coproduction and prototyping of a public health intervention to prevent smoking in UK secondary schools described in Figure 2. This framework was selected as it provides pragmatic instruction to guide coproduction and prototype development with key stakeholders. Ensuring that the intervention content meets the needs of those delivering and receiving the intervention was paramount. Through a process of iterative prototyping, Hawkins's framework enabled researchers to address any design issues in the early stages of development (Hawkins et al., 2017).

Figure 2: Hawkins 3-Stage Framework for Coproduction and Prototyping.



In stage 1 relevant theories and evidence are examined to ensure that the intervention is based on the best evidence and clinical knowledge. Stakeholder consultations are held to gain greater insights into the problems associated with eating and drinking after stroke and the interventions available. In stage 2 a breakfast group intervention and implementation toolkit are iteratively coproduced. In stage 3 the intervention and toolkit are prototyped and tested for feasibility and acceptability in three UK stroke services.

#### 1.9.2 Experience-based Codesign

Hawkins and colleagues' (2017) three-stage framework is complemented by Experience-based Codesign (EBCD), an evidence-based collaborative approach aimed at improving the patient and staff experience in the UK health service. EBCD originated from the work of Professor Paul Bate and Dr Glenn Robert (2007). Initially developed within the NHS and tailored for the NHS, EBCD is founded on the core principle of putting the service user at the centre of the design process (Bate and Robert 2007). Bate and Robert (2007) describe the movement towards re-designing patients' services around the patient as a quiet revolution. Influenced by fields such as engineering and human-centred design, EBCD is a systematic approach to service improvement, employing participatory research methods such as observation and interviews to understand the problem being investigated (Bate and Robert, 2007).

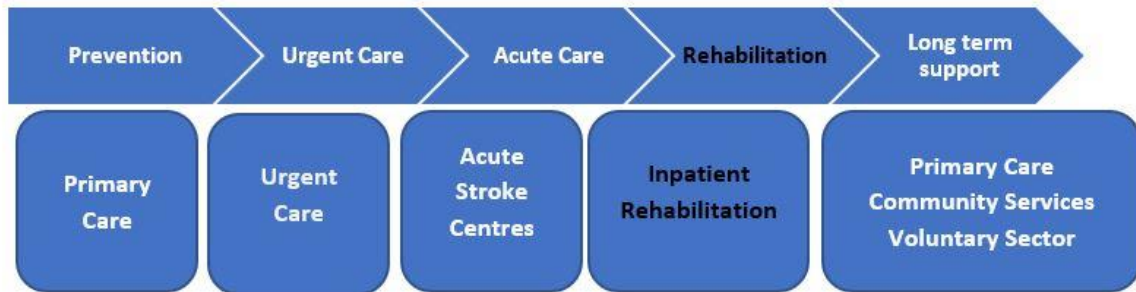
It is not unusual to combine two approaches to intervention development because one single approach does not encompass all the relevant considerations (O'Cathain et al., 2019). In this context, EBCD added to the dimension of stakeholder engagement and added service improvement methods to enhance to quality of the Hawkins 3-step framework (2017).

#### 1.9.3 Where breakfast group interventions fit in the stroke care pathway

Breakfast group interventions are typically conducted in the post-stroke inpatient rehabilitation phase, which usually follows the urgent care phase, approximately 72 hours after admission, illustrated in Figure 3. Inpatient stroke rehabilitation is usually positioned between the urgent care and acute stages before community rehabilitation.

The 2021 NHS England National Stroke Service Model (Lowe and Powell, 2021) mandates that on admission to hospital patients should have a rapid multi-disciplinary assessment and personalised rehabilitation plan which focuses on empowerment to meaningfully participate in rehabilitation. According to the National Stroke Guidelines, specialised stroke unit care should be initiated as soon as possible after the onset of stroke as it provides effective treatment that reduces long-term brain damage, disability, and healthcare costs (Intercollegiate Stroke Working Party, 2016).

Figure 3: Configuration of stroke services in the UK, five delivery phases.



### 1.10 My professional background and previous research

My professional background lies in the field of Occupational Therapy. I have a broad range of experience, but my clinical expertise and career-long passion is stroke rehabilitation. Throughout my career as a clinician, I observed that eating and drinking difficulties were having a significant impact on life after a stroke. This awareness motivated me to explore ways to alleviate the suffering caused by these impacts. I was successful in obtaining a National Institute for Health Research Patient and Public Grant which facilitated collaboration with stroke charities and enabled me to engage in discussions with stroke survivors and their carers about their unique experiences. I conducted visits to five stroke services in the UK to gather insights from clinicians on their perspectives on eating and drinking interventions. These early interactions sparked the initial formulation of research ideas for this study.

In 2015 I successfully attained an MSc in clinical research and since then have developed a portfolio career combining research roles with teaching and clinical leadership. My first study involved stroke survivors using disposable cameras to capture lived experiences. This was subsequently published in the British Journal of Occupational Therapy (Jones and Nasr, 2018). Although a relatively small participatory research study it provided important insights into the lived experience of stroke survivors with eating and drinking difficulties. This research revealed that stroke survivors expressed a desire for increased opportunities to practice eating and drinking skills during the early stages of rehabilitation. These findings served as inspiration for this extensive programme of research.

Food preparation interventions are core activities for Occupational Therapists working with stroke survivors (Boop and Smith, 2017; Boop et al., 2020). Although they are commonplace there is very little evidence for their effectiveness (Mohapatra and Kulnik, 2021). Based on my accumulated insights, literature review and extensive consultations it became evident

that a group intervention, encompassing food preparation and social dining could have the potential to be beneficial in addressing patients' needs. The literature also suggests that group interventions could increase the intensity and frequency of rehabilitation (English and Hillier, 2011; Sharp, 2018; Miller, 2020), aligning with the national clinical stroke guidance (Royal College of Physicians, 2023).

An important aspect of participatory research is the consideration of reflexivity, positionality, and power relations. Hand and coauthors (2019) discuss the potential barriers faced by older people engaging in participatory research and the lack of power and influence they can have on the research questions. Scholars outline the importance of understanding 'what and who' drives the project, ensuring that stakeholders have the power to influence the co-creation process (James, Blomberg and Liljekvist, 2015). Aligning to the principles of ethical participatory research the key stakeholder's voices should be heard and researchers need to be accountable for choices and decisions (James, Blomberg and Liljekvist, 2015). Reflexivity in this research will be discussed in Chapters 3 and 9.

In 2020 I commenced a Clinical Doctoral Research Fellowship funded by NIHR and HEE which has funded this PhD research.

### 1.11 Choice of methods and how these fit with my core beliefs and values

In all aspects of my work, I aim to keep patients and family at the centre. I value lived experience and aim to ensure that this influences how I design services and research programmes. I believe that rehabilitation interventions should be personalised and tailored to individuals' needs. I also believe that patients, carers, and families should be involved in all aspects of research processes. As an Occupational Therapist, I value meaningful occupations and seek to understand the impact of changes in occupational performance. I appreciate the complex interactions between the person, their occupational and their environment (Strong et al., 1999).

As a clinical leader in the NHS and a qualified service improvement coach, I have expertise in using improvement science methodologies to develop and transform clinical services. Developing a sustainable intervention that translates into clinical practice requires an element of organisational change. The 6-stages of the EBCD method provide a robust framework for stakeholder engagement to guide the codesign activities. By combining EBCD with the Hawkins 3-Stage Framework a structured process and clear framework for intervention design was established.

### 1.12 Thesis Structure

The research reported in this thesis is presented in 9 Chapters:

- Chapter 2 provides an overview of the background literature.
- Chapter 3 explains the aims, study design and methods. It includes the logic model and ethical considerations for the study.
- Chapter 4 reports the findings of Stage 1 of the Hawkins Framework and evidence review, a systematic review exploring the psychosocial impact of eating and drinking difficulties.

- Chapter 5 reports Stage 1 of the Hawkins Framework stakeholders' consultations including interviews with patients, carers and staff, ethnographic observations, and video recordings.
- Chapter 6 reports on Stage 2 of the Hawkins Framework coproduction. This Chapter presents the findings of the stakeholder workshops and how the intervention was iteratively developed.
- Chapter 7 reports Stage 3 of Hawkins Framework prototyping and how the intervention and implementation toolkit were tested in three hospital sites.
- Chapter 8 reports on the feasibility and acceptability of the intervention and the perceived benefits.
- Chapter 9 provides an overview of how the study met the aims and objectives, a summary of key findings in relation to the research and the original contribution to knowledge, strengths and limitations of the research, a dissemination plan and research impacts recorded to date.

The thesis is written in the third person except where it is appropriate for the content of the research to be written in the first person.

## Chapter Two: Background

### Introduction to the Chapter

This Chapter will focus on relevant literature for this PhD study. It sets the context for the field of research. Subsets of literature will be organised that provide a foundation for the context for eating and drinking intervention development. This will include an overview of food and drink consumption from a sociological and anthropological perspective. The exploration of the concept of commensality and the cultural significance of social dining within Western cultures. The Chapter will explore the implications of modification to eating and drinking after stroke along with the endeavours of stroke survivors striving to live a normal life. Furthermore, this Chapter will provide an overview of the relevant national clinical guidelines and the national stroke research priorities, highlighting the gaps, and shortcomings in evidence and how this original programme of study will contribute to the existing body of knowledge.

### 2.1 Food and drink as a symbol and pattern for social relations

Food and drink consumption is a necessity for life and is arguably one of the most important activities for human society. Mennell and colleagues' (1992) seminal text titled 'The Sociology of Food' pioneered the discourse around eating, diet and culture and illustrates the importance of food as a social construct.

Mennell discusses food and drink consumption and its relationship to socialisation and human culture (Mennell, et al., 1992). From the earliest origins as far back as 'homo erectus' connections have been made between food-seeking, cooking, and socialisation (Mennell, et al., 1992). It is thought that early food-related activities could have played a significant part in the development of human mental capabilities and social learning (Goudsblom, 1992). Sociologists and evolutionary anthropologists have studied eating, diet, and culture to understand social inequalities, class distinctions, and religious and ceremonial habits (Mennell, et a., 1992).

Functionalist anthropologists explored food production, preparation, and consumption in the context of social and psychological relationships (Richards and Widdowson, 1936). Whilst studying southern African tribes in 1930, Richards and Widdowson (1936) found a symbolic pattern of social relationships related to seeking food, preparing, and receiving food in tribal groups. Seeking food necessitated cooperation with other humans and preparing and receiving food played a part in maintaining social structures within the group (Richards and Widdowson, 1936). Although the functionalist approaches offered valuable insights into understanding food, culture, and social structures they were later criticised for failing to recognise the significance of conflict, individual agency, and human influence on social structures for eating (Goody, 1982; Fischler, 1988, 2011).

There is a significant amount of research covering the symbolic meaning of food in culture and religion around the world (Mennell, et al., 1992). Symbolic meanings fit with long-held traditions in families and wider society. An example is the tradition of a wedding cake, the baking, ceremonial cutting and sharing are related to a long tradition of nuptial feasting

dating back to the 16<sup>th</sup> century (Charsley, 1987). The value of food-related occupations such as sharing a meal, relaxing with friends and social dining is thought to facilitate and influence social relationships (Absolom and Roberts, 2011). Research suggests that regular family meals are associated with increased communication and play an important role in the well-being of the family (Goody, 1982; Utter et al., 2018). Sociologists argue that social positions in the family are directly related to food provision, preparation, sharing and consumption (Mennell, et al., 1992).

Mennell and colleagues (1992) discuss patterns of food consumption concerning three key variables, social class, age, and gender. Variations in food and drink consumption and cooking practices according to social class are widely reported (Hupkens, 2000; Beagan, Power and Chapman, 2015). Regarding age and food consumption research suggests that habits and behaviours acquired in childhood shape adulthood creating patterns that are resistant to change (Mennell, et al., 1992). Studies to clarify the differences in sex and food consumption and the division of labour regarding food activities are extensive (Counihan and Kaplan, 2005). Historically there has been a general assumption that cooking is a 'woman's work'. Research through a feminist lens has focused attention on gender imbalance and the power relationships concerning food production, provision, and consumption (Mennell, et al., 1992; Le Moal et al., 2021).

Research into the sociology of food is an emerging specialism. Sociologists believe that *"food and commerciality are complex constructs with multiple functions that signify rank, rivalry, solidarity, community, identity, inclusion, intimacy and distance"* Mennell et al., 1992). Thus it is more than a pattern, symbol, or demarcation among human groups, it also reflects power, control and autonomy and is therefore a fundamental part of our human nature.

## 2.2 Food and drink consumption in hospitals

In hospitals, there is a significant focus on the adequacy of nutrition and hydration to aid recovery and prevent ill health (Holdsworth, 2012; Ottrey et al., 2018). Malnutrition and dehydration in stroke rehabilitation can lead to increased morbidity, mortality, and extended stay in hospital (Poels et al., 2006). The prevalence of hospital-acquired malnutrition has been reported globally (Cereda et al., 2016; Ottrey et al., 2018). A recent Australian systematic review of 15 studies (between 2015 and 2020) showed that 10%-65% of patients experienced a nutritional decline whilst in hospital (Cass and Charlton, 2022). The studies were from eight different specialties including stroke, geriatrics, and acute medicine. Barriers to good nutritional care included interruptions, meal dissatisfaction, difficulties with swallowing, poor appetite and effects of illness or treatment (Cass and Charlton, 2022).

Moreover in institutions such as hospitals, patients are faced with a set menu which are delivered at regimented times and activities associated with eating and drinking are usually organisationally scheduled and imposed. As patients adapt to these routines their sense of autonomy and individual identity may undergo a form of institutionalisation, in contrast to the more intimate and unrestricted home environment where choices regarding what, where and when to eat are made more freely (Ottrey et al., 2018). In a qualitative analysis by Kitson and colleagues (2012) eating and drinking are identified as fundamental to stroke



care. Stroke survivors articulated difficulties with the mechanics of eating, food preparation and opening the packaging. Additional difficulties were a lack of support and poor-quality hospital food. Other difficulties and experiences will be elaborated further in section 2.5.

Several studies emphasise the importance of visitors and relatives bringing food to the hospital. Mennell and colleagues (1992) write about how food from home is valued as a symbol of individuality and autonomy. Ottrey and team (2018) observed 150 staff, volunteers, and visitors in two geriatric rehabilitation wards. They found that visitors played a key role in achieving patient-centredness by helping stroke survivors access food packaging, feeding individuals, and addressing psychosocial aspects of care.

### 2.3 Commensality, society, and culture

There are schools of thought that proclaim the act of eating and drinking together creates a bond of friendship (Mennell, et al, 1992; Fischler, 2011). Dunbar, (2009) debate that the bonding results from sharing and reciprocation. The act of eating together and social dining dates back to the 12<sup>th</sup> century. It has been described by anthropologists as '*commensality*', derived from the Latin term '*together at the table*' (Mennell, et al., 1992). Commensality is an expanding field of research however the origins of the term are debated in a critical discussion paper by Jönsson and colleagues (2021). The debate poses a question of meaning, does the term mean, sharing the food, the table, the place, or the moment? Fischler, (2011) argues that not all cultures have a table, but all cultures have rules, habits, customs, and acceptable norms associated with commensal dining.

Research on commensality starts with the seminal work of George Simmel's '*Sociology of the Meal*' where he presents 'the meal' as something that can be individual and shared (Simmel 1997). In later years it has been argued that in Western cultures eating is becoming less of a social activity and family mealtimes are declining as a result (Fischler, 1988, 2011). Society has changed the manner of meal times, meals are more flexible, and simplified, eating out and takeouts have become more popular and time spent cooking has been reduced (Fischler, 2011). This discourse is also shared by Falk, (1994). Falk (1994) proposes that loss of commensal eating habits and behaviours will result in a loss of social solidarity resulting in the shared meal being marginalised in modern society.

In recent times scholars dispute the decline of commensal eating and researchers such as Murcott and colleagues (2019) argue there is low-quality evidence supporting the view that social dining is on the decline. Murcott, (2019) and Jonsson (2021) suggest instead that social dining is going through a contemporary evolution. Fischler (2011) cautions that commensal dining is not always successful or a positive experience as people prefer to eat alone, and history has many examples when eating together has been a source of disharmony (Fischler, 2011).

### 2.4 Commensal dining in the hospital

Several studies describe the associated benefits of social dining in hospital environments however, these are largely in geriatric settings and not specific to stroke (Pietro and Boczko, 1998; Stroebele and De Castro, 2004). Research findings suggest that social dining groups with older people can positively influence food intake (Stroebele and De Castro, 2004;

Baptiste, et al., 2014). A few small studies have found that paying attention to the dining environment could identify further opportunities to improve the mealtime experiences of people in hospitals (Baptiste, et al., 2014; Ottrey et al., 2018; Robertson et al., 2020).

#### 2.4.1 Commensal dining in non-stroke specialities

Pietro and Boczko, (1998) explored the effectiveness of breakfast groups as a form of communication therapy with people experiencing mid-stage Alzheimer's disease in a Jewish care home in New York. They conducted a 12-week programme with four groups of patients in two groups who received a structured 5-day programme where they would prepare and eat breakfast together and two groups received standard care (Pietro and Boczko, 1998). Other goals for the intervention included practising cognitive skills, facilitating memory skills, stimulating senses, and preventing isolation. Findings suggest that patients receiving the breakfast group intervention had a significant increase in language skills, improved social relationships and memory function (Pietro and Boczko, 1998). The anecdotal observations of staff provide more insights into the potential benefits for improved mood, improved socialisation, and enjoyment. This small study (20 participants) offers some insights into the potential social benefits of social dining however the study report lacks important methodological details.

#### 2.4.2 Commensal dining in stroke care

Abouhajar and colleagues (2019) conducted a cross-sectional study of 20 patients over five weeks in an Irish stroke rehabilitation ward. Three to six patients were invited to participate in social dining for two days and dining by the bedside for two days. The study aimed to explore the impact of dining context on nutritional intake, mood, and levels of social interaction. This study exhibited some limitations, firstly the arrangements of the dining contexts were not fully explained and secondly only 25% of participants had swallowing difficulties. Findings suggest that there were no significant differences in meal consumption between the bedside and dining room consumption (Abouhajar et al., 2019).

These findings contrast with the findings of a similar study on an acute elderly ward where patients on one ward were taken to a communal dining room and patients on another ward had meals at their bedside (Wright, et al., 2006). This study found that patients experiencing social dining had a higher intake of calories and a trend towards weight gain (Wright, et al., 2006).

Results from the Abouhajar (2019) study suggested that consumption of meals increased with improved conversation increasing the mean consumption from 74% (95% CI = 53.66 - 95.06) to 98% (95% = 65.73 - 129.26) (Abouhajar et al., 2019). There were no associations between food consumption, mood, and social interaction however the patient surveys demonstrated positive outcomes related to social interaction and enjoyment. Only five staff surveys were returned, limiting generalisability however, they reported positive perceptions of the benefits of social dining (Abouhajar et al., 2019). In addition, staff reported that the environment could have been more 'home-like' and less institutional to enhance the patient experience (Abouhajar et al., 2019).

## 2.5 The perceived impact of modifications to diet and fluids

Adjusting food and fluid consistencies is a treatment intervention for people with swallowing difficulties post-stroke (Helldén, et al., 2018). Although modified diet and fluids are thought to reduce complications such as aspiration (McCurtin et al., 2018; Eltringham et al., 2019; Lin et al., 2021), stroke survivors experience a dislike of modifications to diet and fluids which can impact adherence to treatment regimens (Perry and McLaren, 2003b; McCurtin et al., 2018).

Undernourishment is a widely accepted consequence of difficulties with eating and drinking after a stroke (Helldén et al., 2018; Jacobsson et al., 1996; Johansson & Johansson, 2009; Jones & Nasr, 2018; Klinke et al., 2013, 2014; Medin et al., 2010; Perry & McLaren, 2003b; Schimmel et al., 2011; Westergren, Ohlsson, et al., 2001; Westergren, 2008). Stroke survivors described the impact of undernourishment on the ability to concentrate, alertness and energy levels (Westergren, et al., 2001; Westergren, 2008).

Perry and McLaren (2003b) as well as Helldén and colleagues (2018) observed that stroke survivors believed that modifications to food and drink consistencies could affect food choice, impact bowel and bladder function, and reduce the volume of intake. These changes were found to be burdensome for patients and families (Helldén et al., 2018; McCurtin et al., 2018; Perry & McLaren, 2003b).

Lin et al., (2021) discuss dissatisfaction manifesting from the appearance of pureed foods resulting in low appetite which suggests that patients and caregivers may lack knowledge of how to modify food and drink. Similarly, McCurtin et al., (2018) found stroke survivors who had experienced thickened fluids found them 'unpleasant and distasteful'. Despite participants intensely disliking thickened fluids, there is an understanding of the necessity to prevent health complications (Perry and McLaren, 2003b; McCurtin et al., 2018).

Practice recommendations suggest adherence to modifications could be improved by focusing on palatability (McCurtin et al., 2018), exploring personal preferences (Kumlien and Axelsson, 2002), understanding the burden on patients and carers and involving them in treatment decision-making (Eltringham et al., 2019). Lin and coauthors (2021) suggest that providing training on dietary modifications could address multiple issues.

## 2.6 Adjust, adapt, and accept a recovery trajectory

Carlsson (2004); and Kjaersgaard and Pallesen, (2020) describe recovery from eating and drinking difficulties as a uniquely individual experience lived in stages. Klinke and colleagues describe 'the fragility' of stages and how stroke survivors move organically back and forth between these stages during their recovery journey (Klinke et al., 2013, 2014). Stroke services report that the early stages of the post-stroke recovery focus on coping with fear and panic (Jacobsson et al., 2000), and coming to terms with what has happened (Eltringham et al., 2019). At the mid-stages stroke survivors move towards adapting and 'getting by' (Carlsson, et al, 2004) followed by striving for normal (Perry and McLaren, 2003a) and the realisation that life will not return to the way it was before (Jacobsson et al., 1996).

Changes in competence of eating and drinking performance have been found to improve over time (Jacobsson et al., 1997, 2000a). However, Perry & McLaren, (2003b) discuss how the adjustment to new strategies and better coping mechanisms can facilitate progress in the absence of physiological recovery.

The literature suggests that stroke survivors need to adjust and adapt to multiple changes in diet, weight, physical abilities as well as psychological and social well-being (Perry and McLaren, 2003b; Jones and Nasr, 2018). Adjusting, learning new skills, developing coping strategies (Jones & Nasr, 2018) and getting a better understanding of the body's strengths and limitations (Kjaersgaard and Pallesen, 2020) were found to help stroke survivors overcome barriers. Johansson (2009) and Klinke (2014) suggest that family, friends, and caregivers play a critical role in supporting the recovery and adjustment phase. Eltringham and colleagues (2019) also support the view that caregivers facilitate the implementation of recommendations for diet and fluid modifications.

Perry and McLaren, (2003a) also describe the acceptance of limitations as an important element in recovery. Acknowledgement of limitations and modifications (Helldén, Bergström and Karlsson, 2018), are thought to support acceptance. Due to the individualised nature of the recovery, tailored interventions (Eltringham et al., 2019) and individualised support are required to ensure the stroke survivor receives person-centred care (Klinke et al., 2014, Jones and Nasr, 2018)

## 2.7 Striving to live a normal life

Research findings suggest regaining normality is an essential element of the recovery process and stroke survivors have a strong desire to return to a normal way of eating and drinking (Jacobsson et al., 2000; Carlsson, et al., 2004; Jones and Nasr, 2018). Getting back to normality or re-creating a normal life (Carlsson, et al., 2004) are described as 'striving' toward recovery.

Stroke survivors also articulate a 'fight to regain control' (Perry and McLaren, 2003a) and uncover new ways of doing things (Medin et al., 2010). Jacobsson et al., (2000) described how stroke survivors felt imprisoned in an 'uncontrollable situation' and tried to find various ways to 'regain control'. Medin et al., (2010) present a preliminary model of care including several components of 'striving', which include eating safely and properly, being self-aware, analysing own behaviour, avoiding risky choices, and acknowledging the help needed from others.

Other studies describe a series of strategies which embody 'striving' as well as learning new strategies and regaining old eating and drinking habits (Kumlien and Axelsson, 2002; Kjaersgaard and Pallesen, 2020), using assistive devices (Westergren et al., 2001; Perry and McLaren, 2003a; Jones and Nasr, 2018), being careful (Kjaersgaard and Pallesen, 2020) and adopting a trial-and-error approach to learning (Helldén, Bergström and Karlsson, 2018) or learning by doing (Jacobsson et al., 1996; Carlsson, Ehrenberg and Ehnfors, 2004; Jorgen Medin et al., 2010; Helldén, Bergström and Karlsson, 2018).

## 2.8 RCP National Clinical Stroke Guidance and relevant policy

In 2023, the National Clinical Guidelines for Stroke underwent revisions, resulting in the modification of more than half of the 538 recommendations to align with the latest available evidence. Changes that are relevant to this BISTRO study include the recommendation of at least three hours of multidisciplinary therapy and the encouragement for patients to maximise their physical activity levels (Royal College of Physicians, 2023 p.65). These changes pose a challenge for stroke services with limited resources. The guidance emphasises increasing the dose and intensity of interventions and providing a range of interventions including both individualised and group sessions. Daily breakfast groups could provide an opportunity for services to provide the necessary dose of therapy enhanced by functional task training.

The guideline consensus statement recommends that “*competition with self or others*” is introduced to rehabilitation interventions (Royal College of Physicians, 2023 p.71). The International Classification of Functioning, Disability and Health Core Set for Stroke (Branch, 2012; ICF-research-branch, 2013; Sivan et al., 2014) includes competition as a core component of comprehensive stroke rehabilitation. Hoddinott and colleagues (2010) also suggest that competition is considered in the design and delivery of group interventions to improve health outcomes. This suggests that including an element of competition between self and others is a key consideration for the breakfast group intervention design.

The nutrition and hydration recommendations (Royal College of Physicians, 2023) have 23 additional recommendations largely adapted from National Institute for Clinical Excellence guidance, professional body guidance or clinical consensus. It is recommended that people with difficulties eating and drinking be assessed as early as possible with the appropriate tools and patients should be provided with appropriate support to promote independent and safe eating (Royal College of Physicians, 2023 p.74). This is also echoed in the interprofessional dysphagia framework (Boaden et al., 2020). Chapter 1 describes the types of interventions recommended in the Stroke National Clinical Guidelines that would be relevant for people with eating and drinking difficulties. However, it is important to note that there is no mention of group-based eating and drinking interventions or any recommendations regarding meal-time intervention groups aimed at improving nutrition, hydration, and physical abilities.

## 2.9 Stroke research priorities

The Stroke Association partnered with the James Lind Alliance in 2021 and over 1,400 people affected by stroke and care professionals to establish priority areas for research (The Stroke Association, 2021). This programme of research aligns with three of the Stroke Association’s top 10 research priorities for rehabilitation and the long term.

- (1) What factors and interventions can best prevent psychological difficulties, support adjustment, and improve motivation, well-being, and engagement?
- (2) What interventions impact long-term outcomes?
- (3) What is the best time, place, and amount of therapy to get the best outcomes for stroke survivors?

## 2.10 Study research question

Research Question: Can a codesigned breakfast group intervention for acute stroke units provide intensive eating and drinking interventions supported by interdisciplinary skill sharing and an actionable tool kit?

## 2.11 Chapter Summary

This Chapter describes the sociological perspectives on food and commensality, the context of food and drink consumption in hospitals and the impact of stroke on eating and drinking experiences. The background into the field of research discusses gaps and weaknesses in the literature and the relevant aspects of the National Clinical Guidelines, or policy regarding group eating and dining interventions and the relevance of this research to the national stroke research priorities.

## Chapter 3 Aims, Methodology, Study Design and Overview of Methods

### Chapter Summary

This Chapter introduces the literature relevant to developing complex interventions. It explains the choice of a partnership approach and its relation to Hawkins's 3-stage framework for co-producing and prototyping complex interventions. This Chapter also introduces Hawkins's 3-stage Framework and Experience-based Codesign (EBCD) and how they will be combined to develop the breakfast group intervention. The methods selected for addressing the research question will be described, along with their strengths and limitations. Additionally, the study plan and aspects of the study protocol, including governance, risk management, data protection, and storage, will be introduced. Ethical considerations such as regulatory review, compliance, peer review, consenting processes and potential risks to participants will be discussed.

### 3.1 Aims and Objectives

#### Aim:

To codesign a breakfast group intervention and implementation toolkit to improve the way eating and drinking rehabilitation is delivered in acute stroke units.

#### Objectives:

- I. Review research evidence and theories relevant to rehabilitation of eating and drinking difficulties, to inform intervention development and design.
- II. Codesign with relevant stakeholders a breakfast group intervention and supporting implementation toolkit.
- III. Iteratively develop and test the feasibility and acceptability of the prototype intervention and accompanying toolkit in three stroke services.

### 3.2 Methodology of complex intervention development

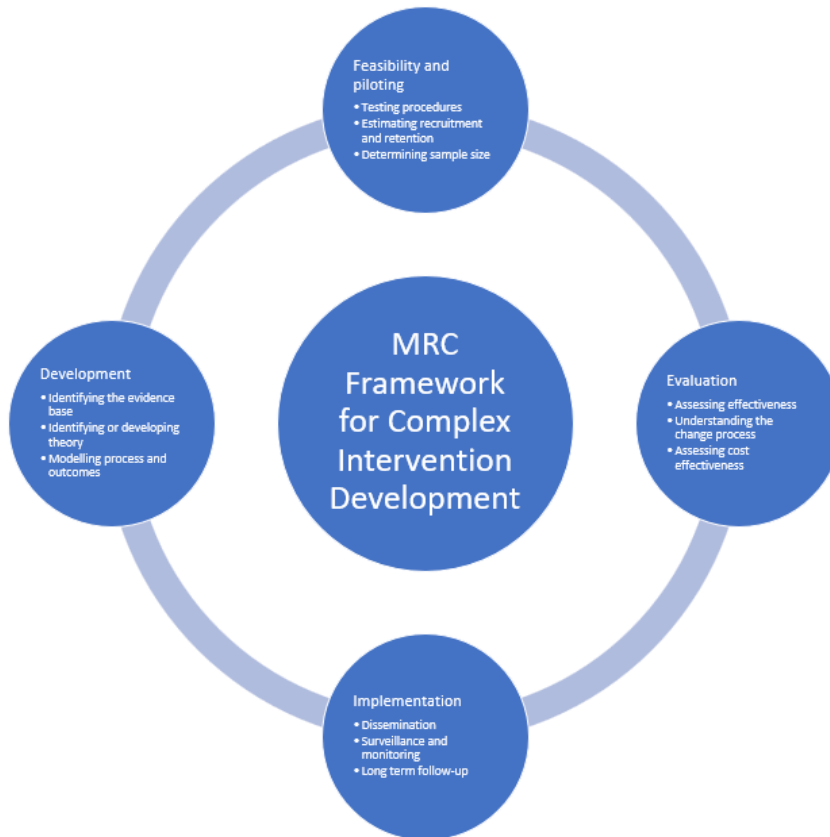
A breakfast group intervention would be considered complex as it is likely to contain several interacting components and strives to achieve a range of variable outcomes (Craig et al., 2008). The MRC guidance for developing and evaluating complex interventions (Figure 4), suggests a phased approach that includes development, feasibility piloting, evaluation, and implementation (Craig et al., 2008). In BISTRo, the first two stages of the MRC framework, illustrated in Figure 4, development, feasibility, and piloting were undertaken. The framework illustrated in Figure 4 has since been updated by Skivington and colleagues (2021), however, this is the version that was published when the study was designed, and the core components are essentially the same.

O’Cathain and colleagues (2019) highlighted a research gap in the evidence base for different approaches to intervention development and they proposed that further clarity and detail were required to support researchers with the development phase of the MRC framework. They conducted a triangulation of evidence from three sources 1) literature on the published approaches to intervention development 2) qualitative interviews with



stakeholders 3) two e-Delphi studies (O’Cathain, et al., 2019). The source data were triangulated and used to develop an accessible quick reference guide for researchers in healthcare on how to develop complex interventions which were used to inform this study (O’Cathain, et al., 2019).

Figure 4a: MRC Framework of complex interventions adapted from Medical Research Council, (2006).

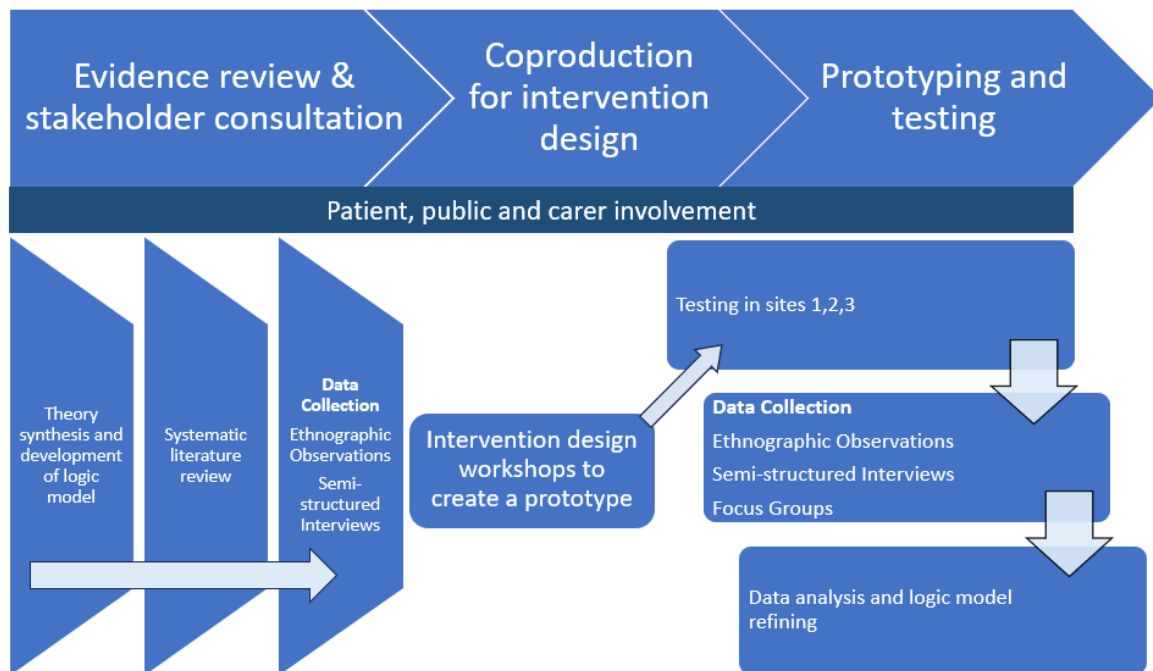


### 3.2.1 Intervention development key principles and actions

O’Cathain and colleagues (2019) suggest that intervention developers utilise evidence, and theory and then work with stakeholders to develop complex interventions. These actions should be guided by the principles of open thinking, iterative processes, and a cycle of dynamic prototyping (O’Cathain, et al., 2019). Furthermore, these cyclic processes involve the use of qualitative and quantitative research methods to explore acceptability and feasibility (O’Cathain, et al., 2019). Methods used in the BISTRo study are illustrated in the figure 4b below. In stage 1 ethnographic observations and semi-structured interviews were deployed to understand the impact of eating and drinking difficulties and generate ideas for the intervention development group. Stage 2 involved stakeholder workshops to codesign the intervention and stage 3 included testing in three hospital sites. Ethnographic observations were undertaken during the prototyping and following testing interviews and focus groups were utilised with participants to investigate feasibility and acceptability.



Figure 4b: The methods used for data collection at each stage of the Hawkins 3-stage framework for coproduction and prototyping.



### 3.2.2 Introduction to intervention development approaches

O’Cathain and colleagues (2019) describe a taxonomy of nine approaches to intervention development (O’Cathain, et al., 2019). They concluded that there was no evidence to support which intervention development approach was better than the other but there was an expert consensus that using a published approach was desirable (O’Cathain, et al., 2019). The intervention development guidance recommends selecting an approach that fits with researchers’ needs and values (O’Cathain, et al., 2019). Evidence suggests that the choice of approach is usually associated with the aims and objectives of the study, context, and potential outcomes (O’Cathain, et al., 2019).

### 3.2.3 Partnership approaches

One such intervention development approach is the ‘partnership’ approach which values stakeholder involvement in decision-making about the intervention and focuses on parity of value of contributions (O’Cathain et al., 2019). The partnership approach emphasises the shared responsibility between researchers and their research (Numans, et al., Schalk, 2019). Partnership approaches describe a collection of approaches such as coproduction (Voorberg, et al., 2015), codesign (Bessant and Maher, 2009) and Experience-based Codesign (Ziebland, 2013; Locock et al., 2014). Partnership approaches usually involve participatory action research (Numans, et al., 2019; Duea et al., 2022; Cornish et al., 2023) as the philosophical approaches align.

### 3.2.4 Participatory Action Research (PAR)

Participatory action research (PAR) evolved from Lewin's work in the 1940s as a process to effect social change (Gray, 2017). PAR has four core principles which align with those of EBCD:

- 1) Democratic and pragmatic approach (Brocklehurst, et al., 2021; Koch and Kralik, 2008).
- 2) PAR is a change agent, and it is action-orientated (McNiff and Whitehead, 2011).
- 3) Data is generated from the experiences of participants (McNiff and Whitehead 2011).
- 4) PAR draws together knowledge from a range of stakeholders and values multiple ways of knowing. It engages those most concerned with the issue being investigated (McNiff and Whitehead, 2011; Koch and Kralik, 2008).

A primary driver of PAR is its foundation in pragmatism and democracy as emphasised by Brocklehurst and colleagues (2021). It is recognised for its democratic approach, which entails involving end-users and research recipients as equal partners in the study. Pragmatism is related to the iterative cycle of design, action, and reflection (Koch and Kralik, 2008). Contextual evidence is included as well as new knowledge generated during the iterative process. PAR includes relevant theory and evidence to inform intervention design (Brocklehurst, et al., 2021).

Contextual knowledge and lived experience are critical to PAR as it involves the exploration of a problem through the eyes of the stakeholder and the generation of actions that lead to change (McNiff and Whitehead, 2011). Brocklehurst and coauthors, (2021) argue that the complexity of health care requires a broader range of research skills and knowledge. Greenhalgh and colleagues (2016) suggest that the move towards participatory and 'co-approaches' is an attempt to '*move beyond the ivory towers of research*' and address the gap between researchers and research users. The methods employed in this study to gather qualitative data are guided by the principles of participatory action research.

### 3.2.5 Hawkins 3-step framework

The framework of actions for intervention development described in O'Cathain's (2019) paper suggests drawing on one or more published approaches for intervention development. Hawkins and collaborators, (2017) have published a pragmatic framework for codesigning an intervention that ensures the feasibility, acceptability, and quality of the intervention fits with the context it is designed. They found that involving stakeholders and end-users in developing the intervention content and delivery methods helped to shape a final product to meet users' needs (Hawkins et al., 2017). The three-stage Hawkins framework is outlined in Figure 2 in Chapter 1.

### 3.2.6 Combining approaches with Experience-based Codesign

Hawkins and colleagues (2017) describe a few weaknesses in their approach. A criticism of the stakeholder coproduction process was that staff altered the content of the intervention before finishing the manual without consulting with patient representatives. Secondly, a

potential barrier to coproduction was the conflict between the views of patients and staff stakeholders and the time-consuming nature of coproduction (Hawkins et al., 2017).

Insufficient detail existed regarding stakeholder activities in the first stage of the Hawkins Framework (2017) for replication in another study. Consequently, the decision was made to combine the methods of stakeholder engagement from Experience-based Codesign (EBCD), as described in Paul Bate and Glenn Robert's work on incorporating experience into healthcare (2007), with the 3-step framework proposed by Hawkins (2017). The practice of combining approaches in complex intervention design is not uncommon among researchers (O'Cathain, et al., 2019). Combining approaches may be necessary when one approach alone does not entirely meet the needs of researchers (O'Cathain, et al., 2019).

The EBCD methods for stakeholder engagement bring together patients, carers, and healthcare professionals in a structured timely approach with key activities to guide the researcher. Experiences are gathered using participatory methods such as interviews, ethnographic observations, and visual methods. Engagement with stakeholders is embedded throughout the development process and decisions are made in consensus with both staff and patient participants. There are six steps to EBCD which are described more fully in Chapter 3 section 3.10 figure 8, they include 1) observing the clinical area 2) interviewing key stakeholders 3) making a trigger film 4) holding patient and staff feedback sessions 5) running codesign workshops 6) holding a celebration event.

### 3.2.7 Framework of actions in intervention development

O'Cathain and colleagues (2019), propose principles for intervention development which recommend researchers remain open to change. Although the idea of a breakfast group was already decided as part of the pre-work before this study, there was a possibility that in the design and refinement stages, alternative ideas might emerge which alter the course of the development and the end product.

This study focuses on the design and refinement stage of O'Cathain and colleagues' (2019) framework for actions for intervention development illustrated in Figure 5. A colour-coded key shows the actions associated with the relevant stages of the Hawkins Framework.

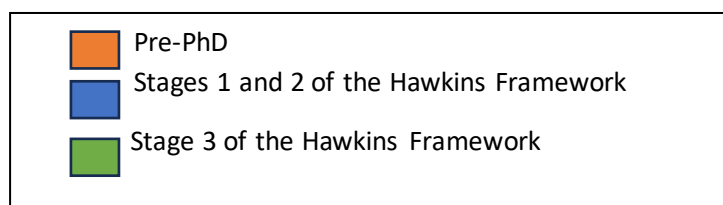
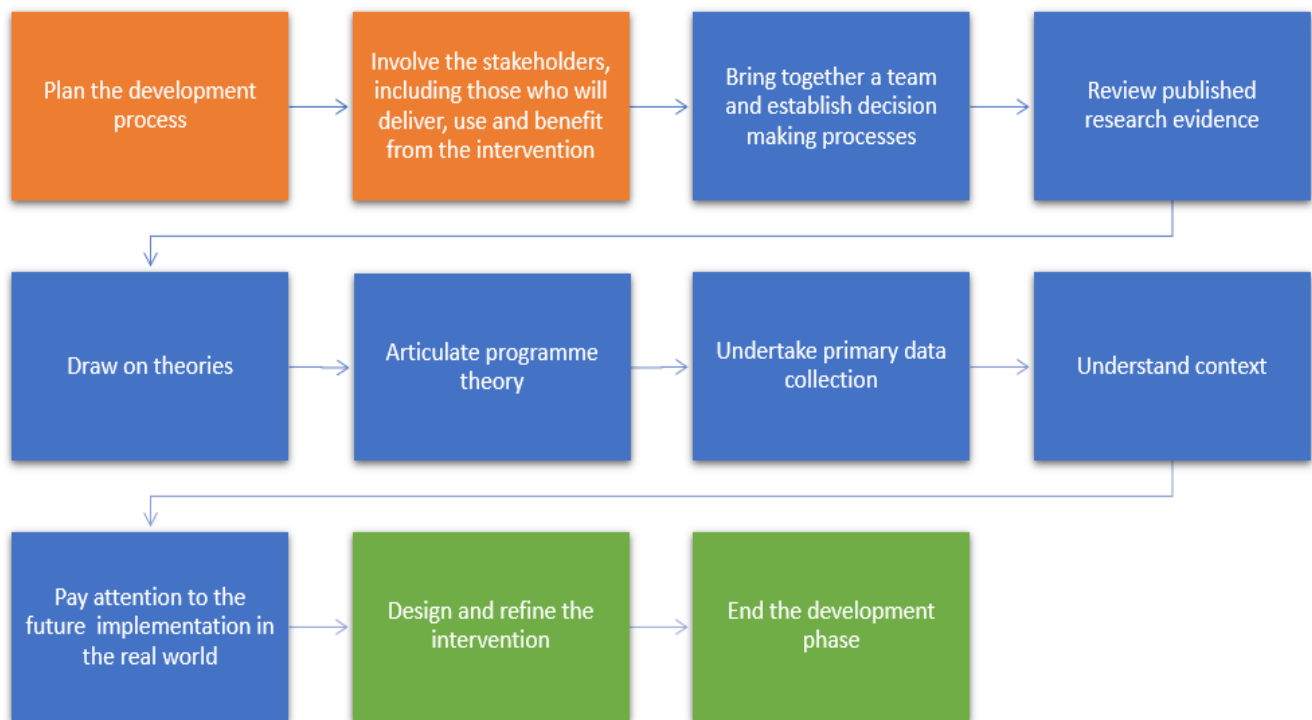


Figure 5: A Framework for actions taken during intervention development.

\*Adapted from O’Cathain and colleagues (2019)



### 3.3 BISTRo study design

The BISTRo study design combined Hawkins's 3-stage codesign approach with EBCD to codesign a breakfast group intervention and implementation toolkit. An infographic describing the study plan, 3-stages, actions, and methods is illustrated in Figure 6. Although the methods are presented sequentially, in practice, an iterative approach was deployed. Intervention development usually combines diverse types of knowledge generation such as user experience, scientific research, tacit knowledge, and theory.

#### 3.3.1 Hawkins Stage 1: Evidence review and stakeholder consultations

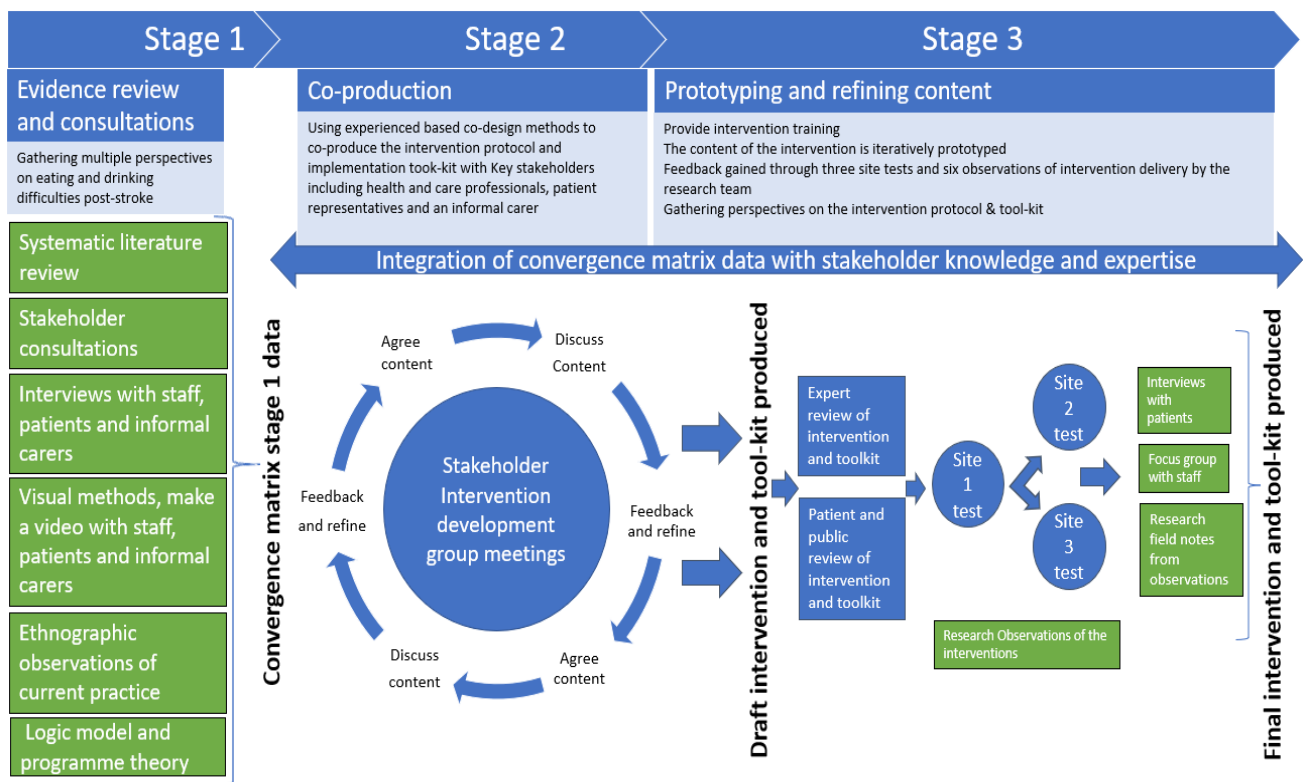
There are six components in Stage 1 of Hawkins's codesign approach (see Figure 6):

- Systematic literature review: to explore the psychosocial impacts of eating and drinking difficulties which is described and presented in Chapter Four and a literature review of relevant research is described in Chapters 1 and 2.

The other five actions in stage 1 are as follows:

- Stakeholder consultations
- Interviews with staff, patients, and informal carers
- Visual methods, making a video with staff, patients, and informal carers
- Ethnographic observations of current practice
- Logic model and programme theory

Figure 6: BISTRO Study plan



Three-stage multi-method framework to co-produce intervention content, resources, training and an actionable implementation toolkit. Adapted from Hawkins Framework for co-production and prototyping

### 3.3.1.1 How patient and public involvement was embedded into the BISTRO study

National Institute for Health and Care Research (NIHR) funders expect researchers to demonstrate how members of the public were involved in their research (National Institute for Health Research, 2021). Public involvement is recognised as part of health research policy (NHS Health Research Authority, 2023) and there is an expectation that it will occur at several points during the research process (Harrison & Palmer, 2015). Patients and families can bring unique insights to a research project (Charalambous et al., 2022). Davies, (2013) proposes a moral argument in terms of accountability for spending taxpayers' money and the right for the public to be involved in these activities. Research data determines that patient and public involvement improves the quality and relevance of the research (Stilgoe, et al., 2014; Redman et al., 2021).

Boote et al., (2014) argue that patient and public engagement carries a risk. There is a risk that research ideas will be deemed unimportant or not relevant. NIHR recommended that for this reason patient and public involvement (PPI) is brought into a project as early as possible (National Institute for Health Research, 2019). Before the PhD commenced, the PPI group played a significant role in the fellowship application. They also advised on the lay summary and potential blockages to recruitment. Involving patient and public representatives in research can support the development of accessible processes and materials as well as informal data analysis and guide the dissemination of outputs (Broomfield et al., 2021). They were also consulted on the ethics application and participant information sheets to ensure they were understandable and non-coercive. An example of a

participant sheet can be found in Appendix 25. During the study, they provided advice on the acceptability of patient interview questions and the dissemination plan as well as intervention design in stage 2 of the Hawkins Framework (2017).

#### 3.3.1.2 Stakeholder consultations

A consensus paper on the principles of stakeholder involvement in research (Goodman et al., 2020) defines stakeholder involvement as an umbrella term for collaborative research with patients and stakeholders. Collaborative approaches involve open communication about the study and research processes. Stakeholder consultations in research are usually participatory and have a focus on patient-centred outcomes (Goodman et al., 2020). Terms such as engagement and involvement are used interchangeably in the literature and therefore the term 'involvement' is adopted in this study to reflect the participation of people other than the research team in the BISTRO study.

Stakeholder involvement is not without challenges and has recently been the source of academic debate. The optimum amount of stakeholder involvement required for a participatory research study is not clearly defined in the literature (Goodman et al., 2020). Barriers to stakeholder involvement include; managing multiple stakeholders with differing viewpoints (Skivington et al., 2021), difficulties with creating joint ownership (Voorberg et al., 2015), unequal power dynamics between the researchers and stakeholders (Steen et al., 2018; Oliver et al., 2019; Williams et al., 2020), the need for specific expertise in coproduction approaches, (Rousseau et al., 2019), the number of resources required (Steen et al., 2018) and time commitment to train participants (Oliver et al., 2019).

Stakeholder consultations in the BISTRO study included informal face-to-face and in-group meetings with stroke rehabilitation healthcare professionals. Consultations with a stroke charity support groups and a stroke patient and public panel. Notes from these meetings were taken and utilised to shape the creation of topic guides for interviews.

#### 3.4 Semi-structured interviews with staff, patients, and informal carers

Interviews are one of the most popular methods of qualitative research (Gubrium and Holstein, 1997, 1998) and are more commonly used in social science research and they are predominantly used in EBCD research (Green et al., 2020). They capture unique lived experiences, and they enable interviewees the opportunity to share their narratives from their perspectives (Gubrium and Holstein, 1998; Kvale, 2007; Kvale and Brinkmann, 2009). They have been used extensively in collecting data on the experience of eating and drinking difficulties with stroke survivors' difficulties (Carlsson, et al., 2004; Helldén, Bergström and Karlsson, 2018; Eltringham et al., 2019).

There are several different types of interviews including, narrative (Smith and Sparkes, 2008; Nasr et al., 2016), active (Gubrium and Holstein, 1997, 1998), grounded theory (Charmaz, 2014) and feminist (Oakley, 2016). Semi-structured interviews involve the researcher preparing questions in advance whilst also allowing for flexibility to modify the questions to issues that emerge during the interview (Braun and Clarke, 2013).

Several authors have written extensively about qualitative interviews (Kvale and Brinkmann, 2009; Rubin, et al., 2011). Kvale and Brinkmann, (2009) have published seven stages of the interview process. By comparison, Rubin, and colleagues (2011) have a similar linear

programme of steps however they have adopted a more flexible approach allowing the researcher to make changes to the interview. Kvale, (2007) proposes interviews are a learning process for the interviewer and the interviewee. Interviewees can change their responses based on new insights and interviewers can change their questions to clarify ambiguities or explore new meanings (Kvale, 2007), thus the interview is a dynamic process.

#### 3.4.1 Types of interviews

There are many types of interview method however the three main types fall into three categories structured, semi-structured and unstructured which are delineated by the extent to which the questions are structured. Other features that distinguish each interview type are the flexibility of the interviewer, the types of questions and reflexivity (Braun and Clarke, 2013). Structured interviews are predominantly closed questions and are used to collect quantitative data. Semi-structured interviews allow the researcher more flexibility with the research questions and unstructured interviews are guided by a list of themes as opposed to a list of questions. Semi-structured interviews have been selected for this study as they enable the researcher to have a list of questions prepared in advance with scope for flexibility to explore the interviewee's stories further or develop new lines of inquiry according to the respondent's narratives (Braun and Clarke, 2013).

The field of qualitative interviewing is broad and complex and there are many ways to approach interviewing. Hollway, (2000) suggest that interviews are not always straightforward and cautions researchers against assuming that narrative storytelling will just happen. To guard against a paucity of narrative, authors King and Horrocks, (2010) provide some suggested modes of narrative interviewing. One such mode is narrative enquiry which has been used in interviews to explore the lived experiences of stroke survivors (Nasr et al., 2016).

Narrative stories are experiences through which meaning is derived (Nasr et al., 2016). They are social, cultural, and psychological insights into the internal world of an individual and the social and cultural contexts in which they operate (Smith and Sparkes, 2008). Narrative enquiry allows the interviewee to lead the storytelling. This has proven particularly helpful when the researcher aims to access information about strategies that people are using to adapt to a disability. King and Horrocks, (2010) argue that participatory approaches such as narrative inquiry can address the asymmetry of power and focus on the 'voice of the participant'.

Adopting a narrative inquiry requires the interviewer to interact with the interviewee in a collaborative open style. There are several modes of narrative interviewing described in the literature. One mode developed by a group of researchers in London is the biographic-interpretive method which is defined as using one question to open up the conversation (Chamberlayne, 2000). The interviewee is invited to talk for 10 minutes and then there is a break where the data is reviewed and then a further session is planned with follow-up questions. This approach requires a considerable amount of discipline and relies on further questions yielding sufficient data for the next stage.

Jefferson and Hollway's work on fear of crime (Hollway, 2000; Hollway and Jefferson, 2012) led them to develop a mode of interviewing called Free-association Narrative Interviewing (FANI). This mode of enquiry features open questioning, inviting storytelling (Hollway and



Jefferson, 2012) and avoiding questions that detract from the narrative as well as following up on the interviewee's phrasing to keep the focus on the story (King and Horrocks, 2010). The FANI mode of narrative enquiry addresses the potential for the interviewer to influence the content of the interview by focusing on the interviewee's storytelling. It also aligns with the coproduction ethos of this study. Unlike the biographic-interpretive method, it provides the opportunity for the researcher to ask follow-up questions and probe in more depth. This is particularly helpful if the interviewee is struggling to articulate their story, narrative inquiry was selected as the preferred mode for BISTRo.

#### 3.4.2 Challenges with qualitative interviewing

Challenges in qualitative interviewing have been widely explored (Kvale, 2007; Roulston, 2011; Creswell, 2013). Experts in the field advocate deploying a critical stance towards reflecting on the external and internal factors in research that could affect the outcomes of a study (King and Horrocks, 2010). Two challenges identified in this study were the number of interviews and the potential for power dynamics to influence outcomes, both of which are discussed below.

#### 3.4.3 Sampling

There is a debate amongst seasoned researchers about the number of qualitative interviews required in any study and what is considered appropriate (Baker et al., 2012). The National Centre for Research Methods report consulted 14 prominent methodologists in the field to answer the question of quantity. They concluded that it is dependent on several variables such as practical issues, data saturation, and the nature and purpose of the research (Baker et al., 2012). The in-depth interview data is going to be synthesised with data from ethnographic observations and eight trigger videos, for practical and time constraints a maximum of five participants were recruited.

#### 3.4.4 Attending to the Hawthorne Effect

The Hawthorne effect is a familiar concept in research (McCambridge, et al., 2014) which describes the awareness of being studied and the potential impact on participants' behaviours. In recent years this phenomenon has been researched further and there remains some ambiguity on its value as a term (Wickström and Bendix, 2000). McCambridge, and colleagues (2014) suggest that there is no single effect; moreover, there are multiple factors influencing the behaviour of research participants. Wickström and Bendix, (2000) argue that instead of using this ambiguous term when referring to the impact of the researcher on the participants, researchers need to be specific about the variable that could influence study outcomes.

One such variable is the nature of 'power' in the interview relationship. Kvale and Brinkmann, (2009) discuss power symmetry and urge researchers to be aware of the unequal positions between researcher and interviewee. Braun and Clarke, (2013p.88) label this concept as '*interviewing across difference*'. Experts in the field suggest a power imbalance could affect the contribution of the interviewee (King and Horrocks, 2010, Creswell, 2013), the interviewer may unwittingly or intentionally influence the dialogue or direction of the interview.

To mitigate asymmetry in power dynamics Kvale and Brinkmann, (2009) suggest a more collaborative style of interviewing where the researcher approaches questioning from a position of constructing knowledge. King and Horrocks, (2010) expand on this idea further



when they describe the features of participatory and collaborative approaches to interviewing. They propose that interviewing in a participatory or collaborative style can break down the traditional barriers that exist between academics and participants in research (King and Horrocks, 2010). This ethos also fits with the FANI style of narrative inquiry.

### 3.5 Visual methods, making a video with staff, patients, and informal carers

Trigger films are used in EBCD to convey to key stakeholders the experiences of staff and patients around current service delivery (Blackwell et al., 2017). The terms 'film' and 'video' are used interchangeably in the literature (Baumann et al., 2020) the preferred term for this study is 'video'. Short videos explore the problem, existing management, and priorities for change (Brady, et al., 2020). Telling stories and experiences enables discoveries and insights that may not have been revealed otherwise (Tomlin, 2018).

Investigating what occurs in real-world settings when it occurs can highlight routines, activities, and behaviours (O'Reilly, 2012). A detailed understanding of practice in action can contribute to the understanding of the phenomena being investigated (O'Reilly, 2009). Videos can provide a means of recording what happens as opposed to what people recall has happened (O'Reilly, 2009). Trigger videos with patients, and informal and formal carers were utilised in the refining and design phase.

The use of videos in healthcare research is an emerging field (Baumann et al., 2020). Trigger videos are commonly used in healthcare for educational purposes, and they have been used to generate discussions about areas for improvement (Arora, et al., 2021). Trigger videos are a common method used in EBCD to capture lived experiences (Brady, et al., 2020; Raynor et al., 2020; Silcock et al., 2023). Where videos are not used, researchers have used other ways to trigger discussion such as quotes from interviews, user experience examples and experience mapping (Green et al., 2020).

Although alternatives exist, experts in EBCD recommend the use of videos as they are a critical component in the codesign process to visualise experiences and help participants emotionally and cognitively acquaint themselves with the subject material (Donetto, et al., 2014b). They are also useful to triangulate with other research methods (Catalani and Minkler, 2010).

#### 3.5.1 Types of visual methods

Visual methods are commonly used in social research and increasingly in psychology research (Reavey, 2012) and they tend to fall into three categories: analysis of previously produced images, asking participants to produce their images or the researcher making a video. Reavey, (2012 p351) describes one of the benefits of visual methods as the ability to '*give voice to the underserved*' by providing the opportunity to surface their concerns, giving rise to powerful discussions with key stakeholders. Video methods amplify beyond a visual image to give the viewer a picture of facial movement, gesture, sound, and narrative (Baumann et al., 2020). In BISTRo several short trigger films were made from a montage of video clips edited together.

### 3.5.2 Challenges for visual methods

The production of trigger videos can be time-consuming. Instead of omitting this important aspect of engagement, users of EBCD advocate using an accelerated method which involves editing together existing archive footage. This has proven to be a less time-consuming and effective way of creating video content (Donetto, et al., 2014a). In the absence of any suitable footage, a decision was made to create new video content for the study. This process facilitated the development of film editing skills, in addition to creating content which could be used in future studies.

Participants' reluctance to appear in videos might have posed a barrier to recruitment for this aspect of the study. Typically, trigger videos are exclusively used in the projects they are intended for. However, to create the greatest influence, ethical approval was secured for using video footage in publications, social media and during conference presentations. The ethical and privacy concerns associated with filming are thought to be potential barriers to recruitment (Baumann et al., 2020). A participant information sheet specific to the trigger videos was developed with feedback from the Stroke PPI to address any concerns that participants might have about taking part and to mitigate the risks of low recruitment all participants were made to feel at ease with the video content before it was shared wider by viewing the final edits.

Video-based methods can be susceptible to the concept of social desirability bias. Despite efforts to motivate participants to candidly share their stories and experiences, their awareness of how the content would be disseminated or their desire to present themselves in a particular way may have influenced their narratives (Catalani and Minkler, 2010). Triangulation of the data and involvement of different participants in other aspects of the study could address this risk of bias. A list of the videos made for this study and links to view them can be found in Appendix 1.

### 3.6 Ethnographic observation of current practice

Investigating what occurs in real-world settings when it occurs can highlight routines, activities, and behaviours (O'Reilly, 2012). A detailed understanding of practice in action can contribute to the understanding of the phenomena being investigated (O'Reilly, 2009). Ethnographic observations were used to support data collected through semi-structured interviews. They can also provide a means of recording what happens as opposed to what people recall has happened (O'Reilly, 2009). Observations of two stroke wards at breakfast time provided data to inform the intervention development.

#### 3.6.1 Challenges with ethnography

In BISTRo, the unique challenges specific to the way ethnography was used include the researcher's influence and power dynamics and the generalisability of findings. Ethnography is typically associated with research over a prolonged period to ensure that sufficient data has been collected to build an understanding of the culture. Charmaz, (2014) cautions against a '*smash and grab*' approach to targeted short observations. However, Rashid and colleagues (2015) argue that modern ethnography leans towards less time in the field to adapt to contemporary standards and demands. Ethnography in BISTRo was conducted in short bursts of observations over a four-month period which aligns more comfortably with

the focused ethnography where participants are conveniently available (Higginbottom, et al., 2015).

Qualitative research faces scrutiny regarding the potential influence and power of the researcher, which may influence the data recorded. Therefore, researchers need to be cognisant of their impact on the research process. Several authors emphasise the importance of reflexivity in contemporary ethnography (O'Reilly, 2009; Higginbottom, et al., 2015; Rashid, et al., 2015). Reflexivity is the ability to be aware of one's impact, feelings, and assumptions. Cubellis and coauthors (2021) propose that the iterative nature of ethnography naturally fosters reflexivity as the researcher actively participates and reflects upon the data and their role in the research.

Various methods of participating in reflexivity are recommended, including maintaining a journal to document the researcher's thoughts and feelings (Rashid, Caine and Goetz, 2015), engaging in peer review (Bryman, 2006) and triangulation of data with other research methods (Moran-Ellis, 2006; Cubellis, et al., 2021). To be cognisant of reflexivity a personal journal was used to record mindful observations and thoughts about researcher influence.

### 3.6.2 Defining features of ethnography

Ethnography is qualitative research rooted in anthropological study. It is designed to create deep immersion into the research participants' world (Emerson, et al., 1995). Anthropologists argue that understanding a group or phenomenon requires prolonged observation (Silverman, 2009). Ethnography is used to examine individual or group interactions, behaviours, language, and cultural nuances (Creswell, 2013). Expanding upon this Wolcott (2008) argues that ethnography is the study of social behaviour in an identified group context. Ethnography has been used in healthcare research as evidenced by the studies of Higginbottom, et al., (2015), Black et al., (2021) and Cubellis, et al., (2021). Furthermore, it is integrated into the stages of EBCD, where observation plays a pivotal role in understanding the problem being studied.

A scoping review by Black and colleagues (2021) found ethnography can be successfully used in healthcare improvement projects to provide valuable insights, encourage reflection, and facilitate problem-solving. This supports an earlier debate on the merits of ethnography in healthcare research (Savage, 2000). Savage, (pg.1400 2000) suggests that '*ethnography can be useful in the predesign stage of research and can generate questions for research that can be followed up by other methodologies*'. O'Byrne, (2012) also argues that ethnography has generated knowledge that has been crucial for developing health-related interventions. Key principles include participation of the researcher, through observation, listening, dialogue, and building trust (O'Reilly, 2012). It also involves theory, attempts to be non-reductive and pays attention to patterns in behaviour (Creswell, 2013).

### 3.6.3 Types of ethnography

The field of ethnography is complex. There are multiple epistemological and ontological frameworks and methods to collect data (Rashid, et al., 2015). Creswell (2013) describes two types of ethnography: realist and critical. The realist approach is traditionally used in cultural anthropology and is written in the third person and usually involves an objective approach where facts and processes are recorded (Creswell, 2013). The critical approach is focused on giving a voice to those who are powerless. It is concerned with equality, politics

(Creswell, 2013), imbalance in culture and addressing social repression (Rashid, et al., 2015).

Rashid, and colleagues (2015) present three more types of ethnography: institutional, focused, and visual. Institutional ethnography is concerned with understanding relationships between individuals and institutions, and visual ethnography is associated with the use of visual images and recordings (Rashid, et al., 2015). The third type, focused ethnography, aligns more closely with the BISTRO study aims. According to Higginbottom and coauthors (2015), focused ethnography is relevant to gathering data on topics of specific importance in healthcare research. BISTRO seeks to gain insights into the culture, processes and behaviours of staff and patients around breakfast-time activities to inform the development and evaluation of the prototype intervention.

### 3.7 Logic model and programme theory

Logic modelling has a history in public research and researchers in health care promote logic models as an opportunity to understand the cause-and-effect loop or relationship between core components in an intervention (Hawe, 2015). Logic models have been used in other codesign intervention research using experiences based codesign (Silcock et al 2023, Ayton et al 2020). There is a risk that simple logic models applied to complex interventions have insufficiencies however a logic model is not stationary it can be adapted and iteratively developed as more is learned about the programme being studied (Hawe, 2015).

Logic models can be used to explain to stakeholders the programme theory that informs the intervention, the contexts, mechanisms involved and the potential outcomes (O’Cathain, et al., 2019). They are designed to be organic, changing and adapting as the intervention develops. Rehabilitation theories, change theories, social learning theories, self-efficacy theories and other theories related to successful task performance are explored during the intervention development (De Silva et al., 2014). The logic model for BISTRO was developed collaboratively with the stakeholders throughout the project, examples of the evolution of the model can be found in Appendix 2.

### 3.8 Hawkins Stage 2: Coproduction for intervention design

A Stakeholder Intervention Group (SIG) was established with key stakeholders including patient representatives, informal carers, and healthcare professional representatives (from nursing, physiotherapy, speech and language therapy, dietetics, occupational therapy, psychology, and support staff). This group codesigned the breakfast group intervention and implementation toolkit in ten workshops. The methods for stakeholder engagement are described in Chapter 5 however a workshop plan is provided below in Figure 7 to show the outline plan.

### 3.9 Hawkins Stage 3: Prototyping and testing (acceptability and feasibility)

Prototyping is the development of new services or interventions. In intervention design, it is still a relatively new idea (Lambeth & Szebeko, 2011). The origins of prototyping are in manufacturing and product design (Hawkins et al., 2017). In healthcare research prototyping with stakeholders has been used to gain feedback to improve the quality and design of a product (Hawkins et al., 2017). Prototyping in public services has been defined as exploratory prototyping, a way to test out the viability and functionality of a product or

service (Lambeth and Szebeko, 2011). Prototyping in service design involves the collaboration of ideas and creative activities to generate innovative solutions (Lambeth and Szebeko, 2011).

Intervention development involves iterative prototyping (Lambeth and Szebeko, 2011; Hawkins et al., 2017; O’Cathain, et al., 2019). This involves exploring what might work and what might not work in each scenario and testing out specific components. Lambeth & Szebeko (2011) suggest a series of small tests in short cycles (see Figure 7).

Figure 7: Outline plan for stakeholder workshop activities.



The BISTRo intervention was tested three times in three different hospital stroke services. Version 1 prototype was tested in site 1 for two weeks. Following this it was refined, and version 2 was tested for a further two weeks in site 2, then site 3 commenced testing and refinement. The intervention was offered to patients Monday to Friday for ten sessions.



Conducting prototyping testing across three different sites allowed the CI to assess the intervention's applicability to other stroke services within the integrated care system. It also provided exposure to different staffing models and care pathway configurations. The decision to test the intervention on weekdays was a pragmatic decision based on pre-study consultations. Stroke unit staff believed that staffing levels on weekdays would enhance the chances of intervention success. This is particularly relevant considering that the majority of stroke services in the UK do not offer a comprehensive seven-day service.

### 3.9.1 Research methods used in step 3 Hawkins Framework

#### 3.9.1.1 Ethnographic observations

Observations in real-world settings can identify routines, activities, and behaviours (Booth et al., 2001; Gerrish and Lacey, 2013). A detailed understanding of the intervention in action can contribute to the understanding of the phenomena being investigated (Gerrish and Lacey, 2013). During prototyping, each site had two ethnographic observations while the intervention was being delivered. These were led by the CI and another member of the stakeholder group was invited to join the observations. The field notes from these six observations were typed up verbatim and uploaded to NVivo for analysis.

#### 3.9.1.2 Quantitative data

Quantitative data was also collected during the prototyping phase. Including demographic data about the participants, the number of interventions patients experienced, two weeks before and two weeks during the intervention, and the reasons for not attending a group. Clinical outcome measures focus on confidence with eating and drinking, socialising, and attitude towards abilities.

The data facilitated a comparison of demographics across the sites considering factors such as gender, age, and the type of stroke patient participants, as well as age, gender, and years of experience in stroke rehabilitation of staff participants. Additionally, data concerning the number of sessions and the reasons for non-attendance were gathered as part of the assessment of acceptability and feasibility. The data was analysed to gain insights into attrition and reasons for non-attendance.

#### 3.9.1.3 Quantitative data collection

Quantitative data was obtained by the site Principal Investigators (PI) and the Chief Investigator (CI) at the time of participant recruitment and consent, as well as during the prototyping phase. Data collection utilised anonymised Excel speed sheets ensuring secure storage in accordance with the data management outlined in this Chapter. The data was collated into tables for comparisons and where appropriate the data was analysed using GraphPad Prism 9 a scientific software program used by researchers to assist with data analysis and visualisation.

#### 3.9.1.4 Challenges of quantitative data collection

To collect information regarding the quantity of eating and drinking interventions in the two weeks preceding the prototyping, an examination of the patient's notes was conducted. The PIs carried out this task. It proved to be more challenging than anticipated due to the lack of detailed information in the patient's notes making it difficult to ascertain if the intervention

had occurred. The encountered challenges were addressed through discussion between the CI and PI, and the CI developed a clear definition of an intervention for the PIs to deploy (see below).

*Intervention definition- 'An eating and drinking rehabilitation intervention involves activities with the patient related to swallowing, and chewing, as well as eating and drinking physical functions. It encompasses an evaluation of dietary requirements, such as the Malnutrition Universal Screening Tool (MUST), and is conducted with therapeutic objectives, including assessment and practice with the aim of improvement. It does not include the process of updating or revising care plans for nutrition and hydration.*

While in the prototyping stage, information was gathered regarding the quantity of breakfast group interventions that patients participated in. However, any supplementary one-to-one interventions occurring outside of the breakfast group were not counted. This was an oversight as the total number of overall interventions in patients might have been greater than what was reported in Chapter 6.

#### 3.9.1.5 Focus groups

After the prototyping stage, focus groups were conducted with staff that were responsible for delivering the intervention and semi-structured interviews were conducted with stroke survivors who had received the intervention. Focus groups have a well-established history in social research (Krueger and Casey, 2000; Bloor et al., 2001; Litosseliti, 2007) and are a common method in health research (Moynihan et al., 2012; Green, 2013) used to explore views and attitudes toward complex phenomena. In stroke research, they have been employed to inquire about stroke survivors' lives, garner opinion and probe in-depth (Demain et al., 2013; Jones and Nasr, 2018; Drummond et al., 2020). Moreover, focus groups have proven effective in gathering multiple views from staff in stroke services that are implementing new interventions (Horne et al., 2015; Baker et al., 2022; Levy et al., 2022).

Focus groups usually have 6 to 12 participants and it is common to have more than one focus group especially when the researchers are looking for diversity of views (Litosseliti, 2007). Litosseliti, (2007) recommends a minimum of three groups to provide an in-depth exploration and account for unexpected variations in the behaviour of individuals or the group. With several focus groups, the researcher can compare and contrast the findings (Krueger and Casey, 2000). The goal of a focus group is to collect people together who have a topic in common, they are likely to be a homogeneous group to maximise the possibility of exploring the topic being studied (Krueger and Casey, 2000).

Focus groups were chosen for several reasons. Firstly they provided an efficient way to gather views from multiple staff participants in one single session which did not impose significantly on clinical time. Secondly, the conversational nature of a focus group allows for the exploration of diverse views from different professional groups providing rich data on context and depth to research findings. Thirdly a group approach can help the researcher

understand the social norms for different contexts and provide insights into the site-specific factors that influenced participants' perceptions.

Three focus groups were organised involving a selection of staff members who delivered the prototype intervention across three sites. At the point when they provided informed consent to participate in delivering the intervention, they were given the option to participate in a post-intervention focus group.

#### 3.9.1.6 Defining features of focus groups

Focus group participants usually have similar characteristics to provide narrative data in a focused discussion to help the researcher understand a topic of interest (Krueger and Casey, 2000). Focus group participants are invited to share their views, they listen to other participants and can reflect on what is said before giving their opinions. They are different to interviews as they have a dynamic quality with the participants of the group influencing each other (Litosseliti, 2007). The moderator will ask open questions to generate insights into the lived experience of the participants. They help generate new ideas and gain insights into behaviours and attitudes.

#### 3.9.1.7 Types of focus groups

Focus groups are defined by the context in which they occur and the manner in which they are moderated. Groups can be conducted in several ways, including sessions led by two moderators who facilitate the group together working in sync or by moderators who deliberately present opposing views. Additionally, focus groups can be overseen by one of the participants themselves or led by the researcher acting as the sole facilitator. These sessions can take place in person or online, offering flexibility in case of COVID-19 restrictions, as focus groups can easily transition to an online format.

#### 3.9.1.8 Procedures for the focus groups

A topic guide for the focus group was collaboratively developed with the stakeholder group. Open-ended questions were designed to extract insights on various aspects, including the execution of the intervention, its acceptability, and feasibility. This approach allowed for in-depth exploration of the intervention components, the level of workforce commitment, perceived challenges, and potential benefits. The focus groups were recorded and transcribed verbatim. The transcripts were uploaded to NVIVO for analysis utilising the approach to data analysis as proposed by Thomas & Harden, (2008).

#### 3.9.1.9 Challenges for focus groups

Experts in the field recommend that researchers receive training on the art of conducting focus groups as they can be difficult to facilitate (Krueger and Casey, 2000; Jude Robinson, 2019). The CI possessed some prior experience in facilitating focus groups. Additional supplementary training in qualitative research methods was incorporated into the NIHR Clinical Doctoral Training Programme to refresh and enhance my skills as a facilitator. Proficiency in group facilitation is valuable in preventing participants with strong views from influencing or silencing the voice of others (Litosseliti, 2007).

Organising focus groups can be time-consuming and pose logistical challenges, especially difficult when involving staff from different professional groups (Litosseliti, 2007). However, these groups were planned in advance and consent was secured prior to commencing the intervention prototyping. Given the limited number of participants in each group, it is important to exercise caution and not to make generalisations when drawing conclusions.



However, the robustness of the study's findings was strengthened through the utilisation of multiple focus groups and data triangulation with other research methods (Farmer et al., 2006; O’Cathain, Murphy and Nicholl, 2010).

In focus groups, the role of the moderator is vital in maintaining the flow of the dialogue, ensuring that all participants have a voice, and keeping the group discussion focused (Krueger and Casey, 2000; Caretta and Vacchelli, 2015). Caretta and Vacchelli, (2015) caution against the researcher aligning with one particular point of view as this could potentially stifle contributions from others. As this group of staff knew each other, there could be pre-existing power dynamics and hierarchies that may have influenced contributions. Careeta and colleagues (2015) propose that researchers should engage in self-reflection regarding these power dynamics and their impact on the agenda or shaping data collection. To be cognisant with these challenges I kept a reflection journal and maintained a reflexive stance.

#### 3.9.1.10 Semi-structured interviews

Semi-structured interviews were chosen because they offered a person-centred approach to gaining a deeper understanding of the participant's perspectives and giving individuals the freedom to explore the context and circumstances around their experiences and viewpoints. Interviews were selected over focus groups due to the expectation that patients would find a one-to-one setting more conducive to open dialogue. This choice also addressed concerns related to patients with aphasia or cognitive impairments who might face difficulties expressing their views in a group setting. Additionally, the geographical dispersion of patients across three sites introduced geographical challenges which interviews mitigated.

The post-prototyping interviews were conducted with patients who had received the intervention in sites 1,2 and 3. At the time when they provided consent to the intervention, they were given the option to participate in a post-intervention interview.

#### 3.9.1.11 Procedures for the interviews

The interviews were carried out within one week of completing the prototyping. This timing was chosen to ensure that patients could recall their experiences of the intervention. Additionally, it was done for logistical considerations, as patients might have been discharged home before the interview could be conducted. The interviews were scheduled by the CI with the patients. They were invited to a private room away from the stroke rehabilitation wards to provide a neutral environment where they felt comfortable sharing their lived experiences. A topic guide was used to guide the interview and ensure that specific questions around feasibility and acceptability were addressed. Interviews were recorded with the permission of the participants. Following the interview the recording was transcribed and uploaded to NVivo software. The data was analysed using Thomas and Harden's 3-step method of qualitative data analysis (Thomas and Harden, 2008).

#### 3.9.1.12 Challenges for the interviews

To maintain a non-directive approach, participants were encouraged to speak openly. As the Chief Investigator, it was crucial to be mindful of the potential influence that behaviour and body language could have on participants. Participants may have wanted to provide an overly positive view rather than their true opinion as a result of social desirability bias (King and Horrocks, 2010). To minimise bias participants were instructed at the start of the interview that it was acceptable to provide negative or less favourable responses to

encourage honesty and provide assurance that all perspectives were valuable. Active listening skills were deployed to show the participants that the researcher was engaged and interested as well as providing verbal cues such as *'tell me more'* or *'can you expand on that'*. To encompass a wider range of perspectives participants from all three sites were given the chance to participate in the interviews. Twelve were conducted, five in site 1, four in site 2 and three in site 3.

### 3.10 Experience-based Codesign

Experience-based Codesign is primarily a quality improvement approach developed in response to a desire to improve the quality of care (Bate and Robert, 2007a; Suutari et al., 2022). EBCD is a systematic approach with an emphasis on changing or improving a product, service, or intervention to have a positive effect on staff or patient experiences (Bate and Robert, 2007). First used in 2006 for a head and neck cancer study (Bate and Robert 2007b) EBCD has been used in the UK and six other countries (Raynor et al., 2020) although it is predominantly used in the UK NHS where it originated (Green et al., 2020).

Rooted in experience design sciences and social science anthropology (Bate and Robert 2007), the resources for the EBCD approach and its implementation toolkit were initially hosted by the King's Fund but have since moved to The Point of Care Foundation (The Kings Fund, 2012).

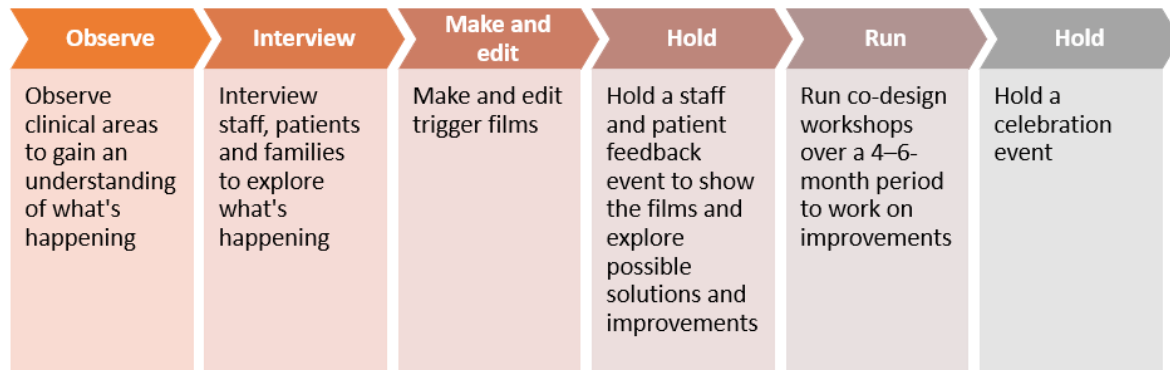
EBCD is an improvement approach used extensively in healthcare (Blackwell et al. 2017, Bowden et al. 2013) and it has been successfully adapted for use in participatory research to develop person-centred interventions (Raynor et al., 2020). A key component of EBCD is the focus on understanding experiences rather than systems and processes. Moreover, the inclusion of service providers and patients in the data collection process provides a balance of perspectives. Green (2020) argues that this addresses the criticism of Palumbo, (2016) that codesign approaches can be one-sided, favouring patient perspectives and forgetting staff.

EBCD is influenced by learning theory and narrative-based approaches. Learning theory explains how we receive and process learning through experience. It emerged from the work of Argyris and Schon (1978) and latterly Kerr (2008). The philosophical viewpoint of learning theory relates to a core principle of EBCD 'to understand we need to stand back, pause and reflect to gather information and fully understand the problem' (Bate and Glenn 2007). The researchers assume the role of 'student and learner'. They facilitate reflection to learn about the experiences of others and explore lived experiences. The people who understand the realities are thought to be the experts in the relationship (Bate and Robert, 2007a).

EBCD is a narrative-based approach (Bate 2004) focused on the richness of the information, powerful narratives, and storytelling (Bate and Robert 2007b, Wright et al 2017, Bowmen 2013). Narrative approaches are also thought to bring together the experiences of the patient and staff (Charon, 2001). However, a challenge of the narrative approach is the process of understanding and extracting the story and converting this 'new knowledge' into ideas that could improve services (Bate and Robert 2007).

Historically more attention has been paid to involving stakeholders in redesigning services and EBCD was developed as a framework for this purpose. Laterally it has been used in participatory research approaches (Suutari et al., 2022). The six-staged process (Bate and Robert, 2007a) involves creating a stakeholder group of patients, carers and staff who work together on identified improvement priorities (Robert et al., 2015). Figure 8 gives an overview of the published approach on the Point of Care Foundation website (The Point of Care Foundation, 2022).

Figure 8: Overview of the EBCD process.



When used in research studies EBCD is described as a participatory action research method (Blackwell et al., 2017; Goodrich, 2018; Donetto et al., 2021). Ziebland and colleagues, (2013) have written about combining EBCD with participatory action research (PAR). However, Robert (2013) argues that the underpinning principles of PAR have influenced EBCD and therefore EBCD is a participatory research method.

### 3.11 Study setting

BISTRo is a multi-centre study to design a breakfast group intervention and implementation toolkit. All data collection took place in the South Yorkshire Integrated Care System (SY ICS). The SY ICS is a collaboration of health and care partners including local authorities, the NHS and voluntary sector organisations which cover a population of 1.5 million people. People in SY ICS die younger than the national average and most people in SY ICS reported living with multiple health conditions in the 2011 census (SY ICS, 2019). There is a life expectancy difference of years between the most deprived and the least deprived areas (9.6 years for women and 12.4 years for men) (SY ICS, 2019). Cardiovascular conditions contribute significantly to this gap.

To support the people of SY an Integrated Stroke Delivery Network (ISDN) has been introduced to improve services and bring together partners that have a stake in stroke care across the region. All stroke services in SY are partners with the ISDN. The ISDN led the reconfiguration of stroke services so that three hospitals offer hyperacute interventions such as brain scanning and thrombolysis the clot-busting drug, but all six hospitals offer inpatient acute stroke and rehabilitation care.

The feasibility and acceptability of the BISTRo intervention were assessed in three of these hospital sites, two that have hyperacute services and that had acute stroke rehabilitation wards. The sites were selected as they were convenient and accessible for the researcher. The study was advertised at regional stroke meetings. A poster about the study was shared

with all stroke services as well as a verbal presentation. Five stroke services were eligible to take part and three expressed an interest. Meetings were held with those teams interested in taking part. An agreement was sought from the NHS managers in those sites to proceed with the recruitment of the site. Once verbal agreement was given, the relevant research departments were contacted to commence conversations about site initiation.

### 3.12 Ethics approval, assessment of risk and data management

#### 3.12.1 Ethical approval

The [Health Research Authority Qualitative Research Protocol](#) (HRA, 2018b) was used to guide the development of the BISTRO protocol and the ethical procedures required. This involved NHS patients and NHS healthcare professionals and thus needed NHS Ethical approval. NHS ethics was applied for on the 1<sup>st</sup> of October 2021 and following amendments approval was granted on the 5<sup>th</sup> of January 2022 (REC 21/NW/0313).

#### 3.12.2 Assessment and management of risk

The project was managed in accordance with the [Health Research Authority \(HRA\) research decision tool](#) (HRA, 2022). A project safeguarding risk assessment was created as per the University of Sheffield's Preventing Harm in Research and Innovation safeguarding policy. This guards against causing harm to anyone involved in the project and ensures that they are treated with respect and that confidentiality is observed.

For additional assurance, BISTRO was registered with the NHS Clinical Research and Innovation Office which provided scrutiny and oversight. All relevant staff had Good Clinical Practice Certification and NIHR informed consent training. The study was delivered in accordance with the UK Policy Framework for Health and Social Care Research which sets out the principles of good practice in the management and conduct of health and social care research across the UK (NHS Health Research Authority, 2023).

#### 3.12.3 Data management plan

All personal information was maintained and kept secure (Chan et al., 2013). All electronic data was stored confidentially in a restricted access project folder stored on the x:/ Drive on the University of Sheffield server only accessible by the research team. Data was depersonalised using codes or pseudonyms. Data on site was kept securely in separate locations or using encrypted digital files within password-protected folders. Sharing data was limited to essential people. Storage of participant data from patients, stakeholders, and health care professionals such as demographic information name, gender, type of stroke, job role, and number of years of experience with stroke was recorded on an Excel spreadsheet. Accessible only by the research team and stored in a restricted access project folder stored on the x:/ Drive on the University of Sheffield server that only the research team have access to.

All transcripts from interviews and focus groups were typed up and stored on a secure University of Sheffield server as soon as possible after the data collection had taken place. Once transferred to the University server, the audio recording was immediately deleted from the device. Participants were given pseudonyms or labels for the research write-up so that they could not be identified. Original notes from ethnographic observations and non-

participant observations were stored in a locked filing cabinet only the research team had access to at each site and these were destroyed at the end of the study.

### 3.13 Data Protection and Storage

Data storage, management and sharing were in accordance with the Data Protection Act (UK.GOV, 2018) and the University of Sheffield General Data Protection Regulation (GDPR) guidance. Collaboration and data-sharing agreements were set up between the three hospital sites. Identifiable information about participants will be kept for five years after the study has finished. This study complies with the General Data Protection Regulation (GDPR) law.

### 3.14 Regulatory Review & Compliance

Before any site could enrol patients into the study, appropriate approvals from participating organisations were in place. Amendments to the study were submitted to the sponsor and appropriate body for them to issue approval for the amendment (Table 1). Three amendments were submitted during the study the details of these are presented below:

Table 1: Study Amendments that received ethical approval.

Date	Amendment	Rationale	Outcome
20.10.22	Replace the MMSE Cognitive Screen with the 6CIT Six-item Cognitive Impairment Assessment	The MMSE was no longer licenced for free use in the NHS, so a free alternative screen had to be sought	Approved
25.11.22	To take photos during the prototyping of patients participating in the breakfast groups.	To promote the study and illustrate the group in action. For use in patient information leaflets, thesis, conference presentations, publications, and social media communications.	Approved
01.12.22	To use the audio from interviews and film taken during the study for promotion and communications.	To promote the study and provide further illustrations to multiple audiences of the study outcomes.	Approved

Protocol deviations, non-compliances, or breaches and any changes from the approved protocol were documented in the site file. Site Principal Investigators (PI) reported deviations directly to the Chief Investigator (CI) and the study sponsor (STH).

### 3.15 NIHR INCLUDE Guidance

The [INCLUDE Guidance](#) (NIHR, 2020b) was used to ensure individuals with specific barriers to inclusion in research could participate, such as under-served groups in stroke research, adhering to the following principles:

- ✓ Capacity and decision-making, the use of recorded procedures that adhere to legal and ethical governance.

- ✓ Use of support strategies to assist understanding and engagement for those with communication and/or capacity issues.
- ✓ Use of the continuum of decision-making from informed consent with full assumed dissent or assent.
- ✓ Involving a personal consultee to support engagement where necessary.

Risks for those taking part were minimised by ensuring that this study did not interfere with their freedoms or privacy. Media and illustrations were used to adapt the participant information to support people participating with communication and or capacity difficulties. Advice on study materials content, readability and accessibility was sought from a communication expert and the PPI panel (Palmer et al., 2013).

### 3.16 Informed consent

For consent to be ethical and valid in law, participants must be capable of giving consent for themselves. BISTRO followed the principles of the Health Research Authority for consenting (HRA, 2018). The resources and participant information sheet (any written material e.g., information leaflet and consent documents) were approved by the REC, local regulatory requirements, and legal requirements.

Stroke service managers were consulted about the sites participating in the study during the early stages and informal consent was gained from them before approaching staff to take part. Potential participants were approached with sufficient time to allow them to reflect on the implications of participation and not feel pressured to take part. Those with fluctuating mental capacity or communication difficulties were provided with extra time and an aphasia-friendly version of participant information. Written informed consent was taken from all participants. Consenting processes were supported by conversations so that potential participants could ask questions and clarify any concerns about taking part. The researcher's contact details were at the bottom of all study correspondence and the researcher was available for meetings during the recruitment periods. Any adult regardless of their mental capacity was supported with information to engage with this research.

The [ASSENT Guidelines](#) (Bunning, 2022) (Assent-based process for the inclusion of adults with impairments of capacity and/or communication in ethically sound research) were used to make adaptations and accommodations to promote the inclusion of adults with communication and capacity difficulties. Where it was assessed by the clinical team that a person lacked capacity an assessment was made by the CI or PI. The assessment and results were recorded in the patient's medical record. If the person was deemed to lack capacity a nominated consultee was arranged. This only occurred on one occasion. A person was appointed to advise the researcher about the wishes and feelings of the potential participants concerning the project (the participant's brother). The consultee was asked to provide an opinion for the person lacking the capacity to join the study and to discuss directly with the participant their wishes about participation in the study. The opinion of the consultee on whether the person would like to participate in the study was recorded on the consultee declaration form. In this case, they thought it was favourable for their relative to participate in the study.

During the study, the CI kept the consultee updated on all material changes to the study and the participant's condition. The consultee had the right to withdraw the participant from the study at any point without affecting the participant's care. If the participant regained full capacity during the study the consultee's decision remained valid, however at this point the CI or direct care team would provide the participant with verbal and written information to consent. If the participant refused consent following regaining capacity or withdraws consent the participant would be immediately withdrawn from the study. If the participant's capacity status were to change during the study the direct care team would be aware of this and inform the CI. This does not necessarily mean that the participant needs to be withdrawn from the study, but a consultee would be appointed. This scenario did not occur during the study.

### 3.17 Chapter Summary

This Chapter has set the scene for the next phase of the project which includes three stages of Hawkins et al, (2017) Framework. It has described the aims and objectives and the study plan in detail. It has discussed the research methodology and I have focused on the weaknesses of different methods and how they might be mitigated.



## Chapter Four. Hawkins 3-Stage Framework, Stage 1 Evidence Review.

### Introduction to the Chapter

This Chapter focuses on the evidence synthesis of stage 1 Hawkins Framework (2017). It presents a systematic review using a qualitative evidence synthesis (QES) approach to explore the perceptions of stroke survivors, and formal and informal carers, on the psychosocial impacts of eating and drinking difficulties. The aim, methods, findings, discussion, and implications for this thesis and future research are described.

### 4.1 Systematic review aims and research question

In recent years there have been numerous studies exploring the phenomenon of eating and drinking difficulties after stroke. However, researchers have mainly explored the impact of physical impairments and to date, scant attention has been paid to the impact on social and psychological well-being. Systematic qualitative evidence synthesis has been chosen to address the following:

**Question:** What are the views of stroke survivors' formal and informal carers on the psychosocial impacts of eating difficulties?

**Aim:** To understand the impact of eating and drinking difficulties on psychological and social well-being after stroke.

This review was conducted primarily by the Chief Investigator (NJ), and a second researcher (KD) assisted with critical appraisal and consistency checking. KD is an experienced stroke clinician with research experience. Two of the PhD supervisory team provided guidance when there was a difference in opinion (SM/AO). The details of which will be discussed below.

### 4.2 Design and methods

This study uses a qualitative evidence synthesis (QES) approach to understand the perceptions of stroke survivors' informal and formal carers on the psychosocial impacts of eating and drinking difficulties. QES is also known in the literature as a qualitative systematic review (Booth, 2016). QES was formally recognised in 2016 by the Cochrane Collaborative Qualitative Methods Group as an important method of synthesising qualitative evidence which can contribute to knowledge and healthcare recommendations (Gülmezoglu et al., 2013). QES has recently been used for synthesising qualitative evidence of specifically stroke survivors' views (Pohontsch et al., 2021; Connor et al., 2023).

### 4.3 Reporting guidance

This review was conducted in accordance with the PRISMA-P checklist, the preferred reporting checklist recommended to address maintaining quality in systematic reviews (Moher et al., 2009). The ENTREQ checklist (Appendix 3) was also used to enhance transparency in reporting the synthesis of qualitative research (Tong et al., 2012). Although this is not actually a reporting checklist but offers researchers guidance to improve the reporting of synthesis of qualitative health research (Tong et al., 2012). The protocol was



also registered on the International Prospective Register of Systematic Reviews (PROSPERO) registration number CD42022332330.

#### 4.4 Eligibility criteria

The objective was to identify studies that report on the perceptions of stroke survivors, informal carers or formal carers regarding eating and drinking difficulties, specifically psychological and social impacts. Those with a diagnosis of acquired brain injury who were not confirmed as having a stroke, were excluded (McKenzie et al., 2021). The views of healthcare professionals and informal carers were included because they could have views relevant to the review aims (Luker et al., 2015, 2017). Studies of interest included those which included views on the psychosocial impact of eating and drinking difficulties.

The eligibility criteria were initially formulated using the PCC process: (P) population (C) concept and (C) context method (Joanne Briggs Institute, 2011). PCC is an adaptation of PICO (Moher et al., 2009). PCC is a less restrictive way to develop a question, using it to provide broader inclusion criteria where there are a range of qualitative studies and the phenomenon of interest is lived experience (Joanne Briggs Institute, 2011). Prior to commencing the review, a pre-review scoping exercise was conducted to identify the types of studies that were available using the PCC process (Table 2).

Table 2: Population, concept, and context eligibility criteria.

PCC Process	
<b>Population</b>	Adult (18 and over) with a diagnosis of stroke. No restrictions on time after a stroke.
<b>Concept</b>	Psychosocial impacts on eating and drinking difficulties.
<b>Context</b>	Hospitals, care homes, rehabilitation centres including outpatient services and patients' own homes.

This informal scope of the literature indicated there might be a limited number of suitable studies available and there would be a mixture of qualitative methods, so a decision was taken to include all relevant studies regardless of methodology. Initial scoping of the literature and personal familiarity with the subject matter prior to systematic searching, indicated that 1990 to 2021 would yield relevant papers. Therefore the criteria for searching was set between 1990 and 2021 as it was deemed that this would provide sufficient studies to address the review question. Following this pre-review scoping exercise, the PICoS tool was discovered (Pohontsch et al., 2021). This tool offered additional categories for searching complementing the PCC process. Pohontsch and colleagues (2021) formulated the tool categories with the inclusion and exclusion criteria which added detail and transparency and was a preferable plan for this review.

##### 4.4.1 Inclusion and Exclusion Criteria

This qualitative review aimed to understand and provide insights into the meaning and significance of the phenomena of psychosocial impacts of eating and drinking difficulties. To determine a focused selection of studies and provide greater clarity for replicability (Stern, et al., 2014) the PICoS scheme was employed to ensure the inclusion and exclusion criteria

were robust (see Table 3). Pohontsch and colleagues (2021) successfully utilised the PICoS approach in a similar systematic review, using QES to explore the healthcare needs of people with speech and language difficulties after stroke. The incorporation of study design, language, publication status and type of publication was instrumental in ensuring the selection of appropriate selection of studies.

The perceptions of formal and informal carers were included in the review as they offered an additional dimension to understanding the phenomena of interest. However, papers that explored the impacts of eating and drinking difficulties on carers were not included. The studies focused mainly on stroke survivors. The term ‘informal carers’ was used to describe carers, spouses, or life partners of stroke survivors.

Types of study considered for inclusion included interviews, focus groups, case study designs, longitudinal studies, and ethnographic studies including participant and non-participant observations. Literature reviews were included as they provided a synthesis of primary research data. Commentaries such as discussion papers, letters, books, and editorials were excluded. However, reference lists were searched for relevant studies. Conference abstracts were not considered unless there was a derived published study linked to the abstract which could be located. Details of the full inclusion and exclusion criteria are provided below.

Table 3: Inclusion and exclusion criteria for study selection.

Criteria	Inclusion	Exclusion
<b>Population</b>	Adult stroke survivors eighteen years of age and over. Informal carers (parents e.g., co-habiting and non-cohabiting, partners e.g., spouse, common-law partners that live with the stroke survivor). Formal carers (Health Care Professionals in the NHS, Stroke Rehabilitation Professionals, Care Home staff).	People who have not had a stroke.
<b>Phenomena of interest</b>	Perceptions of psychosocial impacts of eating and drinking difficulties.	The study focuses on the views of stroke survivors, informal and formal carers only.
<b>Context of the study (geographical location and or clinical setting)</b>	Hospital inpatient environments (acute care, subacute care, and rehabilitation wards /units) and community settings including the stroke survivors’ own homes and residential or care homes.	
<b>Study design</b>	All types of primary qualitative studies, reviews, case studies, and mixed methods studies. Studies with sufficient qualitative data e.g., qualitative data analysis section.	
<b>Languages</b>	English language papers only.	
<b>Publication status</b>	Published full text.	

<b>Type of publication</b>	Journal article.	Conference proceedings and abstracts.
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\*Table adapted from (Pohontsch et al., 2021)

#### 4.5 Search strategy

Eight databases were searched that were considered relevant to the topic of the review using a combination of search terms relevant to the aim: Cumulative Index to Nursing and Allied Health (CINAHL EBSCO), NHS Centre for Reviews and Dissemination, Medline (Ovid), PubMed, Psych INFO, Embase (Ovid), Scopus and Web of Science. Key search terms were generated and discussed with an experienced medical librarian to ensure a systematic approach was followed. Search terms were tested in preliminary searches to ensure relevant studies were identified. A single verbatim search is included in Appendix 4.

The search strategy was designed to be as sensitive as possible to avoid large numbers of records being found. More precision with search terms can be achieved by using truncation (Psycho\* or eat\*) to avoid inadvertent exclusions (Booth, 2008). A building block approach (Booth, 2008) was used to add concepts together using the Boolean operators e.g., AND/OR. Medical subject headings (MeSH) terms were used to broaden the scope of the search to similar words and concepts. The final search terms are shown below in Table 4.

To minimise publication bias (Booth, et al., 2012) other methods of searching were deployed, e.g. examining the reference lists of relevant studies, citation and author searching as well as searching clinical trials and systematic review databases. Snowballing citations helped to locate bodies of literature on the relevant topic (Ritchie and Lewis, 2003). An extensive search of grey literature was also undertaken (Thomas and Harden, 2008) using free text searches such as 'stroke, eating and /or drinking and psychological or social' to search for studies in Google Scholar and internet searches. Searches for this review were conducted in December 2020. The findings from this review were synthesised into a mind map and this was shared with the codesign stakeholder group as part of the intervention design workshops (Appendix 5).

Table 4: An example of MeSH terms used in the PubMed search.

<b>Population</b>	<b>Concept</b>
<b>Stroke</b> <ul style="list-style-type: none"> <li>• <b>Brain Infarction</b></li> <li>• <b>Brain stem infarctions</b></li> <li>• <b>Cerebral infarction</b></li> <li>• <b>Haemorrhagic stroke</b></li> <li>• <b>Ischemic stroke</b></li> <li>• <b>Embolic stroke</b></li> <li>• <b>Thrombotic stroke</b></li> </ul>	<b>Psychosocial</b> <ul style="list-style-type: none"> <li>• Intervention, Psychosocial</li> <li>• Interventions, Psychosocial</li> <li>• Psychosocial Interventions</li> <li>• Psychological Intervention</li> <li>• Intervention, Psychological</li> <li>• Interventions, Psychological</li> <li>• Psychological Interventions</li> </ul> <b>Psychological</b> <ul style="list-style-type: none"> <li>• Side Effects, Psychological</li> <li>• Psychological Side Effect</li> <li>• Side Effect, Psychological</li> </ul>

	<ul style="list-style-type: none"> <li>• Psychological Side Effects</li> <li>• Psychosocial Factors</li> <li>• Factor, Psychosocial</li> <li>• Factors, Psychosocial</li> <li>• Psychosocial Factor</li> <li>• Psychological Factors</li> <li>• Factor, Psychological</li> <li>• Psychological Factor</li> <li>• Factors, Psychological</li> <li>• Psychologists</li> <li>• Psychologist</li> </ul> <p>Social</p> <ul style="list-style-type: none"> <li>• Interaction, Social</li> <li>• Social Functioning</li> <li>• Functioning, Social</li> <li>• Functioning, Social</li> <li>• Social Functioning</li> </ul>
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#### 4.6 Selection of studies

Identified studies from eight electronic databases were collated in Endnote where the screening of papers occurred in two stages:

4.6.1 Stage 1 section process: All relevant article titles and abstracts were screened by one reviewer to identify potentially relevant papers and remove duplicates (NJ). Following this, 50% of the papers were checked by the second reviewer (KD) and differences were discussed; the final decision for inclusion was made by NJ. For studies where a decision on inclusion could not be made, the full paper was obtained for detailed assessment against the inclusion criteria by the two reviewers (NJ and KD) (Sataloff, et al., 2008).

4.6.2 Stage 2 selection process: For those studies identified as being potentially relevant, full texts were obtained. A record of rejected studies was noted for transparency. NJ and a second reviewer (KD) independently checked all the retrieved studies to see if they met the inclusion criteria. Disagreements about study eligibility were resolved by consulting the wider supervisory team (SM, AO) and the final decision was made by NJ. Only one study by Lin et al., (2021) was excluded following discussion with the supervisor team. The exclusion resulted from insufficient narrative data for analysis.

When multiple reports of a study were identified, they were reviewed to ensure that they included different data and aims or reported on a different aspect of the study. If the studies included the same patient cohort and were conducted in the same period, they were treated as one single study.

#### 4.7 Data extraction

All studies meeting the inclusion criteria were subject to a data extraction process to assess the completeness of data, facilitate comparison of studies and demonstrate studies were approached consistently (Booth, et al., 2012). A data extraction Excel spreadsheet was created to provide a record of the raw data and to support data synthesis (Booth, 2016). This was piloted on a selection of studies to ensure that all relevant information was captured. The following characteristics were extracted: author(s), title, country, year, the study aims and objectives, study type, participant characteristics, key findings and outcomes, details of any interventions and any evident quality issues. KD read 50% of the papers and independently checked the data extraction forms for accuracy and completeness. KD found a few small additions that had been missed and checked the other papers to ensure that similar omissions were not made.

#### 4.8 Quality assessment

The use of quality assessment tools to assess trustworthiness, relevance, and quality for systematic reviews is widely accepted (Higgins et al., 2022). However, the use of quality assessment in qualitative research is hotly debated (Garside, 2014). There is a lack of consensus on whether a quality assessment should be used to include or exclude qualitative research from systematic reviews (Barbour, 1998; Garside, 2014; Long, et al., 2020).

It has been argued that the quality of qualitative research cannot be defined using a predefined set of criteria (Howe and Eisenhart, 1990; Buchanan, 1992). Given the range and variety of qualitative methodologies, researchers argue for a more pragmatic approach (Dixon-Woods, 2004). Over the past few years, the debate regarding the necessity of quality assessment has evolved from the question of whether it should be carried out to determining the key aspects of a study that hold the most significance in the assessment process and deciding the course of action when a study is deemed to be of low quality. (Garside, 2014).

Suggestions to improve the trustworthiness of qualitative research include: involving more than one researcher in the assessment process (Mays, et al., 2005; Garside, 2014), adopting a minimum set of questions to stimulate appraisal (Dixon-Woods, 2004) or using a published checklist (Sataloff, et al., 2008). Consequently, a recognised and published critical appraisal tool for qualitative research was selected to assess the quality of studies in this review, and 50% of the studies were independently assessed by the second reviewer (KD). For transparency, it is important to record that one of the papers included in this review was co-authored by myself and by Nasrin Nasr (Jones and Nasr, 2018).

Cochrane Qualitative and Implementation Methods Group recommend the use of the Clinical Appraisal Skills Programme (CASP) tool for quality assessment in health-related qualitative evidence syntheses (Long, French and Brooks, 2020). The CASP qualitative tool was used in this review to identify flaws and weaknesses in the individual studies as well as assess the impact on the review in its entirety (Booth, et al., 2012).

## 4.9 Data Synthesis

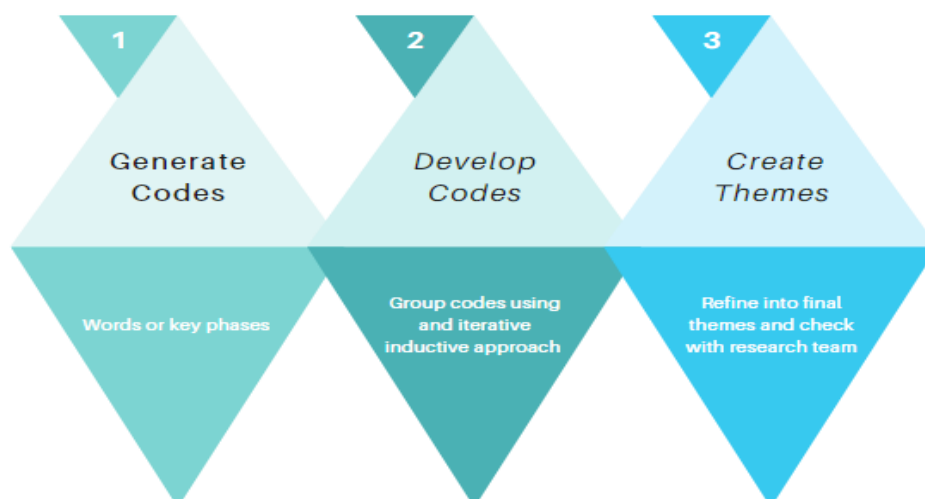
The included twenty-one studies were uploaded to the NVivo software for thematic analysis. Thomas & Harden's, (2008) three-stage approach was used to synthesise and analyse the qualitative data (Figure 9).

**Stage 1**-Initial coding was line-by-line. Codes were generated using a phrase or word to describe the findings. This was an iterative process with codes grouped using an inductive approach. Some sentences had multiple codes. New codes were developed with each study reviewed adding to those already developed. A total of seventy-seven codes were created.

**Stage 2**- Descriptive themes identified from the data during the preliminary synthesis were iteratively and rigorously scrutinised. Relationships between the characteristics of individual studies and their reported findings were explored. The findings of different studies were compared. Seventy-seven codes were condensed into eighteen codes to capture the meaning of the grouped concepts.

**Stage 3**- Eighteen codes were used to develop six themes which described the perceptions of stroke survivors, and their informal and formal carers, on the psychological and social impacts of eating and drinking difficulties. These were reviewed by the second reviewer (KD) and PhD supervisors (SM, AO).

Figure 9: Harden and Thomas (2008) 3-stage approach to qualitative data synthesis.



### 4.9.1 Search Results

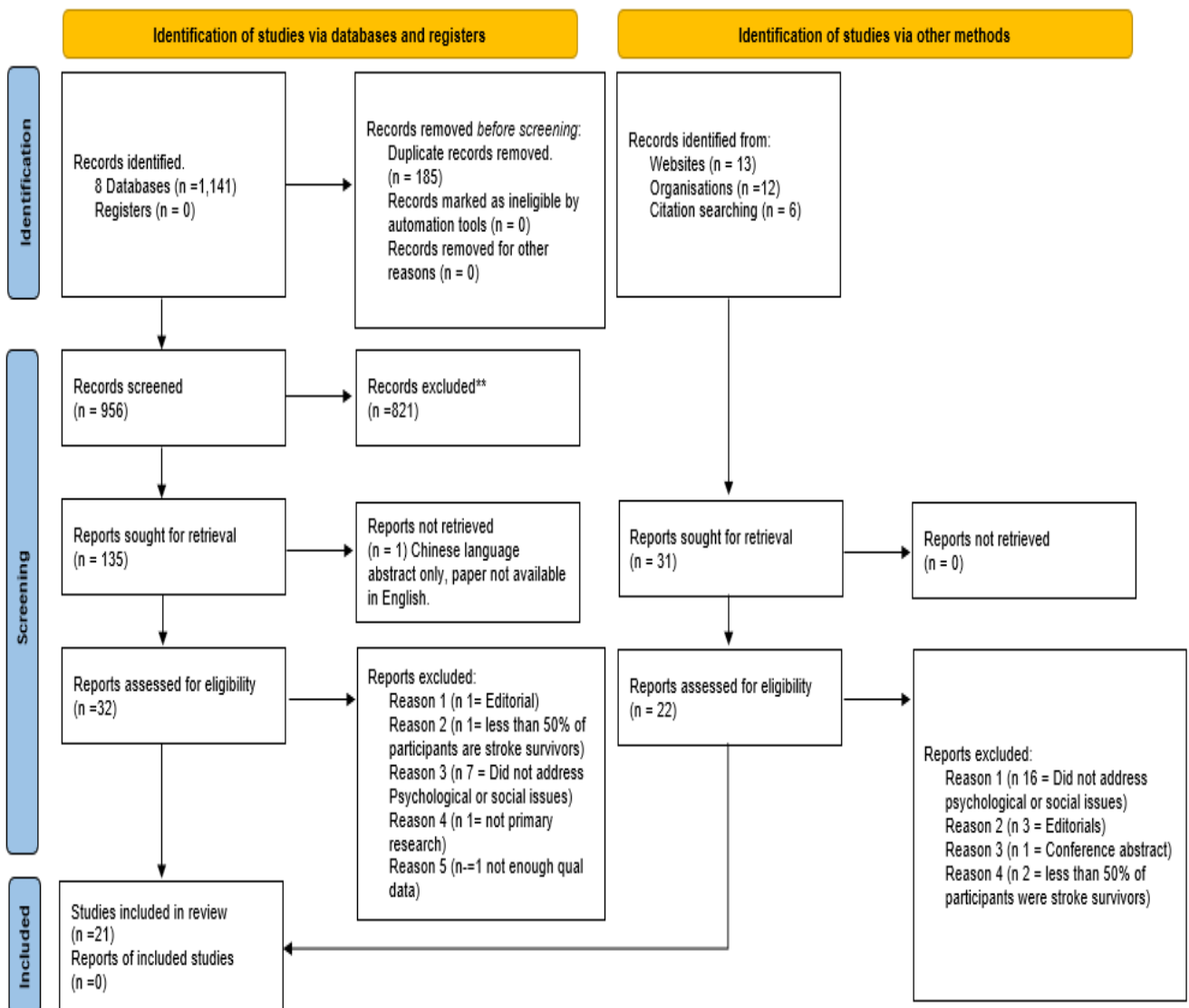
The left side of the PRISMA diagram shows the process for identification of studies from database searches which yielded 1,141 references; 185 of which were duplicates and were removed immediately, leaving 956 eligible studies for screening. These were screened by NJ and 821 studies were excluded. This left 135 studies that met the inclusion criteria. These abstracts were sought for retrieval and review by NJ, which resulted in one publication being disregarded. This publication had an English abstract however the main body of text was written in Chinese and there were no versions available in the English language so this study was excluded. This left 134 studies. These were screened for eligibility against the inclusion criteria and 102 were excluded leaving 32 studies to be assessed in more detail. Following a full article review 11 studies were rejected. The reasons for this are listed on the

PRISMA diagram below (Figure 10). Reasons included that the study did not address or mention psychosocial impacts of eating and drinking difficulties and following consultation with AO, one study was excluded (Lin et al., 2021) from the review on the grounds that there was insufficient qualitative data to analyse. This left 21 studies for inclusion in the review.

The right side of the PRISMA diagram shows the identification of studies via other methods of searching. These searches which included grey literature yielded 31 studies for retrieval and screening. From these 22 were assessed as relevant and these were assessed in more detail against the eligibility criteria. None of these studies were included in the review for the following reasons: n=16 did not address psychological or social aspects of eating and drinking difficulties, n=3 were editorials, n=1 conference abstract and n=2 included a mixture of patients with other neurological deficits where less than 50% were stroke survivor participants. Therefore identification of studies from databases was the most successful searching method. This resulted in 21 studies being identified for review.

In accordance with the PRISMA checklist, a full-text review of each study was completed independently by NJ and KD to ensure the studies met the inclusion and exclusion criteria. A PRISMA flow diagram detailing this process provides transparency on the selected studies and the reasons for exclusion are illustrated below (Moher et al., 2009).

Figure 10: PRISMA flow diagram.





## 4.9.2 Characteristics of the Studies

### 4.9.2.1 Types of studies included

The sample of 452 stroke survivors in the 21 studies was highly heterogeneous: n=227=male and n=225 female; at varying stages of their stroke recovery. Eight different types of study were included, the majority of investigations were mixed methods (n=9) followed closely by interview studies (n=8). Six studies combined interviews with some form of observation of eating a meal. There was a focus group study, concept analysis, narrative literature review and cross-sectional study.

### 4.9.2.2 Research settings

As expected, research settings varied according to the stage of recovery, from hospital to home or other rehabilitation facilities. The most common setting was a patient's own home (n=9). Three studies were conducted in a hospital and then followed up at home, three were in hospital only and the other four were a mixture of a day-care facility (n=1), a care home (n=1) and outpatient departments (n=2).

### 4.9.2.3 Countries included

The studies were spread across seven different countries with Sweden having the majority of studies (n=8) followed by the UK (n=4), Iceland (n=2), Ireland (n=1), Brazil (n=1), Switzerland (n=1) and Denmark (n=1).

### 4.9.2.4 Informal carer participants

Five studies involved informal carers, but scant information was provided about their roles or contributions to the study. Only one study (Johansson and Johansson, 2009) described whether the carers were cohabiting with stroke survivors. Johansson and Johansson, (2009) was the sole study with only informal carers (n=9); the other four studies had a mixture of informal carers being present to support conversation within the interviews n=1 (Jones and Nasr, 2018,) informal carers contributing to the interviews (Jacobsson et al., 1996; Eltringham et al., 2019) and included informal carers interviewed as proxies (Perry and McLaren, 2003).

### 4.9.2.5 Formal carer participants

Formal carers included health or social care professionals caring for stroke survivors. As a range of health and care professionals are involved in the formal care of stroke survivors it would be usual to find a variety of participants in these studies (Intercollegiate Stroke Working Party, 2016). Only one study included formal carers (Kumlien and Axelsson, 2002) which explored the views of formal carers and the experiences of stroke survivors undertaken in a Swedish care home.

### 4.9.2.6 Sample sizes

Sample sizes within each study ranged from n=3 (Carlsson, et al., 2004) to n=113 (Perry and McLaren, 2003b, 2003a).

### 4.9.2.7 Number of days, months, and years post-stroke

Studies ranged from 1 day to 17 years post-stroke. Six of the studies were conducted in the first six months post-stroke, and four were conducted between 1 day and 1 year. The other



studies were conducted from six months up to 10 years with the majority being around 1-2 years (n=3).

#### 4.10 Overview of Themes from evidence synthesis

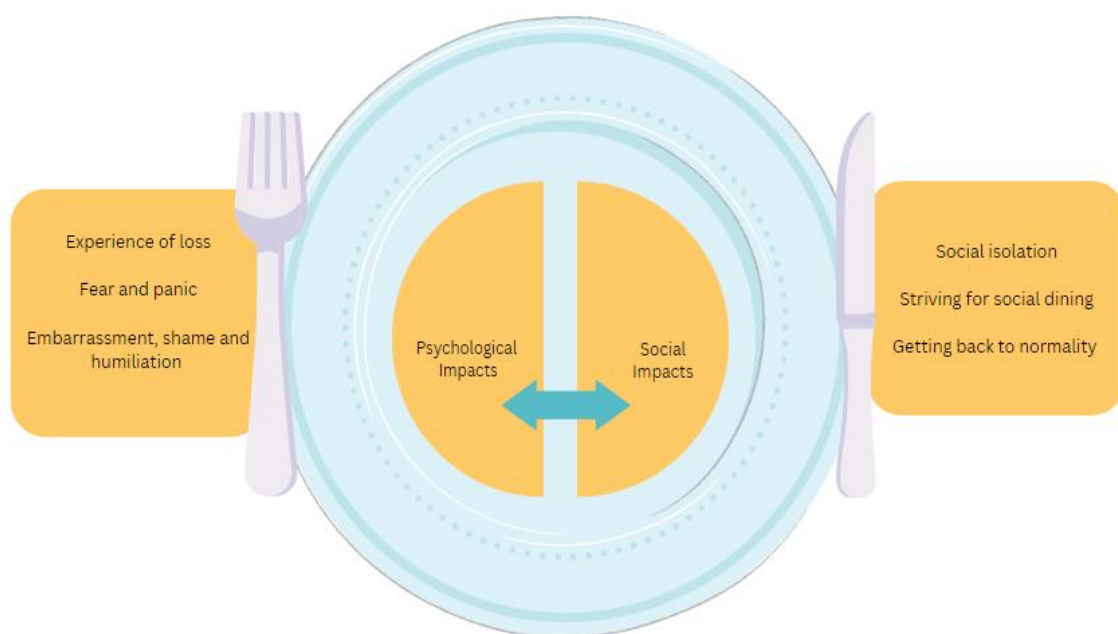
The complexity of eating and drinking difficulties and the impact on physical abilities, psychological well-being and social participation were described in all studies. Although all of the included studies addressed psychological and social impacts to some degree, these issues were not always the sole focus of these studies.

The term 'psychosocial' was mentioned in seven papers. However, when addressing this issue, authors tended to write about psychological and social issues as separate entities. Even when they tended to be addressed and labelled separately, these issues were referred to as related concepts (Klinke et al., 2013; Jones and Nasr, 2018; Kjaersgaard and Pallesen, 2020). Perry and McLaren, (2001, 2003a) recognised the importance of both psychological and social impacts, arguing that they have equal parity to physiological impacts. This was supported by Jones and Nasr, (2018) in a study to explore eating difficulties 6 months post-stroke. Jones and Nasr, (2018) identified several subthemes related to psychosocial aspects of recovery that suggested they were integral to understanding the impacts of eating and drinking disabilities. Following evidence synthesis of all studies, two themes were inductively developed to illustrate the psychosocial impact of eating and drinking difficulties (see Figure 11):

Theme 1 Psychological impacts had three subthemes: 1) experience of loss, 2) fear and panic, and 3) embarrassment, shame, and humiliation.

Theme 2 Social impacts also had three subthemes: 1) social isolation 2) striving for social dining 3) Getting back to normality (illustrated in Figure 2 below).

Figure 11: Overview of themes from systematic review evidence synthesis.



#### 4.10.1 Psychological Impact

The psychological impact of eating and drinking difficulties was recognised in all 21 studies. Stroke survivors were afraid of the consequences of swallowing difficulties, experiencing fear and panic. Following changes in eating and drinking abilities, stroke survivors experienced humiliation, frustration, and loss of dignity. They described how this resulted in a desire to isolate or avoid social eating occasions.

##### 4.10.1.1 Experience of loss

Three types of loss associated with eating and drinking difficulties were identified:

- 1) Loss of physical eating and drinking abilities (Carlsson, et al., 2004)
- 2) Loss of activities related to eating and drinking (Carlsson, et al., 2004; Medin et al., 2010)
- 3) Loss of joy and pleasure associated with eating and drinking (Jacobsson et al., 1996; Jones and Nasr, 2018; McCurtin et al., 2018).

Loss of activities associated with eating and drinking included growing one's food (Carlsson, et al., 2004), shopping (Medin et al., 2010a; Medin et al., 2012; Jones and Nasr, 2018), preparing and cooking food (Jacobsson et al., 1996; Carlsson, Ehrenberg and Ehnfors, 2004; Jones and Nasr, 2018).

Stroke survivors also identified a loss of pleasure associated with social dining (Jones and Nasr, 2018) including attending events or activities which would involve eating or drinking such as weddings or funerals (Helldén, Bergström and Karlsson, 2018). Carers described a loss of intimacy due to a lack of conversation over meals and reduced closeness due to the repulsion of observing messy eating (Johansson and Johansson, 2009).

Eating and drinking experiences after stroke were perceived as no longer pleasurable (Jacobsson et al., 2000a). The loss of joy and pleasure from consuming food and drink was associated with discomfort in the mouth and throat resulting from swallowing difficulties (Jacobsson et al., 2000b; Klinker et al., 2013) and changes in sensory functions leading to altered taste and smell (Klinker et al., 2014; Jones and Nasr, 2018; Kjaersgaard and Pallesen, 2020).

A study involving informal carers of stroke survivors discussed the change in roles and responsibilities experienced by both patients and carers (Johansson and Johansson, 2009). Role changes such as who did the cooking and mealtime preparation. Stroke survivors expressed frustration at not being able to regain roles associated with eating and drinking such as preparing and cooking food (Carlsson, et al., 2010; Jones and Nasr, 2018).

Stroke survivors described the loss as irrevocable and devastating (Perry and McLaren, 2003a; Carlsson, et al., 2004) and it was compared to the experience of grief (Carlsson, et al., 2004; Eltringham et al., 2019). Stages of this grief were marked by anger and fear (Eltringham et al., 2019), abandonment (Carlsson, et al., 2004), isolation (Klinker et al., 2013), bewilderment and despair (Perry and McLaren, 2003b), low mood (Westergren, 2008) and depression (Kumlien and Axelsson, 2002; Perry and McLaren, 2003b).

Conversely, Medin et al., (2012) found that some stroke survivors saw the change in eating-related activities as a positive, embracing the relief of not having to shop or cook anymore (Medin et al., 2010). Carlsson and colleagues (2004) followed three stroke survivors at 3 months and 18 months after stroke to explore lived experiences of eating difficulties. They discovered that stroke survivors were figuring out ways to accept disabilities to overcome the sense of loss by adjusting to new ways of eating and drinking.

#### 4.10.1.2 Fear and Panic

Several studies described the debilitating experience of fear associated with eating and drinking difficulties. Stroke survivors were fearful of aspirating on food and fluids, resulting in life-threatening pneumonia (Kumlien and Axelsson, 2002; Klinke et al., 2013; Eltringham et al., 2019). Fear was also related to choking (Jacobsson et al., 2000b; Carlsson, et al., 2004), excessive coughing (Johansson and Johansson, 2009; Klinke et al., 2014), and the ultimate fear of suffocation leading to death (Jacobsson et al., 2000b; Kumlien and Axelsson, 2002; Perry and McLaren, 2003a).

*“He was expecting repercussions as a consequence of his dysphagia. His informal caregiver stated he was convinced he was going to develop pneumonia.”*

(Said by an informal carer in Eltringham et al., 2019)

Feelings associated with loss of physical abilities were anger (Perry and McLaren, 2003a; Medin et al., 2010; Eltringham et al., 2019), frustration (Perry and McLaren, 2003b; J Medin et al., 2010), and resentment (Perry and McLaren, 2003a, 2003b). Jacobsson and colleagues (1996) described difficulties with the transportation of food and drink as aberrant or unsynchronised movements of the hand and mouth. This observation was reinforced by the results of a study by Jones and Nasr (2018), where the fear of encountering difficulties with the transportation of food and drink from the table to the mouth, as well as the oral manipulation of food and drink inside the mouth, were articulated by two-stroke survivors during an exploration of their lived experience (Jones and Nasr, 2018).

Fears associated with the impaired execution of hand-to-mouth movements included anticipation of clumsiness (Jacobsson et al., 2000a), making a mess (Perry and McLaren, 2003b; Jones and Nasr, 2018), spillages (Jacobsson et al., 1996; Carlsson, et al., 2004; Medin et al., 2010), leakage and drooling from the mouth (Jacobsson et al., 1997; Klinke et al., 2013, 2014).

Jacobsson and coauthors (1997) described four aspects of eating performance which encompassed the handling of food, lip closure and biting, manipulation of food in the mouth and the act of swallowing. Stroke survivors perceived an inability to proficiently execute any of these aspects as a threat because it deviated from the societal norms for eating (Helldén, et al., 2018; Jones and Nasr, 2018). The risk of being unable to achieve a clean and efficient performance in eating and drinking was seen as a barrier to social dining (Johansson and Johansson, 2009; Medin et al., 2010; Medin et al., 2012; Klinke et al., 2013; Helldén et al., 2018).

Klinke et al., (2014) described this as a state of vulnerability and suggested that feeling safe and secure was important to ensure that adequate food and drink was consumed. This was illustrated in a study by McCurtin and colleagues (2018), who investigated what stroke survivors thought about drinking thickened fluids. Participants reported that although they did not like the thickened drinks, they appreciated that it was reducing the risk of complications and therefore served a beneficial purpose.

#### 4.10.1.3 Embarrassment, shame, and humiliation

Embarrassment, shame, and humiliation were commonly experienced emotional states. These terms were used interchangeably in the literature to describe the emotional impact of eating and drinking difficulties. Examples of these states were found in early stroke recovery (1-3 months) (Kumlien and Axelsson, 2002; Eltringham et al., 2019) as well as later stroke recovery stages (6 months plus) (Carlsson, Ehrenberg and Ehnfors, 2004; Jorgen Medin et al., 2010; Jones and Nasr, 2018).

Feelings of embarrassment and humiliation were associated with not being able to independently feed oneself and needing to rely on others for help (Carlsson, et al., 2004; Medin et al., 2010; Eltringham et al., 2019). Social embarrassment related to a change in one's appearance such as disfigured facial muscles (Schimmel 2017, Jacobsson et al., 2000b), leading to food leakage (Jacobsson et al., 2000b), coughing attacks (Jacobsson et al., 2000b; Kumlien and Axelsson, 2002) and concerns about what other people were thinking about changes in habits or performance (Jacobsson et al., 2000b; Kumlien and Axelsson, 2002; Johansson and Johansson, 2009; Kjaersgaard and Pallesen, 2020).

The experience of these emotions evoked a desire to conceal difficulties from others (Perry and McLaren, 2003a; Klinke et al., 2013; Kjaersgaard and Pallesen, 2020) and avoid situations or certain foods which were perceived as problematic (Medin et al., 2012, Klinke's et al., 2014). This is illustrated below by a stroke survivor talking about going out for a meal.

*"I look at the menu and sort of thing, well I can have soup; safe there. I won't have steak because I won't be able to cut it. I'll have curry because that's easy for me, I can use a spoon or fork for that."*

(said by a stroke survivor (Perry and McLaren, 2003b).

A phenomenological investigation involving seven stroke survivors (ranging from 7 months to 8 years post-stroke) documented their efforts to preserve a sense of dignity by denying the existence of difficulties (Klinke et al., 2014). This view is supported by an earlier study conducted by the same researcher, which discussed how stroke survivors were trying to conceal difficulties by avoiding social dining with unfamiliar people or leaving uneaten food that they could not easily manage (Klinke et al., 2013). Perry and McLaren, (2003a) associate the concept of concealing difficulties with a desire to appear and feel normal whilst managing self-conscious feelings.

The experience of feeling 'child-like' was reported in several studies (Perry and McLaren, 2003b; Jones and Nasr, 2018). Four participants in the Jones and Nasr, (2018) study

discussed regressing to childlike behaviour with messy eating, dependency on someone to cut up food, and dribbling and leakage from the lips.

*“I can’t use both hands to cut food up, whoever I go out with will usually do it for me but you know, you feel self-conscious, you know somebody has to cut your food up like a child.”* (said by a stroke survivor Jones and Nasr, 2018).

Conversely, Klinke and colleagues (2014) reported an instance where a stroke survivor regarded having someone else cut their food as not overly burdensome but rather as a way to ‘make the best of things’ (Klinke et al., 2014). Jones and Nasr, (2018) described the embarrassment of feeling ‘child-like’ and self-conscious which impacted the desire to and willingness to participate in social dining. This view was validated by the research of Klinke and colleagues (2013), (2014); and Kjaersgaard and Pallesen, (2020) all of whom examined how the lack of control and the experience of reverting to childlike behaviours generated anxiety and restricted social participation.

#### 4.10.2 Social impacts

The findings related to the social implications of eating and drinking difficulties were discussed in the context of social isolation which was either self-imposed or stemming from the emotional impacts of these difficulties.

##### 4.10.2.1 Social isolation

Stroke survivors discussed the experience of social isolation which was related to negative feelings (Perry and McLaren, 2003a; Kjaersgaard and Pallesen, 2020). Reasons for wanting to be alone included consumption of food and drink taking much longer than usual (Jacobsson et al., 1996, 1997), anxiety (Kjaersgaard and Pallesen, 2020), humiliation (Klinke, 2014) and reduced trust in abilities due to changes in eating and drinking habits. Eating was viewed as a task to manage alone (Carlsson, et al., 2004) and thus isolation was self-imposed.

Other factors limiting or reducing social contact were difficulty concentrating (Klinke et al., 2014), low energy levels (Kjaersgaard and Pallesen, 2020), reduced alertness (Kumlien and Axelsson, 2002) and fatigue (Jacobsson et al., 1997; Klinke et al., 2014). These elements had an adverse effect on the desire to eat and also influenced the willingness to engage in social dining. In a pilot study conducted by Westergren (2008) which involved 89 stroke survivors, the investigation explored the relationship between fatigue and nutritional intake six months after stroke. The results indicated that the stroke survivors experiencing fatigue had poor nutritional status and those with suboptimal nutritional status were more susceptible to experiencing fatigue. Westergren, (2008) concludes it is essential to contemplate interventions aimed at enhancing eating and drinking abilities to prevent fatigue from culminating in unfavourable nutritional and functional outcomes.

##### 4.10.2.2 Striving for social dining

The importance of social activities related to eating and drinking, such as dining with friends and family and celebratory events, was highlighted as significant for stroke survivors (Perry and McLaren, 2003b, 2003a). Social dining was closely associated with feelings of pleasure and enjoyment (Johansson and Johansson, 2009; Eltringham et al., 2019), holding personal meaning in the lives of individuals (Klinke et al., 2013).

The loss or absence of social dining was considered to have a detrimental impact on well-being (Klinke et al., 2013). Jones and Nasr, (2018) described a preference for social engagement over isolation, emphasising the desire to participate in social dining activities. Social dining was perceived as a symbol of resuming life after a stroke and was viewed as a measure of progress and achievement (Jones and Nasr, 2018). Other researchers found that social dining was a way to connect, socialise and sustain social relationships (Klinke et al., 2013; Kjaersgaard and Pallesen, 2020).

Helldén et al., (2018) described how people wanted to overcome problems to participate in social gatherings. Perry and McLaren, (2003a) found that people were seeking ways to adapt to eating and drinking difficulties and coped better when dining with familiar people. This was validated by stroke survivors in Medin's study (2010) which discussed their feelings about eating in front of strangers.

*"I suppose I'm a bit cautious... Yes, you feel ashamed... You're afraid of spilling... I do not really want to eat with unfamiliar people!"*

(said by a stroke survivor in Medin et al., 2010)

Social dining had to be carefully planned in advance (Medin et al., 2010; Medin et al., 2012; Kjaersgaard and Pallesen, 2020). This view is supported by a finding in Jones and Nasr's study (2018).

*"For some, it was no longer a spontaneous activity. Eating out required a number of strategies to navigate inhospitable environments, menu choices and seating arrangements".* (Authors comments (Jones and Nasr, 2018).

#### 4.10.2.3 Getting back to normality

A recurring theme was the aspiration to return to a state of normalcy (Jacobsson *et al.*, 1996; Perry and McLaren, 2003a; Carlsson, et al., 2004; Jones and Nasr, 2018). Perry and McLaren, (2003a, 2003b) described this as compartmentalising the impacts of the stroke to minimise their psychological effect and create a new way of being. Finding normality was about getting back to life but accommodating the effects of stroke (Perry and McLaren, 2003b). Carlsson, et al., (2004) discussed this as a 'striving process'. They described how striving to regain activities and achieve normalcy involved three stages of adjustment (Carlsson, et al., 2004). Relearning, dealing with loss, and adjustment to dependency.

Adjustment to eating and drinking difficulties was also discussed in other studies. Jacobsson et al., (1996) described it as a process of realisation, and Perry and McLaren, (2003a) depicted it as working towards a status of 'getting by'. Klinke et al., (2013) referred to it as reconnecting with pre-stroke habits and Kjaersgaard and Pallesen, (2020) discuss the process of learning to live with the consequences of stroke. Despite the negative impacts stroke survivors were in the process of acquiring the ability to adapt and cope (Helldén, Bergström and Karlsson, 2018).

Jacobsson and colleagues (2000b) and Jones and Nasr, (2018) found that stroke survivors were learning from experience and from other stroke survivors to generate solutions and strategies to strive towards mastery of the consequences of stroke. Learning to cope



involves creating new strategies (Perry and McLaren, 2003a; Medin et al., 2010a; Jorgen Medin et al., 2010b) and experiencing a sense of achievement. Regaining some control and mastery was perceived by stroke survivors as a victory (Perry and McLaren, 2003a; Klinke et al., 2014).

## 4.11 Discussion

### 4.11.1 Summary of Findings

In summary, the psychosocial impacts of eating and drinking difficulties are multifaceted involving the loss of physical abilities, enjoyable activities and sensory pleasure associated with food and drink. Emotions encompass fear, panic, embarrassment and shame, and uncertainty about the future, and are often confounded by health-related insecurities. Social isolation driven by embarrassment about stroke impairments is common and can lead stroke survivors to deliberately distance themselves from social interactions. Stroke survivors are working to regain competence with eating and drinking to restore their independence and reclaim a sense of normalcy, including the ability to participate in social dining occasions without discomfort or shame.

#### Experience of loss

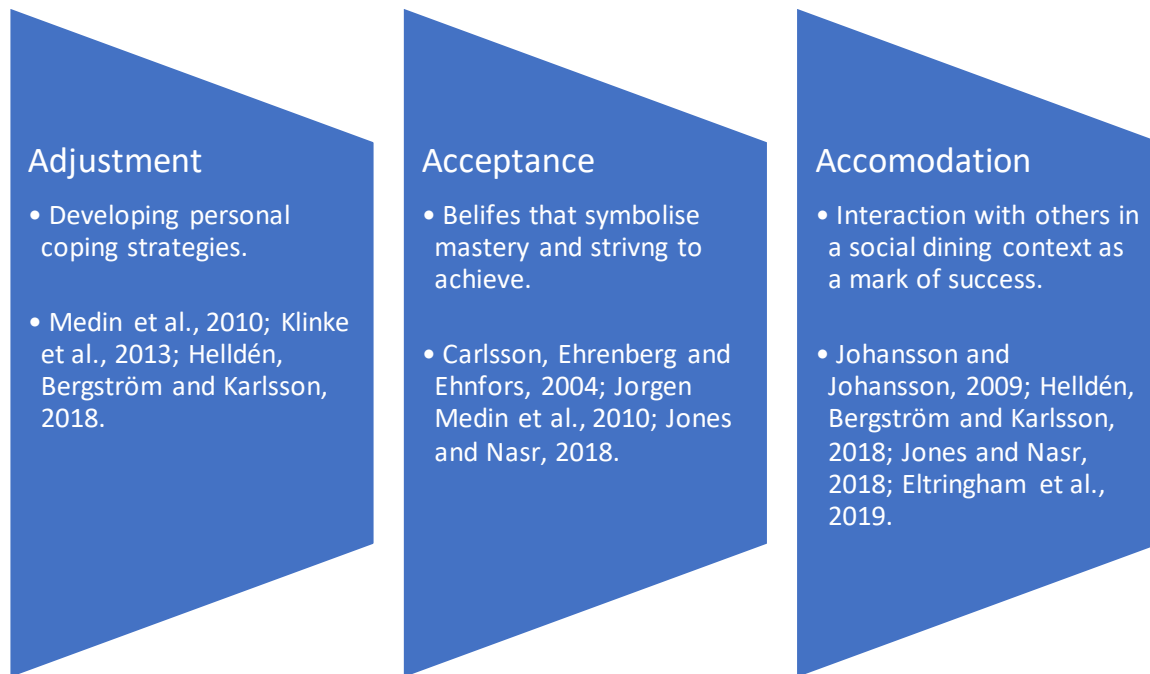
Studies exploring the phenomena of eating and drinking difficulties in conjunction with other neurological conditions such as multiple sclerosis and head and neck cancers also revealed a common loss of self-confidence and dignity among participants (Ekberg et al., 2002; Dornan et al., 2021). Similarly, research exploring the broader impacts of stroke has identified a sense of loss as a significant psychological consequence (McKevitt et al., 2011; Lou et al., 2017). A secondary thematic analysis of primary narrative interview data by Kitson and others (2013) confirmed the prevalence of loss as an experience amongst stroke survivors. To understand the phenomena of loss, Charmaz's work (1983, 1995) on the loss of self in the context of chronic illness and adaptation to impairment can be informative.

Charmaz's study (1983) with 57 chronically ill individuals suggested that illness-related suffering was closely linked to loss of self. Subsequently, the sociological construct of 'loss of self' was associated with the disruption of activities of daily living rather than the illness itself (Charmaz, 1990). Charmaz, (1995) further expanded on the concept of loss and the process of adaption to it by proposing three stages to overcome the experience of loss. These stages involve assessing the loss and redefining the goals, accordingly, accepting feelings instead of denying them and learning to live with illness rather than fighting against it. The findings of the studies reviewed exhibited these various stages of loss, indicating that Charmaz's research on the loss of self and the stage of loss offers a framework to understand how stroke survivors might navigate their way through eating and drinking difficulties.

An additional theory that provides some understanding of the recovery process associated with eating and drinking difficulties after a stroke is the model of illness adjustment proposed by Radley and Green, (1987). This features four modalities that describe how individuals adjust to chronic illness. The modalities represent opposing views, those that support adjustment, acceptance, and accommodation, and those that reflect loss, denial, resignation, and a feeling of being overwhelmed. This model aims to explain how individuals

progress through stages of adjustment displaying different modalities at various stages of recovery. Their exploration emphasises a recovery trajectory, led by a personal journey of adjustment from chronic illnesses highlighting the importance of re-engaging in social participation and roles. The recovery processes of adjustment, acceptance, and accommodation, align with the recovery aspects associated with eating and drinking difficulties found in this study as illustrated below (Figure 12):

Figure 12 Recovery process for eating and drinking difficulties, a synthesis of evidence.



#### Fear and panic

Fear and panic stemming from issues like choking, coughing, and concerns about contracting pneumonia were reported in 14 studies. While Carlsson (2004) noted that fear might diminish with time, for some, fear remained a constant presence (Perry and McLaren, 2003b, 2003a; Medin et al., 2010). Klinke (2014) and McCurtin (2018) suggest that learning new strategies to prevent post-stroke consequences such as coughing, choking, or messy eating could be beneficial. This is supported by a study with head and neck cancer survivors who found that coping strategies helped them manage fear and worry associated with eating and drinking difficulties (Dalton et al., 2022).

Dalton et al., (2022) demonstrated that emotion-based coping strategies such as positive re-appraisal and distraction could be deployed to help participants reframe their view of what constitutes normal eating. Despite experiencing discomfort and negative emotions participants used family and social dining experiences to reintroduce positive meaning and a sense of purpose to help them cope (Dalton et al., 2022). This suggests that group social dining interventions could be of merit for stroke survivors.



### Embarrassment, Shame and Humiliation

Stroke survivors with eating and drinking difficulties experienced a range of negative emotions such as shame, humiliation, and embarrassment. Kitson et al., (2013) conducted a secondary thematic analysis of narrative interview data exploring the fundamentals of care for stroke survivors which revealed that for every physical need, there were corresponding accounts of fear, embarrassment, humiliation, and loss of confidence. Kitson et al., (2013) argue that frameworks should bridge the physiological and psychosocial fundamentals of care to preserve dignity and prevent unnecessary humiliation among stroke survivors.

Embarrassment and humiliation were often linked to feeling self-consciousness and difficulties in handling food on the plate (Jacobsson et al., 1996) or transferring food to the mouth smoothly (Jacobsson et al., 1996). Changes in eating and drinking habits heightened self-consciousness for stroke survivors (Perry and McLaren, 2003a; Eltringham et al., 2019; Kjaersgaard and Pallesen, 2020).

Insights from Burges and colleagues (2018) work with head and neck cancer survivors shed light on how eating and drinking difficulties impact an individual's emotional well-being. They developed an 'Altered Eating Framework' with 25 head and neck cancer survivors to assess the food-related quality of life, revealing that caution, carefulness and effort required to eat and drink could deprive people of a pleasurable dining experience (Burges et al., 2018). The emotional effects of eating and drinking difficulties appeared to negatively affect the experience of pleasure (Burges et al., 2018).

The Framework defines altered eating as a *"changed state of any combination of physical, emotional and social interceptions with food and eating that has a negative impact on health and well-being"* (Burges Watson et al., 2018). This acknowledges the importance of emotional impacts and the multi-factorial nature of the issue, offering researchers and clinicians the opportunity to develop more innovative interventions (Burges Watson et al., 2018). Participants in the study reported that coming together to discuss their eating and drinking difficulties and experiment with food was a therapeutic experience which potentially offers valuable insights for future interventions in this area.

### Social impacts

No specific studies explored the social impacts of eating and drinking difficulties after stroke. However, eleven studies addressed the importance of social eating and the impact of eating and drinking difficulties on the ability or desire to socially dine with others. A recent literature review summarised the evidence for communal dining and its influence on functional outcomes in rehabilitation and residential aged-care facilities, suggesting that communal dining was likely to improve nutritional outcomes (McLaren-Hedwards et al., 2021). However, this study did not consider the potential benefits of socialisation and so further stroke-specific studies are required to explore this relationship.

Earlier stages of stroke recovery (up to 3 months post-stroke) received relatively little attention regarding the impacts of eating and drinking difficulties on social life, likely due to the number of studies being conducted 6 months post-stroke. However, one study within

the initial three months post-stroke described avoidance of social settings, especially if unfamiliar individuals were involved in the eating occasion (Medin et al., 2010).

In studies conducted six months post-stroke, conflicting reports emerged about how stroke survivors were experiencing social eating. Helldén and colleagues (2018) found that restaurant visits were less enjoyable, and the unpredictability of eating and drinking difficulties made family gatherings something to dread or avoid. Conversely, participants in Jones and Nasr, (2018) relished the opportunity to participate in family rituals such as Sunday lunch and used social dining opportunities to practice cooking skills and become more proficient with eating and drinking.

#### Social Isolation

Kjaersgaard and Pallesen (2020) found that some stroke survivors were socially isolating themselves as a result of feelings of shame and embarrassment related to compliance with social norms for eating. These findings resonate with a similar study involving individuals with Parkinson's Disease, where participants experienced stigma, and avoidance of public eating situations, resulting in decreased participation (Murray-Smith et al., 2019). Eriksson and Tham, (2009), in a longitudinal study on how stroke survivors adapt to difficulties with performing everyday activities after a stroke, suggest that loss of ability to perform tasks like eating and drinking affects one's self-identity. Eriksson and Tham (2010a) explain this is why stroke survivors strive to resume independence in these activities, to preserve their sense of self and social identity.

This review found that eating and drinking difficulties altered the dynamics between loved ones during meals (Johansson and Johansson, 2009; Klinke et al., 2013; Kjaersgaard and Pallesen, 2020), leading to a disconnection associated with the disruption to usual intimacy and conversation during meals, feelings of discomfort, and the need to concentrate more to preserve dignity, often resulting in avoiding social eating potentially leading to social isolation.

#### Striving for Social Dining

Whilst there were concerns about eating in the presence of others, most studies suggested that social dining was something to strive for. Hung, and colleagues (2016) conducted focus groups with care staff in a long-term care facility to capture the views on the advantages of social dining. Their findings suggest social dining offered opportunities for patients to socialise with fellow in-patients, mobilise, access support, and enhance personal autonomy (Hung, Chaudhury and Rust, 2016). Providing an open environment where residents had support to choose and prepare their meals in a home-like atmosphere made the experience of dining more enjoyable and socially stimulating for residents (Hung, Chaudhury and Rust, 2016). Daily rituals like having coffee, and a choice of what to eat fostered feelings of safety, comfort and independence which reinforced the sense of self and promoted personalised care (Hung, Chaudhury and Rust, 2016). However, it was important to note that social dining was not preferred by everyone, and the quality of the experience varied depending on the patient cohort (Hung, Chaudhury and Rust, 2016).

### Getting back to normal

Klinke and colleagues (2013) observed that individuals with severe difficulties were imitating eating and drinking to appear normal. Improvements in energy levels and overall quality of life have been associated with social dining (McLaren-Hedwards et al., 2021) however stroke survivors perceive social dining as challenging due to the need for careful planning, coordination, and self-consciousness (Jones and Nasr, 2018). Eltringham and colleagues (2019) emphasised the importance of taking inpatient stroke survivors to the dining room for meals. Klinke and coauthors (2013) endorsed the idea of interventions focusing on the re-integration of social dining proposing that setting goals to promote progress could potentially lead to increased enjoyment of social dining.

Stroebele and De Castro, (2004) explored the effect of ambience on food uptake and choice. The presence of others during dining was thought to have a significant effect on food and drink consumption (Stroebele and De Castro, 2004). This factor was coined as 'social facilitation' based on studies with normal populations who tended to eat and drink more in social dining contexts (Polivy et al., 1979; Clendenen, et al., 1994). The sight of food, accessibility of the environment and presentation of portion size were also thought to be important factors.

Stroke survivors showed a decreased inclination to engage in social dining with unfamiliar individuals (Medin et al., 2010). However, they were actively working towards reintegrating social dining with their families (Kumlien and Axelsson, 2002; Klinke et al., 2014). Their goal was to regain their previous life or establish a new sense of normal (Perry and McLaren, 2003a; Carlsson, et al., 2004).

Eriksson and Tham, (2009) discuss five characteristics through which stroke survivors conceptualise difficulties with performing everyday activities. These include the desire to actively participate in tasks, attempting them despite changes, and striving for mastery. (Eriksson and Tham, 2009). Findings suggest resumption and practice of normal activities in the context of simple daily routines can lead to a sense of normalcy and mastery despite the disruption caused by the consequences of stroke.

A longitudinal study by Eriksson and Tham, (2010b) sought to understand how stroke survivors were experiencing gaps in everyday occupations in the first year after stroke. Eriksson and Tham (2010b) reported participants were expressing worry, loss and grief over occupations that were lost or difficult to perform. This supports the view that feeling safe and secure is important to building confidence.

### 4.12 Strengths and limitations

This systematic review is the first to specifically explore the psychosocial impacts of eating and drinking difficulties after a stroke. This term psychosocial was noted in seven of the twenty-two papers identified however the impacts of eating and drinking difficulties on psychological and social well-being were discussed separately or jointly. Psychological impacts were more commonly reported. Social impacts were discussed but not explored in depth.

The optimal method for assessing the quality of qualitative research remains a subject for debate. Nevertheless, there is consensus that adhering to reporting standards provides transparency in the research process and is advisable to incorporate additional measures to evaluate trustworthiness (Garside, 2014). All of the papers were critically appraised by two researchers NJ and KD and any challenges were checked with the supervisory team for rigour.

This study had a robust approach to reporting using the PRISMA guidelines to document the search process (Moher et al., 2009). A recognised quality assessment tool was used to critically appraise the selected papers (CASP, 2018) and the ENQTREQ guidelines were used for reporting on the qualitative synthesis (Tong et al., 2012). Synthesis of multiple qualitative studies drawing together data from across different contexts can provide an in-depth understanding of human experiences (Tong et al., 2012). This review included mixed methods qualitative studies from different contexts, interviews being the largest type of study.

This review did not define a time frame for the stroke recovery period, so the studies were included up to 17 years post-stroke (2 weeks to 17 years). This breadth of period provided data from acute to mid to long-term stages of recovery which added to the richness of the study findings. It also included a range of study settings for the studies including hospitals, homes, care homes and outpatient rehabilitation centres although there was a high level of heterogeneity similar psychological and social impacts were experienced throughout the period. The balance between male and female participants was evenly matched by chance alone. In research, it is important to consider the sex-specific differences that can affect generalisability. Each year globally a relatively even number of both sexes have a stroke (47% of all strokes occur in men and 53% of all strokes occur in women) so a balanced number of participants from each gender reflects the worldwide stroke data (World Stroke Organisations 2022).

The majority of the papers included were from high to medium-income, developed countries so the results may not be generalisable to low-income countries due to cultural and contextual differences. Studies came from seven different countries with Sweden being the biggest contributor with eight of the papers. Only 4 of the studies were from the UK so this could limit generalisability to National Health Services contexts however qualitative research is less concerned with the country of origin and more concerned with the experiences, and social and psychological phenomena being studied.

A plan was agreed to only include studies that had 50% of stroke survivors participants which could have led to studies with multiple neurological conditions being missed. There was only one study with a mixed cohort of patients, and this included someone with a brain tumour. One review has missing data for the age and sex of participants the author (Eltringham et al., 2019) was contacted and the missing data was provided in an email.

#### 4.13 Implications for clinical practice, other research, and BISTRo study

Several studies have found that stroke survivors report psychosocial needs that are unmet post-stroke (Chen et al., 2019; Kim et al., 2021). The need for psychological care to support

stroke survivors with the lasting effects of stroke, especially with the emotional and social impacts of stroke, is recommended in the National Clinical Stroke Guidelines (NICE, 2023).

National Stroke Clinical Guidance largely focuses on dysphagia, (swallowing difficulties) and general aspects of rehabilitation related to activities of daily living (Royal College of Physicians, 2023). Although eating and drinking rehabilitation is covered in the guidance (sections 4.8, 4.18, 4.26, 6.3 Royal College of Physicians, 2023) there are unanswered questions about best practice for eating and drinking interventions that incorporate the physical act of transportation of food and drink to the mouth and interventions that address the psychosocial impacts of eating and drinking (Royal College of Physicians, 2023). Participation in activities of daily living such as eating and drinking are recommended and the translation of upper-limb rehabilitation into everyday activities such as self-feeding is supported (Royal College of Physicians, 2023). Without specific guidance on these aspects of stroke care and rehabilitation, clinicians have no evidence to guide practice and therefore more research is required to inform future national stroke guidance on this significant area of stroke recovery.

#### 4.14 Implications for this thesis

This review makes a significant contribution to the understanding of stroke survivors' experiences with eating and drinking difficulties. It highlights the important components which need to be taken into account when addressing interventions for this population. In addition, it emphasises the important role of social dining in maintaining social connectedness and preventing social isolation.

Eating and drinking difficulties have primarily been approached from a psychological perspective with interventions focusing on regaining function and addressing impairment. This study illuminated the experiences of stroke survivors from a psychosocial perspective. Eating and drinking difficulties post-stroke are a complex and multifaceted phenomenon that requires an approach that encompasses both the psychological and social impacts of eating and drinking.

This review identified several inadequacies of care such as concerns about staff skills, knowledge, and competence to support them with eating and drinking difficulties. Several studies described patients who experienced poor continuity of care after leaving the hospital. Participants felt that they did not have enough training or information on how to cope with eating and drinking problems resulting in feelings of abandonment. These inadequacies in care can be shared with the intervention design group to inform the development of the intervention. Findings from this review suggest that gaining knowledge of stroke survivors' previous habits, life experiences and preferences could be beneficial for the breakfast group intervention. Moreover, it is important information for tailoring the intervention to personal needs. Understanding the psychological and social impacts of eating and drinking difficulties can help clinicians in developing rehabilitation strategies that address these impacts.

Rehabilitation programmes for eating and drinking could include opportunities for social dining so that stroke survivors experience social connectedness with other stroke survivors

on how to manage eating and drinking difficulties and practise being comfortable with eating and drinking in front of other people. However social dining is not universally liked and so approaches to support people with eating and drinking difficulties need to consider individual preferences, desires and consider dining with familiar people.

#### 4.15 Recommendations for further research

Eating and drinking difficulties are complex phenomena as the literature describes the impacts to be multifactorial including psychological, social, psychological, and cultural. This systematic review contributes to existing knowledge about eating and drinking difficulties but provides important insights into the psychosocial impacts that affect stroke survivors' recovery from eating and drinking impairments. It identifies gaps in existing literature where future research is needed. Five recommendations in order of priority describe the research gaps identified to help researchers prioritise future research questions.

- Recommendation 1 Future studies exploring interventions to address the psychological, and social impacts, as well as physiological impairments, are welcomed.

As eating and drinking rehabilitation is a central component of recovery (Royal College of Physicians, 2023), future studies are required to develop interventions which address eating and drinking rehabilitation focusing on the multiple factors that impact stroke survivors and their families. The desire to eat, drink and participate in social meals with family and friends is influenced by how stroke survivors are emotionally coping with changes in eating habits and past experiences. However, there are no studies describing interventions that address the psychological or social impacts. Thus, rehabilitation programmes for eating and drinking should include opportunities to address the emotional impacts and practice eating and drinking in a safe and supportive environment.

- Recommendation 2 Research into the role of family and carers in supporting stroke survivors with eating and drinking difficulties.

The important role that family and carers play in supporting stroke survivors with eating and drinking difficulties was explored (Jacobsson et al., 1996; Medin et al., 2010; Medin et al., 2010; Eltringham et al., 2019). There was only one paper that focused on the lived experience of family and relatives (Johansson and Johansson, 2009). This is an area of research that deserves more attention, particularly around the role that families have in supporting loved ones, their own lived experience, and carer burden, particularly how eating and drinking difficulties affect social participation for carers and what carers need to know about eating and drinking rehabilitation.

- Recommendation 3 Longitudinal studies following stroke survivors through the recovery of eating and drinking difficulties over an extended period to help determine what factors influence specific outcomes.

Previous research has focused on one temporal point in stroke recovery for example:

3 to 6 months (Jones et al., 2018, Westergren, et al., 2001; Kumlien and Axelsson, 2002; Perry and McLaren, 2003b, 2003a; Kjaersgaard and Pallesen, 2020)

1-2 year (Jacobsson *et al.*, 1997; Carlsson, et al., 2004; Pontes *et al.*, 2017)

2-17 years (Helldén et al., 2018, Jacobsson et al., 1996; Klinke et al., 2014).

No studies have specifically looked at the phenomena of psychosocial impacts across a stroke recovery journey. There is a need for research that explores the lived experience through a temporal sequence of events so that researchers can observe the developments over time and identify factors that impact health outcomes.

- Recommendation 4 Research to explore how the psychosocial impacts of eating and drinking difficulties affect socialising behaviours and social participation at different stages in the recovery process.

Several studies discuss the impact of eating and drinking difficulties on social participation such as family occasions, social dining and events where food is present and a number of studies have shown that this is an important aspect of stroke recovery however this is not investigated in any depth (Johansson and Johansson, 2009; Helldén et al, 2018; Jones and Nasr, 2018; Eltringham et al., 2019; Kjaersgaard and Pallesen, 2020).

Eltringham et al., (2019) discuss the cruelty of loss of eating enjoyment related to social and family celebrations. Helldén et al., (2018) explore how going to restaurants is less and less joyful and the limitations of this on social life. Jones and Nasr (2018) found a reduced desire to eat in public places which resulted in avoidance behaviour. This is an important area of enquiry however relatively little is known about how the psychological and social impacts of eating and drinking difficulties affect stroke survivors socialising behaviours throughout their recovery and what interventions would be suitable to address these at key stages.

- Recommendation 5 Research the experience of clinicians in supporting stroke survivors with eating and drinking difficulties, in particular, clinicians' training and development needs and how clinicians can work best together to support stroke survivors.

Most studies have focused on the lived experience of the stroke survivor. Formal carers such as stroke clinicians and the rehabilitation team are mentioned when stroke survivors describe not getting enough support (Helldén et al., 2018) or concerns about health professionals having adequate knowledge about eating and drinking difficulties (Kjaersgaard and Pallesen, 2020). Eating and drinking rehabilitation is the business of the multi-disciplinary team in stroke rehabilitation and NHS managers need to know how best to address training needs.

Each professional has their area of expertise whether that be nutrition, hydration, the physical aspects of eating or the psychological impact. Little is understood about the role of the formal carer in supporting people with eating and drinking difficulties. There is a paucity of research focusing on multidisciplinary interventions to understand how stroke clinicians

can work together to address eating and drinking difficulties. The relationships between informal and formal carers and their contributions to recovery should also be included.

#### 4.16 Chapter Summary

The findings from this review provide a synthesis of evidence on the topic of psychological and social impacts of eating and drinking difficulties which inform the decisions and recommendations for developing a breakfast group intervention. This original perspective amplifies the importance of the psychosocial impacts of eating and drinking difficulties for stroke survivors.



## Chapter Five. Hawkins 3-stage framework, stage consultations

### Summary of Chapter

Stage 1 of Hawkins Framework for coproduction and prototyping is designed to collect as many different perspectives on the subject as possible using a variety of enquiry methods (Hawkins et al., 2017). This Chapter is split into six parts.

- 1) Methods and findings from the trigger videos.
- 2) Reports on consultation meetings with members of the stroke-specific patient and public involvement group.
- 3) Reflections from observations in clinical practice.
- 4) Methods and findings from interviews with staff, patients, and informal carers.
- 5) Methods and findings from two ethnographic observations of breakfast time on two wards.
- 6) Convergence matrix and implications for intervention design.

### 5.1 Methods and findings from the trigger videos

#### 5.1.1 Sampling, recruitment, and consent

In qualitative research, purposive sampling is commonly used to target populations that can provide insights and an in-depth understanding of the topic being investigated. Purposive sampling was used to attract participants for the trigger videos as described in Chapter 3.

Participants were recruited using posters and emails to local stroke services. The posters inviting clinicians to take part in the videos, or the study were displayed in staff rooms situated on the stroke wards in site 1,2,3 and a collective email about the study and how staff could participate was sent to stroke team leaders to disseminate to staff working in inpatient stroke rehabilitation teams (in site 1,2,3). Similarly, information about participation in the trigger videos was shared with patients and carers in the stroke wards in site 1,2,3 and with the Sheffield Stroke Patient and Public Panel members (PPI).

During this time there was some uncertainty about the impact of the hospital's COVID-19 restrictions and the prevalence of COVID-19 and how this would affect recruitment to research. All non-COVID research studies have been paused during the first 18 months of the pandemic and research studies were only just starting to resume as part of the post-pandemic NHS recovery plan. Despite NHS services being in the 'recovery phase' they were still significantly affected by staffing shortages and COVID outbreaks.

Those expressing interest in participating in making some short films were provided with patient information sheets by either the Chief investigator (CI) or the Principal Investigator (PI). They were also offered a conversation with the CI to answer any questions before taking informed consent (as described in Chapter 3).

#### 5.1.2 Filming environment and technology

Patient and carer representatives were given the choice of participating in making a trigger video on hospital grounds or in their own residences. All three individuals chose to be

videoed at home. Hospital staff were filmed in a private room on hospital grounds. The videos were created using a Sony DSCWX350 digital camera and mini tripod for stability. These recorded videos were then uploaded to the editing software Abode Premier Rush, a desktop editing application suitable for novices aiming to make simple and concise edits to short video clips. Subsequently, three trigger videos were produced using the recordings from eight individual participants.

### 5.1.3 Characteristics of participants

Five staff, two stroke survivors and one informal carer gave informed consent to participate in making the trigger videos. Six of the participants were female, two males. The characteristics of participants are described below in Table 5.

Table 5: Characteristics of video participants

Role	Gender
Carer	Female
Stroke survivor 1	Female
Stroke survivor 2	Male
Nurse	Male
Occupational Therapist 1	Female
Occupational Therapist 2	Female
Psychology Assistant	Female
Speech and Language Therapist	Female

The trigger videos were created by the Chief Investigator asking questions to facilitate content. Participants were encouraged to keep talking and lead the conversation however the CI had two topic guides of questions, one for staff and one for patients and carers which would ensure that the conversations between myself and the participant stayed focused on topic. This also helped with consistency between participants and ensuring that there was sufficient content for the master videos. Topic guidelines are commonly used in semi-structured interviews and have the flexibility to be adapted should the researcher wish to respond to new findings or change the direction of the conversation. They were used in this situation to ensure that the time available was used efficiently and also to facilitate conversation when the participant's content dried-up. Before commencing filming a final check was undertaken to ensure that people were comfortable with being interviewed.

### 5.1.4 Ethical issues

All participants were provided with a copy of their video to review. As part of the consent process, it was agreed that participants could withdraw consent at any time if they were uncomfortable with sharing any of the content. None of the participants had any issues with the video content before editing and the three trigger videos were used in the stakeholder workshops to generate ideas and discussions about the intervention components (Donetto, et al., 2014b).

### 5.1.5 Data analysis and editing

Before editing the footage the content created in the eight videos were transcribed verbatim and imported to NVivo for analysis. The analysis involved detecting themes, differences, and dissidence. The data was analysed using Thomas and Harden's (2008) 3-step approach to thematic analysis described in Chapter 3. The data was read interactively for familiarisation and mind maps were developed iteratively in tandem with coding to present the data to stakeholders.

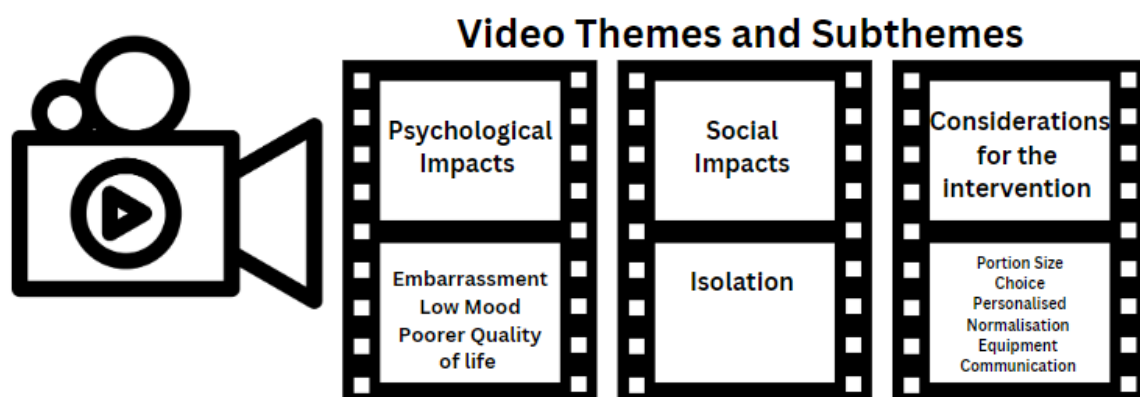
Mind maps are widely known as a tool for notetaking, studying and learning (Elhoseiny and Elgammal, 2016). They have also been used in stakeholder engagement research (Murtagh *et al.*, 2017) to conceptualise ideas and themes data. Braun and Clarke(2013) suggest visual mapping as a technique for exploring relationships between themes and subthemes (Braun and Clark, 2013). Examples of one of the mind maps can be found in Appendix 7. Throughout the analysis process, themes were formulated and structured to reveal significance and illustrate the relationship between the three primary concepts and their corresponding subthemes (Braun and Clark, 2013).

### 5.2 Video themes and subthemes

The video content described the features of eating and drinking rehabilitation that were important to patients and staff. The content was emotive as participants described a range of emotions and psychological impacts. The potential benefits of a breakfast group intervention were explored, and participants proposed ideas for the intervention.

Three themes are presented below in Figure 13. 1) psychological impacts, 2) social impacts and 3) considerations for the intervention. Each theme has several subthemes displayed below the primary theme.

Figure 13: Video data key themes and subthemes.



## 5.3 Psychological Impacts

### 5.3.1 Embarrassment

All staff acknowledged the indignity of eating and drinking difficulties and recounted scenarios where they had observed patients experiencing embarrassment. Fear of embarrassment was associated with changes in eating habits, such as eating foods one-handed. Another example was the indignity of having to wear a plastic apron.

*“Some patients are comfortable with asking us to put a plastic apron on. Other people are highly embarrassed by that so it’s a hugely complex issue” (Nurse)*

### 5.3.2 Low Mood

Four staff recognise the impact of eating and drinking difficulties on mood and see social eating groups as a potential opportunity to improve mood. The Speech and Language Therapist elaborates on this below,

*“I feel people are very alone in their difficulties and can feel quite low so seeing that there are other people who are also struggling with the same things and engaging with one another would be really valuable” (Speech and Language Therapist).*

### 5.3.3 Quality of Life

The Speech and Language Therapist discussed how pleasure derived from eating and drinking has a positive impact on quality of life. The stroke survivor also recognised the importance of eating and drinking for health and well-being. The quote below illustrates the association between social eating and drinking and improved well-being.

*“I think it’s important for your health, and also well-being, and also it’s good to share, like a coffee morning or a breakfast because you can have the ends of the day or the beginnings of a day and have a little chat, as it makes life a lot easier so eating and drinking in a social sense is really good” (Stroke Survivor).*

## 5.4 Social Impacts

### 5.4.1 Isolation

Three staff proposed that patients in individual rooms exhibited signs of social isolation. Although single rooms afford a degree of privacy, staff perceived them as a potential contributor to loneliness. This perspective resonated with the experience of a stroke survivor who likened the rooms to prison confinement.

*“I didn’t like it, I thought I was in prison, and I think for me my godsend was my iPad because then I could speak to the outside world and that all of the time. And I used to write a lot and listen to the radio” (Stroke Survivor).*

Both stroke survivors discussed the positive influence that socialising with other stroke survivors had on their well-being. This was illustrated by a stroke survivor when she shared how important it was to talk about the stroke with other survivors.

*“It was nice, there was a meeting where you talked about when you had a stroke, and depending on your speech, you could talk about it and all the rest of*

*it. That was good for somebody that had a stroke because then they could try to say what they thought when they had a stroke". (Stroke Survivor).*

The importance of social interaction was reiterated by the Speech and Language Therapist when she discussed evidence for the importance of social interaction for people with dysphasia and aphasia.

*"I think that kind of social interaction is so hard really if you are just lying in your bed on the stroke unit all day, groups are a kind of designated space to have a chance to come together and sit around and have a chance to talk to other people. All the evidence suggests that patients with swallowing difficulties and communication difficulties have significantly reduced, quality-of-life and it's about the lack of social interaction especially with people who have swallowing difficulties" (Speech and Language Therapist).*

## 5.5 Considerations for the Intervention

### 5.5.1 Portion Size

Both staff and stroke survivors talked about the importance of getting the portion size right. The informal carer discussed catering for bigger appetites and individualising portions. The Nurse recalled a scenario of how getting the portion size right was influential in 'not over-facing' patients with too much food.

*"I think of, classically, the little old lady. You put a whole plate down and she thinks 'I can't eat that' and then she doesn't eat any of it. Whereas if we put 1/3 of that down, she probably would have eaten all that and then might well be persuaded to have some sponge and custard after that, so I think those would be the building bricks of it" (Nurse).*

### 5.5.2 Choice

The ability to make menu choices was linked to a sense of self-sufficiency. A stroke survivor discussed his struggle with insufficient food intake due to his inability to express hunger or complete the menus independently. The informal carer related a story about her husband's inadequate food intake and how this affected his energy levels. The Nurse emphasised the importance of nutrition and hydration for overall health, highlighting how poor nutrition could lead to pressure sores. The informal carer stressed the importance of involving the family in choosing from the menu as they are best aware of their loved ones' preferences.

### 5.5.3 Personalised

There was convergence with all five staff videos on the importance of individual and person-centred rehabilitation. The Psychology Assistant describes her opinion on person-centred care.

*"I think it maybe it's about considering what this means for the individual so thinking about what their personal goals are, is there something specific that they want to achieve if you're working with someone, and this might not necessarily be an aspect that they deem to be important to them they may not have that willingness to work" (Psychology Assistant).*

Other staff talked about a focus on the quality of life (Speech and Language Therapist), holistic approaches (Nurse) and a personalised plan recording eating habits, likes and dislikes (Occupational Therapist 1). Occupational Therapist 2 discussed personal preferences and gave an example of getting family members to bring in preferred teabags from home as a method of personalising care.

Four transcripts emphasised the importance of addressing personal preferences and the subsequent effect on patients' engagement with food. Taking into consideration pre-stroke food and drink habits was suggested as a way to personalise care and encourage improved intake of food and drink. Only one participant (Nurse) discussed past experiences in association with culture. He suggested that hospitals could provide more culturally sensitive breakfast food to normalise the experience for people from different cultures. Otherwise, there was an absence of data around personalising food and drink items to meet cultural or religious beliefs.

#### 5.5.4 Normalisation

Occupational Therapist 2 and the Psychology Assistant emphasised the importance of creating an environment where patients felt 'at home' and were able to participate in what was considered to be normal activities. One such example was patients engaging in everyday conversations. Patient 1 talked about how being in a group helped her to practice communicating with other people. She described how finding shared interests with other patients reminded her of normal life.

Among the eight transcripts, five of them referred to the pleasure and enjoyment derived from eating and drinking experiences. The Nurse, for example, shared personal experiences of preparing food with his grandchildren and teaching them about the origins of food. These experiences highlighted the importance of food to him and demonstrated that cooking with his grandson was a valuable means of strengthening their bond. Through understanding his relationship to food and its importance in his family relationships he had a deeper understanding of its importance for stroke survivors. This was evident in the empathy with which he discussed the challenges of losing the ability to eat and drink and his strategies for assisting individuals to reclaim a sense of normality.

The informal carer also talked about her husband's enjoyment of food and drink and how she tried hard to emulate food from home by choosing items on the menu he liked or bringing in additional from-home foods to supplement his diet. She perceived that food was a comfort and described the importance of getting this right below.

*"He always used to say it was the only thing he was enjoying now in life because he couldn't do other things, eating was so important, as well as getting the right food for him". (Informal Carer)*

#### 5.5.5 Equipment

A stroke survivor talked about the importance of having adapted cutlery and how she liked to 'have a go' without asking for help. The Informal carer shared how she had purchased lots of assistive devices that they didn't get on with resulting in them not using anything. This suggests that having an opportunity to test out devices in the group could enable a try-

before-you-buy approach. Staff talked about having the ‘right tools for the job’ and how this might mean a process of assessment. The quote below illustrates how having cutlery accessible could avoid the embarrassment of having to ask.

*“They always gave you a spoon as well so that was good you didn’t feel you had to ask for a spoon if you can’t do it. It was there in case you need it and that was a good thing you know. You didn’t need to say. You didn’t have to ring down and say I can’t do it” (Stroke Survivor).*

#### 5.5.6 Communication

The Nurse discussed how effective care plans could improve patient care around nutrition and hydration. Occupational Therapist 1 reiterates this by talking about the quality and quantity of what is documented about eating and drinking difficulties.

*“I think we could improve where we document it and the level of detail we go into. You know often we find it’s very brief and actually, it doesn’t say much, do they need assistance, are they able to do anything for themselves, what level of help they need?”(Occupational Therapist 1).*

Occupational Therapist 1 suggests that when it's documented clearly, and people can see immediately what's needed it helps everyone to work collaboratively to meet patient's needs.

In summary, all the ideas and suggestions revealed during the video footage analysis were used to create a table of suggestions for the intervention design (see Appendix 8 for examples of ideas and suggestions).

## 5.6 Reports on consultation meetings with members of a stroke-specific patient and the public involvement group (PPI).

### 5.6.1 The PPI Group consultations

The Combined Acute and Community Care Group have a Stroke-specific Patient and Public Panel to support research development within the stroke pathway. Their mission is to actively collaborate with researchers on research projects. As the PPI group were already formed, trained, and experienced in critiquing stroke research there wasn't a necessity to create a new group for the BISTRO study.

This group is facilitated by a member of the NHS staff. The panel is made up of stroke survivors who have lived experience of life after a stroke. Participation in the group is voluntary and meetings occur up to six times a year. The panel have a mixture of abilities, including individuals with aphasia. Getting the views of people with aphasia is important as they are often excluded from studies (Charalambous et al., 2022) and if they do participate engagement is characterised as tokenistic (Charalambous et al., 2022; McKeivitt et al., 2010).



### 5.6.2 PPI consultation timeline

The Chief Investigator presented BISTRo developments to the PPI panel on three occasions during the study. These occurred online in stage 1 (February 2022) and stage 2 during prototype development (October 2022 and March 2023). Questions and critical feedback were encouraged. A summary of the specific feedback from each consultation meeting and any outcomes that informed the intervention design are shared below.

### 5.6.3 PPI Consultation Meeting 1 February 2022

Meeting 1 was an introductory meeting to ensure the panel was conversant with the purpose of the study. This meeting was important for building rapport so that the panel were comfortable engaging with the researcher and providing constructive feedback.

The panel discussed the importance of nutrition, and hydration for the success of rehabilitation. They shared stories from their own experiences about how food was critical to their well-being, especially in the early days of stroke recovery. They talked about the constraints of nursing time on the wards, particularly in the mornings. Views were expressed about the importance of the breakfast group intervention focusing on benefits for stroke survivors rather than making things easier for the ward staff. They expressed concern about how the group would be staffed given the challenges of staffing numbers in the mornings. Panel members shared lived experiences of eating and drinking difficulties and outlined five priorities for intervention development.

- 1) Addressing swallowing problems.
- 2) Getting food and drink from the plate to the mouth.
- 3) Meeting personal food preferences.
- 4) Addressing the needs of people with aphasia who are not able to articulate their needs.
- 5) Accessible lids and packaging for food and drink products.

The panel were concerned about the inclusion of people who could not get to the dining room independently. They thought it was important for everyone to have the opportunity to participate in a breakfast group, especially people who needed help getting up washed and dressed.

The key points from this session were added to a table of considerations for intervention design. Following the meeting, a stroke survivor and his wife made contact to say that they would like to be part of the research team and contribute to the stakeholder group. A meeting was set up in a local café to discuss the study and provide the participant information sheet for the Stakeholder group and they both gave informed consent to participate.

### 5.6.4 PPI Consultation Meeting 2 October 2022

The panel discussed concerns about the social aspect of the breakfast group. They were worried that some people might not want to eat in front of others, especially those with swallowing difficulties. The panel wanted to know if adapted cutlery would be available. They made some suggestions such as having ramekins for jam and butter so people could help themselves. They asked how the intervention could be consistent across three sites to ensure all patients received the same intervention. The key points from this session were



added to a table of considerations for intervention design including items for an environment checklist.

#### 5.6.5 PPI Consultation Meeting 3 March 2023

An update on prototyping was provided and the panel critiqued the BISTRo patient booklet. The PPI panel were invited to the 10<sup>th</sup> and final workshop, a celebration and dissemination event. The panel were keen to know if the breakfast groups would continue beyond the study and were concerned about sustainability. One member asked if younger patients could be included, they noted most of the participants seemed older. The inclusion criteria were discussed, and reassurance was provided on accessibility. The key points from this session were added to a table of considerations for intervention design.

#### 5.6.6 Reflections on the PPI involvement

Broomfield and colleagues (2021) advocate constructive involvement of the patient and public in research. The involvement of a patient and a public involvement group has enhanced the outcomes of the intervention development stage by providing critical friend feedback to ensure that the recruitment processes were aphasia-friendly and accessible to all patients several other studies have had similar results. This study involved patients and the public in the development of participant information and recruitment strategies. This resulted in healthy recruitment rates, all targets were met and in some cases exceeded. This resonates with the findings of Broomfield and colleagues (2021) who propose that public involvement creates a more accessible study and can influence the likelihood of recruitment.

## 5.7 Reflections from observations in clinical practice: delivering social dining interventions during the COVID-19 pandemic.

### 5.7.1 Context of observations

The following observation is a personal reflection and therefore is written in the first person. The stroke team were asked by NHS managers to explore the possibility of running rehabilitation groups with COVID restrictions in place as part of the NHS plan to resume normal services. The observations of group rehabilitation took place in site 1 where I was working clinically. The observations took place when the clinical team tested whether it was possible to conduct a social dining group in the stroke ward with COVID restrictions in place.

Prior to commencing the observation I was invited to contribute to a generic risk assessment for delivering a rehabilitation group during pandemic restrictions. The risk assessment included points for consideration in running the group such as personal protective equipment (PPE), proximity of seating and potential cross-contamination. Risk assessment sign-off by the trust's COVID reinstatement group was required for all departments. The observation was informal, and no notes were taken however a reflection and debrief session was held afterwards with those running the group and one of the clinicians' made notes of any learning from the group.

### 5.7.2 Cohort of patients

Following clinical governance approval the stroke rehabilitation team developed a plan to deliver group rehabilitation programmes which included patients socially dining together. Patients on the wards were allocated to cohorts of six. These cohorts were designed to reduce the risk of cross-infection by keeping patients in the same cohort for group activities during their hospital stay. The number of patients participating in groups ranged from 3-4 patients from the cohort of 6. They were brought from their bedsides into the communal room and sat at individual tables two metres apart. Masks and aprons were worn in accordance with the risk assessment. Patients were positioned at their tables so they could see and talk to each other. This arrangement took a little bit of manoeuvring; wheelchairs were positioned at angles to support eye contact and conversation.

### 5.7.3 Managing COVID restrictions

I participated in my clinical role to support the social dining group. Any movement between patients required a replacement of PPE. Once patients were about to start eating and drinking, they were able to remove their masks and hold conversations between themselves. I observed that having equipment and PPE organized on mobile trolleys made delivery smoother.

### 5.7.4 Informal staff feedback

The Speech and Language Therapist said she was pleased that she was able to see four patients in one hour and conduct joint assessments with other healthcare professionals. The Speech and Language Therapist was able to make changes to recommendations for diet and fluid intake based on her assessments.

Staff highlighted that observing the two-meter distancing rule was a challenge with the space available. Staff were unable to move swiftly between patients, compounded by the need to change PPE for each patient. Additional staff were needed for this session because of COVID precautions. Team members had positive comments about patients engaging and those with speech difficulties being able to practice polite conversation.

### 5.7.5 Informal patient Feedback

I observed that patients seemed to enjoy the social interaction with other patients, and they appeared keen to have the opportunity to be independent in eating their meals. Two patients said that they liked being able to socialize with other patients. One patient expressed a desire to work on feeding using her affected arm. Patients discussed how much they enjoyed connecting with other stroke survivors, although this could have been related to the social isolation, they had experienced during COVID due to most patients being confined to their rooms.

### 5.7.6 Viability of social dining with COVID restrictions

Extra effort was required to deliver a social dining group with COVID-19 restrictions; however, staff largely felt the benefits were worth the additional effort. Patient feedback was encouraging, and this was illustrated by patient requests to attend future social dining groups.

Having the opportunity to participate and observe allowed me to contemplate the workings of a breakfast group and consider potential risks to manage. It showed me the feasibility of conducting a group involving social eating and drinking despite the restrictions, with the hope that these would be lessened by the time the prototype stage was reached. Furthermore, it provided insights into optimising the room layout for space efficiency and highlighted the importance of creating the right environment for both staff and patients, a knowledge that would inform the intervention development stage. The observational opportunity also assured that even if COVID-19 measures were to intensify, the study could still proceed under stringent restrictions.

## 5.8 Methods and findings from interviews with staff, patients, and informal carers.

### 5.8.1 Introduction to interviews

The purpose of the pre-prototyping interviews was to gather multiple perspectives on the lived experience of eating and drinking difficulties from stroke survivors and informal and informal carers. Interviews were chosen to uncover insights which would inform intervention design. The questions were framed from the perspective of meaning and experiences in an open exploratory style (King and Horrocks 2010).

### 5.8.2 Sampling, recruitment, and consent

Purposive sampling was used to recruit participants with lived experience of eating and drinking difficulties or who possessed professional expertise in assisting individuals with post-stroke eating and drinking. In this case, prior experience with breakfast groups was not necessary as the purpose of these interviews was to gain insights into the phenomena of eating and drinking difficulties and the current context of inpatient rehabilitation for eating and drinking interventions.

The interviews were restricted to site 1 for practical constraints such as COVID precautions, access to participants and time constraints. Recruitment posters were posted on two stroke wards and in staff areas (Appendix 10). The opportunity to participate in the study was shared at team meetings and an email memo was sent out to all stroke clinical leads inviting interested staff to engage with the Chief Investigator.

Those interested in participating were provided with a participant information sheet and offered the opportunity to speak with a member of the research team for further information. Due to COVID restrictions, the site 1 Principal Investigator acted as a 'gatekeeper' to facilitate conversations with potential participants. The advantage of having a gatekeeper was that they could identify suitable patients for the interviews and approach them with information about the study. King and Horrocks (2010) proposed that gatekeepers should have a good working knowledge of an organisation and the authority to gain access to potential participants. The disadvantage of using a gatekeeper is that they may intentionally approach certain participants creating a bias or skew to recruitment. To balance these risks any gatekeepers involved in the study had GCP training and specific NIHR informed consent training before commencing their roles.

Two staff from the stroke rehabilitation team (P1/P2) and two stroke survivors consented to participate in the interviews (P3/P4). A member of the community stroke team was approached by a stroke survivor and his partner about participating. P5 was living in a care home but still under the care of the community stroke service. Following discussions about participation, his partner also agreed to be interviewed so they were interviewed together. (P5/C5). Dyadic interviews where two people are interviewed together are not uncommon in qualitative research (Marwaa et al., 2023).

#### 5.8.3 Location of interviews

All interviews were conducted in privacy. P1, P2, P3 and P4 were interviewed in the hospital as this is where the staff and patients were situated. P5 and C5 were interviewed together in a local care home.

#### 5.8.4 Interview Procedures

The interviews were scheduled for 45 minutes to 1 hour. To address the potential sensitivity of the topics discussed and the risk of emotional distress during the interviews, they were given the choice to pause, terminate, or reschedule the interview if they felt distressed, following guidelines proposed by King and Horrocks, (2010).

All interviews were audio recorded using a Dictaphone and transcribed verbatim the following day. Interview transcripts were uploaded to NVivo software and analysed separately using thematic synthesis as described by Thomas and Harden, (2008). After analysis, the recordings were securely deleted in accordance with the data management plan.

#### 5.8.5 Interview topic guides

These interviews in stage 1 of Hawkins Framework (2017) were conducted using two separate interview topic guides, one tailored for staff and another for patients and carers. These guides were designed with simple, open questions developed to explore the phenomena of eating and drinking difficulties after a stroke. The questions aimed to seek opinions, emotional experiences, behaviours, beliefs, and sensory experiences related to eating and drinking (King and Horrocks, 2010). Insights gained during the interviews were used to probe and explore in-depth in accordance with the FANI approach (King and Horrocks, 2010) as detailed in Appendix 11 (example Topic guides for interviews).

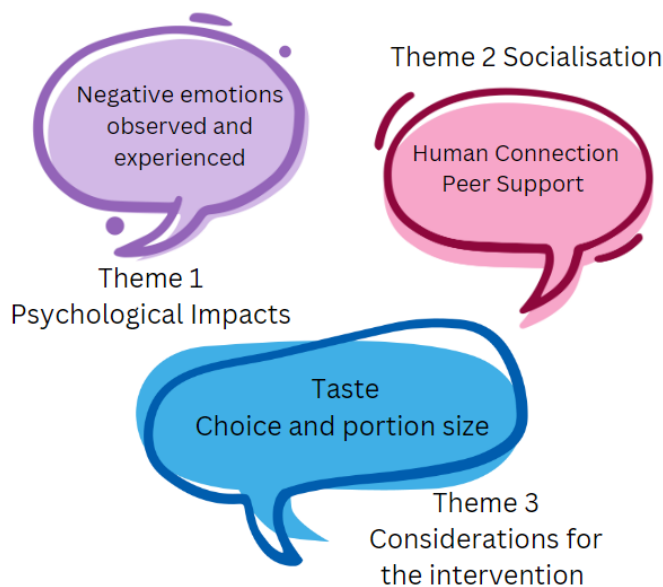
#### 5.8.6 Data Analysis

A thematic analysis was conducted, following Thomas and Harden's, (2008) 3-stage qualitative analysis method. The analysis process began with the iterative creation of a mind map that encapsulated the primary concepts extracted from each interview, as suggested by Elhoseiny and Elgammal, (2016) and Murtagh and colleagues (2017).

#### 5.8.7 Pre-prototyping Interview Themes

The analysis of the data yielded three overarching themes. Theme 1: Psychological impacts which describe the negative emotions that were observed or experienced. Theme 2: socialisation, with two subthemes 'human connection' and 'peer support'. Theme 3: considerations for the intervention, with two subthemes 'taste' and 'choice and portion size' Figure 14.

Figure 14: Pre-prototyping interview themes.



#### 5.8.8 Psychological impacts

The negative emotions experienced or observed were related to isolation, loss, anger, and embarrassment. Feeling embarrassed or recognition of embarrassment was a common discourse amongst all five interviews. Staff members were aware that the stroke survivors felt embarrassed by changes in eating habits, whilst patients discussed their difficulties and the desire for increased privacy stemming from feelings of shame. Patient 4 elaborated on her anxieties and embarrassment associated with dining in social settings with other people. The informal carer also noted how embarrassment frequently led to emotional reactions resulting in her husband.

#### 5.8.9 Socialisation

Staff participants discussed the potential of social dining and resuming normal activities in a safe space. They highlighted the importance of physical support and how this might be easier by grouping patients together, however, they were primarily interested in the potential for socialisation. Participant 1 discussed how socialising with other stroke survivors could help by listening to other stroke survivors' lived experiences.

*“Lots of people say that they just feel that if they're with another stroke survivor, they feel and that somebody understands them, that they're not alone in what they're going through” (Participant 1).*

#### 5.8.10 Human Connection

One of the staff participants emphasised the importance of human connection and how the environment could influence feelings of isolation. This staff member was particularly concerned about the social isolation experienced by patients. In both stroke wards, there was only one shared bay where two patients could cohabit. The remaining patients all had individual rooms. She explains some of the benefits of bringing people together to dine.

*“I think there is a natural human instinct around socially gathering. I think that it's good from a psychological point of view for our patients. There are many*

*good things about having their own room and ensuite, but also some patients do describe it as being a very long day. They can become very isolated in those rooms. There is also that it's easier to support and manage several people together than it is for every person in their own room. So, I think there are good things about it from both of those points of view" (Participant 2).*

The importance of social connection is also highlighted by a staff participant. She described how the opportunity to connect with other stroke survivors in the dining room facilitates conversation and storytelling. This storytelling helps to develop a rapport with others which can have a positive effect on emotional well-being. Thus suggesting that this connection fosters peer support.

*"Taking them to the dining room, they've enjoyed a social experience and they've had a chat and they've gone 'Oh I talked with this lady over here and they're telling stories over their meal'. Whether the stories were about life before or after their stroke I would say was a positive way to support patients. So, it's not always just about the physical support that they get, but it's also about that emotional and social support and I've definitely seen that when I've taken people to the dining room, it cheers my soul (laughs)" (Participant 1).*

Findings also suggest that socialising with other patients serves as an opportunity to draw inspiration, encouragement, and support from one another. This view is supported by Participant 2 who describes how patients might compare how they are progressing with other patients. They compare how they are progressing to where others are in their recovery, and it is perceived that this helps stroke survivors not feel alone.

*"And I think they can maybe draw encouragement and support from each other and particularly in that conversation talking about where they've progressed, maybe what they're finding difficult, just normalizing the situation for them, and showing them. Yeah, I think the main thing for me is showing them that they're not alone in this" (Participant 2).*

#### 5.8.11 Peer Support

The term peer support was not explicitly discussed. However, it was alluded to by both members of staff as a potential benefit of social dining (P1/P2). Staff participants talked about the value of patients supporting one another. One example was how patients when they were with other stroke survivors would reminisce about what happened when they had the stroke. This is illustrated by Participant 2 as she described the importance of having people with similar experiences to talk to.

*"Lots of people say that they just feel when they are with another stroke survivor, they feel that somebody understands them, that they're not alone in what they're going through" (Participant 2).*

Conversely, one staff member (P2), two patients (P3/P5) and the carer (C5) all addressed concerns about not feeling sociable and wanting to be alone. P5 and C5 discussed feeling overwhelmed in group situations and P5 explained that he doesn't like people watching him eat in the communal dining room. P3 said he had one meal in the dining room and didn't

like it, he preferred to eat alone in his room. This is echoed by P2 who highlights that socialising was not for everyone and it was important to give patients the choice.

#### 5.8.12 Considerations for the Intervention

##### Taste

Participant 3 was sitting at the side of a board labelled 'What Matters to You'. She gestured to the board and began to explain why 'black pepper' was written on it. She said that she liked black pepper, holding up a pepper pot. She explained that she added pepper to hospital food to improve the taste. All patients had a 'What Matters to You' board which was used by clinicians as a method of communication with other staff and visitors about the patient's personal preferences. Although not exclusively they were used to note food and drink preferences. Participant 3 explained that she originated from Pakistan, she liked spicy food, and she described the food in the hospital as 'lacking flavour'. Participant 5 and Informal Carer 5 also discussed the need to spice up the food to improve taste experiences. Participant 5 explained that his taste buds were affected by the stroke and now he liked to have stronger flavours that he could detect like chilli or lemon.

##### Choice and portion size

Two staff members (P1/P2) felt it was important to give patients a choice although P1 remarked "*It wasn't a hotel and options were limited*". All three patients also discussed the limited choices for breakfast although in two cases this might have been related to the dietary restrictions or swallowing modifications. All three patient participants thought that portion sizes were adequate for their needs.

## 5.9 Methods and findings from two ethnographic observations of breakfast time on two stroke wards.

### 5.9.1 Introduction to ethnographic observations

One of the first activities in Experience-based Codesign is observation which can provide insights into how the service works for both staff and patients. Researchers can gather unique perspectives and develop a better understanding of the problem (Bate & Robert, 2007b, 2007a). Ten hours of observations were conducted on two-stroke wards at site 1. The observations were conducted by the Chief Investigator (CI) and site Principal Investigator (PI).

### 5.9.2 Sampling, recruitment, and consent

Purposive sampling was used to identify participants to take part in the ethnographic observations. Purposive sampling was used to identify participants who had specific knowledge and experiences relevant to the study (Higginbottom et al., 2015). The CI attended staff meetings to promote the study and posters with contact details were left in staff areas on the ward. All patients on two wards were approached to see if they would be interested in taking part in the study.

The CI and PI provided a participant information sheet to individuals who expressed an interest in being observed as part of the study. The CI also extended an offer to meet with



anyone interested, allowing potential participants time to consider the implications of taking part. Among those interested in participating, three patients asked for a meeting with the CI to gain a better understanding of what taking part in the study involved. However one of the three opted not to participate, primarily due to concerns related to data protection and the NHS, which were not specific to the study. The participant did not feel that his personally identifiable data would be safe despite providing assurances. Those who decided to participate provided informed consent, a process overseen by the site PI or CI.

#### 5.9.3 Procedures for ethnography

Two observations were conducted by the CI and site PI on two mornings in separate hospital wards. Both researchers were observing at the same time. Due to the layout of the wards and the location of rooms, the researcher worked independently following staff around and observing patients on opposite sides of the ward. O'Reilly (2009) suggests using a framework to guide data collection can be helpful in ethnography especially where there is more than one researcher. A few question prompts were pre-determined by the CI to help the researchers stay focused on the observations however the approach was largely flexible giving the observers the freedom to note observations about the environment, interactions, and conversations in field notes.

Asking questions is a fundamental part of ethnography (O'Reilly, 2009). During the observations, the researchers asked participants questions and made field notes of responses (Emerson et al., 1995). In accordance with O'Reilly's recommendations, (2009) post-observation notes were made on the same day of the observations to capture any thoughts that the researcher had after the session. The two researchers met after the observations to reflexively discuss their observations and note any reflections and observations in the field notes.

#### 5.9.4 Data analysis

The field notes were typed up verbatim and uploaded to NVivo for analysis using Thomas and Harden's, (2008) approach to thematic data analysis as described in Chapter 3.

#### 5.9.5 Participants

For anonymity, the names of the wards were changed to Wards North and South. The South Ward had 14 patients in residence. Three patients consented to be observed during breakfast time - one female and two males. All five staff consented to be observed; one housekeeper, three support workers and one student nurse. The reasons for not taking part includes; no difficulties with eating and drinking n=3, feeling unwell n=2, new admission or waiting to be discharged n=2, not clinically appropriate n=3 and declined n=1.

On North Ward 6 patients out of 16 consented to participate in observations: three males and three females. Two staff consented to participate: a housekeeper and a support worker. The reasons for not taking part were no difficulties with eating and drinking n=4, preparing to go home or newly admitted n=2, not clinically appropriate n=4.

#### 5.9.6 Delays in data collection

On the morning of the first observation the wards were poorly staffed due to illness and many of the patients were not up and dressed or ready for breakfast. It was decided that this would not be a good day to start the observation as it would be difficult to observe

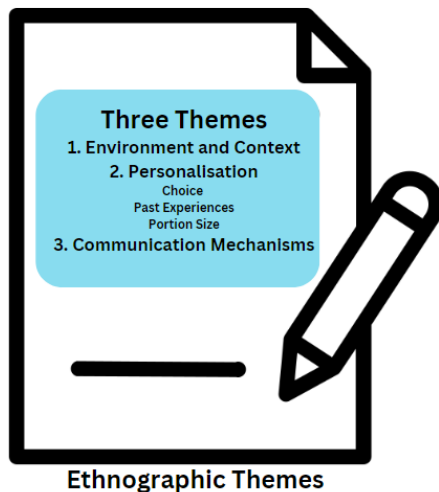


patients and the site Principal Investigator was needed to increase staffing numbers for safety. Further dates were set, and these dates went ahead as planned.

#### 5.9.7 Overview of themes from ethnographic observations

The Ethnographic observations yielded three themes. Theme 1 was Environment and context, Theme 2 was Personalisation with three subthemes choice, past experiences and portion size, and Theme 3 was Communication mechanisms illustrated in Figure 15.

Figure 15: Three ethnography themes.



#### 5.9.8 Environment and Context

The stroke wards were situated in site 1. Both wards had a similar case mix of patients. On each ward, there was one bay of two beds the other patients had individual rooms. Patients requiring closer observation were allocated a bed in the shared bay. To observe patients the researchers had to walk in and out of rooms. Breakfasts were made in the ward kitchen and taken to the patient's rooms by a member of staff. Those furthest away from the kitchen appeared to have less contact with staff regarding breakfast routines.

Both wards had patient dining rooms but neither of them was used for bringing patients together to dine on the day of the observations. Patients remarked that the dining rooms were not used, and a member of staff suggested this was because during COVID the space was used for staff meetings, and it had not transitioned back to a space for patient use. A Housekeeper from South Ward explained.

*"I've only worked here for two years, and this dining room hasn't been used very much. There were some groups in here a little while ago, but it all fizzled out. I do not know why it fizzled out, perhaps it stopped due to Covid" (House Keeper).*

This implies that implementing a breakfast group intervention in the dining rooms could be more challenging due to staff members being out of the practice of escorting patients to communal areas. Additionally, patients may also prefer to have breakfast at their bedside since this has been the customary routine since their admission.

Patients remained confined to their rooms, where their interactions with staff were primarily centred around practical activities like delivering meals, providing medication,

completing menus for the following days, and fetching the trays. During this time patients were eating and drinking in solitude. The sense of isolation and limited access to assistance could affect dietary choices as illustrated in this account from a patient in North Ward.

*“I always order things that I can use one hand with, I can’t hold a knife in the left hand, and you do not get offered any help. The choice is limited due to difficulty with using my left hand”.*

During the observation, a patient was taken to the dining room in South Ward. The housekeeper kept a watchful eye on her while multitasking with meal preparation for others and taking food orders. The patient struggled to make progress with her breakfast and even fell asleep. The logistical challenges of moving between patients along a lengthy corridor limited the oversight and support that staff could provide. Patients eating in their rooms were largely left to manage on their own. Notably, the staff did not enquire if patients needed help with cutting up food, nor did they offer adapted devices such as plate guards, specialised cutlery, or non-slip matting. Three patients expressed difficulties with using cutlery and handling their food, yet not of them were utilising the aids or devices available on the ward to facilitate independent eating, nor had such options presented to them. Despite this patients were trying to do as much for themselves as possible, and this exchange illustrates the desire for independence.

*The patient sees me enter the room. He says, “This damn right hand”. I asked what was troubling him “I’m worried about dropping food he says”. He shows me that he has some movement in his right hand but weakness in the upper arm. He tries to hold a spoon and although he can grip it with his fingers, he doesn’t have the power or strength to move the arm on his own. He’s attempting to lift the affected hand to his mouth. The spoon falls out of his hand onto the bed. He tried again (Field Notes North Ward).*

The challenges presented by the physical environment were exacerbated by the staffing constraints of having a large space to cover. The majority of staff were occupied with the tasks of toileting, bathing and dressing patients, leaving little time for assisting with eating and drinking activities. In North Ward, one patient was observed eating his breakfast while still in bed, as he had not yet been offered a wash. He struggled to maintain an upright position, leaning heavily to one side, with his stroke-affected arm hanging down the edge of the bed. Field notes indicated that there were no therapy staff on the ward while the observations were taking place. Supporting the patients with eating and drinking was primarily the role of the nursing team who were fully occupied with other tasks and duties. Therefore patients had very little assistance with eating and drinking.

#### 5.9.9 Personalisation

##### Choice

There was a choice of food, but it was limited if patients were on a gluten-free or homogenised diet. Patients had mixed views about choice. Some thought there was a good choice and others said there was not enough. It was observed that a patient in North Ward ordered porridge, but she did not like porridge and was struggling to eat it. Despite being offered another choice she tried to persevere. She did not like to say that she did not want

the porridge. There appeared to be no resources to support a conversation about menu choices such as a menu in picture format.

*“I do not think she likes porridge, but she can’t remember, although she is eating it very slowly. She leaves most of it and moves on to the crustless toast. Only 4 small pieces. Not very much food is consumed for breakfast”.*

*(Field Notes North Ward)*

Field notes record that there were no resources to support a conversation about menu choices such as menu in picture format.

#### Past experiences

Three patients talked about their food likes and dislikes and the food they were looking forward to having at home. This gentleman from South Ward talked about his favourite meal and how he would still be able to have this with a few adaptations.

*“I like meat and potato pie you know, it’s on my ‘what matters to me’ board, meat and potato pie, (looks longingly), I thought I might not be able to have it in the future but the nutritionist says I can have the meat if it’s minced or crushed and they said I could have mincemeat but my wife will do that”.* (Field Notes Patient).

Field notes record that all of the patients had a ‘what matters to me board’ but very few had food likes and dislikes listed. A couple had notes on whether the patient had sugar and milk in hot drinks.

#### Portion Size

Patients had differing views about portion size. Some liked the size of portions and felt full after every meal whereas others felt that they had too much food and would have preferred smaller portions so that they didn’t feel that they were having to leave much on the plate. A patient in South Ward said:

*“There’s a bit too much for me, I won’t eat all of that. It’s better for me if it’s a small quantity, you feel better when you have eaten it all”.*

There did not seem to be an option to have a smaller plate size for smaller appetites although there was the option of a larger portion on the breakfast menu. There was variation in personal preferences for portion size and observations suggest that the size of the portion can affect appetite and desire to eat, therefore this is an important consideration for the intervention.

#### 5.9.10 Communication Mechanisms

Several methods were established for conveying information concerning patients’ dietary and fluid requirements. Information sheets were affixed to walls, containing relevant details. Staff members carried paper handovers in their pockets specifying the types of diets, and preferences. The ‘What Matters to Me’ boards included patients’ food and beverage preferences, and there was also a symbol-shape system in use to signify those vulnerable to dehydration and malnutrition, although not all staff seemed to grasp this system or know

what it was for. When asked about what might be documented in patient notes about nutrition and hydration a staff nurse in North Ward said:

*“I do comment on nutrition and hydration, but it is generally only a sentence, limited text”. (Field Notes North Ward).*

There did not seem to be a consistent mechanism for the communication among staff about patients eating and drinking preferences.

#### 5.9.11 Reflections on the on the operationalisation of the intervention

Findings suggest that having patients together in one room at breakfast time could facilitate closer monitoring and help patients feel less isolated. Moreover, patients believe they would benefit from social interaction with other stroke survivors. A central point of communication regarding eating and drinking preferences would be helpful and a detailed history of preferences for eating and drinking. Observations identified a need for resources that explain the breakfast menu for individuals who have aphasia or memory problems.

Whilst observing ward coordination it became evident that the patients attending breakfast group would need to be prioritised for washing and dressing, so a method to communicate prioritisation be helpful.

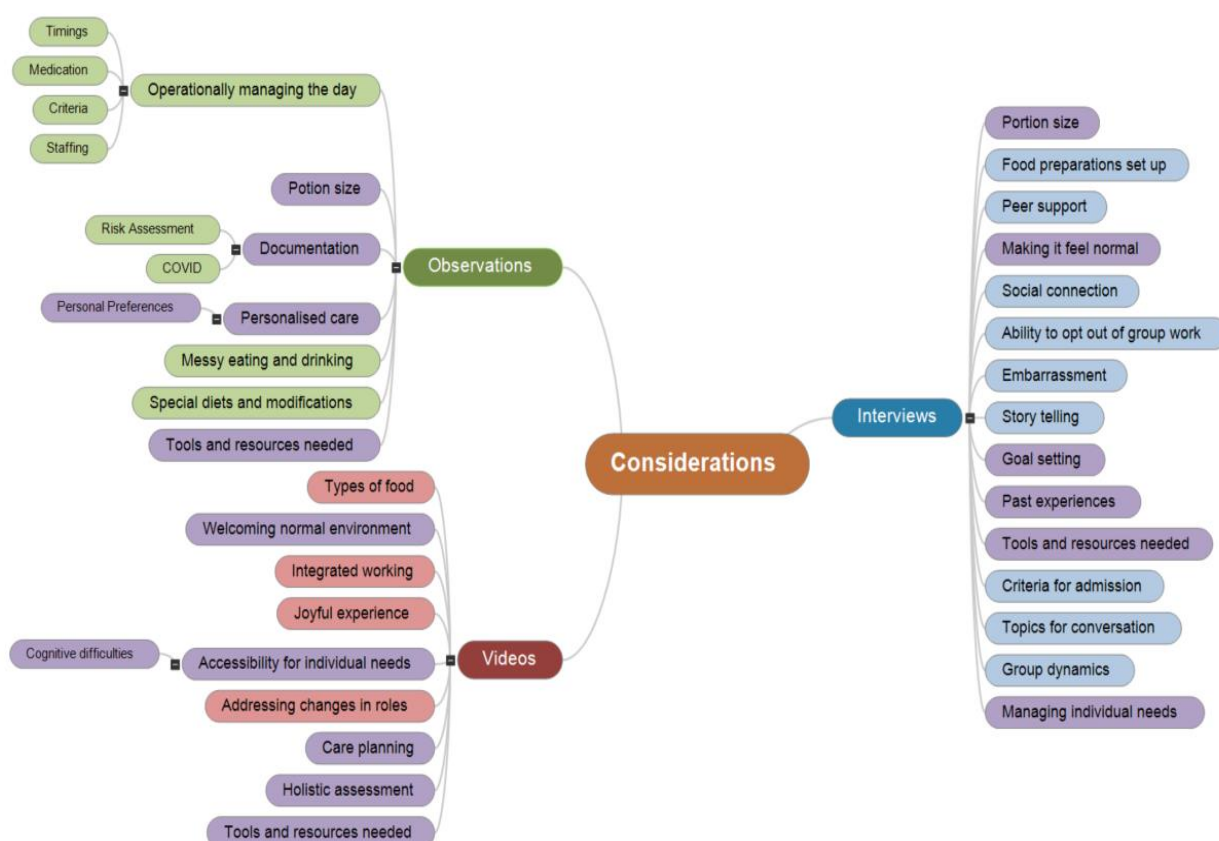
Being in a room segregated from other patients and hospital staff resulted in limited access to physical assistance which influenced food choices and impacted what patients could do for themselves. This ultimately might lead to reduced food and nutrition intake.

## 5.10 Convergence matrix and implications for intervention design.

### 5.10.1 Introduction to the convergence matrix

Each data set was initially examined independently, and subsequently, the results were combined to identify areas of convergence, complementarity, disagreement, and silence in line with Farmer et al., (2006) and Nurjono et al., (2018). The analysis commenced by reading each set of findings iteratively and building a mind map of relevant aspects (Elhoseiny and Elgammal, 2016). The data from clinical observations and ethnographic observations were integrated with similarities highlighted in purple (Figure 16). This process of colour coding facilitated the re-familiarisation of all the data sets before a comprehensive convergence matrix was developed.

Figure 16 Mind map of considerations for the intervention, convergence in the data.



The complete version of the convergence matrix can be found in Appendix 12. The headings of the matrix include the theme, aspect of the themes, type of data set (literature, observations, interviews, and videos), and a summary of convergence, complementarity, disagreement, and silence followed by a conclusion. The conclusion details 1) items relevant to the context for the intervention 2) potential benefits and or outcomes 3) items relevant to how to deliver the intervention. This table is an abridged version of the master convergence matrix which was used to inform discussions in the stakeholder codesign Stage 2 of Hawkins's Coproduction and prototyping framework (Hawkins et al., 2017).

Table 6: Summary of the convergence matrix

Theme	The context for the intervention	Potential benefits and outcomes	How to deliver the intervention
<b>Poor Nutrition and Hydration – impact on health</b>	The impact of poor nutrition and hydration is widely discussed in the literature and the consequences and implications of discussed in all 23 papers.	Healthy and nutritious snacks are discussed as a solution to poor food intake. Although healthy eating is vital in reducing the risks of further stroke, it did not feature highly in observations, 5.8 and videos.	Consider weight monitoring and documentation as part of the eating and drinking intervention. Consider snacks as part of the intervention. Explore what resources are required to support patients and carers with diet modification and fluids. To explore resources for information on healthy eating/snacks.
<b>Recovery Trajectory</b>	Explore the concept of recovery on a trajectory with the intervention design group. Discuss if the intervention should be adapted over time.	Consider outcomes may vary according to where people are in their recovery. As recovery is personalised people might be at different stages in the group. How	Consider recovery as an invisible entity. How can recovery and change be made visible to stroke survivors? Codesign a measure of progress. Outcomes that reflect meaningful progress for the individual.

		would this affect the group dynamic?	
<b>Adjustment and Adaptation</b>	Increasing self-awareness was highlighted as a valued strategy, and the role of significant others in the adjustment process was acknowledged in DS 1,2,3,4.	As stroke survivors adjust to eating and drinking difficulties their self-confidence and performance outcomes may change. Outcome measures would need to reflect change and progress.	Consider the role of family and carers in managing eating and drinking after a stroke. How would they be involved with the intervention? What additional information do significant others need? Does the concept of adaptation and adjustment need to feature as a topic of discussion? Consider how patients might record their own progress in the intervention.
<b>Striving to live a normal life</b>	Exploring the concept of 'striving' in the codesign process. How can patients be supported to strive for regaining a normal life?	Personalised goals would reflect what people wanted to regain or strive towards.	Consider what mechanisms could be implemented to demonstrate recovery that would support a sense of progress and mastery. Consider a mechanism for recording personalised goals.
<b>Strategies</b>	A focus on strategies and compensatory approaches. Intrinsic and extrinsic strategies.	Multiple strategies were mentioned in each data set. Strategies could be verbal, or physical support or aids and adaptations. Strategies could be taught by a member of staff and practised in the group.	To consider which strategies would be utilised and promoted in the intervention. Include strategies in the staff training pack for breakfast groups. Discuss strategies in the training package and give examples of types of strategies. Create a place for recording strategies to help stroke survivors and staff remember them.
<b>Participation</b>	Participation in social activities while dining is viewed as beneficial. This also links to peer support and social impacts.	Patients were encouraged to converse with each other in a group. Consider a measure of social confidence as not everyone will feel confident enough to converse in a group.	Consider whether topics are discussed at mealtimes. Should there be a programme for discussions, or will it be more organic?
<b>Social engagement-negatives</b>	Eating in a group would not be for everyone. Some patients may prefer to eat alone due to the need for privacy. People may drop out of the group because of the experience.	Negatives of social dining found in DS 1,2,3. It's not for everyone so there might be some attrition from the intervention.	Consider the patient information leaflet to address the issue of eating in a group and sensitives.
<b>Negative psychological impacts of eating and drinking difficulties</b>	A strong theme on the negative impact of eating and drinking difficulties. Multiple examples in all data sets.	Consider those outcomes could be affected by negative emotions and low mood.	Consider how mood is assessed. Identify and normalise the experience of negative emotions in the intervention. Look at resources to support mood. Consider interventions that can reduce embarrassment and preserve dignity. Consider the negative emotional impact and how this can be addressed in the training programme for staff to raise awareness.
<b>Types of assessment for eating and drinking difficulties</b>	Assessment is the precursor to intervention. The assessment identifies previous eating and drinking habits as well as the current level of ability.	Previous eating and drinking habits influence preferences.	Consider including an assessment for eating and drinking function in the toolkit that addresses previous habits and preferences.
<b>Eating and drinking interventions</b>	Very little evidence of group eating and drinking interventions. No examples in the literature of breakfast groups.	Consider what components would be incorporated into the breakfast group intervention as there are no previous studies to draw ideas from.	Consider components of the intervention such as education, advice, strategies, practice, dysphagia-specific techniques, and social conversation.
<b>Consequences of eating and drinking difficulties</b>	The consequences of eating and drinking difficulties were multifaceted.	Potential to improve nutrition and hydration, address weight issues and improve performance of eating and drinking.	Consider how to address changes in eating habits and messy/noisy eating. Consider how nutrition/ fluid intake is documented. Consider how to

			address weight loss/gain and healthy eating.
<b>COVID Impact</b>	Need to consider COVID restrictions and the impact on eating and drinking interventions. DS 2,3,4 all mentioned the impact of COVID-19 on eating and drinking rehabilitation.	The patients shared experiences and feelings of isolation due to a lack of socialisation with other patients. Some dining rooms had not been used since COVID restrictions were lifted as they had been used for other purposes or the habit of taking patients to the dining room was lost. Potential for introducing more socialisation.	Infection control plan. COVID risk assessment. Involve the infection control team and engage managers in the operation plan to ensure it's COVID-proof. Have a contingency plan for COVID-19 escalation.
<b>Environment</b>	The need to reduce distractions was discussed in DS 1 and 4. DS 1 talks about the impact of environmental factors on the senses. Distractions were thought to be counterproductive during interventions for eating and drinking.	A group environment could be over-stimulating for people with cognitive issues. Need to consider people's sensory impairments as part of the criteria for inclusion.	Consider how the dining area can be made more homely to create a normalised setting for a group meal. Include in the standard operating procedure the environmental conditions. Consider strategies to reduce distractions.
<b>Rehabilitation Approaches</b>	Research gaps- rehabilitation of eating and drinking under-researched. More research is needed on eating and drinking interventions such as meal-time groups, social dining and preparing food in stroke rehabilitation.  No interventions took place during four breakfast observations on two wards.	Recognition that joint and integrated working is beneficial, but there is an absence of integrated and collaborative working in current practice.	Consider rehabilitation theory and how this is applied to the breakfast group intervention. Explore integrated working and what intervention elements would promote an integrated approach. Consider what documentation processes would be integrated. Develop personalised rehabilitation goal documentation that can be used at each session.
<b>What's important to staff</b>	The research literature describes how patients perceive a lack of knowledge and skills among stroke healthcare professionals about eating and drinking rehabilitation. Papers exploring staff views on their knowledge and skills for supporting people with eating and drinking difficulties were not included in the review. Staff believe breakfast groups are a good opportunity to share skills and learn from each other.	Concerns about staffing levels would need to be addressed in the operational plan. By bringing patients together more support could be provided. There is potential for economies of scale.	Consider who else might be involved with eating and drinking to support staff. Possibility of volunteers or family being part of the interventions. Staffing levels need to be included in the intervention. A training package for staff would be beneficial.
<b>What's important to patients</b>	Two references to choosing spicy food (both patients of Asian origin). One reference to diets specific to religious beliefs and culture. Consider how we cater for different cultures at breakfast time. Portion size and choice were discussed in DS 2,3,4,5.	Possibility of increased intake of food and drink with a more supported context. Possibility of addressing weight concerns and providing strategies for managing swallowing. Daily intervention could provide better consistency for patients.	Consider how portion size can be addressed in the intervention and where there are opportunities to promote choice in the menu. Consider the types of plates and bowls used to reflect portion choice. Explore where choice can be promoted. Consider cultural needs.
<b>Perceived potential of the breakfast group</b>	Recognising that social dining is not for everyone, however, there is a perceived benefit to people being able to eat and drink together socially. The value of peer support was highlighted in WP3,4.	Breakfast groups are perceived as normal social dining experiences WP3,4. A potential outcome is improved peer support.	Consider activities that support social connection. Allow people to choose to eat alone- it's not for everyone. Consider the peer support component and how this is managed. Consider what elements could be included to normalise the activity.
<b>Positive emotions</b>	Eating and drinking are seen as activities that are not just essential to life, they bring joy. There is a degree of pleasure from eating and from social experiences that revolve around eating and or drinking.	Possible outcomes might be enjoyment. Conversely, people may find they do not enjoy eating in a social group as much as they did before the stroke.	Consider how we make the intervention pleasurable and facilitate experiences which create joy for participants. Consider how 'fun' can be injected into the intervention. Address the loss of eating joy in the participant leaflet and toolkit.



<b>Types of support</b>	Recognition of the importance of family and significant others in providing support for eating and drinking difficulties.	Support comes in various forms, physical assistance, advice, and guidance. Potential for patients to receive multiple types of support during the group. Getting the balance between offering support and promoting independence is vital.	Consider how significant others and family would be involved in the intervention or education.  Address concerns about dependence on others in the intervention.
<b>Fatigue</b>	Fatigue was discussed in DS 1,3,4,5. Patients talked about lack of sleep and the impact on their energy.	Fatigue levels could impact the success of the intervention. conversely, patients may feel they have more energy after eating and drinking more at breakfast time.	Consider how fatigue would be addressed in the intervention and training plan.
<b>Personalised care</b>	A personalised plan or approach was thought to be beneficial. Tailoring interventions to patients' needs and also their personal preferences. This was not explored very well in the literature but there was evidence of this in DS 2,3,4.	Patients may respond better to a personalised approach.	Consider how the intervention can be tailored and personalised for everyone. Personal goals are included in the toolkit. Consider how personal experiences and habits can be included in the intervention.
<b>Culture</b>	The culture was only mentioned in DS4. Is this because it's not an issue or is this because staff do not consider this to be important? Need further exploration in the codesign phase.	There is a danger of being culturally insensitive and not as inclusive.	Consider provision for people with diverse cultural backgrounds. Capture food preferences related to culture in the assessment.



## Chapter Six: Hawkins 3-stage framework: Stage 2 Coproduction

### Chapter Summary

This Chapter will describe Stage 2 of the Hawkins approach to intervention development and how Experience-based Codesign was used to enhance the coproduction processes. This Chapter has five parts:

1. Aims and objectives of the coproduction
2. Establishing the Stakeholder Intervention Development Group (SIDG)
3. Format and structure of the SIDG workshops
4. Key findings from each workshop
5. Discussion of the coproduction process

### 6.1 Aim and objectives of the coproduction

**Aim:** To establish a stakeholder group to codesign a breakfast group intervention and implementation tool kit.

**Objectives:**

- 1) To establish a stakeholder intervention development group (SIDG) where stakeholders will work together collaboratively to codesign a breakfast group intervention and implementation tool kit.
- 2) To involve a diverse set of stakeholders in coproduction and shared decision-making processes so that the end product is developed with a wide range of perspectives.
- 3) Create a space for codesign where equity is valued, trusting partnerships are developed, and stakeholders are empowered to work together to address concerns and challenges, share knowledge and experience ownership of decisions made.

### 6.2 Establishing a SIDG

#### 6.2.1 Recruiting stakeholders

Healthcare professionals, patients and informal carers were invited to collaborate as equal partners to codesign a breakfast group intervention and implementation toolkit. Healthcare professionals working in stroke rehabilitation in inpatient services, stroke survivors, and informal carers were invited to participate. A recent systematic review of EBCD studies in healthcare settings recommended limiting the period between information gathering and the codesign phase to minimise the risk of stakeholder drop-out and provide more clarity when reporting on EBCD studies around recruitment and drop-out rates (Green et al., 2020).

Recruitment targets were originally set at ten participants however a strategic decision was taken to over-recruit, allowing for the potential attrition of stakeholders, and managing any uncertainty while sustaining stakeholders' engagement during the four months of prototyping as it was anticipated to be challenging as a result of the COVID-19 pandemic.

The SIDG was recruited using an expression of interest advertisement via the South Yorkshire Stroke Integrated Delivery Network and the Sheffield Teaching Hospitals NHS FT PPI Group. Participants were invited to collaborate as equal partners. Information about the study and the opportunity to participate in the stakeholder group was circulated in South Yorkshire amongst stroke services. Each site had a Principal Investigator (PI) to support recruitment for the study. To recruit staff, posters were put on the stroke wards and participant information sheets (PIS) via hospital email systems and at team meetings. Patients and carers were approached by staff on the stroke wards advertising the opportunity to participate.

Those interested were offered a conversation with the CI or the site PI. Potential participants were given 24 hours to consider taking part. To attract patients and informal carers several patient and public forums and stroke charities were attended to attract participants.

#### 6.2.2 Sampling stakeholders

Purposive sampling is widely used in qualitative research for the identification and selection of information-rich cases with limited resources relevant to the phenomenon of interest (Palinkas et al., 2015). This involves identifying and selecting individuals or groups of individuals who are especially knowledgeable about or experienced with a phenomenon of interest (Creswell et al., 2011). Although this was not qualitative research, purposive sampling was used to identify staff from varied disciplines, seniority, and experience in stroke care (Hall et al., 2020) and patients and informal carers who were diverse in age, gender, and ethnicity.

#### 6.2.3 Informed consent to the SIDG

Those interested were offered a conversation with one of the research team. The commitment to attend ten stakeholder workshops was discussed to ensure potential stakeholders were fully informed about what it would entail. Due to COVID-19, it was not possible to consent all participants in person. One patient and his wife asked to meet at a local café to complete the consent forms. Several hospital staff consented to the study online using the MS Teams digital platform.

Guidance on participant payments was followed (Health Research Authority, 2023). Stakeholders were aware they would be awarded a £20 voucher on completion of the research as a thank-you for their contribution. They would also be provided with a personal thank you letter from the research team and a certificate of involvement for evidence of continuing professional development.

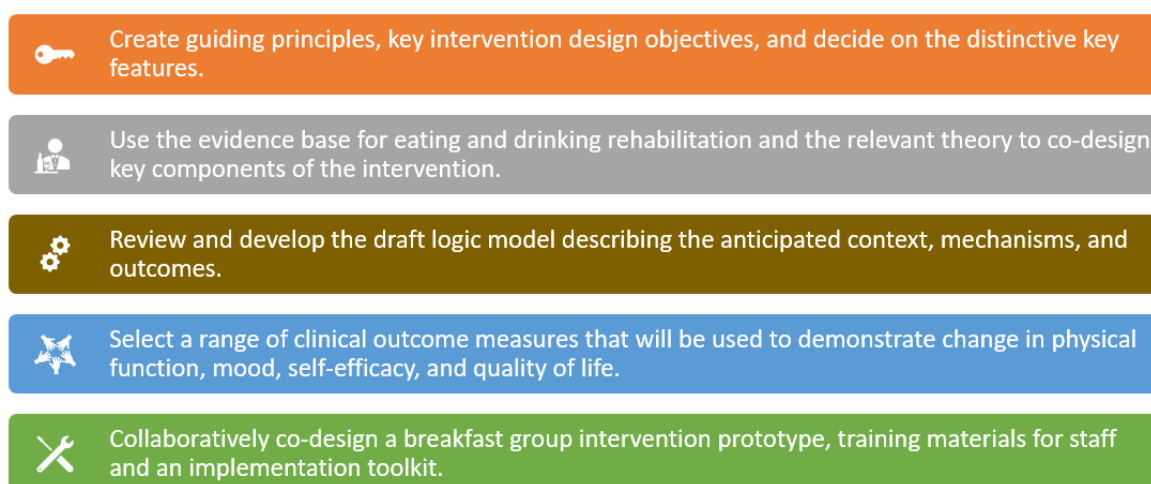
#### 6.2.4 Content of the workshops and key activities

The workshops were facilitated by the CI; however, the agenda and the content of the sessions were stakeholder-led. The stakeholders set ground rules for the coproduction process to ensure they were participatory and collaborative. The workshops were recorded and made available for the stakeholders for further reflection after each workshop.

In between workshops, the stakeholders were encouraged to engage with the researcher by providing feedback on items discussed and prototypes of the intervention or toolkit. Methods deployed for communication included email, telephone calls, text messages or WhatsApp (mobile phone messaging application).

Using themes arising from the evidence review and intervention planning stage, stakeholders identified five key activities that the stakeholder group needed to undertake. These are presented below in (Figure 17).

Figure 17: key stakeholder activities



#### 6.2.5 Description of the SIDG members

Fifteen participants consented to the stakeholder group, thirteen females and two males. Two patients and one informal carer were recruited, along with nine healthcare professionals. The healthcare professionals came from a range of clinical disciplines shown in Figure 18.

Figure 18: Stakeholders' characteristics

Stakeholder Characteristics	Gender	Number
Occupational Therapists	All female	4
Speech and Language Therapists	All female	4
Dietician	All female	2
Patient representatives	1 Female 1 Male	2
Informal carers	Female	1
Nurse	Male	1
Psychology Assistant	Female	1

## Format and Structure of the Meetings

### 6.3 SIDG and COVID Impact

Hospitals were still working under COVID-19 restrictions which prevented onsite meetings with non-NHS employees and meetings in close physical proximity. NHS staff were also under relentless clinical pressure and working with high levels of staff sickness. EBCD activities are usually conducted in person, but due to the pandemic, the stakeholder workshops were undertaken online. Therefore, it was anticipated that meetings might need to be flexible, and attendance would be variable.

Participants committed to attending the online meetings when they consented to the study. However, as the SIDG commenced it became clear that 100% attendance would not be possible due to work pressures, shifts, illness, and leave from work. One participant moved to Australia after consenting to join the study and wasn't able to attend the workshops due to the time differences between countries, but she was keen to participate. Arrangements were made for her to meet with the CI in separate one-to-one online meetings at 7:30 am due to the time difference. She agreed to watch the recording of the SIDG workshops and have a separate session the following week to discuss the recording and provide feedback. To ensure everyone had the opportunity to contribute if they missed a meeting, all members were offered feedback sessions outside of the stakeholder meetings. Methods such as telephone calls, email, text, and separate one-to-one meetings were deployed.

#### 6.3.1 Stakeholder Meeting Plan

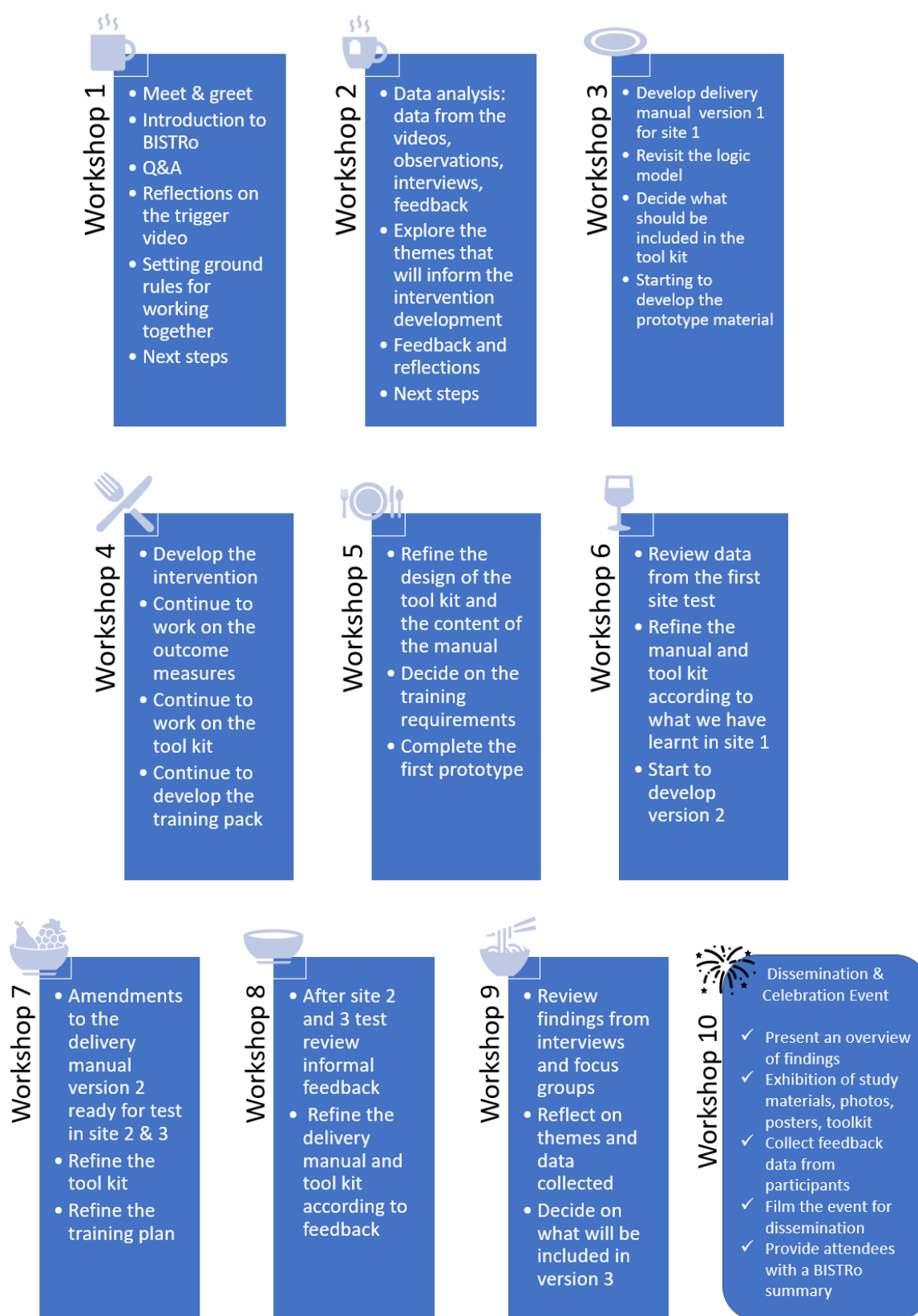
A total of ten workshops were scheduled, with nine dedicated to the development of the intervention, and the tenth serving as the concluding session for dissemination and celebration, as illustrated in Figure 19. SIDG meetings were scheduled two weeks apart in the early stages of development and less frequently toward the end of the development stages. The online workshops were conducted using a secure online platform (MS Teams from an account hosted by the NHS).

Workshops were scheduled to start in June 2022 with an initial launch meeting. It was anticipated that they would run for four months. Each workshop was planned for one hour. Participants were sent a pack of information in between workshops to review and provide feedback. Each workshop would have a bespoke agenda provided by the CI and circulated in advance. At the start of every meeting, there would be an opportunity for the group to add or change agenda items.

#### 6.3.2 Outline for each workshop

An outline plan for each meeting was developed in preparation for the beginning of the workshops (Figure 19). This was used as a guide for the activities in each workshop to ensure that the workshops kept to the timeline for the study and progressed the work plan at a comfortable pace. For example, the first meeting involved getting reflections about the trigger video, the fifth meeting involved deciding what was to be included in the intervention, and the sixth meeting was a reflection on how using the prototype of the intervention went in site 1- see below.

Figure 19: Contents of each workshop.



### 6.3.3 SIDG Meeting Facilitation

In EBCD methods the group has an appointed leader accountable for the project. As this was a PhD study, I took the leadership role in the stakeholder meetings. BISTRo had three principal investigator roles (PIs) at each site. The site PIs were invited to join the stakeholder group and engage in the online workshops. Their involvement proved beneficial, particularly when individuals needed help with online features or to get conversations going.

## Key findings from each workshop

### 6.4 Workshop 1

Workshop 1 launch meeting commenced with introductions and an icebreaker activity in which stakeholders shared stories about their favourite food or drink. Ground rules for coproduction were discussed followed by an activity to capture ideas to create a set of rules. The first trigger video *'Importance of eating and drinking'* (Appendix 1) was shared and stakeholders were encouraged to discuss their reactions to the content.

#### 6.4.1 The agenda

The first workshop started with an introduction to the BISTRo study aims and objectives (Figure 20). Stakeholders had an opportunity to ask questions about the study and clarify any issues about their role. Coproduction principles were introduced and there was a collaboration activity using Google Jam board for coproducing the ground rules to govern how the group would like to work together.

Figure 20: Example of Workshop Agenda 1 SIDG

**BISTRo Study**

**AGENDA LAUNCH MEETING MENU**

**Item 1 starters**

- Introductions
- Getting to know each other

Task 1: Please introduce yourself and tell us why you have agreed to be part of the study.

Task 2: Tell us something about your favorite food and drink

**Item 2 Hors d'oeuvres**

- Opportunity for questions and answers about the study

**Item 3 Appetizers**

- Video 1: why is eating and drinking important?

**Item 4 Main course**

- Setting our ground rules for meetings

Task 3: How would we like to work with each other?

**Item 5 Deserts**

- Plan for the next meetings

23<sup>rd</sup> June 1-2pm  
6<sup>th</sup> July 12-1pm  
21<sup>st</sup> July 11-12pm

**Item 6 Grab your coat time and pay the bill**

Any other business and close of the meeting

Join today's Zoom Meeting

Click on the link below

<https://phu.zoom.us/j/98671608946?pwd=emM5Mk4inQ1NlWFAvSUxvUmU4dHRROi09>



Additionally, an illustration of coproduction principles was shared from a recent study in stroke rehabilitation. This study involved stroke survivors and informal carers in coproduction workshops to create an intervention for addressing sedentary behaviour post-stroke, as described by Hall and colleagues (2020). Google Jam Board was employed to capture and document ideas.

#### 6.4.3 Trigger Video Feedback

The trigger video *'Importance of eating and drinking'* (Appendix 1) was used to introduce the stakeholders to the study and to generate ideas about the problems that staff, informal carers and patients encounter. The stakeholders were asked to reflect on the video and share their thoughts and experiences.

Post-it notes were organised into themes (Appendix 13) which included nutrition and hydration, social connection, pleasure experienced, and impacts of eating and drinking. Participants discussed aspects of the video that they could relate to, feelings that resonated with their experiences and topics they thought were important for the intervention. Stakeholders seemed to quickly build an emotional connection to the topic.

#### 6.4.4 Summary of Decisions from Workshop 1

The outputs from Workshop 1 were circulated one week after the workshop and stakeholders were invited to provide feedback via email, phone, or WhatsApp. Following the ground rules activity a draft set of rules was drafted and circulated for comment see Figure 21. The stakeholders decided that the best way to collate ideas would be in a table listing the 'considerations' for the breakfast group intervention. This table was updated after each workshop.

Figure 21: Workshop 1 draft ground rules.



### BISTRo Ground Rules

- If you need support to take part please say so
- Time out is ok
- Listen as well as speak – make space for others
- Everyone should be able to speak if they want to
- Respect each other's point of view
- Value the different types of lived experience, skills, and expertise we bring
- Confidentiality – personal information stays in the room
- Keep it relevant – let's focus on what we are doing
- Be honest and tactful
- 'Jargon Busting' is a good thing! – point out jargon to keep language clear
- If I need time to speak don't rush me
- We will use the features in zoom to ensure everyone gets a turn to speak

## 6.5 Workshop 2

### 6.5.1 The agenda

Workshop 2 commenced by orientating stakeholders to the online platform. We reviewed the draft ground rules for working together (Figure 21). The second trigger video was viewed '*Impacts of eating and drinking difficulties after stroke*' (Appendix 1). Stakeholders were encouraged to share thoughts, emotions and ideas that were triggered by the video. A summary of the key findings and data analysis from two ethnographic observations, five interviews and eight videos were presented in a series of mind maps. (This data was presented in Chapter 5). Stakeholders were facilitated to discuss ideas that would inform intervention development and as ideas were generated, they were added by the CI to the data collection table.

### 6.5.2 Discussions about ethnographic observation data

The primary findings from the field notes of two ethnographic observations were presented. There was an animated discussion about portion size, feelings of hunger and enhancing the variety of food and drink choices. The ethnographic data sparked a sharing of personal stories, including one from a stroke survivor who recounted not knowing he could have more than one Weetabix for breakfast. He described feeling like he was starving, and his wife had to bring in extra food to supplement his diet.

An informal carer spoke of her concern that people with aphasia could not read the menu and the absence of non-written alternatives. Several stakeholders recalled stories where patients requested the last item on the breakfast menu because simply it was the item they could remember. A consensus emerged that gathering information about the breakfast food options on each site and creating an aphasia-friendly menu was necessary. The discussion extended to constraints imposed by ward routines, prompting a conversation about the importance of providing snacks for patients who skipped breakfast entirely.

### 6.5.3 Discussions about interview data

Interview data influenced discussions about COVID-19. It was agreed that specific attention would need to be paid to infection control measures, moreover, it was suggested that a standard operating procedure and risk assessment were required. There was a discussion about how to incorporate and promote healthy eating principles in the intervention and it was recognised that some people may not like eating in a group context. Stakeholders thought this could be discussed as part of the consenting process.

### 6.5.4 Discussions about the trigger Video data

The second trigger video '*Impacts of eating and drinking difficulties after stroke*' led to a conversation about post-stroke fatigue. Stakeholders discussed the impact of fatigue on physical and mental performance. They also discussed the importance of good nutrition and hydration in combating fatigue. This topic triggered conversations about the pleasure of eating and drinking. A stroke survivor talked about the necessity to eat and how eating in the hospital was something that needed to be done for recovery rather than for enjoyment or pleasure.



### 6.5.5 Summary of Decisions from Workshop 2

The workshop recording and the table of considerations were used to create a mind map of considerations for intervention development (Figure 22). This was shared with the stakeholders post-meeting for comments.

Figure 22: Mind map summary of considerations for the intervention from workshop 2 discussions.



Other decisions agreed upon were as follows:

- 1) Create an aphasia-friendly menu to enable discussions about food choices.
- 2) Scope what each site can offer for breakfast and create a bespoke menu.
- 3) Develop documentation to support running a group during COVID restrictions.
- 4) Include food choices and preferences in the assessment documentation.

## 6.6 Workshop 3

### 6.6.1 Agenda

Workshop 3 commenced with a discussion about the online platform. Several participants struggled with accessing the documents circulated post-meeting. This was largely due to device capabilities. It was agreed that documents pre- and post-meeting would be shared in several formats e.g., word doc, PDF, and PowerPoint to ensure everyone could access the

content. This workshop focused on the intervention design and elements for the implementation toolkit.

#### 6.6.2 Discussion about the components of the BISTRo toolkit

There was a discussion about the need to write personalised goals and treatment plans and stakeholders were considering how to create a sense of normality, to normalise eating and drinking difficulties. The group made suggestions about how the environment could be modified and enriched to support engagement, following concerns about the impersonal hospital context. One stakeholder suggested tablecloths and flowers to help stroke survivors feel more 'at home'.

The group also discussed the importance of peer support and how this might be facilitated in the group context. In this workshop, the psychological needs of patients were discussed at length as the stakeholders wanted to ensure the intervention would address emotional needs. The stakeholders were also concerned with the best methods to communicate dietary needs which was triggered by thinking about how stroke survivors had struggled to communicate their preferences.

#### 6.6.3 Discussing the logic model

The concept of using a logic model to describe the intervention was introduced to the stakeholders to facilitate thinking about the potential outcomes of the intervention. Several versions of the logic model were shared with the stakeholders these can be found in Appendix 2 (Logic model development is discussed in Chapter 3). Whilst discussing the content of the logic model, a stakeholder questioned the word 'Mastery'. She thought that it evoked an idea of accomplishment, command, and proficiency. She explained:

*"It's a strong word but is it appropriate? You may not have mastered it, there are different levels- the top of your game might be different to other people. Are you at the level you are comfortable with but not mastering yet or would this be seen as a measure?"*

Although she was the only stakeholder to make a point about the use of this term others agreed with her rationale for not using this word in the logic model and it was decided that an alternative word would be used.

#### 6.6.4 Summary of Decisions Made at Workshop 3

Other decisions made in this workshop 3 included:

- 1) Include specifications for the environment setup in the BISTRo implementation tool kit.
- 2) Design communication methods for indicating modifications to diet and fluids.
- 3) Family and carers would not be involved in the intervention due to COVID restrictions, but they would be invited to contribute to collecting information about the patient's eating and drinking history.
- 4) The intervention would be adapted to local contexts, but the stakeholders would need to agree on what the core standardised components would be.

## 6.7 Workshop 4

### 6.7.1 Agenda

Workshop 4 focused on the components of the intervention, tool kit and outcomes measures. Specific concerns were raised about staff engagement and COVID-19 infection rates.

### 6.7.2 Discussions about intervention components

Stakeholders expressed a desire for the breakfast group intervention to distinguish itself from the traditional 'social dining'. They identified three essential elements that would differentiate it from standard social dining: involvement of a multi-disciplinary team, hands-on physical rehabilitation, and food preparation activities. These were visually mapped out on a PowerPoint during the conversation, and the addition of intensity, peer support, and psychological support was proposed. Together this created five components to the intervention.

### 6.7.3 Discussions about the implementation toolkit components

One of the stakeholders told a story about how everyday porridge was brought into her room, and she asked, *'is it gluten-free?'*. Almost every time they would take the porridge away to check. The stakeholders agreed that with different staff contributing to the group everyday communication methods for safety were important. Stakeholders generated several ideas on how to address this problem. Ideas were added to an 'idea board' (Figure 23) the merits of which were discussed at length. The stakeholders were unanimous that the intervention needed to improve communication. Other considerations were reducing stroke survivors having to repeat their stories and creating continuity of care. Emotive storytelling from the stakeholder stroke survivors and informal carer provided powerful triggers for idea generation.

Figure 23: Idea board for improving communication about dietary needs.



A stakeholder recalled a wedding she had attended where place cards were used, and this story sparked the suggestion of having a 'name place card' with dietary needs discretely written on the inside. Other suggestions included stickers for the main dietary needs that

would help to identify people with special diets such as dairy-free, gluten-free, modified diets and fluids A prototype design was created using a storyboard see Appendix 14 for the storyboard example.

Further ideas included a patient-held booklet that would support the delivery of the intervention. The stakeholder brainstormed ideas for the content which included a record of physical abilities, upper limb function, diet status, preferences, portion size, goals, and treatment plan. Stakeholders agreed that a section to include helpful information for discharge from the hospital such as advice and strategies, would be beneficial. This is illustrated in the quote below.

*“For me, it’s to make sure when you leave you feel confident for getting home and starting again because when I left, I was frightened to death. I didn’t know what I could make or eat- it would be nice to think I could leave knowing what I could have. Instead, I was a mess- that’s the essence of it all, to make you feel involved in yourself and enjoy your life again, to be able to go home and feel that you can cope and have a nice meal”. Stakeholder Stroke Survivor.*

#### 6.7.4 Discussions about Staff Engagement

Stakeholders had concerns about the practical challenges of delivering the intervention in each site and concerns about how to engage the wider multidisciplinary team. These concerns were clearly articulated by one of the Occupational Therapists.

*“I was thinking about how hard it is at the minute and the culture on the ward and how we can get patients into the group and how will we sell it. How we will promote this, and why we are doing this?” Stakeholder Occupational Therapist.*

There was consensus that engagement was an important part of the preparations for site testing and as a result of this discussion one of the stakeholders suggested arranging an engagement event to introduce the study to other team members with the specific aim of creating a ‘buzz’ about the study.

#### 6.7.5 Discussions about Covid-19

Staff stakeholders were particularly concerned about COVID-19 escalation and policy changes in response to rising numbers of COVID-19 cases in hospitals. There was a suggestion that backup plans might be needed e.g. social distancing measures. Stakeholders expressed their anxieties about potential disruption, and we discussed the possibility of lowering recruitment targets as a potential response.

A staff stakeholder instigated a conversation about contingency planning for reduced staffing and what minimum staffing might look like on each site. There was a consensus that one registered member of staff would need to be present for each group. The group considered whether one day of the intervention could be missed if staffing levels were insufficient. Reducing the number of patients in each group was debated. Pragmatically stakeholders were concerned with the optimum conditions for the breakfast group to thrive and what the minimum staffing provision could be in times of pressure.

#### 6.7.6 Summary decisions made from workshop 4

Actions agreed upon included:

1. To develop the implementation toolkit resources and create a master list of items required.
2. Develop a strategy for multidisciplinary team engagement for each site
3. To develop a COVID contingency plan.
4. Finalise version 1 of the patient intervention booklet.
5. Set dates for training and prototyping with each site to avoid NHS winter pressure periods (November/ December 2022).

#### 6.8 Workshop 5

##### 6.8.1 Agenda

The agenda for Workshop 5 included further prototyping activities and discussions about operationalising the intervention.

##### 6.8.2 Prototyping the Toolkit Items

The prototype for the BISTRO implementation toolkit was in the early stages of development. Draft examples were shared with the group for a 'check and challenge process'. We went through each item collating thoughts and feedback. A draft outline for the training manual was created and agreements were reached on which elements of the manual would be fixed and which elements could be tailored to each site.

There was a suggestion from staff stakeholders that there needed to be a method of communication between the BISTRO team and the ward staff to identify which patients needed to be ready for the breakfast group. Solutions to communicate who would be attending the group were generated. Ideas included a sign above the bed, wristbands, and a neck scarf, all of which were discarded due to impracticalities. The group decided that a sticker for clothing titled '*I'm ready for breakfast group*' would be an effective way to communicate who needed to be ready on time. One stakeholder proposed a wipeable board for the nurse's station. The idea of a 'first up-board' that would display patients' names was popular and a prototype design was discussed.

##### 6.8.3 Discussion about staff joining patients with a drink

An animated debate ensued about whether staff should have a drink with the patients during the breakfast group. Infection control guidance formed a significant part of the discussion. Some stakeholders felt this was unprofessional and others felt that it would make the group more relaxed and be less formal for the patients. There was also the issue of personal protective equipment guidance and whether staff would be wearing masks which would make having a drink difficult. Several stakeholders were concerned about who would pay for the coffee and tea as there were rules about staff not using patients' food and drink. This was quite a contentious issue, so the stakeholders decided to take this back to the individual sites and have further site-specific conversations to explore this further.

##### 6.8.4 Operationalising the study plan

Agreements were made about the training manual content. Each site had a different system for patient notes, so the site PIs were tasked with process mapping a plan for

documentation. Soft launch dates were planned for sites 1 and 2. The environment checklists and menu items for each site were reviewed. There was a brainstorming activity for the requirements of a COVID contingency plan and plans were made to start recruiting staff to deliver the intervention in site 1. It was decided that patients would be recruited nearer to the testing date due to the risk of patients consented being discharged home before the start of prototyping.

#### 6.8.5 Summary of actions from this workshop

Decisions from this workshop include:

1. Create a prototype first-up board and an 'up-for-breakfast group' sticker.
2. Include guidance on staff having a drink during the group in the training manual.
3. Complete the process for study communication and distribute it to each site.
4. Consensus was reached on having one booklet for both patients and families, in the interest of keeping it simple.

### 6.9 Workshop 6

#### 6.9.1 Agenda

Workshop 6 continued with finalising the prototype intervention and toolkit. Technical issues and staff pressures proved disruptive to the effectiveness of the workshop. The likelihood of starting prototyping was in jeopardy due to COVID-19 escalation and a two-week postponement was thought likely.

#### 6.9.2 Difficulties in this workshop

This workshop was hampered by technical issues. Several people struggled to join and those that did join had lots of issues with buffering which wasted 15 minutes of the meeting. Stakeholders kept having to leave and rejoin which was disruptive to the flow of the meeting.

#### 6.9.3 Discussions about the potential impact of COVID-19

There were serious concerns about the ability of sites to deliver the study; one site had closed to admissions due to increased COVID-19 prevalence and another had significant issues with staff illness. The soft launch in site 1 and the prototyping start date were postponed due to a COVID outbreak resulting in stroke wards closing to admissions.

#### 6.9.4 Discussions about prototypes

Storyboarding was used to finalise ideas for version 1 of the prototype (Appendix 15). The majority of the resources had a clearly defined prototype mock-up detailed in a Microsoft Word document and on PowerPoint slides. This was shared with the stakeholders to review and feedback on (Appendix 16).

Stakeholders felt that promoting accessibility and inclusion was important and they discussed how independence could be facilitated in the breakfast group. Strategies such as accessible fruit juice in jugs, dycem mats and plate guards to stop food from falling off the plate, were discussed. As well as assistive devices there were suggestions about how everyday objects would be adapted to increase accessibility. For example, collecting glass pudding dishes to hold jams and other condiments.



One stakeholder asked if clothing protectors could be provided for people with swallowing difficulties. Plastic aprons were suggested, but it was acknowledged that these are not aesthetically pleasing for people or discrete. A patient representative stakeholder said they *'hated the plastic aprons'*, so there was a suggestion of an adult bib or a box of tissues on the table could provide an alternative. The logistics of laundering material bibs were seen as problematic. There were also concerns about preserving dignity. A consensus was reached that offering napkins, disposable wipes and aprons were preferable solutions.

#### 6.9.5 Summary of actions from workshop 6

Decisions made in Workshop 6 include:

- 1) Review the manual and room checklists to ensure that they promote accessibility and inclusivity.
- 2) To finalise the prototyping for site testing in site 1.
- 3) To add to the manual requirements for eating with dignity.
- 4) To agree on new dates for site 1 testing so that it could be completed before the next stakeholder meeting.

### 6.10 Workshop 7

#### 6.10.1 Agenda

Workshop 7 focused on feedback from site 1 testing and the creation of version 2 of the intervention manual and toolkit for further testing in sites 2 and 3. The stakeholders heard feedback from two ethnographic observations of prototyping on-site, field notes and staff reflections. Ten key learning points and reflections that influenced the next iteration of the intervention for site testing are summarised below.

#### 6.10.2 Key learning points

- 1) Infection control- On day two of site 1 prototyping an infection control nurse arrived unannounced to inspect the ward. She suggested the tables were moved slightly more apart. Staff were initially concerned that this would affect group cohesion, but they discovered that three tables created seated pairs and the pairs of patients enjoyed conversations with their table partners but were still able to converse with other pairs as well.
- 2) Environment- Patients were waiting for long periods to be able to make their toast and consequently ate at different times. Staff reflected that this affected individuals socialising. In week two more tables were brought in to create additional food preparation stations.
- 3) Conversational tools- Observations revealed that the toolkit communication resources were not used as conversations between participants and staff were flowing freely. Field notes describe laughter and animated conversations.
- 4) Amendments to the patient booklet- In week two (site 1), patients became familiar with the routine of the breakfast group, and they were observed using their intervention booklets independently.
- 5) The stickers to signify attendance were either worn on clothing or put in the patient booklet. One patient suggested a space be created in the booklet for an attendance sticker or stamp.

- 6) Written goals in the booklets were being reviewed daily and patients were encouraged to write in their booklets. Recommendations were made for more writing space for the daily log. Staff delivering the intervention requested combining the treatment plan and goal-setting sections.
- 7) Staffing rotas- The skill mix was deemed to be feasible although it was suggested that at least one of the three staff members attended consistently for patient continuity.
- 8) Patient choice- It was noted that no religious or cultural issues were highlighted. Field notes show that two African patients discussed their traditional breakfast foods. Staff feedback that the breakfast menu was limited and that they encouraged patients to bring in food from home. In the second week, field notes record that patients were bringing in food from home such as teabags and soft fruits.
- 9) Staff noted that most patients had two drinks during the group as well as two breakfast choices which would not be usual practice.
- 10) Snacks from a trolley were offered at the end of the group and most patients seemed keen to take a mid-morning snack.

#### 6.10.3 Summary of actions from workshop 7

Feedback from this workshop and discussions with the stakeholders informed version 2 of the intervention training manual and implantation toolkit. Decisions made included:

- 1) Update the infection control procedures in the manual.
- 2) Ensure testing in sites 2 and 3 had adequate food prep workstations and equipment.
- 3) Retain conversational tools in the toolkit to explore if they are used in sites 2 and 3.
- 4) Changes to the patient booklet in response to staff and patient feedback- add a sticker section, create more space for the daily log and merge the treatment plan and goal-setting section.
- 5) Recommend a consistent member of staff for the rota to promote consistency.
- 6) Update the training manual to support encouraging patients to bring in food from home.

### 6.11 Workshop 8

#### 6.11.1 Agenda

This was a short meeting. Sites 2 and 3 were in the midst of site testing therefore the workshop was used to discuss informal feedback from the site testing.

#### 6.11.2 Delays to site testing

Due to unforeseen circumstances, site 3 had to delay its start date by two weeks. A managerial decision was taken to move the stroke ward to another location, and it was decided that this would cause significant disruption. This took the prototyping time frame into the official hospital winter pressure period which introduced a greater risk of disruption, but it was decided there were no alternatives but to delay. Although the start date was changed there was an additional delay due to hospital reconfigurations which meant that the intervention could not start on the first day. This resulted in the patients in site 3 only having nine days of the intervention programme available to them.



## 6.12 Workshop 9

### 6.12.1 Agenda

Workshop 9 focused on informal feedback from the site prototyping and discussions about how the toolkit would need to be updated. The preliminary findings from data collection in sites 2 and 3 were presented. The findings from the acceptability and feasibility stages are discussed in detail in Chapter 7.

## 6.13 Workshop 10 Celebration and Dissemination Event

In accordance with the EBCD approach, the final workshop was a dissemination and celebration event. Held at a local conference venue, guests included clinicians, stroke survivors, informal carers, NHS Managers and NHS Leaders, commissioners, and Stroke Charities. This was an open research event where narrative data was collected from attendees about their reflections on the study. A filmmaker took photos and recorded the proceedings. Those choosing not to be filmed or photographed were provided with a blue wristband so that they could identify during editing.

The room was arranged to simulate a breakfast intervention with bright tablecloths, flowers, and napkins. Each table had an acrylic table menu holding the program. The first hour was a series of presentations. A stroke survivor and an informal carer shared their experiences of eating and drinking difficulties, the CI presented a summary of key findings and two members of the stakeholder group talked about their experiences of being involved in the study. The second hour was a networking lunch where guests could view the exhibition, photo gallery and network.

The interactive elements of the event included selfie sticks on each table with quotes from the study so that delegates could take photos of themselves. Each table had post-it notes where delegates were invited to make comments and add reflections to a flip-chart board. Each place setting had a blue gift tag. The tags were used to collect thoughts about the study. A video describing the study findings was played during the networking lunch the link for this can be found with the other media outputs in Appendix 1.

The exhibition contained four academic posters that had been presented at conferences (Appendix 17) and an illustrated storyboard showing the codesign element of the study (Appendix 18). There was a photo gallery of over 100 photos taken of the intervention in action and a poem written by a stroke survivor specifically for the event about her lived experience of eating and drinking difficulties (Appendix 19). A display of quotes from the study was scattered around the room and a BISTRo table and toolkit were set up for people to explore. A selection of photos from the event can be found in Appendix 20. A link to a 12-minute video about the open research event which has been shared on social media platforms can be found in Appendix 1. The feedback from participants about the study and the event has been incorporated into the research impact tool presented in Chapter 9.

## Discussion of the coproduction process

### 6.14 Summary of findings

Ten workshops were delivered successfully to consider evidence from literature and stakeholder consultations, create a prototype breakfast group intervention and consider the results of the feasibility and acceptability testing which are discussed in Chapter 7.

### 6.15 Strengths and limitations

#### 6.15.1 Online workshops

The COVID-19 pandemic had a significant impact on research delivery (Benson et al., 2021; Shamsuddin, et al, 2021). The workshops were originally planned to run in person; however, it became evident that this would not be feasible. I identified some training needs which were met through taking a course titled '*Taking your research online*' with the Social Research Association. Upon reviewing relevant published literature to identify the best methods for conducting as discussed by Shamsuddin and colleagues (2021). Furthermore, the academic research community had not clearly defined the term 'workshop' (Shamsuddin, Sheikh and Keers, 2021). Additionally, there was also insufficient evidence on the ethical dilemmas of recording online workshops (Shamsuddin, Sheikh and Keers, 2021). However, this challenge was anticipated and robust data management plans were submitted for NHS ethics approval.

Online research was not a new phenomenon, gaining popularity over the last ten years (Benson et al., 2021), especially during the pandemic, there was a resurgence of online methods. Despite this concerns remained about how taking the workshops online would affect the quality of the outcomes and how stroke survivors and informal carers would cope with using online platforms.

Barriers to access such as broadband width, suitable devices, and use of software programs were considered. Other considerations included digital inequalities and the potential for sample bias due to the need for technology to participate in the workshops (Benson *et al.*, 2021). Familiarisation with the MS Teams platform and its features took time especially as people were using it on a range of devices. As a result of having family online meetings during the COVID-19 lockdowns, most people were comfortable with methods of online communication (Shamsuddin et al., 2021). Several participants had difficulty accessing and using the Google Jam board. Although whiteboarding tools such as Jam Board are thought to enhance participation in online workshops (Shamsuddin et al., 2021) the participants did not find these easy to use. Therefore a compromise, the hybrid method was introduced where some people used the platform during the workshop and others gave verbal feedback which was recorded by the CI.

Conducting online workshops as opposed to in-person has the advantage of lower costs (Woodyatt, et al., 2016). This study attracted participants from across South Yorkshire which could have involved a significant amount of costs associated with travel, room hire and refreshments. Clinicians reported that they preferred the online workshops as this had less

of an impact on their time and made contributing during staffing pressures more feasible. In addition, stroke survivors appreciated online workshops did not require as much physical energy to attend.

#### 6.15.2 Leadership and online workshops

It has been documented that without sufficient leadership codesign processes may encounter difficulties (Cowdell et al., 2022). There is widespread acknowledgement that productive meetings necessitate effective leadership as emphasised by LeBlanc and Nosik, (2019) and the primary responsibility of a leader is to establish an environment conducive to participants' active contributions. The ethos of EBCD is working in partnership with stakeholders and collective leadership (Bate and Robert, 2006). Donetto and colleagues (2014) stress the importance of clinical leadership in EBCD projects however if the researcher is the leader this could introduce a power inequity. One of the challenges of codesigning is that it can be described as messy or chaotic. Rousseau and coauthors (2019) suggest leadership is a stabilising factor that provides a clear vision and purpose for the project and keeps the project on track.

A scoping review by Cowdell and coauthors (2022) on the engagement stakeholders in intervention design found that power balance was a concern in two-thirds of studies. Cowdell et al., (2022) conclude that leadership roles can vary, and it may not be possible to create the conditions for truly shared decision-making or stakeholder-led meetings however democratic processes and conditions for creating parity of esteem for all participants might be more realistic and achievable.

#### 6.15.3 Building rapport online

A potential barrier to online workshops is the effort needed to build up a rapport to manage sensitive subjects (Woodyatt et al, 2016; Shamsuddin et al, 2021). All participants were respectful, engaged well and quickly built up a rapport by sharing personal stories. This aligns with the findings of (Woodyatt et al, 2016) who found that conducting online research could create a safer space for sensitive experiences to be discussed as the degree of separation from other participants is a more anonymous environment.

The icebreaker session was successful in building rapport as people disclosed personal stories about themselves and commonalities were discovered. Stakeholders were laughing with each other about their food and drink stories which helped to lighten the mood and build rapport.

When stakeholders could not attend, they listened to the audio recording of the workshop and sent feedback by email, phone, or WhatsApp. The flexibility of being able to consider the data over time was helpful for those under clinical pressure and also those who needed to reflect on feedback. This resonates with Richard and others (2021) who reported that idea generation was suited to online workshops as they can facilitate rapport and trust building over time.

## 6.16 Implications of findings for future studies

### 6.16.1 Strategies to facilitate communication online

Using the examples of coproduction principles (Hall et al., 2020; National Institute for Health and Care Research, 2021) was a helpful way to develop ground rules. The ground rules were visited at the start of every meeting and stakeholders were asked if they wanted to add or change any rules. One challenge identified was bringing together clinicians and lay people. Rousseau et al., (2019a) discovered that translating findings for lay members could present a barrier to the codesign process. Although avoiding jargon was included in the co-created ground rules it was difficult at times to avoid and clinicians tended to revert to their usual modes of language. Broomfield et al., (2021) overcome the use of unfamiliar language by creating a set of accessible definitions. In this study, the patient and informal carer stakeholders were quick to point out jargon, and acronyms and seek clarification with one another. It is possible that having a specific ground rule on this permitted individuals to call out the use of any jargon.

### 6.16.2 Strategies to improve effectiveness included getting verbal feedback

Hall and colleagues (2020) found that workshop reflection was a vital element of stakeholder engagement. They proposed that all stakeholder workshops are evaluated, and feedback is provided so that participants can comment on the accuracy of notes and summaries (Hall et al., 2020). This also ensures the credibility and trustworthiness of the data collected. LeBlanc & Nosik, (2019) suggest that workshop evaluation takes a more formal approach such as using a structured checklist. For consistency of post-meeting reflections, a checklist was used to guide each post-workshop reflection note-taking. This included items such as whether all participants had the necessary material and did all participants remained engaged and participated as expected.

### 6.16.3 Facilitation of continuity with communication

Nine online workshops were recorded so that post-meeting the content could be reviewed, and anyone missing could catch up. Following each workshop, the data generated were analysed interpreted and used to inform the content of subsequent workshops. Any discrepancies were discussed with the SIDG at the next meeting. One week after each workshop a feedback pack was circulated via email along with an agenda for the next meeting. Stakeholders were provided with any links to films or resources and the data collected in Jam Boards was shared to ensure that any additional comments could be captured.

### 6.16.4 Translating data for stakeholders

The stakeholders were asked to work with multiple data sources. The information could be conflicting and difficult to prioritise. In addition to processing large amounts of data, the stakeholders also had their views and opinions. Rousseau et al., (2019a) caution that tacit knowledge of stakeholders could overturn much stronger evidence posing a threat to incorporating multiple data sources. A further limitation could be the complexity of codesign which requires the synthesis of large diverse data sets. To support the translation of the data, for stakeholders, the findings of the pre-intervention data collection were assimilated into mind maps. Although this helped the stakeholders compare the findings and make sense of the theme's researchers need to be mindful of their role in the

translation of data and how this could influence views and perspectives (Rousseau et al., 2019a).

#### 6.16.5 Family participation

Although it was widely acknowledged that it would be beneficial to be able to invite family members into the hospital to support and observe loved ones with eating and drinking, there was concern about this idea in the context of COVID-19. Firstly, due to current restrictions, there was a limited visiting policy. Secondly, the group acknowledged that some patients may not be comfortable with having strangers present during an intervention. It was suggested that involving patients’ families and friends in completing the assessment booklet would be a good touch point for family engagement. They would be able to support capturing information on personal preferences. Further studies might consider how family and carers can be more involved in breakfast group interventions, especially in light of the recently published NICE guidelines for stroke which recommend family and carers are involved in goal setting and other aspects of rehabilitation where possible (NICE, 2023).

#### 6.16.6 Combining design modes

Six modes for codesign are described by Rousseau and colleagues (2019), the EBCD approach taken in the BISTRo study aligns best with creative partnership and negotiated design modes. The creative partnership approach involves maximising creative idea generation. It could be argued that this study research team lack the expertise of design professionals. However, the CI has some expertise from working with designers on previous research projects and has utilised informal liaisons with experts in the field to test out ideas.

The negotiated mode focuses on the practical application of real-world implementation however, a criticism of real-world thinking is the propensity to stifle the creative process. A disadvantage of using creative modes is the likelihood of stakeholders prioritising creative ideas over scientific knowledge (Rousseau et al., 2019a). These theories of how to approach intervention design have informed the planning of the stakeholder workshops. Using a hybrid of both design modes suited the BISTRo study as the intervention development moved through the Hawkins Framework 3 stages (2017). Table 7 describes how BISTRo drew on both design modes during the stakeholder coproduction stage.

Table 7: Modes of intervention design adapted from Rousseau et al., (2019a).

Mode	Stabilising	Working with knowledge	Creativity
Creative Partnership Design	Skills as a facilitator and confidence with online platform features impacted the flow and quality of the meeting outputs. The stakeholders were prepared to be creative and were generating multiple ideas. A consensus was sought, and attention was paid to equality in decision-making.	The scientific knowledge was assimilated into thinking about the impacts of eating and drinking difficulties. There was a focus on the practical implications for delivery and tacit knowledge informed the creative process. Scientific knowledge was accepted and not challenged.	Each meeting had a strong focus on creating ideas and ‘no idea was a bad idea’. Stroke survivors were less inhibited in their idea generation, whereas clinicians tended to think in terms of what was practicable in practice.

Negotiated Design	The logic model was used to anchor thinking about potential outcomes. The stakeholders had a clear purpose and shared vision to develop the breakfast group. They worked together cohesively.	There was a focus on practical application and what would work in the different sites. Ideas were developed into products that would be part of a tool kit.	A dialogue of what would work in practice was a constant theme. Although the group were able to think creatively, they wanted to ensure the intervention was fit for purpose and acceptable for those delivering and receiving the intervention.
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### 6.17 Chapter Conclusion

The Chapter discussed Hawkins Framework Stage 2 coproduction (2017) which was operationalised using ten workshops to codesign the intervention and implementation toolkit. It presents how a stakeholder intervention development group (SIDG) worked collaboratively to codesign a breakfast group intervention and implementation tool kit. The findings of each workshop show how decisions were made that influenced the development of the prototypes. Combining EBCD with Hawkin’s Framework (2017) provided stakeholders with a structure to guide the steps of coproduction and created a creative space where stakeholders were empowered to work together to address concerns and challenges, share knowledge and experience ownership of decisions made.

## Chapter Seven: Hawkins 3-stage Framework: Stage-3 Prototyping Part 1

### Summary of Chapter

This Chapter has four parts.

- 1) Describes how stage 3 of Hawkins' Framework was iteratively used to develop a prototype.
- 2) Describes the characteristics of participants in the prototyping stage.
- 3) Describes the intervention using the TIDier guidelines (Template for Intervention Description and replication).
- 4) Describes the implementation toolkit, the purpose of each item, how it was used in prototyping and implications for the final version.

### 7.1 Using Hawkins Framework to iteratively develop the prototypes

As described in Chapter 3, the Hawkins three-stage framework (Hawkins et al., 2017) was used to develop the BISTRo intervention. Prototyping is a key part of intervention development (seen in Figure 6). Three iterations of prototyping are described below.

#### 7.1.1 Iteration 1

Based on outputs from Stakeholder Workshops the researcher created a mock version of the intervention and implementation toolkit. In accordance with Hawkins' Framework (Hawkins et al., 2017) an action research process was undertaken by the researcher and the Stakeholder Intervention Development Group (SIDG). The intervention and implementation toolkit were iteratively adapted in response to feedback.

#### 7.1.2 Iteration 2

Version one of the intervention and toolkit was tested in site one for two weeks (10 sessions of the Breakfast Group). The researcher and the site Principal Investigator observed the intervention being delivered twice during each testing phase. Observation field notes were made which were typed up afterwards verbatim and analysed in NVivo. Staff delivering the intervention were asked to reflect on their experience and note any learning in a logbook that was part of the toolkit. Following prototyping, informal feedback on the content of the intervention and toolkit was sought from the patients and staff participants as well as other key stakeholders. Notes were made of these meetings. The feedback collected in these various methods was used to refine the prototype and create version two of BISTRo with the SIDG.

#### 7.1.3 Iteration 3

Version two of the intervention and toolkit was tested in sites two and three for two weeks (10 sessions of the Breakfast Group).

## 7.2 Characteristics of the participants involved in prototyping

### 7.2.1 Characteristics of staff participants

Across the three sites, 61 staff members were recruited to deliver the intervention although 8 withdrew before the study commenced (Table 8). Attrition was anticipated considering the period of prototyping was late autumn and the COVID-19 pandemic was still significantly affecting the NHS staffing levels and resulting in higher than-average sickness levels. Only 3 male staff participated in study delivery. The NHS has a 67.8% female-based workforce (NHS Improvement and NHS England, 2021) therefore higher numbers of female staff were expected.

Although site 1 recruited three members of nursing staff, none of them were able to participate due to staffing shortages. The dietician in site 1 was also unable to participate due to staffing levels. Site 2 attempted to recruit nursing staff but only one expressed interest at the request of her manager and she did not go on to consent to the study. Site 3 had a psychology assistant participate which was different to the other sites; they were the only site successful in consenting and retaining nursing staff for intervention delivery.

Table 8: Characteristics of staff participants.

Characteristics	Site 1	Site 2	Site 3	Totals
<b>Number of Staff Consented to Deliver Intervention</b>	20	22	19	61
<b>Reason for Withdrawal</b>	3= Staffing shortages (Nursing and Dietetics)	2= Staffing shortages (Physiotherapy) 2= Absence from work	1= Absence from work	8
<b>Number of Staff Delivering the Intervention During Prototyping</b>	17	18	18	53
<b>Gender of Staff</b>	19 Female 1 Male	Female 22	17 Female 2 Male	58 Female 3 Male
<b>Professions Represented</b>	Dietetics, Speech and Language Therapy, Physiotherapy, Occupational Therapy, Nursing.	Dietetics, Speech and Language Therapy, Physiotherapy and Occupational Therapy.	Speech and Language Therapy, Physiotherapy, Occupational Therapy, Nursing, and Psychology.	6 professions represented
<b>Mean number of years worked in stroke</b>	6.55	6.7	9.4	7.55 average years

### 7.2.2 Characteristics of patient participants

Sixteen patients were recruited to the prototyping stage (Table 8); sites 1 and 2 recruited 6 participants and site 3 recruited 4. The overall target number of participants was 15 which was achieved. Site 3 had fewer patients which was attributed to the cohort of admissions at



the time of recruitment and there were fewer suitable patients on this site during prototyping. The study recruited 7 males and 9 females; this reflected the balance of patient genders in the stroke wards at the time of the study. This representation is similar to the UK stroke population with women being more likely to have a stroke than men (Stroke Association, 2016). The overall mean age across the three sites was 71 years with a range of 58-89 years. The mean age reflects the higher number of people having stroke occurring in people over 65 years (Stroke Association, 2016). Three out of the sixteen identified as black British ethnicity. People with black ethnicity are twice as likely to have a stroke and therefore it is important to have them within the sample (Table 8).

Patient participants in sites 1 and 2 had similar numbers of weeks post-stroke (5.1 and 5), site 3 was lower at 1.5. This could be attributed to the configuration of the stroke pathways in the three sites or as a result of the patient cohort at the time of the study. Patients can stay in the hospital after a stroke for anything from a few days to several months. As each stroke affects people differently the recovery process and expected length of stay are individual. Over the past eight years, there has been a drive toward early supported discharge in stroke services (Stroke Association, 2016; Royal College of Physicians, 2023). Early supported discharge is designed for people with mild to moderate disabilities and it means that people can be discharged home earlier. People with eating and drinking difficulties are likely to have complex impairments and therefore would be more likely to stay longer in the hospital (Westergren et al., 2002; Attrill et al., 2018). Therefore 1.5-5 weeks post-stroke is a reasonable timeline for the BISTRO intervention to take place in the hospital.

Table 9: Characteristics of patient participants.

Number of patients	Site 1		Site 2		Site 3		Totals	
Number consented	6		6		4		16	
Ethnicity	3 White British, 2 African, 1 Caribbean		6 White British		4 White British		13 White British 3 Other Ethnicities	
Gender	4 Females	2 Males	2 Females	4 Males	3 Females	1 Male	9 Females	7 Males
Type of stroke	1 Haemorrhagic	5 Ischemic	1 Haemorrhagic	5 Ischemic	0 Haemorrhagic	4 Ischemic	2 Haemorrhagic	14 Ischemic
Mean age of patients	70		72		71		71	
Mean number of weeks since date of stroke	5		5		1.5		3.8	

### 7.3 Description of the intervention using the TIDier guidelines

For feasibility studies, good quality reporting is recommended (Lancaster and Thabane, 2019) so that clinicians can implement interventions to replicate results (Hoffmann et al.,

2014). Reporting guidelines such as the 12-item TIDier checklist can be used by researchers to describe the intervention in a research study (Hoffmann et al., 2014). The breakfast group intervention is presented in Table 9 using TIDier guidance (Hoffmann et al., 2014).

Table 10: BISTRo Intervention Description using the TIDier Guidelines template adapted from Hoffman et al., (2014).

TIDier item	TIDER Explanation	BISTRo Description												
<b>Brief name</b>	<b>Names that describe the intervention</b>	Breakfast group intervention.												
<b>Why</b>	<b>Rationale, theory of goal of the elements of the intervention</b>	<p>Definition: Breakfast groups bring together stroke survivors to make their breakfast as part of their functional rehabilitation treatment plan. They eat and drink together in a social dining context. This was delivered over five days Monday to Friday by a range of healthcare professionals experienced in stroke rehabilitation.</p> <ol style="list-style-type: none"> <li>1. By increasing the intensity of eating and drinking practice in a daily breakfast group intervention participants have greater opportunities to practice whilst in hospital.</li> <li>2. Regular practice, support and rehabilitation of eating and drinking skills could help participants feel more confident with eating and drinking.</li> <li>3. Social dining provides an opportunity for peer support and making social connections with other stroke survivors which could be beneficial for psychosocial well-being.</li> <li>4. Creating a team of mixed disciplines working together as a multi-disciplinary team could help stroke clinicians work better together as a team around eating and drinking rehabilitation.</li> </ol> <p>Therefore features of the intervention include; intensity, multi-disciplinary, peer support, social dining, and psychological support.</p>												
<b>What</b>	<b>Materials used by the patients and the staff</b>	<p>Components of the implementation toolkit consist of 21 items organized into three groups: those for staff preparation, those for staff delivering the intervention, and those for patients utilizing the intervention.</p> <table border="1"> <thead> <tr> <th colspan="2">For staff to prepare for BISTRo delivery</th> <th>Details</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>Standard operating procedure for COVID</td> <td>For governance processes and assurance.</td> </tr> <tr> <td>2</td> <td>COVID risk assessment</td> <td>For governance processes and assurance. Together the risk assessment and Standard operating procedure (SOP) provide help for contingency planning.</td> </tr> <tr> <td>3</td> <td>Training packs</td> <td>Pack 1 – Introduction to the study, rationale, why it matters, tool kit and intervention components.</td> </tr> </tbody> </table>	For staff to prepare for BISTRo delivery		Details	1	Standard operating procedure for COVID	For governance processes and assurance.	2	COVID risk assessment	For governance processes and assurance. Together the risk assessment and Standard operating procedure (SOP) provide help for contingency planning.	3	Training packs	Pack 1 – Introduction to the study, rationale, why it matters, tool kit and intervention components.
For staff to prepare for BISTRo delivery		Details												
1	Standard operating procedure for COVID	For governance processes and assurance.												
2	COVID risk assessment	For governance processes and assurance. Together the risk assessment and Standard operating procedure (SOP) provide help for contingency planning.												
3	Training packs	Pack 1 – Introduction to the study, rationale, why it matters, tool kit and intervention components.												

		Pack 2- Outcome measurement, key theories, goal setting.
4	Training Manual	This guide provides staff with instructions on how to set up the room, deliver the intervention and address frequently asked questions.
5	Do not disturb sign	For the door to the group session.
6	First-up boards	A3 Board for patients' names. For nursing and therapy staff to use as a visual reminder of who needs to be ready first to attend breakfast group.
7	Checklist for environment	To set up the group.
8	Checklist for the specialist equipment (each site has its own)	Ensure equipment is out and ready for use.
9	Room set-up pictures	The layout of the room and workstation guidance.
10	Table cloths	One for each table.

No	Resources for staff to deliver BISTRo intervention	Details
11	6 CIT cognitive screen for eligibility	6 CIT is a cognitive assessment used to screen suitable participants for the BISTRo intervention. The assessment screens for any significant cognitive issues which would indicate severe impairment. This is used with clinical reasoning to decide on eligibility for the study.
12	Patient outcome measures	To be completed on all patients in the study at the initial assessment and the endpoint assessment. The Self-confidence measure is in the patient BISTRo Booklet. <ul style="list-style-type: none"> <li>A. CASM social confidence measure</li> <li>B. CASM Positive attitude measure</li> <li>C. Self-confidence measure</li> </ul>
13	BISTRo Eating and Drinking Assessment	A blank assessment and a template with guidance. To be completed as part of the initial assessment for the breakfast group. This is a conversational tool which illuminates goals and plans treatments for the breakfast group.
14	Aphasia having a supported conversation	This guidance is for staff less familiar with working with people who have aphasia. It provides some tips and techniques on communication styles and how to make communication more accessible.
15	Topics for conversation	To simulate conversation amongst the patient group if needed.
16	Word of the week resources	WOW resources, short for word of the week are 10 current news stories shorted into keywords or short sentences with images to support the text. They are used to support conversations with people who have aphasia. This is a free resource that stroke units can sign up for on the internet.
17	Diet stickers small	Used to keep track of patient's diet and fluid specifications. For use inside the place name cards.

		<table border="1"> <tr> <td>18</td> <td>Large food and drink labels</td> <td>These stickers can be used for packaging and to identify items for people with aphasia.</td> </tr> <tr> <td><b>No</b></td> <td><b>Items for patients to use in BISTRo intervention</b></td> <td><b>Items</b></td> </tr> <tr> <td>19</td> <td>Menu</td> <td>Each site has a site-specific menu and an acrylic menu holder for the table so patients can choose their breakfast/drinks.</td> </tr> <tr> <td>20</td> <td>Place name cards</td> <td>One for each patient at the start of the group. Ensure they are out on the table each day.</td> </tr> <tr> <td>21</td> <td>Stickers A) 'Ready for breakfast group' stickers B) 'Been to a breakfast group' stickers</td> <td>A. Used to promote the group; they are designed for patient participants to wear on the morning of the group. A way to identify patients to staff and also for staff to engage with the intervention. B. These can be used by patients to put in their BISTRo Booklets to show they have attended.</td> </tr> <tr> <td>22</td> <td>Intervention Booklet</td> <td>A patient-held booklet to record personal preferences and eating and drinking rehabilitation. Patients can also log daily progress, goals, and treatment plans.</td> </tr> </table>	18	Large food and drink labels	These stickers can be used for packaging and to identify items for people with aphasia.	<b>No</b>	<b>Items for patients to use in BISTRo intervention</b>	<b>Items</b>	19	Menu	Each site has a site-specific menu and an acrylic menu holder for the table so patients can choose their breakfast/drinks.	20	Place name cards	One for each patient at the start of the group. Ensure they are out on the table each day.	21	Stickers A) 'Ready for breakfast group' stickers B) 'Been to a breakfast group' stickers	A. Used to promote the group; they are designed for patient participants to wear on the morning of the group. A way to identify patients to staff and also for staff to engage with the intervention. B. These can be used by patients to put in their BISTRo Booklets to show they have attended.	22	Intervention Booklet	A patient-held booklet to record personal preferences and eating and drinking rehabilitation. Patients can also log daily progress, goals, and treatment plans.
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22	Intervention Booklet	A patient-held booklet to record personal preferences and eating and drinking rehabilitation. Patients can also log daily progress, goals, and treatment plans.																		
<b>When provided</b>	<b>Staff members, expertise, and training given</b>	<p>Expertise: The group requires one qualified member of staff; the others can be supporting staff or other qualified staff. At least one staff member should have expertise in stroke rehabilitation. Students can join the session when there are sufficiently experienced members of the stroke team present. Staffing combinations are the responsibility of each site.</p> <p>Training: All staff who deliver the intervention attended two training sessions lasting one hour. Topics included how to set up the room, key components of the intervention, the toolkit and its application, rehabilitation theory and components of clinical practice pertinent to the intervention. (These sessions were delivered by the researcher online or in person according to preferences and work commitments for this feasibility study).</p>																		
<b>How</b>	<b>Model of delivery</b>	There is a mix of professions each day delivering the intervention, between three and four according to the patient case mix. Staff are rostered each day to lessen the burden on one profession in the team.																		
<b>Where</b>	<b>Location, relevant infrastructure, and features</b>	The group is delivered near to or on the stroke ward. Sufficient space is required for the participants to sit at tables and mobilise to workstations where they can make their breakfast. Ideally, 2-3 participants should be making breakfast at once to ensure that they can sit together and socially dine after preparation.																		
<b>When and how much</b>	<b>Number of times delivered, intensity, schedule,</b>	The breakfast group runs Monday to Friday for 1-1.5 hours which includes bringing the patients to the room and settling them into the group and taking them back to the ward afterwards. Ten sessions were delivered over two weeks.																		

	<b>duration, or dose.</b>	
<b>Tailoring</b>	<b>How the intervention was tailored to the individual or site</b>	<p><b>Tailoring to site</b></p> <p>Each site had a different staffing model according to the skill mix of available staff and the needs of patients. Due to high levels of staff sickness attributed to the COVID-19 pandemic, staffing was pragmatic and flexible to accommodate last-minute changes in this feasibility study.</p> <p><b>Tailoring the intervention</b></p> <p>Participants had the flexibility to choose their breakfast items, and portion sizes, and there were no restrictions on drinks. At site 2, they could use personalized China teapots and homely patterned mugs for making tea.</p> <p>Food and drink items were clearly labelled with aphasia-friendly stickers. When packaging posed challenges, staff transferred the contents to other containers, such as decanting jam into ramekins, to facilitate self-service for participants. Each site had access to different products.</p> <p>To make the intervention more meaningful, participants were given opportunities to prepare a variety of breakfast foods. They were also encouraged to bring in their own tea bags and fruit to complement the meal. Rehabilitation teams continuously adjusted how participants received their breakfast to ensure personalisation and alignment with individual treatment programs.</p>
<b>Modify</b>	<b>Describe any modifications</b>	<p>The physical environment at each site was modified until the team members were satisfied with the layout. This involved moving workstations and getting additional equipment to avoid queues.</p> <p>Seating plans were adjusted to place patients next to each other to support communication needs as well as accommodate preferences and build rapport.</p> <p>The Patient Booklet was iteratively adapted according to feedback from participants and staff. Three versions were created during field testing.</p>
<b>How well Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve</b>	<p><b>Intervention adherence</b></p> <p><b>To what extent was the intervention delivered as planned</b></p>	<p><b>Adherence:</b> All participants were offered 10 breakfast sessions. 142 sessions were attended from the available 160. An average of 9 sessions were attended.</p> <p><b>Fidelity:</b> The ethnographic observations were designed to assess how well the intervention adhered to the intervention training manual. The intervention was delivered on three sites as planned. The recruitment targets were met for patients and exceeded significantly for staff as more staff wanted an opportunity to participate in the study than anticipated. A larger cohort of staff also gave the flexibility of the site for staff absence and low staffing levels as a result of COVID-19. Originally it was planned that the prototyping in each site would be spread out to allow for</p>

fidelity,  
describe  
them.

sufficient time for feedback and iterating. Due to COVID restrictions, staffing and an unscheduled ward move (site 3), the order that the site's prototyping was re-arranged and the time in between each test were concertinaed. This didn't impact the sites but impacted the research team and the time they had to turn around iterations for testing much quicker.

#### 7.4 The implementation toolkit the purpose of each item, how it was used in prototyping and implications for the final version.

In prototyping, it is usual for items to be developed for testing (Lambeth and Szebeko, 2011). These are called 'mock-ups', working drafts of ideas which can be tested and iteratively improved or abandoned due to lack of suitability (Lambeth and Szebeko, 2011). 'Toolkit' is an umbrella term for a collection of specifically designed mock-ups to support the delivery of an intervention (Sanders *et al.*, 2014). Toolkits originated in design-led participatory research. Mock-ups are usually 2D or 3D components such as documents, pictures, and resources (Sanders *et al.*, 2014). In codesign research the toolkit items are often called 'artefacts' and end users would contribute to the development of artefacts for prototype testing (Sanders *et al.*, 2014). Mock-up is the preferred term used for the items in the implementation toolkit that are being tested for feasibility and acceptability.

During BISTRo an implementation toolkit prototype was developed with 21 mock-ups. The contents of this were listed earlier in Table 10.

- **Purpose-** mock-up description and the intended purpose of each item.
- **How was the item used in prototyping-** any site-specific adaptations or modifications
- **Implications-** learning from the prototyping on sites 1-3 and implications for version 3 of the BISTRo Toolkit.

Data to inform this analysis was collected from participant interviews, focus groups, observations, and the intervention log book.

The toolkit has three components which are discussed below:

- 1) Mock-ups for staff to prepare for BISTRo delivery.
- 2) Mock-ups for staff to deliver the BISTRo intervention.
- 3) Mock-ups for patients to use during BISTRo.

#### 7.5 Toolkit Mock-ups 1) Mock-ups for staff to prepare for BISTRo delivery

##### 7.5.1 Mock-up 1 & 2 Standard operation procedure and COVID risk assessment

- i) **Purpose:** Stakeholders were concerned about what barriers might arise as a result of COVID-19 restrictions and what to do in the event of a COVID-19 outbreak. In response, two documents were codesigned to assure the delivery team and senior managers that all necessary safety procedures were being taken to prevent cross-infection and manage risk. A Standard Operating Procedure (SOP) and risk assessment designed to meet

general COVID-19 restrictions and advise staff on the ways to adapt the group in the event of COVID-19 escalation. The contents of the documents could be used in their entirety or adapted to site-specific documentation.

ii) *How was the item used in prototyping:* Site 1 received a visitation from an infection control nurse in the first week of delivery. Modifications were made to the organisation of the tables which satisfied infection control guidance such as single-use items (Figure 1). Site 2 and 3 shared the risk assessment and SOP with senior managers but no further requests were made for information or changes.

iii) *Implications:* Despite concerns about infection control risk from the clinical teams no further issues were raised, and NHS managers seemed satisfied by the evidence of a risk assessment and SOP document being available. While pandemic conditions were still impacting the NHS an escalation approach was taken in response to local infection rates. A risk management strategy was advisable to ensure that participants were safe and protected and any changes to infection control guidance did not impact programme delivery.

#### 7.5.2 Mock-up 3 &4 Training Manual and training slide decks

- i) *Purpose:* The training manual was developed by the stakeholder group to help the healthcare professionals deliver the intervention. It starts with the aim of the study and a description of the intervention, the working assumptions for the intervention and the inclusion/ exclusion criteria. The guidance describes the preparation required on the day of the intervention and the key components of the intervention the fixed and the components which can be tailored. It also guides the principal investigator on the research activities. The training manual is accompanied by two training PowerPoint packs. The Chief Investigator used the training manual in the delivery of two training sessions using the slide decks.

Training Pack 1 introduces the study. What the literature says about the topics and describes some of the potential benefits. It also describes the theory of change and the key intervention components. It gives instructions on the research elements of the study, on the day planning and how to use the contents of the toolkit. Concluding with how feasibility and acceptability are being assessed.

Training Pack 2 outlines the utilisation of the patient booklet within the intervention. It covers outcome measures and the underlying theories, including social learning theory, goal-setting theory, self-efficacy theory, and peer support theory. The pack serves as a refresher for clinicians on essential principles of neurological rehabilitation, self-management, compensatory approaches, neurological rehabilitation methods, and the 'What Matters to You' approach. Additionally, it emphasises being mindful of clinical presentations such as upper limb and subluxed shoulder issues, communication difficulties, fatigue, cognition, and perceptual deficits.

- ii) *How was the item used in prototyping:* The manual was used in the training sessions to prepare healthcare professionals for delivering the intervention. The training packs were



delivered to all healthcare professional participants after they consented to participate in the study via a mixture of in-person and online sessions. Sessions were offered over two weeks before the intervention was delivered. The site Principal Investigators (PI) ensured that all consented staff attended both sessions.

Sites 1 and 2 found it relatively easy to get staff signed up for the hour sessions. According to staff availability and COVID restrictions, some staff attended in person and some sessions were delivered online using Microsoft Teams. Site 3 had more difficulty getting staff signed onto sessions. This site also had nursing support staff joining the project and they found it more difficult to access training due to work commitments. To address this the CI offered some evening sessions online and three support workers joined online evening sessions to receive the training.

- iii) **Implications:** A flexible approach to providing the training using a hybrid of online and in-person sessions made compliance easier. It also meant that nursing support staff could be recruited to the study, and this is something that sites 1 and 2 struggled with and didn't manage to achieve. Several additional training needs were identified during staff focus groups that were not covered in the training slide deck, for example, several speech and language therapists highlighted that they would benefit from more training on moving and handling including facilitation of the upper limb. Future studies should consider the exploration of training needs.

Figure 24: Image of the training manual.



(Image sources: Natalie Jones 2022)

#### 7.5.3 Mock-up 5 Do not disturb sign

- i) **Purpose:** Door signs were created in response to stakeholders' concerns about interruptions during the group. From previous experience, interruptions were thought to be disruptive to the therapeutic group process. Two copies were provided in the toolkit.
- ii) **How was the item used in prototyping:** Site 1 used the signs. They reported that it did limit the number of people coming in and out of the room while the group was in progress. Site 2 did not use the signs as they felt that the open plan layout



negated the use. During the ethnographic observations nursing staff were regularly dropping into the group to give patients medication and do vital observations such as blood pressure. Field notes reflect that this did not appear to disrupt the flow of the group and the nursing staff joined in the conversation at the tables and chatted with patients naturally. Site 3 was not able to use any signs which needed to be fixed to walls or doors after they were relocated to a newly decorated unit.

- iii) **Implications:** There was an absence of comments about distractions and disruptions to the group which may indicate that this was not a problem. There was a consensus with the stakeholders that a door sign would minimise disruption and that this could be left to the site's discretion.

Figure 25: Image of the door signs introduced to minimize distractions.



(Image sources: Natalie Jones 2022)

#### 7.5.4 Mock-up 6 First-up Boards

- iv) **Purpose:** First-up boards were a solution to ensure patients were ready on time for the breakfast group. First-up Boards are A3-sized cards for recording the names of participants in the BISTRO study who need to be up, washed, and dressed first in preparation for the breakfast group (Figure 4). Sites were issued with 10 cards, one for every day of the study. The cards were designed to be displayed in ward areas where staff coordinating the day's activities could refer to them.
- v) **How was the item used in prototyping:** Site 1 used the First-up Boards as a visual prompt for the rehabilitation team in the nurse's office. Site 2 reported they did not need to use the boards as nurses used their whiteboard and handover sheet to identify patients for the group. They also had a team WhatsApp group to communicate on the day. Site 3 used the boards in week one but halfway through the programme they moved to a new ward and following this, boards were not allowed. They were forbidden to use the boards or stick anything on walls or doors. Site 1 and Site 3 had one member of therapy staff working an early shift at 7am so they were able to join the nursing handover and communicate breakfast group plans.

- vi) **Implications:** Sites did not rely solely on the first-up board for communication. As different nursing staff were on shift each day it was important to have a variety of methods as well as several visual prompts to remind staff about which patients to get ready for the breakfast group. In site 3 the therapy staff were part of the nursing team getting patients up, washed and dressed. In site 2 the nursing staff were the main staff group getting patients ready and in site 1 there was a mixture of nursing and therapy staff getting patients ready.

Despite the variation in staffing model having a range of communication methods seemed to be the most effective way to ensure patients were ready on time for the group. The most successful methods appeared to be putting names on the electronic or paper nursing staff handover sheets and a member of the therapy staff attending the ward handover meetings to plan the day. The first-up boards were not a necessary part of the toolkit although some found them helpful. A future recommendation is for the clinical team to have a clearly defined communication process for ensuring the relevant patients are ready for the group.

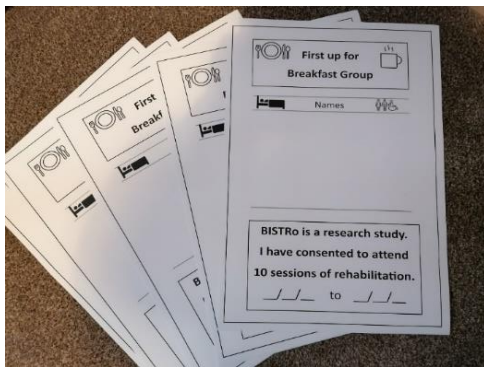


Figure 26: First-up boards used to ensure consented patients were ready to come to the breakfast group at a specific time.

(Image sources: Natalie Jones 2022)

#### 7.5.5 Mock-up 7 Environment Checklists

- i) **Purpose:** The environmental checklists were codesigned for healthcare professionals to guide the set-up of the BISTRO intervention as well as standardising the set-up across three sites.
- ii) **How was the item used in prototyping:** The checklists were used in all sites initially. Sites 1 and 3 had a consistent staff member managing set-up so it was easier to remember without having to refer to the list. Site 2 had more staff rotating so they used the checklist intermittently. All three sites reported that they adjusted the room set-up according to learning from each day. Site 1 experimented with different workstations and utilised the space more economically. Site 1 and 2 needed to get more tables and equipment to create more workstations for food and drink preparation. Specifically, to meet the requirement for avoiding cross-contamination for people on gluten-free diets. The process of room set-up was iteratively making changes and improvements to suit the tasks and patients each day. Site 1 and 2 also discussed the need for a seating plan to ensure that patients were seated with people and that they had something in common. Seating plans were adjusted as the staff got to know the patients and their abilities.

- iii) **Implications:** The environmental checklists were a useful tool to get the programme established. Findings suggest that checklists are specific to the site and developed locally. The checklist works best if iteratively adapted according to site specifications and learning how best to organise the room as the intervention continues. A modifiable template was included in iteration 1.

Figure 27: An environment checklist



(Image sources: Natalie Jones 2022)

#### 7.5.6 Mock-up 8 Checklist for equipment

- i) **Purpose:** The equipment checklists were codesigned to ensure that a range of eating and drinking equipment was available for patients. It was also a method of auditing what equipment was available on each site for the group. The checklist tool was created specifically for each site.
- ii) **How was the item used in prototyping:** The checklist was used in the first few days but after that, it was not required as all sites created a tray or box of items which they got out each day. During observations at site 1, a clinician noted the scarcity of equipment such as plate guards, adapted cutlery and drinking cups. Observations in site 1 noted that patients were observing other patients using adapted cutlery and asking to try it out themselves.
- iii) **Implications:** Although all sites had a small selection of specialist eating and drinking equipment available BISTRO highlighted the need for more. Staff were making lists of equipment they needed e.g. extra toasters and kettles as well as more adapted specialist equipment such as specialist cups, plates, and cutlery. Having the equipment available meant that it could be introduced when required and this was thought to be beneficial for staff and patients. Therefore, a recommendation for BISTRO version 3 is that equipment checklist templates are included that can be adapted for site-specific equipment.

Figure 28: Equipment checklists were modified for each site.



(Image sources: Natalie Jones 2022)

#### 7.5.7 Mock-up 9 Room Set-up Slide Deck

- i) **Purpose:** The room set-up photos were a systematic plan of how to set up the room to aid staff in delivering the intervention and provide some continuity for patients.
- ii) **How was the item used in prototyping:** The pictures were thought to be helpful although having a consistent member of staff on each day was also useful. Workstations were tables set up around the room for participants to mobilise to make food and drink. Each site set up the stations differently according to space and resources available. Workstations were developed over several days through a process of trial and error to figure out what was needed and where. Staff modified the set-up according to the popularity of stations e.g., started with one toaster and moved to two toasters to avoid queuing. All sites had a kettle and drink-making facilities, a toast-making station, and a microwave for porridge.
- iii) **Implications:** The main problem was not enough food and drink-making equipment. Two out of sixteen participants mentioned queuing as a negative experience. Additional workstations were required for gluten-free diets which added to the need for more equipment. Site 1 focus group discussed the issue of queuing and how they were trying to get more toasters and another microwave to lessen the bottleneck. Observations in site 1 also noted that queuing also impacted conversation as the patients were eating at different times and unable to engage in conversation while they were up making breakfast. The organization of the workstations in all three sites was an evolving learning process, making changes and adapting over time. All three sites started to create 'wish' lists for more equipment.



Figure 29: Room set-up photos for the training manual.

(Image sources: Natalie Jones 2022)

#### 7.5.8 Mock-up of 10 Table cloths

- i) **Purpose:** The tablecloth was a suggestion from the stakeholder group to make the room feel more 'homely'. Wipeable tablecloths would also be helpful for spillages. Six were brought for the study.
- ii) **How was the item used in prototyping:** All sites used the tablecloths. Several patients were observed to comment on how they were bright and colourful (Field Notes 1 and 3). One patient commented on how it was '*ok to make mistakes because of the wipeable surface*' (site 3 field notes patient).
- iii) **Implications:** Brightly coloured tablecloths are recommended for use in future interventions.



Figure 30: Brightly coloured wipeable tablecloths.

(Image sources: Natalie Jones 2022)

### 7.6 Toolkit Mock-ups 2) Mock-ups for staff to deliver BISTRo intervention

#### 7.6.1 Mock-up 11 6-CIT Cognitive Assessment

- i) **Purpose:** The 6-CIT is a standardised assessment for cognition. (<https://patient.info/doctor/six-item-cognitive-impairment-test-6cit>). It has six questions and takes 3-4 minutes to administer. It was used to screen for cognitive deficits which might preclude a participant from taking part in the intervention.
- ii) **How was the item used in prototyping:** Although the 6-CIT helped assess cognitive function it was found to not be suitable for use with people who had communication difficulties or learning disabilities.
- iii) **Implications:** Clinicians relied on clinical reasoning and team discussions to agree on suitability for the group. Future studies would need to consider screening assessments that were suitable for people with communication difficulties.

#### 7.6.2 Mock-up 13 BISTRo Eating and Drinking Assessment

- i) **Purpose:** The eating and drinking assessment was codesigned by the stakeholder group to ensure that participants in the study had a comprehensive and person-centred assessment of their needs before starting the group intervention. The assessment was a conversational tool for health professionals to record patients' abilities, preferences, and stroke impacts that affect eating and drinking performance. The assessment was designed with a focus on 'what matters to you'. The assessment was a baseline view of



patients' abilities before commencing the programme and to facilitate the completion of the patient booklet.

- ii) **How was the item used in prototyping:** All three sites reported that they did not refer to the assessment once it was completed to inform the delivery of the group. References to it were absent from the patient interviews and staff focus groups. One staff member described repetition between the assessment and the booklet as a duplication of information.
- iii) **Implications:** A suggestion from the staff focus group on-site 2 was that the assessment was combined with the patient booklet as this was used every day and was a reference point for patients. To avoid repetition for the patients and duplication of staff the patient assessment and booklet were combined in BISTRo version 3.

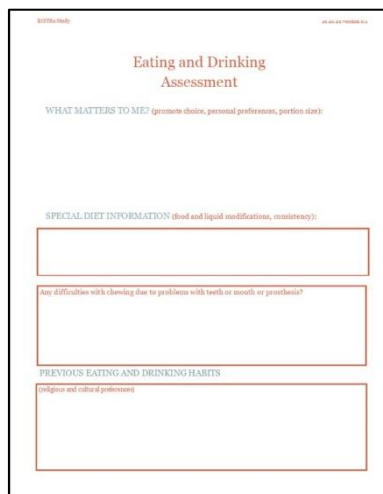


Figure 31: BISTRo eating and drinking assessment.

(Image sources: Natalie Jones 2022)

### 7.6.3 Mock-up 14,15,16 Aphasia guidance on supported conversation, topics for conversation ice breakers and word of the week resources (WOW).

- i) **Purpose:** Stakeholders thought that the staff leading the breakfast group might need some conversational tools to support conversations or to get conversations going. Resources from 'Word Of the Week' [23rd June.pptx \(live.com\)](#) (WOW) were included in the toolkit as all three sites have access to this resource. WOW is an online collection of weekly resources about news events and topical media which can be downloaded. It includes resources and pictures to facilitate conversation. The stakeholders also suggested some icebreaker questions and the researcher searched for some separately on the internet. These resources were put together in a pack in the toolkit box. This was joined by supported conversation guidance with was taken from Site 1 Speech and Language Therapy resources.
- ii) **How was the item used in the prototype:** The WOW resources were put out on the table in site 1 and site 2 however they were only observed in use once. The icebreaker questions were not observed in use in six observations. Although the stakeholder group thought conversational tools would be needed in the prototyping there did not appear to be any issue with conversations getting started. Quite quickly participants were chatting amongst themselves and asking each other questions. Field notes show that conversation ebbed and flowed but

this was mainly due to people eating and drinking rather than an absence of what to talk to each other about. Conversations were broad and diverse.

- iii) **Implications:** Although resources to facilitate conversations were deemed beneficial by staff, they were not consistently utilised across all three sites. Nevertheless, the stakeholder group believed that these resources should still be incorporated into version 3 of the toolkit for staff reference.

#### 7.6.4 Mock-up of 18 Large Food product labels

- i) **Purpose:** Product stickers were a suggestion from the stakeholder group as a method of ensuring that patients with difficulties reading English would be able to identify food and drink products independently. This was also a method of identifying gluten-free products. It was important to a stakeholder that people with aphasia or non-English speaking participants were able to use food and drink products as independently as possible. The group decided on a list of items which would be frequently used at breakfast, and this checked with the site housekeeping teams to ensure that the correct products were on the list.
- ii) **How were the items used in prototyping:** Each site has a set of site-specific stickers in A4 sheets. The stickers were used on all sites.
- iii) **Implications:** There was no mention of the stickers in the stroke survivor interviews or the staff focus groups although in the observations there was evidence of them being used regularly. The stickers cost £54.00 to produce, they were costly, but they seemed to be helpful for patients. Once the template is set up it would be possible for sites to make up and print themselves. Therefore, inclusion for future kits is recommended for version 3.



Figure 32: Large food product stickers to identify products.



(Image sources: Natalie Jones 2022)

## 7.7 Toolkit Mock-ups 3) Mock-ups for patients to use in the intervention

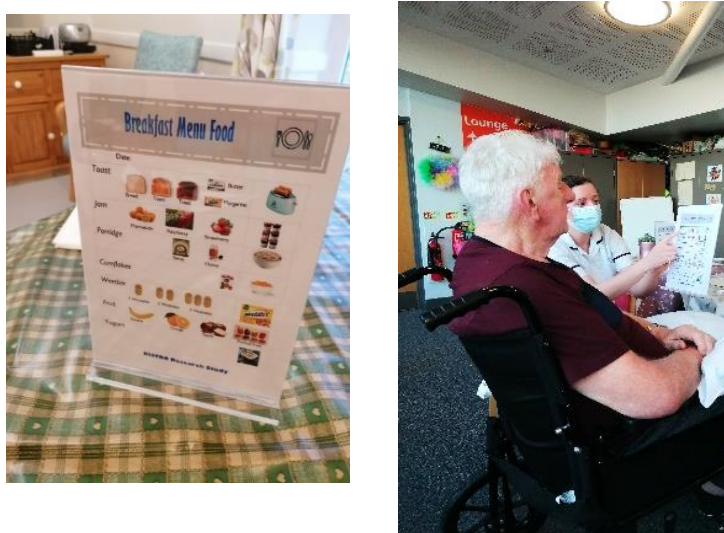
### 7.7.1 Mock-up 19: Menus

- i) **Purpose:** The stakeholder group suggested that there was an aphasia-friendly menu for each site which included the available food products. It quickly became

evident that a different menu was required for each site as access to products varied.

- ii) **How was the item used in prototyping:** The menus were opportunities to promote choice so that conversations would take place about what people could make for breakfast. It was also a way to show participants what was on offer. In the stakeholder consultations, there were stories of patients being given lists of foods and them saying the last one on the list as it was the one, they could remember. Pre-intervention observations (site 1) observed a patient eating porridge that they didn't like because they were unable to articulate what they wanted.
- iii) **Implications:** The menus were found to be useful in most cases until participants were familiar with the choices. They were used with people who had aphasia and observation notes patients coming into the room sitting down and picking up the menus just like they would in a restaurant. Speech and language therapists valued the ability to use them to support conversation. Recommendation to include menus in version 3.

Figure 33: Aphasia-friendly menu.



(Image sources: Natalie Jones 2022)

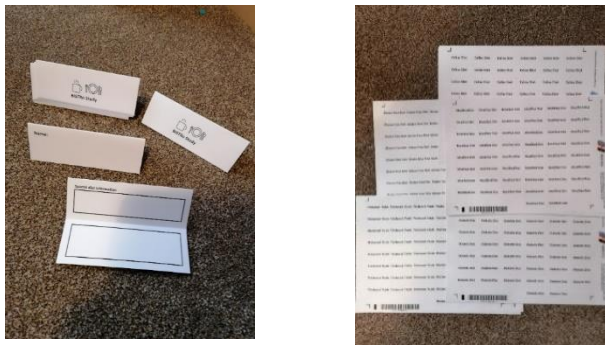
#### 7.7.2 Mock-up 20 & 21 Place name cards and small diet stickers

- i) **Purpose:** The place name cards were a suggestion by an Occupational Therapist who has recently attended a wedding and thought the idea was transferable to the breakfast group. The concept behind this was a way to ensure the group knew each other's names and that the staff delivering the sessions would easily learn patients' names. The idea to put details of how people liked their beverages came from a stroke survivor as a suggestion to avoid unnecessary questions e.g. how you like your tea, on multiple occasions. This idea was developed to display the



- details of special diets so that this information could also be discreetly and easily accessed. Although systems to identify specialist diets were in evidence (pre-intervention observation field notes site 1) staff discussed that they often had to check and double-check patient notes or sheets and this way the information was more readily to hand.
- ii) **How was the item used in prototyping:** The cards were used on all three sites in every session. Information such as preferences for drinks, diet and full modifications written on the inside of the place name card or the toolkit stickers were used. Staff in all three focus groups liked the place name idea and how it helped them remember dietary specifications.
  - iii) **Implications:** Staff frequently referred to the cards during sessions to check on preferences and special dietary needs. This tool was valued by both staff and patients and was included in version 3 of the toolkit.

Figure 34: Place name cards and dietary modification stickers.



(Image sources: Natalie Jones 2022)

### 7.7.3 Mock-up 21, Stickers

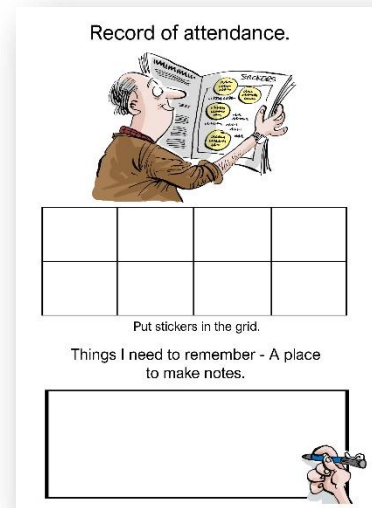
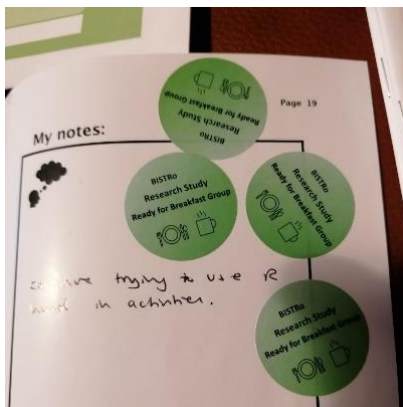
- i) **Purpose:** Stickers titled '*I'm ready for breakfast group*' were a solution to the problem of patients listed for the breakfast group not getting ready on time. The stickers were designed to be worn on clothing as a visible reminder to staff about the breakfast group (Figure 36).
- ii) **How was the item used in prototyping** In site 1 the stickers were used as predicted. Staff forgot to offer them to participants before the group and so they were not used as a first-up strategy. Instead, they were offered to patients during the session to stick in their books as a visual reminder that they had attended the group Figure 17. This use of the stickers spurred several patients to ask for a star sticker to put in their books as a stamp for attendance. In Version 2 of BISTRo, a star sticker was created for testing in sites 2 and 3 that could be used as an attendance sticker and space was created in the booklet for a section to add the star stickers (Figure 36 Iteration 2).
- ii) **Implications:** Stickers were appreciated by some patients. Others thought they were unnecessary and 'childish'. A stamp or sticker for attendance was appreciated by the majority of patients and therefore should be included in BISTRo version 3 (Figure 36 Iteration 3).

Figure 35: Ready for breakfast group stickers, star stickers and stamp of attendance.

Iteration 1

Iteration 2

Iteration 3



(Image sources: Natalie Jones 2022)

#### 7.7.4 Mock-up 22, Patient Booklets

- i) **Purpose:** The patient booklet was designed to be a daily record of the patient's breakfast group experience as well as to record personal preferences, abilities, goals, and treatment programme. Patients could write their logs or staff would write for patients in the patient's own words. The book was designed to be a visual prompt that could be taken home when they leave the hospital as it included a section on things to would be useful to remember. It was also a place to record the outcome measures which were completed at the beginning and end of the programme.
- ii) **How was the item used in prototyping:** The booklets were used to record a daily account of the programme.
- iii) **Implications:** The booklet generated a significant amount of feedback data and surprisingly was seen as pivotal to the intervention process. The main positive feedback was that patients liked the daily log as they had a visual record of their goals being achieved (see Appendix 21 for some images of the booklet).

Iteration 1 & 2

Iteration 3

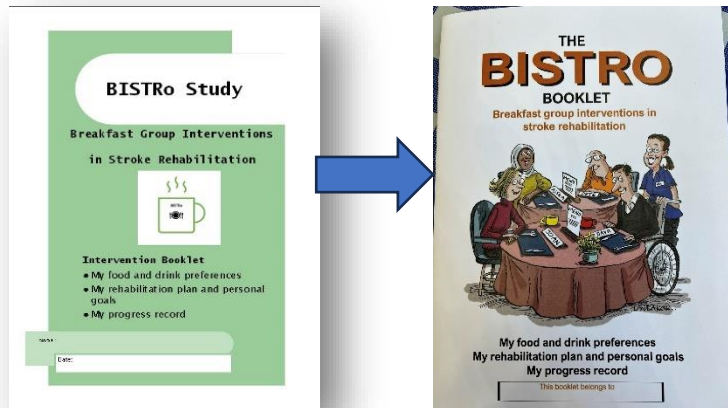


Figure 36: BISTRO Booklet Version. Iteration 1 was tested in site 1, this was iterated into version 2 for testing in sites 2 & 3. Version 3 was developed after site 2 and 3 prototyping.

(Image sources: Natalie Jones 2022)

#### 7.7.5 Summary

This Chapter described how Hawkins' Framework (2017) was iteratively used to develop the prototype intervention and toolkit. The characteristics of the participants in the prototyping were presented and a description of the intervention and implementation toolkit items was given. The knowledge gained was deployed in the creation of a final intervention and toolkit.

## Chapter Eight: Hawkins 3-stage framework: stage-3 Prototyping Part 2

### Summary of Chapter

This Chapter comprises five sections.

- 1) Utilises the Sekhon Theoretical Framework of Acceptability (2017) to report the results pertaining to the acceptability of the intervention as perceived by both staff and patients.
- 2) Explores the feasibility of the intervention and toolkit through the application of the Tickle-Degnens Framework (2013).
- 3) Examines the potential benefits of the intervention.
- 4) Refines the logic model.
- 5) Discussion and reflections from prototyping.

### 8.1 Sekhon's Theoretical Framework of Acceptability (TFA)

There is growing recognition that the concept of 'acceptability' is a critical consideration in the design, evaluation, and implementation of complex healthcare interventions. However, the published literature provides limited direction on how to assess acceptability. Sekhon's research (2017, 2018) aims to provide researchers with a theoretical framework which encompasses multiple constructs for assessing the acceptability of healthcare interventions. This framework is designed to evaluate the anticipated and experienced acceptability, considering the perspectives of both the deliverers and receivers of the intervention.

The Theoretical Framework of Acceptability (TFA) comprises seven constructs which are organised alphabetically. The extent to which they cluster or influence each other has yet to be defined. Sekhon and coauthors (2017) propose quantitative and qualitative research methods that can be used to assess the acceptability of an intervention during the development and feasibility phases. Qualitative methods might include semi-structured interviews and focus groups which should focus on the acceptability of the content and the methods of delivery. Quantitative methods might include rating scales such as satisfaction measures with potential intervention deliverers or receivers and, attrition rates and discontinuation reasons (Sekhon et al., 2017). In this research study, a combination of methods were employed to evaluate acceptability (see Table 11).

Table 11: Overview of the research methods used to evaluate acceptability.

Method	Development and Feasibility Stage
Quantitative	<ul style="list-style-type: none"><li>• Number of attendances</li><li>• Attrition rates</li><li>• Reasons for non-attendance</li></ul>
Qualitative	<ul style="list-style-type: none"><li>• Semi-structured interviews with patients who received the intervention</li><li>• Focus groups with staff who delivered the intervention</li></ul>

The seven constructs in the TFA 1) effective attitude 2) burden 3) ethicality 4) intervention coherence 5) opportunity costs 6) perceived effectiveness 7) self-efficacy, were used to guide data analysis and provide a structured way to organise and present the data from the interviews and focus groups. The table below illustrates each construct and the key themes identified from the data which will be discussed below (Table 12).

Table 12: The seven constructs of acceptability in relation to findings from prototyping.

Theoretical Framework of Acceptability						
<b>Affective Attitude</b> <ul style="list-style-type: none"> <li>• Sufficient equipment and environment</li> <li>• Sustainability</li> <li>• Enjoyment</li> <li>• Routine</li> </ul>	<b>Burden</b> <ul style="list-style-type: none"> <li>• Staffing</li> <li>• Fatigue</li> </ul>	<b>Ethicality</b> <ul style="list-style-type: none"> <li>• Food culture</li> <li>• Diversity</li> </ul>	<b>Intervention Coherence</b> <ul style="list-style-type: none"> <li>• MDT working</li> <li>• Knowledge and skills</li> <li>• Intensity</li> <li>• Peer support</li> <li>• Social Dining</li> <li>• Psychological support</li> </ul>	<b>Opportunity Costs</b> <ul style="list-style-type: none"> <li>• Economic impact</li> </ul>	<b>Perceived effectiveness</b> <ul style="list-style-type: none"> <li>• Intensity</li> </ul>	<b>Self-efficacy</b>

\*Adapted from Sekhon’s Theoretical Framework of Acceptability (2017).

### 8.1.1 TFA Construct 1 Affective Attitude

Affective attitude is the first construct of acceptability, which describes how an individual feels about the intervention (Sekhon 2017).

#### 8.1.1.1 Having sufficient equipment and environment

During the interviews, all 16 patients were questioned about their opinions regarding the breakfast group. The majority of patients did not express any dislikes. However, two patients mentioned their dissatisfaction with the need to wait in line for equipment like toasters and microwaves, which caused delays in receiving their breakfast. This is exemplified by one patient expressing concern about the timing of her breakfast in relation to her medication

*“I am diabetic and sometimes it was a little bit late, as I am taking medication. I pity those who can't talk. What time do they take their medicine? They can't say ‘I need to take it’. I did not want it to be late”. Site 1 Patient Participant.*

During the focus group at site 1, a staff member expressed their dissatisfaction with the limited space available, which aligned with the concerns raised by patients regarding queuing to use equipment. This contrasted with site three, which had four patients and did not raise similar concerns. Site two on the other hand had a significantly larger room allowing them to establish three workstations with sufficient spacing between them. When

asked about the environment one of the occupational therapists said that this would be a priority for change.

*“I’d change the space, I’d have it in a bigger room and maybe think about the wider environment, so making sure there was enough space for things. We’ve got a good set-up for patients now because it seemed to be quite cramped with the tables that we had for the breakfast items before”. Site 1 Focus Group Occupational Therapist.*

Based on feedback from patients and staff, additional tables, kettles, and microwaves were procured by clinical teams. This allowed a greater number of patients to simultaneously prepare and enjoy breakfast together. To ensure smooth group activities in the future, it is crucial to address room layout, accessibility, and equipment planning before the group begins.

#### 8.1.1.2 Feelings about the sustainability of the Breakfast Group

The issue of the breakfast groups' long-term viability was a topic of discussion in all three focus groups. In sites 1 and 3, staff members expressed feelings of sadness regarding the study's conclusion. This led to contemplation among the staff about the possibility of continuing to provide the intervention even after the study's conclusion these conversations mainly revolved around patients expressing their strong desire for breakfast groups to continue as illustrated in the following quote.

*“I think they were quite sad when the study finished because they had built up that rapport, that confidence and I think it was a shame”. Site 3 Focus Group.*

The main motivations for desiring the continuation of the breakfast group included that it was something to look forward to and the joy experienced during interactions with other patients. Both staff feedback and ethnographic observations revealed a strong desire for individuals to participate in the breakfast group. Several expressed a reluctance to miss the group, even if they had initially had some reservations. The following example from a participant interview helps to illustrate the sentiments.

*“I had a really bad night last night and I was determined in the night that I wasn't going to go to breakfast club, I was going to send a message down with one of the nurses that I wasn't going, and I didn't feel up to it. But I had to go, to work through the things that we do in there, yes, I was glad I went this morning. It was a real eye-opener; it was just what my state of mind this morning needed”. Site 3 Patient Participant Interview.*

When questioned about their opinions on breakfast group participants several participants expressed the view that the opportunity should be extended to other patients. They suggested that it should be offered at various meal times or extended beyond the study's two-week period. The following quote emphasises the perceived value of these interactions with fellow stroke survivors, which was considered to be beneficial.

*“I thought it was a wonderful idea, I think it should be spread out to other meal times. People are in their rooms for hours and hours. It's someone to talk to*

*that's in the same boat so it doesn't matter. Everyone has similar problems, I enjoyed it, it's a good idea". Site 1 Participant Patient Interview.*

One participant conveyed his astonishment regarding the positive outcomes he experienced from the group. He specifically appreciated that it provided him with a positive start to the day and made everything more bearable.

*"Yeah, I honestly thought I would get nothing out of it at all and it was the complete opposite, really good. There was more communication, it was just better, and it opened up a different side. It made everything more tolerable. Everything was just more normal, and it made a difference to the rest of the day because it was a lively start to the morning". Site 2 Participant Patient Interview.*

Another method of understanding acceptability was analysing attendance and attrition data (Table 13). The group's attendance exceeded initial expectations, particularly considering the challenges posed by the COVID-19 pandemic. Details regarding meeting attendance and the reasons for non-attendance can be found in the table below (Table 13). On average, each patient attended nine sessions. Given the nature of the acute stroke ward, it was expected that some stroke survivors might occasionally be unwell and unable to attend. Two patients had experienced falls unrelated to the study, temporarily preventing their participation. The primary reason for non-attendance was patients being discharged home, with two individuals discharged before the completion of the two-week programme. Additionally, site 3 only operated for nine out of the 10 days due to an unforeseen ward relocation.

Table 13: Study breakfast group attendance data.

Meeting attendance	Site 1	Site 2	Site 3	Totals
Mean number of attendance at group	9.5	9.5	8	9
Reasons for non-attendance	3 sessions missed  1=headache 2= not slept & fatigue	7 sessions missed  3= Feeling unwell 4= Discharged home before completion of the 2-week programme (Two patients)	8 sessions were missed 4= the ward was closed for 1 day for moving to another location- the intervention was not delivered on this day. 3= due to injury from a fall on the ward (Two patients) 1= Discharged home before completion of the 2-week programme	18 missed sessions  160 available sessions.  11.25% of sessions were missed.

Given the pragmatic nature of this study, it was decided during the early stages of ethical approvals that patients would not be kept in the hospital for the study. The study manual states that if patients were discharged home their place could be available to other patients who might be interested in participating. Since patients were at various stages in their recovery some were approaching their discharge to return home. However, in prototyping, these scenarios didn't arise, and the site continued with a reduced number of participants until the end of the programme. This decision was influenced by the lack of suitable participants and the fact that the assisting group had developed a strong bond, leading to the choice to proceed with the existing cohort.



#### 8.1.1.3 Feelings of enjoyment

Staff participants were asked about their positive impressions of the breakfast group intervention. Two staff members shared their opinions. One staff member provided insights from the patient's perspective, focusing on their observations of the patient's activities. The other staff member fed back on observations of staff-to-staff interactions and discussions about the breakfast group.

*“The patients love it. You could just see that they were getting a lot from being around the other patients, talking to each other every day, because people were looking forward to it”. Site 1 Focus Group Physiotherapists.*

*“I like that there is quite a buzz about it, you know in the multi-disciplinary team, the nurse that was doing MDT, every time they got to a patient that was in the group, they referred to it in the MDT and said this patient has really benefited from going to BISTRo club, so it does feel there's a bit of a buzz about it”. Site 1 Focus Group Speech and Language Therapist.*

A number of staff members became visibly emotional when discussing the group and their personal enjoyment of it. They discussed the positive influence on patients participating in the study, as well as the effects on their own participation in the group.

*“I thought it was going to be good because I have been involved in breakfast groups in other places, but I didn't expect it to be as changing for me as an OT as it was for the patients. I knew it was going to be good. I knew it was going to be worthwhile. I knew we were going to see changes but the bonding between patients, the intensity which helped them proceed through their goals despite being unwell was incredible”. Site 3 Focus Group Occupational Therapist 2.*

Further examination of the data in order to understand why the group was characterised as ‘transformative’ revealed several insights. Initially, Occupational Therapist 2 explained how she felt like she was a ‘proper OT’ during those two weeks. Intimating that her role in ‘hands-on’ rehabilitation was somehow diminished or lacking usually. She also explained how she got to know patients better by being part of the delivery team and as such had more consistent contact with them. She described how getting to know patients on a ‘deeper personal level’ changed her relationship with them and her approach to communication. She would allow them more time to communicate their needs and she recognised the significance of human interaction for the participants. These insights from her experience provide possible explanations for why other staff might have found the group enjoyable.

#### 8.1.1.4 Feelings about routine

Staff discussed how they appreciated the continuity of the group. The routine was helpful for the ward staff as this assisted in embedding daily planning to get patients ready on time. Staff also discussed how the patients appreciated the routine of getting ready for the breakfast group and how this created a daily rhythm with patients who started to initiate getting up and ready by themselves.

*“I think there is an organisation to it, but when you have got the organisation sorted, it works really well. I think you need that continuity if you have a gap, you lose patients, and they initiate themselves getting up because they know it's happening. Whereas I think if we didn't have it every day, I think we would lose momentum”. Site 1 Focus Group Physiotherapist 1.*

The site 2 focus group discussed how the routine of daily interventions was acceptable to patients and staff. Reasons for this included providing some normality which mimicked usual home routines and structuring the day as emphasised below.

*“I wonder as well if the routine helped, they all got up in the morning. They all went down to the breakfast room and normally in life you have some form of routine even if you're retired you might get up at the same time to read your paper or whatever. They got that routine in the morning. They were ready. They knew that there was a plan and maybe that translated into the rest of the day”. Site 2 Focus Group Occupational Therapist 2*

Patient narratives supported the view that a daily routine was acceptable. Patients focused on the value of social contact in motivating them to get up. The routine was thought to provide a sense of organisation and structure to the day. The quote below illustrates the distinction between days when the breakfast club was held and weekends. It is worth noting that the patient also mentioned the effort she put into dressing up for the group, implying that it was an occasion for dressing up.

*“I think every day is useful as it gives you that routine, into that day, because Saturday and Sunday for me were ‘no’ days, nought days, they didn't centre around anything. Whereas breakfast club days centred around something. I got up at a certain time, I got dressed up. I put something nice on 'cause I was going to mix with other normal people so I could dress normally, and it set me up for the day, all in all, it is an excellent, excellent scheme”. Site 3 Interview Patient Participant.*

This finding is emphasised by two further quotes. The idea of wanting to ‘look your best’, get up and get dressed for the group was also found in site 1 field notes and a site 2 patient interview. There are also field notes from site 3 describing how patients brought in clothes from home to ‘look nice’ for the group.

*“Well it gets you up and out and you are not stuck in bed, it's a reason to get dressed. You can sit and talk to people when you are fed up. You get depressed sitting there all day on your own”. Site 2 Interview Patient Participant.*

*Occupational Therapist 2 says “The women were dressed really well. In fact two of them would compete, they were putting skirts on, spraying themselves with perfume. It's an occasion”. Site 1 Field Notes.*

The daily routine of breakfast groups received predominantly positive feedback from both staff and patients, with no comments to suggest otherwise.

## 8.2.2 TFA Construct 2 Burden

Burden is the second construct, this is related to the perceived amount of effort (time/expense) required to participate in the intervention (Sekhon et al., 2017)

### 8.2.2.1 Burden of staffing

All three focus groups discussed staffing shortages, primarily attributed to the pandemic's impact. Some staff members who expressed interest were unable to participate, resulting in feelings of disappointment. At Site 1, a roster for group staffing was established and successfully implemented, although substitutes were needed on a couple of days due to staff illness. Site 3 acknowledged the need for a more structured approach, suggesting the implementation of a formal roster to avoid overburdening the site PI and another OT. Site 3's OT 2 proposed having a regular therapist each week to provide consistent support for the group, promoting patient continuity and a goal-focused approach.

One Occupational Therapist on site 2 discussed how hard it was to ensure there was enough staff for each day. The team has been affected by long and short-term sickness during the prototyping period. She acknowledged it was a challenge to staff every day, but a daily group was better for the patients. As she was the site coordinator for staffing the group perhaps, she felt this challenge more than other staff.

*"I think doing it every day was just a bit much. I think it would probably be better for the patients if it was every day. They enjoyed the routine of it, and I think the patients would probably say they want it every day". Site 2 Focus Group Occupational Therapist 2.*

In summary, having a rota to organise staff for the group and one consistent team member to cover each week was thought to provide continuity for patients and reduced the perceived amount of effort to run the group, lessening the burden on the team to provide the daily group.

### 8.2.2.2 Burden of effort related to fatigue

The data indicates that insufficient sleep has the potential to affect the desire to attend breakfast groups. In considering whether it is acceptable to have morning interventions, the CI considered attendance and attrition data and narratives related to fatigue. Several patients discussed the impact of fatigue and tiredness on their willingness to attend the group. One patient at site 3 expressed a strong desire to participate in the breakfast group, even when feeling exhausted.

In site 1, two patients missed a session due to an inadequate night's sleep. In site 2, two patients separately discussed difficulties sleeping in the hospital, attributing it to noise from fellow patients calling out in the night. They shared how this had a negative effect on their desire to attend breakfast group. During ethnographic observations, patients were frequently observed discussing tiredness and lack of sleep. Those who complained about sleep deprivation were shown sympathy by other patients. Although tiredness appeared to

be a factor in attendance, there were no indications that a morning eating and drinking intervention was unacceptable.

### 8.2.3 TFA Construct 3 Ethicality

The third construct is ethicality, the extent to which the intervention fits with the individual's values and beliefs Sekhon (2017).

#### 8.2.3.1 Food culture

Another aspect of acceptability to contemplate is whether patient participants consider the intervention to be culturally acceptable. None of the patients spontaneously raised or discussed any issues relating to food, culture, and religious beliefs. However, when asked specifically about this in the focus groups, two staff members in site 1 discussed culturally specific breakfast food the other sites did not offer any comments on this matter.

*"I wondered about different options for breakfast because I think different cultures have different things. It's a very British breakfast experience, cereals, and toast. I think that would be an interesting thing to investigate this a bit more". Site 1 Focus Group Occupational Therapist 2*

*Occupational Therapist 1 replies. "I know one lady said that they grind sweetcorn because they're from Nigeria. They take the sweetcorn kernels and grind it up into a powder and then they make a porridge out of that, so that would be like their morning breakfast. And then I'm sure she said they have crickets on top and that's their morning breakfast. But we do not offer anything outside the norm. I'm not saying that we can offer crickets".*

The lack of discussion or concerns regarding food, culture and religious practices could be related to there being only three out of sixteen participants from a non-British background. However, when patients were asked specifically about culture and food none of them raised any issues. Future studies should aim to recruit participants from diverse backgrounds to understand if there are any cultural or religious nuances.

#### 8.2.3.2 Diversity

An additional factor to consider is whether patients perceive the presence of fellow stroke survivors as beneficial or whether observing individuals with diverse disabilities was regarded as acceptable. In interviews, four patients pointed out that they observed varying degrees of disability amongst other patients, and this was seen as largely positive. Patients utilised the observed differences to assess and contrast their own recovery and progress with others, gauging whether they improved more or less than their peers. A patient from site 2 noted that despite the differences everyone seemed to get along well.

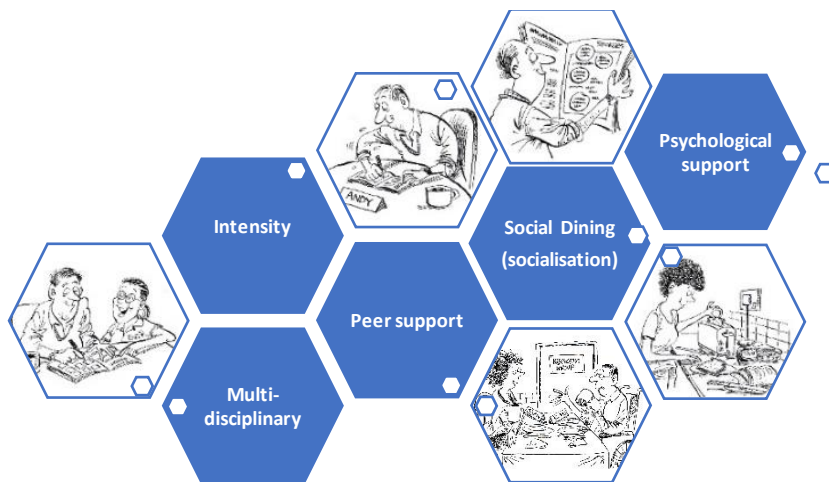
*"There was no looking down on anybody because maybe someone couldn't speak or maybe someone couldn't use their arm and so it was great, it was everybody together which made a big difference". Site 2 Patient Participant.*

Another patient from site 1 talked about everyone being ‘similar’ in their problems. A site 3 patient talked about seeing people with different problems and how fortunate this made him feel. A patient participant in site 3 also described the ‘diversity of people’ and how she drew comfort from this. She reflected that a stroke could affect people from all ‘walks of life’, and stroke does not discriminate who it affects. The diversity of the group was mostly seen as positive motivation, providing reassurance and inspiration.

#### 8.2.4 TFA Construct 4 Intervention coherence

Intervention coherence is the perceived level of fit between the components of the intervention and the intended aim of the intervention, the extent to which participants understand the intervention and how it works (Sekhon 2017). The five identified intervention components are intensity, multi-disciplinary, peer support, social dining, and psychological support as illustrated in Figure 38. To explore intervention coherence each intervention component is discussed in relation to relevant findings.

Figure 37: Five components of the BISTRo intervention.



##### 8.2.4.1 Multidisciplinary team working

The intervention presented a staffing model where staff would be rostered and rotated to deliver the intervention, thereby distributing the responsibility for daily implementation across a larger pool of staff. The team approach advocated for a multi-disciplinary model of care with staff working closely together from different professions. Both sites had a significant number of volunteers who consented to participate in delivering the intervention. A small number of staff were unable to take part in intervention delivery after consenting due to wider staffing issues or sickness.

Sites discussed the benefits of working collaboratively and how this had improved multidisciplinary teamwork. Working more collaboratively with other professions was seen as largely positive. An Occupational Therapist from site 1 discussed the collaborative approach and how this was beneficial for meeting patients' goals.

*“I think the positive thing for me, was that it brought us together in terms of an MDT. So it was like a really positive reason for us to work together and be collaborative about meeting our patient's goals and that was a really big success for me”. Site 1 Focus group Occupational Therapist 1.*

Site 3 Occupational Therapist 2 described how working closer together gave her a better understanding of colleagues' pressures. This was followed by a discussion about how team relationships had improved during the study period. This was attributed to closer working relationships breaking down some barriers that existed within the team. Relationships changed as a result of the therapy and nursing teams working more closely together which involved the sharing of ideas and an increase in supportive conversations. Understanding each other's pressures better and coming together in a collaborative effort had seemingly positive impacts. Another consequence of closer multidisciplinary teamwork was gaining a better understanding of colleagues' roles and the impact that this had on developing collaborative patient goals.

*“I feel closer to the other staff. I feel like I understand their job more. It's helped me with my sessions, thinking about what I can do. In other services that I have worked in you kind of get the team around the patient, it almost feels like we developed that because we were working together for the same goal that really helps”. Site 3 Field Notes Psychology Assistant.*

There were no examples of where team relations had changed negatively during BISTRO however it was a small sample size from the wider team and it's possible that staff may not have wanted to disclose any less-than-positive examples in a focus group setting.

#### 8.2.4.2 Knowledge and skills

Every staff member participated in a training programme for the intervention. In assessing whether this was acceptable and fit for purpose several aspects were identified. Field notes from site 1 revealed that some staff had expressed concerns about their understanding of thickened fluid protocols. Meanwhile, Speech and Language Therapists in sites 1 and 3 had reservations about their proficiency in handling upper limb movements. It is worth noting that the training packages for the intervention did not cover specific therapeutic moving and handling skills or thickened fluid protocols as this was an assumed level of knowledge for staff working in a stroke rehabilitation team. It's possible that additional training requirements existed but were not openly discussed, as staff might have felt reluctant to communicate their training needs with other colleagues. These matters warrant further investigation in future research.

#### 8.2.4.3 Intensity

The sessions were delivered according to the training manual and sites managed to address issues with staffing if they arose. Staff discussed the importance of daily routine and consistency, and patients appreciated the regularity of the intervention.

#### 8.2.4.4 Peer support

The intervention was designed to create a space for peer support. Eight of the patient participants spoke about peer support specifically and it was inferred in the other eight

transcripts. Peer support took several forms which are discussed in more detail in 'Perceived Benefits' below.

#### 8.2.4.5 Social Dining

Reflecting on the coherence of the intervention is crucial, particularly in assessing whether patients comprehended the social aspect of the group and felt at ease with therapeutic interventions, as well as eating and drinking in the presence of others. All patients expressed a preference for sharing breakfast time with fellow participants. Across all three sites, patients shared their feelings of loneliness when dining alone, emphasizing that conversations in shared rooms were not as fulfilling as those in the group setting. Observation field notes highlighted increased spontaneity and chattiness among patients as they became acquainted. The positive impact of social interaction with other patients emerged as a prominent theme, evident in 28 references across 13 data sets. The following example illustrates how relationships developed over a short period.

*"It's not just the physical stuff either you know. The social interaction, communication, and the conversation that they had. At the beginning of the week, they were all just finding their feet and getting to know one another, but then towards the end, we had patients who wouldn't have initiated the conversation, and they were sparking conversation with other patients. They all knew each other's names and they were saying 'Oh how have you slept?'  
Site 1 Focus Group Occupational Therapist 1.*

There is sufficient evidence to suggest that the patients found the social aspect of the group acceptable and valuable.

#### 8.2.4.6 Psychological Support

One of the aims of the intervention was to address the emotional and psychological issues that stroke survivors experience as a result of eating and drinking difficulties. It was anticipated that bringing people together would promote socialisation and peer support, potentially leading to a favourable effect on wellbeing. Staff in all three sites noted improved mood and morale of patients during and after attendance of the group. This quote illustrates when a fellow patient was feeling low, his peer offered encouragement and made a concerted effort to lift his spirits.

*"(Patient's name) was really upset because he did not know if he would see Christmas at home, but I said to him, it's a long time to Christmas. Here a week is a long time. So try not to be negative and put a bit of positivity in your head and think, 'I am going home for Christmas'. Hopefully, it stopped him crying and made him believe there were some other ways of looking at it. It's what I have done for myself really. It helps to share it with other people". Site 3 Interview Patient Participant.*

When low mood was identified by staff conversations took place to help patients reflect on their progress. The patient booklet was used as a reference point to illustrate progress and have conversations about progress. An example of this was a conversation between a Therapy Assistant and a patient in site 1 captured in field notes.



*(Patient's name) was very down on herself today. She was despondent about her abilities. The Therapy Assistant sat down to speak to her about her goals and went through the booklet showing her what she had achieved since she had been attending breakfast group.*

*The patient said, 'I have tried but not always succeeded'.*

*The therapy assistant was encouraging and said, 'But trying is the most important part'. The Therapy Assistant made the patient laugh by talking about her tea-making skills and as a rapport was built, they had a further conversation about what goals the patient would like to achieve and what she might want to achieve in the next breakfast group.*

*At the end of the conversation (patient's name) seemed to be in better spirits. Field notes site 1.*

Occupational Therapist 3 in the site 3 focus group remarked on how a good mood created in the breakfast group seemed to carry over into other treatment sessions later that day. She gave an example of a patient who in the beginning didn't engage with the other patients but as time went on started to relax and smile. She notes that in other sessions he was more engaged and had greater enthusiasm for trying new things after breakfast group. Occupational Therapist 2 suggested this might be due to building a rapport with him. Therapy Assistant 2 in site 3 explained how the family were also seeing a change in the patient's mood.

*"I've had a lot of positive feedback from families, so patients have obviously gone away and spoken to their families and the families have come to us and said 'it's made such a difference to them. It's massively improved their mood and (patient's name) is really enjoying it. Site 2 Focus Group Therapy Assistant.*

The findings indicate that patients were receiving psychological and emotional support within the group. Moreover, the social component had a positive influence on mood, fostering greater engagement with their rehabilitation program. Qualitative data revealed individuals sharing personal stories and expressing fears and emotions related to life after a stroke. Based on this, it is reasonable to conclude that the breakfast group intervention was coherent in providing emotional and psychological support to patients, and participants found it acceptable to share their emotional vulnerabilities with fellow patients.

#### 8.2.5 TFA Construct 5 Opportunity costs

The fifth construct of acceptability is opportunity costs, which are the extent to which benefits, profits or values must be given to engaging in the intervention (Sekhon 2017).

Economic assessment was not a component of this study as the intervention was in the development stage. However, this is a factor to consider in future studies. The team highlighted that they needed extra equipment to deliver the intervention, so they approached managers to get additional toasters and kettles for the group. Thus, there were financial considerations associated with obtaining additional equipment.

## 8.2.6 TFA Construct 6 Perceived effectiveness

The sixth construct of acceptability is the extent to which the intervention is perceived as likely to achieve its purpose (Sekhon 2017).

### 8.2.6.1 Intensity

The analysis of intervention frequency was conducted as part of the evaluation of whether breakfast group interventions deliver an intensive dose of rehabilitation. Table 14 illustrates that during the 2-week study period, all patients received a greater number of interventions compared to the preceding 2-weeks (indicated in Table 14). No evidence emerged to suggest that the intensity of the intervention was unacceptable. However, challenges were noted in relation to staffing levels and ongoing staff absence related to the pandemic. Potentially this could have affected the feasibility of a five-day programme however all three teams were able to deliver the intervention daily despite these challenges.

All sixteen patients found it acceptable to be involved in and participate in the intervention. Moreover, there were no issues with seeing other patients have swallowing assessments or receiving hands-on support for balance or upper limb rehabilitation.

A total of 91 more sessions were delivered during BISTRo prototyping. There was one anomaly in the data, and this was patient 5 in site 2 who had 30 interventions before BISTRo and 10 sessions during BISTRo (Table 14). This particular patient has several difficulties with swallowing and communication which warranted daily interventions from Nursing (14), Speech and Language Therapy (10), Dietetics (4) Occupational Therapy (1) and Physiotherapy (1). During BISTRo his interventions dropped from 30 in two weeks previous to 10 during prototyping. A potential explanation for this could be that in the following two weeks he was recovering and therefore needed fewer interventions or that during the BISTRo sessions, he would have been treated by several professionals all in the same hour negating the need for separate uni-professional interventions.

Another issue to note is that in addition to the breakfast group intervention, patients may have had other sessions related to eating and drinking rehabilitation as uni-professional one-to-one sessions. These were not counted, so there may have been more than 91 sessions.

Table 14: Number of interventions 2-weeks before the study commencement and 2-weeks during the study.

The number of interventions for eating and drinking received two weeks before the intervention delivery compared to 2 weeks during BISTRo.	Patients	2 weeks prior	After BISTRo 2 weeks	Patients	2 weeks prior	After BISTRo 2 weeks	Patients	2 weeks prior	After BISTRo 2 weeks	Site 1 patients had 39 more treatment sessions.  Site 2 had 24 more treatment sessions  Site 3 has 28 more treatment sessions  Total = 91 sessions more in 2 weeks.
	P1	7	9	P1	3	9	P1	0	6	
	P2	3	10	P2	3	5	P2	0	9	
	P3	4	10	P3	8	10	P3	2	9	
	P4	3	9	P4	2	9	P4	2	8	
	P5	2	10	P5	30	10				
	P6	0	9	P6	4	10				

An unanticipated finding was how patients seemed to increase the quantity of food and drink they were consuming in the morning. Observations revealed that patients were selecting two types of breakfast food and consuming several drinks. Thereby ensuring they did not experience feeling hungry and had energy for other activities that day. Observing other patients have more than one portion encouraged others to have additional portions and patients also started to ask relatives to bring in food from home such as soft fruits for porridge or cereal.

### 8.2.7 TFA Construct 7 Self-efficacy

Self-efficacy is the seventh and final construct. It describes the participant's confidence that they can perform the behaviours required to participate in the intervention (Sekhon 2017).

Staff in all three focus groups expressed favourable views regarding the influence of breakfast groups on patients' self-confidence. In site 3, four patients reported that the intervention had improved their self-confidence. One patient at site 3 described how she would make other patients their first cup of the day and how she enjoyed this matriarchal role. She described how opportunities to have conversations with other patients had improved her self-confidence.

*"I think it helps my confidence when you sit and take part in conversations and help each other when one is upset. I think it's been brilliant; I really do, and I think you have to do it with every patient group when this one has gone you can get in a new group, because you get different ideas all the time, and it's different people to talk to". Site 3 Interviews Patient Participant.*

Observation notes in site 3 highlight a patient discussing how trying different tasks has helped to build his self-confidence.

*"I am always looking forward to it, I was trying to achieve something else different every day. Not just butter toast but do something else which I am capable of doing. I know if I do that, I am capable of something else, so it gave me confidence". Site 3 Field Notes Patient.*

Although some patients expressed concerns about their abilities there were no comments to suggest that patients did not feel capable of taking part in the group to some degree. Moreover, there were observations of staff grading the activities to accommodate varying abilities and provide support where people needed extra help. Overall patients felt that being in the group was helping them to gain self-confidence.

### 8.2.8 Reflections on assessing acceptability

The TFA constructs helped to assess the acceptability of breakfast group interventions in the prototyping stage of intervention development. It was useful to consider both quantitative and qualitative findings in the context of the experience of deliverers and receivers of the intervention. Findings of the Sekhon (2017) TFA assessment can provide insights which may inform future studies such as participant retention, attrition, and reflections on the

experience of the intervention which may affect participant engagement. The findings did not indicate any evidence to suggest that breakfast group interventions were unsuitable or deemed unacceptable, as assessed by the seven constructs of the Theoretical Framework of Acceptability (Sekhon 2017).

The prevailing view of staff and patients towards the intervention was overwhelmingly favourable. The implementation and outcomes of the intervention were congruent with the logic model, as there was evidence of intensity, collaborative teamwork, peer support, socialisation, and psychological support. While the teams successfully delivered the interventions, it was recognised that this posed a challenge, necessitating whole team engagement for success. While the intervention development did not primarily focus on the knowledge and skills required for delivering the intervention delivery, several issues emerged related to knowledge and skills gaps, indicating a need for this to be addressed in future studies.

### 8.3 The feasibility of the intervention

Feasibility studies aim to develop and design the basis of an intervention that can be tested practically in real-world contexts and withstand upscaling to the rigours of a randomised control trial (Tickle-Degnen, 2013). Tickle-Degnen, (2013) proposes that four aspects of the intervention can be assessed for feasibility 1) process 2) resources 3) management 4) scientific basis. This typology is used as a framework for exploring aspects of the feasibility of the BISTRO intervention.

#### 8.3.1 Tickle-Degnen 1: Process

##### 8.3.1.1 Recruitment

An integral aspect of evaluating the feasibility of an intervention involves determining whether it can successfully recruit all eligible participants. Sites 1 and 2 did not experience any issues with getting sufficient numbers for the group. Site 3 had an unusually low number of stroke survivors admitted to the hospital during the recruitment period and therefore they were one participant short of the required target of five. To compensate for this, sites 1 and 2 over-recruited.

The study successfully recruited to target for staff and patients. More staff than anticipated wanted to be involved with intervention delivery. Therefore all three sites took the opportunity to over-recruit staff which provided a buffer to cope with staff absence when there was a surge in staff contracting COVID-19 during the intervention delivery period. The PIs reported that the eligibility criteria were easy to follow, and they were able to use their experience and skills to ascertain which patients to approach.

##### 8.3.1.2 Screening for cognitive impairment

Following ethical approval to use the Mini-Mental Status Exam (MMSE) for screening cognitive impairment it became unavailable due to changes in copyright for the tool. Another cognitive assessment was found to replace the MMSE and an amendment to ethical approvals was sought to use the 6-CIT assessment. The 6-CIT is as effective as the MMSE in screening for cognitive impairment in older people in hospitals (Tuijl et al., 2012). It is a screen for dementia and cognitive deficits (Abdel-Aziz and Larner, 2015) which has

been converted into many languages and it is also suitable for people with visual deficits (Larner, 2015).

The site PIs reported that the 6-CIT was less sensitive for people with speech and language difficulties and some patients were unable to answer the questions in the assessment even though they were deemed clinically suitable for the breakfast group. One gentleman had a learning disability and dyslexia, so he was unable to complete the 6-CIT although he was found to be suitable for the group. One patient was unable to complete it due to aphasia. In these situations, a pragmatic decision was made using clinical reasoning. For future studies, a suitable aphasia-friendly screening tool would need to be sought.

### 8.3.2 Tickle-Degnen 2: Resources assessment

#### 8.3.2.1 Environment

The physical space in the room raised concerns because of the sufficient number of workstations and the need for space for patients in wheelchairs to manoeuvre. Available space could dictate the number of patients in the group. Mapping out the room and where the workstations would be situated could support the planning process although the set-up of the room evolved as lessons were learned through experience. The physical space was considered a vital factor in ensuring optimal rehabilitation opportunities.

#### 8.3.2.2 Staffing and resource utilisation

The duration of the intervention was variable, typically ranging from one hour to two hours. This variability was influenced by factors such as case mix, staffing levels and the support required to assist patients in attending the group. It was noted that coordinating the patients to arrive at the group simultaneously posed challenges, particularly when staffing was lower. As a result, some patients were observed waiting in the room for up to thirty minutes for the group to start. Nevertheless, during this waiting period, patients were observed to be enjoying chatting with fellow patients and enjoying their first drink of the day.

#### 8.3.2.4 Equipment

The availability of kitchen equipment varied, and at all three sites, staff made requests for more food and drink-making appliances to reduce patient wait times and queuing at workstations. Staff successfully acquired additional kettles and toasters, with managers demonstrating a willingness to buy extra items when requested. Having adequate kitchen equipment was observed to improve the patient experience as well as satisfy infection control guidance.

### 8.3.3 Tickle-Degnen 3: Management

The management assessment included the staff's capability to carry out the planned activities, and management of the research process such as ethical approvals, data management, and compliance with the intervention protocol.

#### 8.3.3.1 Staffs capability to carry out the breakfast group intervention

Site 1 had a Housekeeper who played a significant role in preparing the room, arranging the food and drinks, and aiding in the organisation of workstations to ease the workload of the

delivery staff. At Site 2, an Activity Coordinator was instrumental in setting up the group and assisting patients with their breakfast, focusing on facilitating the social dining experience. However, the Activity Coordinator was not trained in moving and handling and did not participate in rehabilitation activities, her primary responsibility was to enhance the social aspect of the dining experience.

All three sites had an Occupational Therapist consistently involved in supporting the group setup. This assisted less experienced staff during the setup and ensured continuity for the patients. In each site, three staff members prepare the room and assist in intervention delivery, with various professions depending on the available staffing groups for each site.

The daily organisation of tasks differed based on the specific site context, as illustrated in Figure 39, which outlines the site staffing plan. Each site had certain staff members providing continuous coverage, while others rotated. Site 3, for example, had two OTs working together to prepare patients for the group. Figure 40, displays a typical staff rotation schedule for each site. Site 1 and 3 participated in the nursing handover at 7:30 am, which facilitated the process of ensuring that the right patients were washed and dressed for the group. In contrast, Site 3 did not employ a formal staffing rota, instead organizing this in the team's daily planning sessions. Sites 1 and 2 used a written rota, which was adapted as staffing changes occurred.

Figure 38: Site staffing plan.

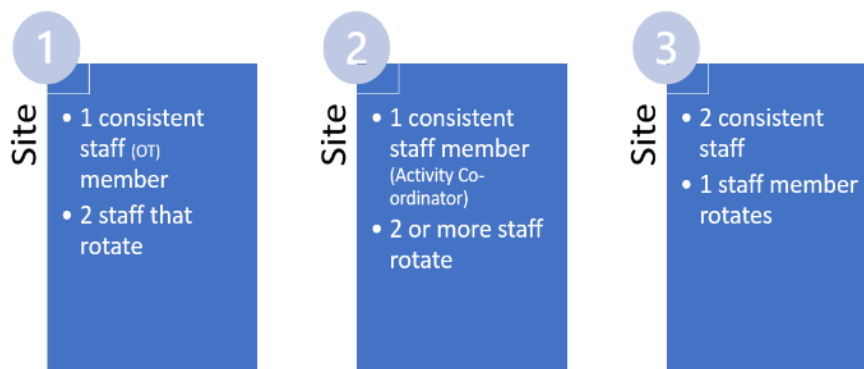
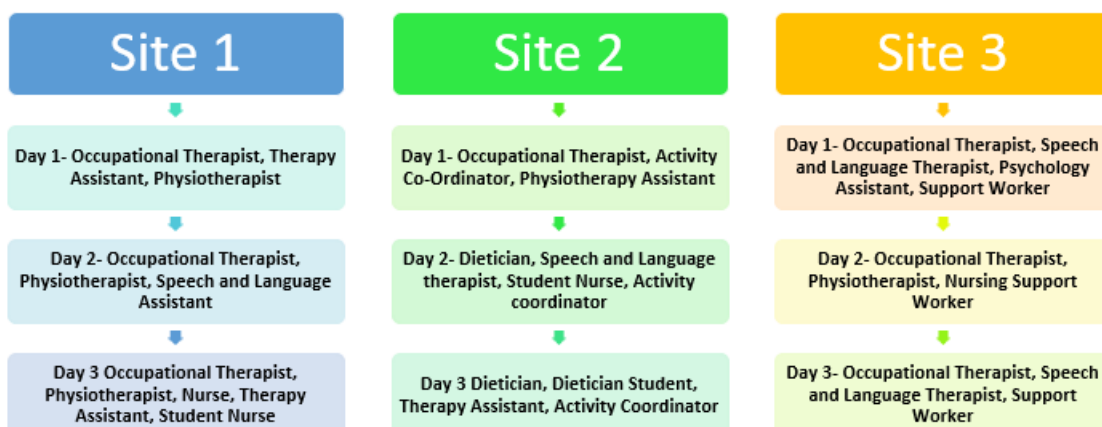


Figure 39: Site staff rota example.



#### 8.3.3.2 Carrying out research management activities

The site Principal Investigators served as the study's gatekeepers, offering support for recruitment, planning, and organisation. Having a dedicated research team facilitated communication within each site, particularly because the site PIs had established relationships with the multidisciplinary teams. Administrative capacity was generally not a concern, except for Site 3, which had to temporarily suspend intervention delivery for one day due to an unforeseen ward relocation.

Despite the added challenges posed by COVID-19, all planned research activities were successfully executed. There were no issues encountered in screening and obtaining consent from participants. Patients consistently completed the patient-held booklets daily to record their progress, and aphasia-friendly materials were appropriately utilised. No adverse events were reported, and instances where patients were unwell or missed the group due to a fall injury were determined to be unrelated to the intervention. Given the acute stage of recovery, such occasional unwell days or falls were considered acceptable.

Several modifications were made to ethical approvals, as detailed in Chapter 7, but no breaches of ethical approval occurred. These amendments included changes to the inclusion and exclusion criteria for outcome measures (from MMSE to 6-CT) and an adjustment to the consent process to include the use of audio recordings, photographs, and film in the dissemination of study findings.

#### 8.3.4 Tickle-Degnen 4: Scientific assessment

This facet of feasibility encompasses safety considerations, the level of burden imposed, and the intervention's alignment with patient needs. Importantly, no safety procedures were violated during the study. The infection control nurse provided supplementary guidance on single-use items and seating arrangements, reinforcing safety measures. Patient participants did not report any burdens associated with the frequency or intensity of the intervention. Instead, they expressed appreciation for the daily format and routine. The study successfully continued throughout the pandemic, even amid heightened restrictions, without interruptions. The patient-held booklet effectively recorded individual preferences, and the process of daily reflection log completion or goal review ensured the promotion of a patient-centred approach. Additionally, the patient assessment incorporated the patient's social eating history and preferences.

#### 8.3.5 Reflection on feasibility and Tickle-Degnen

Tickle-Degnen's (2013) typology for feasibility studies provides insights as to whether the study is feasible to be conducted for future evaluations as well as explores key domains of feasibility. Given the various factors that can affect the successful execution of a study, this typology is designed to identify and evaluate any potential threats that might hinder or impede delivery. Encouragingly there were no practical or ethical issues that would prevent the study from fulfilling its primary aim of developing and testing out a breakfast group intervention. The results indicate that conducting a study of this nature is feasible even in challenging circumstances. The insights obtained from this study could be extrapolated for application in a larger multi-site trial.



The primary obstacles to feasibility encompassed altering how staff manage morning routines on a ward, optimising staffing resources to deliver an intensive daily intervention, and introducing a multidisciplinary collaborative component that brought about substantial adjustments to the operational delivery of stroke care and eating and drinking rehabilitation in all three sites. There were no findings to suggest that breakfast group interventions were not feasible to deliver on an acute stroke ward.

#### 8.4 Potential benefits of the intervention

Leung, (2013) describes perceived benefits as the perception of positive consequences, a term used to describe the motives for “*performing a behaviour, adopting an intervention or treatment*”. Attitudes, beliefs, and motivations are thought to play an important role in neurological rehabilitation (Becker, 1974; Dixon et al., 2007). The perceived benefits of BISTRo fell into four categories, perceived benefits of BISTRo as a rehabilitative intervention, social benefits, psychological benefits, and peer support benefits.

##### 8.4.1 Perceived benefits of BISTRo as a rehabilitative intervention

###### 8.4.1.1 Opportunity to practise activities of daily living

Patients were observed in all sites practising with adaptive equipment such as cutlery, trollies, and bread and butter boards. Patients were also discussing which devices they found helpful and in two sites patients were observed to take out their phones and order adapted cutlery online when they had found it useful in the group. Patients talked about how practising was helping them prepare for going home and having the opportunity to have a go was important. Practising helped them to know what was possible and what they might try at home. A site 1 patient describes how practising encourages her to try more.

*“At least I was able to practise making my breakfast, because at first when I had the stroke, I was thinking am I even going to be able to make my own meals, is it even going to be possible? But when I did that at least I thought, OK I can do it, I think next time I will keep on pushing and pushing”.*

Photographs taken by the CI captured patients practising tasks during the breakfast group. Figure 41 shows a patient practising using a trolley to transport the drink she made from the kitchen to the breakfast group table.

Figure 40: Patient practicing with a trolley.



(Image sources: Natalie Jones 2022)

#### 8.4.1.2 Provides a daily and structured routine

Staff discussed the value of the daily routine highlighting its role in maintaining continuity for the patients as well as creating structure for the day. Additionally, they also explored the importance of high-intensity interventions in acute stroke rehabilitation. Staff at site 1 emphasised that making food and drink within the context of appropriate times (e.g. making breakfast at breakfast time) was more effective than doing it at random times during the day.

#### 8.4.1.3 Improves accessibility to promote independence

Patients expressed their appreciation for the chance to prepare their breakfast and experiment with various disability aids. They found it valuable to have access to the items on the table, enabling them to initiate breakfast independently if they were capable. Staff members also conversed about how the table arrangement improved task accessibility for patients, observing that it encouraged self-sufficiency as discussed below.

*“I think maybe things were more accessible for patients, so usually the activity coordinator would have served the patients their breakfast. She would have poured the cereal for them and would have helped. So I think we made things easier for patients to get hold of things so they could try to do it themselves”.*  
*Site 2 Focus Group Occupational Therapist 3.*

#### 8.4.2 Perceived benefits of BISTRo as a social intervention

Staff on all three sites discussed the benefits of patients socialising together. The relaxed and familiar environment was thought to help people feel comfortable socialising with other patients, the dining experience and the objects on the table created a familiar and normal context for patients. Patients discussed the benefits of being social with other patients, developing friendships and how being in the group reduced feelings of isolation.

*“It all became normal because we were all becoming friends and we could talk to each other normally about different things and work together and have jokes together”.* *Site 2 Interview Patients Participant.*

The benefits of socialising were discussed by patients in all three sites. They contrasted the social element of the group with previously feeling isolated and discussed the need for company and socialisation and it was comforting to find out that others were experiencing the same thoughts.

*“You know my thoughts were their thoughts as well, we were all thinking the same things. It's nice to know you are not isolated on your own and that other people are going through the same thing”.* *Site 3 Interview Patient Participant.*

#### 8.4.2.1 Perceived benefits of social learning

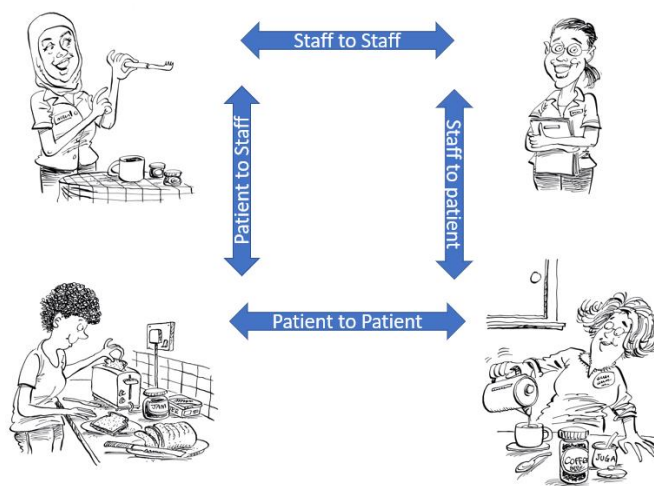
Both patients and staff perceived that BISTRo helped them to learn. Learning was multimodal, staff to staff, staff to the patient, patient to patient and patient to staff. As described in Figure 21 below.

### Staff learning from other staff

Staff talked about what they had learned from other staff whilst participating and observing in the group. They were talking away new knowledge and using this in their practice.

*“The questions that are OT related, I feel like I could answer them better now, which before I wouldn't have and the group just helped me do that in a natural way without anything formal, informal training you just kind of learn from each other. I learnt watching others and it was kind of rewarding much more than I thought it was going to be”. Site 3 Focus Group Psychology Assistant.*

Figure 41: Four Ways of social learning in breakfast group interventions.



There were examples of patients learning from staff how to manage and adapt to an impairment or embed strategies into their daily activities the in group. Occupational Therapist 2 in site 3 talked about how she was teaching a patient to use her Zimmer frame whilst making a hot drink. She described the practise each day and how by the end of the week she had mastered using the Zimmer frame as well as making tea. The therapist taught the patient how to sequence the tasks and use her Zimmer frame safely.

### Staff learning from patients

Occupational Therapist 2 in site 3 reflects on how she is learning from patients in the group and taking away this knowledge to work with other patients in the community.

*“I was also thinking patients are best teachers, we do not always stop and say what could we do better, what could we do differently, but this group enables us to do that. So many things that I have taken away to use with my community patients.” Site 3 Focus Group Occupational Therapist 2.*

Another example of staff learning from patients came from the focus group in site 3. A Psychology Assistant describes how she is changing the way she writes up sessions after her

experiences of using the patient booklet. She has changed her style of writing up notes to write from the patient's perspective, making her note writing more patient-centred.

*“We go away, and we write our notes. A reflection I had was, I go away and write my notes quite differently now. That’s because I have had that conversation with them while using the BISTRo booklet. You actually put the patient's perception down in your section of the notes and I think that is really important it's always what ‘we see’ and what ‘we think’ and what ‘we perceive’ but now it's completely different to that, it's about ‘what the patient thinks’ so that’s different”.*

#### Patient-to-patient learning

Patients engaged in mutual observation, drawing inspiration from one another as they underwent their rehabilitation journeys. Through this observational learning, patients recognised that everyone faced their own set of challenges, and making mistakes was an integral aspect of the recovery process, thereby contributing to their overall learning and growth.

*“It's a lot more because you are interacting, you are talking about your disabilities, everybody has got different disabilities. I am learning from it. (Patients name) had got something wrong and (patient name) has got something wrong, we have all something wrong, but I am learning about it”. Site 3 Patient participant interview.*

#### 8.4.2.2 Social influence, changing the fabric of the therapeutic relationship

Staff and patients talked about getting to know one another as people and how the social experience of the group brought about deeper richer staff-to-patient relationships.

*“That has been massive for me. I have really noticed the difference between how I think about those people and how I work with them and how I am thinking about their futures in a much more humanised way. We formed a different relationship with this group of patients different to what we usually do with other patients on the ward, because we had that opportunity”. Site 3 Focus Group Occupational Therapist 2.*

Patients emphasized the significance of establishing stronger connections with the staff. A patient at Site 3 illustrated how a closer working relationship with the staff facilitated mutual understanding. Field notes documented instances where staff openly discussed their interests, music preferences, holiday experiences, and life stories. The observed shift in the therapeutic relationship between staff and patients implied a more relaxed approach to the usual professional boundaries within the breakfast group. Surprisingly, this shift was not problematic; in fact, it seemed to enhance patients' sense of ease. A patient at Site 3 shared his perspective on the impact of this relationship.

*“I liked that people treated me as a human being, they didn't look at me as disabled or anything like that, they encouraged me to do things, so that's what I liked about it and what I got out of it most”. Site 3 Interview Patient Participant.*

#### 8.4.2.3 Social context, creating a sense of normality

The opportunity to perform 'normal' activities such as eating, drinking, and making breakfast was discussed in relation to feeling more human. A desire to feel normal and reduce feelings of self-consciousness was expressed in all three sites. A site 3 patient shared she was normalising her difficulties.

*"The return to normality, that I am probably going to have to do this for the rest of my life, yet it's acceptable and it would be acceptable in society if we went out for lunch which (husband) which I do quite a lot. Nobody would be gawping at me, I think that is a big fear of mine, that people are looking at me, judging me and thinking I am stupid, I am not stupid I am an intelligent woman, I may have lost a bit of my direction, but I am not stupid by any means". Site 3 Interview Patient Participant.*

A participant from site 1 also describes how the breakfast group supported the idea of getting back to normal. Staff also discussed the importance of creating a sense of 'normality' through doing interventions when they are temporally appropriate. Staff in site 2 discussed how delivering eating and drinking interventions at breakfast time created a sense of normality with the routine and the activity which held more meaning for patients. One patient in site 3 commented she had not felt 'human' since coming into the hospital.

*"When I came in the door, I lost my dignity and humanity. I felt very helpless before coming to breakfast group". Site 3 Interview Patient Participant.*

She mentioned that participating in the breakfast group boosted her motivation and provided a sense of being treated as a human being. This feeling of humanity was associated with experiencing moments that brought a sense of normality. The room's arrangement with tablecloths, flowers, and crockery contributed to creating a dining atmosphere resembling a theatre of normality, as observed in the field notes. Other patients at Site 3 also emphasized the importance of being treated as human beings and the need for human interaction.

The activity coordinator mentioned the significance of having a cup of tea with patients in making things feel more normal, as noted in the Site 3 field notes. A staff member in the Site 3 Focus Group acknowledged that preparing people for the breakfast group enhanced their sense of individuality and humanity. One gentleman in Site 3 discussed how witnessing others with eating difficulties helped normalize such challenges, creating a relaxed atmosphere within the group and fostering friendships that allowed him to better understand fellow patients.

*"it's just normal, yeah just carry on, it's just normal and that's the thing I got out of it, it was more, not in sympathy, it was more understanding of each other. It was relaxing it was great. It made it more normal because we were all becoming friends and we could talk to each other normally about different things and work together and have jokes together. Everything was just more normal, and it made a difference to the rest of the day because it was a lively start to the morning". Site 2 Interview Patient Participant.*

### 8.4.3 Perceived benefits of BISTRo as a psychological intervention

#### 8.4.3.1 Improving Mood.

Patients noted an enhancement in their mood as a result of their involvement in the group. This positive impact on participants' emotions was consistently reported across all three data sets. Patients referred to the breakfast groups as a motivating factor, providing a safe environment for them to open up, express their feelings, and embrace the possibility of making mistakes. In two instances, patients shared deeply personal emotional experiences and traumas, receiving comforting and reassuring responses from both fellow patients and staff members (observed at Sites 1 and 3). Additionally, two patients described the group as uplifting, a sentiment that was also evident in the social interactions noted in the field notes. Patients encouraged and cheered each other on when they observed positive changes or progress, as illustrated below.

*“I walked with the physio today in the breakfast room and the other residents encouraged me to do that it was very uplifting”. Site 1 Interview Patient Participant.*

Numerous instances demonstrated how the group viewed breakfast groups as a mood enhancer, countering feelings of loneliness and isolation, or serving as a diversion from negative thoughts. Staff observed improved mood in the group and also a carryover of ‘good mood’ into other sessions later that day. Staff reported that families of patients were noticing how much patients were getting from the group and reporting this in conversations with staff. This example shows how families were noting an improvement in the patient's mood and they were attributing this to the breakfast group.

#### 8.4.3.2 Influencing psychological mindset

Patients and staff engaged in conversations regarding the transformation of their beliefs and the shifting of their mindsets as a consequence of their participation in the group. They shared how the group was equipping them for their eventual return home and bolstering their self-assurance. Furthermore, they emphasized the significance of observing other stroke survivors' eating and drinking habits, which served as a motivating factor, encouraging them to take action. Three patients talked about the belief that the breakfast group was preparing them for going home and helping them feel more confident about socially dining.

This was also echoed by a participant in site 2 who also discussed how the breakfast group had helped him mentally prepare for home while building his confidence to eat in front of other people. He talks about feeling self-conscious and how doing things in the breakfast group helped him to feel more normal.

*“Another thing I was worried about is when I get home with my family and we go out for meals, I was worried about how people would see me eating and things. But I was there in the breakfast club with people in the same situation as me and it didn't bother me one little bit and it didn't bother them, so I'm taking that away. I feel OK to go on and have meals out now as I didn't feel people were looking at me eating or looking at the way I spread the toast or anything like*



*that it felt natural. It's helped me feel more confident about eating in front of people". Site 2 Interview Patient Participant.*

A patient in site 3 also talked about home preparation but he focused on how making breakfast gave him the confidence to know he could do tasks which was an important affirmation for his wife.

#### 8.4.3.3 Encouragement

Patients talked about how staff were helping and encouraging them to try out different ways of doing things and also use their bodies in different ways to strengthen their muscles. They talk about how other seeing other patients striving at activities they were encouraged to try as well.

*"You hear more so it encourages you, you think at least I will get there. I will get there. Like there was (patient's name) he used to walk with his stick, it motivated me, so much that I said, am I going to do that? So the next time I tried, my mind focused on what he did, he was able to walk, so I managed to walk, and my friend came and said, let's go. I walked and she took me around. Like yesterday I even walked and came back it was quite motivating on that front". Site 1 patient participant interview.*

Several participants describe they are motivated and inspired by other stroke survivors. Seeing other people experience similar situations helped them to not feel isolated. Several patients talked about being in the 'same boat' or 'port' and how seeing other patients go through the same experiences and achieve goals encouraged them but also affirmed that they would get there as well. A site 1 patient explains the importance of encouragement.

*"Relationships and encouragement were important, we were encouraging each other ' someone to say- 'come on you can do it' and I think maybe some people were quite emotional through talking and we would say it's okay, it's okay. We would say, you are not alone in this port, other people are experiencing the same so that's encouragement which comes down to relationships and communication. Because you can talk to one another you know that everyone is going through different versions of it". Site 1 Interview Patient Participant.*

#### 8.4.4 Perceived Benefits of BISTRo as a peer support intervention

Patients discuss how much they enjoyed being with each other. The social conversation reflects the diverse topics that were discussed and during the observations, there were many occasions of laughing and jollity. One patient talked about the fun he and another patient had playing pranks on each other. Patients and staff talked about the bonds that developed. Several patients had swapped phone numbers to keep in contact with one another post-study.

##### 8.4.4.1 Peer friendships

Patients used various words to describe other patients, 'fellow colleagues' (site 1) 'compatriots' (site 3) and 'compadre' (sites 3). They talked about developing new



friendships. Staff also observed the development of peer-to-peer relationships. Sites 1 and 3 both discussed the camaraderie that had developed amongst the patients suggesting a degree of mutual trust and friendship. Site 1 also discussed the perceived benefit of solidarity, a sense of unity and peer support. At Site 2, a patient finds that as they get to know one another better, they gain insights into people's backgrounds and are able to see past the impact of the stroke.

*“Once you get talking to people you ask them questions and they ask you questions and they reveal something about themselves, that's nice to know, because they are not just a stroke. They are a person with a background”. Site 2 Interview Patient Participant.*

Site 3 patients talked about how they had started as a group of patients and become friends. The concept of friendship was featured in all three sites. A patient in site 2 also talks about the friendship he developed with another patient they were able to joke and prank each reflecting a level of trust. This site 3 patient wrote about friendship in her patient Booklet.

*“I really mean this; we came together in here as patients and are leaving as three friends”. Site 3 Booklet Patient Participant.*

#### 8.5 Outcome measurement findings

This section explores the outcome measures that were part of the implementation toolkit, the findings, and the potential implications for future research. It is important to note that this study did not aim to develop new outcome measures but to utilise available, off-the-shelf measurement tools.

Three outcome measures were used in the patient booklet (Table 15). The CaSM (Horne, 2016; Horne et al., 2017) a psychometric stroke-specific measure of confidence that measures positive attitude and social confidence and a Likert scale outcome measure was developed with the stakeholder group to measure self-confidence (these measures are discussed in Chapter 3). Table 15 shows the scores of all three measures before and after the intervention was delivered.

Each score was administered on day one of the intervention and on day ten, the last day of the intervention or on the day the patient was discharged home whichever came first. According to the written abilities of patients they were either completed independently or the questions were read out and a member of staff scored them for the patient with the patient. These are patient-reported outcome measures.

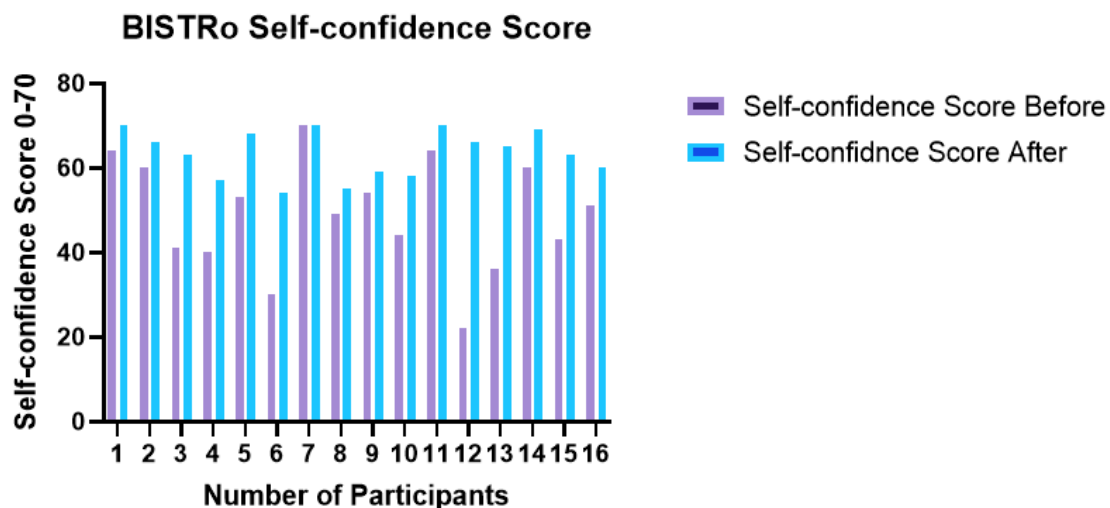
Table 15: Three outcome measures used in BISTRo (CaSM and Self-confidence Scale) aggregated scores.

Site	ID	CaSM Positive Attitude scale 0-24			CaSM Social Confidence scale 0-18			Self-confidence with eating and drinking scale 0-70		
		Pre	Post	Difference	Pre	Post	Difference	Pre	Post	Difference
Site 1	P1	22	24	2	13	21	7	64	70	6
	P2	22	27	5	18	18	0	60	66	6
	P3	24	24	0	12	18	6	41	63	22
	P4	16	16	0	11	10	-1	40	57	17
	P5	12	15	3	11	8	-3	53	68	15
	P6	12	17	5	8	7	-1	30	54	24
Site 2	P7	23	22	-1	11	12	1	70	70	0
	P8	20	20	0	15	14	-1	49	55	6
	P9	17	17	0	0	7	7	54	59	5
	P10	18	15	-3	13	10	-3	44	58	14
	P11	22	22	0	15	15	0	64	70	6
	P12	16	18	2	12	13	1	22	66	44
Site 3	P13	15	19	4	8	11	3	36	65	29
	P14	20	24	4	11	3	-8	60	69	9
	P15	17	22	5	15	16	1	43	63	20
	P16	24	24	0	10	16	6	51	60	9
<b>Total</b>		<b>300</b>	<b>326</b>	<b>26</b>	<b>183</b>	<b>199</b>	<b>16</b>	<b>781</b>	<b>1,013</b>	<b>232</b>
<b>Mean scores</b>		<b>18.75</b>	<b>20.375</b>	<b>1.625</b>	<b>11.43</b>	<b>12.43</b>	<b>1</b>	<b>48.81</b>	<b>63.31</b>	<b>14.5</b>

### 8.5.1 Self-confidence measure (Likert Scale)

The simple Likert scale required a score from 1-10 against seven questions exploring perceived self-confidence related to eating and drinking. Figure 42 shows the score before and after the intervention plotted on a line graph for each patient. All patients but one (site 2 patient 1) improved their score for self-confidence with eating and drinking (Table 5). The line graph shows improvement ranging from +5 to +44.

Figure 42: Stacked Bar Chart of the self-confidence measure before and after the intervention was delivered.



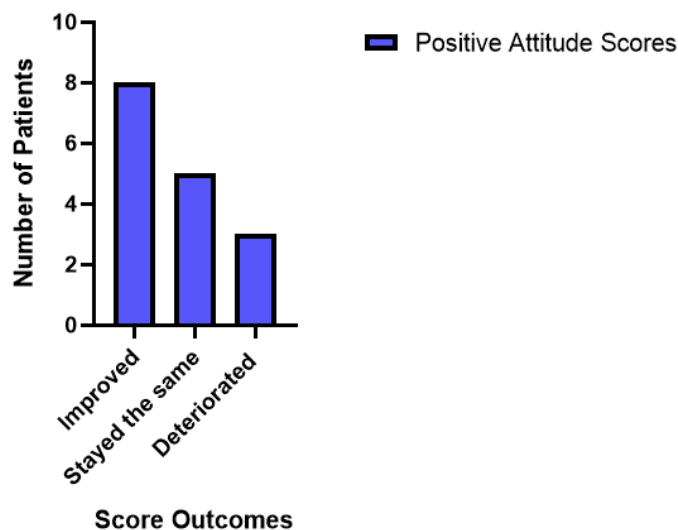
Informal feedback from staff collected from the study log books confirmed that the self-confidence measure was simple to administer, relevant to patients' difficulties and quick to complete. Ethnographic observations noted staff having positive discussions about the measure which supports the view that the self-confidence scale has merit and should be kept in version 3 of the BISTRo patient booklet.

### 8.5.2 CaSM measure of positive behaviour

In the absence of a purpose-made measure for eating and drinking a consensus with the stakeholders was reached to use a published measure which has been evaluated for use with stroke survivors. The positive attitude score had eight questions which were scored on a scale of strongly agree, agree, disagree to strongly disagree, which the patient had to tick the relevant answer for the question. Each answer had a value from 0-3, the maximum score was 24. The questions are not specific to eating and drinking but they provide an idea of attitudes, self-belief, positivity, and level of comfort with body image. Figure 44 shows the aggregated outcome scores. Although eight patients improved their scores, five stayed the same and three had a deteriorating score.

Figure 43: CaSM positive attitude scores.

### Results of Positive Attitude Score



One explanation for the deterioration in the positive attitude score was that several of the participants were approaching discharge and experiencing apprehension and low mood. Several others were disappointed not to be going home for Christmas and they had been emotional about this decision during the breakfast group (see quote below). This is supported by field notes taken in site 3 where the mood of the group was noted to be low, and several patients had cried about the news that they were not able to go home for Christmas. Occupational Therapist 1 in site 3 suggested that the positive attitude score reflected how patients were feeling generally as it was specific to eating and drinking problems which could account for the results.

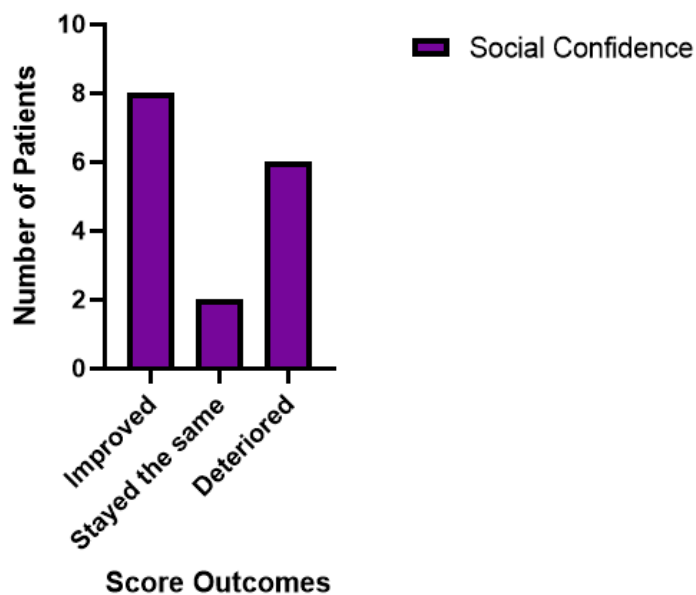
*“I would say two of our patients in particular dipped in mood and confidence towards the end of the group as they were coming to terms with delays to discharge, staying in the hospital over Christmas. Christmas itself and the expectations it brings – and the realisation that they were going home at a level lower than their usual level of ability. I know the outcome measures were not related to eating and drinking specifically and I think these patients struggled to separate this from how they were feeling in general”. Site 3 Occupational Therapist 1 Field notes.*

#### 8.5.3 CaSM measure of social confidence

The social confidence score had six questions about socialising, concerns about how other people see the stroke survivor, meeting people and feelings about how the stroke survivor communicates with other people. Participants could answer on a five-point scale from strongly agree to strongly disagree. Each answer had a value of 0-3 with a maximum score of 18. The social confidence scores also had a deterioration of social confidence with six patients scoring lower in the end-point assessment. Eight patients had improved scores and two stayed the same (Figure 44).

Figure 44: CaSM social confidence scores.

### Results of Social Confidence Score



The reason for the deterioration in score was explored by the CI during the focus groups with staff. Several possible reasons emerged during the conversation. Firstly, log book feedback reflected that the general nature of the questions could have affected the responses as patients were not specifically relating the questions to the breakfast group experience. It was also noted that social confidence might have been lower after patients were exposed to more social contact illuminating their limitations. A patient from site 2 explains why his scores stayed the same. He felt that his social confidence didn't change, and the scale was not differentiated enough.

*“Some of the other questions I ended up answering were the same from day one to the last day. Do you have confidence? Well, I had confidence before, and I still have confidence. It was basically the same confidence because it was narrow-highly confident, confident, no confidence, lacking. There was nothing in between. I was more confident, but I was still confident do you understand what I mean?” Site 2 Patient participant interview.*

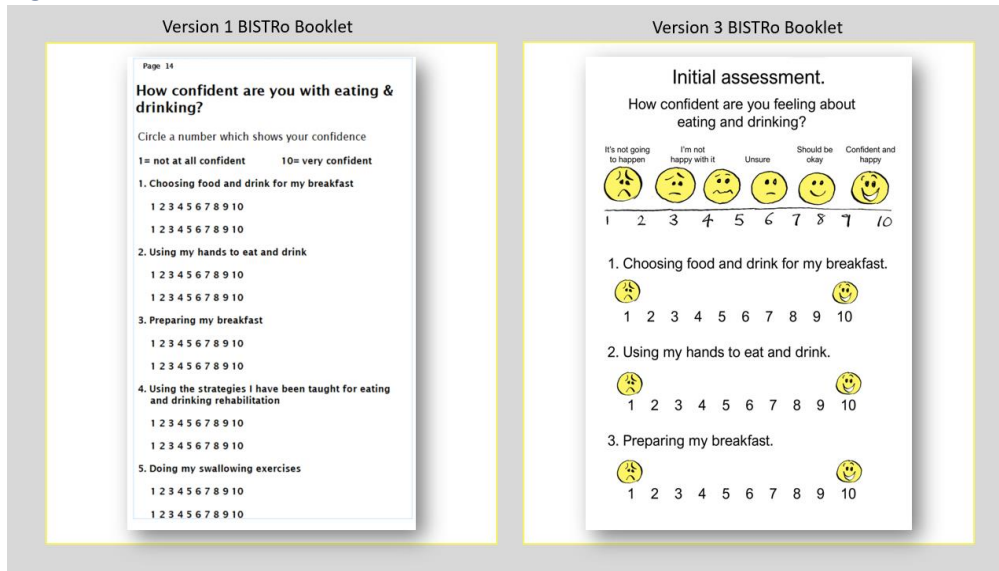
#### 8.5.4 Other issues with the selected outcome measures.

One patient from site 2 suggested grey as a contrast colour on the assessment format was difficult for him to read. He also disliked the font size of the CaSM. Therapists also note in their log books that the questions were cramped in versions 1 and 2 of the booklets.

In Stakeholder Workshop 9 the illustrator was engaged to make the self-confidence measure easier for people with aphasia easier to understand by creating some smiley faces to accompany the descriptors for each score in the scale (Figure 26).

Another decision taken with stakeholders was to separate the scores before and after so that the initial assessment and final assessment were in different places in the book relevant to the other content. Figure 26 shows version 1 of the measure with both before and after scores in parallel on the left page and the final format version (3) on the right side of the page shows the change in format, scale descriptors and aphasia-friendly smiley faces.

Figure 45: Two iterations of the self-confidence outcome measure.



(Image sources: Natalie Jones 2022)

In stakeholder workshop 9 there were discussions about the outcome measures that would go into version (3) of the BISTRo Booklet. Concerns were raised about the CaSM not being specific to eating and drinking and therefore it did not capture the specific changes and attitudes to eating and drinking as expected. The deterioration in scores did not reflect the narratives provided by patients in the interviews or the experience of the staff. It was agreed that the CaSM was not specific enough to capture the changes specific to eating and drinking performance or social dining.

The simple Likert scale on self-confidence related specifically to eating and drinking was the preferred measure for version 3 of the patient booklet. It was acknowledged that this was not a standardised outcome measure, but it provided a measure of change specific to the intervention. Stakeholders made three recommendations, i) it would be prudent to review the literature to see if any other measures have been published since the selection of measures was made ii) explore the development of a specific outcome measure related to breakfast group interventions in future research iii) incorporate a test meal assessment before the intervention starts and at the end of the intervention so that the functional abilities and progress could be measured.

Although improved mood was noted as a potential outcome of the logic model a standardized outcome measure for mood was not included in the bundle of outcome measures tested in the prototype. Learning from prototyping suggests that a measure of mood before and after the 2-week programme could have proven useful in understanding the impact of BISTRo on psychological well-being. However, a standardised and validated

mood score could have reflected how people were feeling generally and not reflected the benefits of the BISTRO intervention on mood. Findings suggest that improved mood is an outcome of the BISTRO intervention and therefore future studies should look to assess mood in relation to eating and drinking performance and social dining.

## 8.6 'Refining the Logic Model'

Logic models are a visual representation of ideas and theories about how a programme might work. In the first year of the PhD, the early logic models were developed by the CI in collaboration with the supervisory team. Later versions were developed with the stakeholders to frame the purpose and expected outcome of the interventions (Mills, Lawton and Sheard, 2019). The BISTRO logic model has been through several iterations in response to learning.

In response to stakeholder feedback, the logic model was split to create two versions, one for patients and one for staff. The rationale was that combining them was becoming too complex. (The logical model development and rationale are discussed in Chapter 3). However, even though it was thought that a separate one for staff and patients would be preferable to provide a more focused representation merging them in later iterations has streamlined the model and provides a comprehensive overview of the whole programme.

### 8.6.1 Revised logic model

The revised logic model integrates perspectives so the programme inputs, outputs and outcomes can be viewed in their entirety. Inputs describe the context, resources and staffing required to run the group as well as the therapeutic approaches being utilised. Participants are those delivering and receiving the intervention. Activities are the type of activities conducted by staff to deliver the intervention or the type of therapeutic activities that patients are doing in the intervention. Products are the outputs from the intervention delivery that are tangible and evidenced in the findings. The outcomes or impacts for both staff and patients are included in the last three columns which are broken down into short-term, medium-term, and long-term (see Figure 46) below the revised logic model and final version).

### 8.6.2 Things removed from the logic model after the prototyping stage

The term 'mastery' was removed from the patient outcomes column. The term 'mastery' was hotly debated by the stakeholders before and after the intervention prototyping. Patient representatives and informal carers were uncertain about the term 'mastery' and whether this accurately reflected progress in eating and drinking. Concerns were voiced such as '*the inpatient stay is only part of the recovery journey. Can mastery be achieved at this stage?*'. Mastery as a term is associated with narrative health research (Braun, 2020) to describe how people who experience illness or injury strive for 'mastery'. It is also a term widely used in the literature associated with the Kielhofner Model of Human Occupation and Occupational Therapy professional language (Kielhofner, 1980; Kielhofner et al., 1980).

Discussions with the stakeholders ensued about whether the term was relevant to current practice and if a suitable alternative could be agreed upon. It was agreed that improved



performance or achieving independence reflected that patients were achieving mastery over their eating and drinking difficulties and therefore 'mastery' was removed.

It was difficult to assess positive identity as an outcome as this was deemed to be an individual concept and the questions in the CaSM did not relate to positive identity specifically for eating and drinking, they were much more general questions and patients found them irrelevant. Following a discussion with the stakeholders, the CaSM positive identity scale was removed from version 3 of the BISTRo patient booklet and also it was removed from the logic model.

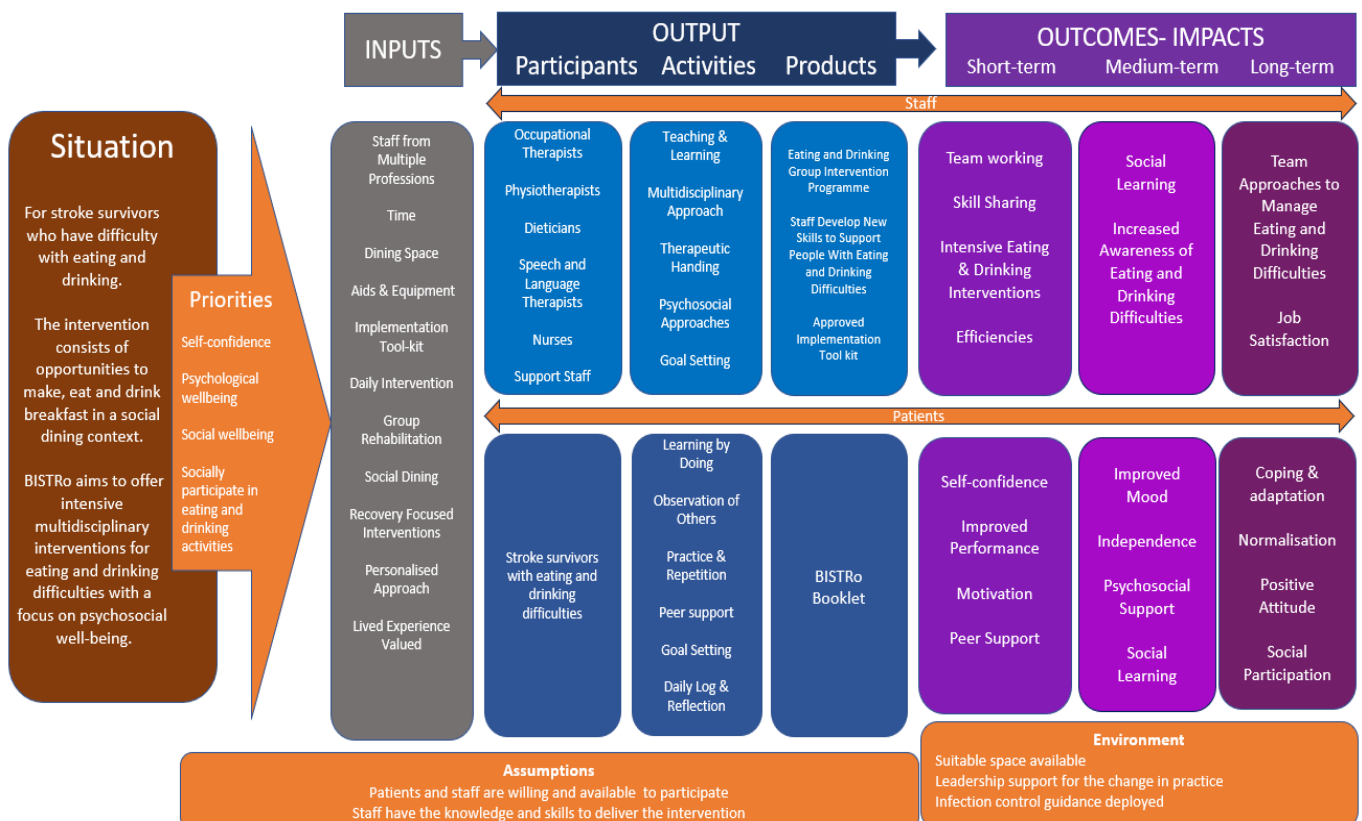
### 8.6.3 Logic model additions

The findings related to peer support suggest that motivation was an outcome of the intervention. Patients were experiencing peer and staff encouragement, achieving goals, and recognising their progress which they described as motivating. They also gained motivation to push themselves from seeing other people perform and achieve. This inspiration was motivating them to 'have a go' and strive for more improvement.

The prototyping findings indicated that social learning was taking place for staff and patients. Therefore social learning was added as an outcome for both staff and patients.

Another unexpected outcome of the intervention for staff was their pleasure in being involved with the intervention. Staff reported enjoying the sessions as much as patients. In this joy, they spoke animatedly about the intervention, their experience of delivery and how much they enjoyed seeing the patients enjoy themselves. Therefore job satisfaction was added to the revised model.

Figure 46: Revised Logic Model.



## 8.7 Discussion

### 8.7.1 Reflections on breakfast group interventions as a neurorehabilitation intervention

In Chapter 1 the principles of neurorehabilitation were explained with a particular focus on practice, feedback, and goal setting as the three principles most relevant to breakfast group interventions. This section will now explore whether these concepts were evident in the findings of the intervention prototyping.

### 8.7.2 Reflections on practise

In this study, the concept of 'practise' emerged as a reoccurring theme, with patients being given the opportunity to practise various activities associated with breakfast preparation and consumption. Staff members gave examples of patients' progress throughout the week and this progress was documented in the BISTRo patient booklet, where a daily record was kept. The data related to 'practice' aligns with the principle of task-specific practice, which originates from the movement science and motor learning theory (Schmidt et al., 2018). Task-specific training in stroke rehabilitation focuses on the practice of activities of daily living that hold meaning for the individual (Hubbard et al., 2009). Staff discussed how making breakfast held personal significance for patients, as it prepared them for going home and engaging in activities related to eating and drinking, thus it had a clear purpose.

### 8.7.3 Reflections on the importance of feedback

The BISTRo patient booklet served as a source of extrinsic feedback. It was utilised to record patients' daily experiences, with entries written in the patient's own words by either the patients themselves or the staff. Feedback conversations centred on progress and the tasks that patients wanted to try out the following day. This process was observed as an exchange of information regarding task performance, a reflection of previous task performance and the establishment of performance goals for the future. Parker and colleagues (2014) argue that feedback should be personalised, simple, rewarding, and measurable. The BISTRo booklet was tailored and personalised to individuals' needs and captured their aspirations in their own words, allowing them to review previous days to gauge their progress.

### 8.7.4 Reflections in goal setting

In accordance with best practice, patients were encouraged to record their personalised goals in the BISTRo booklet. Conversations about these goals were a consistent part of the intervention, aimed at motivating those unable to see a change in abilities. Both NICE and the National Clinical Guidelines for Stroke recommend that goal setting is person-centred, meaningful, and collaborative (Nyong and Playford, 2017; Royal College of Physicians, 2023). However, Sugavanam's (2013) review of qualitative and quantitative studies found there are no consistent approaches to goal-setting processes.

Staff members recognised breakfast groups as a mechanism for achieving goals related to regaining independence and acknowledging that stroke survivors were actively striving for progress. Locke and Latham's early work on goal setting emphasises motivation and goal-driven behaviour informed by Bandura's research on self-efficacy (Locke *et al.*, 1981; Locke

and Latham, 2002; Latham, et al., 2017). Bandura's concept of self-efficacy highlights the confidence gained through the accomplishments of specific tasks or personal goals and the reciprocal relationship between self-belief and a sense of achievement (Bandura, 1978). This sense of self-efficacy was also evident in the findings, as stroke survivors found value in the daily log, which allowed them to record daily achievements and review past accomplishments. By setting their own goals and documenting their daily experiences, they could more readily observe their progress and personal change.

#### 8.7.5 Reflections on social interaction

While Maier and colleagues (2019) have included social interaction as one of their principles of neurorehabilitation there is a limited evidence base supporting the view that social intervention is an integral part of the rehabilitation process. This study offers some explanations for the significance of social interaction as an important component of a neurological intervention and adds to the body of evidence. An important finding in this study was the evidence of social learning which was observed in various modes of communication transactions. Comparison with fellow stroke survivors was also found to have a positive effect. Social learning and interactions were evident in peer support and the development of interpersonal relationships between patients and staff members. The social component of the intervention was found to have a significant influence on mood, and positive mindset as well as provide valuable learning opportunities for patients.

Stroke survivors used words to describe their peers such as comrade, compadre and friend, they spoke of togetherness and staff observing this described it as solidarity. Consuming food together in a social context appeared to activate social bonding which resonates with the research on commensality (Fischler, 2011; Jönsson, et al., 2021; Le Moal et al., 2021), where closeness grows through social connection, creating a social space for people to engage with one another. Findings suggest that being with other stroke survivors reduced feelings of loneliness and socialising had a therapeutic effect on both mood and wellbeing.

#### 8.7.6 Reflections on the prototyping

Prototyping the intervention was a way to ensure that the end product met the needs of those delivering and receiving the intervention. It can minimise risks of wasted time and resources and create efficiencies and the practicalities have been addressed in advance (Lambeth & Szebeko, 2011). However, it can also be time-consuming and lengthy, requiring the engagement of multiple stakeholders. The advantage of testing in multiple sites was that different contexts could be assessed for feasibility and acceptability. Although the sites were in one region the stroke pathways, service configuration, staffing complement and ward environments were significantly different. Multi-site prototyping provided insights into the feasibility and performance of breakfast group interventions in varying conditions which provided a more comprehensive understanding of how it performs in different locations leading to more generalisable results.

#### 8.7.7 Reflections on the concept of failure

During the prototyping discussions, stakeholders were worried about 'failure' sharing concerns about the multiple factors that could impede the success of delivering the study or implementing the intervention. Lambeth and colleagues (2011) pose that failure is an

accepted part of the prototyping as this helps the researcher to learn what works and what doesn't work. Failure in codesign can lead to the refinement of ideas so that any shortcomings in the initial concepts can be addressed. As the CI, I provided ongoing reassurance and permission that the codesign and prototyping process may include failure as part of the iterations and that this was an expected part of the approach.

A journal reflection highlighted the contrast between my perspectives as a CI and the concerns and discomfort of stakeholders regarding the fear of failure. This difference in outlook could be attributed to my background as a service improvement coach which has shaped my belief that failure can serve as a catalyst for growth, innovation, and improved outcomes. There has been a long-standing political and policy debate about the 'blame culture' in the NHS (Hunt, 2016; Tasker, 2023) and the desire to move towards a learning culture. Failure is associated with negative consequences and as a result, people are less inclined to embrace change.

These deep-rooted issues drive behaviour and subsequently a fear of 'getting it wrong' or fear of speaking up (Hunt, 2016; Tasker, 2023). As the facilitator of these conversations, it was important to acknowledge concerns and explore them through collaborative problem-solving. Those less familiar with the principles of service improvement may have been more cautious or have risk-averse perspectives on failure. I noted that my influence as a researcher was on reframing the obstacles and shifting the focus from the 'concept of failure' to the potential for change and learning. In future codesign projects I will dedicate time and space at the start of the research to explore attitudes towards 'failure' and embracing failure as part of the journey and I will ensure that there is ongoing check-in time for conversation about risk and acceptance of imperfections.

#### 8.7.8 Chapter Summary

This Chapter applies the Theoretical Framework of acceptability (TFA) by Sekhon (2017) to present the findings concerning the intervention's acceptability as perceived by both staff and patients. It discusses the practicality and feasibility of the intervention and toolkit using Tickle-Degnen's Framework (2013). It investigates the perceived outcomes and benefits of the intervention and presents a revised logic model.

## Chapter Nine: Discussion

### Chapter Summary

This Chapter is in five parts:

- 1) Revisits the original research question and the aims and objectives of the study.
- 2) Presents a summary of findings in the context of the stroke national clinical guidelines and contemporary research.
- 3) Discusses the strengths and limitations of the chosen methods and their implications for clinical practice and fellow researchers.
- 4) Describes' the challenges and obstacles encountered during the study.
- 5) Articulates the original contribution of this thesis to the field of stroke rehabilitation and recommendations for future research.

#### 9.1 How the aims and objectives of the study were met

The necessity for this study arose from a notable gap in stroke-related literature concerning group-based eating and drinking interventions. BISTRO serves to enhance the knowledge of breakfast group interventions in the field of stroke rehabilitation and makes a meaningful contribution to the growing theoretical discourse that is emerging in practice around group eating and drinking interventions and their application in stroke rehabilitation. Clinicians are seeking evidence of the acceptability and feasibility of breakfast group interventions to inform their clinical practice and offer valuable guidance for planning and structuring such interventions, ultimately aiming to improve patient outcomes.

This study aimed to codesign a breakfast group intervention and implementation toolkit to improve the way eating and drinking rehabilitation is delivered in acute stroke units. This aim has been met as a breakfast group has been designed, implemented, and tested and is still being delivered in three stroke services.

*Objective 1: Review research evidence and theories relevant to rehabilitation of eating and drinking difficulties, to inform intervention planning and design.*

This objective was met by conducting a review of the relevant literature on breakfast group interventions and a specific systematic literature review to understand the psychosocial impacts of eating and drinking difficulties (Chapter 4). The findings of this contributed to the development of the intervention (Chapter 6).

*Objective 2: Codesign with relevant stakeholders a breakfast group intervention and supporting implementation toolkit.*

This objective was met ( Chapter 6). A group of stakeholders and a stroke PPI group interactively codesigned a prototype intervention.

*Objective 3: Iteratively develop and test the feasibility and acceptability of the prototype intervention and accompanying toolkit in three stroke services.*

This objective was met (Chapters 7 and 8). A prototype was delivered in three NHS sites and assessed using data from twelve interviews and three focus groups. It was found to be feasible and acceptable. The prototype was refined and ready for use in a future feasibility study and Randomised control trial.

## 9.2. How the breakfast group intervention addressed current national guidance

Eating and drinking interventions in stroke rehabilitation are not new concepts but historically they have been delivered on an individual basis. Very little is written about group meal-time interventions in stroke rehabilitation and even less so concerning breakfast group interventions. Despite this, the key components of the intervention as described in the logic model (Figure 47), peer support, goal setting, multidisciplinary approach, practice, and repetition- have an evidence base and are promoted individually as good clinical practice in the National Clinical Stroke Guideline (Royal College of Physicians, 2023).

National Clinical Guidelines for Stroke (Royal College of Physicians, 2023) recommend that people with motor recovery goals have a minimum of three hours of multi-disciplinary therapy daily and this is also recommended in the new NICE Stroke Rehabilitation in Adults guidelines (NICE, 2023). Intensive interventions are thought to produce better clinical outcomes although the evidence is mainly related to physical aspects of rehabilitation rather than psychosocial interventions (Royal College of Physicians, 2023). BISTRo is a multidisciplinary intervention which can provide one hour of intensive rehabilitation every day (Royal College of Physicians, 2023). Therefore breakfast groups provide clinicians with the opportunity to meet one-third of the new rehabilitation intensity target.

Breakfast groups were found to offer an opportunity to tackle the emotional and social aspects that emerge due to a change in eating and drinking. The NICE guidance for Stroke Rehabilitation emphasises the importance of addressing emotional well-being during interventions (Section 1.6.2 NICE, 2023) and they encourage the exploration of interventions that not only offer intensity but also address psychosocial factors (NICE, 2023).

A new addition to the 2023 RCP guidelines is the recommendation that multi-disciplinary teams incorporate the practice of functional skills into daily routines, taking a personalised approach (Royal College of Physicians, 2023). BISTRo provides a context for deploying functional practice by incorporating the preparation of food and drink with the consumption of food and drink as well as addressing personal needs.

The guidelines put forth by the Royal College of Physicians (2023, pg. 65) advocate for the involvement of trained healthcare professionals in the rehabilitation process under the guidance of a qualified therapist. The BISTRo delivery model encompasses a mix of registered and trained staff. This blend of diverse skills, expertise, professional backgrounds, and staff grades facilitated the daily implementation of the intervention within the scope of this study. The responsibility for staffing and overseeing the group is not borne by a single profession alone. Distributing the staffing responsibilities has provided flexibility and has also allowed smaller professions like dietetics and psychology to make contributions, albeit with lower frequency.

### 9.3 Findings in the context of existing research

A review of research evidence and theories relevant to the rehabilitation of eating and drinking difficulties was undertaken (Chapter 5) to inform intervention planning and design. The vast majority of research in this area has focused on the physical impacts of stroke on eating and drinking difficulties. A few studies address the psychological and social impacts (Perry and McLaren, 2003; Medin et al., 2011; Kjaersgaard and Pallesen, 2020) but relatively little is understood about the impacts of these on recovery. To the CI's knowledge, this is the first multidisciplinary eating and drinking breakfast group intervention study of its kind that has a focus on the psychosocial aspects of recovery as well as physical rehabilitation.

Other specialities such as dementia care (Pietro and Boczko, 1998; Li et al., 2020; Anantapong et al., 2021) and head and neck cancer (Ganzer et al., 2015; Dornan et al., 2021; Dalton et al., 2022) have explored the perceptions of altered eating and drinking habits and the subsequent psychosocial impacts. There were no such studies with stroke populations. To address this gap in research I conducted a systematic review of the psychosocial impacts of eating and drinking difficulties on stroke survivors.

The review provides new insights into the lived experience of stroke survivors, highlighting for clinicians the aspects of lived experience which need to be addressed in rehabilitation. Six key themes are presented for clinicians and researchers to consider when assessing and delivering care 1) experience of loss 2) fear and panic 3) embarrassment, shame, and humiliation 4) social isolation 5) striving for social dining 6) getting back to normal.

The experience of loss associated with impaired motor and sensory functions is similar to head and neck cancer survivors who describe the types of loss experienced which include; loss of taste (Burges Watson *et al.*, 2018), loss of confidence (Dalton *et al.*, 2022) and loss of social activities related to eating and drinking (Ganzer et al., 2015). Both patient populations also describe experiencing shame and embarrassment leading to avoidance of eating and drinking (Dornan *et al.*, 2021).

Despite the impacts of eating and drinking difficulties, stroke survivors are striving to regain confidence, adapt to disability and develop effective coping strategies so that they can get back to normal. This desire to regain eating and drinking abilities was also found in several studies with head and neck cancer patients who reported the desire to adjust and take control (Dornan *et al.*, 2021) and adapt to changes in eating habits (Ganzer et al., 2015; Dalton et al., 2022).

Some limited studies have indicated that communal dining in stroke wards can enhance nutritional intake (Lewis and Lang, 2018; Abouhajar et al., 2019). However, these studies exclusively concentrated on communal dining as an intervention and did not incorporate a rehabilitative aspect. In a similar investigation, Lin, and colleagues (2021) implemented a six-week food preparation program for stroke survivors with dysphagia who were living at home to enhance their dietary well-being. While there are a few conference abstracts and service improvement projects detailing stroke services experimenting with meal-time groups, they lack detail on the specific components and are not codesigned with stroke survivors and healthcare professionals. Notably, while there are studies aimed at understanding the challenges of eating and drinking difficulties and those aimed at improving nutrition and



hydration, this is the first study to examine a meal-time intervention with a focus on the rehabilitation of both physical and psychosocial recovery.

This systematic review identified gaps in research for future studies and critical gaps in evidence for eating and drinking interventions that address psychosocial needs. From this review, a breakfast group intervention was codesigned and assessed for feasibility and acceptability. Six key themes from the review were taken forward into the intervention design stage to ensure that the end product would address the issues most important to stroke survivors and healthcare professionals.

## 9. 4 Findings in the context of existing theory

### 9.4.1 Social Comparisons theory

Social comparisons theory was developed by social psychologist Leon Festinger in 1954. The basic premise of the theory is that people evaluate their own performance by comparing themselves to others (Hoddinott et al., 2010). The comparisons can occur in various domains such as physical appearance, intelligence, achievements, and social status (Hoddinott et al., 2010). In BISTRo patients were comparing themselves to peers. Festinger talks about upward and downward comparisons of similarities and differences (Hoddinott et al., 2010), and this concept was observed during the study. A criticism of social comparison theory is that it doesn't take into consideration temporal comparisons which involve comparisons with the past, present and future (Hoddinott et al., 2010). There was evidence of stroke survivors reflecting on their previous and current abilities as well as how they would cope in the future.

### 9.4.2 Social Cognitive Theories

Social cognitive theories are a group of theories which focus on how people learn and develop through interactions with others (Jones, et al., 2008; Jones and Riazi, 2011). They provide a framework for understanding human behaviour, and how people learn and adapt following illness (Jones and Riazi, 2011b). Albert Bandura introduced two foundational concepts that served as the basis for a collection of theories. Firstly he studied how individuals learn from one another through observation, imitation, and modelling behaviour (Bandura, 2004). Chapter 2, Section 2.1 delves into the research by Mennell and associates (1992), which underlines the significance of food and communal dining in human culture. Mennell emphasises how social dining serves as a pathway for social learning. During the prototyping phase, social learning manifested itself in four distinct ways, and these are prosed as a potential advantage of the intervention in Chapter 8.

Secondly, he introduced the idea of self-efficacy and how an individual's self-belief can affect their ability to achieve a particular goal (Bandura, 1978). Self-efficacy is a psychological construct derived from social learning theory (Jones et al., 2008). Ouyang and colleagues (2023) propose that it is an influential factor in stroke recovery. Core elements of self efficacy are described by others as; self-belief (Appalasaamy et al., 2019), ability to self-manage (Amiri et al., 2022) and improved functioning (Rasyid et al., 2023).

A recent review by Ouyang and colleagues (2023) found that interventions based on Bandura's social cognitive theory were effective in improving confidence post-stroke. They

identified four key principles i) ability to perform a task, ii) observation and modelling, iii) social support iv) understanding physiological states could increase receptivity.

The breakfast group enabled patients to prepare and enjoy their morning meals, and with practice, they noticed improvements and achievements. Patients expressed a desire to explore new tasks and used peer-to-peer observations to assess their progress and strive for improvement. Healthcare professionals and peers offered valuable social support, providing positive verbal encouragement. Ouyang and colleagues (2023) suggest that "receptivity," which involves understanding one's physiological state, can enhance the willingness to embrace and experiment with new concepts. This receptivity was evident when patients filled out their daily logs, as they deliberated on which new tasks to attempt the following day based on their observations of others and their aspiration to attain greater competency with the tasks.

#### 9.4.3 Focus orientated theory

The stroke literature on recovery from eating and drinking difficulties discusses coping strategies (Medin et al., 2010; Klinke et al., 2013; Helldén et al., 2018), adjustment (Dallolio et al., 2018) and striving to regain life after a stroke. Coping theory is important in rehabilitation because it provides a lens through which to understand the psychosocial impacts of stroke and it helps rehabilitation teams to work with individuals to develop effective coping strategies and adjust to stroke-related disability.

The transactional model of coping and stress by Folkman and Lazarus (Lazarus, 1993) has had a significant impact on stroke rehabilitation, with its conceptual framework being utilized in psychosocial interventions. The model is based on the dynamic intervention between a person and their environment when dealing with stress (Lazarus, 1993). A strength of the model is the holistic person-centred approach to coping strategies. However, it has been criticised for the lack of sophistication and sensitivity to predict behaviour changes, address cultural differences, and apply to complex scenarios (Biggs, et al., 2017).

The desire to cope was featured in the findings of the literature review and was also discussed as an important element of the stakeholder conversations. Coping was also discussed in Chapter Six in relation to how self-confidence can enhance beliefs and motivation. Interviews undertaken after the prototyping stage found that patients appreciated a safe place to try out new tasks and also make mistakes. This intervention aimed to influence how patients felt about their abilities and to facilitate coping strategies. During the breakfast group stroke survivors were gaining new skills and regaining those lost which involved deploying a range of strategies and mechanisms. Coping strategies observed included problem-solving, seeking social support, emotional expression, distraction, and positive reframing. Effective coping can help individuals navigate difficult circumstances, reduce the negative impact of stress, and maintain psychological and emotional well-being.

#### 9.4.4 Motivational therapy

Motivation is defined as 'being moved to act' (Bandura, 2004). There are different ways people are motivated, producing varied outcomes There are extensive motivation theories in the field of human psychology which have interconnected ideas (Vroom, 1964; Bandura,

1978; Locke and Latham, 2002). Self-determination theory is one theory developed by Edward Deci and Richard Ryan in the 1980s and it provides a perspective on understanding human behaviour and the underlying motivations (Elliot, Dweck and Yeager, 2017). Motivation can be described on a continuum which also involves intrinsic and extrinsic factors (Elliot, Dweck and Yeager, 2017). In stroke rehabilitation healthcare professionals use motivational theories to understand what drives individuals, their readiness to engage in rehabilitation and adherence to treatment plans (Maier, Ballester and Verschure, 2019).

A principle of self-determination theory is autonomy and the importance of choice, control, and self-volition (Elliot, Dweck and Yeager, 2017). The results of step 1 in the Hawkins Framework affirmed the significance of personal preference and choice for stroke survivors. Similarly, the observations presented in Chapter 5 of the ethnographic observations further validate the notion that elements within the intervention, including portion size, breakfast menu options, and customization of both the intervention and booklet, were highly appreciated by both patients and staff.

Two other fundamental concepts in self-determination theory are competence and relatedness (Elliot, Dweck and Yeager, 2017). The BISTRO booklet daily log was viewed as a positive way to record and measure competence. Patients were using their booklets to reflect on progress and affirm what they had achieved. This affirmation was important when patients were having less confident days or if they were struggling to see progress. Self-determination theory focuses on the basic need to acquire competencies as central to motivation. Those intrinsically motivated enjoy opportunities to test out their skills, competence and autonomy and experience a feeling of reward (Elliot, Dweck and Yeager, 2017). There was evidence of patients thinking about BISTRO in this way. It was an opportunity for them to practise and improve their eating skills.

Relatedness is described as a connection to other human beings (Elliot et al., 2017). A sense of belonging, demarked by positive exchanges (Elliot et al., 2017)). Relatedness involves creating meaningful relationships which is thought to be essential for well-being (Elliot et al., 2017). Peer support is one such meaningful relationship which is recognised as a psychosocial intervention in stroke rehabilitation (Royal College of Physicians, 2023). It provides an opportunity to develop relationships with other stroke survivors. The breakfast group was referred to as a 'club' and patients were seen waving and communicating with one another out of the group. The connection they developed in the group was sustained beyond. There was a sense of community and friendships blossomed. With this, a deeper connection was experienced, and peer-to-peer support enabled deeper sharing.

#### 9.4.5 Expectancy theory

Expectancy theory is based on the assumption that effort leads to a certain positive outcome (Locke and Latham, 2002). It relies on a degree of self-belief and the value assigned to the outcome which Vroom, (1964) refers to as valence (anticipated satisfaction and expectations) and instrumentality (the belief that performance will yield results) (Locke and Latham, 2002; Latham, et al., 2017). This gives insights into why the setting goals process is important as this can trigger thoughts and expectations and create a belief that the results are achievable. A weakness of this theory is the reliance on emotional and self-motivation

which doesn't take into account that people might be motivated by other factors or that goals may be harder to achieve than anticipated. The impact of a stroke on an individual's motivation could affect valence and instrumentality and stroke survivors may not be in a position to accurately assess or predict their capabilities.

If the person's values or beliefs are different to those proposed in the goal-setting conversation the stroke survivor might be less motivated or committed to the agreed goal. This was observed on two occasions where stroke survivors believed their performance to be lacking and not progressing as they thought it should. On both occasions, a member of staff knelt beside the individuals and took to time to encourage self-reflection and review what they had achieved and how much they had changed since admission. On both occasions, the patient booklets were used as a visual aid to show this progress. During the breakfast groups, there were opportunities at the end of each session to discuss personal beliefs about progress. Several patients said that having the conversation or writing it down reinforced their level of abilities and made it more visible to them.

#### 9.4.6 Commensality

Commensality as discussed in Chapter 2 refers to the act of eating and sharing meals together with others. It encompasses the social and cultural aspects of dining and the experience of sharing food with family, friends, or members of a community. Commensality often involves not just the consumption of food but also the social interactions, conversations, and bonding that occur during shared meals. It plays a significant role in many cultures and can have important social, psychological, and even health-related implications. This study found that commensality was a significant component of the intervention. When asked about the benefits of breakfast group interventions the majority of the patients described aspects related to social connection and the act of dining with others as the most important factors. Additionally, the social learning that took place during observations and interactions played a significant role in helping people to progress.

### 9.5 Strengths and limitations of the research

#### 9.5.1 Reflections on Hawkins' 3-step Framework

Hawkins's three-step framework offered a practical roadmap for creating, co-producing, and prototyping a new healthcare intervention. However, there was a gap in the framework's coverage when it came to reporting stakeholder engagement, where more comprehensive information was necessary. To strengthen patient and public participation and provide a structured approach to coproduction activities, the Hawkins Framework (2017) was augmented by the integration of Experience-based Codesign methods (EBCD). EBCD introduced a level of structure that was absent in Hawkins's original framework (2017), enhancing the rigour of the codesign aspect of the intervention.

Hawkins recommends the testing of a new intervention with a small sample size of the target population (Hawkins et al., 2017). BISTRo was prototyped and iteratively tested with sixteen stroke survivors in three hospital sites in one county. Feasibility studies are not intended to have large sample sizes and instead rely on qualitative data and descriptive statistics (Tickle-Degnen, 2013). Raynor and colleagues (2020) argue the benefits of using multiple-site testing before larger randomized trials are to try out an intervention in

multiple different care pathways and bring together clinicians who don't normally get a chance to work together.

While the BISTRo study evaluates the acceptability and feasibility of the breakfast group intervention, it's important to note that this represents the initial phase within the MRC Framework for the development and assessment of complex interventions (Redfern, et al., 2006; O’Cathain et al., 2019). The subsequent steps involve expanding to a more extensive clinical trial. The results indicate that breakfast groups are well-received in a particular UK region, but the intervention now requires testing with a significantly larger sample of stroke survivors encompassing diverse geographical areas and a broader range of ethnic backgrounds.

It's important to identify and address real-world issues affecting feasibility and acceptability in the early stages of intervention development (Hawkins et al., 2017) to ensure the intervention is fit for the intended purpose and threats to implementation are addressed (Tickle-Degnen, 2013). Following prototyping in three sites, the research data and informal feedback were used to inform the final version (v3) of the intervention and toolkit. Involving the end users of an intervention can ensure engagement with the intervention and support future implementation and translation of research findings into practice (Hawkins et al., 2017).

A strength of the Hawkins 3-step Framework was the use of multiple data sources. There were twelve data collection points during the study which included collecting data using a range of from a variety of people. The people involved in the first in-depth interviews were different to the people involved in the ethnographic observations and the people involved in the consultations were different to those involved in the intervention prototyping. Thus enabling a deep and rich understanding of the lived experiences gained from multiple perspectives (Raynor et al., 2020).

A criticism of the Hawkins 3-step Framework is the lack of published detail around stakeholder engagement. Others have noted this (Maindal et al., 2021) and chosen to combine approaches as suggested in the O’Cathain and coauthors (2019) guidance for complex intervention development. Experience-based Codesign (EBCD) was selected by the CI to combine with Hawkins's 3-step Framework (2017) as it was a recognised and published approach with relatively strong evidence-based and clearly defined methodological stages.

#### 9.5.2 Reflections on EBCD

The advantages and strengths of EBCD have been widely reported in the literature (Donetto, Tsianakas and Robert, 2014). One such advantage is the engagement of patients and staff in service improvement work (Boaz et al., 2016). The engagement of individuals who receive and deliver an intervention in designing or developing the intervention is thought to increase buy-in for the project and foster a greater responsibility for the implementation (Moore and Buchanan, 2013).

Another strength of EBCD is the opportunity to change beliefs and attitudes through emotional engagement (Brady, Goodrich, and Roe, 2020). The trigger videos were used in BISTRo to enable emotional engagement with understanding the lived experience of eating

and drinking difficulties. Emotional and intellectual connection with the experience data and the trigger videos gave greater insights into the difficulties experienced by stroke survivors which informed the development of specific elements of the intervention protocol and the implementation toolkit.

Bate and Robert, (2006) discuss the wider impact of using EBCD alluding to the move in health care policy towards patient-centred care. More recently there has been a seismic shift towards personalised care, signalled by the release of the comprehensive personalised care model (Sanderson, Kay, and Watts, 2019; NHS England, 2021). EBCD aligns with the model's key principle of what 'matters to you' and 'supported self-management.

EBCD provides a collaborative grassroots approach that aligns with the findings of Moore and Buchanan, (2013), who uncovered that smaller-scale projects led by clinical experts, uniting staff to tackle real-world challenges and devise effective solutions, can bring about sustainable change. The utilisation of quality improvement methods in research for co-creating and implementing novel interventions is gaining traction (Green et al., 2018). EBCD presented BISTRO with the chance to collaborate with both recipients and providers of the intervention, ensuring it was suitable and redressing the power imbalances that can often be present in research (Brady, Fredrick, and Williams, 2013; Cooke et al., 2017; Cornish et al., 2023).

In their work from 2019, Palmer and colleagues (2019) delineate the contextual hurdles and drivers within EBCD, emphasising the significance of acknowledging these elements and their impact on project outcomes. The breakfast group intervention was designed to be delivered in three stroke services, with contextual differences across the sites, encompassing staffing, resources, and organisational structures. The study intervention development group were challenged to devise an intervention that displayed the adaptability required for each site context whilst standardising the essential core components.

The global pandemic introduced an additional layer of complexity when conducting a study. Following the initial workshop, attendance fluctuated; nevertheless, a majority of those unable to attend actively participated by reviewing the recordings and post-meeting materials, and providing valuable feedback. The project managed to maintain ongoing support and commitment from stakeholders. This success can be attributed to the general enthusiasm for the project and the emotional investment of stakeholders in the research, as well as the engagement-promoting techniques inherent in EBCD approaches. Those who granted consent to participate in the project were driven by a shared aspiration to establish a more structured approach to delivering breakfast group interventions and improving outcomes for patients.

### 9.5.3 Reflections on combining Hawkins 3-step Framework and Experience-based Codesign.

This study represents an innovative approach to combining Hawkins's 3-step Framework (2017) with the methodologies of Experience-based Codesign (Bate and Robert, 2006). This fusion led to the development of a comprehensive study design diagram that can be shared with fellow researchers for their use. By integrating these approaches, a response to Hawkins's (2017) critique, which highlighted the lack of guidance on stakeholder consultations, has been addressed. While EBCD follows a well-defined 7-step process, this



study introduced an additional 8th stage, titled 'measure impact,' as delineated in Figure 50. In Stage 8, a research impact tool is introduced to collect data on the impacts of the research.

An example of BISTRO's research impact data collection can be found in Figure 49, with further insights into research impacts available in Appendix 24. Notably, one of this study's unique contributions is the study diagram, illustrating the synergy between Hawkins' 3-step framework and EBCD, demonstrating their collaborative use in the codesign of the breakfast group intervention. Another distinctive and original contribution is the cartoon storyboard, designed to guide readers through the codesign process, available in Appendix 18.

#### 9.5.4 Reflections on stakeholder engagement and coproduction

Power dynamics and tension could exist and negatively impact relationships between the patient representatives and NHS staff (discussed in Chapter 3). Steen and colleagues (2018) write about the 'dark side of coproduction', its potential pitfalls and how it can go terribly wrong. Others also argue that coproduction isn't easy and serious challenges can derail the process (Palmer et al., 2019; Dobe, Gustafsson and Walder, 2023). Stroke survivors may feel like they don't have a voice (Palmer et al., 2019) and NHS staff could be uncomfortable with hearing stories of lived experience (Donetto et al., 2014).

Williams and coauthors., (2020) launched a counter-argument to Steens's (2018) assertions criticising their lack of depth in their definition of coproduction, as well as neglecting to discuss the contexts, structures and academic failings that might affect the outcomes. Moreover, they dispute the use of the words 'dark' and 'evil' to describe the challenges in coproduction and how the discourse by Steen and colleagues (2018) is largely from the author's perspective, not acknowledging the value of coproduction as an '*egalitarian*' and '*non-emancipatory*' approach to research.

During this research study, balancing the needs of different stakeholders was challenging at times. There were occasions when stroke survivors proposed ideas that would not work in clinical practice. However, this provided an opportunity for dialogue and a greater understanding of each other's realities. As the CI, I had to strike the balance between this being a researcher-led PhD study and living the principles of coproduction. Coulter and colleagues (2014) argue the moral ethics of asking patients for their opinions and experiences and then not using them can stifle coproduction. Although there was tension between the views of the stakeholders as the chief investigator, I made the final decisions, and I led the workshops with the ethos of reaching consensus and shared decision-making.

#### 9.5.5 Reflections on the use of design approaches

The disciplines of design and health usually operate in different spaces (Craig, Reay, and Nakarada-Kordic, 2019). In recent years the NHS has been looking for alternative ways to redesign services and has realised that by bringing in designers to NHS contexts the synergy between health and design can be advantageous (Chamberlain and Craig, 2017).

I have actively engaged in multiple NHS projects where designers have been integral to the team, contributing to the development of innovative products, including telemonitoring devices, female urinals, a flushing commode, and head and neck support for individuals with



motor neurone disease (Reed et al., 2015), redesign of rehabilitation programs for spinal injuries (Wolstenholme et al., 2014) and enhancements to hospital environments (Bowen et al., 2013). Despite the existing evidence of collaboration between designers and healthcare professionals, this field remains relatively new, offering ample opportunities for further exploration and learning (Craig, et al 2019)

These learning opportunities have enabled me to develop skills in using codesign and creative methods, understand the nuances of involving service users and develop a passion for codesign methods. Using creative and participatory methods to generate ideas for the intervention provided non-threatening ways for stakeholders to collaborate and have constructive dialogue.

In my fellowship, I encountered a funding constraint that precluded the hiring of a designer for the study. Nonetheless, I leveraged my prior experiences, as described earlier, engaged in conversations with colleagues immersed in the field of design, and delved into design literature to gather insights. My inspiration for creativity was drawn from Langley and coauthors' (2022) description of creative practice:

*“Creative practice as a way of being and doing; a marriage of divergent and convergent thinking and acting, where each half informs the other. The use of artistic and/or novel ways of inquiring; thinking, seeing, exploring, reflecting, questioning, communicating, documenting, and recording”.*

These learning opportunities empowered me to develop proficiencies in employing codesign and creative techniques, grasp the intricacies of engaging service users and sparked a passion for codesign methods. The utilisation of creative and participatory methods to generate ideas for the intervention offered non-intimidating ways for stakeholders to engage in collaborative and constructive dialogues.

Given the shift in the paradigm towards involving public and patient representatives from marginalized groups, researchers must adopt creative approaches for effectively collaborating with seldom-heard voices (NIHR, 2020; Broomfield et al., 2021). In the context of BISTRo, I enlisted an illustrator to create visuals for the BISTRo booklet and the storyboard. My role was primarily facilitative to ensure an impartial depiction of requirements and ideas in the illustrations. This final product can be shared as a reference for other clinicians and researchers working on codesign in similar projects (see Appendix 18 and 21 for examples of the illustrator's outputs).

The illustrator remained responsive to stakeholder feedback, making iterative improvements to the booklet's pages. The most contentious and contested aspect of the booklet was the pages on weight. There were disagreements on the language used to describe being overweight and underweight and the content of the page. This took several iterations to navigate the tensions and arrive at an agreeable design. Having an illustrator involved in this element helped to alleviate the tensions and provide a space where coproduction could thrive.

#### 9.5.6 Reflections on sample bias and recruitment

Qualitative research aims to reflect diversity in the specified population and can no longer rely on convenience sampling (Barbour, 2001). Purposive sampling offers the CI opportunities to recruit a broader range of participants and avoid selection bias found in other methods of sampling (Barbour, 2001).

A limitation of the study could be the imbalance between patients and carers and NHS staff in the stakeholder group. As recruitment was taking place during the pandemic this could have impacted the number of stroke survivors wanting to participate in research. Palumbo, (2016) suggests that there is an 'unwillingness' of patients to get involved in projects about health care provision and the medical model of paternalistic care is a barrier to engagement. Recruitment for BISTRo was impeded by staff shortages due to COVID-19 and the suitability of the patient case mix to participate (site 3). Besides these, the willingness of stroke survivors did not seem to be an issue.

Due to there being more NHS staff than patient representatives in the stakeholder group, they could have dominated the conversation. However, the stakeholders were respectful of each other and used the ground rules to ensure that everyone had an opportunity to contribute. There was a range of professional backgrounds which also provided diverse views. NHS staff were keen to hear about the lived experiences of patients and informal carers and any decisions were made by reaching a group consensus. There was also a patient and public panel with 10 stroke survivors which were consulted on three occasions during the design, refinement and prototyping stages which compensated for the lack of patient representatives on the stakeholder intervention development group.

#### 9.5.7 Reflections on the by-products of research

Some members of the Stakeholder Group have become champions of the intervention in their organisations, and this has created a community of problem-solving and sharing where the stakeholders work together to share ideas, and resources and overcome issues in clinical practice together. An example of this is the sharing of the aphasia-friendly menus from one site to the others. Through discussions in the stakeholder meetings, NHS staff were enthused about having better aphasia-friendly menus for all patients. Although we were co-creating one for BISTRo, staff started to work outside of the study to share areas across the sites to develop ideas for a generic aphasia-friendly menu. Site 1 shared a template they had developed for the other sites to adapt and use. Boaz and colleagues (2015) describe this as a 'by-product of research', an impact of healthcare research that *'has arisen as a by-product of the original study'*.

#### 9.5.8 Reflections on operationalising the intervention

The local implementation of the intervention and toolkit was pragmatic to fit with organisational contexts. Craig et al., (2006) assert that variability in how interventions are applied locally is an 'under-recognised' aspect of complex intervention development and fidelity is complicated. Site Principal Investigators were asked to record any deviation from the research protocol, and none were recorded. Pragmatically the research protocol had core elements which were fixed and other elements which could be adapted to site-specific needs. Craig and coauthors (2006) suggest that controls are applied to limit variation but

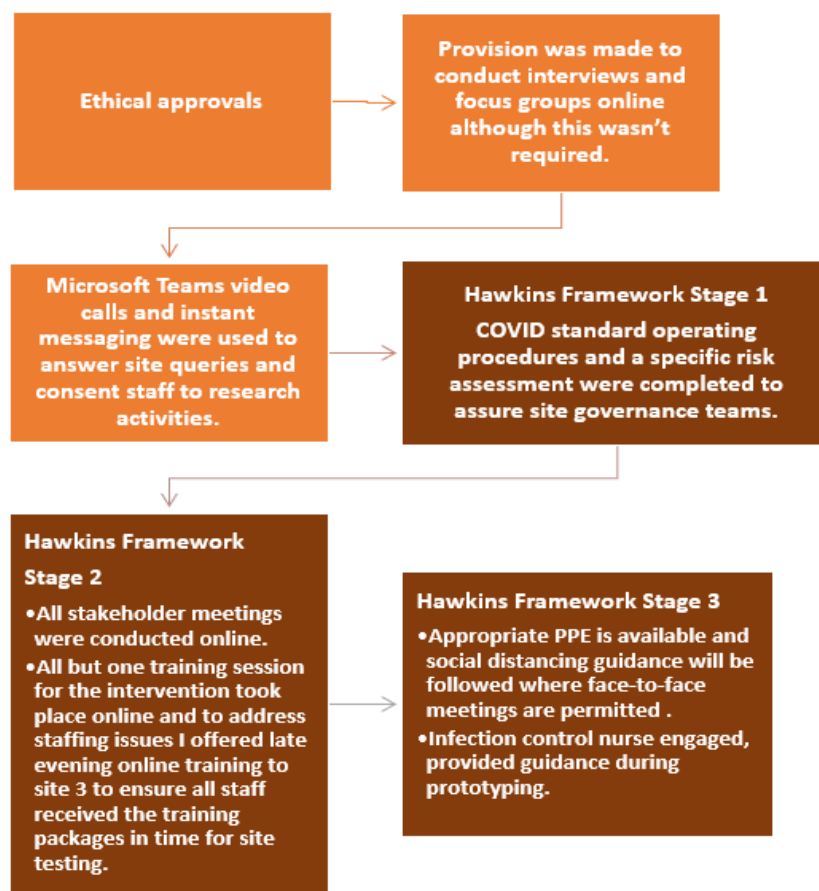
argue that variation can be tolerated in some circumstances where it is advisable to adapt to specific contexts. To mitigate unplanned variation the research protocol provided clear guidance on where variation was permissible.

The original plan for BISTRo was to iteratively prototype the intervention. The time frames for prototyping allowed a brief period between testing for any improvements and changes to the intervention and toolkit to be made. What happened in reality was that a COVID outbreak at the site shut down the ward for two weeks halting the start date for prototyping in site 1 for three weeks (version 1). This compressed dates between sites 1 and 2 testing. Then the original site 2 was informed that the whole ward would be moving to another location in the hospital, so they had to swap places and became site 3. There was a gap between sites 1 and 2 where the materials were new versions of the intervention, and the toolkit was created to test in site 2. However, due to delays created by staffing pressures and ward moves site 2's prototyping overlapped with site 3 (version 2). This resulted in no time to make any changes to the materials so sites 2 and 3 tested the same materials. Version 3 of the intervention protocol and toolkit were created following feasibility and acceptability assessments (interviews and focus groups) with those delivering and receiving the intervention.

During the study NHS staff on each site reported a reduction in admissions to the stroke pathway. This is supported by a systematic review by Dusen and colleagues (2023) who found that 84% of stroke studies reported decreased admission rates during COVID-19. Moreover, those participating in studies had on average a higher rate of stroke severity which could have affected suitability for certain studies.

The fluctuating situation with COVID-19 created a continuous level of uncertainty for the study. It was anticipated that the escalation of COVID-19 status in the winter period could affect the progress of the study by delaying or restricting activities. A COVID-19 outbreak at site 1 delayed prototyping and during the study adjustments were made to staffing rotas to accommodate unplanned fluctuating staffing levels. Planned contingencies were made for COVID-19 and these are described below (Figure 47).

Figure: 47 COVID Contingencies.



### 9.5.9 Reflections on the staffing model

Originally the plan was for patients to replace those patients discharged home on a rolling programme. In reality, this did not happen and the cohorts of patients in sites 1, 2 and 3 did not experience new patients joining. This could have influenced the bonding that occurred during the groups as the group dynamics and relationships were not disturbed by newcomers. Future studies need to be mindful of the pace of patient flows through an in-patient acute pathway and the pressures to discharge as soon as the stroke survivor is medically fit and care plans are in place. Future studies with a longer treatment phase should consider how patients can be added to a rolling programme of breakfast group interventions and the optimum time for introducing the programme with acute cohorts of patients.

All sites in the first week tended to have one consistent member of staff each day which helped to carry over knowledge of patients and BISTRO delivery requirements. However, once everyone was experienced in the delivery of the group there was less requirement for the same person to be present. The majority of the staff recruited to deliver the intervention delivered it once or twice in the two weeks. Reasons for not being able to deliver the intervention post-consent included staff sickness (COVID impact) and low staffing levels. When staffing levels were insufficient to release a member of staff (this happened in Dietetics, Physiotherapy and Nursing) other professions were able to provide an additional

member of staff or students to support delivery. No BISTRo sessions were cancelled due to staffing.

#### 9.5.10 Reflections on BISTRo versus usual care

Patients in BISTRo received significantly more eating and drinking interventions than they did the two weeks previous to the study. This data set is limited to four weeks (2 weeks before BISTRo and two weeks during BISTRo). However, this indicates that the intensity of eating and drinking interventions can be increased by introducing a daily group (Monday-Friday).

The intervention was only tested Monday-Friday. As this is a pragmatic study, early staff consultations discovered that it would not be possible to deliver the group at weekends due to the lack of seven-day services in stroke rehabilitation. Although some services have a weekend service, current service models focus on new patient assessment and discharge planning and not rehabilitation interventions. It was important to design an intervention that could be adopted as usual practice and delivered in real-world settings. The three participating sites had a skeleton weekend service which was focused on admission assessments. Rehabilitation programmes tend to be delivered five days a week, although if staffing models permit this study found that there is no reason why BISTRo can not be delivered seven days a week. A future study could explore BISTRo as a seven-day model of delivery.

#### 9.6 Trustworthiness and reflexivity

Trustworthiness is assured through the implementation of the principles of reflexive qualitative research (Barbour, 2001) and acknowledging bias (Daniel, 2019). Unlike quantitative research Barbour, (2001) argues that quality checklists can be counterproductively reducing qualitative research to a list of technical procedures.

In BISTRo trustworthiness was assured through the following activities:

- Reflexive practices.
- Peer debriefing and academic supervision during stages of data analysis (Long and Johnson, 2000).
- Presentation of research findings at conferences to attract peer review and critical commentary (Long and Johnson, 2000). For example findings from BISTRO were presented at several local, national, and international conferences, a list of these can be found in Appendix 17.
- Transcribing all the recordings and iteratively conducting data analysis to ensure that the 'participants' voices' were accurately heard (Long and Johnson, 2000).
- Consistent and rigorous process for coding (Thomas et al., 2004).
- Multiple coding, sections of the data sets were shared with PhD supervisors, stakeholder group and site principal investigators to check coding, themes, and interpretations (Barbour, 2001).
- Triangulation of the data in two convergence matrices to address internal validity by checking the convergence and dissonance of the findings from different data sources (Appendix 12 and 22) (Long and Johnson, 2000; Barbour, 2001)

- In respondent validation, the stakeholders were asked to check data to facilitate the iteration of the prototype research protocol and toolkit (Barbour, 2001). This was undertaken during data analysis to ensure the data was fresh in my mind (Long and Johnson, 2000).

#### 9.6.1 Reflexivity and considering the influence of the researcher

Researchers need to consider their position and influence when doing the data collection, data analysis and interpretation. Rigour in qualitative research is produced through reflexivity (Rashid, Caine, and Goez, 2015). Reflexivity is the recognition of the '*researchers' subjective feelings and attitudes*' (Long and Johnson, 2000). A researcher can work reflexively through journaling to note personal reflections and feelings or assumptions made during and after the research has been conducted (Rashid, Caine, and Goez, 2015). A journal was used throughout this study and personal reflection notes were made on the ethnographic field notes (Rashid, Caine, and Goez, 2015). I recorded my thoughts, beliefs, and decisions during data analysis to lessen the influence of my views on the data (Long and Johnson, 2000).

I have influenced the study in several ways:

- Firstly I am an occupational Therapist experienced in stroke rehabilitation. I am known in the South Yorkshire integrated delivery network of local stroke services. My reputation may have influenced and obligated people to participate in the research or have affected the contributions of staff (Suutari *et al.*, 2022). Also at the time of the study, I was working in the stroke services at site 1 as an Occupational Therapist. I was familiar with the healthcare professionals in the stroke wards who would be participating. There is a risk that staff could be influenced to participate due to previous relationships. To account for this I worked with the site's Principal investigator who was part of the clinical team to ensure that all eligible staff and patients were able to participate.
- Secondly, the close working relationship between myself and the stakeholders created a bond that also could have influenced the outcome of the study (Higginbottom, Pillay and Boadu, 2015). Despite these potential biases, there were some advantages to having a clinical role in the area such as access to potential participants, understanding and knowledge of the organisational configurations of stroke services and an ability to adapt the intervention to local contexts.
- Thirdly my ability to lead and sustain engagement and the demands of the stakeholder meetings for several months and weeks was important, but the high level of energy put into this could have influenced the engagement of the stakeholders. The meetings were limited to one hour to increase the likelihood of people attending. Attendance figures could have been influenced by the buy-in of senior leaders to the study. As there was a level of interest and enthusiasm for the study NHS staff had the support and permission of senior managers to prioritise the meetings.

Finally, although I approached this project with an open mind, the plan to develop a breakfast group intervention was predetermined as part of the NIHR Doctoral Fellowship application process. Despite this I have attempted to let the data lead the development of the key themes and the stakeholders lead the design of the intervention whilst remaining objective about what the end product would look like. In summary, I have conducted this research with methodological rigour, being self-critical and using reflective practices as discussed (Nordgren et al., 2008).

#### 9.6.2 Reflections on inclusion

The disparities in stroke prevalence and care between racial, ethnic and socioeconomic groups in high-income countries such as the UK and USA are examined in the literature (Cruz-flores et al., 2011; Faigle and Cooper, 2019; O'Carroll and Demaerschalk, 2021). However, this remains an under-researched area and little is documented about the clinical outcomes for ethnic minority groups admitted with a stroke to UK hospitals (Fluck et al., 2023). We know there are barriers to involving people from black and ethnic minority groups in research (Dawson et al., 2018; NIHR, 2020) but little is known about how this impacts the outcomes of stroke research.

I used the NIHR INCLUDE guidance for improving the inclusion of underrepresented groups in research (NIHR, 2020). There were no participants from black and ethnic minorities in the stakeholder and PPI groups, however, 19% of those receiving the intervention were non-white British, which is above the average population norms for South Yorkshire. People from black and ethnic minority groups also agreed to participate in the pre-intervention observations. However, the lack of representation in the Stakeholder Intervention Design Group may have influenced prototype development.

There is evidence to support the view that people with aphasia or those who cannot consent to stroke research in the usual way are often excluded from research (Brady et al., 2013). Researchers have been challenged to design consent processes that recognise the barriers experienced by those with disabilities, communication and learning disabilities (Russell et al., 2023). Shiggins and fellow authors (2022) argue that people with aphasia should be included in stroke research as standard practice. This study successfully recruited a number of participants with aphasia.

To address cultural preferences around eating and drinking I included a question about cultural and religious sensitivities in the three focus groups and twelve interviews. One participant mentioned that there could be more choices of breakfast food, culturally specific to two participants originating from Africa who discussed having a maize derivative for breakfast. All other respondents did not raise any issues relevant to the cultural or religious appropriateness of the intervention or the food and drink consumed.

#### 9.6.3 Generalisability and transferability

Generalisability is whether or not the results generated in one study can be applied to participants in a wider study or a different population (Braun and Clarke, 2013). Langhorne and Legg, (2003) highlight one of the challenges in evidence-based stroke rehabilitation is the lack of generalisability, as individual rehabilitation trials are only relevant to the context



or the phenomena being studied. There is a view that generalisability is not relevant for qualitative research (Braun and Clarke, 2013) and the same standards for quantitative research can not be applied. A concept more frequently used in qualitative research is transferability. Transferability is when the researcher can provide a comprehensive description of the study, the contexts, participants, and methods used and consider the contexts in which the findings might be relevant or not relevant (Braun and Clarke, 2013; Daniel, 2019).

Nordgren, and colleagues, (2008); Forero and coauthors., 2018; and Daniel, (2019) all suggest that transferability requires reporting rigour. I used the TIDier template (Hoffmann and Walker, 2015) to report the intervention description so that other researchers can decide if their context is sufficiently similar to the BISTRo study to warrant a replicable transfer (Braun and Clarke, 2013). Other ways to demonstrate transferability are, the selection of participants who are knowledgeable about the topic being investigated (Forero et al., 2018), the results can be transferred to other groups, people, and contexts (Braun and Clarke, 2013) and the findings have meaning to those not involved in the study (Cope, 2014).

The use of multiple sites provided an opportunity to increase the diversity of participants. A larger study with more participants would increase the heterogeneity of the sample and make the findings more generalisable to the wider stroke population. No younger stroke survivors (under 59 years of age) were included in this study. Future studies should aim to include patients from a younger demographic as the number of younger people having a stroke has increased by 25% since 1990 and 1 in 4 strokes (65%) occur in people under 65 years (Stroke Association, 2016).

The sites involved being in one region in the north of England may be a geographical limiting factor. The demographics of Sheffield, Rotherham and Doncaster have a slightly higher than average white population which was reflected in the recruitment demographics. Although the study included non-white British participants (Caribbean, African, Asian) they were in small numbers and there were no South, East Asian or European participants.

Future studies to test BISTRo on a larger scale should aim to have a broader range of ethnicities, socioeconomic groups, and those for whom English is a second language. Future studies may be needed to strive for even greater diversity so that BISTRo is tested in contexts and populations that reflect the national population data.

### 9.7 Original Contribution to knowledge

This systematic review was the first one in its field, bringing together existing literature that contributes to existing evidence gaps for interventions to address eating and drinking difficulties after stroke. Current National Clinical Stroke Guidelines promote early intensive multidisciplinary rehabilitation to aid recovery and prevent longer-term complications (Royal College of Physicians, 2023).

Breakfast group interventions are a novel intensive approach to eating and drinking interventions. Traditional interventions are usually uni-disciplinary and for most professions less frequent than daily. There is very little evidence or scholarly writing that clinicians can

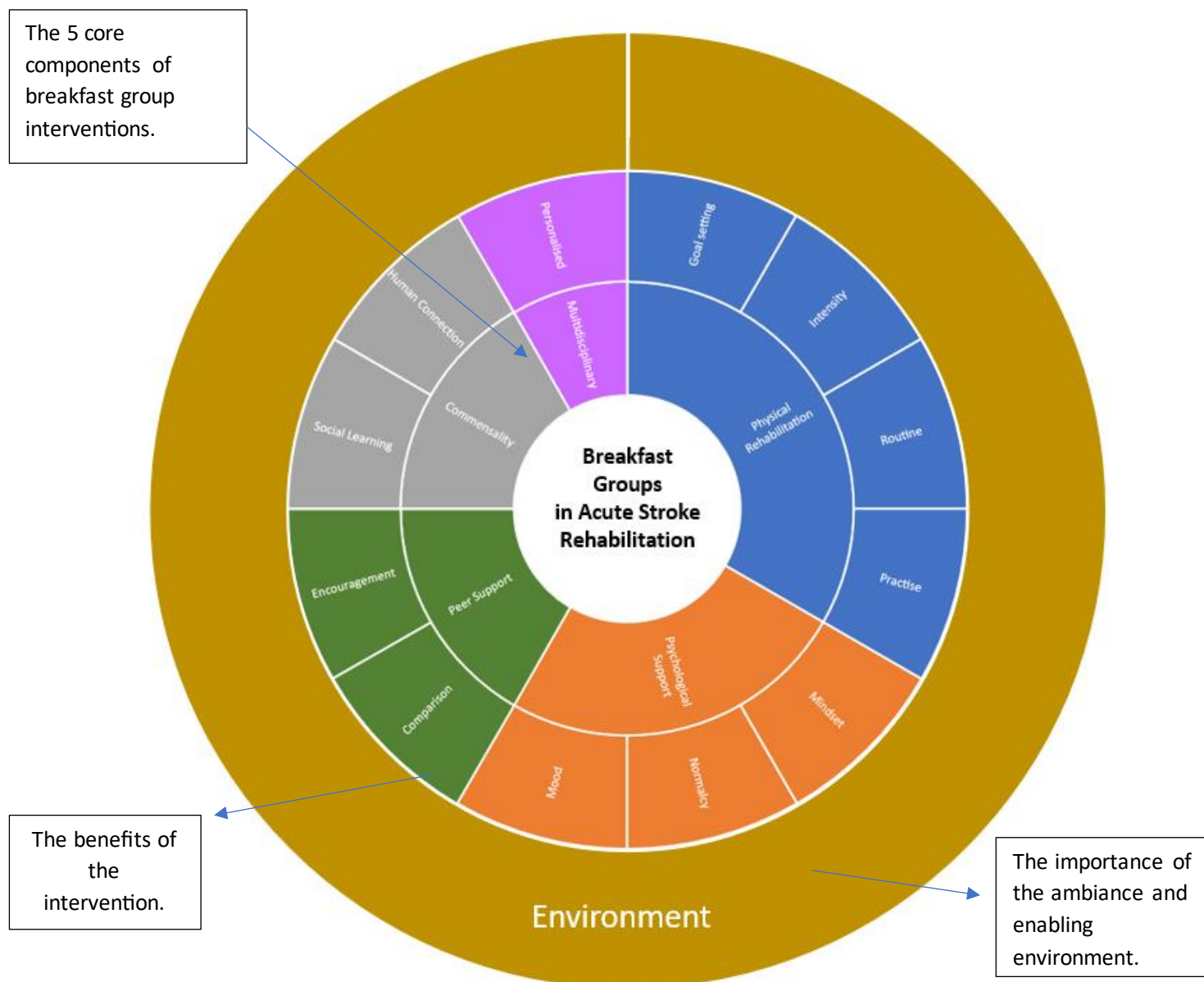
draw on to inform practice around group eating and drinking interventions. BISTRo is the first study of its kind in the UK that develops a new intervention in this area and shows that it is both acceptable and feasible. The intervention is now ready for use in a fully powered clinical trial.

This original contribution to clinical practice is a model for clinical practice (Figure 48) that will guide professionals in the core components of the intervention, highlighting the specific elements that were identified through the qualitative research undertaken at the prototyping stage and how these can positively affect patients' experiences of the breakfast group intervention. This model specifically reflects the importance of getting the breakfast group environment right to create a social ambience and ensure the activities are accessible and enabling. It describes the core components of the intervention which include social and psychological aspects. It describes some of the potential benefits that were found to have therapeutic value. The practice model provides busy clinicians with information about the intervention, and it can be used alongside the logic model to understand the proposed theory of change for breakfast group interventions.

A concise and visual original logic model which describes the inputs, outputs and expected outcomes of a breakfast group intervention has been developed to communicate the theory of change. The model will be published for clinicians to use to understand the benefits of breakfast groups so others wishing to adapt the intervention to their contexts can make sure they maintain the core components of the intervention.

The three sites participating in the study have sustained delivering this breakfast group intervention one year after the research stopped in their trust and are continuing to use the patient booklet and BISTRo toolkit. Since presenting the study at several national and interventional conferences, I have had a steady stream of interest from UK stroke units wanting to find out more about the study and considering starting the BISTRo breakfast group intervention. In the spirit of open research and dissemination, the toolkit, resources, and patient booklet will be made available to download from the university repository, ORDA.

Figure 48: Model for breakfast group interventions.



### 9.8 Future research

I intend to carry forward the knowledge gained from this study into the subsequent stage of my clinical academic career advancement. This phase will encompass seeking post-doctoral funding opportunities to enhance my expertise in clinical trials. This will enable me to plan and oversee a Randomized Controlled Trial (RCT) aimed at assessing both the efficiency and cost-effectiveness of interventions involving breakfast groups.

### 9.9 Dissemination plans

The results of this study will be shared locally with patients, and healthcare professionals and more widely at national and international conferences. Results will be published in high-impact journals and shared on social media and through patient story videos. I have

completed a comprehensive dissemination and impact plan for Bistro which can be found in (Appendix 23).

This project represents the initial stage in the effort to enhance the psychosocial aspects of post-stroke eating and drinking. The results obtained from this research will serve as the foundation for a proposal to conduct a randomized control trial. If breakfast groups are conclusively validated as a beneficial approach for post-stroke eating and drinking recovery, I will dedicate my efforts to establishing a solid evidence base. This evidence can then be integrated into future NICE guidelines and support its widespread implementation within the NHS, thereby transforming patient care.

### 9.10 Research Impact

Researchers are accountable for ensuring the research findings and impacts are shared widely with those who consume and use the research and with other key stakeholders (Sainty, 2013; Jones, Cooke, and Holliday, 2021). Bodies such as the UK Research Councils, RCUK and Universities UK are promoting the discourse of open research and the principles that research findings should be freely available. Coproduction research can generate outputs and tools which are instantly useable in clinical practice (Cooke et al., 2017). In this study, an open research event was held as the last stakeholder workshop to make transparent the researcher's processes, findings and outputs and also share the BISTRo tool kit. Open research events are opportunities to make scholarly findings and outputs from projects available to those who would use the research as well as those it intends to affect (Vitae, 2011, 2023).

In previous projects, I have co-created a research impact tool called VICTOR which can be used to capture research impacts at the organisational level. This tool has been published and has been adopted by the Royal College of Nursing Research Society as well as used by other clinical academic researchers to record and amplify research impacts (Jones, Cooke and Holliday, 2021a; Jimenez Forero and Palmer, 2022). I therefore use VICTOR to identify research impacts from BISTRo (Figure 50) and I have added one more step to the EBCD process named 'measure impact' (Figure 51). This signals the importance of capturing the obvious and more nuanced research impacts from the study.

Figure 49: Example of research impacts using VICTOR research impact tool (full report in appendix 24).

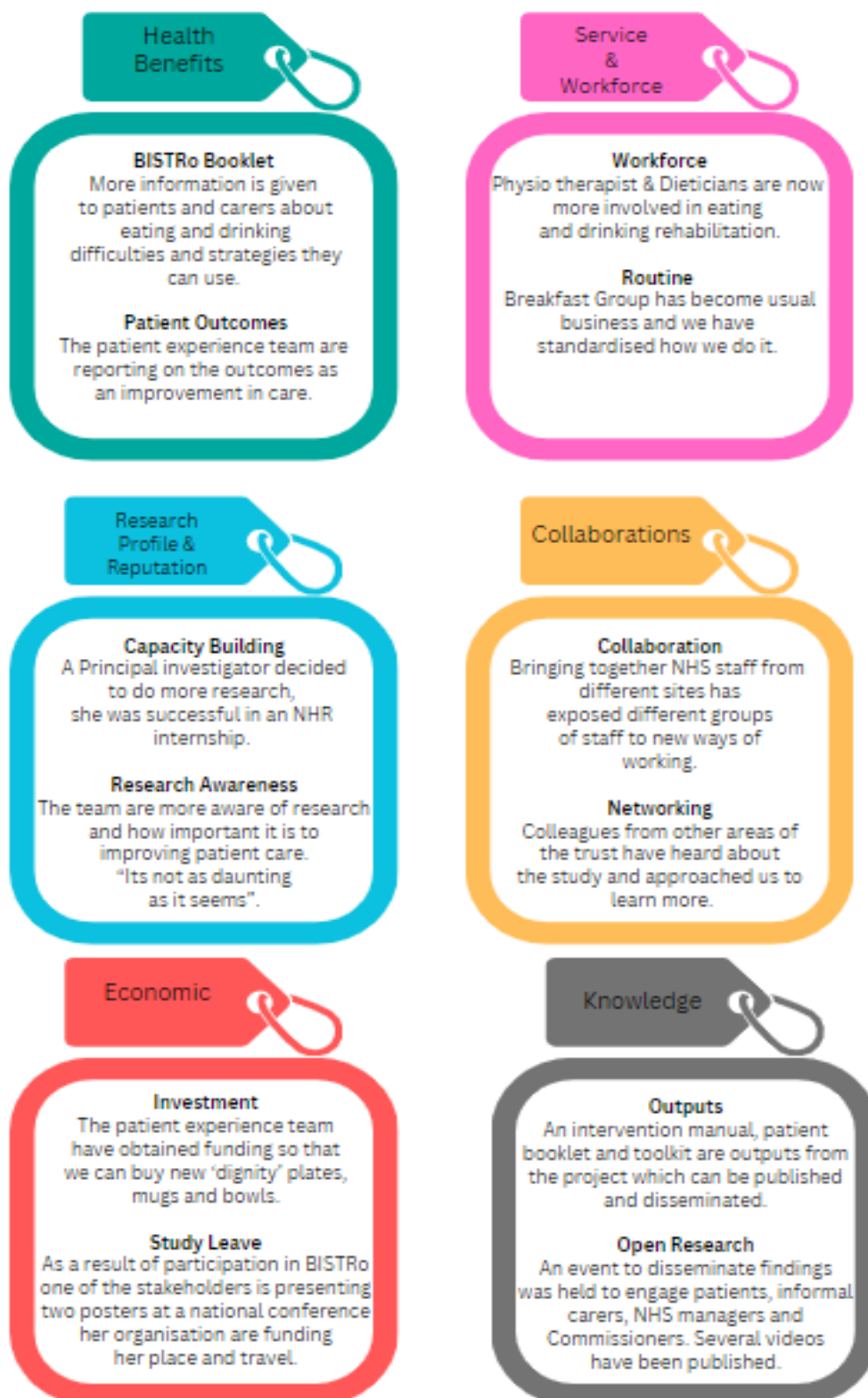


Figure 50: Revised version of the EBCD 8-step process.



### 9.11 Conclusion

A new breakfast group intervention and implementation toolkit was codesigned and the intervention was found to be feasible and acceptable in three NHS stroke services. BISTRO offers an intervention that addresses both the physical and psychosocial aspects of recovery to help stroke survivors regain independence with eating and drinking activities whilst improving their emotional well-being and longer-term quality of life. This study offers a sound basis for future research and upscaling to a fully powered randomised control trial of effectiveness and cost-effectiveness.

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## Appendix 1: BISTRO Media, links to video's made during the study

BISTRO Study Tigger Video 1: Exploring the importance of eating and drinking after stroke. <https://youtu.be/xhdwlYLu1VU> (6.52mins)

BISTRO Study Trigger Video 2: The impact of eating and drinking difficulties after stroke. <https://youtu.be/s9gPNyNJDjM> (11.10mins)

BISTRO Study Trigger Video 3: What to consider if you are planning a breakfast group intervention. [https://youtu.be/UQZ\\_3NRXBCo](https://youtu.be/UQZ_3NRXBCo) (28.26mins)

An Occupational Therapist 'what matters to me?'  
<https://youtu.be/mFHxb6dkqUQ> (7.41mins)

BISTRO Study: The story of developing a breakfast group intervention for stroke survivors. <https://youtu.be/xTvDX6bs4vQ> (10.36 mins)

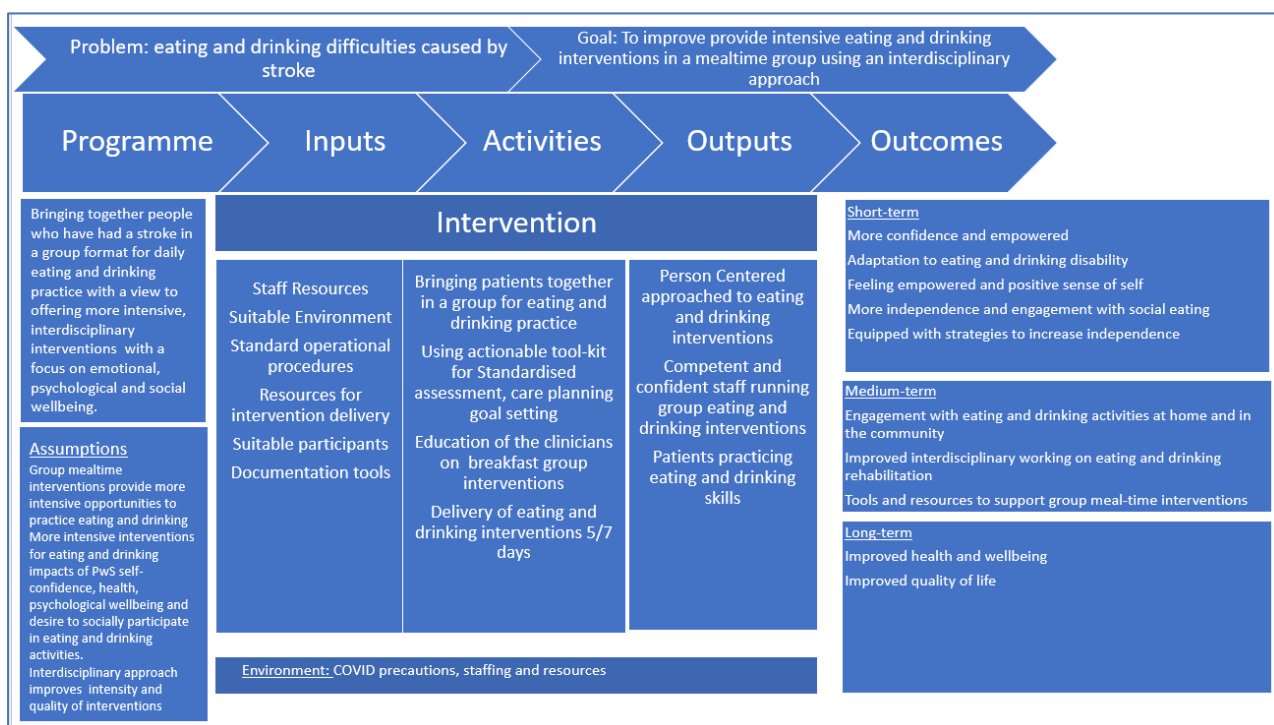
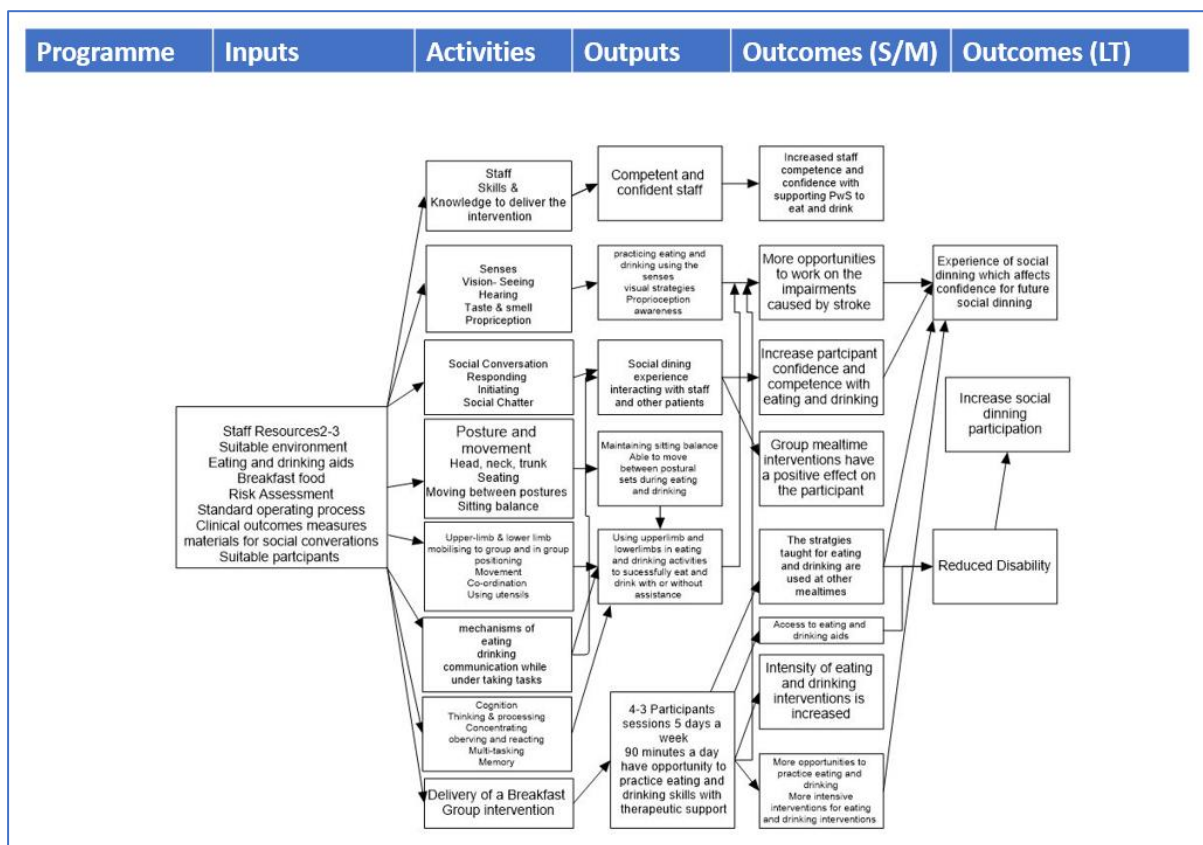
BISTRO Study: Experiences-based codesign with stroke survivors & informal carers in stroke research. <https://youtu.be/mFHxb6dkqUQ> (16.37mins)

Systematic Review: Psychosocial impacts of eating and drinking difficulties after stroke. [https://youtu.be/yCUxd\\_4hU28](https://youtu.be/yCUxd_4hU28) (4.32mins)

Open research event.

<https://youtu.be/b4vGBdhDpLA?si=FbaWpbWDBhu7ZKBk> (12.27mins)

## Appendix 2: Logic Model Evolution



## Appendix 3: ENTREQ Checklist

### The ENTREQ Checklist

Enhancing transparency in reporting the synthesis of qualitative research

Number	Item	Guide and description	Reported on page X completed
1	Aim	State the research question the synthesis addresses.	x
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for the choice of methodology	x
3	Approach to searching	Indicate whether the search was pre-planned	x
4	Inclusion criteria	Specify the inclusion/exclusion criteria	x
5	Data sources	Describe the information sources used	x
6	Electronic Search strategy	Describe the literature search	x
7	Study screening methods	Describe the process of study screening and sifting	x
8	Study characteristics	Present the characteristics of the included studies	x
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion	x

10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings	x
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected	x
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	x
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	x
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies.	x
15	Software	State the computer software used, if any.	x
16	Number of reviewers	Identify who was involved in coding and analysis.	x
17	Coding	Describe the process for coding of data	x
18	Study comparison	Describe how were comparisons made within and across studies	x
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	x
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	x
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies	x



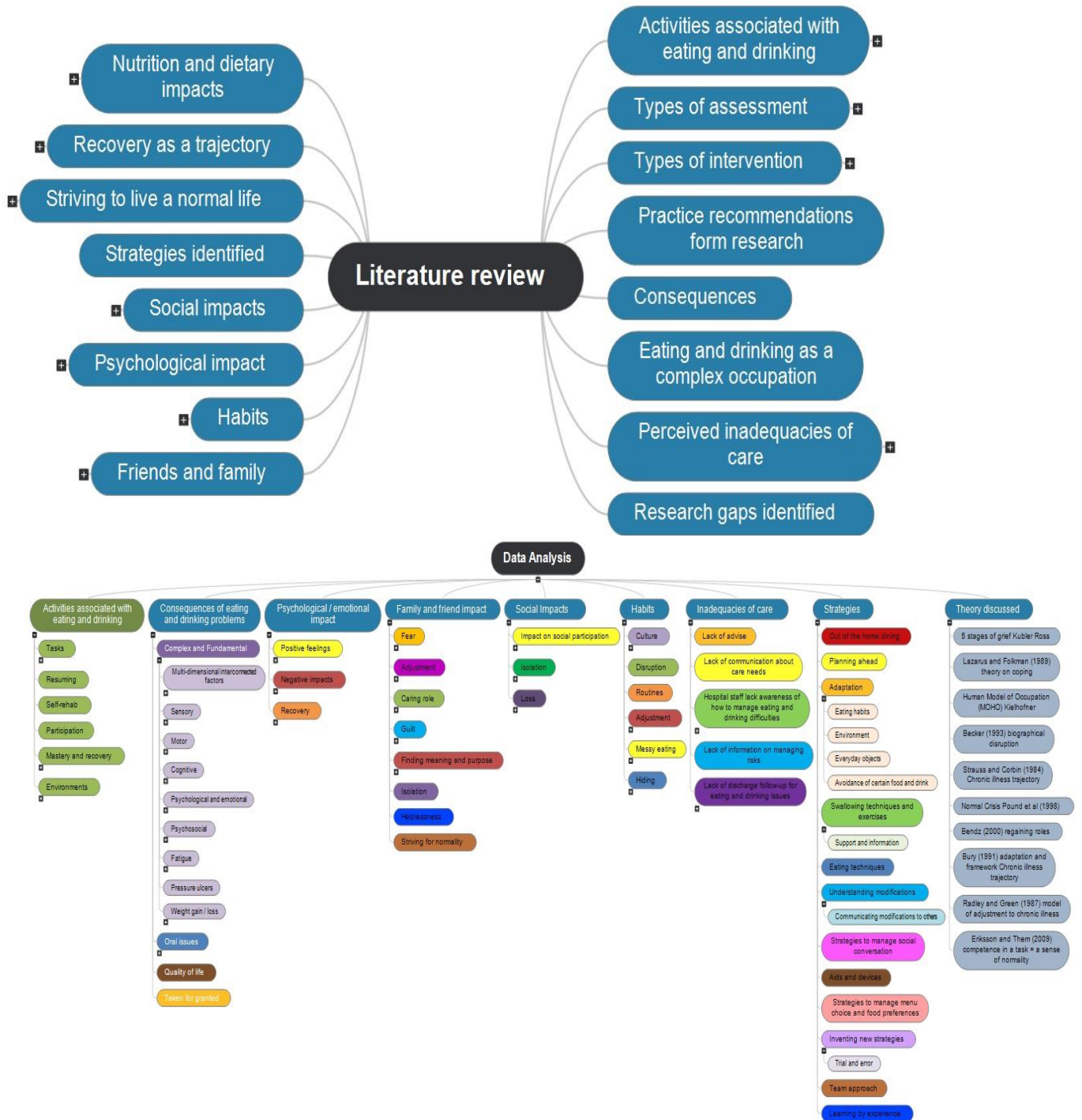
## Appendix 4: Single Verbatim Search: Systematic Review

Example Search Strategy Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily Search Strategy:

- 1 Stroke Rehabilitation/ or Embolic Stroke/ or Haemorrhagic Stroke/ or Stroke/ or Thrombotic Stroke/ or Ischemic Stroke/ or Stroke, Lacunar/ (122966)
- 2 eat\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (164670)
- 3 drink\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (207536)
- 4 Swallow\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (33018)
- 5 2 or 3 or 4 (389702)
- 6 1 and 5 (2042)
- 7 Psychosocial.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (110940)
- 8 emotion\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (253727)
- 9 well\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (3384231)
- 10 7 or 8 or 9 (3654992)

## Appendix 5: Mind Map

Summary of themes from the qualitative evidence synthesis on psychosocial impacts of eating and drinking difficulties.



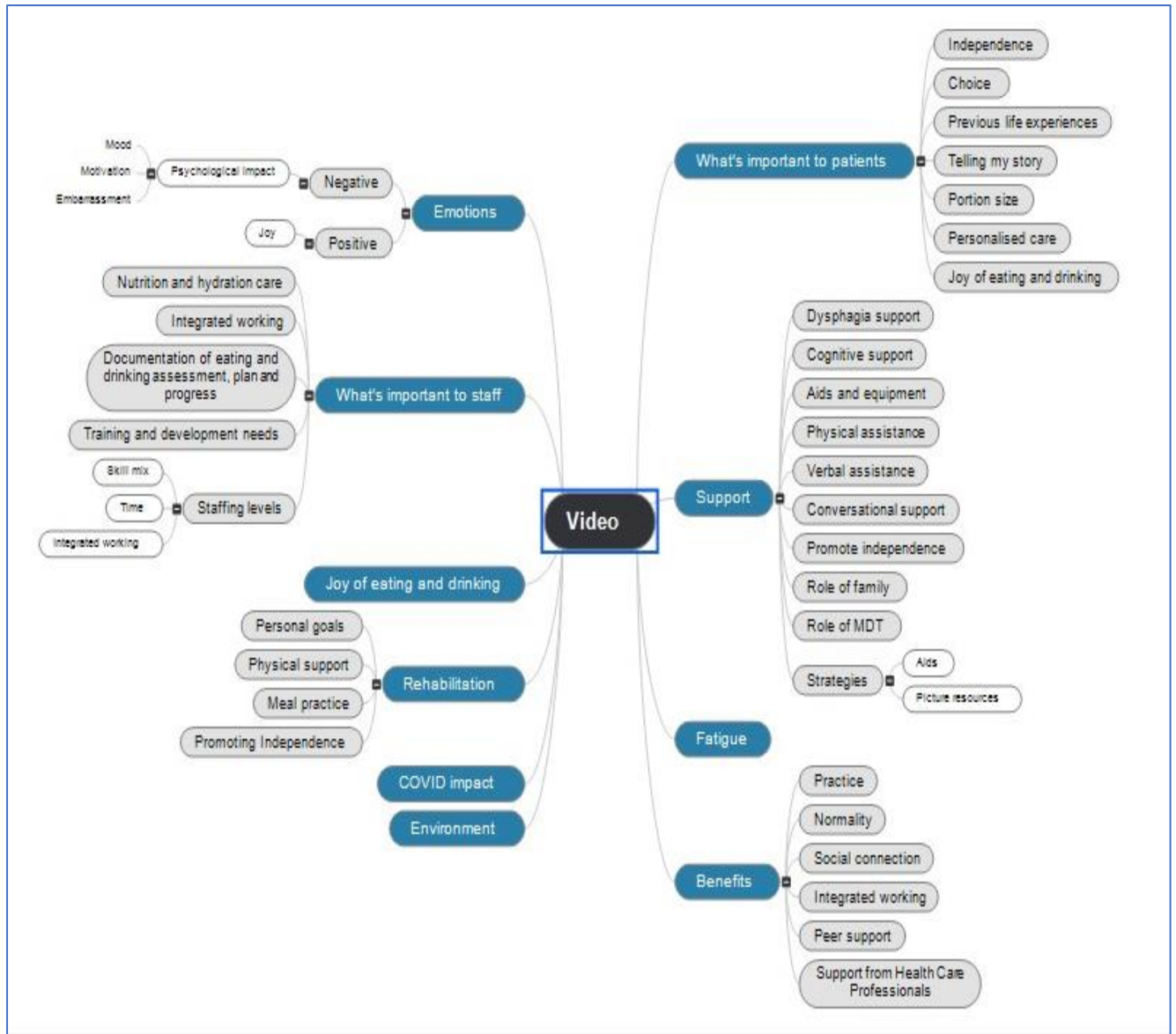
## Appendix 6: Systematic Review: Data Extraction Table

Author	Type of Study	Country	Male	Female	Total M/F	Age Range	Location	Carers Participating	Years Post-stroke
Carlsson et al., (2004). Stroke and eating difficulties: long-term experiences.	Mixed methods. Qualitative Interviews & participant observations of meals.	Sweden	2	1	3	68-82	Community (Daycare facility n=2 Home n=1)	x	1.5-2 years
Eltringham et al., (2019). Experiences of Dysphagia after Stroke: An Interview Study of Stroke Survivors and Their Informal Caregivers.	Qualitative Interviews	UK	2	3	5	67-81	Hospital and Community (mixture not specified)	2 carers present in 2 interviews 1 carer-only interview n= 3	8-100 days
Helldén et al., (2018). Experiences of living with persisting post-stroke dysphagia and of dysphagia management – a qualitative study.	Qualitative Interviews	Sweden	5	x	5	54-95	Community (n=4 Home)	x	3-10 years
Jacobsson et al., (1997). Outcomes of Individualized Interventions in Patients with Severe Eating Difficulties.	Mixed methods Structured observations of eating. Video recordings were undertaken. Advice was given and this was described as an intervention.	Sweden	14	1	15	42-79	Hospital Facility	x	2-17 years
Jacobsson et al., (2000). How people with stroke and healthy older people experience the eating process.	Mixed methods. Test of oral function, meal test, which was observed, and video recorded. Interview whilst eating.	Sweden	17	13	30	48-80	Hospital Facility	x	1-14 days
Jacobsson et al., (1996). Eating despite severe difficulties: assessment of poststroke eating.	Mixed methods. Case study analysis. Quantitative data included clinical outcome measures for function and assessments of impairments. Interviews. 1 test meal and subsequent regular meal assessments which were recorded. Field notes were taken.	Sweden	4	1	5	42-68	Hospital and Community – assessed in hospital and interviews at home location	Carers present n=4 (n= 4 at first interview and n= 3 at second interview at home)	9months-17 years
Johansson et al., (2009). Relatives' experiences of family members' eating difficulties.	Qualitative interviews.	Sweden	2	7	9	50-79	Community	n= 7 spouse and n= 2 parents n= 6 were living together n= 3 living apart	2.5-15 years
Jones, N., & Nasr, N. (2018). The experiences of stroke survivors with managing eating 6 months post-stroke.	Focus group. Participatory methods using digital cameras.	UK	4	3	7	49-68	Community	n= 1 carer	Over 6 months
Kjaersgaard, A., & Pallesen, H. (2020). First-Hand Experience of Severe Dysphagia Following Brainstem Stroke: Two Qualitative Cases.	Mixed methods. Case study and semi-structured interviews.	Denmark	2	x	2	53-62	Hospital and Community follow-up on discharge	x	Day 1- 6 months
Klinke et al., (2014). Living at home with eating difficulties following stroke: a phenomenological study of younger people's experiences.	Qualitative Interviews	Iceland	5	2	7	34-65	Community n=5 and Rehabilitation Centre n=2	x	7 month-8 years
Klinke et al., (2013) Recognizing new perspectives in eating difficulties following stroke a concept analysis.	Concept analysis	Iceland	N/A	N/A	N/A	N/A	Concept analysis	x	N/A
Kumlien, S., & Axelsson, K. (2002). Stroke patients in nursing homes: eating, feeding, nutrition and related care.	Mixed methods. Interviewed nurses and took data from patient notes 2weeks before the interview. Combined with data from the interviews and the notes. Also used the Resident Assessment instrument to score the patient's state of health.	Sweden	13	27	40	55-92	Care Homes and Community	x	0-1 year post-stroke
McCurtin et al., (2018). Plugging the patient evidence gap: what patients with swallowing disorders post-stroke say about thickened liquids	Qualitative Interviews.	Ireland	8	6	14	50-81	Community	x	3mths-12 years
Medin et al., (2010). Striving for control in eating situations after stroke.	Mixed methods. Observations of eating were conducted to establish abilities, other outcomes included	Sweden	7	7	14	59-87	Community (same study as below but	x	3 months

## Appendix 6: Continued Systematic Review: Data Extraction Table

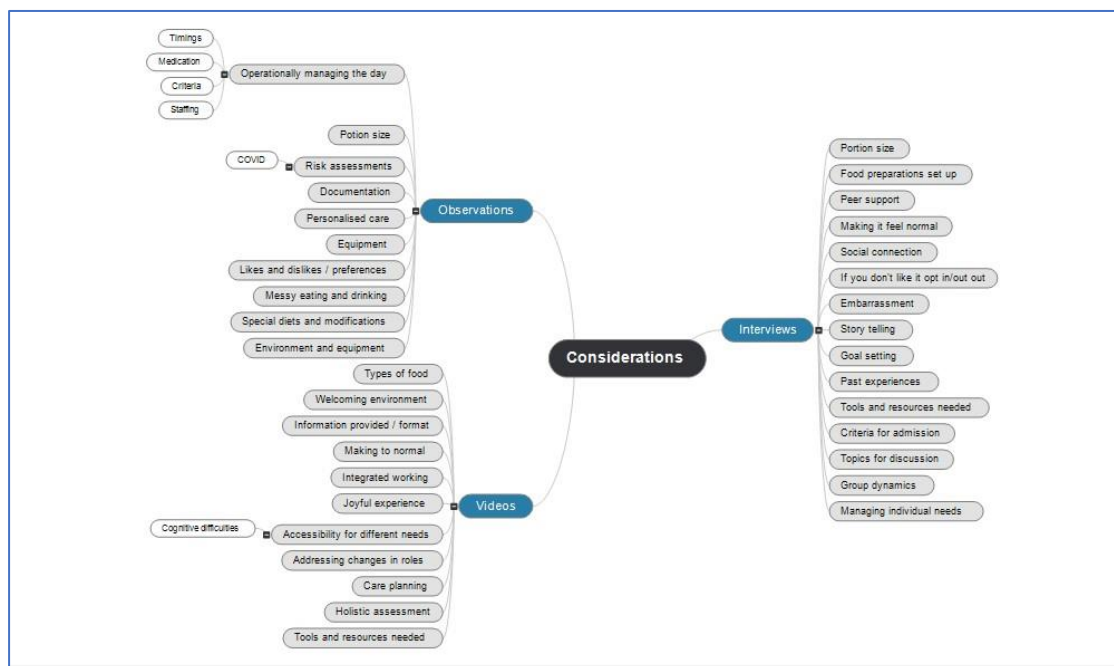
	nutrition and functional scores. Semi-structured Interviews were conducted. At three months post-stroke.							1 <sup>st</sup> interview reported on at 3 months)	
Medin et al., (2012). Eating difficulties among patients 3 months after stroke in relation to the acute phase.	Qualitative semi-structured interviews at 6 months post-stroke.	Sweden	6	7	13	60-87	Community (same study as above but 2 <sup>nd</sup> interview reported at 6 months)	x	6 months
Perry et al., (2003a). Eating difficulties after stroke.	Qualitative interviews.	UK	47	66	113	Mean age 67	Community	n= 9 carers (included as proxies)	6 months
Perry et al., (2003b). Coping and adaptation at six months after stroke: experiences with eating disabilities.	Qualitative interviews.	UK	Same study as above	Same study as above	Same as above	Same as above	Community	Not mentioned in this study	6 months
Pontes et al., (2017). Quality of life in swallowing of the elderly patients affected by stroke.	Cross-sectional study.	Brazil	16	19	35	60-90	Community Out Patient Clinics	x	1 year
Schimmel et al., (2017) Oro-facial impairment in stroke patients.	Literature Review	Switzerland	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Westergren et al., (2008). Nutrition and its Relation to Mealtime Preparation, Eating, Fatigue and Mood Among Stroke Survivors After Discharge from Hospital - A Pilot Study.	Mixed methods. Cross-sectional design with structured interviews and assessments.	Sweden	45	44	89	77 mean age	Community	x	Day 1-6 months
Westergren et al., (2001). Eating difficulties, complications, and nursing interventions during a period of three months after a stroke.	Mixed methods. Interviews and observations, other tests including swallowing, function, nutrition, oral function, and respiratory status.	Sweden	14	10	24	77 mean age	Hospital	x	2 weeks to 3 months post-stroke

Appendix 7: Mind Map, themes from trigger video data collection.





## Appendix 8: Ideas and Suggestions for the Breakfast Group



Examples of the considerations and ideas, generated during stakeholder conversations.

### Stakeholder feedback on the key elements of the intervention, toolkit, and training.

Topics	Interview/ literature/ video data	Your thoughts	Comments
Environment	Consider how the dining area can be made more homely to create a normalised setting for a group meal. How do we create an environment that's not interrupted? What other things do we need to consider about the environment?	<p><u>The room</u></p> <p>Tablecloths, cutlery set out, flowers (artificial) on the table, napkins, cups/plates/bowls and in another area for when needed, not just plastic beakers if appropriate</p> <p>Paper serviettes</p> <p>Chairs- can't sit on them- not easy to sit up on the table- dribble food because of the gap.</p> <p>Separate tables for smaller groups</p> <p>Perching stool versus ordinary chair/ trolley</p> <p>Squeezy bottles – packing- pe-used jars – ketchup</p> <p>Pasta plates</p> <p>Spoon in a jam pot with smaller dishes, ramakins</p> <p>Packets for cereal – choice of volume – not premeasured- promote independence with choice of portion size.</p> <p>Needs to be clean, tidy, welcoming, tidying up any 'mess,' e.g. equipment everywhere, putting things behind the curtain</p> <p>Types of chairs, the height of a table</p> <p>Risk assessment for the group/room use was documented separately and communicated to the ward manager.</p>	<p>Develop a checklist for the room equipment and organisation.</p> <p>Develop signs for the doors and other places.</p> <p>Develop a mechanism for signalling a specialist diet.</p> <p>Develop a checklist for specialist equipment.</p> <p>Get three aphasia-friendly menus.</p>
		<ul style="list-style-type: none"> <li>Adaptive cutlery</li> <li>Butter Board</li> <li>Rocker knife</li> <li>Plate guards</li> <li>Chopping boards</li> <li>Decent-sized plates</li> </ul>	
		<p>Portion size</p> <p>Consider snacks as part of the intervention.</p> <p>Consider the types of plates and bowls used to reflect portion choice.</p> <p>Consider how portion size can be addressed in the intervention and where there are opportunities to promote choice in the menu.</p>	<ul style="list-style-type: none"> <li>Include preferences in the initial assessment.</li> <li>Offer a range of choices and options to eat more if starting with a smaller portion.</li> <li>Consider the 'grazer' vs patients with bigger appetites – the culture of it's OK to have as much or as little as you like</li> <li>Aphasia-friendly visual resources for choosing portion sizes</li> <li>Menus with pictures</li> <li>Accessible menu with the picture, portion size in pictures, small, medium plates bowls</li> </ul> <p>Write specific guidance on portion size.</p> <p>Visual menus for those with communication difficulties.</p>
Diet modifications	<p>What do we need to consider about the presentation of food?</p> <p>Anything we need to address around diet modifications?</p>	<ul style="list-style-type: none"> <li>As normal as possible, we may need picture labelling to aid communication/reading.</li> <li>Include adapted diet options and modifications – according to initial assessment information – to ensure everything needed is available.</li> <li>Containers to avoid small packaging</li> <li>As close to what they'd expect to have at home as possible</li> <li>Using normal crockery/jars etc</li> </ul>	<p>Write guidance on diet modifications included in the training.</p>

## Appendix 10: Example Recruitment Posters

03/09/21

**A research study looking at people who have had a stroke having difficulty eating and drinking support in a group with other patients**

Natalie Jones, Clinical Academic Occupational Therapist  
Professor Sue Mawson, Project Supervisor

**We are doing some research**

**It is about eating and drinking after stroke**

**We need to know more about how to help people recover after stroke**

**This study is about supporting people with eating and drinking difficulties**

**If you join this study you will be offered the opportunity to attend a breakfast group where you can practice eating and drinking with the help of a therapist or nurse and to talk to a researcher about your experiences with eating and drinking difficulties**

**Research tests new ideas in Stroke Rehabilitation**

**We can find out if breakfast groups help rehabilitate people with eating and drinking difficulties**

**We can find out if its possible to do this Monday to Friday on a stroke rehabilitation ward**

**This study will help us to learn more about eating and drinking rehabilitation after stroke**






More information about this study can be provided by contacting

Natalie Jones Tel 07880003229  
[natalie.jones56@nhs.net](mailto:natalie.jones56@nhs.net) or asking a member of staff in the Stroke Services.

Sheffield Teaching Hospitals NHS Foundation Trust  
The University of Sheffield

V1 29/09/21


03/09/21

**FEASIBILITY OF A BREAKFAST GROUP INTERVENTION ON ACUTE STROKE UNITS**

Natalie Jones, Clinical Academic Occupational Therapist  
Professor Sue Mawson, Project Supervisor



**Breakfast Group Interventions in Stroke Rehabilitation (BISTRO) is a research study aiming to find out if it is possible to provide more intensive interventions for people with eating and drinking difficulties which also addresses the psychological impact of changes in eating and drinking experiences after stroke.**



**What the research says...**

Current evidence shows that many people living with stroke experience major problems with eating and drinking. We know that this can lead to malnutrition, dehydration, reduced muscle strength and depression. It can also lead to longer stays in hospital, reduced ability to participate in rehabilitation and in the long-term poorer quality of life.

People living with stroke say the pleasure gained from eating and drinking changes. They describe feeling embarrassed and ashamed and report a loss of self-confidence. Therefore, being able to eat and drink independently is essential for health and well-being.

**What do people living with stroke say...**

People with stroke welcome opportunities to address eating and drinking problems early in their rehabilitation and would like more opportunities to practice the necessary skills needed, to regain independence. Early rehabilitation interventions have the potential to improve long-term outcomes by providing strategies, assistive devices and rehabilitation as early as possible in stroke recovery.

More information about this study can be provided by contacting Natalie Jones Tel 07880003229  
[Natalie.jones56@nhs.net](mailto:Natalie.jones56@nhs.net) or asking a member of staff in the Stroke Service.

Sheffield Teaching Hospitals NHS Foundation Trust  
The University of Sheffield

V1 29/09/21

## Appendix 11: Example: Interview Topic Guide- Staff Participant

Study title: Feasibility of a breakfast group intervention for acute stroke units to provide intensive eating and drinking interventions as well as integrated multi-disciplinary team working and personalized care.

Thank you very much for taking part in this study. My name is Nat Jones, and I work at STH, and I am a PhD student at the University of Sheffield.

As you know, I am carrying out some research to codesign a breakfast group intervention for people with eating and drinking difficulties.

The interview is informal and completely confidential, no personal information will be shared

With your permission, I would like to record the interview. This is so that I can concentrate on what you are telling me rather than spending the whole-time taking notes. Is that OK?

As soon as we have written up the study, all the recordings will be destroyed.

	<b>Main questions</b>	Possible probes if needed
1	To start, I would like to find out a bit about you what can you tell me about your role at ....	How long have you worked in stroke services?
2	I'd like to know more about how your role supports people with eating and drinking difficulties.	Can you describe how you help people with eating and drinking difficulties?
3	How would you like to be involved with helping people with eating and drinking difficulties?	What makes this important to you? Which of these are most important to you?
4	Can you describe some of the difficulties people experience with eating and drinking?	What made you choose these aspects? How do you feel about these difficulties when you see them?
5	What knowledge and skills help you to help people with eating and drinking difficulties?	What formal and informal training have you received? What additional knowledge and skills would you like to obtain?
6	In your experience, who gets involved with supporting people to eat and drink?	Is there anyone not involved that you think should be and why? What impact do you think this has?
7	What are your thoughts about how stroke survivors experience eating and drinking difficulties?	How do you feel about the support that is provided?
	What does good support look like to you? Or what would you like to improve?	Tell me more about how it is achieved. What experiences do you have of good support?
8	Can you tell me about your experiences when things don't work well?	Can you share any examples?
9	What's your experience with eating and drinking interventions, how do you get involved?	Does this include any mealtime groups? Can you share any examples?
10	What are your thoughts about mealtime groups to support people with eating and drinking difficulties, do you have any experience with them?	Are there any pros and cons to consider? Are there any things you think need to be considered when setting one up? How might they help patients?



## Appendix 12 Convergence Matrix: Pre-prototyping data (Stage 1 of Hawkins Framework)

Theme	Aspect of theme	Data Set 1 Literature Review	Data Set 2 Observations	Data Set 3 Interviews	Data Set 4 Video	Convergence, Complementarily, Disagreement, Silence	Conclusion
Poor nutrition and hydration impact on health	Palatability Modifications Snacks	<p>The amount of fluids and food taken after a stroke is reduced (Perry &amp; McLaren, 2003b). Modifications can affect food choices (Helldén et al., 2018). Several studies found that alterations to food or fluids were burdensome for patients and families (Helldén et al., 2018; McCurtin et al., 2018; Perry &amp; McLaren, 2003) Lin et al., (2021) discussed dietary dissatisfaction and poor appetite related to pureed food and found that patients and caregivers may lack knowledge of food and drink modification. Medin et al., (2010) site the relationship between low food consumption, malnutrition, and weight loss as predictors of pressure ulcers. Westergren et al., (2001) found the relationship between malnourishment and pressure ulcers. Although modified diet and fluids are thought to reduce complications such as aspiration (Eltringham et al., 2019; Lin et al., 2021; McCurtin et al.,</p>	<p>Filed notes (LB) One observed patient said, “The tea was horrible on two thinners. He says it tasted horrible, I couldn’t eat the meals they said I could have a jacket potato and cheese I couldn’t stomach anything else. Then I graduated from 2 to one and I enjoyed food more. At 85 I can’t eat two meals a day, but I can eat sandwiches, so I have one hot meal a day and sandwiches. I might have soup or jacket potato and then a hot meal at night and eat it all. I’ve lost weight since I’ve been here. I managed to put weight on here since I went on to one thinner, I’m now 11 stone”. Question “are you enjoying drinking more because it reduced the thickness? P4 replies, “yes, the powder is less. You can’t taste it as much. The hospital food is very nice. I enjoy it. I had salmon the other day, and it was dry. If I was on the straight diet, it would be excellent, and I would enjoy it more”.</p> <p>“Mainly because I’m on this job I’ve had, what’s the</p>	<p><b>Healthy snacks</b> were discussed in Interview 2 (OT) as something that could improve nutritional intake. “And things like patients been offered snacks more during tea and coffee because sometimes there seems to be staff that don’t offer snacks, and I don’t really know why that is. So, make sure that staff offer snacks. But I’d also like to think they could have healthier snacks. So, I think there are healthier snacks. I think, right, there are little pots of fruit and things like that. So rather than just you want a biscuit being offered, would you like something to eat? Do you want to snack? You know, these are the different things you could have and encourage more when they come. I think it would be good if somebody could step up and encourage someone could even be assigned to the room saying if you’re hungry and let us know if you’re thirsty, let us know. You know, so that patients are kind of empowered to ask what they want.</p>	<p>All videos highlight nutrition and hydration as necessary (Nurse, OT, SALT). The Nurse said “There are obviously the issues about nutrition and hydration general health from the patient point of view those of the two concerns, patients who are poorly hydrated and have poor nutrition or more likely to have skin breakdown. And because people’s mobility is affected by stroke the concerns about pressure damage are quite high so that’s a big issue for us, certainly around hydration our biggest concern would be around managing the bladder and bowels. Patients who find it difficult to drink will end up with very concentrated urine. Increasing the risk of urinary tract infections for themselves and bowel management, and reduced mobility will affect them if their hydration is limited, they have hard stools which are very difficult to pass, it’s uncomfortable and difficult to manage so from a nursing perspective there are very big issues but those are the first two that come to mind”.</p> <p>He went on to say, “In terms of our giving people specialists snacks or drinks, for people who are malnourished in some way because it’s not part of mealtimes it sometimes associated with something else it sometimes associated with drug rounds so although a nurse may dispense the appropriate food it sometimes left with them in their room and it’s not really anybody’s responsibility to make sure they have taken that. So that’s something that we could improve on”.</p> <p>Occupational Therapist F “and I think good patient eating and drinking is around offering snacks, making sure we have a full range of snacks and that you know we really keep</p>	<p>Convergence on the importance of nutrition and hydration for health and wellbeing.</p> <p>Convergence on the importance of snacks. Snacks are discussed in Interview 2 OT1, observations 1 patient and in the video Nurse and OT1. Recognition that practices on offering snacks could be improved Interview 2 OT1 and video Nurse.</p> <p>Convergence on concerns about weight loss and weight gain was evident in the literature, interview 5 and several observations referenced weight 7 times.</p> <p>Weight documentation/ monitoring to observe weight loss or gain was discussed widely in the literature, but there was silence in the observations, interviews, and videos.</p>	<p><b>Context for the intervention</b> The impact of poor nutrition and hydration is widely discussed in the literature and the consequences and implications of discussed in all 23 papers.</p> <p><b>Potential benefits and outcomes</b> Healthy and nutritious snacks are discussed as a solution to poor food intake. Although healthy eating is vital in reducing risks of further stroke, it did not feature highly in DS 2,3,4.</p> <p><b>How to deliver the Intervention</b> Consider weight monitoring and documentation as part of the eating and drinking intervention. Consider snacks as part of the intervention. Explore what resources are required to support patients and carers with diet modification and fluids. To explore resources for information on healthy eating/snacks.</p>

		<p>2018), several papers discuss stroke survivor's dislike for this treatment (McCurtin et al., 2018; Perry &amp; McLaren, 2003b).</p> <p><b>Weigh loss as a complication</b> (Helldén et al., 2018; Jacobsson et al., 1996; Johansson &amp; Johansson, 2009; Klinke et al., 2013, 2014; Jorgen Medin et al., 2010; Perry &amp; McLaren, 2003; Schimmel et al., 2011; Westergren, Ohlsson, et al., 2001; Westergren, 2008)</p> <p><b>Weigh gain as a complication</b> (Jones &amp; Nasr, 2018)</p>	<p>word, a special diet. You only get what you can get they don't have other stuff; they don't have other things that I like, but that's not their fault. I can't seem to eat as much or want as much. I would rather go without". She eats another small slice of toast and then says, "I just can't be bothered to get anything else. Some days, I think, just go away and leave me alone".</p> <p>One observation of a conversation between a nurse and a student nurse "I am concerned Mr X is losing weight. What shall I try with him? Can I ask him if he likes anything to see what he fancies?".</p> <p>The qualified nurse asked what his MUST score was and discussed her concerns about his weight loss "he only had two mouthfuls," she said, "I'd like to try him with some rice pudding", said the student nurse. The qualified nurse says, "he had three mouthfuls of Weetabix, but he doesn't like it, and he's given up," the student nurse says "he likes rice pudding so that I could try him with a bit of that, and see if he likes it" the qualified nurse agrees "that's a good idea" and the student nurse replies "wish me luck".</p> <p>One patient said her family were bringing in snacks as they worried she wasn't</p>	<p>Interview 1 AC also highlighted the importance of having palatable food.</p>	<p>on top of patients weights, and you know because we don't offer snacks regularly enough, and we get told time and time again that we need to be offering them. Making sure we have a variety of them".</p> <p>There was agreement on improving the way snacks are assessed and administered.</p>		
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			eating enough. However, they were all unhealthy snacks, and she expressed concern about weight gain.				
Recovery as a trajectory	Experience of living with eating and drinking difficulties.	<p>Illness trajectory goes through phases and is experienced differently at different stages (Carlsson et al., 2004, Kjaersgaard &amp; Pallesen, 2020; Klinke et al., 2013)).</p> <p>Changes in competence in eating and drinking improve over time (Catrine Jacobsson et al., 1997, 2000)</p> <p>Recovery is individualised (Kjaersgaard &amp; Pallesen, 2020)</p> <p>Changes can be fragile, moving back and forward in the trajectory (Klinke et al., 2013, 2014).</p> <p>Perry &amp; McLaren, (2003) discuss progress doesn't necessarily mean recovery. It could reflect an adjustment to new strategies and better coping mechanisms.</p>	Silence – patients talked about progressing through the stages of a modified diet and fluids treatment, but they did not discuss recovery in terms of stages.	<p><b>Trajectory</b></p> <p>Interview 5 Patient and informal carer.</p> <p>The patient and informal carer discuss how the recovery has been slow, then fast, how they both see the recovery in different ways and the need for seeing the signs of recovery.</p> <p>NJ- it's good to have things to aim for and you've achieved so much already.</p> <p>P5- it's been hard to see, it's been very hard and I don't see it.</p> <p>NJ- you don't see it?</p> <p>C5- I bring up the food as evidence of how much he's changed. Because four months ago, it just shows you can.</p> <p>That's the thing, the amount of change that happened in such a short space of time is astonishing.</p> <p>P5- it's not enough for me".</p>	Recognition of recovery is a personal journey links to personalised care.	Complementarily- The trajectory is discussed widely as a concept to understand rehabilitation and recovery over time: the recognition that this is individualised and is always linear.	<p><b><u>Context for the intervention</u></b></p> <p>Explore the concept of recovery on a trajectory with the intervention design group. Discuss if the intervention should be adapted over time.</p> <p>Consider recovery as an individual experience and resources to support this concept.</p> <p><b><u>Potential benefits and outcomes</u></b></p> <p>Consider outcomes may vary according to where people are in their recovery. AS recovery is personalised people might be at different stages in the group. How will this affect the group dynamic?</p> <p><b><u>How to deliver the intervention</u></b></p> <p>Consider recovery as an invisible entity. How can recovery and change be made visible to stroke survivors? Codesign a measure of progress. Outcomes that reflect meaningful progress for the individual.</p>
Acceptance and realisation		<b>Realization life will not return to the way it was before</b> (Carlsson et al., 2004, Jacobsson et al., 1996,	Observations were transactional therefore deeper concepts such as acceptance and realisation were not explored. However,	Acceptance and realisation were not explored in the interviews.	Not evident in the videos.	Although acceptance and realisation are discussed widely in DS1 this doesn't follow in DS 2,3,4.	<p><b><u>Context for the intervention</u></b></p> <p>Not many findings merit exploration in the intervention design.</p>

		<p>Perry &amp; McLaren, 2003a) . “She wanted to be independent but realised that she was not able to eat by herself” (Catrine Jacobsson et al., 1996).</p> <p><b>Early stages focus on fear and panic</b> (Catrine Jacobsson et al., 2000) <b>at six months plus the trajectory moves towards acceptance and normalisation</b> (Perry &amp; McLaren, 2003a)</p> <p><b>Examples of living with acceptance</b> (Eltringham et al., 2019).</p> <p><b>Acceptance of modifications</b> (Helldén et al., 2018) “Another way for the people to cope with dysphagia was to “get by”, accept their limitations and the need for modified consistencies such as thickened liquids or pureed food, and find strategies to maintain social functions or hide their difficulties when with others” (Perry &amp; McLaren, 2003a).</p>	<p>patients talk about understanding the need to change eating habits and live on modified diets.</p>				<p><b>How to deliver the Intervention</b></p> <p>Consider how acceptance and realisation could be addressed in the psychological component of the intervention.</p>
Adjustment and adaptation	Adapting	<p><b>The process of adaptation</b> is found in the literature (Johansson &amp; Johansson, 2009).</p> <p><b>Adapting</b> new skills and coping strategies (Klinke</p>	<p><b>Examples of adjustment in observational field notes.</b></p> <p>Patients adapt their diets, food choices, and modifying strategies—awareness of the</p>	<p><b>Examples of adjustment to diet modification</b></p> <p>Interview 3 Patient  “when I drink now I hold it in my mouth and I do some exercises with my larynx before I swallow it. Because</p>	<p>Video Informal Carer  An informal carer must adjust the food she cooks and how it's prepared to accommodate eating and drinking difficulties.</p>	<p>Complementarily-adjustment and adaptation after stroke are discussed in the literature. There are some limited examples</p>	<p><b>Context for the intervention</b></p> <p>Increasing self-awareness was highlighted as a valued strategy, and the role of significant others in the adjustment process</p>

		<p>et al., 2013 Medin et al., 2010) Adjusting thinking (Klinke et al., 2013, Perry &amp; McLaren, 2003a)</p> <p><b>Adjustment</b> and adaptation to: diet, weigh gain, medication, and packaging (Jones &amp; Nasr, 2018; Perry &amp; McLaren, 2003b)</p> <p><b>Influence of others in adjustment</b> Klinke et al., (2014) talk about the influence of others in the adjustment process.</p> <p>The importance of close family and friends was identified as a critical factor in adaptation. (Johansson &amp; Johansson, 2009).</p>	<p>need to be more careful and self-aware when swallowing.</p> <p>Discussion of the need to be more mindful of healthy eating.</p> <p>Adjustment to new ways of eating and drinking.</p> <p>Patients mentioned the role of the family in supporting adaptation—examples of cooking to accommodate modifications.</p>	<p>the idea of that is it wants to go down quickly enough to go past my lungs because it can be dangerous if it goes into your lungs. When I take the tablets I hold them in my mouth until I'm just about right, and then I swallow them if you do it right you can fairly go right down into your stomach. But sometimes I don't quite do it right and I finish up coughing".</p> <p><b>Examples of adjusting</b> Interview 4 Patient "I have to be very aware of my food I have to be very careful, especially with the swallowing, therefore my drinks are made up. At first, I had to have some thickener to the normal drinks".</p>		<p>of how people are adjusting to DS 2,3,4.</p>	<p>was acknowledged in DS 1,2,3,4.</p> <p><b>Potential benefits and outcomes</b> As stroke survivors adjust to eating and drinking difficulties their self-confidence and performance outcomes may change. Outcome measures will need to reflect change and progress.</p> <p><b>How to deliver the intervention</b> Consider the role of family and carers in managing eating and drinking after a stroke. How will they be involved with the intervention? What additional information do significant others need? Does the concept of adaptation and adjustment need to feature as a topic of discussion? Consider how patients might record their own progress in the intervention.</p>
<p>Striving to live a normal life</p>	<p>Regaining normal life</p> <p>Striving for control</p> <p>Recovery</p>	<p><b>Regaining normal life was mentioned in</b> (Carlsson et al., 2004; Catrine Jacobsson et al., 2000; Jones &amp; Nasr, 2018; Kjaersgaard &amp; Pallesen, 2020; Klinke et al., 2013, 2014; Jörgen Medin et al., 2010; Westergren, Ohlsson, et al., 2001). <b>Struggling towards normality and eating and</b></p>	<p>Post observation reflection (NJ) 'He appears to want to show me what he can do but struggles to execute the movement. I think if he was supported and facilitated, he could manage to feed himself and reflect that he would have benefited from a feeding session'.</p>	<p><b>Striving for recovery</b> Interview 5 informal carer "yes at first, he kept having chest infections because it was over-facing himself as such and it was going on to his chest. We just kept persevering; every time he had a chest infection we just would go right back and say right we're back to the beginning, let's</p>	<p>Video Patient 2 "I went walking on the corridor you know, because it's nice to be able to try to walk and all the rest of it. And all of a sudden three or four of them came on the corridor with me, and the nurse would say oh God what have you done xxx? I'm trying to get them motivated for God's sake, and all of a sudden, they came alive I was doing exercises on the wall and stuff like that and everybody was doing them on the wall, and I thought oh God it's obviously working isn't it, just like that".</p>	<p>Complementarily Strong themes in the literature on 'striving for normal and recovery'. A few examples of this are in DS 2,3,4.</p>	<p><b>Context for the intervention</b> Exploring the concept of 'striving' in the codesign process. How can patients be supported to strive for regaining a normal life?</p> <p><b>Potential benefits and outcomes</b> Personalised goals would reflect what people</p>

	Mastery	<p><b>drinking in a pre-stroke way</b> (Carlsson et al., 2004; Catrine Jacobsson et al., 1996).</p> <p><b>'Getting back to normal'</b> (Perry &amp; McLaren, 2003a, Carlsson et al., 2004).</p> <p><b>Fighting</b> (Perry &amp; McLaren, 2003a)</p> <p><b>Striving for control</b> (Jacobsson et al., 1996, Kjaersgaard &amp; Pallesen, 2020, Klinker et al., 2014, Medin et al., 2010).</p> <p><b>Striving requires adaptation, learning new skills and strategies</b> (Jones &amp; Nasr, 2018)</p> <p><b>Mastery</b> (Jones &amp; Nasr, 2018, Jacobsson et al., 2000, Medin et al., 2010).</p> <p>"New ways of mastering were found, some accepted, and some got used to the new situation" (Medin et al., 2010).</p> <p>"They felt imprisoned in this uncontrollable situation, and tried all the time to interpret new and different signs from the body and master them"(Catrine Jacobsson et al., 2000).</p>		start again. He probably can't remember much of that".			wanted to regain or strive towards.
Strategies		<p><b>Learning new strategies and habits</b> (Kjaersgaard &amp; Pallesen, 2020; Kumlien and Axelsson, 2002). Information leaflets (Eltringham et al., 2019)</p> <p><b>Learning new strategies</b> (Helldén et al., 2018)</p>	<p><b>Learning new strategies and habits</b></p> <p><b>Field notes</b> "This arm is dodgy, I eat with my left hand and a fork or spoon I might use my right to finish off. I'm left-handed and my stroke is right so I can hold a</p>	<p><b>Learning new strategies and habits</b></p> <p><b>Interview 3 patient</b></p> <p>"I've ordered corn beef hash. And it's every so nice the corned beef how they do it and love it. But still and wise to mash it with a bit of mashed</p>	<p><b>Learning new strategies and habits Video</b> Informal carer "so the butter could have been solid in the pack because if you got something like Lurpak butter that is spreadable, that's going to be easier as it's not going to be as much effort and it's not going to tear the toast. Also with jam if you use apart and use a spoon instead of a knife you've got more control over it or marmalade whatever</p>	Several types of strategy were identified, converging on the need to learn new strategies.	<p><b>Context for the intervention</b></p> <p>A focus on strategies and compensatory approaches. Intrinsic and extrinsic strategies.</p>

		<p>Jacobsson et al., 1996, 1997; Johansson &amp; Johansson, 2009; Jones &amp; Nasr, 2018; Kjaersgaard &amp; Pallesen, 2020; Klinke et al., 2014; J Medin et al., 2010)</p> <p><b>Using assistive devices</b> (Jones &amp; Nasr, 2018; Perry &amp; McLaren, 2003a; Westergren, Karlsson, et al., 2001)</p> <p><b>Being careful</b> (Kjaersgaard &amp; Pallesen, 2020) <b>and self-ware</b> ( Medin et al., 2010) <b>although this came with a fear of what others were thinking and seeing and how their behaviours and habits would be seen by others</b> (Catrine Jacobsson et al., 1996, 2000; Jones &amp; Nasr, 2018; Perry &amp; McLaren, 2003a).</p> <p><b>Trial and error</b> (Klinke et al., 2014; Medin et al., 2010, Carlsson et al., 2004)) <b>or learning process</b> (Helldén et al., 2018) <b>or learning to cope</b> (Helldén et al., 2018; Catrine Jacobsson et al., 2000; Perry &amp; McLaren, 2003a)</p> <p><b>Trial and error through practice, learning by doing</b> (Carlsson et al., 2004; Helldén et al., 2018; Catrine Jacobsson et al., 1996; Jorgen Medin et al., 2010).</p> <p><b>Patient information</b> (Eltringham et al., 2019)</p>	<p>knife and fork but is there going up from the table I miss it I miss my mouth”</p> <p><b>Aids and equipment</b> Post reflection- A further consideration from LB was the availability of eating equipment. No eating utensils were available and accessible for patients to use, LB commented that some were on the ward, but they were tucked away in a drawer.</p> <p><b>Being careful</b> Observation field notes She says to me “I’m just about okay you know” the cough has subsided and she takes another piece of toast. The toast is crustless. “I know now that I must be careful with what eat”.</p> <p><b>Self-awareness</b> Observation field notes The patient says “if my wife comes and I’m having my dinner I’m careful because I’m trying to talk, and I cough at the same time. Now I’m aware of it I can chew things longer I make sure it goes down and it goes down slowly”.</p> <p>Patient 4 field notes is eating his breakfast, he tells me that eating has become a careful activity one he needs to concentrate on because it is more effortful.</p>	<p>potato to eat it that consistency is better for me to swallow. And still enjoying it I just can't eat it like I used to. I tend to all of the corned beef ( he smiles) and then potatoes, and anything else that is on there that I fancy. Most of it is done in a way for us to chew and swallow. You can't just get a piece of meat and chop a bit off and eat it; you're not allowed to do it. You have to make sure that is broken up into pieces that you can chew before you swallow”.</p> <p><b>Aids and equipment</b> Interview 2 OT1 “I think things like dycem mats and dishes with heavier bases and we have a couple of those on the ward, not lots of different types of cups. And I'd really like to see different cups as well because I think that's really crucial, perhaps moulded handles and the ones where you can sort of tip it that bit easier to get the liquid out, so not lots and foam fork, knife and spoon handles. I think for patients with a weak grip and usually, my experience is that patients, if they've got an upper limb that's trouble so they'll compensate and use the other hand there's not a lot of patients that will persist with a weaker upper length”.</p> <p><b>Being careful</b> <b>Interview 4 Patient</b> “I have now after a long time started to eat more foods and I have a variety of sweet things I</p>	<p>using, obviously not honey because that's a bit, you know. They would love to get more control over like a desert or a teaspoon, putting the amount on before it is falling off the knife, or getting your knife in a jar to get it further down. Putting the jam in addition that's a wider circumference at the top rather than a jar”.</p> <p>Video Patient 1 “Yes sometimes I would think I'd like a nice cup of tea in a China cup, mug, coffee cup, but no I didn't have a problem. Sometimes if I asked them, I'd have a straw for water or something like that because it's easy. But I didn't find that it was impacted or such with eating at all”.</p> <p><b>Aids and equipment</b> Video Nurse “then it's about had we got the right tools to eat no have got the right knives and forks, do they need a plate guard you know do they need something to wear”?</p> <p><b>Being careful</b> Video Patient 1 “And especially I had to be careful because I was you know gluten-free. And that's not easy especially when you've had a stroke you know they've got to look at things differently”.</p> <p><b>Learning to cope</b> Video patient 1 “The thing with aphasia, you're not doing just the talking your having to like learn all the words. So your brain has to say first, and then you have to speak it so whereas before you didn't have to think about it you would just do it you know”.</p> <p><b>Learning process/ practice</b> Video Nurse “The better the care plan to start with the more chance we have of implementing good practice and that's what we need to do we need to implement what we intend”.</p> <p>Video Psychology Assistant</p>	<p><b>Potential benefits and outcomes</b> Multiple strategies were mentioned in each data set. Strategies could be verbal, or physical support or aids and adaptations. Strategies could be taught by a member of staff and practised in the group.</p> <p><b>How to deliver the Intervention</b> To consider which strategies will be utilised and promoted in the intervention. Include strategies in the staff training pack for breakfast groups. Discuss strategies in the training package, and give examples of types of strategies. Create a place for recording strategies to help stroke survivors and staff remember them.</p>
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			<p><b>Learning process/practice</b> Observation field notes She points to the swallowing chart on her wardrobe door dated the 3<sup>rd</sup> of March 2022. She says “I’ve been having these exercises since then and meals are a time to practice this, so I need the practice” she seems to see having breakfast and lunch as an opportunity to practice her swallowing exercises.</p> <p><b>Trial and error</b> Researcher- How did you learn about all of these things? “Trial and error (laughs), we have had our moments, because that was a hard thing, when he came out of the hospital, I didn’t know what to cook the first night but I wanted to cook something and he would really like. I think that first weekend I did steak and then I realised he couldn’t cut it, and any time I think he was tired at first, he just used to throw his food at the kitchen wall, because we eating in the kitchen and it was just awful”.</p>	<p>can have and erm fruits like bananas which I swallow easily but not everything for example grapes, I can't have as they could cause my airway to block. So, I have to be very careful and so I don't eat hard foods”.</p> <p><b>Learning process/practice</b> Interview 5 informal carer “We got signed off from the tracheostomy, that got signed off last June, and then when he came back to xxxx we went to the throat clinic and they said that's his swallow will just need practice, go off now and carry on and that got me thinking about how doing practice, that well, were just gonna have to try and get him to swallow a bit more and talk more and I think from my point of view, I was kind of prepared to take the risk and xx was prepared to take the risk. So we started surreptitiously to begin with, and I hope that he didn't get a chest infection as it would have been my fault (laughs), that he'd done it but well done you didn't (laughs looking at xx)”.</p>	<p>“I think mealtime groups would be a really beneficial opportunity to practice so whether that be, hat functional aspect, of actually preparing the meal erm, and also opportunities to actually practice the process of eating, so I know for a lot of people that might struggle with swallowing difficulties, so it just provides the opportunity to practice all different areas of eating and drinking within a safe environment”.</p>		
Personal Characteristics		<p><b>Identity, integrity autonomy</b> (Carlsson et al., 2004) <b>Stubborn and patient</b> (Helldén et al., 2018) <b>Values influence perceptions and what’s</b></p>	No personal characteristics identified	No personal characteristics identified	No personal characteristics identified	Disagreement- the role of personal qualities and values only evident in the literature.	<p><b>Context for the intervention</b> Personality, values, and past experiences are linked to habits.</p>

		<b>considered acceptable</b> (Jorgen Medin et al., 2010)					
Participation	Participation in social activities	<b>Participation was discussed widely</b> (Eltringham et al., 2019; Helldén et al., 2018; Johansson & Johansson, 2009; Jones & Nasr, 2018; Kjaersgaard & Pallesen, 2020; Klinke et al., 2014; Lin et al., 2021; J Medin et al., 2010; Jorgen Medin et al., 2010; Perry & McLaren, 2003b) “The social aspects of eating were of prominent importance underscoring the need to focus on what eating signifies to the individual”. (Klinke et al., 2014) “The participants expressed the importance of participation in everyday eating activities and the positive influence that this had on their psychological wellbeing”. (Jones & Nasr 2018).	Patients were in their own rooms- only one patient was taken to the dining room, and they were left alone in there with the TV on.	<b>Social Dining (Interviews 1 and 2)</b> Interview 2 OT1 “I feel like I think the social dining is a really good one because I think it links in very much with our role as OT and looking at the benefit on mood also the way we can support through the use of sort of cutlery, upper limb function. But the social aspect, everything as well”.	<b>Participating in social groups</b> Video Patient 1 and 2 The act of participation in social activities was discussed several times by patients 1 and 2. Watching the football while eating, and doing quizzes in the dining room. Watching Coronation Street together. Chatting about food preferences.  <b>The benefit of talking about your stroke experience with other patients.</b> “Yes, because it was nice, and then there was sometimes there was a meeting where you talk about when you had a stroke, and the person depending on your speech could talk about it and all the rest of it. And mine was simple, to say the least, but at least I said what I thought anyway. That was good for somebody that had a stroke because then they could try to say what they thought when they had a stroke”.	Complementarity around the benefits of social participation and social dining (WP 1,3,4)	<b>Context for the intervention</b> Participation in social activities while dining is viewed as beneficial. This also links to peer support and social impacts.  <b>Potential benefits and outcomes</b> Patients will be encouraged to converse with each other in a group. Consider a measure of social confidence as not everyone will feel confident enough to converse in a group.  <b>How to deliver the intervention</b> Consider whether topics are discussed at mealtimes. Should there be a programme for discussions, or will it be more organic?
Social engagement negatives		<b>Avoidance of social eating situations due to embarrassment, feeling self-conscious and not being able to maintain socially acceptable standards of eating and drinking behaviours</b> (Jones & Nasr, 2018; Klinke et al., 2013, 2014; J Medin et al., 2010; Jorgen Medin et al., 2010; Perry & McLaren, 2003a, 2003b; Schimmel et al., 2011)	<b>Awkward social connection</b> Observation field notes (NJ) “Sometimes, a patient who was on the same table had a stroke that affected his mind. I couldn’t hold a conversation with him. It was better when you had something in common, it felt a bit awkward. If you go into the big dining room the TV is on and everyone is watching”.	<b>Needing privacy when eating</b> <b>In interviews 3 and 4 Patients both expressed anxiety about eating in front of other people and the need for privacy.</b> “it’s a bit more intimate because obviously when you’re reaching over and putting it to your mouth you don’t always get there and you don’t want any on there, so you have to have a plastic apron on. And I feel as though I want to be a bit more private with that. Then I can take my time more as well”.	No negatives to social dining were identified.	Complementarity around the desire to avoid social eating situations in DS 1,2,3- linked to embarrassment and change in eating habits.	<b>Context for the intervention</b> Eating in a group will not be for everyone. Some patients may prefer to eat alone due to the need for privacy. People may drop out of the group as a result of the experience.  <b>Potential benefits and outcomes</b> Negatives of social dining found in DS 1,2,3. It’s not for everyone so there might be some attrition from the intervention.

							<p><b>How to deliver the Intervention</b> Consider the patient information leaflet to address the issue of eating in a group and sensitives.</p>
Negative Psychological impacts	<p>Negative emotions</p>          <p>Shame, embarrassment and humiliation</p>	<p><b>Experiences of negative emotions were recorded in all papers.</b> “Two participants used the term “dark” (P89, P151) to describe the impact of their stroke but had different attitudes. One participant stated, “I call it my dark place where I don’t like and don’t want to be but I can’t do anything about it” (P89). The other stated, “It’s a dark time when you’re laid there and your family’s here and your family’s upset and you think ‘Why me?’ but then you look around and you see other people that are a lot worse than you and it’s a wake-up call, that to say ‘Stop feeling sorry for yourself” (P151). One member of the SVR panel associated the participant’s “dark time” with being unable to eat. For two participants, as they regained their independence, they believed that their determination was the key to their recovery: “I was determined I was going to walk I wasn’t going to be messed about” (P155)”. (Eltringham et al., 2019)</p>	<p><b>Negative Emotion</b> Observation field notes (NJ) “You think your worlds come to an end. I feel bloody useless. I graduated with a wheelchair. I need to ask for help with everything. I can’t walk I’m learning to walk again, and it will be a long job. I had one of these a few years ago but it didn’t affect my coordination as much, I would fall over if you left me”.</p> <p><b>Negative emotion</b> Observation field notes (LB) She eats another small slice of toast and then says, “I just can’t be bothered to get anything else. Some days I think, just go away and leave me alone”.</p>	<p><b>Negative experience</b> Interview 2 OT1 “I guess to be in a situation where you really want to drink, and you can’t get one or you feel like you need a certain type of food and you can’t get it or having thickened drinks or having a diet that is just not what you enjoy. I feel like it must be a really big, big thing for people and have a bearing on general happiness and satisfaction, really and in oral intake”.</p> <p><b>Low Mood</b> Interview 1 AC “And so, let’s talk about the maybe the emotional side of things. When people just don’t want to eat because they’re just not feeling well, they’re feeling really low. I don’t think I’ve seen many people who are just starving themselves because they just don’t want to eat. But sometimes people just don’t feel like eating because they’re depressed, and they just can’t be bothered”.</p> <p><b>Embarrassment</b> Interview 1 AC “They don’t wanna make a mess of their jumper or a mess</p>	<p><b>Emotional impact</b> Video Nurse “and there is quite a big psychological issue for many of the patients. Accepting that they can’t be chewing swallow, accepting what the risk is”.</p> <p><b>Mental health</b> Video Psychology Assistant “I think we can begin to normalise some of those difficulties that people experience and again just linking it back to raising that awareness, that mental health difficulties are really common after a stroke and that impact can be seen on eating and drinking”.</p> <p><b>Low Motivation</b> Video Psychology Assistant “I think for me the most common difficulties that people have experience is the reduced motivation to want to engage in eating and drinking, So follow a lot of people that I work with in particular may suffer with anxiety and that can have a direct impact on their appetite and their drive to want to eat to fuel their bodies and that can have a real negative impact On their overall well-being”.</p> <p><b>Embarrassment</b> Video SALT “swallowing difficulties are common after a stroke and erm yeah and that can affect someone’s intake, their desire to eat if they’re on a modified diet and it’s not very appetising it can really affect things, they can be embarrassed it can get messy it can affect their facial muscles which get a bit weaker”.</p>	<p>Convergence with the experience of negative emotions impacts mood and motivation. Feelings of embarrassment, shame, feeling abandoned DS 1,2,3,4 and a sense of loss was found in DS 1,2,3.</p>	<p><b>Context for the intervention</b> A strong theme on the negative impact of eating and drinking difficulties. Multiple examples in all data sets.</p> <p><b>Potential benefits and outcomes</b> Consider that outcomes could be affected by negative emotions and low mood.</p> <p><b>How to deliver the Intervention</b> Consider how mood is assessed. Identify and normalise the experience of negative emotions in the intervention. Look at resources to support mood. Consider interventions that can reduce embarrassment and preserve dignity. Consider the negative emotional impact and how this can be addressed in the training programme for staff to raise awareness.</p>

	<p>Childlike regression</p> <p>Fear and panic</p> <p>Uncertainty</p> <p>Feeling abandoned, alone and isolated</p> <p>Loss</p>	<p><b>Feelings of shame</b> (Catrine Jacobsson et al., 1996, 1997, 2000; Johansson &amp; Johansson, 2009; Jones &amp; Nasr, 2018; Kjaersgaard &amp; Pallesen, 2020; Klinke et al., 2014; J Medin et al., 2010; Westergren, Ohlsson, et al., 2001)</p> <p><b>Isolation is linked to feelings of shame and embarrassment</b> (Catrine Jacobsson et al., 1996, 1997; Johansson &amp; Johansson, 2009; Kjaersgaard &amp; Pallesen, 2020; Klinke et al., 2013, 2014)</p> <p><b>Feelings of embarrassment</b> (Helldén et al., 2018; Catrine Jacobsson et al., 2000; Johansson &amp; Johansson, 2009; Klinke et al., 2013, 2014; Jorgen Medin et al., 2010; Perry &amp; McLaren, 2003b).</p> <p><b>Feeling like a child</b> (Jones &amp; Nasr, 2018; J Medin et al., 2010; Perry &amp; McLaren, 2003a)</p> <p><b>Fear and panic are associated with swallowing difficulties</b> (Carlsson et al., 2004; Jacobsson et al., 2000, Klinke et al., 2013, Klinke et al., 2014, Perry &amp; McLaren, 2003a, 2003b). Fear and panic are associated with changes in</p>	<p>of what they're doing. It's embarrassing, isn't it? So, they think there's a bit of a shame going on as well. I think patients feel quite embarrassed sometimes, erm, so I think it needs to really be done for their own self-confidence".</p> <p><b>Feeding like a child</b> Interview 1 AC Refers to not feeding people and treating them like children "I'm giving stroke patients as much support for them to be able to do it themselves. So, it's not giving feeding them, they're not children or babies. If it needs to be feeding, then feed them, but giving them as, yeah, giving them as much autonomy over their own eating".</p> <p><b>Abandoned</b> Interview 1 AC "I think when people are left to get on with it and they can't or they don't feel like they want to and then the food gets left, and they're upset by it and because they want to be able to eat it and they can't".</p> <p><b>Abandoned</b> Interview 2 OT1 It's patients sometimes left with a cake or packet biscuits they can't open, you know, just</p>	<p><b>Recognising people feel alone</b> Video SALT "Because I feel people feel very alone in their difficulties and can feel quite low so seeing that there other people are also struggling with the same things and engaging with one another so it would be really valuable".</p>		
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		<p>eating and drinking habits (Jones &amp; Nasr, 2018)</p> <p><b>Uncertainty, dealing with an uncertain future and also what would come next</b> (Eltringham et al., 2019; Helldén et al., 2018; Catrine Jacobsson et al., 2000; Perry &amp; McLaren, 2003a).</p> <p><b>Feeling abandoned by health care services</b> (Carlsson et al., 2004; Helldén et al., 2018; Jorgen Medin et al., 2010).</p> <p><b>Feeling dependent on others for help with mealtime situations</b> (Carlsson et al., 2004; Catrine Jacobsson et al., 1996, 1997; Jones &amp; Nasr, 2018; Jorgen Medin et al., 2010; Perry &amp; McLaren, 2003b)  “Patients were acutely aware of lost bodily control and talked of shame at their appearance and the humiliation of eating dependency.” (Perry &amp; McLaren, 2003a).</p> <p><b>Experience of loss</b>  Physical abilities (Carlsson et al., 2004)  Loss of valued activities around eating and drinking (Carlsson et al., 2004; Eltringham et al., 2019; Perry &amp; McLaren, 2003a, 2003b).  Loss of independence.</p>		<p>that basic stuff of just when you're doing a check have a look.</p> <p>Or the drink is so thick they can't drink it, just those sorts of things. I think that's all part of it as well. So even though ward workers do the most at mealtimes, I feel like outside of that sometimes it gets forgotten about”.</p>		
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		<p>Loss of role (Catrine Jacobsson et al., 1996; Perry &amp; McLaren, 2003a)  Loss of pleasure from eating and drinking in a social context (C Jacobsson et al., 2000; Catrine Jacobsson et al., 1996; Perry &amp; McLaren, 2003b).</p> <p>“Three subjects saw their lives in terms of extreme losses (e.g. stroke as ‘disastrous’ life-shattering experience) and at the point of the interview could neither make sense of it nor see how their lives might be reconstructed” (Perry &amp; McLaren, 2003a).</p>					
Habits and behaviours	Hiding	<p><b>A desire to hide the changes in eating habits</b> (C Jacobsson et al., 2000; Perry &amp; McLaren, 2003a)  <b>A desire to hide struggles</b> (Catrine Jacobsson et al., 2000; J Medin et al., 2010; Perry &amp; McLaren, 2003a).</p>	<p>Observation filed notes- patient talks about hiding the drink thickener so people can’t see he needs it.  “I’ve not thought about having thicker at home too much, I will be okay when I go home. Nobody will know, it’s in there, they won’t know the reason it’s there, it gets put in before you eat”.  Post reflection- interesting that he’s not thought about this before, but the thought was triggered by the conversation.</p>	Nothing to note	Nothing to note	Disagreement- Hiding only identified in WP 1,2	Worthy of consideration but not a strong theme.
Activities associated with eating and drinking		<p><b>The spectrum of eating and drinking activities described</b> (Jones &amp; Nasr, 2018)  <b>Food preparation</b> (Johansson &amp; Johansson,</p>	Not observed or discussed in the acute rehabilitation setting.	The range of activities associated with eating and drinking were not discussed.	<p>Video Patient 2 and Informal Carer</p> <p>Examples of the difficulties encountered with managing the packing of food after a stroke. Specifically with hemiparesis.</p>	Although eating and drinking activities were discussed in DS 1 they were not a focus for the other work packages.	<p><b><u>How to deliver the Intervention</u></b></p> <p>The breakfast group intervention will incorporate food and drink preparation. We need to consider the packaging of</p>

		2009; J Medin et al., 2010; Perry & McLaren, 2003a) <b>Manging packaging</b> (Jones & Nasr, 2018), <b>setting the table</b> (Klinke et al., 2013), and <b>shopping</b> (Klinke et al., 2013; J Medin et al., 2010; Westergren, Karlsson, et al., 2001).			Patient 2 discussed making food and drink as part of her rehabilitation. She described doing this in her nightwear and how she was asked to do tasks she wouldn't have done at home.		food items to make the task accessible. Guide packaging in the resources pack.
Types of assessment for eating and drinking	<p><b>Observation and interview</b> (Jacobsson et al., 1996, Jacobsson et al., 1997, Jacobsson et al., 2000))</p> <p><b>Kratz index</b> ( Jacobsson et al., 1997)</p> <p><b>Eating disability assessment EDAS</b> (Klinke et al., 2013; Perry &amp; McLaren, 2003a) and <b>minimal eating form</b> (Klinke et al., 2013)</p> <p><b>Resident assessment instrument RAI</b> (Kumlien &amp; Axelsson, 2002)</p> <p><b>SWAL-QOL</b> (Pontes et al., 2017)</p>	<p><b>Observations</b> Field notes No assessments for eating and drinking that address skills/abilities or function.</p> <p><b>Assessments observed</b> Assessments for nutrition (MUST) Assessments are specific to dysphagia.</p>	<p>Recognition of the need for a comprehensive assessment.</p> <p>A suggestion is that there needs to be a functional assessment which would include some assistive devices.</p> <p>Interview 2 OT "Because at the minute it's very functional and quite a sort of free-floating in terms of the assessment and maybe that's OK. But I think for where people are struggling with confidence or not quite knowing the right thing, something that perhaps formalizes the assessment and then what to do about that would be quite helpful erm and I think as well just speaking to some of the OTs recently about cognitive issues. One of the things people have said is it's OK doing the assessment, but then it's having things that are disposal to know what to do with next. So it's perhaps having the range of cutlery or things that you can have at your fingertips to just try there and then not just cut them in there, but maybe even different cups and maybe you</p>	<p>Recognition of the need for 'good' assessments being used in the SALT, Nurse OT1 and OT2 videos.</p> <p>Video OT2 "We have got different assessments and resources, different tools something to support assessments at mealtimes that everyone can use. We need almost like a toolkit if there is anything that they can whip out if the patient is you know, the patient is, if they're going to struggle with specific things like cutlery, that we have other cutlery that they can try and is readily available".</p> <p>Video Nurse "What we need to be improving is the quality of our individual care plans, and not only having good assessment and care planning but also implementation of it".</p>	<p>Assessment is key to understanding the difficulties experienced and developing a tailored care plan.</p> <p>No assessments were observed but this was due to the time of day the observations took place.</p>	<p><b>Context for the intervention</b> Assessment is the precursor to intervention. The assessment identifies previous eating and drinking habits as well as the current level of ability.</p> <p><b>Potential benefits and outcomes</b> Previous eating and drinking habits influence preferences.</p> <p><b>How to deliver the intervention</b> Consider including an assessment for eating and drinking function in the toolkit that addresses previous habits and preferences.</p>	

				know, different mats and things like the dycem mats and all of those sorts of things”.			
Eating and drinking interventions	Components of interventions	<p><b>Eating training and practical advice</b> (Carlsson et al., 2004; Catrine Jacobsson et al., 1997; Kumlien &amp; Axelsson, 2002)</p> <p><b>Compensatory techniques and dysphagia rehab</b> (Helldén et al., 2018)</p> <p><b>Oral stimulation</b> (Kjaersgaard &amp; Pallesen, 2020)</p> <p><b>Education</b> (Klinke et al., 2014)</p> <p><b>Strategies to enhance independence and family/social connection</b> (Klinke et al., 2014)</p>	<p>No eating and drinking assessments were observed.</p> <p>No eating and drinking rehabilitation was observed.</p> <p>Patients needing assistance were fed.</p> <p>Patients who could manage were left alone to eat and drink in their rooms.</p> <p>Patients talked about strategies they were using but did not have any assistance with them while being observed.</p>	Patients talked about swallowing strategies or exercises.	<p>Video participants were asked about the benefits of breakfast groups.</p> <p>Strategies were discussed.</p> <p>Staff thought that more could be done to support eating and drinking rehabilitation.</p>	<p>Disagreement- A range of interventions were identified in the literature.</p> <p>Patients talked about swallowing exercises or eating and drinking strategies, including a modified diet and fluids. However, they did not mention any specific eating and drinking interventions or treatments.</p>	<p><b>Context for the intervention</b></p> <p>Very little evidence of group eating and drinking interventions. No examples in the literature of breakfast groups.</p> <p><b>Potential benefits and outcomes</b></p> <p>Consider what components will be incorporated into the breakfast group intervention as there are no previous studies to draw ideas from.</p> <p><b>How to deliver the intervention</b></p> <p>Consider components of the intervention such as education, advice, strategies, practice, dysphagia-specific techniques, and social conversation.</p>
Consequences of eating and drinking		<p><b>Eating and drinking difficulties are described as common</b> (Carlsson et al., 2004; Eltringham et al., 2019; C Jacobsson et al., 2000; Catrine Jacobsson et al., 1996)</p> <p><b>Consequences Dehydration, malnutrition/ nutrition</b> (Carlsson et al., 2004; Schimmel et al., 2011)</p>	<p><b>Nutrition</b></p> <p>Field notes observation</p> <p>An interchange between nursing staff about lack of nutritional intake.</p> <p><b>Messy Eating</b></p>	<p><b>Nutrition and hydration</b></p> <p>They are acknowledged as vital to rehabilitation, health, and wellbeing.</p> <p><b>Messy Eating</b></p> <p>Interview 1 AC</p>	<p><b>Nutrition</b></p> <p>The importance of nutrition and hydration is identified in all videos.</p> <p><b>Messy Eating</b></p> <p>Video SALT</p>	<p>Complementarity- common themes across WPs.</p> <p>The importance of nutrition and hydration is recognised.</p> <p>Consequences of eating and drinking difficulties.</p>	<p><b>Context for the intervention</b></p> <p>The consequences of eating and drinking difficulties were multifaceted.</p> <p><b>Potential benefits and outcomes</b></p> <p>Potential to improve nutrition and hydration, address weight issues and</p>



		<p><b>Clumsiness, and messy eating</b>, (Carlsson et al., 2004; C Jacobsson et al., 2000; Catrine Jacobsson et al., 1996, 1997)</p> <p><b>Leakage and poor lip seal</b> (Perry &amp; McLaren, 2003b; Pontes et al., 2017).</p> <p><b>Pneumonia</b> (Eltringham et al., 2019; Catrine Jacobsson et al., 1997; Kumlien &amp; Axelsson, 2002; Lin et al., 2021)</p> <p><b>Weight loss</b> (Helldén et al., 2018; Jacobsson et al., 1996; Johansson &amp; Johansson, 2009)</p> <p><b>Difficulties with maintaining a healthy diet. Issues related to healthy eating include nutrition, appetite, taste, loss of weight or weight gain</b> Perry &amp; McLaren, (2003b)</p> <p><b>Manipulation of food on the plate and to the mouth</b> (C Jacobsson et al., 2000; Kumlien &amp; Axelsson, 2002; Jorgen Medin et al., 2010)</p> <p><b>Changes with taste</b> (Catrine Jacobsson et al., 1996; Johansson &amp; Johansson, 2009; Klinke et al., 2014; Perry &amp; McLaren, 2003b)</p> <p><b>Cognitive impacts</b> (Jones &amp; Nasr, 2018; Klinke et al., 2013)</p> <p><b>Change in appetite</b> (Kumlien &amp; Axelsson, 2002; Perry &amp; McLaren, 2003b)</p>	<p>Not mentioned, but this could have been due to embarrassment.</p> <p><b>Weigh loss/weight gain</b> Observation of a conversation between a nurse and student nurse about a patient’s weight loss, how to address this with him, and what foods could be offered.</p> <p>Filed notes- The qualified nurse says, “he had three mouthfuls of Weetabix but he doesn’t like it and he’s given up,” the student nurse says “he likes rice pudding so I could try him with a bit of that, and see if he likes it” the qualified nurse agrees “that’s a good idea” and the student nurse replies “wish me luck”.</p> <p>Field notes- the patient's concern about weight loss- “The tea was horrible on two thinners he says it tasted horrible, I couldn’t eat the meals they said I could have a jacket potato and cheese I couldn’t stomach anything else. Then I graduated from 2 to one and I enjoyed food more. At 85 I can’t eat two meals a day but I can eat sandwiches, so I have one hot meal a day and sandwiches. I might have soup or jacket potato and then a hot meal at night and eat it all. I’ve lost weight</p>	<p>They don't wanna make a mess of their jumper, or a mess of what they're doing. It's embarrassing, isn't it? So, they think there's a bit of a shame going on as well. I think patients feel quite embarrassed sometimes, erm, so I think it needs to really be done for their own self confidence”.</p> <p>Interview 3 Patient “it’s a bit more intimate, because obviously when you’re reaching over and putting it to your mouth you don’t always get there and you don’t want any on there, so you have to have a plastic apron on. And I feel as though I want to be a bit more private with that. Then I can take my time more as well”.</p> <p><b>Pneumonia</b> Interview 5 Patient and informal carer discuss the impact of aspiration pneumonia.</p> <p><b>Change in taste</b> Interview 5 Patient and informal carer discuss the change in sense of taste 5- Yay! puts his hands in the air (in delight). I can't taste things yet. C5- he occasionally tastes some things strong things like lemon, and citrusy things. NJ- tart or spicy? C5- this morning or this afternoon? This chilli, sweet chilli chicken, it wasn't overly spicy but because P5's..</p>	<p>“They can be embarrassed it can get messy, it can affect their facial muscles, which get a bit weaker”.</p>		<p>improve performance of eating and drinking.</p> <p><b>How to deliver the Intervention</b> Consider how to address changes in eating habits and messy/noisy eating. Consider how nutrition/ fluid intake is documented. Consider how to address weight loss/gain, healthy eating, and loss of sense of taste.</p>
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			contributory factor to high BP.				
Perceived inadequacies of care		<p><b>Inadequate advice, information on diet modification and swallowing</b> (Eltringham et al., 2019), <b>healthy eating and self-management</b> (Helldén et al., 2018; Medin et al., 2010).</p> <p><b>Concerns about health professionals' knowledge and skills for supporting people with eating and drinking difficulties.</b> (Carlsson et al., 2004; Eltringham et al., 2019; C Jacobsson et al., 2000; Kjaersgaard &amp; Pallesen, 2020).</p> <p><b>Inconsistent approach</b> (Eltringham et al., 2019; Helldén et al., 2018)</p> <p><b>Inadequate documentation</b> (Klinke et al., 2013; Kumlien &amp; Axelsson, 2002)</p>	<p><b>Lack of Knowledge</b> Post observation reflections Identify a potential training need- what to look for with eating and drinking difficulties. Possible training on positioning for mealtimes is required. Why are staff not asking if support is required to cut up food?</p> <p><b>Inadequate documentation</b> Field notes reflections (NJ) No specific care plan for eating and drinking as a function. Nutrition and hydration are covered under enteral feeding. The diet and fluids sections on the handover sheet are sparsely completed. The diet sheet gets put up on the wall in the dining room. This is referred to when patients order their breakfast to see what foods they can and can't have or the diet/fluid consistency. There is also a handover sheet for information, diet, and nutrition. This is also sparsely completed. There is also a diet sheet in the rooms that is not always dated or completed. Reflection- there seems to be a disconnect between the nursing handover and the diet sheets on the ward. The information doesn't translate over, and information is recorded differently.</p>	<p><b>Lack of staff knowledge</b> Interview AC and Interview OT1 Describe on-the-job training but nothing specific to eating and drinking. Both would appreciate more training.</p> <p><b>Inconsistent approach</b> Interview 1 AC "About two months ago, three months ago, and they were getting people in there and it seemed to be quite positive, and it stopped again. So, it seemed very inconsistent. That doesn't seem to be any consistency about it. And yeah, so I think it's more about getting consistent. Just do it once a week rather than trying to do it every day and try and keep that consistency up".</p>	<p><b>Lack of staff Knowledge</b> Transcript Video Patient 1 "Because a lot of people didn't know, and I don't think they understood because I would say I'll be poorly if I have that. And I don't think they understood the problems at all".</p> <p><b>Lack of documentation</b> Video OT1 "Where we document it and the level of detail we go into. You know often we find it's very brief and actually it doesn't talk about do they need assistance you know, were they able to do anything themselves what level of help do they need? Did they fatigue? You know all of those things that they struggle with we never actually comment on in the documentation. I think you know".</p>	<p>Convergence on gaps in staff knowledge and skills.</p> <p>Convergence on the need to improve documentation in WP 1,3,4.</p>	<p><b>Context for the intervention</b> The general opinion of staff is that improvements could be made in documentation and training. However, only a small number of UK studies were included.</p> <p><b>How to deliver the intervention</b> Training needs analysis for the toolkit package. Consider self-assessment of training needs. Documentation needs to be simple, accessible, interdisciplinary, and informative. Include a collaborative care plan and patient goals. Consider where the documentation will be stored and who will have access.</p>

Research gaps identified		<p><b>The following gaps in the research were identified:</b></p> <p><b>Knowledge of the lived experience of stroke survivors in the longer term</b> (Carlsson et al., 2004; Helldén et al., 2018; C Jacobsson et al., 2000; Kjaersgaard &amp; Pallesen, 2020; Klinke et al., 2014; Perry &amp; McLaren, 2003b).</p> <p><b>Support and coping strategies</b> (Jacobsson et al., 1997).</p> <p><b>Environmental factors that impact eating and drinking difficulties after stroke</b> (Catrine Jacobsson et al., 1997; Klinke et al., 2013; Kumlien &amp; Axelsson, 2002; Perry &amp; McLaren, 2003a).</p> <p><b>The role of informal carers and relatives</b> (Johansson &amp; Johansson, 2009; Jorgen Medin et al., 2010; Perry &amp; McLaren, 2003a)</p> <p><b>Need for more research into rehabilitation of eating and drinking difficulties</b> (Klinke et al., 2013; Lin et al., 2021; Schimmel et al., 2011; Westergren, 2008) and <b>individualising care</b> (Klinke et al., 2014).</p>	Not discussed.	Not discussed.	Not discussed.	<p>Research gaps are only highlighted in the literature.</p> <p>Only one reference to using research evidence in the videos (SALT).</p>	<p><b>Context for the intervention</b></p> <p>Most of the studies explored eating and drinking difficulties' lived experiences and impacts.</p> <p>Important to recognise the research gaps.</p> <p>There are no studies on breakfast group interventions.</p>
COVID impact		No studies were undertaken in the COVID era.	Observation post-reflection (LB) Since COVID-19, staff have utilised patient areas on the ward more frequently for staff tasks and functions. The	Interview 1 AC "with COVID, we have done a lot more one-to-one activity, and particularly I think coming out of COVID have looked a lot	Video OT1 "And I think one of the biggest things would be around infection control, and I guess we are living in uncertain times in terms of Covid and what that would look like, things are changing daily so I think however we take it forward we would need to	Staff highlighted the need for additional risk assessments.	<p><b>Context for the intervention</b></p> <p>Need to consider COVID restrictions and the impact on eating and drinking interventions. DS 2,3,4 all</p>

			<p>dining room was used for handovers and ward rounds as there were not enough staff spaces to spread out for social distancing. This has affected the ability to use these bases for patient activities.</p> <p>Observation field note- Housekeeper "I've only worked here for two years, and this dining room hasn't been used very much. There were some groups in here a little while ago, but it all fizzled out I don't know why it fizzled out or why they stopped doing it, whether it was due to Covid. They don't do breakfast groups, but I think it would be good".</p>	<p>more at the psychological care".</p> <p>Interview OT1 "I think COVID has changed things a bit and then trying to start it up again, the wheels are turning quite slowly. And I think certainly a breakfast group is something great, and I think we should be doing that more probably we could do that once a week here, which I think would be a good way of getting going, it's kind of sad, staff, on the whole, want to do social dining, but the COVID issues have been a barrier at the minute. I think with staffing being low know on wants to take patients to the dining room. And yeah. Now's the time and you've put it back on the agenda".</p>	<p>have an element of flexibility around what's happening on the ward".</p> <p>Video Patient 1 "But you didn't get any social mixing, because of Covid, you know, you didn't have 'oh nice to see this time how you?' because you don't see them, you know with eating and drinking it's a very social part of everyday life in normal circumstances".</p>	<p>Staff highlighted challenges with social distancing.</p> <p>Patient areas have been re-purposed due to COVID-19, reducing communal dining spaces.</p> <p>Patients discussed feeling more isolated as a result of the COVID restrictions in the hospital.</p>	<p>mentioned the impact of COVID-19 on eating and drinking rehabilitation.</p> <p><b><u>Potential benefits and outcomes</u></b> The patients shared experiences and feelings of isolation due to a lack of socialisation with other patients. Some dining rooms had not been used since COVID restrictions were lifted as they had been used for other purposes or the habit of taking patients to the dining room was lost. Potential for introducing more socialisation.</p> <p><b><u>How to deliver the intervention</u></b> Infection control plan. COVID risk assessment. Involve the infection control team and engage managers in the operation plan to ensure it's COVID-proof. Have a contingency plan for COVID-19 escalation.</p>
Environment	Factors affecting eating and drinking	Adjusting environmental factors such as eliminating sounds, and creating a calm environment. (Catrine Jacobsson et al., 1997)	Observation field notes (LB) Post reflections observe that it's important to reduce environmental distractions and noise.	Not discussed.	<p><b>Environment</b> Video OT2 "I think really valuing it and having the right environment will help people with their eating and drinking for example I know some of the patients have got concentration and attentional problems, so I know sitting in the noisy bay with people walking past with them getting distracted away from what their eating".</p> <p>Video Patient 1 talks about the importance of the environment</p>	<p>Complementarity Recognition of the importance of an environment conducive to group working.</p> <p>The videos discuss the importance of setting up the dining room like home.</p>	<p><b><u>Context for the intervention</u></b> The need to reduce distractions was discussed in DS 1 and 4. DS 1 talks about the impact of environmental factors on the senses. Distractions were thought to be counterproductive during interventions for eating and drinking.</p>

					<p>"I think when you just in your room sort of you got no nice tablecloth, it's just plonk their and then they give you a drink of tea and you don't want that straightaway you want that after and that sometimes it works that way and sometimes you get everything and it's all there you know that sometimes it would be nice when you go down for a meal instead of having just formica you could have a nice tablecloth you know as though you're at home rather than in hospital environment".</p>	<p><b>Potential benefits and outcomes</b> A group environment could be over-stimulating for people with cognitive issues. Need to consider people's sensory impairments as part of the criteria for inclusion.</p> <p><b>How to deliver the intervention</b> Consider how the dining area can be made more homely to create a normalised setting for a group meal. Include in the standard operating procedure the environmental conditions. Consider strategies to reduce distractions.</p>
<p>Rehabilitation Approaches</p>	<p>Approaches</p> <p>Integration/ joint working</p>	<p>Rehabilitation approaches not discussed.</p> <p>There is no research on interdisciplinary work concerning eating and drinking difficulties.</p>	<p><b>Rehabilitation approaches.</b> NJ and LB both note a lack of consistency in communication between the documents used to communicate rehabilitation needs. LB notes everyone was eating at different times alone in their rooms and didn't have anyone checking on them. Both researchers noted that staffing levels on the ward impacted the number of interactions patients had with staff. There was tension between getting people up, washed and dressed and doing breakfast tasks. Post Reflection- he appears to want to show me what he can do but struggles to execute the movement. <i>If he was supported and</i></p>	<p><b>Rehabilitation approaches</b> Interview 2 OT1 "Patients should be enabled rather than just feeding and it's just being that compensatory approach". "So they are working towards that for going home. Reducing the amount of care and long-term support that they're going to need. Actually achieving their goals. I think it's about making sure that we really communicate about what's important for that patient and how they are eating and drinking. We have got different assessments and resources, different tools something to support assessments at mealtimes that everyone can use. And there's almost like a toolkit if there is</p>	<p><b>Rehabilitation approaches</b> Video OT1 "Eating and drinking for patients is paramount I think it's the foundation for good rehab. I think if they eat and drink then they're going to perform much, much better in every other aspect of their day and you know in terms of achieving their goals. So I think it's absolutely crucial".</p> <p><b>Joint working</b> Video SALT "To build independence, yes really good for joint working, really good for us speech and language therapists seeing a few people all once, you can go to breakfast group and observe a couple of people, having something to eat and drink watching how they get on erm, and also for patients it seems a really valuable way for them to get more therapy input and therapy time, to interact with therapists, and yeah get more therapy input, and also to interact with each other and have some more social engagement being in the hospital, especially after a stroke, especially with people</p>	<p>Complementarily-discussing approaches that include goal setting, and joint or integrated working.</p> <p>Goal setting is thought to be a pivotal component of rehabilitation interventions.</p> <p><b>Context for the intervention</b> Research gaps- rehabilitation of eating and drinking under-researched. More research is needed on eating and drinking interventions such as meal-time groups, social dining and preparing food in stroke rehabilitation.</p> <p>No interventions took place during four breakfast observations on two wards.</p> <p><b>Potential benefits and outcomes</b> Recognition that joint and integrated working is beneficial, but there is an absence of integrated and</p>

		<p><b>Joint information provision is optimal</b> (Jacobsson et al., 1997)</p> <p><b>Importance of attainable goals</b> (Klinke et al., 2014) <b>and mastery of goals post-stroke</b> (Jones &amp; Nasr, 2018; Jorgen Medin et al., 2010).</p>	<p><i>facilitated, I think he could manage to feed himself and reflect that he would have benefited from a feeding session. I note that there are no therapists on the ward at breakfast times. I also note that he's eating breakfast in bed- not suitable for many clinical reasons.</i></p> <p><b>Goals</b> Post reflection note (LB) Essential to ensure rehabilitation goals for eating and drinking are carried over from one day to another.</p>	<p>anything that they can whip out if the patient is you know, the patient is, if they're going to struggle with specific things like cutlery, that we have other cutlery that they can try and is readily available".</p> <p><b>Integration</b> Interview OT1 "I think there needs to be a more joined-up approach to eating and drinking. Erm and I think that involves a wider MDT involvement in assessment at mealtimes, so at the minute, I think it's quite limited to mainly speech and language therapists that will assess at mealtimes, and I don't think we see mealtimes as an opportunity for one in assessment but two actual rehabs. So I think there's a huge opportunity and potential for that, and I think something around documentation around how patients are eating and drinking".</p> <p><b>Goals</b> Interview AC "But I think autonomy and connection, yeah, doing some of their goals within that setting. I think it would be, I think it be beautiful, really beautiful to do".</p>	<p>with communication difficulties as well it can be really isolating". "I also think for eating and drinking and MDT approach is such important because there are so many factors and you work a lot with the dietician work on the intake to make sure people are nutritionally meeting their needs erm but also like I was saying earlier working with physio on positioning and OT on more environmental things that impact on a person's eating and drinking I think and MDT approach is really important". Video OT1 "I think it's everyone's responsibility each profession has a role to play. I think the best model would be a joint approach".</p> <p><b>Goals</b> Video OT1 "I think if there eating and drinking then they're going to perform much, much better in every other aspect of their day and you know in terms of achieving their goals". Video OT2 "I think the therapist we needs to be thinking about what is that person's goals and aims which therapists and health professions would help me with that need?" Video Psychology Assistant "I think its maybe it's about considering what this means for the individual so thinking about what are their personal goals, Is there something specific that they want to achieve because if you're working with someone and this might not necessarily be an aspect that they deem to be important to them or they don't have that willingness to erm work within, I think that could possibly be one of the negative effects but then again it's just about working with that individual to identify what is important to them and how we can support them to achieve those goals". Video OT1 "It's about offering the opportunity to be involved in any aspect of meal preparation for that meal. Is there anything they can do for that breakfast particularly coming to do any aspects of it</p>		<p>collaborative working in current practice.</p> <p><b>How to deliver the Intervention</b> Consider rehabilitation theory and how this is applied to the breakfast group intervention. Explore integrated working and what intervention elements will promote an integrated approach. Consider what documentation processes will be integrated. Develop personalised rehabilitation goal documentation that can be used at each session.</p>
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					themselves? So, they are working towards that foregoing home”.		
What’s important to staff		<p><b>Stroke survivors experienced a lack of adequate knowledge among the nursing staff and healthcare professionals</b> (Carlsson et al., 2004; Eltringham et al., 2019; Helldén et al., 2018; Kjaersgaard &amp; Pallesen, 2020)</p>	<p><b>Training needs</b> Field notes post reflection LB- Again, very dependent on which staff are on as to what questions are asked and what support is given. Could this be an area for training? Provide them with a protocol, a list of questions/adaptive cutlery, etc., if needed.</p> <p>Field notes post reflection- do patients get asked about their diet pre-stroke? What diet advice do they get given? e.g., lifestyle and prevention information. Field notes post reflection- why aren’t staff routinely asking patients if they need any help cutting up food etc.? Is this a training issue</p> <p><b>Staffing levels</b> Observation post-reflection (LB) It depends on how many staff are working and whether they are regular staff or agency staff- this significantly impacts the overall running of the ward, the organisation, whether the staff know the patients, and whether patients would attend a group or not. Reflection- consistency is very important to ensure that rehab and patient goals regarding eating and drinking are carried over from one day to the next.</p>	<p><b>Training needs</b> Interview AC “And because I’m going in, using my knowledge to the best of my ability with what I’ve been told, but is there a better way of doing it? I think that would be quite nice cause because we’ve not had anything specifically on eating and drinking. It might be quite nice”.</p> <p>Interview OT1 “Newer therapists or the newer assistants possibly don’t always know how to support patients, and I think that’s probably the same with ward staff as well”.</p> <p><b>Staffing levels</b> Interview AC Care is mixed depending on staffing levels and whether staff are interested in helping people with eating and drinking. Interview 2 OT1 Not having enough staff is detrimental to the food and drinking support provided. Getting people to the dining room is dependent on staffing.</p>	<p><b>Training needs</b> Video OT2 “good nutrition is key, and particularly for stroke patients, we need to have a bit more training and education on stroke-specific aspects of nutrition and hydration”.</p> <p>Video SALT “think for me making sure that everyone involved has Knowledge and awareness of swallowing difficulties and communication difficulties as well because I think both of those can really impact on the person eating and drinking experience”.</p> <p>Video OT1 “I guess one of the things is raising awareness, education of the staff and whoever is going into sit with the patient, these are the things we are looking out for, why are we doing it, what’s important.</p> <p><b>Staffing levels</b> Video Informal carer “Having the right people to support that’s the crucial thing. If you’ve got a table of four where everybody needs some help, you might have a table of four that doesn’t need as much, you have to assess people before you put people together, so you got different abilities”.</p>	<p>Convergence on the need for addressing training required to support people with eating and drinking difficulties.</p> <p>Convergence on the need to have sufficient staffing to support the time required to support people with eating and drinking difficulties (WP2,3,4).</p>	<p><b><u>Context for the intervention</u></b> The research literature describes how patients perceive a lack of knowledge and skills among stroke healthcare professionals about eating and drinking rehabilitation.</p> <p>Papers exploring staff views on their knowledge and skills for supporting people with eating and drinking difficulties were not included in the review. Staff believe breakfast groups are a good opportunity to share skills and learn from each other.</p> <p><b><u>Potential benefits and outcomes</u></b> Concerns about staffing levels will need to be addressed in the operational plan. By bringing patients together more support could be provided. There is potential for economies of scale.</p> <p><b><u>How to deliver the intervention</u></b> Consider who else might be involved with eating and drinking to support staff. Possibility of volunteers or family being part of the interventions.</p>





			<p>the BISTRo study, would it be possible to have different size bowls and plates to suit individual needs? One patient described being over say faced by the size of the bowl.</p> <p>Patient observation There's a bit too much for me. I won't eat all of that, and if there is still a bit left, they leave it. It's better for me with a small quantity, you feel better when you have eaten it all. Up to now, I have enjoyed it, every time I have it".</p> <p><b>Choice</b> Housekeeper enters- what do you fancy for lunch? P4 answers, "jacket potato with mashed cheese," the housekeeper asks, "soup today?" "No thanks" he replies "what about pudding, she asks?" Ooo yes," he says, "I like their sponge pudding and custard". Post reflection- he becomes animated at the discussion of puddings. "I like pudding for lunch they will offer you a selection of puddings, at home, I like to eat puddings".</p> <p>Patient 2 "The portions are big; oh God I feel full. I like the portion sizes because they fill me up. But there's not enough choice it's hard to choose when you don't like things and you struggle. I'm</p>	<p><b>Choice</b> The importance of choice, interviews 1,2,3, 4, 5 Interview 2 OT1 "I would like to think that I would overhear conversations from the support workers. Like, let's get you in a good position for having your breakfast. What would you like? And I'd like to think that for mealtimes, patients have been given a choice even if they struggle to choose themselves rather than someone choosing for them. Because I know that that sometimes has happened. And I'm surprised by that. I'd like to think that when the housekeeping staff go around, they don't bombard people with it".</p>	<p>someone who's had a stroke, thinking when the next one coming along, mid-day, oh right".</p> <p><b>Choice</b> OT1 "I think there is something around the actual meal itself and making sure we have a variety, choices and that we have different options for different levels of diet, that are going to be appealing to the patient and that the presentation is really considered". Patient 1 "In fact, it was nice for me to have coeliac disease people came up and said what can I have so I had a choice. I'd ask them so I'll have this today and that tomorrow. No problems I enjoyed food definitely".</p>		<p>Consider the types of plates and bowls used to reflect portion choice. Explore where choice can be promoted. Consider cultural needs.</p>
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			right-handed and the weakness is hard. I usually eat with both hands, it's fine but it's hard"				
Archived potential benefits of the breakfast group	Social connection	No data as no studies on breakfast groups were identified.	<p><b>Social connection</b> Post Reflection (LB)- everyone is up at different times. Some are getting up later due to their dependency. No one seems to use the dining room for eating. Everyone stays in their rooms to eat, and food is brought on a tray like in hotel service. Does this feed into the remainder of their rehab and their approach? Some patients/families are often reluctant for the patient to return home due to the nature of the unit. Some have said they don't want to leave as it is like a lovely hotel. Are we encouraging and promoting enablement?</p> <p>Social interaction is recorded by one-to-one rather than group or peer intervention. Patients are eating and drinking alone in their own rooms. Some patients say they would rather eat alone, and others yearn for more contact with other patients.</p> <p>Post reflection (NJ) When there is an interaction, several tasks are often completed at once, so the patient has to think about eating and drinking at the same time as menu choices for taking medication.</p>	<p><b>Social Connection</b> Transcript 1 AC "Taking them to the dining room, they've enjoyed a social experience and they've had a chat and they've gone "oh I talked with this lady over here and they're telling stories over their meal. Whether that be stories that happened before their stroke or about their stroke I would say was a positive way to support patients. So, it's not always just about the physical support that they get, but it's also about that emotional support and I've seen that when I've taken people to the dining room, it cheers my soul (laughs)". <b>Social Connection</b> "Sitting and eating together is generally a good thing, it depends on people's homes and circumstances the number of people these days that would routinely sit around a table and eat together is probably less than it would be 50 years ago. Many people would sit with something on their knees, a tray in front of the television programme. But I think there is a natural human instinct around a social gathering, I think that it's good from a psychological point of view for our patients. And certainly, in the unit might these patients have their rooms with two exceptions on</p>	<p><b>Social connection</b> Video OT 1 "So we are moving away from COVID I think we need to look at returning back to bringing people together at mealtimes because the benefits are just huge and it's one thing that they really miss out on here, is that social interaction with other patients that are going through similar things".</p> <p><b>Social Connection</b> Video OT2 "I think eating and drinking is such a central part of who we are, in interacting with other people Often eating and drinking is such a social thing, who we sit and have breakfast with or meet a friend at lunchtime, or go out for a drink with friends after work, and I think on another level I think preparing food for people is another sign of love, we can do that for loved ones and when there's a change and we can't do that's almost like an impact on our role. So, I think eating and drinking eating and drinking is a big deal for everybody it's a massive part of who we are".</p> <p><b>Social Connection</b> Video Patient 1 "I think it's important for your health, and also well-being, and also it's good to share, like a coffee morning or a breakfast because you can have the ends of the day or the beginnings of a day and have a little chat, as it makes life a lot easier so eating and drinking in a social sense is really good".</p> <p><b>Social Connection</b> Video Patient2 "The good thing is when you have a stroke and this for people on their own you can try to talk to people there next to you that you're on your own you can't, and you waiting till the family come around to see them or whatever. Sometimes it's better to have people chatting away".</p>	<p>Complementarity- the negative impact of social isolation was identified in WP2,3,4.</p> <p>Convergence- the value of social connection was identified in WP 1,2,3,4</p> <p>WP 3,4 – staff enjoyed delivering breakfast groups.</p> <p>Disagreement on social dining- some people prefer not to eat and drink socially.</p> <p>Breakfast groups are any opportunity to practice WP3,4.</p>	<p><b>Context for the intervention</b> Recognising that social dining is not for everyone, however, there is a perceived benefit to people being able to eat and drink together socially. The value of peer support was highlighted in WP3,4.</p> <p><b>Potential benefits and outcomes</b> Breakfast groups are perceived as normal social dining experiences WP3,4. DS 3 and 4 discuss how staff might enjoy the group. A potential outcome is improved peer support.</p> <p><b>How to deliver the intervention</b> Consider activities that support social connection. Allow people to choose to eat alone- it's not for everyone. Consider the peer support component and how this is managed. Consider what elements could be included to normalise the activity.</p>

	<p>Staff enjoy doing breakfast groups</p> <p>Practice</p>	<p>No papers on breakfast groups.</p>	<p>Field notes- this lady has some communication difficulties, having someone describe her tablets and someone else enter the room and start a new conversation at the same time was quite a lot for her to manage. The Housekeeper was task-focused and keen to complete her tasks without any thought to what the nurse was doing. The nurse hung back when the housekeeper butted in about menus; it's possible the nurse was aware that this must be confusing for the patient and held off explaining until the Housekeeper had got her answers and had left the room.</p> <p>Not discussed, no breakfast groups were observed.</p>	<p>each floor. There are very many good things about having their own room and their own ensuite, but also some patients do describe it as being a very long day. They can become very isolated in those rooms, so from the point of view of social human interaction and doing a normal activity when you're in an institution and sitting and eating with other people, that on its own is a really good thing. There is also that it's easier to support and manage several people together than it is for every person in their own room. So, I think there are good things about it from both those points of view".</p> <p><b>Staff enjoy it</b> Interview 1 AC Describes breakfast groups as 'cheering her soul'.</p>	<p>Social connection Video Nurse</p> <p>"But I think there is a natural human instinct around of a social gathering, I think that's good from a psychological point of view for our patients".</p> <p><b>Staff enjoy it</b> Video OT2 "I was able to join a group that's been run before and wow, as an OT just lit me up and it lit all the staff up".</p> <p><b>Practice</b> Video Psychology Assistant "I think mealtime groups would be a really beneficial opportunity to practice so whether that be, hat functional aspect, of actually preparing the meal erm, and also opportunities to actually practice the process of eating, so I know for a lot of people that might struggle with swallowing difficulties, so it just provides the opportunity to practice all different areas of eating and drinking within a safe environment".</p> <p><b>Practice</b> Video SALT "just the opportunity to practice, practice communication, practice eating and drinking, a really nice designated time to practice functional tasks".</p> <p><b>Normal</b> Video OT2 "they had a tablecloth on the table, the napkins folded a certain way they had the butter and spreads in the containers and when I walked into the room it was just, had a real sense of being taken care of, someone is taking the time to make</p>		
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	Normal	Getting back to normal is seen as necessary in the recovery process. Stroke survivors strive to regain everyday life (see 'striving'). There is an aspiration for 'normal' (Helldén et al., 2018)	Not discussed or observed.	<p><b>Normal</b> Interview 1 AC "I am quite interested in this breakfast group or potentially dining group or whatever it could become. Because of this, you see the value of getting people together, particularly over a meal it makes. It's normal in our everyday society. That's what we do when we wanna meet with friends. And it's what makes us human. I think getting together around the table and nattering. So, we should be offering that, I think as much as we can".</p> <p><b>Emotional support</b> Interview 1 AC "Very much there to facilitate a safe space, so that if they want to talk about how they're feeling, they can. And sometimes patients do because that's where they're at. And sometimes patients will reminisce and erm talk about memories. Erm yeah, so it's not always that they wanna talk about their feelings, but it's just making sure that they know that it's a safe place to do that. So, it's not always just</p>	<p>this beautiful and homely and normal and the patients that came in the way they interacted with each other was almost like they had come from being a patient in bed to being a person again you know we talked about holidays, while the speech therapist was looking at what they could swallow and how they were doing that there was also this beautiful interaction going on with the patients and staff where the patient status had gone away and they were people talking you know and I thought that was just magic".</p> <p><b>Peer Support</b> Video Informal Carer "I think it would be helpful because if someone can help someone else, like xx couldn't not open the butter and the jam but someone else mind to being able to use both hands to do it, and then they can help each other and support each other whereas xx was just left on his own".</p>		
	Support	Peer Support	Not observed or discussed.				

				<p>about the physical support that they get, but it's also about that emotional support and I've seen that when I've taken people to the dining room.</p> <p><b>Peer Support</b> Interview1 AC “Lots of people say that they just feel that other if they're with another stroke survivor, they feel and that somebody understands them, that they're not alone in what they're going through. And I think they can maybe draw encouragement and support from each other and particularly in that in that conversation talking about where they've progressed, maybe what they're finding difficult, just normalizing the situation for them and showing them, yeah, I think the main thing for me is showing them that they're not alone in this”.</p>			
Positive emotions	Feeling lucky Gratitude Hope Enjoyment	<p><b>Luck and comparison</b> (Eltringham et al., 2019) <b>Thankful for recovery and every day of life</b> (Carlsson et al., 2004; Eltringham et al., 2019; Catrine Jacobsson et al., 1997; Klinke et al., 2014; Perry &amp; McLaren, 2003a) <b>Hopeful for recovery</b> (Helldén et al., 2018; Catrine Jacobsson et al., 1997, 2000; Perry &amp; McLaren, 2003a)</p>	<p><b>Enjoying</b> Field notes observations (NJ) “The powder is less you can't taste it as much. The hospital food is very nice I enjoy it I had salmon the other day and it was dry. If I was on the straight diet, it would be excellent, and I would enjoy it more”.</p> <p><b>Expression of enjoyment</b> Field note observation (NJ) “I like meat and potato pie you know, it's on my 'what matters to me' board, meat and potato pie, (looks</p>	<p>Interview 1 AC <b>Wanting enjoyment</b> “It's encouraging them, and it doesn't always mean that they have to eat more I suppose, but it's about the experience that they've actually enjoyed that experience or they felt like they've achieved something that to me would be good”. “So, at the end of the day, we wanna make sure that we're providing something that patients can enjoy regularly, not just as a one-off or once a year like Nutrition Week”.</p>	<p>Video Nurse <b>Enjoyment</b> “To me personally, well, it's an essential part of living but also, it's a joy. Certainly, at home we like to take time to prepare food and enjoy having nice food to eat”.</p> <p><b>Enjoyment of breakfast group</b> Video OT2 “We recently had a young stroke survivor on our ward and she loved the breakfast group it was normal, it was fun, and she got something out of it that she didn't get out of any other types of therapies, it was different so for me good eating and drinking means making time for it”.</p> <p><b>Recovery</b></p>	<p>Convergence on the importance of eating and drinking and the enjoyment that eating and drinking inspires.</p> <p>Other positive emotions include hope, gratitude and feeling lucky, although these were only mentioned and not fully explored.</p>	<p><b>Context for the intervention</b> Eating and drinking are seen as activities that are not just essential to life they bring joy. There is a degree of pleasure from eating and from social experiences that revolve around eating and or drinking.</p> <p><b>Potential benefits and outcomes</b> Possible outcomes might be enjoyment. Conversely, people may find they don't</p>

			<p>longingly), I thought I might not be able to have it in the future but the nutritionist says I can have the meat if it's minced or crushed and they said I could have mincemeat but my wife will do that. I can still add my favourite my wife has a long list of things that she can cook for me I enjoy them".</p> <p><b>Hope</b> Observation Field notes (NJ) "I was out of it in a coma. I had lots of strokes. But I've become good at it. I'm just hoping I don't have another one. It could finish me off the next one. I'm taking extra blood thinners now".</p>	<p><b>Importance of enjoyment</b> Interview 1 AC "Eating is a very fundamental thing, isn't it? It's what we all do. It's what hopefully we all enjoy, I imagine for some stroke patients it's not an enjoyable experience, particularly for those who find it really difficult to either a) eat it because of the muscles or b) because it just tastes funny".</p> <p><b>Enjoyment</b> Interview 5 Patient and informal carer The patient and informal carer talk about the pleasure of eating and drinking. P5- just the physical act, it's nice C5- before the stroke xx really used to love food &amp; drink P5- I did C5- we used to go to, not necessarily posh restaurants, just always nice restaurants we would have wine, beer, the full range, stuff like that. xx has very strong food memories. Whereas I can't remember places necessarily but xx can remember what we both ate, the wine and stuff like that. He's got a rubbish memory for everything else (laughs). P5- (XX laughs), I have had a beer and a gin and tonic.</p>	<p>Video SALT talks about the importance of recovery from eating and drinking difficulties. "Personally as well, I think we all have so many reasons why it's important, for nutrition as well, that's why it's really important, the recovery in that kind of thing".</p>		<p>enjoy eating in a social group as much as they did before the stroke.</p> <p><b><u>How to deliver the Intervention</u></b> Consider how we make the intervention pleasurable and facilitate experiences which create joy for participants. Consider how 'fun' can be injected into the intervention. Address the loss of eating joy in the participant leaflet and toolkit.</p>
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Types of support	Importance of support	<p><b>Informal carers can provide a unique perspective on their loved one's difficulties with eating and drinking</b> (Eltringham et al., 2019; Helldén et al., 2018; Klinke et al., 2013; J Medin et al., 2010).</p> <p><b>They also play a role in food and drink preparation</b> (Eltringham et al., 2019; Catrine Jacobsson et al., 1996; Johansson &amp; Johansson, 2009; Klinke et al., 2013).</p> <p><b>They often have their own feedings to contend with, such as guilt</b> (Johansson, 2009), burn out (Eltringham et al., 2019 (Johansson et al 2009),</p>	<p><b>Not asking for support</b> Field notes "I don't like asking for help, maybe I'm stubborn, I think they work too hard, I was never brought up to ask for help".</p> <p><b>Informal carer</b> Field notes, "I thought I might not be able to have it in the future but the nutritionist says I can have the meat if it's minced or crushed, and they said I could have mincemeat but my wife will do that. I can still add my favourite my wife has a long list of things that she can cook for me I enjoy them but I'm not one for eating out".</p>	<p><b>Physical support</b> Interview 2 OT1 "I think in terms of things like positioning, seating and you know freeing up upper limbs of cutlery, everything there's lots of scope from that point of view, I do think". Interview 3 Patient "Well, I don't need any help if I do it right. But occasionally the nurses sometimes bring me medication, they break it up with one of those things that break it up, and they might put in some yoghurt, and they come along with a spoon and they give it to me in a spoon and that's easier that's a good way of doing it. I advise the carers to do that because I can swallow it a lot easier in yoghurt".</p> <p><b>Informal carer</b> Interview 4 Patient "My husband helps or any family member that comes or someone that is familiar with me and the staff here on the stroke unit. They encourage me to eat myself but still one year on I require assistance".</p> <p>Interview 5 informal carer "I bring up the food as evidence of how much he's changed. Because four months ago, it just shows you can. That's the thing, the amount of change that happened in such a short space of time is astonishing".</p>	<p><b>Importance of support</b> Video SALT "I think people having all of the support they need but also people being as independent as possible".</p> <p><b>Not asking for support</b> Video Patient 1 "You didn't have to ring down and say I can't do it. Because I like to have a go you know with myself before I ask people to help me. But I didn't have much of a problem you know".</p> <p><b>Video Informal carer</b> "Yes like a jacket potato, he can't do the skin, so I scoop the potato out for him. And it's little things like that, that you don't realise, salad I chop all the lettuce up instead of leaving it bigger pieces of leaf and do it that way perhaps chop things up more".</p> <p>Video informal carer "The main things were cutting up the meat anything that needs cutting up because he just uses a fork and he hates me having to cut anything up for him".</p> <p><b>Health care support</b> Video SALT "giving the assistance that is required because I think sometimes in terms of staffing, I think patients might not be eating and drinking as much as they could all need to because they don't have time for someone to sit with them and give them lots of encouragement, and the time that they need which means that oral intake is then much more improved".</p>	<p>Strong support themes and the different types of support include verbal and physical assistance, observation, and encouragement. As well, health care staff families, friends and relatives were involved in supporting eating, deciding on the menus and assisting to eat and drink.</p> <p>There is a tension between being helpful and promoting independence. Examples: Not wanting to ask for help, striving for independence, willingly accepting help and when help has a negative connotation.</p> <p>Disagreement with the literature- issues with family taking away independence, treating patients like a child. Recognition that the involvement of family can also be unhelpful.</p>	<p><b>Context for the intervention</b> Recognition of the importance of family and significant others in providing support for eating and drinking difficulties.</p> <p><b>Potential benefits and outcomes</b> Support comes in various forms, physical assistance, advice, and guidance. Potential for patients to receive multiple types of support during the group. Getting the balance between offering support and promoting independence is vital.</p> <p><b>How to deliver the Intervention</b> Consider how significant others and family would be involved in the intervention or education.</p> <p>Address concerns about dependence on others in the intervention.</p>
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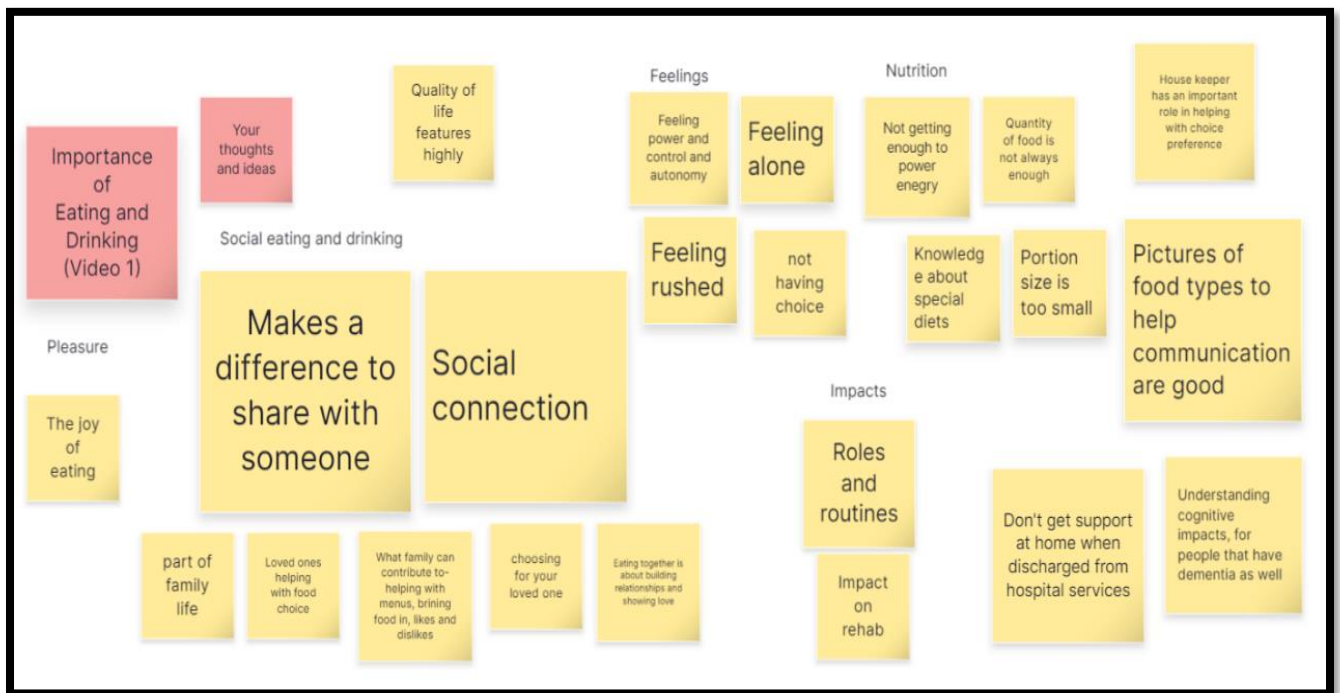


	Health care staff support.	anxiety (Catrine Jacobsson et al., 1996) <b>Family were considered to be part of the team</b> (Eltringham et al., 2019). <b>The negative impact of family involvement</b> (Jones & Nasr, 2018; Jörgen Medin et al., 2010)	<b>Health care support</b> Interview 1 AC “It's because they don't like the food, so I suppose my role there would be there to kind of encourage and maybe go in and talk with them and talk about why they might not want to eat try and courage them and give them the reasons why they should, should is a strong word”.	<b>Health care support</b> Interview 1 AC “Then there's a physical side of things where they might have weakness or they might not be able to actually feed themselves or they might need a bit of support to be able to hold the spoon or hold the fork”.			
Fatigue		<b>Fatigue as an impact of reduced nutrition and hydration</b> (Jacobsson et al., 1996, 1997; Jorgen Medin et al., 2010; Perry & McLaren, 2003b; Westergren, 2008) <b>Fatigue related to eating and drinking difficulties</b> (Jacobsson et al., 1996, 1997; Jorgen Medin et al., 2010; Perry & McLaren, 2003b; Westergren, 2008)	Not discussed or observed.	<b>Fatigue</b> Interview 2 OT1 “So it's the obvious things about delaying swallow and fatigue and all of that as well and particularly you might try self-feeding with patients using a hand over hand technique and if they fatigue, you might give a little bit of support to make sure they maximize their intake that sort of graded approach I don't think is always understood or they're with ward staff. So I think it's a massive area”.	<b>Fatigue</b> Video Informal Carer “When we first started going out after a stroke we always had to go and have coffee and cake, somewhere for him, before we did anything, because the effort of getting out of the house was enough to drain him and we needed to start again. We still do that now all these years later. Everything takes energy out of him and you just have to keep feeding him, because he can't do anything his concentration is not good, it affects all his walking his speech and everything. You always have to be topping up”.  <b>Fatigue</b> Video OT1 Fatigue, so we see a lot of patients that struggle with fatigue, and trying to time them sitting in a chair which is the obviously ideal position for them to be in with managing their eating and levels of energy, is really challenging and often we find some patients will be really tired around the mealtime because they've set out for the morning and then it comes to lunchtime you know one of the most important meals and their two tried to eat anything and it's how we manage that. So, there's lots really”.	Convergence on the impact of fatigue (WP 1,3,4). Post-stroke fatigue and also fatigue related to poor nutritional intake.	<b>Context for the intervention</b> Fatigue was discussed in DS 1,3,4,5. Patients talked about lack of sleep and the impact on their energy.  <b>Potential benefits and outcomes</b> Fatigue levels could impact the success of the intervention. conversely, patients may feel they have more energy after eating and drinking more at breakfast time.  <b>How to deliver the Intervention</b> Consider how fatigue will be addressed in the intervention toolkit and training plan.
Personalised care and individual experience		Individualised support is required (Klinke et al., 2014)	Observations Although personalised care was not discussed, there were examples of	<b>Personal experience</b> Interview 1 AC “I just think it's human, something human about eating	<b>Individual experience</b> Video Nurse “So, it's an individual thing for every patient here depending on their own expectations, culturally	Complementarily-themes related to personalising care in DS 1,3,4. Although this	<b>Context for the intervention</b> A personalised plan or approach was thought to

		<p>Tailoring support to individual needs (Eltringham et al., 2019)</p> <p>Personalised goals (Jones &amp; Nasr, 2018)</p>	<p>individualised tastes and preferences.</p> <p>Filed notes (NJ)</p> <p>Patient 2 The patient said, "at home, I have porridge every day of the week with honey, for my condition. I got to have thickened food".</p> <p>Patient 4 I'll get the carers and I've got a stairlift, I've got everything I need. I'm a typical English man I like Sunday dinner I've never had a hotdog or curry".</p> <p>Patient 5 I'm just a simple man I like simple foods food that keeps me alive and Friday's fish day"</p>	<p>together, isn't it? There's something that makes it more, I don't know personal".</p> <p><b>Individual level interventions</b> Interview 2 OT1 "And I think that that is one I do quite enjoy supporting patients with eating and drinking on an individual level because it does give me the chance to see how they manage a really functional activity and specifically what sort of difficulties that they are having. Yeah, because I think even within the social context, the patients would all have individual needs and they need to be looked at quite thoroughly to make sure we were off in the right level of support for the right patients".</p>	<p>how he is eating at home, how important it is, whether food is simply fuel or whether it is a pleasure. So, you have a complex layer there which is quite diverse".</p> <p><b>Personalised approach</b> Video OT2 "Er it is that every patient has a personalised plan, we discussed with the patient their likes and dislikes, and we discussed what their eating habits were pre-Stroke. Erm that we really try to make their mealtimes and what we are giving them here as personal as possible. Making the time to make things personalised what does that person like how do they like their tea? You know those sorts of things are really, have we got the teabags on the ward so that we can make sure that they've got it? I think personalised is the main thing we know about our patients. When would they eat? How would they eat, what do they like? What's their preference since the stroke has it changed? We are doing it as a tailored treatment plan".</p> <p><b>Personalised goals</b> Video Psychology Assistant "I think its maybe it's about considering what this means for the individual so thinking about what are their personal goals, Is there something specific that they want to achieve because if you're working with someone and this might not necessarily be an aspect that they deem to be important to them or they don't have that willingness to erm work within, I think that could possibly be one of the negative effects but then again it's just about working with that individual to identify what is important to them and how we can support them to achieve those goals".</p>	<p>wasn't observed or discussed in DS 2 it was evident that personalising of food preferences was important.</p>	<p>be beneficial. Tailoring interventions to patients' needs and also their personal preferences. This was not explored very well in the literature but there was evidence of this in DS 2,3,4.</p> <p><b>Potential benefits and outcomes</b> Patients may respond better to a personalised approach.</p> <p><b>How to deliver the Intervention</b> Consider how the intervention can be tailored and personalised for everyone. Personal goals are included in the toolkit. Consider how personal experiences and habits can be included in the intervention.</p>
Culture		<b>Cultural aspects</b> (Jones & Nasr, 2018; Klink et al., 2013)	Not mentioned	Not mentioned	<p>Video Nurse "I think for some, it's about what culturally they are comfortable with. There are some groups for which we are much more aware of this than others. For people with certain religious backgrounds tend to be aware of people like that. For example, people from a West Indian background have a different tradition of what they</p>	<p>Silence- Culture is missing from WP 2,3 and only mentioned briefly in the literature.</p> <p>Food preferences related to culture were mentioned in one video.</p>	<p><b>Context for the intervention</b> The culture was only mentioned in DS4. Is this because it's not an issue or is this because staff don't consider this to be important? Need further</p>

					eat at home. We're probably not culturally sensitive there".	Silence - information about eating and drinking difficulties impact on culture is missing.	<p>exploration in the codesign phase.</p> <p><b><u>Potential benefits and outcomes</u></b> There is a danger of being culturally insensitive and not as inclusive.</p> <p><b><u>How to deliver the Intervention</u></b> Consider provision for people with diverse cultural backgrounds. Capture food preferences related to culture in the assessment.</p>
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## Appendix 13: Reflections on Trigger Video 1 'Importance of eating and drinking?'



## Appendix 14: Idea Board for Place Name Cards

**Resources**

**Name places for the group with the type of diet written inside?**

*"A way of signalling gluten-free"*

*"The place name idea feels most manageable and appropriate. Name places like at a wedding or conference?"*

*"I think there were some really good ideas as someone said about when you go to a wedding and there are just little place cards, I think something more discreet like that might be maybe more beneficial and maybe just a bit less labelling".*


*"I suppose the main thing from my perspective would just be about, like, promoting that dignity and avoiding the stigmatization aspect".*

Dietary needs e.g., gluten-free or level 7 specialised diet


How do you like your tea?  
One for two sugars?

# Appendix 15: Storyboarding, final implementation toolkit prototypes

Ready for breakfast group sticker prototype



Large product sticker prototype




Does anyone have any resources on supporting conversations?


Any last comments or feedback on the resources circulated?

Tool Box products	Plans
Intervention Booklet	One for each patient
BISTRo Intervention Protocol for training	For training staff
Large sticker for packaging	For use on products in the group
BISTRo Menu	For patients in the group
Name place cards	For patients in the group
First-up board	For use on the ward
Do not disturb sign	For use on the doors to the breakfast group
Patient notes page	patients notes
Ready for breakfast stickers	For patients
Leaflet	For patients and others
6-Sit or MMSE assessment	Decision
Conversational tool	For use in the group
Assessment	For staff to use
Risk assessment	For staff to use
Training pack	To deliver to staff

Menu prototype




What do we do about the mini-mental assessment?




Any further thoughts on the outcome measures for self-confidence


### Aphasia drink menu

#### Tea




#### Hot Chocolate






## Resources

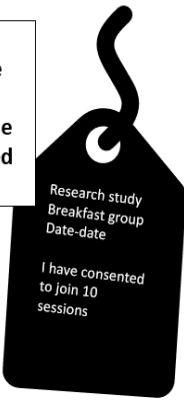
A do not disturb sign




I think the menu needs to reflect what is available at each site.



Something That can go in the paper patient record to show the patient is recruited to this study




Risk assessment



*"whether the toolkit would cover this or if we would need to do another risk assessment. Guidance at the Trust level is now relaxed but on the Stroke Unit's reluctance to support group work".*

A first-up board





Images source: Pixabay (free version)

## Appendix 16: Mock-up examples

Infection  
control


Single-use items

An infection control  
stations creates  
time efficiencies

Ensure there are  
wipes to clean down  
after each patient and  
provide single-patient  
items or enough for  
single use.

Breakfast Group  
Stickers





Stickers can be used in two ways:

- To highlight who is coming to the breakfast group
- At the end of the breakfast group to show attendance.
- Patients can stick these on their clothing or put them on their personal booklets.

BISTRo Study

I'm ready for  
Breakfast Group





### Toast station

- Use large labels for food products.
- Decant butter and jam into personal bowls for infection control.



Label drinks- wipeable jugs


Image Source: Natalie Jones 2022



# Appendix 17: Example of the posters displayed at the open research event (workshop 10)

## Are co-designed breakfast group interventions acceptable and feasible for stroke survivors and health care professionals? (BISTRo Study)

**Mrs Natalie Jones<sup>1,2</sup>, Professor Susan Mawson<sup>1</sup>, Professor Alicia O' Cathain<sup>1</sup>, Professor Avril Drummond<sup>3</sup>**  
<sup>1</sup>University of Sheffield, Sheffield, United Kingdom, <sup>2</sup>Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, United Kingdom, <sup>3</sup>University of Nottingham, Nottingham, United Kingdom



**Stroke Survivors**

"We were encouraging each other, someone to say, come on you can do it and you are not alone!"

Patients enjoyed the dining experience, especially doing something normal and experiencing human connection. This was facilitated by every day objects such as teapots and mugs, bright tablecloths and flowers

**Peer support was valued for:**

- ⇒ Inspiration
- ⇒ Reassurance
- ⇒ Learning
- ⇒ Lifting mood
- ⇒ Providing motivation

**Rehab Team**

The BISTRo intervention was feasible for three stroke teams to deliver.

- ⇒ The toolkit supported inclusivity
- ⇒ Staff valued the opportunity to promote independence
- ⇒ Staff were learning from each other and sharing skills
- ⇒ Daily groups intensified eating and drinking rehabilitation

**Introduction and Background**

Difficulties with eating and drinking after stroke negatively impact health and well-being (Klinke et al., 2013). Stroke survivors six months post-stroke want more opportunities to practice eating and drinking (Jones & Nasr, 2018).

**Aim**

To co-design, a breakfast group intervention and implementation toolkit to improve the way eating and drinking interventions are delivered in hospitals.

**Methods**

BISTRo is a mixed-methods study, using participatory action research methods. Interviews with stroke survivors, focus groups with health care professionals and ethnographic observations were used to investigate the attitudes and beliefs of those delivering and receiving the intervention.

Sixteen stroke survivors participated in a programme of ten breakfast group interventions in three different hospital stroke services.

**Conclusions and implications for practice**

Stroke survivors and rehabilitation teams thought breakfast group interventions were acceptable and feasible to deliver. Stroke survivors had improved confidence with eating and drinking skills and discussed the psychosocial benefits of peer support. Staff perceived improved collaborative working and thought this could optimise provision of a daily intervention.

**Acknowledgments**

Thank you to the stakeholder group who co-designed the BISTRo intervention and supporting toolkit. NHS Ethics 21/NW/0313. Illustrations © Natalie Jones

**References**

Jones, N. & Nasr, N. (2018). The experiences of stroke survivors with managing eating 6 months post stroke. *British Journal of Occupational Therapy*, 81(2), 106-115. <https://doi.org/10.1177/0309070117738487>

Klinke, M. E., Wilson, M. E., Hellebrandt, T. B., & Grondits, H. (2013). Recognizing new perspectives in eating difficulties following stroke: A concept analysis. *Disability and Rehabilitation*, 25(12), 1481-1500. <https://doi.org/10.1080/09638237.2013.820242>

**Logos:** NHS Sheffield Teaching Hospitals, NIHR National Institute for Health Research, University of Sheffield

Natalie is funded through an NIHR/HEE Clinical Doctoral Fellowship NHR 300529

Image Source: Natalie Jones 2022

## Do stroke survivors find daily breakfast group interventions acceptable and feasible? (BISTRo Study)


**Mrs Natalie Jones<sup>1,2</sup>, Professor Susan Mawson<sup>1</sup>, Professor Alicia O' Cathain<sup>1</sup>, Professor Avril Drummond<sup>3</sup>**  
<sup>1</sup>School of Health and Related Research, Rehabilitation and Assistive Technology Group, Sheffield, United Kingdom, <sup>2</sup>Sheffield Teaching Hospitals NHS Foundation Trust, Stroke and Geriatrics, Sheffield, United Kingdom, <sup>3</sup>School of Health and Related Research, Director of Medical Care Research Unit, Sheffield, United Kingdom, <sup>4</sup>University of Nottingham, School of Health Studies, Nottingham, United Kingdom

**Introduction and Background**

Stroke survivors desire opportunities to practice eating and drinking in their rehabilitation to become independent and confident with social dining (Jones & Nasr, 2018).

**Aim**

BISTRo aimed to co-design an acceptable and feasible breakfast group intervention with stroke survivors, carers and health care professionals.



**Methods**

BISTRo is a mixed methods study using participatory action research. A prototype intervention was iteratively co-designed with 15 stakeholders in 9 online workshops.

BISTRo was tested in three UK hospitals. Version 1 was tested for ten sessions in site one and version 2 was tested for ten sessions in sites two and three.

Acceptability and feasibility were investigated using patient interviews (n=12), staff focus groups (n=21) and ethnographic observations (n=6).

Data sets were analysed separately and together using an inductive approach (Harden et al., 2004). A triangulation process addressed completeness, convergence, and dissonance (Farmer et al., 2006).

**Results**


Sixteen stroke survivors were recruited, mean age of 71 years (SD 8.9), White British (13), African (2), Caribbean (1), 89% of the sessions were attended (SD 1.4).

**Five Themes**

1. Feeling normal
  - I'm probably going to have to do this for the rest of my life, yet its acceptable and would be acceptable if I went for lunch with family.
2. Experiencing fun and enjoyment
  - It was the opportunity to do things for yourself, its was tremendous fun as well.
3. Feeling human again
  - We are humans, social animals, it was nice to meet and talk to other people.
4. Not being alone
  - You are not alone in the port, you are together, people help and encourage you.
5. Learning from each other
  - You are interacting and learning from it, you are talking about your disabilities, everybody has got different disabilities. You learn things from each other.

**Conclusions and Implications for Practice**

Breakfast groups were acceptable and feasible. BISTRo also provided key insights into the contexts and mechanisms required for a future definitive intervention trial.



**Acknowledgments & Conflicts of Interest**

Thank you to the stakeholder group for co-designing the intervention. Authors have no conflicts of interest.

Funded through an NIHR/HEE Clinical Doctoral Fellowship Award NHR 300529/NHS Ethics 21/NW/0313 Contact: natalie.jones56@nhs.net @natluj

**Logos:** NHS Sheffield Teaching Hospitals, NIHR National Institute for Health Research, University of Sheffield



## Appendix 18 Storyboard illustration of the codesign process, open research event (workshop 10)

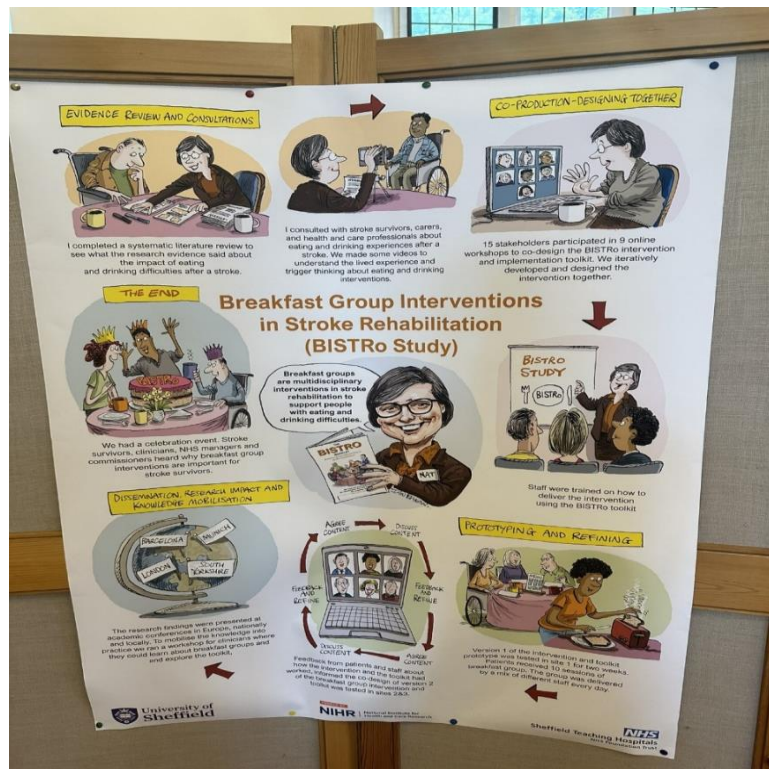
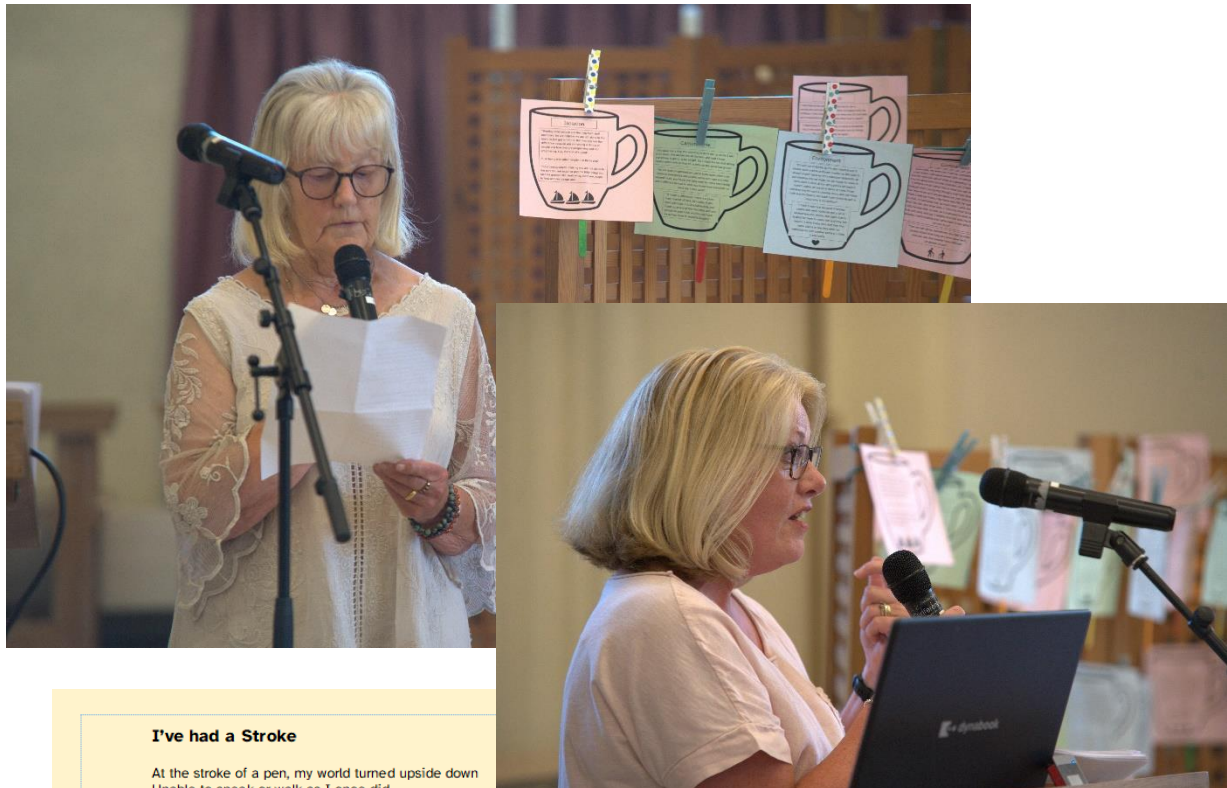


Image Source: Natalie Jones 2022



## Appendix 19: Patient and public engagement in the open research event (workshop 10)



### I've had a Stroke

At the stroke of a pen, my world turned upside down  
Unable to speak or walk as I once did  
I was lonely in a room of my own  
Covid was rife  
Dark and scattered thoughts were all that I had  
Felt as if I was in prison  
Physios came and OTs as well, but touch me not  
Nurses and cleaners all came and went  
Speech therapists came but had little time  
Food was a hurdle, asking for gluten-free  
Caused eyes to roll  
Porridge for my breakfast was a nightmare  
Is this gluten-free? No! Then back it went  
TV and Zoom were a godsend to lighten the gloom  
I needed to be with other people  
I'd had a stroke

Now, I'm at home, feeling quite nervous  
What will I be like?  
Who will help me to live my life independently?  
The family are waiting - hugs all around  
I'm all at sea  
Carers coming to see how I am  
Cooking, washing, and taking my medicine  
All difficult, what can I do?  
Two weeks have gone, and now I'm alone  
Family come around, carers have gone  
Now, I must cope on my own  
Reading, cooking, sitting in the garden  
I'm improving  
After 3 years, yes, I can do most things  
But not as used to do  
I'm still here, still trying out new things  
Be patient I say  
I've had a stroke

By Marge Allen

Image Source: Natalie Jones 2022- Permission to use Poem written for the dissemination workshop.

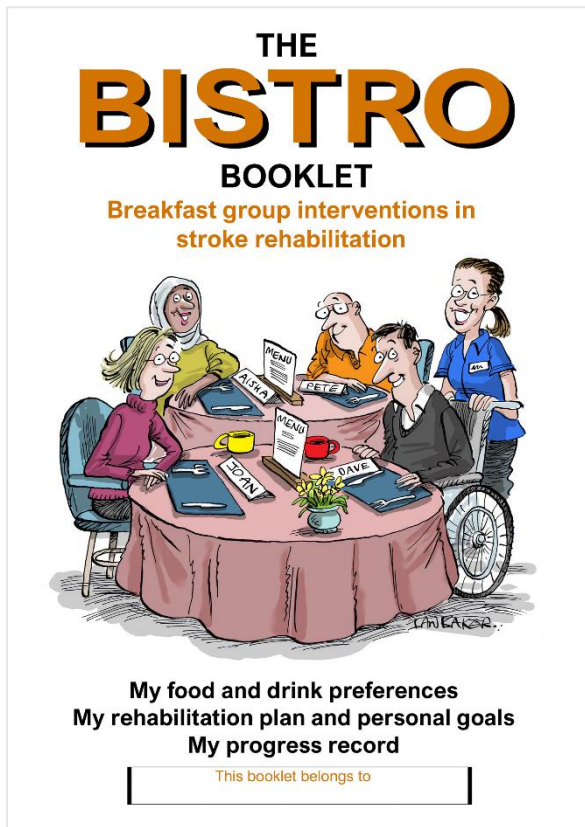
## Appendix 20: Collection of photos from the open research celebration event (Workshop 10)



Image Source: Natalie Jones 2022



## Appendix 21: Images of the BISTRO Patient Booklet



My session record.

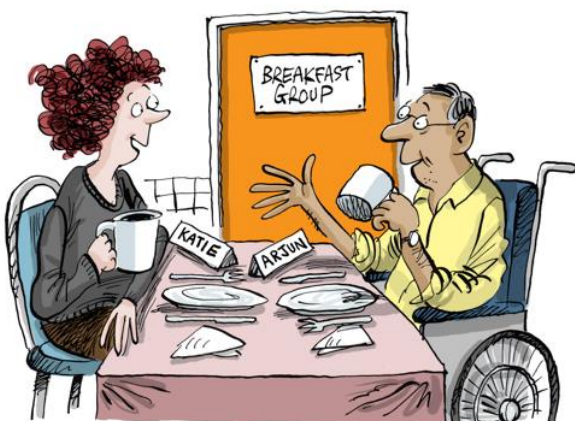


Image Source: Natalie Jones 2022



## Appendix 22 Convergence Matrix: Post Prototyping (Stage 3 Hawkins Framework)

Theme	Aspect of theme	Interviews	Focus Groups	Field Note Observations	Convergence, Complementarily, Disagreement Silence	Conclusion
Topics of conversation	Range of themes	<p>Christmas, particularly about how this year would be different and how they would need to adjust their plans or activities.</p> <p>Discuss with other patients about their stroke, how they feel and how far they have come, how long they have been in the hospital.</p> <p>Discussion about what progress they are making.</p> <p>Occupations.</p> <p>Families, children and grandchildren.</p> <p>Discussion about our therapy, how far we had come and different methods of doing things.</p> <p>How we are going to manage when we go home.</p> <p>Family histories, how technology has changed.</p> <p>World cup.</p>	<p>Music songs and artists they liked. Concerts.</p> <p>The World Cup (football)</p> <p>Hobbies</p> <p>Their homes and gardens, and wildlife in the garden.</p> <p>Knitting.</p> <p>Christmas</p> <p>What they like to eat and their usual mealtime routines.</p> <p>Families and what their family members do.</p> <p>Husbands and wives</p> <p>School</p> <p>Personal life experiences, loss of loved ones.</p> <p>Car boot sales</p> <p>Hobbies</p> <p>Reminiscing about family life and their childhood.</p>	<p>Music, songs and artists they liked. Concerts.</p> <p>Films.</p> <p>There was also occasional singing of favourite songs.</p> <p>Football, particularly the world cup.</p> <p>Other sports, favourite sports.</p> <p>Hobbies</p> <p>Their homes and gardens, wildlife in the garden.</p> <p>Knitting.</p> <p>Favourite foods and how people liked their drinks.</p> <p>What they like to eat and usual mealtime routines.</p> <p>Sleep and how well they had slept.</p> <p>Food, the price of food and how it has risen.</p>	<p>Convergence- Focus groups and observations identified music and sport.</p> <p>All three identified family and Christmas.</p> <p>The interviews with patients identified more personal topics such as stroke experience, progress and life after stroke.</p>	<p>A diverse range of topics.</p> <p>People talked about themselves and their families.</p> <p>Other topics were relevant to popular culture and events or nostalgic such as childhood memories and experiences which were shared.</p> <p>Conversations were quieter when eating but they continued from the beginning to the end of the group.</p> <p>Whole group conversations or one-to-one conversations.</p> <p>Conversations were initiated by the staff but mainly they evolved from peer conversations.</p>

				<p>What aids could be purchased and where from?  Peter Kay tickets.  Family, children and grandchildren.  Where people were born and family histories, what parents did for occupations.  Occupations.  Husbands and wives.  Childhood memories of food, Sunday dinners.  Reminiscing about school, school hymns (followed by some singing)  Dancing and clubs, bingo.  Celebrity Jungle.  Fear of spiders.  Politics.  Christmas shopping and how this year it would be different.  Car boot sales.</p>		<p>Conversations were joyful, there was a significant amount of laughing and sharing of experiences.</p>
Workforce	Challenges and professions engagement.	Silence – note- patients commented on how staff had been helpful and they were appreciative of the support and the experience they had provided but there	Site 1 Three staff recommended. One to support conversation and two to assist patients making breakfast The	Site 2 Physiotherapy was understaffed for the two-week period and therefore would not be able to participate as	Convergence- two sites had an OT working an early shift to attend nursing handover. Silence- patients did	A range of disciplines took part. This varied on each site due to engagement, staffing resources and historical practices.

		<p>were no comments about staffing specifically. Staffing was also not explored as a specific question.</p>	<p>housekeeper played a significant role in preparation. OT at 7am handover to plan the patients.</p> <p>Site 2 Physiotherapy- due to staff shortages were not able to participate although they consented. No nursing staff were recruited. Despite efforts, there was a lack of appetite to be involved. Reasons for this include it's not usual practice, lack of clarity on what their roles would be and historically nurses ' don't get involved in rehabilitation groups, staff shortages in the mornings.</p> <p>Site 3 Didn't rotate staff as much so they had two people that were consistent and one that rotated. Post-study reflections were that a rota system was required</p>	<p>originally planned. No nurses were recruited for the study although the nursing staff were supportive, they were helping patients get washed and dressed, doing drug rounds and doing other activities on the ward. The nurses did come down to the breakfast group to administer medication and when they came into the group they were chatty with the patients and engaged in conversation. No issues with patients being ready.</p> <p>Site 3 In conversation with staff afterwards, they said that the healthcare assistant had attended the group every day and today the psychology assistant speech and language therapist and OT were present dieticians were not available however they</p>	<p>not mention any staffing issues other than appreciation. Site 2 did not have any nurses or physiotherapists. Site 3 did not have any dieticians involved. Site 1 consented a dietician but she was unable to take part due to staffing issues. Site 3 was the only site with psychology involvement. Site 1 consented nurses but none took part due to staffing.</p>	
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			<p>and greater investment from the whole team. Two staff were getting the group members up and ready so this was an additional strain. OT at 7am handover to plan to getting patients up with nursing staff.</p>	<p>wanted to be part of the group if it ran in the future.</p>		
<p>Staff learning and development needs</p>	<p>Learning from each other</p>	<p>Silence- staff training or staff skills were not mentioned.</p>	<p>Site 2 The activity coordinator wasn't trained and experienced in moving and handling patients therapeutically. The SALT identified she wasn't confident with moving and handling.</p> <p>Site 3 The psychologist learns from watching others, she learns about other disciplines' roles by observing. The OT highlights it as an opportunity to educate other staff about each profession's roles.</p>	<p>Site 1 Identified training needs for thickening fluids, activity coordinator. The SALT identified she was less confident with moving and handling.</p>	<p>Convergence- in two sights SALT talked about moving and handling training needs. Silence- patients did not share any concerns about staff skills and knowledge- this conflicts with the systematic review findings.</p>	<p>Training needs for staff were not specifically explored. The training was provided to everyone who consented to deliver the intervention. The training package included the rationale for the study, how to implement and operationalise the intervention and theoretical concepts which underpin the core components. It did not include any practical training or in-depth training on rehabilitation techniques as it was assumed this knowledge was already present.</p>

						Cross-reference with nominal data on the number of years worked in stroke. The data shows a relatively inexperienced workforce that participated.
Team working	Blending skills. Working together collaboratively. Learning from each other.	Silence no examples from patients about staff working collaboratively.	<p>Site 1 <i>S- "Just the fact that we should be using the dining room you know, it takes a whole ward to be involved but actually it's not that hard once you get going to get people in there"</i></p> <p><i>S- "as well as that I would say shift in staff mentality so were all working together, across all the different staff coming together for the patients.</i></p> <p>Site 2 Examples of staff working collaboratively, and learning from each other. Examples of it reducing the divide between some staff groups. <i>S- "I like the other day xx when (SALT) was in it and</i></p>	<p>Site 1 Staff communicating with each other.</p> <p>Site 2 Observations of staff working together, two staff to support a patient make a hot drink.</p> <p>Site 3 Staff working in tandem which required.</p> <p>No exact examples from the transcripts but evidence of staff working collaboratively in the observations.</p>	<p>Convergence Focus groups had multiple examples of staff working together.</p> <p>Complementarily Observations were supported by specific examples in the focus groups.</p> <p>Silence No examples of patients noticing how the staff worked together.</p>	<p>Themes included; the breakfast group facilitated staff to work more collaboratively as a team around eating and drinking.</p> <p>Staff saw the benefits of this in terms of learning from each other.</p> <p>Mechanisms for working together include.</p> <p>Learning from each other, learning by observation. Creates the opportunity to work closer together, and camaraderie.</p>



			<p><i>I was with xx (patient) she wasn't doing a feeding assessment as such but because I wear the hood XX could see my face and I thought that worked quite well"</i></p> <p><i>"if I see you doing something it's a good refresher for me, just like I think all your I could do that</i></p> <p><i>E-like xxx said we all work really well together as a team anyway, it all went to plan!"</i></p> <p><i>Site 3</i></p> <p><i>"I think the positive thing for me, was that it brought us together in terms of an MDT.. so it was like a really positive reason for us to work together and be collaborative about meeting our patient's goals and that was a really big success for me".</i></p> <p><i>"I also learnt so much as well, I mean I usually work in the office most of</i></p>			
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			<p><i>the week but yes doing that group together I felt closer to the others I felt like I understood their job more. It helped me with my sessions, thinking what can I do. The questions that are OT related I feel like I could answer them better now which before I wouldn't have and the group just help me do that in a natural way without anything formal, formal training you just kind of learn from each other. I learnt watching others and it was kind of rewarding much more than I thought it was going to be".</i></p> <p><i>"I want to understand the pressures I want to understand how we can work together and have that camaraderie for our patients because it's a bloody hard job we do and I want to see more of that I want us to walk together in that we</i></p>			
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			<p><i>should be proud of what we do we do rehabilitation we help people change and at times it's a really stressful really hard job but when we do it together it feels doable so want to see more of that. That is the thing that has meant a lot to me doing it together with my peers and learning from each other".</i></p>			
Social dining	Social conversation with others, the process of communicating with others in the breakfast group.	<p>Site 1 <i>"it was nice to meet people and share with them".</i></p> <p>Site 2 <i>"I think it was good and the reason being when you first went in there you didn't know each other erm and as the days progressed you got to know each other a lot more so everybody's personality came out more and they relaxed more. You</i></p>	<p>Site 1 Recognise the value of the breakfast group as an opportunity to socialise with other patients. Describe how patients relaxed as they become more comfortable in each other's company, spontaneously talking to one another and asking about each other.</p>	<p>Site 1 The WOW resources and ice breaker questions were not used as they were not needed. An opportunity to practice communicating and improve speech. Staff talked about how they had seen mood improve during the sessions and day by day as the patients' formed</p>	<p>Convergence Friendliness came up in all three data sets.  Complementarily Patients talked about developing new friends. Staff talked about the friendly atmosphere and how they have observed patients</p>	<p>Patients recognised that it was good to meet other patients and share ideas. This was one of the most common benefits described. They valued social connection and enjoyment. They also talked about social isolation and how this was providing an</p>

		<p><i>found that they were far more interesting and a different person to what you make have expected, so like I say it was good".</i></p> <p><i>"it was just all became normal because we were all becoming friends and we could talk to each other normally about different things and work together and have jokes together".</i></p> <p>Site 3 <i>"you are interacting, you are talking about your disabilities"</i></p>	<p>Friendly atmosphere. Phone numbers were exchanged. WOW resources are only used once.</p> <p><i>"not just the physical stuff either you know the social interaction, communication and the conversation that they had, you know at the beginning of the week they were all just finding their feet and getting to know one another, but then you know towards the end we had patients that wouldn't have initiated conversation were sparking conversation with other patients. They all knew each other's name and they were saying 'oh however you slept?"</i></p> <p>Site 2 Recognise the value of the breakfast group as an opportunity to socialise with other patients.</p>	<p>bonds or become more relaxed with each other.</p> <p>Site 2 WOW, resources were out on the table but not used very much. Patients with aphasia were encouraged to engage in communication with staff and other patients.</p> <p>Site 3 WOW resources were not used. Friendly banter observed. Patients exchanged phone numbers.</p>	<p>sharing phone numbers. The package to support conversation (ice breakers and WOW resources were not needed very much as conversation flowed easily without).</p>	<p>opportunity to combat that feeling. They valued the opportunity to talk to one another about the stroke and how it had affected them. Talk of friendship developing.</p>
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			<p>As patients got to know each other the atmosphere relaxed. An opportunity to practice communicating and improve speech. Recognising that socialising with others can improve mood. Friendly banter and atmosphere.</p> <p><i>“I liked the social interaction between them all and I don't think they quite get that in other groups because they go to the groups and they just do exercises but like here, you identified before the eating is a social thing, when you're at home you don't like sitting room and do it by yourself, getting the normality of that but like seeing other people, being able to be supported by each other”</i></p> <p>Site 3 Friendly supportive atmosphere.</p>			
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			Three patients swapped phone numbers.			
Social Learning	Patients learn from each other. Ripple effect. Carry-over	You learn what other people are going through, and how they are managing. See what others are doing and have a go yourself. Learn what other people are eating and try new things. An environment where it's OK to get things wrong and learn from them.	<p>Site 1</p> <p>See what others are eating and try something new. Ripple effect of people observing and then saying I will have a go at that. Seeing other patients have a go and be inspired to do the same. Patients are sharing what they have done with other people, and they are inspired to have a go also.</p> <p>Site 2</p> <p>Learning from each other during goal setting. Seeing what others are doing and having a go yourself. Staff observed a carryover of mood into other sessions. Being shown how to do things gives them the impetus to go on and try things themselves. They can make a connection</p>	No data on social learning.	Complementarily Several examples of social learning in the interviews and focus group.	<p>Patients are observing others' attempts and progress and this is inspiring them to have a go themselves- links to motivation.</p> <p>Several examples of the ripple effect: inspiration and how the desire to have a go, improved mood or striving to improve had carried over into other sessions. Seeing what others can achieve and being motivated to have a go.</p> <p>Patients diversify their diets as they see other people's choices.</p>

			<p>between what they do in therapy and going home.</p> <p>Site 3 Psychologist says breakfast group participants have a go at things because they have tried them in the breakfast group which is a safe place.</p>			
Psychological state and beliefs	Mood states	<p>Example of how patients felt in a better mood afterwards.</p> <p>Talking to others helps relieve pressure and improves mood.</p> <p>Going to the group is a reason to get up and get going. Something to focus on.</p> <p>Being around other people helps lift the mood. Examples of this are where patients have provided advice.</p>	<p>Site 1 Examples of staff asking about issues affecting mood. Conversations between staff and patients about goals and what they had achieved to improve mood. Examples of staff addressing emotional lability and providing information and support.</p> <p>Site 2 Observations of improved mood from the beginning to the end of the two weeks. Observations of how the 'feel good effect'</p>	<p>Site 1 Improvement noted by staff emotionally and in general mood. Patients would support each other lifting one another.</p> <p>Site 2 The mood was discussed- how people were feeling, how they had slept. One patient was feeling down about his progress and the other patient supportively said it was all about incremental gains.</p> <p>Site 3</p>	<p>Convergence The mood was discussed in all three data sets. Examples of peer-to-peer support to lift mood and staff to patient support.</p> <p>Complementarily The breakfast group was described by patients as 'lifting them-up'. Staff noticed how mood approved across the sessions as people become more familiar with each other and the routines.</p>	<p>Clear examples of how mood was positively affected during the two weeks. Patients talked about how the group 'lifted' them and how they were looking forward to it each day. Examples of carry-over of mood into other sessions and how patients felt it was preparing them for life at home.</p> <p>Overwhelmingly the perceptions were of a positive experience which influenced general wellbeing, motivation and mindsets.</p>

			<p>continued during the day in other sessions. Distraction from disability. Addresses anxieties and impacts mood. Motivation and its link to improved mood.</p> <p>Site 3 The forming of relationships between patients improved mood.</p> <p>The psychologist discussed how being involved in breakfast groups with patients impacted her sessions one-to-one. Easier to develop relationships, and patients were more comfortable with sharing personal feelings.</p> <p>A patient disclosed a traumatic loss with the group and the other patients were thinking about this out of the group and the next group wanted to respond.</p>	<p>Example of the birthday singing and cake to lift the mood. Patients openly talked about how they were feeling on the day. The patient cried and talked about not going home for Christmas and other patients were supportive and tried to help him see the positives. Staff were attempting to jolly patients along.</p>	<p>The ripple effect of carry-over into other sessions was noted by staff.</p> <p>Silence Anxiety and depression were not mentioned in many references to the general improvement in mood and well-being. Close links to peer support theme. No evidence of the group affecting anyone negatively, lowering mood or causing distress.</p>	<p>Self- confidence was explicitly discussed and examples of how it had changed confidence were provided by patients.</p>
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	Mindset	<p>Site 1 One patient talked about how practising and attempting to make her own breakfast changed her thinking about what she could do and encouraged her to 'push' forward and attempt more.</p> <p>Site 2 Another patient talked about how practising put a thought in his head that he could do it.</p> <p>Site 3 <i>"I got up at a certain time, I got dressed, I put something nice on cause I was going to mix with other normal people so I could dress normally and it set me up for the day, all in all, it's an excellent, excellent scheme".</i></p>	Peer-to-peer psychological support examples.			
	Motivation	<p>Site 3 One patient talked about how it was giving her motivation.</p>	<p>Site 1 example Two staff talked about how patients were dressing up for breakfast group, putting on perfume and make-up. It felt like an 'occasion' and this affected the mindset of needing to get up and get going for the day.</p> <p>Site 1 Implied ability to motivate.</p> <p>Site 2</p>	Silence		<p>Complementarily The preparation and anticipation of getting ready for the breakfast group and the experience of the intervention seemed to create a mindset which has a positive effect on mood, and motivation to participate and link to a ripple effect carried over into other sessions during that day.</p> <p>Complementarily Although the word 'motivation' wasn't</p>

	Self-confidence	<p>The motivation to try and strive was implied in several interviews but not explicitly mentioned.</p> <p>Site 1 “I was able to write my goals, what I am confident with and what I have achieved so far”.</p> <p>Site 3 Three patients discussed how the breakfast group had given them confidence or helped their confidence.</p>	<p>Giving patients to the impetus to go on a try things themselves.</p> <p>Site 1 Two staff mentioned how they had observed confidence grow through the weeks.</p> <p>Site 2 One patient talked about how his level of confidence had improved.</p> <p>Site 3 Several staff mentioned it had given patients confidence and inspiration. One staff member thought improving self-confidence was the biggest benefit.</p>	<p>try something new, wanting to use their stroke affected arm.</p> <p>Confidence is not explicitly mentioned but examples of patients striving to improve. Also, see outcome measures self-confidence scores.</p>	<p>used there were multiple examples in all three data sets of patients being motivated to have a go at a new task, and try to use their stroke-affected arm. This was evident in the goal-setting conversations, observed as patients talked about wanting to try.</p> <p>Convergence Focus group and interview had several examples of discussions about confidence and how the breakfast group had helped patients gain confidence in making their own breakfast and given them more confidence for going home.</p>	
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Snacks	Management of snacks.			<p>Site 1 Snacks were offered at the end of each session. There was a snack bowl accessible and it was offered around to patients. One patient came to the bowl at the end of the session and one gentleman filled his pockets with several snacks- staff commented that the patient gets hungry and takes this opportunity to stock-up. Staff were observed asking patients if they were still hungry as second helpings of breakfast were offered.</p> <p>Site 2 Patients were not offered snacks during the intervention as staff felt that there was a good system in place for getting snacks on the ward.</p> <p>Site 3 Snacks were available but patients didn't take them. Staff thought this</p>	<p>Disagreement Snacks were not raised in the interviews or focus groups.</p> <p>Silence None of the patients said they felt hungry. This could be a result of being in the breakfast group as patients were offered a second helping and most patients observed had more than one breakfast item.</p>	
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				was because there were good systems for getting access to snacks on the ward.		
Sharing	Sharing food or other items, staff and patients.	One patient talked about sharing her tea bags 'red bush' other patients saw she was bringing her own and they were asking to try them.	<p>Site 2 "there was one day when xxX really wanted a banana with her Weetabix but we didn't have any and so xxX said I got some in my room you can have one of them".</p> <p>Site 3 Staff talk about bringing in food for the patients such as Cheerios "that was minor the cost of it, it was like a million per cent worth it to give them the experience. Staff- there was like a lady and I said to her what do you have at home and she was like (I don't know) and I said Is it toast, and then eventually she was able to tell me it was Cheerios. So the next morning we gave her Cheerios"</p>	<p>Site 1 Two ladies were bringing in soft fruits and sharing them.</p> <p>Site 2 A staff member had brought in butter so that the tub was 'normal' and smaller for patients to hold.</p>	Convergence There were themes of sharing in all three data sets. Sharing between patients in all three. Staff bringing in food in focus groups and observations.	<p>Patients were sharing food which reflects cultural norms.</p> <p>Staff wanted patients to have had a good experience that reflected normal life and so they were willing to use their own money to bring in items for the group. Site 3 had a teapot and saucers donated by a member of the tea so that patients could enjoy their tea from something other than NHS cups.</p>

Promoting Independence		<p>Site 1  <i>"it was OK cause we had to do things for ourselves"</i></p> <p>Site 2  One patient talks about independence and how the group is helping him to do more for himself.  <i>"So you are not sat there- how many pieces of toast do you want- oh I'll have three or two and it would come there buttered, marmalade and everything. You sit down and you eat it".</i></p>	??	<p>Observed examples of patients being encouraged to do as much as possible for themselves (backed up by photos).</p> <p>Site 1  One patient is making her own toast she's using her right hand to butter the bread she says 'this is challenging for me but I am having a good go and finding a way to do it'.</p> <p>One patient made his own way to the group across the corridor, this patient was blind in one eye and had cognitive impairments but through attending the group every day he had become familiar with the process and was keen to come in and get a place at the table.</p>	Convergence, Complementarily, Disagreement Silence	

				<p>All patients participated in making breakfast. One patient was able to make his own drink and thicken it using the thickener.</p> <p>Site 3 All patients participated in making their own breakfast to varying degrees, so made before breakfast of those partially prepared by breakfast assistance was given when required.</p>		
Preparing me	For home	<p>Site 1 "I think it's good that we eat with other people, it prepares you for when you go home and you are meeting other people and going out to a restaurant and a cafe bar. It's awkward not being able to use this hand, it's awkward, hopefully, I will get used back in this hand, so it prepared you so you don't and suddenly find you can't</p>	<p>Site 2 For adjusting to modified diets.</p>	Silence	<p>Convergence, Complementarily, Disagreement Silence</p>	<p>Two patients talked about the preparation for going home and one member of staff through this would alleviate anxieties they might have about modified diets.</p>

		<p>use your hand, where you have got used to that here at breakfast group”.</p> <p>Site 3  <i>“It's made me feel great, I know when I go home I can make some toast and cut it, I know I can make some coffee. I can put milk in it and stir it, it gives me confidence to do it instead of my wife doing it. I know when I go home I can do it. Another thing I was worried about when I got home with my family and we went out, cause we go out for meals, I was worried about how people saw me eating and things but I was there in the breakfast club with people in the same situation as me and it didn't bother me one little bit and it didn't bother them, so taking that away I feel Ok to go on and have meals out now as I didn't feel people were looking at me eating or looking at the way I spread the toast or anything like that it felt natural. It's helped me feel</i></p>				
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		<i>more confident about eating in front of people”.</i>				
Practice		<p><i>Site 1</i>  <i>“We are helpless we are left alone in the room, to just go on with it. In the breakfast group, I made porridge for the first time for myself, with help of course. I was able to make my tea and cut the banana to add to my porridge, little things but I did them myself. I cut the banana with the help of someone”.</i></p> <p><i>“At least I was able to practice making my own breakfast, because at first when I had the stroke, I was thinking am I even going to be able to make my own meals, is it even going to be possible? But when I did that at least I thought, ok I can do it, I think next time I will keep on pushing,</i></p>	<p><i>Site 2</i>  <i>“I think maybe things were more accessible for patients, so usually the activity coordinator would have served the patients their breakfast she would have poured the cereal for them and would have helped sorry think we made things easier so it was set out easier for patients to get hold of things themselves so they could try to do it themselves maybe”.</i></p>	<p><i>Site 1</i>  A patient who had difficulty initiating activities due to multiple impairments, I observed him spontaneously picking up a packet of wipes opening it and wiping his hands- before he started breakfast preparations. He then poured himself some juice from the jug.</p> <p>A patient who had difficulty initiating activities due to multiple impairments, I observed him spontaneously picking up a packet of wipes opening it and wiping his hands- before he started breakfast</p>	Convergence, Complementarily, Disagreement Silence	



		<p><i>pushing until it is just this hand which is the affected part”.</i></p> <p><i>“the difference is you can help yourself to do something and there are people to talk to”</i></p> <p>Site 3</p> <p><i>“It made me feel like I exist. Just because I have lost my use on my left side, it doesn't mean giving up, there is help out there, and there are aids out there to help you. Who would have thought that six weeks have gone by and I have been getting up already and making a drink for myself? I didn't think I would be doing it quite honestly but you know, with the help of the team, that's involved its fine”.</i></p>		<p>preparations. He then poured himself some juice from the jug.</p> <p>Site 2</p> <p>Patients took turns going to the workstations to make their breakfast. Some patients were making hot drinks and some were making toast. One patient practised with a trolley. A perching stool was brought in to try when a patient was at a workstation making their own breakfast. The trolley was used to transport toast and a hot drink from one table to another.</p>	
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<p>Normality</p>		<p>Normalising eating and drinking after stroke. Helping me to feel normal.</p> <p>The relaxing context makes it feel more normal.</p> <p>Laughing and joking reflect normality.</p>	<p>Site 1 A daily routine that's normal and meaningful.</p> <p>Site 2 Normal activity. The activity coordinator also eats her breakfast with patients. Staff have a hot drink</p>	<p>Site 1 Staff have a hot drink with patients. Patients were observed talking about what they would normally eat for breakfast. Patients talked about how they would adapt e.g. Christmas shopping to ensure they could do the normal things at Christmas.</p> <p>Site 2 The activity coordinator also eats her breakfast with patients as she feels this makes it more normal. Staff have a hot drink. Patients talked about usual routines.</p> <p>Site 3 Staff have a hot drink with patients. Staff commented on how patients are dressed and ready and</p>	<p>Convergence All data sets discussed how it was important to feel normal and how the breakfast group provided a sense of normality.</p> <p>Creating a sense of normality with staff participation in eating or drinking.</p> <p>Disagreement- staff noted that the usual practice would be to do kitchen assessments out of context and patients didn't even consume the food or drink.</p> <p>Silence The environment and how this contributed was not specifically addressed in relation to</p>	<p>Experiencing a sense of normality was important for patients, this also links to the theme of 'feeling human'. Components of the intervention were designed to create a familiar and welcoming experience e.g. the table lay-out, the menus and place settings, and the food prep stations very much like a hotel-format self-service.</p>
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				<p>the dining experience mimics normal life. One patient talked about how making drinks for others was normal for her and she was able to make drinks for other patients.</p>	<p>normality, but it was mentioned as something that was appreciated and created a nice atmosphere.</p>	
<p>Feeling Human</p>	<p>Feeling like a person. Friendlier to humans, kinder, and more agreeable.</p>	<p>Site 1 I thought it was very good it made me back in the real world you met people, spoke to different people, you discussed how far you had got with your treatment.</p> <p>Site 2 One patient said, "You are not just a stroke you are a person". Another patient said, "Humans are social animals so it's nice to meet other people".</p> <p>Site 3 "I liked that people treated me as a human being, they didn't look at me as disabled or anything like that, they</p>	<p>Site 1 "one of the patients said we do like being around each other you know we are people, the other day and I was like Oh, I was quite sad that they felt they hadn't always been treated like that, it's important to get people together".</p> <p>Site 3 A significant number of references to humanising. Talked about treating people with dignity, humanization and treating people like humans. One staff member talked about how she felt</p>	<p>Site 3 One patient commented she had not felt human since coming into the hospital. She said "when I came in the door I left my dignity and humanity" and she explained "I felt very helpless before coming to breakfast group" she said being in the breakfast group was helping her motivation and was also a place she felt like a human being, it was something normal and she was seen as a person. A fellow patient says in agreement "I want to be in breakfast group even when I've not had any</p>	<p>Convergence, Complementarily, Disagreement Silence</p>	

		encouraged me to do things, so that's what I liked about it and what I got out of it most".	differently about this group of patients as she had gotten to know them on a more personal level and has a result felt she had a richer relationship, she was thinking about them- "I have really noticed the difference between how I think about those people and how I work with them and how I am thinking about their futures in a much more humanised way". Two staff talked about making patients feel human "they needed that human contact and I never imagined we'd be going off down that route".	sleep that how important it is".		
Fun and enjoyment	Pleasurable experience	Site 1 One patient talked about the enjoyment of being with people in the same boat. One talked about the enjoyment of meeting other people.	Site 1 <i>"The patients love it you could just see that they were getting a lot from being around the other patients, talking to the each other about your</i>	Site 1 The group covered many topics and the things they talked about made them laugh such as spiders and conkers. One patient picked up	Convergence Strong themes of pleasure and enjoyment. Disagreement The reasons for enjoyment were	Overwhelmingly positive experiences. In contrast, very few participants said they disliked something.

		<p>Site 2 One patient talked about it being good fun and recounted stories of what he had enjoyed about interacting with the other patients. Laughing and joking. Another talked about the experience of enjoyment and related this to being in the company of others.</p> <p>Site 3 <i>"I loved it, I loved making everyone else a drink and more than that I enjoyed making my own because in the hospital nobody makes my tea right".</i></p> <p><i>"I enjoy doing it actually, it asks you at the beginning what you think and what your goals are, you know, what your abilities are and as days go by you fill out everything that you have done on that day, it's amazing what you do find yourself writing that you didn't think would be</i></p>	<p><i>every day, because people were looking forward to it".</i> <i>"I think it was just a real joy to be in the group you know you would go from the beginning to the end just don't stop smiling the whole way through and I even probably cried after a few of them (all laugh), yes I was getting really emotional, there was one patient that really enjoyed it and he was just grinning from ear to ear he was making jokes, he was laughing you know real belly laughs. Which was nice".</i> <i>"I think it's just that sheer enjoyment on the patient's faces, in each group and you just absorb that as a therapist and just leave the group feeling like can we do this every day, you know like, I was talking about it on a course, I'm even smiling now, I was talking about it and I was saying how I wanted it to continue and</i></p>	<p>the menu and said <i>"there are no cocktails on here"</i> and the patient started to laugh one patient was belly laughing. They started to talk about alcohol, drinking and going to the pub.</p> <p>Site 2 Observation of two patients laughing and joking as one pretended to steal another's stick while they were making toast. The group covered many topics and the things they talked about made them laugh- they were talking about favourite songs then one patient said <i>'what about a bit of dirty dancing?'</i> (everyone laughs and patients talk about scenes in the film).</p> <p>Site 3</p>	<p>varied, related to social connection and conversation as well as the joy of being able to do something for yourself or others.</p>	<p>Being with other stroke survivors going through similar experiences was thought to be helpful but the joy came from the social connection, shared experiences, human contact and communication.</p> <p>Less was said about the enjoyment of being more independent or the opportunity to make your own breakfast.</p>
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		<p><i>important but yeah it matters, and I think it does matter to everyone else”.</i></p>	<p><i>the woman was saying, your face just lights up when you talk about it and I think, that is like gold isn't it? If you're feeling that how do the patients feel?”</i></p> <p>A member of staff talked about how a patient relative had told her that his brother was really enjoying it and another patient's daughter also said the same, “They are obviously going and telling their relatives about it because I certainly didn't talk to relatives about it”</p> <p>Site 2 Staff noticed the enjoyment factor and how this positively influenced mood. Several examples.</p> <p>Site 3 <i>“One patient said she felt like royalty because she used to sit at the head of the table (all laugh), she would come back and say</i></p>	<p>There was a lot of laughter in the group as topics were discussed. Patients talked about how they had enjoyed it and that it should be part of the ward routine.</p> <p>Note- patients were enjoying their food and having second helpings. Patients talked about enjoying it openly.</p>		
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			<p><i>I'm Queen because I sat at the head of the table today. And I said you can sit at the top of the table tomorrow. They all got something out of it haven't they, all gained something?"</i></p> <p><i>"we had the funniest times in the group, sometimes they said things and I thought oh my gosh I can't believe you've just said that and then we would all laugh and that's been very bonding for us to them and for them to each other".</i></p>			
Peer support	<p>Friendship Encouragement Emotional support Physical assistance</p>	<p>Site 1 Building friendships <i>"well as I said everyone is in a similar position of varying degrees, some are worse than others but you could talk to everyone, everyone knows what the problems are it's not as if it's a little secret it's all out in the open".</i></p>	<p>Site 1 Solidarity – cheering each other on. <i>"they all cheered when one of the patients got upgraded to a level 7 easy chew, you know they were all pleased so there was that real kind of solidarity".</i></p>	<p>Site 1 Encouraging feedback. Encouraging conversation <i>One patient said to another 'that looks gorgeous' when he had encouragingly made something himself.</i></p>	<p>Convergence All data sets discussed encouragement. Examples of patients encouraging each other, advising, helping, and cheering each other on. Complementarily</p>	

		<p><i>"we spoke a lot together, she brought me into a lot of conversations so it was inclusive in that way".</i></p> <p>Patients swapping phone numbers.</p> <p>Sharing food.</p> <p>Encouragement</p> <p><i>"I walked with the physio today in the breakfast room and I walked there and the other residents encouraged me to do that so that would be good. It was very uplifting".</i></p> <p><i>"we were encouraging each other ' someone to say- 'come on you can do it' and I think maybe some people were quite emotional through talking and we would say it's okay, it's okay, we would say, you are not alone in this port, other people are experiencing the same so that encouragement which comes down to relationships and communication because you can talk to another person someone you don't know but they are all going</i></p>	<p>Forming of friendships</p> <p>Encouraging about progress and also the process of rehabilitation.</p> <p>Site 2</p> <p>Patients help each other with the tasks of making breakfast such as putting jam on toast for each other.</p> <p>Site 3</p> <p>Sharing items.</p> <p><i>"I knew we were going to see changes but the bonding between patients, the intensity which helped them proceed through their goals despite being unwell was incredible".</i></p> <p><i>"that is what I was going to say the psychological benefits exceeded my expectations, they didn't just attend the group together they formed friendships. One of the group members brought really personal stuff to</i></p>	<p><i>One patient said to another 'good job' when he used his spoon with his affected/arm for the first time.</i></p> <p>Observed patients swapping phone numbers.</p> <p>Site 2</p> <p>Encouragement about progress. "you have to look at it as incremental gains, everyday little bit more improvement".</p> <p>Site 3</p> <p>Observation of one patient making hot drinks for the others.</p> <p>Tearful patients being comforted by fellow patients, kind words and physical touch.</p> <p>Disclosure of painful loss and other patients provided words of support and kindness as well as physical touch.</p>	<p>The forming of friendships was discussed in the interviews and the focus group.</p> <p>Although not mentioned explicitly in the observations it was alluded to in the behaviours of patients and how they treated each other with kindness and provided comfort.</p> <p>Solidarity was mentioned in a focus group and companionship was mentioned in the interviews.</p> <p>Silence</p> <p>No negative comments were made about other patients.</p>	
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		<p><i>through different versions of it".</i></p> <p><i>"You hear more so it encourages you, you think at least I will get there. Myself I will get there. Like there was XXX he used to walk with his stick, it motivated me, so much that I said, am I going to do that? So the next time when I tried my mind focused on what he did, he was able to walk, so I managed to walk and my friend came and said, let's go. I walked and she took me around. Like yesterday I even walked and came back it was quite motivating on that front".</i></p> <p>Site 2 Discussing the benefits "companionship or compadre is the word I was looking for, being together and working together and understanding each other. It was just all, became normal because we were all becoming friends and we could talk to each other normally about different</p>	<p><i>the group and shared it and there was mutual support there and they were thinking about each other in between sessions and thinking of what they wanted to say to each other the next day".</i></p> <p>Making drinks for each other. <i>"They knew that a lot was going on for them and it was friendship and it was an opportunity to get off the bay and they got it they got so much from it in terms of self-esteem, just something like making cups of coffee for other people, that was a lovely hosting experience for her, looking after her fellow group members"</i></p> <p>Patients swapping phone numbers.</p>			
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		<p>things and work together and have jokes together”.</p> <p>Site 3 Building friendships, getting to know people. <i>“we came in as patients and are leaving as three friends. I wrote this in my booklet- I feel we have worked together encouraging each other and I wish them all the best for their breakfast meetings”.</i></p> <p><i>“that's it tremendous, good atmosphere, people should have this opportunity. Because of what I have got out of breakfast group, I don't know really what I would have done without it. Because when I go back there I have someone to talk to, I've interacted we have all interacted and I look forward to the next morning when we are all together again”.</i></p> <p><i>“To get talking to other patients everyone has their</i></p>				
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		<p><i>own stories, so I think that helps. Relieving that pressure a little bit. They also become friends, because you a resounding each morning with them for two weeks, I do think it's good, plus it helps you to do little things for yourself that you are not allowed to do on your own".</i></p> <p>One patient recalled how outside of the group a patient comforted him when he was feeling low and gave him a friendly kiss which cheered him up.</p>				
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## Appendix 23: Dissemination Plan

NIHR 300529 / STH20895 Dissemination Activities and Research Impact Examples			
Outputs for CDRF	Summary details		
	Dissemination Plan	Audience	Outputs
<b>Academic Publication</b>	<p>Three high-impact publications will be submitted from BISTRo. They will include findings from the systematic review, qualitative work, and complex intervention framework. Target journals include:</p> <p>Open access publications:</p> <ul style="list-style-type: none"> <li>• BMJ open (Impact Factor (IF) 2.6)</li> <li>• BMC Health Services Research (IF 2)</li> <li>• International Journal of Stroke Rehabilitation (IF5)</li> </ul> <p>Additional publication:</p> <ul style="list-style-type: none"> <li>• British Journal of Occupational Therapy (IF 1.501)</li> </ul>	<p>National and international:</p> <ul style="list-style-type: none"> <li>• Academics and clinical academics</li> <li>• Stroke Clinicians</li> <li>• Researchers interested in complex intervention development</li> </ul>	<p><b>Planned Publications</b></p> <ol style="list-style-type: none"> <li>1. <b>Systematic Review: Jones, N. Mawson, S. O’Cathain, A. Dugmore, K. (2023)</b> A systematic review to identify the views of stroke survivors and informal and formal carers on the psychosocial impacts of eating and drinking difficulties after stroke.</li> <li>2. <b>BISTRo Study (findings 2-3 papers)</b>- i) Step 1 findings interviews, consultations, and ethnographic observations ii) Step 2 prototyping iii) Step 3 feasibility and acceptability of breakfast group interventions.</li> <li>3. <b>Intervention development framework (methods paper):</b> Development of an intervention for breakfast groups in stroke rehabilitation: using a coproduction and codesign framework</li> <li>4. <b>Stakeholder engagement and Experienced based-codesign (methods paper).</b> Exploring patient and public engagement in stroke research: a model for stakeholder engagement</li> <li>5. <b>Using creative methods (methods paper)</b>- Exploring the role of trigger films in coproduction research.</li> </ol>

			<p>6. <b>Conducting research online (methods paper)</b>- Lessons for beyond the pandemic: conducting online stroke research during COVID-19.</p> <p>7. <b>Research impact</b>- the impact of participation in stroke research for patients and NHS organisations using VICTOR as a research impact data collection tool: A case study example from BISTRo a multi-centre breakfast group intervention study.</p> <p>8. <b>Research Impact</b>- an invitation from the Editor to write a follow-up editorial for the British Journal of Occupational Therapy on research impact (autumn 2023).</p>
<b>Other Publications and Dissemination</b>	<p>Thesis</p> <ul style="list-style-type: none"> <li>University of Sheffield repository</li> </ul> <p>Professional publications</p> <ul style="list-style-type: none"> <li>OTNews</li> </ul>	<p>Local:</p> <ul style="list-style-type: none"> <li>Sheffield NHS staff, managers, and commissioners</li> <li>South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) Integrated Stroke Delivery Network</li> </ul> <p>National</p> <ul style="list-style-type: none"> <li>Occupational Therapists in the UK and wider</li> <li>Stroke Researchers</li> </ul>	<p><b>Jones, N.,</b> Delaney, A. and Kelly, M. (2021) ‘Reflections on the art of the possible’, OTNews (May), pp. 52–53.</p> <p>South Yorkshire Integrated Stroke Delivery Network Newsletter Publication of a summary of the study and key findings in a PDF on the 5<sup>th</sup> of August 2023. Distributed via email to five Stroke Services in South Yorkshire.</p>
	Lay Summary	<p>Local:</p> <ul style="list-style-type: none"> <li>PPI Advisory Group</li> <li>University of Sheffield public engagement events</li> <li>Stroke Charities</li> </ul>	<p>BISTRo Findings presented to the Stroke Association Snack and Chatter group on 17<sup>th</sup> August 2023.</p> <p>BISTRo Findings presented to the Sheffield Teaching Hospitals Stroke PPI Panel on March 20<sup>th</sup>, 2023.</p> <p>A summary of the study was provided to three NHS Commissioning Managers for Stroke. 13<sup>th</sup> June 2023.</p>

			A summary of the study was provided for Stroke Service NHS Managers in South Yorkshire. 13 <sup>th</sup> June 2023.
<b>Conference submission</b>	<p>Conference abstracts, papers, and posters.</p> <p>International</p> <ul style="list-style-type: none"> <li>• European Stroke Conferences</li> </ul> <p>National</p> <ul style="list-style-type: none"> <li>• UKStroke Forum</li> <li>• Royal College of Occupational Therapy National Conference</li> </ul> <p>Regional</p> <ul style="list-style-type: none"> <li>• Integrated Stroke Delivery Network Conference</li> <li>• PGR Conference University of Sheffield</li> <li>• Integrated Care System</li> </ul> <p>Local</p> <ul style="list-style-type: none"> <li>• Organisational Conferences</li> </ul>	<p>National and international:</p> <ul style="list-style-type: none"> <li>• Clinicians</li> <li>• Clinical leaders and commissioners</li> <li>• Clinical academics</li> <li>• Academics and researchers</li> </ul>	<p><b>International 2023</b></p> <p><b>Jones, N.,</b> Mawson, S., O’Cathain, A., &amp; Drummond, A. (2023). 9th European Stroke Organisation Conference 24-26 May 2023. Do Stroke Survivors Find Daily Breakfast Group Interventions Acceptable and Feasible? (BISTRO Study). <a href="http://eso-conference.org">eso-conference.org</a></p> <p><b>Jones, N.,</b> Mawson, S., O’Cathain, A., &amp; Drummond, A. (2023). European Life After Stroke Forum 2023 Abstract Book. In ELASC (Ed.), Are codesigned breakfast group interventions acceptable and feasible for stroke survivors and health care professionals? (BISTRO Study) (p. 24). <a href="http://www.elasf.org">www.elasf.org</a>. <a href="https://www.elasf.org/past-events/2023-abstract-book/">https://www.elasf.org/past-events/2023-abstract-book/</a></p> <p><b>National 2023</b></p> <p>Three abstracts were accepted for the 2023 UKStroke Forum. December 2-4.</p> <p>Poster title: Breakfast Group Interventions in Stroke Rehabilitation 'The best hour of my day'. Natalie Jones Clinical Academic Occupational Therapist.</p> <p>Poster title: Breakfast Groups: what are the training needs of allied health professionals working in stroke to deliver interdisciplinary breakfast interventions? Erin Burnside Senior Occupational Therapist and Natalie Jones Clinical Academic Occupational Therapist.</p> <p>Poster title: What’s stopping us? An exploration of the barriers and enablers to completing online training for Allied Health Professionals (AHPs) working in Stroke. Erin Burnside Senior</p>

			<p>Occupational Therapist and Natalie Jones Clinical Academic Occupational Therapist.</p> <p><b>Jones, N.,</b> Mawson, S., O’Cathain, A., &amp; Drummond, A. (2023). Royal College of Occupational Therapy Annual Conference 2023 Book of Abstracts and Session Submissions. Session 6.1. Codesigning an Implementation Toolkit for Breakfast Group Interventions in Stroke Rehabilitation: How Patients and Informal Carers Shaped the End Product., p5.</p> <p><b>Jones, N.</b> RCOT. (2023). Royal College of Occupational Therapy Annual Conference 2023 Book of Abstracts and Session Submissions. P38 A Qualitative Systematic Review Investigating the Views of Stroke Survivors, Formal and Informal Carers on the Psychosocial Impact of Eating and Drinking Difficulties., p71.</p> <p><b>National 2021</b>  <b>Jones, N.</b> (2021) ‘Breakfast Interventions in Stroke Rehabilitation (BISTRo) P181 Abstract 273, in 16th UK Stroke Forum- November 30-December 2, 2021, Virtual, conference abstracts. International Journal of Stroke, p. 47. <a href="#">International Journal of Stroke</a></p> <p><b>Local 2022</b>  <b>Jones, N</b> (2022). South Yorkshire and Bassetlaw Stroke Conference. P1 Breakfast Groups in Stroke Rehabilitation: Designing an intervention and supporting implementation toolkit.</p> <p><b>Local 2021</b>  <b>Jones, N.</b> (2021). Accountable Care System AHP Conference: South Yorkshire and Bassetlaw. P1 Experiences of Stroke Survivors in Managing Eating Difficulties., November 16th.</p>
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<p><b>Other dissemination output</b></p>	<p>Project media creations (videos, infographics, animations, podcasts, and blogs).</p> <p>Eventbrite event to be accompanied by a 'Thunderclap' - a marketing tool to generate social media amplification.</p>	<p>Local NHS:</p> <ul style="list-style-type: none"> <li>• South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) Integrated Stroke Delivery Network</li> </ul> <p>National/International clinicians and academics:</p> <ul style="list-style-type: none"> <li>• YouTube, Twitter, LinkedIn</li> <li>• Professional Facebook groups</li> </ul> <p>Local, and national lay audiences:</p> <ul style="list-style-type: none"> <li>• Including University of Sheffield public engagement events such as the Festival of the Mind</li> </ul>	<p>Blog: Invited to write a blog for the Social Research Association on taking research online. 'Creating Human connectedness in a digital space'. April 21st, 2021.</p> <p><a href="https://sra.org.uk/SRA/Blog/Creatinghumanconnectednessinadigitalspace.aspx">sra.org.uk/SRA/Blog/Creatinghumanconnectednessinadigitalspace.aspx</a></p>
	<p>Slide deck presentations</p>	<p>Regional:</p> <ul style="list-style-type: none"> <li>• South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) Integrated Stroke Delivery Network</li> <li>• SYB Regional Stroke OT Group</li> <li>• <a href="#">SSNP (RCOT Specialist Section)</a></li> </ul> <p>Local:</p> <ul style="list-style-type: none"> <li>• <a href="#">Professional Forums</a></li> </ul>	<p><b>Regional 2023</b>  <a href="#">How did Occupational Therapists get involved in Clinical Research? Sheffield Teaching Hospitals Occupational Therapy Professional Forum 16th March 2023.</a></p> <p><b>Local 2023</b>  <a href="#">BISTRo the story of breakfast groups. Stroke Association Sheffield Stroke Coordinators. 16th March 2023.</a></p> <p><b>Local 2021</b>  <a href="#">Cooking up a complex intervention: recipe for success? Spotlight on Research Conference Sheffield Teaching Hospitals, 24th May 2021.</a></p>
	<p>Project Media (videos, infographics, animations).</p>	<p>Occupational therapists regionally, nationally, and internationally:</p>	<p><b>YouTube Collection</b></p>



	<p>Summaries of clinically relevant findings and project learning.</p>	<ul style="list-style-type: none"> <li>• RCOT Specialist section (Eventbrite support network and email network)</li> <li>• South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) Integrated Stroke Delivery Network</li> </ul>	<ol style="list-style-type: none"> <li>1. Learn more about co-approaches and how I used Experience-based Codesign to develop a breakfast group intervention for stroke survivors (16 minutes). <a href="https://youtu.be/vVGrJeCdcMM">https://youtu.be/vVGrJeCdcMM</a></li> <li>2. Findings from a systematic review exploring the psychosocial impacts of eating and drinking difficulties after stroke (4 minutes) <a href="https://youtu.be/yCUxd_4hU28">https://youtu.be/yCUxd_4hU28</a></li> <li>3. Find out about the BISTRo intervention &amp; how patients, clinicians &amp; informal carers informed the prototype intervention <a href="https://youtu.be/xTvDX6bs4vQ">https://youtu.be/xTvDX6bs4vQ</a></li> <li>4. What matters to you about eating and drinking? An Occupational Therapist tells her story (7 minutes) <a href="https://youtu.be/mFHxb6dkqUQ">https://youtu.be/mFHxb6dkqUQ</a></li> <li>5. Contemporary Occupational Therapy practice and career development. Invited speaker at Sheffield Hallam University. <a href="https://youtu.be/Fi69H4zbtEA">https://youtu.be/Fi69H4zbtEA</a></li> <li>6. Why is eating and drinking important? Video 1 of 3 trigger videos made with stroke survivors, an informal carer and NHS clinicians. They explore why eating and drinking are important to them and for stroke survivors (7 minutes) <a href="https://youtu.be/xhdwYLu1VU">https://youtu.be/xhdwYLu1VU</a></li> <li>7. The impact of eating and drinking difficulties after stroke. Video 2 of 3 trigger videos made with stroke survivors, an informal carer and NHS clinicians. They explore the impact of eating and drinking difficulties after stroke (11 minutes). <a href="https://youtu.be/s9gPNyNJDjM">https://youtu.be/s9gPNyNJDjM</a></li> <li>8. What to consider in breakfast group interventions. Video 3 of 3 trigger videos made</li> </ol>
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			with stroke survivors, an informal carer and NHS clinicians. They explore ideas to consider when developing a breakfast group intervention. Important things to consider, such as practical tips and person-centred suggestions (28 minutes). <a href="https://youtu.be/UQZ_3NRXBCo">https://youtu.be/UQZ_3NRXBCo</a>
	Patient, carer, and public involvement & relevant dissemination activities	<ul style="list-style-type: none"> <li>• Research Participants</li> <li>• Stroke patient and public involvement group</li> <li>• General public</li> <li>• Stroke Charities</li> </ul>	<p><b>Stroke Charities</b> Invited Speaker 17<sup>th</sup> August 2023. Stroke Association Snack and Chatter Group. Welcome Café. Sheffield.</p> <p>Invited Speaker 20<sup>th</sup> March 2023. Sheffield Stroke Public and Patient Panel. ‘BISTRO- so what did we find?’</p> <p><b>Dissemination Events</b> Dissemination and Celebration Event 13<sup>th</sup> June 2023. Sixty-five people attended a mini-conference. The conference was held in the style of a workshop and was an open research event where feedback was collected for use in the study. The event contained guest speakers including a stroke survivor, informal and informal carers. Commissioners, NHS clinicians and Managers, and the Stroke Association were present. There was a photo and poster exhibition and other interactive participator activities for attendees to engage with.</p>
<b>Pathways to impact</b>			
<b>Other outputs</b>	Invited Speaker	Regional and national: <ul style="list-style-type: none"> <li>• South Yorkshire and Bassetlaw Integrated Care System (SYB ICS) Integrated Stroke Delivery Network</li> <li>• SYB Regional Stroke OT Group</li> </ul>	<p><b>National 2022</b> Invited Speaker at an NIHR Conference: Designing and Delivering Inclusive Research. 18<sup>th</sup> November 2022. University of Sheffield. ‘Breakfast Group Intervention in Stroke Rehabilitation’.</p> <p><b>Local 2023</b></p>

		<ul style="list-style-type: none"> <li>SSNP (RCOT Specialist Section)</li> </ul>	Invited Speaker at Sheffield Hallam University for student Occupational Therapists. 13 <sup>th</sup> December 2023. 'Working with complexity in Occupational Therapy'. 2-hour workshop.
<b>Change in policy</b>	<p>All three sites participating in the study have changed their local policy on eating and drinking interventions to include breakfast groups run in the format of BISTRo. This has continued beyond the study closure date and has been sustained for ten months.</p> <p>Site 1 is delivering the BISTRo intervention 4 days a week</p> <ul style="list-style-type: none"> <li>Regularly accommodating 6-8 patients per session.</li> <li>There has been an intentional drive from the multi-disciplinary team to support the smooth running of the group. This has worked well alongside the relaunch of integrated ward working, where one therapist starts at 7 am to assist with getting patients up and ready for the day. The patients who are attending the breakfast group can be prioritised to ensure attendance.</li> </ul> <p>Site 2 is delivering a BISTRo intervention 1 day a week and a social dining group 4 days a week</p> <ul style="list-style-type: none"> <li>The social dining group is run by the activity coordinator and involves patients dining together in a social group.</li> <li>One day a week the group runs to the BISTRo format, and the group has a therapist joining on a rota system to deliver the BISTRo programme.</li> </ul> <p>Site 3 is delivering the BISTRo intervention 5 days a week</p> <ul style="list-style-type: none"> <li>The stroke therapy team have started running the breakfast group daily, with a staff rota to set up and run the group, and daily washing and dressing sessions to prepare. Goals are set for each participant and relevant professionals run the group to help meet their goals.</li> <li>There is improved engagement between therapy and nursing in joint planning and conducting washing and dressing sessions on the ward. Ward staff are not able to attend the group but are aware of it and in support of preparation of patients for the group – improved ethos onward towards rehabilitation approach.</li> </ul>		
<b>Health benefits, safety &amp; quality improvements for research participants &amp; carers during the study</b>	<p><b>Health Benefit</b></p> <p><b>Site 1</b></p> <ul style="list-style-type: none"> <li>Since implementing the breakfast group, we have seen an increase in Occupational Therapy contact time in the SSNAP results.</li> <li>It has led to the reignited social dining at lunchtime within the unit.</li> <li>It has provided another opportunity for Speech and Language Therapists to review patients with dysphagia.</li> </ul> <p><b>All sites</b></p> <ul style="list-style-type: none"> <li>Sixteen patients received an intensive daily ten-day programme of eating and drinking rehabilitation in addition to usual care.</li> <li>Patients were more engaged in their rehabilitation as they had a personalised rehabilitation plan.</li> <li>Patients were encouraged to be more active, had support with physical difficulties and were more mobile during the intervention.</li> <li>Patients and informal carers who took part in the study or participated in the stakeholder intervention development group were able to give something back to the NHS, there was a sense of altruism. They also enjoyed sharing their experiences to benefit others.</li> </ul>		

	<ul style="list-style-type: none"> <li>• Several of the study participants made friends that extended beyond the study. They have exchanged numbers and remained supportive of each other beyond the study.</li> <li>• Positive feedback from staff and patients in all three sites.</li> <li>• More opportunity to assess domestic activities of daily living to ensure carry-over of strategies are being utilised.</li> <li>• Increased independence and control over food choices and how it is prepared.</li> </ul> <p><b>Safety and Quality</b></p> <ul style="list-style-type: none"> <li>• Family members were more involved in the initial assessment and final review.</li> <li>• The sites continue to use accessible methods of delivery to enhance patient safety and experience, this includes aphasia-friendly resources, accessible packaging and dining equipment, table clothes and flowers.</li> <li>• Increased staff awareness and knowledge of the International Dysphagia Diet Standardisation Initiative Framework.</li> </ul>
<p><b>Service and workforce impacts</b></p>	<p><b>Service and Workforce</b></p> <p><b>Site 1</b></p> <ul style="list-style-type: none"> <li>• Site 1 the dietician would not normally get involved in team interventions. She has since joined the delivery team and is part of the staff rota.</li> </ul> <p><b>Site 2</b></p> <ul style="list-style-type: none"> <li>• Site 2 had a greater engagement with physiotherapy in the project which has enabled improved collaboration to develop joint rehabilitation goals for patients and improve communication processes around discharge planning. This collaboration has continued beyond the research project.</li> <li>• Site 2 had a volunteer who is a stroke survivor, he enjoyed coming to the group and has now swapped his days to support the breakfast group and provide peer support.</li> <li>• Site 2 during the study physiotherapy did not participate due to staffing constraints, they have since joined the group and now regularly participate in the breakfast group.</li> <li>• Site 2 Activity co-ordinator had limited experience in setting patient goals, facilitating movement and improving independence. During her social dining group, she tended to assist the patients or do it for them. She has gained clinical skills in moving, handling, and facilitating the upper limbs and she has identified that she would benefit from further training.</li> <li>• Site 2 Completing the interprofessional breakfast group as part of BISTRo has inspired the team to start up other therapeutic groups on the ward including an inattention and sensory upper limb group.</li> <li>• Site 2 we have changed the way we do goal setting. The day before the breakfast group the team set joint goals for the patients that are going to attend the group which are recorded in their 'breakfast group folder'.</li> <li>• Site 2 is aiming to continue to implement this new way of working and is considering the introduction of new volunteer roles called</li> </ul>

'dining companions' to support more meaningful participation in mealtimes and promote independence with eating and drinking.

- Staff other than Occupational therapists who did not routinely use small aids and adaptations have benefitted from seeing and using these with patients in the group. This has led to the identification of extra equipment that was needed e.g. one-cup machine, adaptive cutlery and dycem mats.

### **Site 3**

- Site 3 reports more collaborative working between therapy and nursing in the stroke unit – regarding washing and dressing and the overall ethos of rehabilitation on the ward.
- Site 3 The Dieticians, Speech and Language Therapists and Physiotherapists did not get involved in group rehabilitation before the study and being part of BISTRo has increased their confidence in being part of breakfast groups and they are willing to participate in other groups.
- Speech and Language Therapy staff attend where appropriate to support specific patients with Speech and Language Therapy-related goals.
- We lost the involvement of physiotherapy staff – I hope to change this with further information on the outcomes and value of the group
- The next step is to roll out the use of the booklet with group attendees consistently.
- The ethos and background to the study, and ongoing group delivery have been shared with the patient-centred care team and patient experience team in the Trust, and further training is planned to disseminate the value and outcomes of the group to the stroke MDT.
- The BISTRo study and related information and resources have inspired further breakfast groups for social dining and therapy goals in other areas of the trust – the discharge lounge has set up a Breakfast Club to encourage patients to be up, dressed, and ready to go home. Our inpatient therapy team are looking into setting up a goal-oriented breakfast group for older patients in the hospital to help reduce deconditioning.
- Therapy staff and ward staff worked closer together to help get patients ready for the group. This has led to a more collaborative culture, particularly around washing and dressing tasks. Therapists and nursing staff have been doing more joint sessions, promoting the importance of 'getting up washed and dressed'. This has had a positive impact on staff relationships and the ward culture around collaborative working.
- Ward staff participating in the group were able to learn and practice upper-limb facilitation, transfer techniques and communication support alongside therapists and continue to use these skills in practice and joint sessions.

### **All sites**

- Training for the study and participation raised awareness of the importance of eating and drinking interventions with a wide range of care professionals.

	<ul style="list-style-type: none"> <li>• Students were able to take part in the research. They experienced being part of a research study and learned more about eating and drinking rehabilitation.</li> <li>• Information given to carers in the BISTRo booklet provides richer information on the patient’s needs, abilities, and aspirations. This information can be taken home and used as a reference point.</li> <li>• Improvements in the way rehabilitation goals are agreed upon, BISTRo enabled staff to work more collaboratively with patients on setting personalised and tailored goals. This has influenced and improved how goals for therapy are co-created more generally in the team.</li> <li>• All staff participants in the intervention delivery were trained to deliver the intervention and received topic-specific training on eating and drinking difficulties.</li> </ul>
<b>Research Profile of the Organisation</b>	<ul style="list-style-type: none"> <li>• I have been awarded a Royal College of Occupational Therapy Merit Award for my research impact and professional leadership. This will be presented on the 17<sup>th</sup> of October at the London Shard.</li> <li>• I have been nominated and shortlisted for a Chief Allied Health Professions Research Impact Award- the awards are on the 12<sup>th</sup> of October 2023.</li> <li>• Press Release: The Sheffield Star 29<sup>th</sup> May 2023 ‘Natalie’s rehabilitation work is leading the way’ p21 spread.</li> <li>• Invited to contribute to a Trust publication for ‘What Matters to You’ Day on June 6<sup>th</sup>, 2023. Provided a research career profile and a case study about BISTRo. This document was published trust-wide to celebrate WMTY Day 2023.</li> </ul>
<b>Research Capacity Building</b>	<ul style="list-style-type: none"> <li>• Erin Burnside Principal Investigator on BISTRo was successful in gaining an NIHR Internship. I supervised Erin on this internship, and she completed a service evaluation project using research methods to explore the training needs of healthcare professionals delivering BISTRo. Erin and I had two abstracts submitted for the UKStroke Conference on this work.</li> <li>• Three Occupational Therapists had the opportunity to become primary investigators for the first time. They all received additional training on Good Clinical research practice and taking informed consent and they have developed skills in managing a site file.</li> <li>• Invited to film a 5-minute video of AHP Day. October 20<sup>th</sup> 2020 to promote clinical academic careers. ‘Inspiring Leaders’.</li> <li>• All sites participating feel that they would like to participate in other studies as this has given them confidence that it's possible and this has inspired them to look for other suitable studies.</li> <li>• Site 3 found that there was a change in staff perceptions that patients would not want to participate. Participation in the study has proven this assumption to be false.</li> <li>• Site 2 Since BISTRo the Occupational Therapy Principal Investigator has been significantly more involved in research and is aiming to develop her skills in recruitment and consenting patients and managing site files. She became involved in another stroke study assisting the research nurses to recruit and complete baseline assessments.</li> <li>• Research awareness in all three sites has improved. The teams are more aware of research and how important it is to improving patient care and many now realise that it is not as daunting as it first seems to be involved.</li> </ul> <p><b>Networks and Collaborations</b></p>

	<ul style="list-style-type: none"> <li>▪ Bringing together staff from three stroke units in an ICS has exposed health and care professionals to different ways of working.</li> <li>▪ The aphasia-friendly menus used in Site 1 have been shared with Sites 2 &amp; 3.</li> <li>▪ There is increased collaboration with Occupational Therapists in the ICS.</li> <li>▪ PI from Site 2 is joining a Therapies Research Group and has also been asked to present her experiences on the BISTRo study at an internal OT networking event.</li> </ul>
<b>Economic impacts</b>	<p><b>Site 3</b></p> <ul style="list-style-type: none"> <li>▪ £100 investment for specialist plates and cups</li> </ul> <p><b>Site 1</b></p> <ul style="list-style-type: none"> <li>▪ A commercial company provided 2 hours of training on assistive technology for eating free of charge, 15 Occupational Therapists attended this training and received a workbook to accompany the training.</li> </ul>
<b>Organisation influence and reputation</b>	<p><b>Site 3</b></p> <ul style="list-style-type: none"> <li>▪ The NHS Trust patient experience team visited the group and shared the story of BISTRo across the trust. The Patient Experience Lead has provided some funding for specialist eating and drinking equipment that has a design sympathetic to dignity.</li> <li>▪ The BISTRo study has also demonstrated our ability to plan and implement group activities after the pandemic and inspired ideas for further therapeutic groups in the stroke unit which are now in development.</li> <li>▪ Plan to use the breakfast group as evidence of meeting the new RCP guidelines regarding the importance of time spent in repetitive task practice, and meaningful activity as part of daily routine.</li> <li>▪ Internal trust mini-conference to promote the study across the organisation.</li> </ul>
<b>Knowledge generation and knowledge exchange</b>	<p><b>Knowledge Exchange</b></p> <ul style="list-style-type: none"> <li>• Invited to participate in a research capacity building workshop ‘International perspective on clinical academic careers for Nursing, Midwives and AHPs- learning from the ARCH project in Victoria Australia’. Keynote Professor Meg Morris La Trope University Australia. 25<sup>th</sup> July 2023.</li> <li>• Through collaboration, a free training course was provided by Neater Solutions Ltd. To Occupational Therapists at Sheffield Teaching Hospitals Trust. Fifteen OTs benefited from a 2-hour training session on ‘assistive technology and its application to eating, drinking and activity challenges for people with complex needs. This included the provision of course slides, a handbook and learning materials. 30<sup>th</sup> September 2022.</li> <li>• Invited speaker. I was invited by the North West R&amp;D to present to their NIHR Bridging Award Programme on 17<sup>th</sup> April 2023 &amp; February 2022 ‘Clinical Academics- Topic ‘How to get an NIHR award’. Sharing knowledge on NIHR award applications and how to develop a successful CV.</li> <li>• Invited speaker Sheffield Teaching Hospitals Research Academy CCAG, 9<sup>th</sup> June 2021. ‘How to capture and amplify your impact as a clinical academic’.</li> </ul> <p><b>Knowledge Generation</b></p>

	<ul style="list-style-type: none"> <li>Invited to the launch of the National Clinical Guideline for Stroke in the UK and Ireland. 19<sup>th</sup> April 2023 Science Gallery London, Kings College campus. ‘Evidence-based stroke care: present and future’. Invited by the Royal College of Physicians to contribute to the National Clinical Guidelines for Stroke: Topic Group, Nutrition, Hydration and Language Recovery. Member of the Topic Group. September 2022 to March 2023. Recognition for my contribution is in the <i>National Clinical Guidelines for Stroke for the United Kingdom and Ireland</i>. <a href="https://www.strokeguideline.org/app/uploads/2023/04/National-Clinical-Guideline-for-Stroke-2023.pdf">https://www.strokeguideline.org/app/uploads/2023/04/National-Clinical-Guideline-for-Stroke-2023.pdf</a>.</li> <li>The BISTRo toolkit is a codesigned kit of resources to support the implementation of the intervention. This toolkit will be available on the ORDA repository free to download for anyone wanting to start up a breakfast group.</li> </ul>
<p><b>Other publications resulting from the NIHR Clinical Doctoral Fellowship</b></p>	<p><b><u>Virtual Visit Application</u></b>  Lanfranchi, V. <b>Jones, N.L.</b> Read, J. et al. (2022) ‘User attitudes towards virtual home assessment technologies’, <i>Journal of Medical Engineering &amp; Technology</i>, (June), pp. 1–11. Available at: <a href="https://doi.org/10.1080/03091902.2022.2089250">https://doi.org/10.1080/03091902.2022.2089250</a>.</p> <p><b>Jones, N.L.</b> et al. (2021) ‘Remote home visits: Exploring the concept and applications of remote home visits within health and social care settings’, <i>British Journal of Occupational Therapy</i>, May, pp. 1–12. Available at: <a href="https://doi.org/10.1177/03080226211000265">https://doi.org/10.1177/03080226211000265</a>.</p> <p>Field, B. Read, J. <b>Jones, N.L.</b> et al. (2021) ‘Occupational therapists need to be involved in developing and evaluating technological solutions to support remote working’, <i>British Journal of Occupational Therapy</i>, 84(2), pp. 69–71. Available at: <a href="https://doi.org/10.1177/0308022620979517">https://doi.org/10.1177/0308022620979517</a>.</p> <p>Read, J. <b>Jones, N.L.</b> et al. (2020) ‘Remote Home Visit: Exploring the feasibility, acceptability and potential benefits of using digital technology to undertake occupational therapy home assessments’, <i>British Journal of Occupational Therapy</i>, 83(10), pp. 648–658. Available at: <a href="https://doi.org/10.1177/0308022620921111">https://doi.org/10.1177/0308022620921111</a>.</p> <p><b><u>Primary Care</u></b>  <b>Jones, N.L.</b> et al. (2022) ‘From tiny acorns mighty oaks grow; Natalie Jones talks about primary care, new ways of working and lessons learnt from developing occupational therapy roles.’, <i>OTNews</i> (October), pp. 36–38.</p> <p><b><u>Research Impact</u></b>  <b>(In peer review pending publication)</b> Holiday, J. <b>Jones, N.L.</b> J. Cooke, <b>(2023)</b> What Are the Organisational Benefits of Undertaking Research in Healthcare? An approach to uncover impacts.</p> <p><b>Jones, N.L.</b>, Cooke, J. and Holliday, J. (2021) ‘Making occupational therapy research visible: amplifying and elevating the contribution and impacts’, <i>British Journal of Occupational Therapy</i>, 84(4), pp. 197–199. Available at: <a href="https://doi.org/10.1177/0308022620988473">https://doi.org/10.1177/0308022620988473</a></p>



## Appendix 24 VICTOR Research Impact- Questionnaire- combined site results

### **VICTOR Impact Questionnaire:**

**Principal Investigator, Research Team, Research Manager and Industrial Partners**

**Your name: Natalie Jones**

**Your role: Clinical Academic Occupational Therapist, Chief Investigator BISTRo**

**Date of Questionnaire completion: start 09.09.20-30.08.23**

**Project title: Breakfast Group Interventions in Stroke Rehabilitation**

**Organisation: Sheffield Teaching Hospitals NHS FT and The University of Sheffield**

**A. Health benefits, safety and quality improvements for research participants and carers during the study**

Question	Yes/No/Not Yet	Please give examples/describe
<p><b>1. Health benefit</b></p> <p>Have there been any health or quality of benefits to study participants, family or carers as a result of taking part in the study?</p> <p><i>Prompt: quality of life impacts, access to different treatments; care delivered differently; quality of information provided; health literacy; providing the same quality of care for a reduced cost.</i></p>	<p>Yes</p>	<p>Patients are receiving intensive eating and drinking interventions for two weeks.</p> <p>Family are invited to be involved in the initial assessment and the final review.</p> <p>The motivation to get up and dressed for a purpose as part of the ward's daily routine meant that patients were more engaged in their rehabilitation with the health benefits of sitting upright to eat, and reduced deconditioning from being in bed.</p> <p>Patients at MMH were already encouraged to be up and out of bed for breakfast in the day room. However, there is an increased awareness amongst staff (particularly Physio) of the importance of preparing and eating breakfast as a therapy intervention.</p>
<p><b>2. Experience</b></p> <p>During the study, were there any changes made to patient care that improved the experience of care for participants, carers or family as part of/as a result of being in the study?</p> <p><i>Prompt: Information giving, carer support, carer interventions; health literacy.</i></p>		<p>As above the ethos at MMH was already collaborative. A positive change since the study has been the involvement of Physio in the breakfast group which ensures that joint goals are being made and improves communication around discharge planning and support needs at home.</p> <p>However, this previously positive collaboration has at times caused a negative result as normally during the week the social group with the activities coordinator welcomes all patients. Whereas the breakfast group has specifically chosen patients with goals to meet and at times the nursing staff have been frustrated when they have attempted to bring a patient who is not involved in the breakfast group in and have had to be turned away/unable to join in.</p> <p>Therapy staff and ward staff worked closer together to help get patients ready for the group. This has led to a more collaborative culture of washing and dressing, with therapists and ward staff doing joint sessions, and all promoting the importance of getting up and dressed</p>

		<p>in their own clothes, independence in washing and dressing and participation in breakfast as part of rehabilitation. Change in ward ethos surrounding breakfast. Aiming to continue to implement changed ethos with the introduction of volunteer roles (dining companions) on the ward to support more meaningful participation in mealtimes and promote independence with eating and drinking.</p> <p>Information given to carers as a result of group participation/goals – to advise on support needed for home. Much richer information is based on actual dining experience rather than eating at the bedside.</p>
<p><b>3. Patient safety</b></p> <p>Are there any examples of improved governance and/or safety for patients taking part in the study?</p> <p><i>Prompt: Improvements to the quality of research in terms of scientific quality, standards of ethics and related management aspects – Set up, conduct, reporting and progression towards healthcare improvements</i></p>		<p>Study risk assessment created for localising.</p> <p>Breakfast group becoming part of ward daily routine. Standardisation of setting up the group, and use of resources (e.g.: menu, individual place settings and use of ramekins instead of small packaging).</p> <p>Promotion of rehabilitation goals relating to eating and drinking for group participants – not just social dining.</p> <p>The set up of the breakfast group on a Friday is now the responsibility of one of the therapy assistants who has this as part of her routine, giving the therapists time to do washing and dressings etc. before the group.</p> <p>Agree with the above, the promotion of rehab goals around eating and drinking differs from the social dining they experience on other days of the week.</p>
<p><b>4. Social capital</b></p> <p>Are participants/carers better connected or part of any new networks as a result of taking part in the research?</p> <p><i>Prompt: self-help groups, increased social networks or activities</i></p>	<p>Yes</p>	<p>The public members of the stakeholder group were able to share their experiences and feel like they were contributing to making improvements.</p> <p>Two of the Rotherham participants exchanged details and stayed in touch by phone after discharge. Mutual support. One would like to come back and volunteer to support the group on the ward.</p> <p>Through the study, staff got to know one of the volunteers Philip who comes into MMH and what his views of groups were. The breakfast group is now held on a Friday to ensure he can attend and provide peer support to the patients in the group. Two of the patients in the study planned to get in contact with each other following the study.</p>

**B. Service and workforce impacts**

Question	Yes/No/Not Yet	Please give examples/describe
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<p><b>1. Service change</b></p> <p>Has anyone in the organisation started doing something or stopped doing something clinically as a result of the research?</p> <p>In addition to this; has this resulted in improved care of patients after the study has finished?</p> <p><i>Prompt: quality of life impacts, access to different treatments; care delivered differently; quality of information provided; health literacy – leaflets and guidance.</i></p>	<p>Yes</p>	<p>There is now Physio involvement in the breakfast group which was not present during the study. This has resulted in joint goal setting and treatment creating more efficiency and better use of therapy time.</p> <p>Ward staff have been mostly supportive of the group however do not attend.</p> <p>SLT have not attended the group since the study however they do set goals for the patient to be worked on with a therapy assistant during breakfast group.</p> <p>The patient experience team are reporting on the group at TRFT as an improvement to patient care.</p> <p>The stroke therapy team has started running the breakfast group daily, with a staff rota to set up and run the group, and daily washing and dressing sessions to prepare. Goals are set for each participant and relevant professionals run the group to help meet their goals.</p> <p>There is improved engagement between therapy and nursing in joint planning and conducting washing and dressing sessions on the ward. Ward staff are not able to attend the group but are aware of it and in support of preparation of patients for the group – improved ethos onward towards rehabilitation approach.</p>
<p><b>2. Clinical or generic skills</b></p> <p>Does anyone have new <b>clinical skills</b> as a result of the research? This could include skills developed as a result of being involved in the study or skills that have been developed since the study finished because the benefit of having these skills was demonstrated by the research.</p> <p><i>Prompt: any clinical training</i></p>	<p>Yes</p>	<p>Three Occupational Therapists had the opportunity to be first-time Primary Investigators. They have all received GCP training, and consent training and developed skills in managing research projects.</p> <p>All staff participants in the intervention delivery were trained to deliver the intervention and also received topic-specific training on eating and drinking difficulties.</p> <p>Ward staff participating in the group were able to learn and practice UL facilitation, transfer techniques and communication support alongside therapists and continue to use these skills in practice and joint sessions.</p> <p>The activity co-ordinator had limited</p>

		<p>experience in setting patient goals, facilitating movement and improving independence, during her social group she tended to assist the patients at all times. She has gained clinical skills in moving, handling and facilitation of upper limbs during the study and has identified that she would benefit from further training. Several of the SLTs have also benefitted from this opportunity to be involved from a physical moving and handling point of view.</p> <p>Staff other than OT who did not routinely use small aids and adaptations have benefitted from seeing and using these with patients in the group. This has led to the identification of extra equipment that was needed e.g. one-cup machine, adaptive cutlery, dycem mats etc.</p>
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<p><i>Please note research skills are also covered in the next section.</i></p>		
<p><b>3. Workforce</b></p> <p>Has the workforce changed as a result of the research? For example, have there been any changes to job roles or structures?</p> <p><i><b>Prompt:</b> This could be during the study or after the study</i></p>		<p>Site 1- the dietitian did not previously get involved with group interventions for eating and drinking. As a result of this study, she joined the intervention delivery team.</p> <p>As above dietitians, SLTs and Physio did not get involved in groups before the study and this has increased their confidence in being part of breakfast groups and what their goals would be.</p>
<p><b>4. Collective action</b></p> <p>Has taking part in this research influenced your team to do anything different together?</p> <p><i><b>Prompt:</b> Collective changes to patient care, skills, confidence and/or quality improvements</i></p>		<p>More collaborative working between therapy and nursing on the stroke unit – with regards to washing and dressing and overall ethos of rehabilitation on the ward.</p> <p>Completing the interprofessional breakfast group as part of BISTRO has inspired the team to start up other therapeutic groups on the ward including an inattention and sensory upper limb group. The day before the breakfast group the team set joint goals for the patients that are going to attend the group which are recorded in their “breakfast group folder”.</p>
<p><b>5. Guidelines</b></p> <p>Is there a different use of, or further adherence to, clinical guidelines as a result of the study – either during the study or afterwards?</p> <p><i><b>Prompt:</b> these could be national guidelines, or those developed more locally as a result of the study.</i></p>		<p>Plan to use the group as an example of meeting the new RCP guidelines regarding the importance of time spent in repetitive task practice, and meaningful activity as part of daily routine, not just in therapy sessions.</p> <p>The group has also demonstrated our ability to plan and implement group activities after the pandemic and inspired ideas for further therapeutic groups on the stroke unit – in development.</p>

**C. Research Profile of the organisation and research capacity**

Questions	Yes/No/Not Yet	Please give examples/describe
<p><b>1. Research culture</b></p> <p>Has the study changed the culture and attitudes to research in the service or organisation?</p> <p><i>Prompt: Are you measuring impact now; increased willingness to get involved in research; increase in confidence; Patient and Public Involvement</i></p>	<p>Yes</p>	<p>PI from site 1 is thinking about doing more research in the future and looking for research awards to support her development.</p> <p>Increased confidence that the team can participate in research that has benefits for our patient group. To participate in another study this year.</p> <p>Change in perception that patients in the acute ward were so willing to participate.</p> <p>PI from site 2 has been significantly more involved in research and hopes to improve the research culture within Stroke therapies. To develop skills in recruitment and consenting patients and the paperwork/documentation she became involved in another stroke study COMMITS, assisting the research nurses to recruit and baseline for this. She has also got a place and started the NIHR Clinical Research Internship and is planning a service evaluation project with links to BISTRO.</p>
<p><b>2. Research Awareness</b></p> <p>Has staff awareness of research changed as a result of the organisation taking part in this study?</p> <p><i>Prompt: Any examples of how this was achieved or is evident?</i></p>		<p>Yes, the whole MDT were aware of the group and continued benefits for patients.</p> <p>Feel the MDT is more aware of research and how important this is in improving patient care and also that it is not as daunting as it seems to be involved.</p>
<p><b>3. Research capacity</b></p> <p>Has anyone developed new <b>research skills</b>, knowledge and experience making them more likely to be involved in future research?</p> <p><i>Prompt: New career choices, research roles, individual clinical and research links; collaborations on further grant applications</i></p>		<p>PI from site 3 wants to be a PI for more studies and is making plans to access the NIHR Primary Investigator training programme.</p> <p>Not sure yet</p> <p>See above.</p>

Questions	Yes/No/Not Yet	Please give examples/describe
<p><b>4. Networks and collaborations</b></p> <p>Has the organisation joined or created any new research networks, partnerships, or collaborations as a spin-off from the research?</p> <p>These may be internal or external.</p>	<p>Yes</p>	<p>Bringing together staff from three stroke units in an ICS is exposing health and care professionals to different ways of working.</p> <p>The aphasia-friendly menus used in site 1 have been shared with sites 2 &amp; 3. By getting together and discussing resources the teams are starting to share resources.</p> <p>Good to have increased collaboration with other OTs in the network. PI from site 2 is joining a DBTH Therapies Research group and has also been asked to present experiences on BISTRo at an internal OT networking event.</p>
<p><b>5. Engagement</b></p> <p>Has the study attracted the interest of others who were not involved before the study?</p> <p><i>Prompt: Colleagues in your department, other departments, and/or other organisations?</i></p>		<p>Patient experience team to report on the study and subsequent group as a positive development in the stroke unit. TRFT communications team to report on the group and use of menus and other resources to support patients.</p> <p>Colleagues have been interested during and after the study. The ward manager of MMH General Rehab has been interested in learning more and will likely attend the celebration event.</p>



**D. Economic Impacts**

Question	Yes/No/Not Yet	Please give examples/describe
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<p><b>1. Cost-saving/cost-effectiveness changes</b></p> <p>Has the adoption of research findings realised any cost savings or promoted cost-effective service (i.e. same costs better quality of care)?</p>		<p>No cost-effectiveness measures but utilization of resources could prove more effective, would need to look at SNAP data.</p>
<p><b>2. Commercialisation</b></p> <p>Did the research develop products that generate income or create commercial innovations?</p>		<p>N/A</p>
<p><b>3. Income</b></p> <p>Was the study commercially funded and sponsored? Did it generate any income for the organisation?</p> <p>Did it generate any grant income?</p>		<p>N/A</p>

**E. Organisation's influence and reputation**

Question	Yes/No/Not Yet	Please give examples/describe
<p><b>1. Cohesion</b></p> <p>Has taken part in the research impacted relationships between professions/departments/sectors?</p>	Yes	The health and care professionals have started to connect and share resources.
<p><b>2. Reputation</b></p> <p>Has taking part in the study had an impact on the profile/reputation of your team or organisation?</p>		Site 2 was struggling with the engagement of nursing staff in the project. They decided to do a launch event to share the vision for the study and create buy-in. The CI went to visit the senior nurse and shared the BISTRO video which was made to facilitate thinking about the project. Following these two activities, the senior nursing team became engaged and the Matron pledged to release a nurse every day for the project. She has discussed this with the chief nurse and put her full support behind the project.
<p><b>3. Recruitment and retention of staff</b></p> <p>As a result of the study has there been any impact on recruitment into roles and retention of staff</p>		

Question	Yes/No/Not Yet	Please give examples/describe
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<p><b>1. Formal dissemination</b></p> <p>Have there been any dissemination events, presentations, conferences or publications about the study, within the organisation or externally?</p>		<p>Workshop and open research event 13<sup>th</sup> June. Presented at 2 European conferences and National Stroke Conferences. Oral presentation at the RCOT Conferences 2023 and a poster. Poster at the UK Stroke Forum 2023. Presentation at the NIHR Stroke Conference.</p>
<p><b>2. Knowledge sharing</b></p> <p>Are there any new ways of sharing knowledge within the organisation or between your organisation and others as a result of the research?</p> <p><b>(Prompt:</b> new groups, networks, face-to-face/other media)</p>		<p>Knowledge sharing between organisations-aphasia-friendly menu. Knowledge sharing around operationalizing breakfast groups.</p>
<p><b>3. Outputs</b></p> <p>Have any tools useful for practice been developed by the research that the organisation is now using?</p>		<p>Recipient of a Merit Award from the Royal College of Occupational Therapy. Winner of the Chief Allied Health Professionals Award for Research Impact. Winner of the patients and public award UK Stroke Forum 2023.</p>

### F. Anything Else

If you feel the research study impacted in ways not outlined in the previous questions, please outline your findings here.

This documentation has been produced as part of the VICTOR study, funded and supported by NIHR CLAHRC Yorkshire and Humber and CRN Yorks and Humber. The VICTOR study is hosted by Sheffield Teaching Hospitals NHS FT © 2018

## Appendix 25: Example Patient Participation Information Sheet.

### Participant Information Sheet: Mealtime Observations

#### Breakfast Group Interventions for Stroke Rehabilitation (BISTRo)

**Study title: feasibility of a breakfast group intervention for acute stroke units, to provide intensive eating and drinking interventions as well as integrated multi-disciplinary team working and personalized care.**

You are being invited to take part in a study as part of my PhD research project. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

#### **What is the project's purpose?**

Current evidence shows that many people living with stroke experience major problems with eating and drinking. We know that this can lead to malnutrition, dehydration, reduced muscle strength and depression. It can also lead to longer stays in hospital, reduced ability to participate in rehabilitation and in the long-term poorer quality of life. People living with stroke say that the pleasure gained from eating and drinking changes after stroke. They describe feeling embarrassed and ashamed and report a loss of self-confidence with eating and drinking. Being able to eat and drink independently is essential for health, well-being, and social activities.

People with stroke welcome opportunities to address eating and drinking problems early in their rehabilitation and would like more opportunities to practice the necessary skills needed, to regain independence. Early rehabilitation interventions have the potential to improve long-term outcomes by providing strategies, assistive devices, and rehabilitation as early as possible in stroke recovery. People participating in meal-time rehabilitation groups enjoy the social aspects of sharing a meal together and welcome the opportunity to practice their rehabilitation strategies in a more meaningful and purposeful way.

Healthcare professionals are using meal-time groups to provide opportunities to practice eating and drinking in rehabilitation. They are delivering this in a variety of ways but are unsure about which way is best. Healthcare professionals think that this aspect of stroke care could be improved with working together better together as a team.

This study aims to find out if it is possible to improve patient experiences of eating and drinking rehabilitation by providing more intensive interventions in a breakfast group format, delivered by a range of health care professionals. This will be supported by a toolkit comprising of collaborative assessments, care plans, goal setting and outcome measures.

This research question and study design have been shaped by patients, stroke researchers and healthcare professionals. They will also be involved throughout the study as the breakfast group intervention and supporting tool kit will be co-designed by stakeholders. The breakfast group format and toolkit will be tested on three-stroke wards in South Yorkshire and Bassetlaw Integrated Care System.

This study aims explore whether delivering breakfast group interventions five days a week are feasible and acceptable to patients and healthcare professionals in stroke rehabilitation wards.

The results of this study will be shared locally with patients, health care professionals and more widely at national and international conferences. Results will be published in journals, reports and shared on social media.

### **Why have I been chosen?**

Participants in this study will have been identified by the nursing or therapy team as they are inpatients on a stroke rehabilitation ward and after stroke are experiencing difficulties with managing eating and drinking.

### **Do I have to take part?**

Taking part in this research study is entirely voluntary and if you don't not wish to take part, there will be no negative consequences and declining to take part will not affect your care in any way. You may decide to discontinue participation at any time. You do not have to give a reason. If you wish to withdraw from the research, please contact Natalie Jones tel. 07880003229, tell your treating therapist, or a member of the nursing team and they will replay a message to myself.

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

Whilst you can withdraw from the study at any point any data collected in the study up to the point you leave will be included in the study findings.

### **What will happen to me if I take part? What do I have to do?**

A researcher will observe the mealtime activities that take place on the ward. The researcher who is a stroke rehabilitation clinician will observe the health care professionals organise meals, the patient eating meals and the activities on a ward that take place to ensure people are getting food and drink. Observation provides valuable insights into how the service works and what patients and staff perspectives might be.

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

It is not anticipated that there would be any discomforts, disadvantages, or risks to taking part in this research. If you wish to withdraw from the research, you will be able to do so at any time.

### **What are the possible benefits of taking part?**

Whilst there are no immediate personal benefits for those people participating the ward observations it is hoped that this work will enable the researchers to understand the difficulties encountered with eating and drinking problems and this information will contribute to the design of the Breakfast Group Intervention study.

### **Will my taking part in this project be kept confidential?**

All the information that we collect about you during this research will be kept strictly confidential and will only be accessible to members of the research team. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. If you agree to us sharing the information you provide with other researchers, then your personal details will not be included. If you specifically wish to be named in publications or reports on the research findings, then specific consent for this will be obtained as part of the informed consent process. If you agree to us sharing

the information you provide with other researchers (e.g., by making it available in a data archive) then your personal details will not be included. All participants will be given pseudonyms.

### **What is the legal basis for processing my personal data?**

According to data protection legislation, we are required to inform you that the legal basis in which we are applying to process your personal data is 'is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)) and will comply with the requirements of the General Data Protection Regulation (GDPR), the UK Data Protection Act 2018, and the Common Law Duty of Confidentiality.

As we will be collecting some data that is defined in the legislation as more sensitive information about your health and progress in rehabilitation, we also need to let you know that we are applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes.

### **What will happen to the data collected, and the results of the research project?**

Your personal information will be anonymised (your name and other identifiers will be removed), and your data will be securely stored as an encrypted, password protected file on the central University server. Any observations notes made by the researcher of the breakfast group will be only used for the purposes of analysis by the research team. Anonymised quotes may be used for illustration in publications, conference presentations and lectures. No other use will be made of them without your written permission, and no-one outside the project will be allowed access to the study data.

We aim to send a full report to the NHS Hospital Trust but will also send a summary to each participant, we also aim to publish several academic articles, links to which will also be sent to the NHS Hospital Trust for them to circulate. Your personal data will be stored until the end of the project (so we can send you the results). Your anonymised data will be stored for 5 years after the end of the project. All data will be stored securely according to NHS policies.

Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way.

### **Who is organising and funding the research?**

This research is organised by Sheffield Teaching Hospitals NHS Foundation Trust the research is funded by the National Institute for Health Research.

### **Who is the Data Controller?**

Sheffield Teaching Hospitals NHS Foundation Trust will act as the Data Controller for this study. This means that Sheffield Teaching Hospitals NHS FT is responsible for looking after your information and using it properly.

### **Who has ethically reviewed the project?**

This project has been ethically approved by the NHS governance approvals from the Health Research Authority and it has been independently reviewed by the National Institute for Health Research.

### **Who do I contact if I have a complaint?**

Should you wish to raise a complaint please contact:

Natalie Jones Chief Investigator  
Stroke Pathway Assessment Rehabilitation Centre  
Norfolk Park Road  
Sheffield  
S2 3QE  
Tel 07880003229

However, should you feel that the complaint has not been handled to your satisfaction by the Chief Investigator please contact [claire.conconnon@nhs.net](mailto:claire.conconnon@nhs.net), who will then escalate the complaint through the appropriate channels. If the complaint relates to how your personal data has been handled, please contact The University of Sheffield Data Protection Officer [dataprotection@sheffield.ac.uk](mailto:dataprotection@sheffield.ac.uk). Further information about how to raise a complaint can be found in the University's Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

**Contact for further information**

If you have further questions or want more information on the project, please contact the Chief investigator, Natalie Jones [Natalie.jones56@nhs.net](mailto:Natalie.jones56@nhs.net) or [Tel 07880003229](tel:07880003229)

If Natalie Jones is unavailable, please contact the local Primary Investigator .....

The participant will be given a copy of the information sheet and, if appropriate, a signed consent form to keep.

**Many thanks for considering taking part in this research study**

Thank you.



(Image Source: Natalie Jones 2022)