Development of a complex intervention providing cognitive care after stroke



Georgina Claire Hobden

Lincoln College

University of Oxford

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Abstract

Post-stroke cognitive impairment is highly prevalent and recent systematic reviews have identified managing cognitive changes as one of the most commonly reported unmet needs in the long term after stroke. In the UK, national clinical guidelines provide a clear outline of 'best practice' cognitive care, but audit data have shown that cognitive care falls below recommended standards in many respects. A pragmatic and scalable intervention that provides enhanced post-stroke cognitive care may help to address these clinical gaps and stroke survivor needs.

The overarching aim of the research presented in this thesis was to develop a UK-based intervention providing Level 1 post-stroke cognitive care. The research was guided by the Medical Research Council framework for complex intervention development and thus prioritised evidence, theory, and stakeholder perspectives. Four highly iterative and mutually informative research projects were conducted to develop the intervention. First, an online modified Delphi survey was conducted to establish expert consensus on the intervention features. Then, stroke survivors and family members participated in semi-structured interviews to share their perspectives on two of the core intervention features (cognitive screening and cognitive trajectory discussions). A scoping review was conducted to map and identify gaps within the current literature describing stroke survivor and family member psychoeducation needs about cognition. Finally, stroke survivors, family members, and healthcare professionals participated in a series of co-production activities to develop a novel cognition-focused psychoeducation resource to be used in the intervention. After synthesising key findings from these four projects to design the intervention and

corresponding programme theory, the final empirical chapter presents preliminary results from initial feasibility testing of the intervention and the protocol for a future planned study to assess the feasibility of running a full-scale cluster randomised controlled trial to evaluate clinical effectiveness.

Overall, the research provides an important contribution to the field of post-stroke rehabilitation by offering a clearly delineated and pragmatic psychological care intervention. Should the intervention prove clinically and financially effective in a future planned cluster randomised controlled trial, it might meaningfully improve post-stroke psychological care within the UK. In the meantime, while this ambitious research programme is ongoing, key findings presented in this thesis may usefully inform local clinical service improvements.

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List of Abbreviations

ADL	Activity of Daily Living
BCW	Behaviour Change Wheel
CDI	Communication Debilitating Illness
CLCE-24	Checklist for Cognitive and Emotional Consequences
COM-B	Capability, Opportunity, and Motivation Behaviour
CONSORT	Consolidated Standards of Reporting Trials
CRT	Cluster Randomised Controlled Trial
DASS-21	Depression Anxiety and Stress Scale
DOLA	Differentiated Overt Learning Activities
EBM	Evidence-Based Medicine
ENRICH	Enhanced Reviews of Psychological Changes
EQ-5D-5L	EuroQol 5 Dimensions 5 Levels Scale
ESD	Early Supported Discharge
FSS	Fatigue Severity Scale
GAD-7	Generalised Anxiety Disorder Scale
GM-SAT	Greater Manchester Stroke Assessment Tool
ICAP	Interactive, Constructive, Active, Passive
ISDN	Integrated Stroke Delivery Network
JBI	Johanna Briggs Institute
JLA	James Lind Alliance
MDT	Multidisciplinary Team
MMSE	Mini-Mental State Examination
MOCA	Montreal Cognitive Assessment

MRC	Medical Research Council
mRS	Modified Rankin Scale
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NIHSS	National Institute of Health Stroke Scale
OCS	Oxford Cognitive Screen
OUH	Oxford University Hospitals
PCC	Population, Concept, Context
PHQ-9	Patient Health Questionnaire
PPI	Patient and Public Involvement
PRECiS	Patient Reported Evaluation of Cognitive State for Stroke
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews
QOLIBRI	Quality of Life Brain after Brain Injury Scale
RCT	Randomised Controlled Trial
REC	Research Ethics Committee
SSNAP	Sentinel Stroke National Audit Programme
SWCRT	Stepped-Wedge Cluster Randomised Controlled Trial
TIA	Transient Ischaemic Attack
UK	United Kingdom

Chapter 1 Introduction

1.1. Chapter overview

The overarching aim of the work presented in this thesis was to develop a complex intervention to enhance cognitive care within the existing post-stroke care pathway in the United Kingdom (UK). This chapter presents the empirical and conceptual background to the research. The chapter begins by providing a broad overview of the prevalence and impact of stroke. It then hones in on cognitive changes after stroke, describing their prevalence at different timepoints and their impact on patient outcomes. Other common psychological changes after stroke (low mood, anxiety, and fatigue) are discussed in brief, but it is worth emphasising that the original focus of this thesis and the complex intervention was on addressing cognitive changes after stroke specifically.

The chapter then outlines the current clinical care pathway for stroke, emphasising the substantial geographical heterogeneity and the need for service improvement and increased standardisation. Large scale NHS service delivery improvement plans are described, before the chapter turns back to cognition. I summarise relevant national clinical guidelines related to post-stroke cognitive care and illustrate the extent to which standards are currently being met using national stroke care audit data. Having established that post-stroke cognitive care in the UK has been falling below ideal standards in recent years, the chapter then explains that managing cognitive changes

in the months and years after stroke is one of the most commonly reported unmet needs among patients.

Ultimately, this empirical and conceptual background demonstrates the need for a novel and scalable intervention to address the well-evidenced and troubling gaps in post-stroke cognitive care provision in the UK. As such, the chapter concludes by outlining the primary aim of the research presented in this thesis – to develop an intervention providing enhanced post-stroke cognitive care – and the specific objectives addressed within each empirical thesis chapter.

1.2. Prevalence and significance of stroke

Each year, there are an estimated 13 million new strokes worldwide (Johnson et al., 2019) and 100,000 within the UK specifically (e.g. Rothwell et al., 2004). While stroke mortality rates have been declining due to improvements in primary and secondary prevention, as well as more effective acute stroke treatments (Seminog et al., 2019), stroke remains one of the leading causes of disability worldwide (Feigin et al., 2014, 2017, 2022). Furthermore, as the global population expands and ages, the incidence and prevalence of stroke is expected to increase, leading to a corresponding increase in stroke-related disability (Katan & Luft, 2018).

1.2.1. Stroke symptoms

Multiple sequelae contribute to the high rates of disability after stroke, including changes in motor, sensory, and psychological functioning (e.g., Broussy et al., 2019).

Psychological changes may involve reductions in cognitive functioning, low mood and anxiety (Cumming et al., 2016; Hackett & Pickles, 2014; Knapp et al., 2020; Kusec et al., 2023), as well as fatigue, which is argued to have at least a partial psychological basis (Oslo Chronic Fatigue Consortium et al., 2023). The following sections describe the prevalence and significance of cognitive changes after stroke, given that they are the primary focus of the work presented in this thesis. Other psychological changes are also discussed briefly.

Cognitive changes after stroke

Whilst definitions vary, post-stroke cognitive impairment generally refers to a group of complex and heterogeneous conditions where stroke either causes or contributes to impaired cognitive ability (Huang et al., 2022). Usually, patients with pre-existing cognitive decline are excluded from this definition, in order to differentiate patients with pre-stroke dementia from those with specific stroke-induced cognitive impairments (Huang et al., 2022). Nevertheless, *post*-stroke dementia is a common sequalae of stroke and overlaps substantially with post-stroke cognitive impairment, being defined as any dementia following stroke in temporal relation (Mijajlović et al., 2017).

Domains of cognitive function that may be affected by stroke are variously defined and labelled but may include language, memory, visuospatial attention (i.e., neglect), executive function, number processing and praxis (Demeyere et al., 2015). Conceptualising cognition as a multifaceted construct comprising several domains derives from a long neuropsychological tradition, but stands in contrast to historically (and – in some spheres – presently) prominent views of cognition as a singular

construct within the broader medical community. Nevertheless, this multidomain conceptualisation of cognition has gained traction within clinical and research spheres and is now captured within national and international clinical guidelines (Intercollegiate Stroke Working Party, 2023a; Royal College of Physicians, 2016; Stroke Foundation Australia, 2021; The European Stroke Organisation (ESO) Executive Committee and the ESO Writing Committee, 2008). For example, the National Clinical Guideline for Stroke (2016) acknowledged that "Each cognitive domain (e.g. perception, attention, memory) should not be considered in isolation because most everyday activities draw on a range of abilities. Assessment and treatment need to take this overlap into account." (Section 1.3.1. provides further detail on clinical guidelines).

The multifaceted nature of cognition makes it difficult to estimate post-stroke cognitive impairment prevalence; prevalence estimates depend on the specific cognitive domain being assessed (Kusec et al., 2023; Milosevich et al., 2024; Nys et al., 2005), the characteristics of the included cohort, and cognitive assessment tools used (e.g., Bath et al., 2017; Hurford et al., 2013). Nevertheless, previous research generally indicates that cognitive impairment affects a large proportion of stroke survivors in the first weeks after stroke (range: 48-98.4%) (Demeyere et al., 2016; Hurford et al., 2013; Lesniak et al., 2008; Milosevich et al., 2024; Nijsse et al., 2017; Turunen et al., 2018).

Over the longer term, post-stroke cognitive impairments vary in their severity and trajectory, with currently no reliable way to predict long-term outcomes on an individual level (Quinn et al., 2021; Tang et al., 2020). Likely due to natural recovery mechanisms including brain plasticity, a proportion of stroke survivors recover from acute

impairments in cognitive functioning (Kusec et al., 2023; Milosevich et al., 2024; Nys et al., 2005). Although pinpointing the exact recovery rate is complicated by heterogeneity between studies, a recent systematic review and meta-analysis reported a 38% pooled prevalence for cognitive impairment (no dementia) in the first year after stroke (Sexton et al., 2019). However, chronic cognitive impairment after stroke does not always represent a stable impairment, as cognitive functioning has been shown to decline further from the acute to chronic post-stroke stages in a proportion of stroke survivors and results from recent studies have raised the possibility that 'new' cognitive impairments, not present in the weeks after stroke, may develop in the chronic stages in some cases (e.g., Kusec et al., 2023; Milosevich et al., 2024).

Evidence that some stroke survivors develop 'new' cognitive impairments in the months and years after stroke is challenging to explain, when considering relatively stroke-specific cognitive impairments, like apraxia, and these findings may by an artifact of testing methods used in previous studies (e.g., assessments in acute and chronic stage conducted by different practitioners) (Kusec et al., 2023; Milosevich et al., 2024). Nevertheless, there is firm evidence that stroke survivors are at a significantly increased risk of developing vascular and mixed dementia, which tend to be characterised by problems affecting memory, executive function, and attention (e.g., Pendlebury & Rothwell, 2019). Though the mechanisms by which post-stroke dementia develops are not well understood, recent research suggests there may be an interplay between focal stroke pathology and pre-existing neurodegenerative brain health markers, such that those with more severe cortical atrophy may be less likely

to recover from initial stroke-related cognitive impairments (Hobden et al., 2023). In terms of prevalence, a recent systematic review and meta-analysis of 44 studies found that approximately 20% (pooled prevalence) of stroke survivors experience clinically defined dementia one-year after stroke (Craig et al., 2022), broadly echoing results of an earlier meta-analysis that found pooled prevalence of post-stroke dementia in the first year after stroke ranging from 8% in those with minor stroke and 34% in those with severe stroke (Pendlebury & Rothwell, 2019).

Post-stroke cognitive impairments are not only prevalent, but also predictive of both cognitive and functional recovery (Barker-Collo & Feigin, 2006; Filler et al., 2023; Narasimhalu et al., 2009). Furthermore, cognitive impairment after stroke is often a substantial barrier to reintegration into pre-stroke social and occupational roles and thus may limit meaningful participation in activities of daily living (ADLs) (Adamit et al., 2015; Stolwyk et al., 2021). This perhaps partially explains why cognitive impairment after stroke has been identified as a key predictor of health-related quality of life after stroke, independent of physical impairment and disability (Hochstenbach et al., 2001; Nys et al., 2006; Sturm et al., 2004).

Other psychological changes after stroke

Previous research supports a potential association between post-stroke cognitive impairment with reduced mood, increased anxiety, and other extended outcomes that are thought to have at least a partial psychological basis (e.g., fatigue) (Cumming et al., 2016; Tay et al., 2021). Specifically, evidence indicates those with cognitive impairment are twice as likely to experience reduced mood, increased anxiety, and/or

fatigue in the first year after stroke, compared to those without cognitive impairment (Falck et al., 2019; Skogestad et al., 2021; Williams & Demeyere, 2021). Furthermore, post-stroke cognitive changes, low mood, anxiety, and fatigue have all been associated with reduced post-stroke participation and quality of life (Ezekiel et al., 2019; Kusec et al., 2023; Mole & Demeyere, 2018).

As in the case of post-stroke cognitive impairment, prevalence estimates for post-stroke depression and anxiety vary substantially. Nevertheless, a recent systematic review and meta-analysis of 97 studies found the pooled prevalence of post-stroke anxiety to be 18.7% in studies using interviews, and 24.2% in studies using self-report scales (Knapp et al., 2020), while the pooled prevalence of post-stroke depression across 61 studies was estimated to be 31% (Hackett & Pickles, 2014). Although the majority of previous studies have examined depression and anxiety in the acute stage post-stroke (Hackett & Pickles, 2014; Knapp et al., 2020), a recent study found that depression and anxiety rates were relatively stable up to two-years after stroke (Kusec et al., 2023), suggesting that these psychological difficulties do not necessarily dissipate as stroke survivors adjust to post-stroke changes. Adjustment after stroke is indeed a huge challenge for many patients, as accepting 'who I am now' compared to 'who I used to be' requires careful reflection and oftentimes scaffolding and support from trained professionals (Gracey et al., 2009).

In terms of post-stroke fatigue, there is debate and controversy about the most accurate conceptualisation, with previous definitions focusing to varying extents on fatigue as a physiological or somatic condition, fatigue as a performance decrement,

and fatigue as an experience (Phillips, 2015). Though some definitions also recognise psychological contributors to fatigue (Phillips, 2015), papers addressing these psychological components have not always been well-received, with critics arguing that to conceptualise fatigue as a (partially) psychological construct is equivalent to telling patients 'it is all in your head' (Sharpe & Greco, 2019). Recently, however, important nuance has entered the frame, with researchers beginning to recognise that post-stroke fatigue – much like cognitive impairment – may not be a unitary condition, but rather a cluster of disorders with potentially dissociable mechanisms driving and maintaining symptoms (Kuppuswamy et al., 2024). Ultimately, this conceptualisation recognises that the extent to which fatigue is driven by psychological versus physiological factors is likely to vary substantially. Moving briefly away from conceptual debate and towards pragmatic considerations of prevalence, previous studies have generally highlighted an increased prevalence of fatigue among stroke survivors compared to age-matched controls (van der Werf et al., 2001), with a recent systematic review and meta-analysis reporting a pooled prevalence among stroke survivors of 50% despite substantial heterogeneity across included studies (Cumming et al., 2016).

1.3. The UK stroke care pathway

As stroke is a life-threatening medical emergency that also causes heterogeneous chronic symptoms, stroke care is necessarily complex and multifaceted. Patients usually require input from a range of clinical specialists over an extended period of time, covering hyperacute medical management (stroke specialist clinicians), rehabilitation for physical impairments (physiotherapists), support for functioning in

daily life activities (occupational therapists), secondary prevention (primary care practitioners), support in adjusting to changes psychologically and managing cognitive impairments (clinical psychologists and clinical neuropsychologists).

While it is widely acknowledged that stroke care should cover all sequelae of stroke relevant to the patient and should span across the time period for which support is required (Gittins et al., 2020), healthcare practitioners, services, and systems are often forced to strike a pragmatic balance between what is ideal and what is feasible to deliver. Attempts to strike this balance have resulted in a post-stroke care pathway that looks more like a series of (well-evidenced) stepping stones than a continuous pavement. Clinical trial data supports the effectiveness of a number of specialist stroke services (e.g., specialist inpatient stroke care units, Early Supported Discharge stroke services, community stroke specialist rehabilitation teams) (Langhorne et al., 2005, 2020; Legg et al., 2004; Saka et al., 2009) and provision of these services has improved over recent years (Intercollegiate Stroke Working Party, 2023b). However, these services are not always configured into a single streamlined stroke care pathway, which naturally impacts the consistency and therefore quality of care patients receive.

Recognising this issue, the National Stroke Programme has outlined a plan to integrate stroke services across the UK through the development of Integrated Stroke Delivery Networks (ISDNs), regional collaborations of stroke services spanning the full care pathway designed to enhance and streamline stroke care through strong clinical and network leadership, upskilled workforces, and improved information transfer

systems (NHS, 2021). Figure 1.1 provides further detail on the scope, span, and objectives of ISDNs.

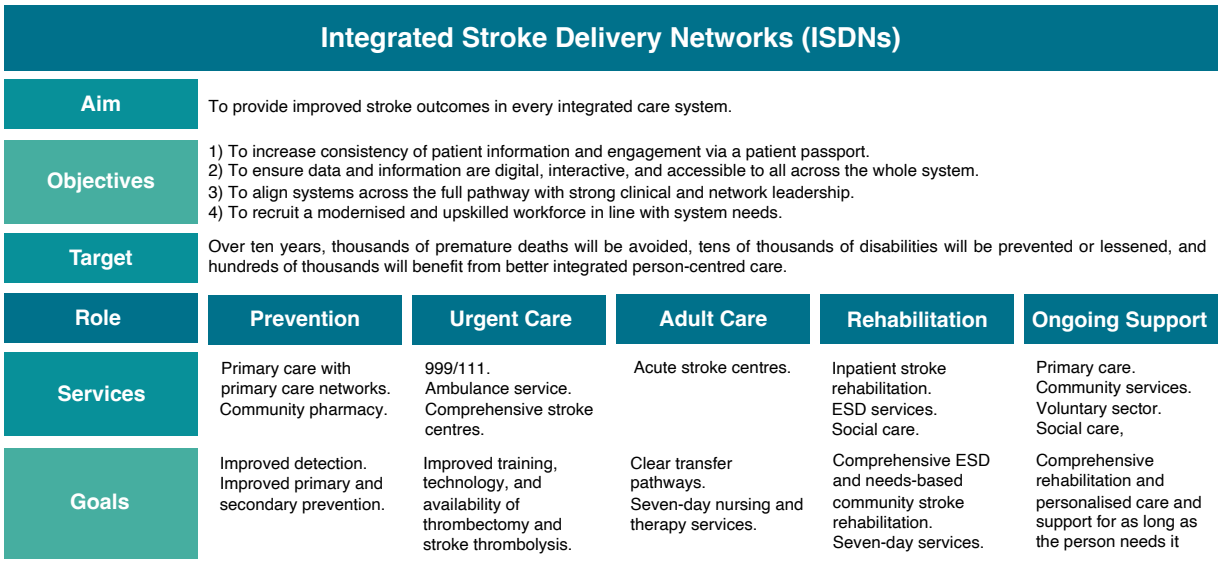


Figure 1.1. The responsibilities and breadth of ISDNs. Adapted from Hargroves et al. (2022).

1.3.1. Cognitive care in the UK stroke care pathway

This nationwide service improvement programme provides an ideal context to consider post-stroke cognitive care provision and ways to enhance the care being provided. The following sections of this thesis will outline current recommendations on 'best practice' post-stroke cognitive care within the UK, drawing on the National Clinical Guideline for Stroke (Royal College of Physicians, 2016). Recommendations from the 2016 guideline are cited (Royal College of Physicians, 2016), despite the recent release of an updated guideline (Intercollegiate Stroke Working Party, 2023a), as the work presented in this thesis commenced before this update was provided. It is worth noting briefly that recommendations pertaining to post-stroke cognitive care remain largely unchanged, though some further detail is provided in places.

Organisation and service delivery for post-stroke cognitive care

The National Clinical Guideline for Stroke recommends that psychological care, including cognitive care, should be provided by stroke services in both acute and community settings – in other words, care should be provided across the stroke care pathway (Royal College of Physicians, 2016). Though reports published by the National Institute for Health and Care Excellence (NICE: NICE, 2011) and the National Health Service (NHS) Stroke Improvement Programme (NHS Improvement, 2011) advocate for psychological care to be provided using a stepped care model (i.e., the least intensive form of intervention is delivered first, with escalation to more intensive treatments where necessary), the National Clinical Guideline for Stroke argued that definitions provided in these reports are in fact more in line with a matched care model, where the level of care provided depends on the initial awareness of need. Similarly advocating for a matched care model of psychological support, the guideline recommended that all members of the multidisciplinary team (MDT) should have sufficient knowledge and skills to support those with mild impairments (Level 1), whilst those with moderate impairments (Level 2) should be supported by MDT members with more specialist skills and competencies. Access to specialist clinical psychology and neuropsychology support should be available but reserved for those with the most severe and/or persistent needs, or impairments that are significantly impacting on safety and/or decision-making (Level 3).

In 2011, the NHS laid out detailed recommendations for providing Level 1, Level 2, and Level 3 psychological support after stroke (NHS Improvement, 2011). They recommended that Level 1 care for psychological changes should involve routine

assessment of cognition and mood, active listening, normalising and not minimising the experience of psychological changes, providing advice and information to support adjustment, goal setting, and problem solving, and signposting for informal support and further professional assistance where required. Level 2 should offer the above, as well as brief psychological interventions, and there should be clear pathways in place for referring to clinical psychology specialists (Level 3) where this is required. Finally, Level 3 support should include all the above, in addition to structured suicide risk assessments and development of personalised prevention plans, six-week and six-month reviews to monitor progression of psychological changes, and consideration of psychoactive medication. In terms of psychological care delivery, recommendations are that all MDT members should be competent in delivering Level 1 psychological screening and support, whereas MDT members with "additional competence in psychological care" (NHS Improvement, 2011, p.14) should provide Level 2 support and Level 3 support should be provided by specialist clinical psychologists and neuropsychologists.

Early post-stroke cognitive screening

According to clinical guidelines, a full medical assessment should be performed as soon as possible after stroke and this should include an assessment of cognition (attention, memory, spatial awareness, apraxia, perception) (NICE, 2013; Royal College of Physicians, 2016). Routine cognitive screening should be undertaken using standardised measures, with additional more in-depth cognitive assessment recommended for stroke survivors returning to cognitively demanding activities, such as driving or professional employment (Royal College of Physicians, 2016).

Audit data supports excellent adherence to these recommendations. The Sentinel Stroke National Audit Programme (SSNAP) is a major UK healthcare quality improvement initiative that requires stroke services to record both the care provided to individual stroke patients (clinical audit) and the structure of their stroke service (organisational audit) (NHS England, 2023b). National audit data covering the period April 2019 to March 2020 – the most recent data reporting period when the research presented in this thesis begun – indicated that 79% of stroke patients received a cognitive screen by discharge from acute services (Intercollegiate Stroke Working Party, 2020), with a further 16% considered too unwell to complete a screen. Only 3% of patients did not receive a cognitive screen due to organisational reasons, with 0.6% of patients refusing a cognitive screen and a further 0.9% of patients not receiving one for unknown reasons.

Nevertheless, selecting the appropriate cognitive screening/assessment tool is a substantial challenge, as there are a large number of validated measures available and no widely agreed 'gold standard' (Quinn et al., 2018). Furthermore, while the National Clinical Guideline for Stroke provides examples of appropriate cognitive screening tools – like the Montreal Cognitive Assessment (MoCA: Nasreddine et al., 2005) and the Oxford Cognitive Screen (OCS: Demeyere et al., 2015) – it does not recommend using one tool over another. As such, individual clinicians and services are often left to select their own cognitive screening approaches, despite there being a complex and hard to navigate literature surrounding their relative merits and limitations. In practice, tools may be selected not only on the basis of their psychometric properties, but also on the basis of practical and temporal constraints

(i.e., administrable at bedside without demanding extensive clinical time) and individual familiarity with the tool (Ablewhite et al., 2019; Quinn et al., 2018). Nevertheless, Quinn et al. (2018) have argued that cognitive screening tools should only be used in acute settings when they meet all of the following criteria: (1) Feasible for use in acute setting, (2) Acceptable test properties, and (3) Coverage of core cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, social cognition).

In practice, the Mini-Mental State Examination (MMSE: Folstein et al., 1975) and MoCA (Nasreddine et al., 2005) have long since been used for early-stage post-stroke cognitive screening (Mancuso et al., 2018). Both tools are quick to administer and, although they were both initially developed as dementia screens, there is some evidence supporting their validity for use with stroke populations (Cumming et al., 2013). However, the MMSE has been shown to lack sensitivity to stroke-specific cognitive impairments (Blackburn et al., 2013; Pendlebury et al., 2012) and the MoCA is similarly limited by its emphasis on memory, attention, and executive function skills. Relatedly, results on both tools may be confounded by frequently co-occurring problems after stroke. For example, the MoCA and MMSE require substantial verbal ability, meaning that stroke survivors with language impairments may fail memory tasks and then be labelled inaccurately as having a memory impairment. Similarly, stroke survivors may fail memory or executive function tasks due to visuospatial attention impairments, limiting their ability to attend to one side of the page. This problem is compounded by the fact that both tests provide a single total score, which

is often binarised as ‘pass or fail’ based on an impairment cut-off, making it difficult to gauge specifically which cognitive domains are impaired or ‘spared’ after stroke.

Recognising the lack of openly available cognitive screening tools that are sensitive to stroke-specific cognitive impairments and able to delineate impairments in separate cognitive domains, Demeyere et al. (2015) developed and validated the OCS, which meets all three quality criteria outlined by Quinn et al. (2018). In contrast to the single total score offered by the MMSE and MoCA, the OCS offers domain-specific results reflecting attention, executive function, language, memory, number processing and praxis. Furthermore, the OCS can be administered at bedside in 15-20 minutes, and it is inclusive for patients with and unconfounded by language impairments and visuospatial neglect. Results from two studies showed that this inclusive design resulted in better completion rates of the OCS, compared to both the MMSE and MoCA (Demeyere et al., 2016; Mancuso et al., 2018), and there is evidence to support its increased sensitivity and specificity to post-stroke cognitive impairments versus the MoCA (Demeyere et al., 2016). Even though clinical guidelines do not endorse the OCS over and above other tools for early post-stroke cognitive screening, given the lack of high-quality studies comparing different screening strategies and their impact on patient outcomes (Quinn et al., 2021), the OCS has been gaining popularity over recent years for early post-stroke cognitive screening. Currently, there are over 2500 licensed users of the OCS, compared to just over 200 in 2015 when the OCS was first made openly available.

Later stage post-stroke cognitive monitoring

The National Stroke Strategy from the UK Department of Health (Department of Health, 2007), echoing other national and international policies (Duncan et al., 2005; Lindsay et al., 2010; National Stroke Foundation, 2010), recommends that stroke patients receive a review of their health and social care needs at six-months, twelve-months, and then annually after stroke. These reviews are supposed to flag any health and social care needs that were not originally identified or emerged later after stroke and to ensure access to further specialist review, advice, support, and rehabilitation is provided when there is a clinical need (Rothwell et al., 2013).

However, access to clinical stroke reviews falls below recommended standards in clinical practice, according to clinical audit data. Indeed, SSNAP data covering the period April 2019 to March 2020 indicated that only 30% of eligible stroke patients received the recommended six-month review (Intercollegiate Stroke Working Party, 2020). Furthermore, conduct of clinical stroke reviews has historically been heterogeneous in practice and cognition has not always been assessed. Standardised tools – like the Greater Manchester Stroke Assessment Tool (GM-SAT: Rothwell et al., 2013) – have been developed to improve the quality and consistency of six-month stroke reviews. The GM-SAT covers a wide range of potential unmet needs, including physical, health, emotional, and social needs, and it allows clinicians to explore these topics through a person-centred and tailored dialogue. However, while the GM-SAT is undoubtedly a valuable addition to post-stroke clinical reviews, it addresses cognition only at a surface level, advising clinicians to ask “Do you have any new problems remembering things or concentrating?” but offering no further guidance on how to

progress in cases where patients respond in the affirmative. Behavioural screening tools for cognition are also rarely incorporated into clinical stroke reviews, even though many patients lack awareness about the precise nature and severity of post-stroke cognitive problems and there is evidence that reduced awareness of cognitive impairments is associated with poorer post-stroke outcomes (Boosman et al., 2014).

The lack of attention paid to cognition within post-stroke clinical reviews is concerning, given that managing cognitive changes is one of the most frequently reported unmet needs in the months and years after stroke (Chen et al., 2019; Guo et al., 2021; Lin et al., 2021). A recent systematic review found that 62% of stroke survivors reported unmet needs six-months after stroke, and this rose to 81% of patients two-years after stroke (Lin et al., 2021), echoing the results of an earlier systematic review that found 74% of stroke survivors reported at least one long-term unmet need on average across the included studies, which covered a range of chronic (>six-month post-stroke) timepoints (Chen et al., 2019). Whilst these unmet needs spanned a variety of areas – including informational support, physical functioning, and social activity/participation – Lin et al. (2021) found that managing cognition was the most frequent unmet need, reported by 42% patients in studies that used the post-stroke checklist. The second most commonly reported unmet need was managing mood (40% patients), whereas unmet needs related to mobility – the third most common need – were reported by 39% patients. Whilst these studies were not specific to the UK stroke population, the systematic review by Chen et al. (2019) included two UK-based studies that investigated unmet cognition needs. In these studies, unmet needs surrounding

memory and attention were reported by 26-59% of patients six-months post-stroke (McKevitt et al., 2011; Rothwell et al., 2013).

Recovery and rehabilitation of cognitive problems

If clinicians identify during clinical reviews that cognitive impairments are persisting in the months and years after stroke, patients should be offered more comprehensive interventions to support them in developing compensatory behaviours and adaptive skills (e.g., using memory aids), according to national clinical guidelines (Royal College of Physicians, 2016). Those with particularly severe or persistent cognitive problems should receive specialist assessment and treatment from clinical psychology experts. Here too, intervention should focus on management rather than 'cure', given the lack of high-quality evidence supporting pharmacological (see Mijajlović et al., 2017 for an overview) and non-pharmacological interventions to restore or ameliorate cognitive impairment after stroke (Cochrane reviews: das Nair & Lincoln, 2007, Chung et al., 2013, Bowen et al., 2013).

However, again, evidence indicates that provision of long-term psychological support after stroke is currently falling below ideal standards. A Care Quality Commission review found that post-stroke psychological support was provided in less than 40% of geographical regions in the UK (Care Quality Commission, 2011). While this review was conducted over a decade ago, recent SSNAP data showed that follow-up psychological support at six-months post-stroke was still being received by only 66% of those who needed it in the period April 2019 to March 2020 (Intercollegiate Stroke Working Party, 2020). Reasons for this are likely to be complex and multifaceted, with

poor follow-up rates potentially reflecting under provision of services, poor integration of services, and understaffing of services. As a 'first step' to address this, the British Psychological Society Division of Neuropsychology recently released a briefing paper that outlined workforce recommendations for community stroke services to ensure adequate neuropsychology support can be offered to stroke patients over the months and years after stroke (Division of Neuropsychology, 2023). The report illustrated the health economic impact of their recommended workforce enhancements, with substantial cost savings to the NHS forecasted – for example, through improved health-related outcomes, community functioning, quality of life.

1.4. Enhancing the UK stroke cognitive care pathway

While the NHS Long Term Plan (NHS England, 2019) highlighted improving stroke care as an important national priority, the above evidence indicates the importance of paying particular attention to post-stroke *cognitive* care, as current practice is falling below recommended standards in many areas. Encouragingly, the importance of investigating post-stroke cognitive changes was recently recognised in a research priority setting exercise conducted by the James Lind Alliance (JLA), where 'cognition' was ranked as the second most important rehabilitation research priority after 'mental and emotional problems' (Hill et al., 2022; James Lind Alliance, 2022). In particular, the report urged investigation of the following key questions as a matter of urgency:

> *What is the best way to assess for, understand the impacts of and track progression in all areas of cognition – including using standardised measures - across the stroke pathway; what and how can interventions and services*

involving multidisciplinary teams and families be made accessible, and how can information on these problems be provided? (James Lind Alliance, 2022)

1.4.1. Building evidence

The above questions are indeed ones that should be addressed as a matter of urgency but, even once we understand how best to assess, understand the impact, and track progression of cognitive changes, 'persuading' healthcare systems like the NHS to channel limited clinical resources towards post-stroke cognitive care will require high-quality evidence. There is without doubt evidence of clinical need, but the crucial 'next steps' will be to demonstrate that improved cognitive care is both clinically and economically beneficial. Just as high-quality randomised controlled trials (RCTs) and cluster randomised controlled trials (CRTs) have demonstrated the effectiveness of – for example – specialist stroke inpatient units (Stroke Unit Trialists' Collaboration, 1997) and Early Supported Discharge (ESD) stroke services (Bautz-Holter et al., 2002), resulting in (to all intents and purposes) nationwide implementation of these care delivery models, RCTs and CRTs are likely to provide the most powerful and persuasive evidence to support improving cognitive care as a clinically reasonable use of limited NHS resources. Still, high-quality evaluative trials are only possible once there is a clearly delineated intervention to be evaluated against a carefully considered control condition and, at present, clarity is lacking with regards to the design of a Level 1 post-stroke cognitive care intervention.

1.5. Thesis aims and objectives

Recognising this lack of clarity, the overarching aim of the research presented in this thesis was to develop an intervention providing Level 1 post-stroke cognitive care, with a vision that this intervention may eventually be implementable and scalable within the existing UK stroke care pathway should it prove to be clinically effective. While the research presented in this thesis was positioned firmly within the development stage of the research process, it is rare that complex intervention development begins with an entirely blank slate, as clinical experience and pre-existing evidence often contribute to an inkling about what will work and why (Skivington et al., 2021). Although rarely discussed in the context of intervention development, designers have referred to the 'fuzzy front end' of the design process and how a 'fuzzy' initial hunch is gradually clarified and refined through an iterative process of reflection, consultation and reconsideration (Sanders & Stappers, 2008). The work presented in this thesis indeed began at the 'fuzzy front end' of the design process (Sanders & Stappers, 2008) with the development of an initial basic problem – intervention – outcome model and intervention skeleton, both of which were grounded in clinical guidelines, research team expertise, and study collaborator input. As suggested by its name, the problem – intervention – outcome model shown in Figure 1.2 was developed as a simple diagrammatic summary of the problem to be addressed, the intervention envisioned, and the target outcome (i.e., problem-intervention-outcome model). The intervention skeleton provided a description of the following pre-set core intervention components and was outlined within the National Institute for Health and Care Research (NIHR) fellowship programme by which the work was funded (Demeyere, 2021):

- **Core Intervention Feature 1:** Cognitive reviews involving cognitive assessments to monitor post-stroke cognition over the medium- to long-term.
- **Core Intervention Feature 2:** Cognition trajectory guide to facilitate discussions about future cognitive trajectories and likely cognitive prognoses.
- **Core Intervention Feature 3:** Psychoeducation about cognition to support stroke survivors in adjusting to and managing cognitive impairments in daily life.

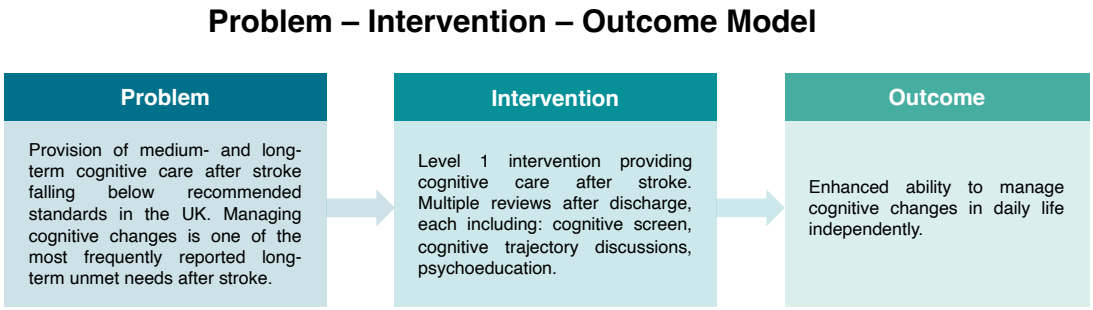


Figure 1.2. Basic problem-intervention-outcome model developed at the outset of the research programme. This was held in mind throughout the research programme and provided a grounding focus.

While the core intervention features outlined within the intervention skeleton constrained the intervention development process to some extent, they ultimately ensured the final intervention would be aligned with clinical 'best practice' recommendations and they provided a valuable framework upon which to hang key research objectives. Research objectives addressed within each thesis chapter are presented in Table 1.1.

Objective		Method
1	To establish expert healthcare professional and researcher consensus on the complex intervention features.	Modified Delphi survey
2	To explore stroke survivor and family member experiences of cognitive screening (Core Intervention Feature 1). To explore stroke survivor and family member perspectives on the advantages and disadvantages of cognitive trajectory discussions (Core Intervention Feature 2).	Semi-structured interviews
3	To map and identify gaps within the current literature describing stroke survivor and family member psychoeducation needs about cognition (Core Intervention Feature 3).	Scoping review
4	To develop a novel psychoeducation resource about cognition (Core Intervention Feature 3) to be used within the complex intervention.	Co-production work
5	To gauge the feasibility and acceptability of a single cognitive review according to stroke survivors and healthcare professionals. To develop the protocol for a future scale study to assess the feasibility of running a full-scale evaluative trial of the final intervention.	Feasibility testing

Table 1.1. Research objectives addressed within the thesis.

1.5.2. Iterative intervention development

The research was conducted using an iterative staged approach, in line with the Medical Research Council (MRC) framework for complex intervention research (see Chapter 2 for further detail). As such, several key objectives were identified before the work commenced, but others were informed by and developed from preliminary findings. Figure 1.3 illustrates the thesis structure, documenting the specific research projects conducted and their primary aims. Crucially, although the figure implies that information and insights flowed unidirectionally from one chapter to the next, knowledge transfer was in fact far more fluid and unconstrained than this as research

projects were temporally overlapping and mutually informative. In this sense, I held in mind findings from each research project as they evolved and progressed, such that the projects were all constantly 'in conversation' with one another. Ultimately, the 'final' intervention presented in Chapter 7 resulted from a continual iterative process of critical reflection and revision of ideas and approaches.

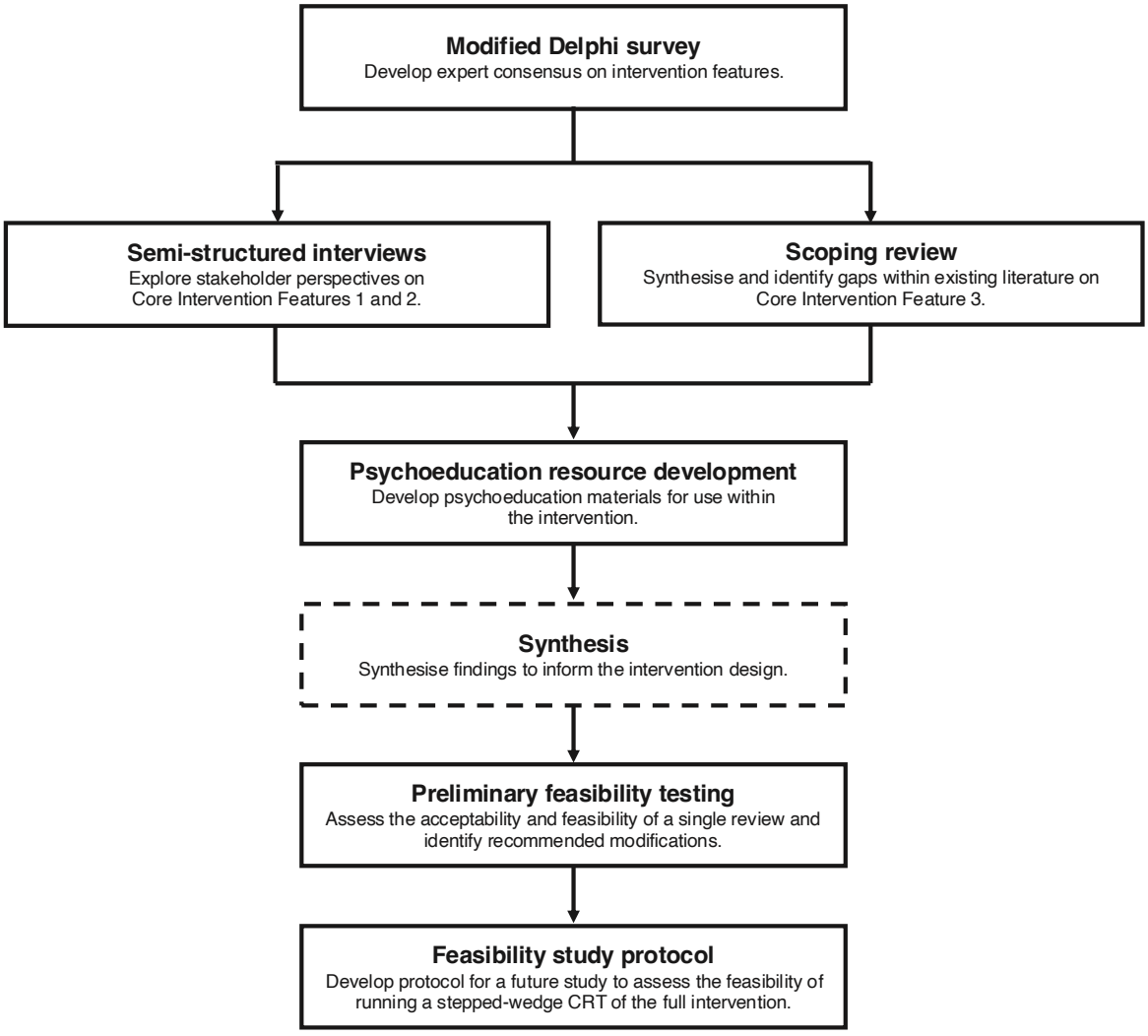


Figure 1.3. Flow diagram showing the overall thesis structure. Each box represents a single thesis chapter. Unbroken lines are used to denote empirical thesis chapters. Dashed lines are used to denote the synthesis chapter that bridges the development and feasibility testing stages of research. Arrows suggest how results informed subsequent chapters, but information flow was in reality iterative and multidirectional.

1.6. Thesis chapter summaries

Chapter 3 presents a modified Delphi survey, the primary aim of which was to establish consensus among UK-based expert healthcare professionals and researchers on the cognitive care intervention features. Broadly, the survey sought to address system-level questions, like 'When should cognitive reviews be offered within the stroke care pathway?', 'Which stroke survivors should be offered cognitive reviews?', and 'How should healthcare professionals be supported to deliver cognitive reviews?' Another key objective was to 'zoom in' on the cognitive reviews themselves in order to establish what these reviews should include, in terms of cognitive assessments, self-report measures, and assessment of other psychological changes (e.g., low mood, anxiety).

Chapter 4 presents two thematic analyses of semi-structured interviews conducted to explore stroke survivor and family member perspectives on two of the core intervention features. Specifically, Part A considers stroke survivors' experiences of cognitive screening, with the hope that previous experiences may shed light on ways to improve the cognitive screening process within the cognitive reviews included within the intervention (Core Intervention Feature 1). Part B then considers stroke survivor and family member perspectives on cognitive trajectory discussions (Core Intervention Feature 2).

Chapter 5 presents a scoping review that aimed to map and identify gaps in existing literature describing stroke survivor and family member psychoeducation needs regarding cognition (Core Intervention Feature 3). A secondary objective was to

identify psychoeducation needs reported in previous studies and factors potentially influencing variation in these needs, in order to inform a psychoeducation resource to be used within the cognitive care intervention. Here, the goal was to gain translational insight that could be used to develop a prototype psychoeducation resource to be evaluated and revised in the subsequent research project.

Chapter 6 presents co-production work conducted to evaluate and revise iteratively the aforementioned psychoeducation resource providing information about post-stroke cognition. Stroke survivors, family members, and healthcare professionals were involved in the co-production work by providing quantitative and qualitative data on iterations of the prototype. Key objectives for each prototype iteration were: (a) To identify positive feedback, negative feedback, and recommended modifications (predominantly informed by qualitative data), and (b) To gauge the success with which the prototypes met the intervention requirements based on findings presented in previous thesis chapters.

Chapter 7 bridges the gap between the development and feasibility testing stages of research. As a synthesis chapter, it draws together findings from earlier chapters to inform the design of the 'final' intervention. Note that it is considered 'final' in the sense that no further development work will be conducted, but further revisions and changes will be made to the intervention design as the feasibility testing, evaluation, and implementation stages of the research progress. This chapter also includes the programme theory specifying and an accompanying logic model.

Chapter 8 documents the two-stage approach currently being used to assess the feasibility and acceptability of the 'final' intervention (Part A) and running a future stepped-wedge cluster randomised trial (SWCRT) to establish the clinical effectiveness of the intervention (Part B). At the point of thesis submission, an iterative process to establish feasibility of the intervention is ongoing, so preliminary results presented in Part A should be interpreted with caution. The feasibility SWCRT is anticipated to run between December 2024 – December 2026, so Part B presents the protocol for this multisite study.

1.7. Chapter summary

This chapter introduced the empirical and conceptual background to the thesis and thus explained the rationale for developing an intervention providing Level 1 cognitive care after stroke. The overarching thesis structure and content were outlined, including the specific aims of each research project. The next chapter provides further detail on the methodological approach.

Chapter 2 Methodological background

2.1. Chapter overview

Having outlined the conceptual and empirical background to the research presented in this thesis and introduced the rationale for developing an intervention providing Level 1 post-stroke cognitive care, this chapter provides the methodological background to the research. The importance of developing complex interventions to address healthcare needs is explained, before the interdisciplinary approach taken here is justified. Then, key research frameworks that informed the intervention development process are described. Recognising the predominantly qualitative nature of the research presented in this thesis, I also provide a brief summary of thematic analysis methods and justify the approach taken here.

2.2. Complex interventions

Complex interventions are often appropriate for addressing healthcare needs, as they take a multifaceted and often adaptable approach that recognises the intricacy, heterogeneity, and contextuality of these needs (Craig et al., 2008; Moore et al., 2015; Skivington et al., 2021). Whilst there is no sharp distinction between interventions that are simple versus complex, the following factors have been acknowledged to affect intervention complexity (Campbell et al., 2000; Craig et al., 2008; Moore et al., 2015; Skivington et al., 2021).

First, complexity is increased as the number of groups and/or organisational levels targeted by the intervention grows, as this creates an increased need for coordination, customisation, and communication across different stakeholders and settings. Additionally, the number and difficulty of behaviours required by those delivering and/or receiving the intervention affects complexity by increasing the demands placed on skills, training, adherence, and coordination. Where there are more interacting components within the intervention, its complexity further increases through the need for integration and synchronisation across these components. Including more components also introduces the possibility for complex synergistic interactions between them. When interventions are designed to be delivered more flexibly, adaptable protocols and personalised approaches that meet diverse and evolving needs may also be required, further increasing complexity. Finally, how the intervention aligns with, adapts to, or interacts with the social, cultural, economic, and political contexts in which it is implemented fundamentally impacts complexity.

While complex interventions offer the advantage that healthcare needs can be addressed in a tailored and holistic way, complexity also introduces challenges. There is a risk of potential overcomplication in the design process if unnecessary intervention components or layers are introduced without careful consideration and justification (Rogers, 2008). Furthermore, researchers must strike a balance between personalisation and standardisation. While it is an important advantage of complex interventions that they are typically designed to be responsive to diverse needs and contextual factors that may evolve over time, insufficient standardisation may lead to

challenges evaluating clinical effectiveness and scaling the intervention more widely (Datta & Petticrew, 2013).

To ensure the potential advantages of complex interventions are realised and disadvantages mitigated, researchers must engage in a careful process of investigation, reflection, justification, and revision throughout the complex intervention 'lifecycle'. However, just as the design of a complex intervention is multifaceted, so too is the intervention lifecycle, with the MRC framework for complex intervention research outlining the following core stages: intervention development, feasibility testing, evaluation, and implementation (Craig et al., 2008; Skivington et al., 2021). In the development stage, intervention designers strive to identify and delineate the core components of the intervention and to understand the mechanisms by which it might contribute to target outcomes. Feasibility testing then aims to determine the extent to which the intervention components are feasible and acceptable to administer in a more naturalistic setting, and the feasibility of running an RCT or CRT of the intervention may also be assessed. If and when an intervention is shown to be sufficiently feasible, researchers may progress to the evaluation stage, where the primary aim is to determine the clinical and – in some cases – cost effectiveness of the intervention. Finally, in the implementation stage, interventions that have been proven clinically and/or fiscally effective are rolled out, while monitoring and adjusting delivery to optimise intervention effectiveness and sustainability.

While these stages were originally implied to progress linearly from development to implementation (Campbell et al., 2000; Craig et al., 2008), more recent revisions of

the MRC framework have better accounted for the inherent 'messiness' of complex intervention research by proposing a more iterative and context-sensitive approach (Skivington et al., 2021). In this sense, though the stages are generally characterised by different priorities and research activities, they are inherently overlapping and mutually informative (Skivington et al., 2021). Researchers are therefore advised to hold in mind throughout the complex intervention lifecycle considerations central to each research stage, in order to ease transitions from one stage to the next and enhance the extent to which the intervention is ultimately feasible and effective.

The work presented in this thesis sits predominantly within the development stage of complex intervention research, as defined within the MRC framework for complex intervention research (Craig et al., 2008; Skivington et al., 2021), as the overarching aim was to develop a UK-based intervention providing Level 1 post-stroke cognitive care. Nevertheless, recognising the overlapping and mutually informative nature of each complex intervention research stage (Craig et al., 2008; Skivington et al., 2021), I made sure to hold in mind key considerations pertinent to feasibility testing, evaluation, and implementation throughout. Also worth noting is that the final empirical thesis chapter (Chapter 8) sits within the subsequent feasibility testing stage, thus demonstrating how the main body of development work presented in this thesis will contribute to an ongoing and extensive process of further complex intervention research, hopefully culminating in an evaluation of effectiveness and widescale implementation.

2.3. Interdisciplinarity

Addressing healthcare challenges requires not only a holistic intervention, but also a holistic and collaborative approach to the research itself, so that expertise and insights spanning multiple disciplines can be drawn together. Indeed, among myriad other factors, the efficacy of healthcare interventions often depends on psychological factors (e.g., motivation to seek out and adhere to interventions), contextual constraints (e.g., financial limitations of healthcare services and systems), and social considerations (e.g., taboos and prejudices as barriers to treatment seeking). By taking an interdisciplinary approach, researchers are able to interrogate and incorporate these and other diverse considerations to maximise the clinical and cost effectiveness of their interventions. Furthermore, interdisciplinarity enables researchers to combine methodological approaches that are rooted in separate disciplines but have the potential to offer complementary insight. For example, while qualitative methods originating in the social sciences may be ideal for gathering stakeholder views on the acceptability of an intervention, clinical effectiveness may be better evidenced using quantitative approaches rooted in evidence-based medicine (EBM), like RCTs.

UK research council agendas increasingly encourage interdisciplinarity and multidisciplinarity (Hopkins et al., 2021; NIHR, 2023; UK Research and Innovation, 2022, 2023a), recognising that researchers will need to collaborate and consider factors spanning a range of fields to solve many of the so-called ‘grand challenges’ facing society today (Pimentel et al., 2023). Nevertheless, collaborating meaningfully across disciplines and integrating approaches with their roots in different fields is undeniably challenging. Disciplines use varying terminology, favour different methods,

hold contrasting priorities, and are founded upon philosophical ideologies that sometimes conflict (Lach, 2014; Wear, 1999). Researchers who adopt an interdisciplinary approach face an uphill struggle as they navigate diverse literature where different meanings are ascribed to the same terms, and as they side-step traditional evidence hierarchies that see certain methods as 'less than' others (Mazzocchi, 2019). Remaining within a single discipline shields researchers to some extent from these contradictions, but intervention design is necessarily constrained and impact likely to be more limited (Pimentel et al., 2023).

2.4. Prioritising rigour and flexibility

The complex nature of healthcare needs (Sturmberg & Martin, 2013), the inherent 'messiness' of human variability (Ogden, 2016), and the situatedness of complex interventions within equally complex systems (Moore et al., 2019) necessitated a highly interdisciplinary approach to intervention development in the research presented in this thesis. Within this approach, I recognised the importance of committing to scientific rigour while also prioritising flexibility. Committing to scientific rigour meant selecting an established framework to use as a 'methodological scaffold' but conceptualising the framework as a guideline rather than a prescriptive manual allowed flexibility in the intervention development process.

The following sections will describe previously used complex intervention development approaches, with a predominant focus on the MRC framework (O'Cathain, Croot, Sworn, et al., 2019; Skivington et al., 2021), as this was ultimately selected as the methodological scaffold for the research presented in this thesis. The

rationale for selecting the MRC framework among alternatives will be provided, though gaps and ambiguity within the framework will also be acknowledged. Recognising particular ambiguity in how to integrate stakeholder perspectives (O'Cathain, Croot, Sworn, et al., 2019; Skivington et al., 2021), the rationale for integrating co-production principles in aspects of the research presented will then be introduced.

2.4.1. Rigour in complex intervention development

Complex intervention development has been described as a 'black box' as important development processes and decision-making at this stage of the research process have historically been underreported (Hoddinott, 2015). Nevertheless, there is increasing recognition that intervention developers need to pay close attention to and report transparently on this stage of research in order to reduce research waste and maximise intervention effectiveness (Hoddinott, 2015; O'Cathain, Croot, Sworn, et al., 2019). If this recommendation is not followed, researchers risk running expensive evaluations of interventions that may be fundamentally flawed, not acceptable to the target population(s), or unfeasible in relevant contexts (Hawe, 2015a; O'Cathain, Croot, Sworn, et al., 2019).

In an effort to promote scientific rigour and open the 'black box' of intervention development, a number of frameworks, guides, and methodologies have been produced. These are henceforth referred to collectively as 'approaches', in line with terminology used by O'Cathain, Croot, Sworn, et al. (2019) in a systematic methods review that fundamentally informed the methodological approach taken in the research presented in this thesis. Having searched five electronic bibliographic databases for

descriptions of intervention development approaches, O'Cathain, Croot, Sworn, et al. (2019) identified eleven approaches that were categorised into the following eight discrete taxonomies: partnership, target population-centred, theory and evidence-based, implementation-based, efficiency based, stepped or phased based, intervention-specific, and combination. Approaches in these categories are generally rooted in separate disciplines, have varying methodological priorities, and are characterised by diverse philosophical ideologies.

Ultimately, after considering the relative merits and limitations of each category, the decision was made to use a theory and evidence-based approach. As defined by O'Cathain, Croot, Sworn, et al. (2019), theory and evidence-based approaches to complex intervention development prioritise high-quality evidence and formal theory. Initially popularised within the field of evidence-based medicine (EBM), they typically endorse traditional evidence hierarchies that consider carefully controlled RCTS and systematic reviews of homogenous trials to be the most convincing evidence (Burns et al., 2011). Theory is recognised as valuable yet inextricably tied to evidence – theory derives from evidence and evidence helps to refine theory, with this cyclical relationship serving to crystallise and hone both our conceptual knowledge and theoretical understanding of phenomena.

There were several key factors that influenced the decision to use a theory and evidence-based approach in the research presented in this thesis. First, the EBM-type focus on systematically integrating high-quality evidence and evaluating clinical outcomes seemed well-suited to the context for which this intervention was being

developed. Specifically, the vision was that the intervention might one day be implementable within the existing UK stroke care pathway and, given the emphasis on high-quality evidence within NHS commissioning standards (Department of Health, 2013; NHS England, 2023a), I recognised the need for the intervention to be firmly grounded in empirical evidence. Additionally, the emphasis on theory spoke to the values I had 'grown up' with as a student in psychology, a field that recognises theory as a core explanatory factor for human behaviour and any resultant outcomes. Ultimately, to understand not only *whether* the intervention works but *how* it works, I realised theory would be indispensable. Finally, although priority is usually given to evidence and theory, approaches within this category increasingly allow space for stakeholder perspectives to shape the intervention and research processes, aligning with my fundamental belief that research and clinical services should be thoroughly person-centred and grounded in user needs.

2.4.2. Using the MRC framework

Within the overarching MRC framework for complex intervention research described above, specific guidance for developing a complex intervention is provided (Campbell et al., 2000; Craig et al., 2008; Skivington et al., 2021). This guidance is among the most widely used theory and evidence-based approaches to complex intervention development (O'Cathain, Croot, Sworn, et al., 2019), though other less commonly used approaches include intervention mapping (Eldredge et al., 2016) and the theoretical domains framework (French et al., 2012).

Initial iterations of the MRC framework provided relatively sparse guidance on developing interventions, essentially outlining the importance of "identifying existing evidence, identifying and developing theory, and modelling process and outcomes" (Craig et al., 2008, p.2) but offering little detail on *how* to achieve these proximal aims. Recognising this gap, Bleijenberg et al. (2018) drew together insight from a range of other intervention development approaches to enrich this stage of the framework. However, recognising that methodological priorities and philosophical ideologies characterising alternative intervention development approaches in fact conflicted with those of the overarching MRC framework, O'Cathain, Croot, Duncan, et al. (2019) conducted a consensus exercise to provide researchers using the MRC framework with expert guidance on actions to take during the development stage of research.

After undertaking a review of published intervention development approaches, interviewing developers (i.e., authors of articles or books detailing intervention development approaches) and wider stakeholders (e.g., journal editors, research funding panel directors), and conducting two consensus building Delphi surveys, O'Cathain, Croot, Duncan, et al. (2019) identified a set of "key actions for developers to consider" (p.2). Though it would be easy to overlook this wording, it in fact captures an essential underlying principle of the guidance – namely, that the development stage of research is inherently iterative, creative, dynamic, and evolving, so developers should *consider* undertaking certain actions but remain flexibly minded and open to change. Indeed, they implicitly advised intervention developers not to interpret the actions as a sequential list and instead emphasised that actions would often need to be undertaken in parallel, addressed in a dynamic way, revisited regularly, and

conceptualised as mutually informative. Table 2.1 summarises all eleven actions outlined by O'Cathain, Croot, Duncan, et al. (2019), a brief explanation as to how these actions were incorporated in the research presented in this thesis, and signposting to thesis sections that provide further detail.

Action	Factors	Considerations
Plan the development process	Identify the problem to be targeted.	UK long-term post-stroke cognitive care provision falling below recommended standards. Stroke survivors report managing cognitive changes as a long-term unmet need. Need for a pragmatic and scalable Level 1 cognitive care intervention. See Chapter 1 for further discussion.
	Obtain sufficient resources and funding for intervention development.	ESRC studentship; NIHR advanced fellowship.
	Identify one or more intervention development approach on which to draw.	MRC framework for complex intervention development used as a methodological scaffold and principles of co-production used to incorporate stakeholder input in aspects of the research (Chapter 3 and Chapter 6).
	Be open to applying approach(es) flexibly depending on the problem and context.	Openness to flexibility evidenced by, among other factors, conceptualisation of MRC guidance as a methodological scaffold rather than a prescriptive manual (see Section 2.4).
	Produce a protocol detailing activities to be undertaken.	Initial protocol developed but revised iteratively throughout research programme. Similarly, some research objectives set at the outset of research programme, but others developed in response to evolving information (see Section 1.5).
Involve stakeholders	Work closely with stakeholders throughout the intervention development process.	Stakeholders involved in all research projects presented in this thesis. Stakeholders included stroke survivors, family members, and UK-based healthcare professionals.

	Integrate patient and public involvement.	Patient and Public Involvement Group comprising 5 stroke survivors and 3 family members consulted throughout research programme. Advised on study methodologies, triangulated findings, and contributed to some extent to co-production activities (see Chapter 6).
	Identify the best ways to work with each type of stakeholder, acknowledging that different ways may be relevant for different stakeholders at different times.	A range of research methods used to incorporate stakeholder perspectives, including modified Delphi survey (Chapter 3), semi-structured interviews (Chapter 4), in-person and online co-production groups (Chapter 6).
Bring together a team and establish decision-making processes	Include individuals with relevant expertise in different areas.	Research team members and study collaborators had expertise in clinical health interventions, clinical health trials, co-design, qualitative research, stroke medicine, clinical psychology, clinical neuropsychology, primary and secondary stroke care, community stroke rehabilitation, and lived experience of stroke.
	Making final decisions about the content, format, and delivery of the final intervention may be challenging and may lie with only some members of the team.	Decision-making processes were collaborative within certain constraints (further discussion in Chapter 9).
Review published research evidence	Continually review published evidence to identify existing interventions and to understand the evidence base for each substantive component.	Initial review of literature at outset of research programme identified recent high-quality systematic reviews of interventions providing post-stroke psychological care (e.g., Hickey et al., 2019; Merriman et al., 2019) and Cochrane reviews on interventions for specific cognitive impairments (Bowen et al., 2013; Chung et al., 2013; das Nair & Lincoln, 2007). Overall, no high-quality evidence supporting the effectiveness of these interventions. Substantive components outlined in initial intervention skeleton based on further reviewing of literature and clinical guidelines. Literature regularly reviewed throughout research programme.
	Remain open to evidence that the intervention and/or components may not work as intended.	Research resulted in informal development of hypotheses about subgroups of stroke survivors for whom the intervention may not function optimally (further discussion in Chapter 9).

Draw on existing theories	Identify one of multiple theories to inform the intervention.	Multiple theories held in mind and used as loose guiding principles (see Section 2.4.2).
Articulate programme theory	Develop a programme theory and consider representing it or parts of it within a logic model.	Programme theory and logic model capturing basic conceptualisation of problem-intervention-outcome (Figure 1.2) developed early on and served as guiding framework (see Chapter 7).
	Refine the programme theory throughout the development process.	Initial programme theory and logic model formally revised after development work (Chapter 7).
Undertake primary data collection	Use a wide range of research methods.	A range of methods employed throughout research programme, including modified Delphi survey (Chapter 3), semi-structured interviews (Chapter 4), scoping review (Chapter 5), and co-production focus groups and one-to-one interviews (Chapter 6). Methods were selected based on specific objectives, alignment with research priorities and philosophical positioning, and suitability in the context of participant access considerations.
	Be open to using qualitative and quantitative methods depending on specific research objectives.	Qualitative methods used predominantly (Chapter 3, Chapter 4, Chapter 5, Chapter 6) with some quantitative survey data (Chapter 3, Chapter 6).
Understand context	Understand the context in which the intervention will be implemented.	Careful consideration of the current disparateness of stroke care services, geographical heterogeneity in service provision, yet ongoing efforts to improve service integration (see Chapter 1).
Pay attention to future implementation of the intervention in the real world	Hold in mind potential facilitators and barriers to future implementation.	Recognition of staffing and resource shortages within the NHS and stroke care services specifically, including shortage of psychology specialists, but recent calls for further psychology specialists to be integrated in stroke care pathway and improving stroke care highlighted as key NHS priority (Chapter 1). As discussed above, recognition of current segregation across stroke services but efforts to improve integration.

Design and refine the intervention	Design an early version of the intervention.	Initial intervention skeleton designed based on clinical guidelines, research team expertise, and study collaborator input (see Section 1.5).
	Be open to the fact that it will need to be refined and optimised iteratively, depending on its acceptability and feasibility.	Initial intervention skeleton elaborated, clarified, and revised based on four interrelated research activities (Chapter 3, Chapter 4, Chapter 5, Chapter 6), with further revision anticipated based on results of ongoing feasibility testing (Chapter 8).
End the development phase	There are no established criteria for ending the development stage, but the concepts of data saturation and information power may be useful to hold in mind.	The decision was made to progress to the feasibility testing stage of research after establishing expert consensus on the key intervention features (Chapter 3), exploring stakeholder perspectives on core intervention features (Chapter 4, Chapter 5), developing a psychoeducation resource to be used in the intervention (Chapter 6), and carefully synthesising findings to develop an intervention firmly grounded in evidence, theory, and stakeholder perspectives (Chapter 7), which the Patient and Public Involvement Group confirmed would be appropriate for addressing the identified need.

Table 2.1. MRC framework guidance on complex intervention development. The table lists all eleven actions recommended by O'Cathain, Croot, Duncan, et al. (2019). Listed factors to consider are non-exhaustive but correspond to those identified in their original article and incorporated in this thesis. The table is adapted from one provided in their original article and expanded with considerations pertinent to the research presented in this thesis specifically.

Integrating theory

The importance of theory for psychological interventions has long been recognised, as identifying both the empirical and theoretical bases of an intervention helps researchers understand the specific mechanisms by which the intervention inputs (i.e., components) lead to outcomes. Understanding these potential mechanisms enables researchers to design interventions with a higher likelihood of success and to maximise effectiveness of already successful interventions among different

populations and within diverse contexts (Moore & Evans, 2017; Rogers, 2008). Later on, in the evaluative stage of complex intervention research, theory offers a lens through which researchers can select appropriate outcome measures (Salkovskis, 2002) and interpret results (Michie & Prestwich, 2010), ultimately increasing the likelihood of gaining a meaningful understanding of intervention efficacy.

A systematic review of online interventions to promote health behaviour change found that comprehensive integration of theory within the intervention design process indeed seemed to enhance the overall effectiveness of the intervention (Webb et al., 2010). Although the interventions generally had a small impact on health outcomes, results of a meta-regression indicated that more comprehensive integration of theory generally resulted in larger effect sizes. Whilst another systematic review found little evidence that the use of theory improved effectiveness of health behaviour interventions, the authors suggested this may have been due to loose integration of one or multiple theories within the development process (Prestwich et al., 2014).

It has been argued that the tendency to apply theory only loosely is a direct result of the MRC framework providing insufficient guidance on how to identify and select relevant theory and incorporate it throughout the research programme (Michie et al., 2011, 2018; Michie & Prestwich, 2010). While an early iteration of the MRC framework stated that “best practice is to develop interventions systematically, using the best available evidence and appropriate theory” (Craig et al., 2008, p.2), specific guidance was lacking. Updated recommendations have stated that researchers should “Identify an existing theory or framework of theories to inform the intervention at the start of the

process" (O'Cathain, Croot, Duncan, et al., 2019, p.3), without suggesting how exactly candidate theories should be identified, weighed against one another, or evaluated for quality. Insecurity in selecting and evaluating theory at this early stage in complex intervention research may fundamentally compromise the theoretical fidelity of development work (Hardeman et al., 2005).

Recognising this potential gap in the MRC framework, Michie et al (2011) developed the Behaviour Change Wheel (BCW), a theoretical framework designed to be applicable to "every [behaviour change] intervention that has been or could be developed" (Michie et al., 2011, p.3). Their approach offers a systematic and comprehensive way to design behaviour change interventions and it has been used in tandem with the MRC framework within a number of previous complex intervention development programmes (e.g., Desse et al., 2022; Wray et al., 2021). Very broadly, the BCW focuses on understanding behaviour, identifying potential drivers of behaviour change, and selecting appropriate intervention strategies. First, the Capability, Opportunity, and Motivation Behaviour (COM-B) system helps researchers analyse the (proposed) key determinants of behaviour, which are characterised as: capability (psychological and physical capacity to engage in the behaviour), opportunity (external factors that prompt or make the behaviour possible), and motivation (psychological processes that energise and direct behaviour). The BCW is then used to link COM-B components to intervention functions, which are conceptualised as nine broad categories representing the types of strategies that can be used to bring about behaviour change. Specific behaviour change techniques are then selected from the Behaviour Change Techniques taxonomy, which provides a

supposedly comprehensive list of 93 separate techniques (e.g., goal setting, social support).

The broadness and flexibility of the BCW offers the potential to reduce the concerning levels of theory variability within the psychological and complex intervention literature – that is, the vast number of partially overlapping theories used to underpin complex intervention design (e.g., theory of planned behaviour, health belief model, self-regulation theory). However, the approach has also been subject to serious criticism (Moore & Evans, 2017; Ogden, 2016), as have other so called "off-the-shelf" theories (Moore & Evans, 2017, p.132). The below paragraphs focus on two criticisms that raise serious questions about the appropriateness of the BCW for the research presented in this thesis.

First, researchers have questioned whether it is realistic – or even desirable – to systematise all behaviour and psychological processes in a 'one size fits all' manner, as the BCW seems to encourage and facilitate. Citing empirical evidence predominantly from health psychology to illustrate what those working clinically know only too well, Ogden (2016) emphasised the inherent variability in patient populations and how behaviour can usually only be changed for some people some of the time. Systematising behaviour using theoretical frameworks like the BCW, she argued, fundamentally neglects this human variability and overlooks the very real gaps that exist between what people intend to do and what they actually do. In other words, the BCW falls down in its failure to differentiate psychological *motivation* to act from *action* itself.

Some researchers have further argued that the push towards incorporating theory into complex intervention development has led researchers to rely on overly simplistic behavioural approaches, like the BCW, that only address the individual level of the intervention (Moore et al., 2015; Moore & Evans, 2017). For example, the BCW encourages researchers to conduct a detailed analysis of the behaviour they seek to change by homing in on individual-level determinants, like knowledge, skills, beliefs, and incentives. Furthermore, using the COM-B system, the approach urges researchers to focus on individual-level capabilities, opportunities, and motivations, thus directing attention to psychological and physical factors, with little consideration of broader systemic factors.

In reality, complex healthcare interventions usually work at multiple levels, ranging from the individual patient to the broader healthcare system. Hawe (2015b) argued that incorporating theory only at the most proximal level (i.e., individual patient behaviour) has resulted in interventions that are "minimally disruptive" (p.265) to the problems they seek to address. Whilst complex system level theories may not always be as neatly packaged as behavioural theories, both Hawe (2015b) and Moore and Evans (2017) have argued that it is critical to look towards theories with power to explain how the intervention operates within its context (e.g., healthcare services and systems). To this end, they recommended reaching across disciplines to identify theories relevant to each intervention level, once again highlighting the importance of interdisciplinarity in complex intervention research.

In summary, while many researchers acknowledge its importance, there is little consensus in terms of how to integrate theory within complex intervention development approaches, like the MRC framework. Approaches like the BCW offer a convenient way to address the most proximal level of the intervention – that is, how the intervention achieves behaviour change for individual patients – but there are concerns about whether such systematisation is appropriate or desirable, given the inherent 'messiness' of human variability (Ogden, 2016). Furthermore, and despite their dominance in the complex intervention literature, behavioural theories neglect to consider the broader context within which the intervention operates, resulting in interventions that have been described as minimally disruptive (Hawe, 2015b). These concerns were fundamentally troubling in the context of the intervention being developed in this thesis, given that the vision was a systemic one of eventually implementing the intervention in an exceedingly complex healthcare system in order for it to be accessed by a highly diverse patient population with heterogeneous sociodemographic, clinical, and cognitive profiles.

Therefore, at the outset of the research presented in this this, I reflected that researchers may do best to acknowledge the diverse and conflicting opinions about theory integration and select an approach that aligns most closely with their own values and assumptions. I echo other researchers' calls for greater clarity in the MRC framework's guidance on integrating theory and I fully support endeavours towards increasing parsimony and reducing theory variability within the literature. However, I also firmly believed based on both my clinical and fundamental *human* experience that realising both individual level and systems level change is nowhere near as simple as

taxonomisation approaches like the BCW imply. Ultimately, therefore, I opted to hold in mind multiple theories pertinent to the intervention (e.g., Y-shaped process model: Gracey et al., 2009; self-discrepancy theory: Higgins, 1987; models of psychological growth: Ryff & Keyes, 1995; models of psychological development: Vygotsky, 1968; learning models: Chi & Wylie, 2014) and use them as loose guiding principles when considering potential intervention mechanisms and contextual relationships. While I ultimately acknowledge and agree with Michie and Prestwich (2010) that this somewhat unsystematic and 'light touch' approach may not be optimal, I considered it to be a pragmatic compromise that would allow the insights provided by multiple theories to inform the intervention without constraining the design process nor skewing it to consider only the individual patient-level.

Developing a programme theory

The importance of theory within the MRC framework is further reflected by the emphasis on developing and articulating a clear programme theory (O'Cathain, Croot, Duncan, et al., 2019; Skivington et al., 2021). Though variously defined in the literature, in this thesis, I have endorsed the definition that a programme theory is a uniting theory that describes how intervention inputs and activities contribute to a chain of intended or observed outcomes (Rogers, 2008; Rogers et al., 2000). Logic models are, in essence, a diagrammatic summary of the programme theory – or parts of it – that specifies how and under what circumstances the intervention is anticipated to work (Rogers, 2008). Programme theories and logic models provide an important opportunity to operationalise not only whether an intervention works as intended, but through what mechanisms and under what circumstances the inputs and activities

contribute to eventual outcomes. Such nuanced insight enables researchers to better tailor and adapt complex interventions to ensure they operate with maximal clinical and cost effectiveness (Mills et al., 2019; Rogers, 2008; Skivington et al., 2021).

Nevertheless, not all researchers have been convinced that it is feasible or desirable to operationalise a complex intervention in a uniting programme theory or logic model. In particular, it has been argued that this approach makes problematic assumptions about parsimony and predictability that may not hold true in the context of interventional complexity and the chaotic conditions of the real world (Stufflebeam, 2004). This issue of over-privileging parsimony and oversimplifying causality is potentially compounded by the fact that much of the guidance on developing logic models appears to be problematically informed by simplistic linear behaviour-determinant-intervention models (Fletcher et al., 2016). Such guidance has resulted in a wealth of logic models – so called Type 1 logic models (Mills et al., 2019) – that imply a single oversimplified causal pathway from input to outcome that generalises across users and contexts. According to Mills et al. (2019), these logic models have relatively limited utility for 'opening the black box' of complex interventions in terms of specifying their mechanisms of action and contextual interactions.

Recognising the limitations of Type 1 logic models, some researchers have gone much further to model complexity by attempting to capture in logic models how intervention efficacy hinges on the interplay between the evidence base, contextual receptiveness, and the provision of appropriate facilitation (Mills et al., 2019). Logic models that capture this level of complexity – so called Type 4 logic models – are invaluable in the

implementation stage of research, as defined in the MRC framework (Skivington et al., 2021), where it is arguably just as important to capture contextual and thus implementational complexity as it is to model interventional complexity. Still, Rogers (2008) argued that the art of developing a maximally useful logic model is in "knowing when to simplify and when, and how, to complicate" (p.30) and, while it is usually invaluable to capture contextual complexity in the implementation stage of research, Mills et al. (2019) have in fact argued that Type 4 logic models may have more limited utility during intervention development, feasibility, and evaluation stages.

Indeed, offering a balanced perspective on all four types of logic model identified from their scoping review of existing literature, Mills et al. (2019) noted that – despite their limitations – Type 1 logic models may in fact be highly appropriate and beneficial in the early planning stages of complex intervention research, as they enable researchers to operationalise the basic problem, solution, and outcome, without getting lost in the 'messiness' stemming from the interventions' contextual situatedness. As such, the research presented in this thesis began with the development of such a Type 1 logic model (Figure 1.2) – essentially a problem-intervention-outcome model – that operated as a grounding focus for the research but with a view that it would be revised and expanded regularly as the research progressed. Indeed, Type 2 models may be better able to inform feasibility testing and evaluation stages of research and to elucidate reasons why an intervention may be more or less feasible/effective among certain populations and under certain circumstances, as they capture relevant contextual factors potentially contributing to proximal and target outcomes, without elaborating on interactional aspects of the

intervention and contextual factors that may overcomplicate feasibility and evaluation research. Ultimately, although the linearity of Type 2 models limits their ability to fully capture how individual- and system-level outcomes emerge from interactions between the intervention and its context, their interpretability and testability are far greater than Type 4 models (Mills et al., 2019). As such, the initial Type 1 logic was revisited in light of findings from the development work presented in this thesis, in order to inform the development of a Type 2 logic model (Chapter 7).

Integrating stakeholder perspectives

Over the last decades, the UK healthcare system has been characterised by a shift away from the traditional provider-centred model of care (Stewart, 2001) towards a model that places the needs, preferences, and priorities of patients firmly at the centre of decision-making and care delivery (Department of Health, 2013; NHS England, 2019). In this patient-centred – or person-centred – model of care, the conceptualisation of 'patient as consumer' is exchanged for one of 'patient as partner', affording patients greater autonomy and involvedness in their own healthcare. Crucially, this shift towards person-centredness by no means amounts to a rejection of evidence-based medicine, rather person-centredness happily exists within an evidence-based framework of healthcare commissioning (Department of Health, 2013).

Just as person-centredness has become an increasingly crucial aspect of healthcare delivery within the UK, so too have user-centred approaches to complex intervention development grown in popularity (O'Cathain, Croot, Sworn, et al., 2019). Indeed, in

their taxonomy of intervention development approaches, O'Cathain, Croot, Sworn, et al. (2019) identified two categories of approaches where intervention users have extensive input in the development process, rather than being positioned purely as consumers. These were partnership approaches – like co-creation, co-design, and co-production (Bessant & Maher, 2009; Spencer et al., 2013; Voorberg et al., 2015), user-driven design (Kushniruk & Nøhr, 2016), and experience-based co-design (Locock et al., 2014; Robert, 2013) - and target population based approaches – like the person-based approach (Yardley et al., 2015), user-centred design (Erwin, 2013; Erwin & Krishnan, 2016a, 2016b), and human-centred design (Norman, 2013).

Furthermore, and as mentioned above, even approaches like the MRC framework that have traditionally prioritised high-quality empirical evidence and theoretical understanding have in recent years come to acknowledge the importance of incorporating stakeholder perspectives (O'Cathain, Croot, Duncan, et al., 2019; Skivington et al., 2021). However, MRC guidance affords flexibility in the way in which users – or stakeholders – are involved in the intervention development process (O'Cathain, Croot, Duncan, et al., 2019; Skivington et al., 2021), recommending simply that researchers should "Work closely with relevant stakeholders throughout the development process" (O'Cathain, Croot, Duncan, et al., 2019, p.3) and "Identify the best ways of working with each type of stakeholder, from consultation through to coproduction, acknowledging that different ways may be relevant for different stakeholders at different times." (O'Cathain, Croot, Duncan, et al., 2019, p.3). Ultimately, as my goal was to achieve a balance between both flexibility and rigour in the research presented in this thesis, there was a need to more clearly articulate how

stakeholders would be involved in the research. To this end, the relative advantages and limitations of specific partnership and target population-based approaches were carefully weighed, and I considered how each of them might enhance versus limit the cognitive care intervention development process specifically. Key considerations are summarised in Table 2.2, with the following sections providing further detail on and rationale for using co-production (as defined by Spencer et al., 2013) in several parts of this thesis (Chapter 3 and Chapter 6) and individual semi-structured interviews elsewhere (Chapter 4 and Chapter 8).

Category	Approach	Advantages	Disadvantages
Partnership	Co-creation, co-production, co-design	Active involvement of end users in various stages of development (depending on specific framework used) resulting in interventions with high user satisfaction; group-based decision-making enhances generalisability and sparks creative and collaborative problem-solving.	Potential barriers to stroke survivors and healthcare professionals accessing group-based research activities (e.g., physical impairments limiting ability to travel, geographical heterogeneity of healthcare professionals, digital poverty and digital illiteracy). Focus on developing a solution may limit extent to which lived experience is shared. Additional potential barriers to disclosing around sensitive topics, like lived experience of cognitive changes and receiving cognitive care, in group settings.
	User-driven	Participation of users goes beyond co-creation, co-production, and co-design as users lead the creative thinking process and designers are positioned as facilitators; reversing power dynamic may enhance user autonomy and empowerment, with a likely positive impact on openness and engagement.	More challenging to integrate with MRC framework as users may not have extensive knowledge of existing evidence, theory, and subsequent stages of intervention research, potentially leading to a highly user-centred intervention that is in conflict with existing evidence and theory, and with substantial evaluative and implementational challenges.

	Experience-based co-design	In depth patient narrative sparks ideas for action and improvement, with 'first hand' accounts generating priorities and solutions that service providers may not have otherwise generated.	Heterogeneity of post-stoke cognitive care services within the UK and post-stroke cognitive profiles rendering it unlikely that one (or a small number of) narratives will adequately capture the diversity of experiences; risk of developing an intervention that addresses needs of a sub-group but with only limited generalisability.
Target population based	Person-based approach	Focus on individual users rather than user groups facilitates a more nuanced understanding of individual experiences and may enhance ability to adjust research process to meet accessibility needs.	Fragmented insight and conflicting perspectives may be difficult to integrate in overarching guiding principles; emphasis on individual perspectives may result in neglect of broader systemic considerations.
	User-centred design	Focus on usability and functionality results in interventions that are easy, efficient, and satisfying for users.	Users are generally involved in the end-stages of design (e.g., testing and refining prototypes), which may limit their ability to influence foundational design decisions, meaning there may be a substantial mismatch between prototype and user needs.
	Human-centred design	Holistic approach focused on human experience moves beyond issues of usability and functionality to address broader psychological, social, and contextual considerations.	Often results in highly customised solutions that may be challenging to implement widely (i.e., across stroke care pathway).

Table 2.2. Summary of intervention development approaches that prioritise user input. These approaches were identified by O'Cathain, Croot, Sworn, et al. (2019). The table summarises key advantages and disadvantages of each approach in the context of the research presented in this thesis. Weighing of these advantages and disadvantages contributed to the methodological decision to use a co-production approach in two chapters (Chapter 3, Chapter 6) and semi-structured interviews in a third chapter (Chapter 4). The table is adapted from one provided by O'Cathain, Croot, Sworn, et al. (2019).

Co-creation, co-production, co-design

Broadly, co-creation, co-production, and co-design (henceforth referred to collectively as co-development approaches) offer a way to collaborate with stakeholders to bridge complex intervention research and clinical practice. While a diversity of

methodological approaches have been labelled with these terms potentially due to their largely unregulated across myriad disciplines (Heimburg & Cluley, 2021; Vargas et al., 2022), definitions of co-creation, co-design, and co-production tend to share a fundamental emphasis on integrating insight from users in the design and/or delivery of an intervention through group-based activities, with these approaches tending to position service users as active and equal contributors to the design and delivery of successful services (Cahn, 2000, 2008; Spencer et al., 2013; Vargas et al., 2022; Voorberg et al., 2015). Furthermore, the research process itself is fundamentally underpinned by the principles of equality, diversity, accessibility, and reciprocity (Social Care Institute for Excellence, 2022).

While some researchers have called for definitional clarity and clearer delineation within the literature around the terms co-creation, co-design, and co-production (Vargas et al., 2022), Durose et al. (2017) pragmatically recommended that researchers should side-step definitional ambiguity when selecting a co-development approach and endorse any approach meeting two fundamental quality criteria. First, the approach should open the 'black box' of co-development, such that there is a clear process for converting input (stakeholder perspectives) to output (complex intervention features) that is reported transparently. Second, the method should move beyond assumptions that certain types of evidence are better than others. Specifically, although quantitative and statistically oriented methods may be best placed to answer questions about clinical effectiveness, health and social care improvement initiatives often necessitate an understanding of "how the process is viewed and experienced by

service users and staff" (Glasby, 2011, p.92) and this insight may be better obtained using qualitative methods.

The co-production approach delineated by Spencer et al. (2013) appeared to meet these two criteria and their definition of co-production – "an approach to public services which involves citizens, communities, and the professionals who support them, pooling their expertise to deliver more effective and sustainable outcomes and an improved experience for all involved" (p.7) – appealed in its inherent flexibility. Though steps to co-produce services (or in this case, an intervention) are less clearly operationalised in their framework than in other partnership approaches like the experience-based co-design method (Bate & Robert, 2007; King's Fund, 2012; Locock et al., 2014; Robert, 2013), Spencer et al. (2013) outlined several core stages that offered the potential to be used flexibly in this research programme: (1) Identify and build your team, (2) Define and share assets, (3) Co-create the vision by developing will, (4) Co-design the solution by building ideas, (5) Co-deliver the solution by building execution, and (6) Co-evaluate the solution by measuring the impact of change. Each of these stages should be fundamentally underpinned by a commitment to maximising opportunities for contribution and establishing relationships of trust and equality.

Though arguably lacking in nuance and detail, the co-production framework proposed by Spencer et al. (2013) appealed in its transparent acknowledgement that co-production, by its nature, cannot be a 'one size fits all' method. This was a 'hunch' I had in the early stages of the research, but an uncomfortable one in the sense that acknowledging it would require me to move outside my scientific comfort zone of

following step-by-step methodological instructions. Indeed, endorsing this framework would require a transition away from scientific 'black and white thinking' where methods are seen as either 'right or wrong', and towards a grey area where I would need to recognise that myriad methods might be 'good enough' (Durose et al., 2017).

Throughout the research presented in this thesis, I recognised the importance of stakeholder input and held in mind core principles outlined by Spencer et al. (2013) to facilitate meaningful collaboration with stakeholders. In practical terms, stakeholders were involved in two group-based research projects (Chapter 3 and Chapter 6) that broadly followed the first four co-production steps recommended. Later steps of co-delivery and co-evaluation, though fundamentally important, were considered outside the scope of the complex intervention development stage of research. Despite the strengths of this approach, I did have concerns that individual perspectives and lived experience related to sensitive topics may be challenging to discuss in group-based settings and that the focus on developing a solution may limit the extent to which lived experience would be probed. As such, the decision was made to conduct complementary one-to-one semi-structured interviews exploring important but potentially sensitive topics pertinent to the intervention design (Chapter 4). Crucially, drawing on these different methods (co-production and semi-structured interviews) was in line with MRC guidance stating that "different ways [of working] may be relevant for different stakeholders at different times" and thus that researchers should be open to using "a wide range of research methods throughout" (O'Cathain, Croot, Duncan, et al., 2019, p.3).

The challenge of integrating co-production principles

Existing literature shows how partnership approaches like co-production can usefully complement the MRC framework for complex intervention development. Indeed, there are multiple examples where researchers have successfully integrated these development approaches to design complex healthcare interventions that are rooted firmly in evidence, theory, and stakeholder needs. To name just a few, Desse et al. (2022) used the MRC framework with the BCW and a co-design approach to develop a complex intervention for managing diabetes in Ethiopia. Similarly, when developing a self-management intervention for stroke survivors with aphasia, Wray et al. (2021) used the MRC framework and BCW in tandem with co-production methods. While feasibility testing is underway in both cases, making it difficult to conclude with confidence whether their integrated development approaches resulted in effective interventions, the rigour and holisticness of their approaches provides grounds for optimism.

Nevertheless, little consideration has been given within these and other articles to the inherent challenges of integrating intervention development approaches that are ultimately founded in different disciplines and hold contrasting priorities. While integration certainly affords advantages, in that limitations of different approaches may be offset and gaps filled, researchers must consider carefully how the strengths of each approach can be harnessed while preserving their methodological integrity and thus scientific rigour. Table 2.3 summarises key similarities and differences in the MRC framework development approach (O'Cathain, Croot, Duncan, et al., 2019) and a partnership approach, like the co-production framework outlined by Spencer et al.

(2013). Throughout the research process, it was crucial to be aware of core differences between these approaches, but I ultimately chose to focus on ways they could usefully complement one another such that evidence, theory, and stakeholder input could be meaningfully integrated and equally prioritised.

	MRC framework	**Co-production**
Taxonomy	Theory & evidence-based approach	Partnership approach
Disciplinary origin	Evidence-based medicine	Social sciences
Philosophical positioning	(Neo)Positivist	Constructionist/realist
Focus	Rigour; health outcomes; clinical effectiveness; cost effectiveness; adherence; feasibility of implementation.	Meaning; acceptability; usability.
Gathering evidence	Iterative to some extent; systematic reviews; scoping reviews; observational methods; experimental methods; some stakeholder involvement but loosely delineated; analysis mainly quantitative.	Highly iterative; user interviews; focus groups; workshops; ethnography; analysis tends to be qualitative.
Evaluating intervention	Focused on clinical and cost effectiveness; RCT designs; experimental designs.	Focused on acceptability and usability; in the wild testing; cooperative evaluation; think aloud.

Table 2.3. Summary of the similarities and differences between the intervention development approaches used in this thesis.

2.5. Qualitative methods

The majority of research in this thesis used a qualitative approach, as I saw this as the richest way to understand, probe, and integrate stakeholder perspectives on key questions related to the complex intervention design. As described above, I selected data collection methods flexibly depending on the specific research project aim and characteristics of the participant group, considering methods to be acceptable so long

as they were in line with the dual quality criteria outlined by Durose et al. (2017). In terms of data analysis, while myriad approaches exist (e.g., content analysis, grounded theory, interpretive phenomenological analysis), I was drawn towards thematic analysis, as I considered this family of approaches to afford both rigour and flexibility. Recognising thematic analysis to be an umbrella term (Braun & Clarke, 2021a), the following sections describe the specific methods used within this thesis, with brief reference to the philosophical positioning of this work.

2.5.1. Thematic analysis

Although many articles have implied thematic analysis is a single clearly delineated method (Clarke & Braun, 2018), often citing the seminal paper by Braun and Clarke (2006), recent commentaries have clarified that there exist a number of different thematic analysis methods (Braun & Clarke, 2021a, 2023a, 2023b). In this respect, thematic analysis is perhaps better conceptualised as a family of methods, with specific methods sharing certain similarities with one another but often occupying fundamentally different ontological and epistemological positions (Braun & Clarke, 2021a, 2023b). In an attempt to bring clarity to the field and highlight methodological heterogeneity, Braun and Clarke (2021a, 2023b) delineated three thematic analysis taxonomies, which are briefly outlined below: coding reliability approaches, codebook approaches, and reflexive thematic analysis.

The qualitative spectrum

When describing thematic analysis taxonomies, Braun and Clarke (2023b) drew on the distinction first made by Kidder and Fine (1987) between ‘small q’ and ‘Big Q’

qualitative approaches. ‘Small q’ approaches, they argued, use qualitative tools and techniques (e.g., line-by-line coding) but are situated within a (neo)positivist paradigm that prioritises objectivity, reliability, and accuracy. This stands in contrast to ‘Big Q’ qualitative approaches that encompass a qualitative procedure *and* a ‘qualitative’ philosophy, where knowledge is seen as partial and provisional. Nevertheless, dichotomising methods as either ‘small q’ or ‘Big Q’ arguably oversimplifies the heterogeneity of qualitative methods that have been described. Instead, methods may be better conceptualised as residing somewhere along a qualitative spectrum.

Coding reliability approaches

Coding reliability approaches to thematic analysis, like those described by Boyatzis (1998) and Guest et al. (2012), sit firmly towards the ‘small q’ end of the qualitative spectrum. Qualitative ‘tools’ are employed in a generally systematic way, with multiple coders often working independently to apply a predetermined set of codes to qualitative data, with the goal of analysing data while minimising subjectivity and bias. Coding reliability approaches have been used in a number of complex intervention research studies (e.g., Aguirre et al., 2011; Grimshaw et al., 2020; Prest et al., 2023; Prothero et al., 2019, 2019). Using a heavily structured coding framework – as advised by coding reliability approaches – offers an efficient way to deliver qualitative analyses that may help shed light on the design of a complex intervention. However, the emphasis within these approaches on consistency and reproducibility may come at the expense of adaptability and flexibility, which is a crucial limitation in the context of complex intervention development, where dynamic and iterative design are key

principles underpinning the research process (O'Cathain et al., 2019; Skivington et al., 2021).

Reflexive thematic analysis

Reflexive thematic analysis sits towards the opposite end of the qualitative spectrum, as qualitative methods (e.g., line-by-line coding, theme development) are employed within a firmly non-positivist philosophical framework (Braun & Clarke, 2019a, 2021a). The process outlined by Braun et al. (2023b) involves six recursive stages: familiarisation, coding, generating initial themes, reviewing and developing themes, refining, defining and naming themes, and writing up. Whilst these bear resemblances to the stages outlined within coding reliability approaches (Boyatzis, 1998; Guest et al., 2012), reflexive thematic coding is generally less structured, more flexible, and organic (Braun & Clarke, 2019a). Furthermore, the end goal is not to generate a reliable or 'accurate' account of the data, but rather an insightful and meaningful one that acknowledges the temporal and contextual situatedness of the data, the analysis, and the researcher (Braun et al., 2023b; Braun & Clarke, 2021b).

The conceptualisation of themes also differs from coding reliability approaches. Whereas coding reliability approaches tend to conceptualise themes as topic summaries (i.e., overviews of frequent comments or sentiments expressed by participants), reflexive thematic analysis considers themes to be "patterns of shared meaning underpinned by a central organising concept" (Braun & Clarke, 2021a, p.39). Furthermore, and crucially, themes are actively produced – rather than being passively discovered – at the intersection of the data, the researcher, and analytic context. As

such, the knowledge produced by any reflexive thematic analysis is contextually situated, partial and provisional (Braun et al., 2023). In direct contrast to coding reliability approaches that see researcher bias as a 'threat' to rigour and quality, however, reflexive thematic analysis sees the interpretive role of the researcher as a valuable resource for developing meaning (Braun et al., 2023).

Codebook approaches

Codebook approaches, like framework analysis (Ritchie & Spencer, 1994) and template analysis (Crabtree & Miller, 1999; King, 1998), sit more towards the midpoint of the qualitative spectrum (Braun & Clarke, 2021a). Compared to thoroughly 'Big Q' approaches like reflexive thematic analysis, codebook approaches generally offer a more structured and systematic approach to theme development, which may involve early theme development and conceptualisation of themes as topic summaries (Crabtree & Miller, 1999; King, 1998). However, in contrast to coding reliability approaches that tend to be either explicitly or implicitly positioned within a positivist framework, codebook approaches may be more philosophically flexible, in the sense that they may be compatible with a number of philosophical orientations. For example, template analysis is compatible with a constructionist orientation – which posits that knowledge and meaning are constructed through social interactions and cultural practices – or a critical realist orientation – whereby an objective reality independent of human perception is said to exist, although our perception of this reality is thought to be inevitably coloured by social and cultural contexts (King, 2024). By offering a systematic method that can be used across philosophical frameworks, codebook approaches have been seen as a pragmatic way to 'do' qualitative research in applied

settings, where it is often important to deliver rich translational findings efficiently (Braun & Clarke, 2021a).

As in reflexive thematic analysis, codebook approaches generally acknowledge and embrace the interpretive role of the researcher in the data analysis process. To fully harness the value they can bring, researchers using a codebook approach to thematic analysis are encouraged to reflect on their individual values, assumptions, and interpretations and to consider how these factors shape the final analysis and themes presented (Braun et al., 2023b; Braun & Clarke, 2021a). The word 'reflect' is key, as researchers are encouraged to move beyond mere *acknowledgement* of their positionality relative to the subject matter and to interrogate exactly how their positionality may have shaped the data analysis and final theme structure. Indeed, Folkes (2022) has emphasised the importance of moving beyond a 'shopping list' approach, where researchers list hollow positionality statements (i.e., descriptive statements of how their characteristics resemble or differ from those of their participants). Recognising positionality as invariably fluctuating and interweaving with the methodological and analytical process, Folkes (2022) encouraged qualitative researchers instead to engage with and critically reflect on their positionality throughout their work, echoing past recommendations that qualitative researchers should regularly turn their scrutiny and critical examination towards themselves (Patnaik, 2013).

Selecting thematic analysis approaches

Having outlined the differences between thematic analysis taxonomies, Braun et al. (2022) emphasised there is not one correct way to 'do' thematic analysis. Instead, they encouraged researchers to recognise the potential advantages and limitations of different approaches, and to make an informed decision about the optimal analytic approach for their specific research project, considering their specific research aims, the pragmatic factors that may constrain the analysis, and their philosophical ideologies (Braun & Clarke, 2021a).

The methodological decisions made during this PhD research were inevitably grounded in my own epistemological and ontological beliefs – namely, that there exists an objective reality independent of human perception but that our understanding of said reality is inevitably mediated by the social and cultural lenses through which we view it. Qualitative methods used in this thesis needed to align with this critical realist philosophical positioning, and the diversity of questions that were to be addressed within the research necessitated the use of different methods. When probing stroke survivors' experiences of cognitive assessment (Chapter 4), I recognised how reflexive thematic analysis might best accommodate the complex and nuanced nature of lived experience, encouraging deep interpretive engagement with the data in a participant-centred way. Nevertheless, other research projects demanded a more descriptive analytic approach to identify actionable and pragmatic feedback that might improve the complex intervention for a broader population, rather than reflecting a uniquely situated viewpoint (Chapter 3, Chapter 6, Chapter 8). As such, a codebook approach to thematic analysis (template analysis) was used in these chapters.

Throughout the research presented in this thesis, I recognised my own role in interpreting and 'making sense' of the data. Within an electronic journal, I critically examined my various roles, identities, values, and assumptions and considered not only *if* but specifically *how* they may have shaped the final 'stories' presented. Key reflections recorded within this journal are presented towards the end of each relevant empirical thesis chapter.

2.6. Chapter summary

This chapter outlined key methodological considerations that fundamentally shaped the research presented in this thesis. After introducing the interdisciplinary approach taken throughout the research programme, the chapter outlined and justified the specific framework used to guide the intervention development process – namely, the MRC framework for complex intervention development. Having acknowledged the importance of theory and stakeholder perspectives within the MRC framework but the lack of clarity with regards to integrating these factors in complex intervention development work, the chapter then explained the decision to hold in mind and loosely integrate a range of theories, and to use co-production principles and semi-structured interviews. I discussed fundamental challenges to integrating these diverse approaches but emphasised my commitment to balancing rigour with flexibility, explaining that the gaol was to harness the strengths of each approach while preserving their methodological integrity. Finally, having acknowledged the predominantly qualitative nature of the research presented in this thesis, the chapter concluded by describing how the philosophical positioning of this work fundamentally shaped the decision to use reflexive thematic analysis and template analysis. Marking

the start of the empirical section of this thesis, the next chapter presents a modified Delphi survey conducted to develop consensus on the complex intervention features.

Chapter 3 A modified Delphi survey to develop consensus on the complex intervention features

3.1. Chapter overview

The previous chapters introduced the empirical, conceptual, and methodological background to this thesis. This chapter marks the beginning of the empirical section of the thesis. The aim of the overarching research programme was to develop an intervention providing Level 1 post-stroke cognitive care. This chapter presents a modified Delphi survey conducted to establish 'expert' consensus on core features of the intervention. Figure 3.1 shows the position of this chapter within the thesis.

3.2. Contribution

I contributed to the research presented in this thesis chapter by conceptualising the study, formulating the study aims and objectives, determining the study methodology, recruiting participants to the study, collecting data, curating data, analysing data, circulating results to participants, drafting the original research article, editing the draft based on co-author feedback, and managing the submission process. Prof Nele Demeyere was involved in conceptualising the study, formulating the study aims and objectives, advising on study methodology, recruiting participants, and reviewing the original research article. Dr Eugene Tang was involved in conceptualising the study, advising on study methodology, and reviewing the original research article. My PhD supervisors provided feedback on this chapter.

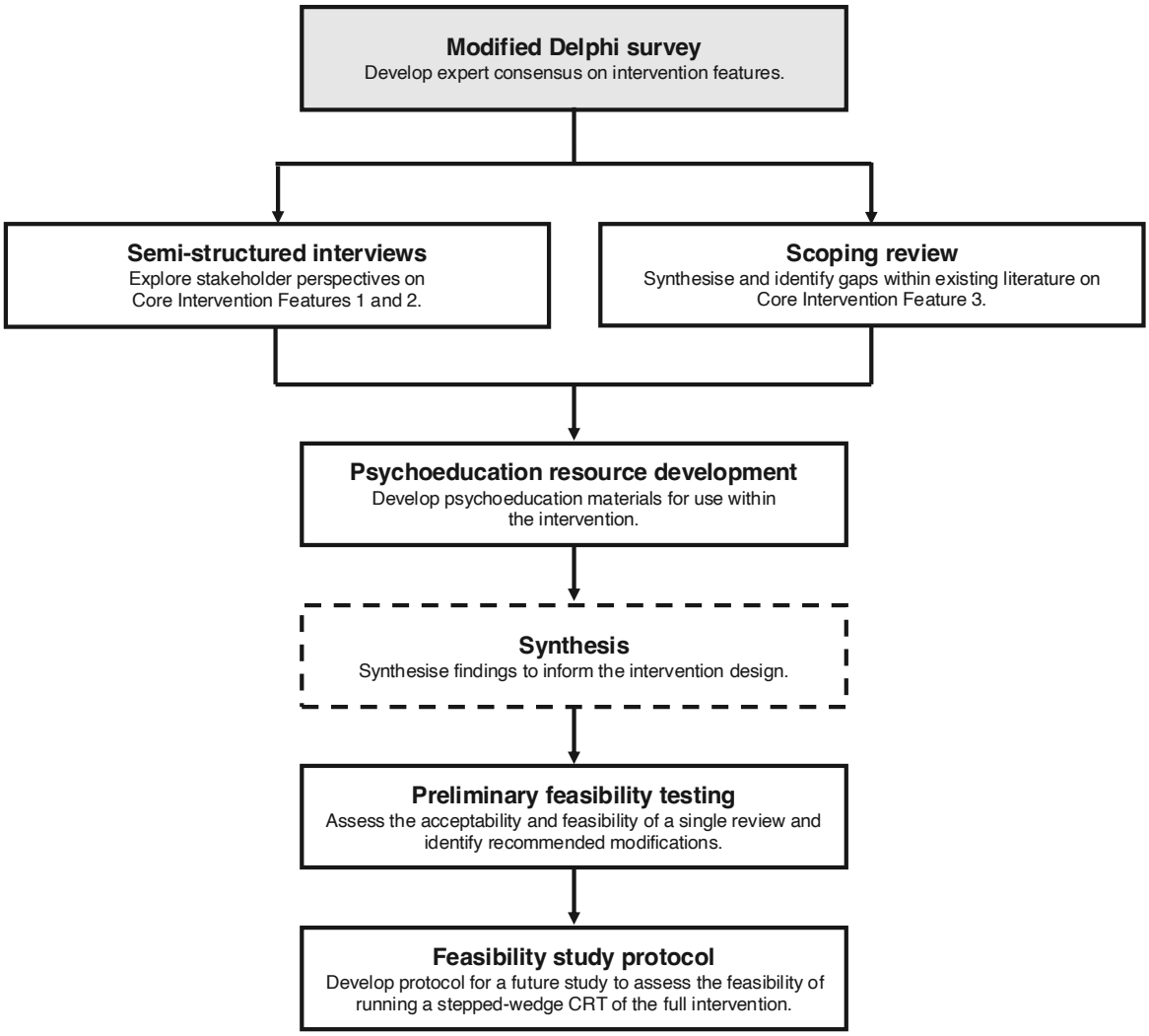


Figure 3.1. Position of modified Delphi survey (highlighted in grey) within the overall thesis.

3.3. Impact statement

The research presented in this chapter is currently under peer-review:

- **Hobden, G.**, Tang, E.Y.H., & Demeyere, N. (In review). Expert consensus on the structure and content of an enhanced UK-based care pathway for psychological changes after stroke: A modified Delphi survey. *BMC Health Services Research.*

3.4. Background

As outlined in Chapter 1, cognitive impairment affects 48-98.4% of people in the first weeks after stroke (e.g., Demeyere et al., 2016; Hurford et al., 2013; Lesniak et al., 2008; Milosevich et al., 2024; Nijsse et al., 2017; Turunen et al., 2018). Although a proportion of people with stroke recover from these early impairments (Demeyere et al., 2019; Kusec et al., 2023), prevalence of cognitive impairment more than six-months after stroke remains high (41-57%) (Lopes et al., 2021; Turunen et al., 2018; Williams & Demeyere, 2021).

UK clinical guidelines recommend that cognitive screening should be a routine aspect of in-hospital care for stroke (Intercollegiate Stroke Working Party, 2023a) and SSNAP data confirm that cognitive screening is conducted before discharge in 92.4% of cases (Intercollegiate Stroke Working Party, 2023b). However, provision of post-discharge cognitive care is more variable within the UK. SSNAP data on six-month clinical reviews indicated that 33.9% of stroke survivors with psychological needs related to mood, behaviour, and/or cognition did not receive support in the financial year 2019-2020 (Intercollegiate Stroke Working Party, 2020). While data on *exclusively* cognitive needs are not available from SSNAP, two recent systematic reviews have confirmed that managing cognitive changes is one of the most frequently reported unmet needs in the long term after stroke (Chen et al., 2019; Lin et al., 2021). These reviews and meta-analyses were not constrained to UK-based studies, but examining results from studies conducted in the UK confirms a high prevalence of cognition-related unmet needs: At six-months after stroke, unmet needs related to memory and attention

difficulties were reported by 26-59% of UK-based stroke survivors (McKevitt et al., 2011; Rothwell et al., 2013).

Improving long-term cognitive care in the UK is crucial to help stroke survivors and family members gain the insight and skills required to adapt successfully to post-stroke cognitive impairment. Indeed, both the NHS Long Term Plan (NHS England, 2019) and Demand Signalling Report (NHS England, 2022) have called for in general improved long-term care after stroke and cognitive support has been highlighted as one aspect of care requiring particular attention. Furthermore, psychological and cognitive changes have been highlighted as *the* top research priorities to improve outcomes after stroke in a recent priority setting exercise by the JLA (Hill et al., 2022; James Lind Alliance, 2022).

However, despite increasing recognition that further research and improved care is required, supporting post-stroke cognitive changes over the longer term represents a substantial challenge, as previous clinical trials have found no strong evidence for direct interventions to improve post-stroke cognitive functioning (see Cochrane reviews: Bowen et al., 2013; Chung et al., 2013; das Nair & Lincoln, 2007). Cognitive rehabilitation programmes that focus on monitoring, psychoeducation, and signposting to specialist neuropsychological care when clinically indicated may prove beneficial (Merriman et al., 2021). However, there is a current lack of high-quality evidence evaluating the efficacy of such interventions (Kontou et al., 2021) and no consensus on the optimal design for an easily scalable and implementable approach.

The aim of the work presented in this thesis was to develop a pragmatic, scalable, and implementable intervention to address the identified need for long-term cognitive support after stroke in the UK. Here, I used an online modified Delphi survey approach to develop expert stakeholder consensus on the key features of the intervention. The specific research questions addressed were:

a. Who should receive cognitive reviews? Specifically, should cognitive reviews be offered to those with and without cognitive impairment detected in hospital and should review timepoints differ depending on in-hospital cognitive function?

b. How should cognitive reviews be conducted? Given recent increases in remote healthcare provision (Chapman et al., 2020; Fox-Fuller et al., 2022; Webb et al., 2022) and the availability of cognitive screening tools validated for online use (e.g., Webb et al., 2023), should in person and/or online cognitive reviews be offered?

c. What should cognitive reviews include? A wide variety of tools are used to assess post-stroke cognition in clinical practice (Lees et al., 2014), with approaches ranging from brief screens to comprehensive neuropsychological assessment batteries (Quinn et al., 2018). Which approach(es) should be routinely incorporated within the intervention and should reviews assess psychological changes beyond cognitive impairment (e.g., low mood, anxiety)?

d. What training might be required to support healthcare professionals to administer cognitive reviews? Healthcare professionals in community-based stroke teams have reported a lack of confidence when conducting post-stroke cognitive assessments and few opportunities for training (Ablewhite et al., 2019). What type of training would best support skill development and confidence building?

3.5. Methods

3.5.1. Ethics and research governance approval

The University of Oxford Medical Sciences Interdivisional Research Ethics Committee (REC) provided ethical approval for this study (University of Oxford REC Reference: R76686/RE001).

3.5.2. Participant recruitment

Potential participants were recruited through snowballing methods after emailing professional contacts of the research team and social media (Twitter). Potential participants were provided with detailed information about the study and invited to ask any questions. They were then asked to complete an online (Microsoft Forms) consent and screening form to confirm they met eligibility criteria for the study. While recognising the challenge of identifying and labelling expertise, the following eligibility criteria were developed to ensure the modified Delphi survey panel included practice-based/research-based experts: (1) Self-reported professional interest in and/or

experience with cognition after stroke; (2) Self-reported professional occupation as either (a) An (allied) healthcare professional with at least five years' experience working with stroke survivors in the United Kingdom, or (b) A researcher with at least one published peer-reviewed stroke research article within the last ten years as first, second, or last author.

The goal was that recruited participants would vary in their specific professional occupations and geographic locations, given that post-stroke care is multidisciplinary in nature (Clarke & Forster, 2015) and given the long-term goal of standardising the post-stroke care pathway across the UK in order to address healthcare inequalities. However, the precise composition and size of the panel was not defined a priori. Instead, I aimed for an initial sample size of at least 30, in line with recommendations for Delphi surveys (Nasa et al., 2021). Note that these recommendations acknowledge the importance of incorporating sufficient viewpoints but also the pragmatic constraints of the Delphi approach, requiring personalised feedback after each round.

3.5.3. Survey design

At the start of the first survey round, participants were asked to provide demographic information on their gender, age, professional occupation, years in this occupation, and geographical region in which they worked. The Delphi items were then presented. The first-round Delphi items were developed based on a set of 'candidate intervention features'. Candidate features were identified by drawing on existing literature (e.g., Merriman et al., 2019; Merriman et al., 2021), national and international clinical guidelines specifying 'best practice' for post-stroke cognitive care (Intercollegiate

Stroke Working Party, 2023a; Royal College of Physicians, 2016; Stroke Foundation Australia, 2021; The European Stroke Organisation (ESO) Executive Committee and the ESO Writing Committee, 2008), expertise of research team members and collaborators, and lived experience from our Patient and Public Involvement (PPI) Group. Candidate intervention features were fed into the first round of the survey as a series of statements. For example, the candidate feature "Stroke-specific cognitive screen" was converted to the statement "Cognitive reviews should include a stroke-specific cognitive screen (15-20 minutes) (e.g., Oxford Cognitive Screen; OCS)". Participants were asked to indicate whether they agreed, disagreed, or had no opinion about each statement. Categorical response options (i.e., agree, disagree, no opinion) were used to reduce participant burden, to make sure participants were clear about the consequences of their votes, and to ensure that the final results were actionable and implementable within a complex intervention. Participants were invited to provide free-text comments in response to each statement and at the end of the survey. Survey questions from each round are provided in Appendix 1.

The survey was designed to include two to four rounds, with the maximum set to account for likely participant attrition and fatigue (Hasson et al., 2000). I planned to end the survey when at least one of the following criteria was met: (1) Consensus reached on all survey items, (2) Four survey rounds completed, (3) Little indication that consensus would be reached on the outstanding statements (a priori definition: <5% movement towards consensus from previous round for all statements that had not yet reached consensus). The aim was to achieve a 100% response rate for each

survey round, but rounds were accepted as valid if the response rate was at least 70%, recognising likely participant attrition (Hasson et al., 2000).

3.5.4. Survey procedure

Eligible participants were contacted by email and invited to complete the first survey round by following a hyperlink to an online questionnaire (Microsoft Forms). Subsequent survey round hyperlinks were also circulated by email. Participants were given ten working days to complete each survey round and were encouraged to contact the research team if they had questions or concerns that they would not be able to complete the round within this timeframe. Participants were emailed a reminder to complete each round five working days after its opening if they had not yet completed it. Participants who had not completed the round when it closed after ten working days were excluded from subsequent round(s).

Once each round was closed, results were analysed for consensus and the subsequent survey round was developed (see below for detail). Each participant who had completed the round was emailed a personalised summary of the results from the previous round (Appendix 1). For each statement that did not reach consensus, the personalised summary presented the participant with their response (i.e., agree, disagree, no opinion), the overall group response (i.e., percentage agree versus disagree) and anonymised free-text comments provided in response to the statement (Hasson et al., 2000). For participants' information, a summary of items that did reach consensus was also presented. To promote consensus-building, participants were

encouraged to read and reflect on the personalised summaries before completing the subsequent survey round.

3.5.5. Data analysis

Survey data were analysed for consensus using Microsoft Excel. Consensus was defined a priori as ≥75% agree/disagree after responses of 'no opinion' were excluded (Keeney et al., 2006). Survey items that did not reach consensus were fed back into the subsequent round(s) without altering them in any way.

In terms of qualitative analysis, free-text responses from the first and final round of the survey were analysed. When analysing free-text responses from the first survey round, the primary goal was to identify additional candidate intervention features to enter into the second survey round. For this analysis, template analysis – a 'medium Q' codebook approach to thematic analysis (Braun & Clarke, 2021a) – was selected as an appropriate method for several reasons (King, 1998, 2024). First, as the aim was to identify pragmatic and actionable intervention features, it was recognised that the analysis should ideally take place at a mostly descriptive level. Template analysis appealed as a pragmatic middle ground between "scientifically descriptive" coding reliability approaches and "artfully interpretive" (Bager-Charleson & McBeath, 2022, p.2) reflexive thematic analysis. Second, the analysis needed to be delivered efficiently, as there was scheduled to be only one week between the first round closing and the second round opening. One week was expected to allow sufficient time for analysis and developing personalised summary sheets, while reducing the likelihood that participants would leave a healthcare service and thus lose their email access, or

that they would lose interest or forget about the study (Williamson et al., 2017). By using a structured yet flexible approach to coding and theme development that allowed relatively early identification of descriptive themes (i.e., topic summaries), template analysis would facilitate efficient delivery of the final results. Finally, the philosophical flexibility of template analysis meant it was compatible with the critical realist positioning of this work.

Initial data familiarisation involved reading and re-reading free-text responses to each survey item, while making rough working notes. Then, I coded relevant sections at a semantic level (i.e., sections explicitly or implicitly suggesting an additional or different candidate intervention feature) using the comment function in Microsoft Word. Codes and accompanying quotations were compiled into a Microsoft Excel file that enabled me to see the dataset and initial codes at a glance and to start identifying any overlapping perspectives. From this file, I developed initial candidate themes (i.e., intervention features), which I compiled in a separate Microsoft Excel sheet. I considered how this template did or did not fit to participants' responses by considering it against the codes, quotations and – at times – the raw data, and revising it iteratively. Using and adapting the Microsoft Excel file throughout this process meant I was able to easily adjust themes and consider at a glance whether they were supported by the data. Final themes, which represented actionable and implementable intervention features, were discussed and agreed by all members of the research team, with research team discussions providing crucial reassurance that important aspects of the data had not been overlooked. These final themes were then converted into new survey items to be fed into the subsequent round. Note that no attempt was made to

identify further candidate intervention features from subsequent survey rounds as introducing new items 'late' in the study would limit the time available for them to reach consensus.

Free-text responses from the final survey round were analysed with the primary goal of identifying similarities and differences in participant viewpoints for statements that did not reach consensus. Here, the aim was to gain insight into *why* the statements did not reach consensus and whether – despite the lack of consensus – participants shared any similar viewpoints that had the potential to meaningfully influence the design of the intervention. Template analysis (King, 1998, 2024) was selected for very similar reasons. Again, the goal was for the analysis to be mostly descriptive, though with some room for interpretation, and the method needed to be compatible with the critical realist positioning of the work.

Like before, initial data familiarisation involved reading participants' responses and making rough notes. Then, relevant sections of qualitative data from all participants were coded using Microsoft Word at a mostly semantic level, though with some room for interpretation, and these codes and quotations – which were compiled in a Microsoft Excel file – were used to inform an initial template comprising candidate themes. In terms of the balance between description and interpretation, while the goal was to remain 'close' to participants' responses and not to extrapolate too far beyond what was said, drawing on my own assumptions and perspectives enabled me to consider patterns that were less directly evident, which was particularly important in cases where survey responses were very brief or explanations not fully elaborated.

The initial template was considered against codes, quotations, and raw data, being revised iteratively throughout this process. Storing the codes, quotations, and evolving template in a single Microsoft Excel enabled me to consider the theme structure and data at a glance and to easily implement changes and restructuring. Research team discussions played a crucial role in ensuring important aspects of the data were not overlooked. The final themes and subthemes were agreed by the research team, though subtle revisions to the theme titles and boundaries were made during the writing process.

While the aim was for the additional candidate intervention features, as well as similarities and differences in viewpoints, to be firmly grounded in the data (i.e., inductive approach), I acknowledged my inevitable role in shaping the analysis and results, recognising that the themes would be developed at the intersection of the data, the analytic context, and the interpretations and assumptions I brought to the analysis as a researcher. Section 3.8 summarises important reflections.

3.6. Results

Figure 3.2 shows the number of participants who completed each stage of the research. Table 3.1 presents demographic details for participants who completed each survey round. The following sections summarise participant demographics and quantitative results from each survey round in turn.

3.6.1. Quantitative results

Screening and consent

The screening form and consent form were completed by 54 participants, 51 (94.44%) of whom met the inclusion and exclusion criteria. The 3 participants who were excluded were healthcare professionals, but they did not have at least five years of experience working with stroke survivors in the UK.

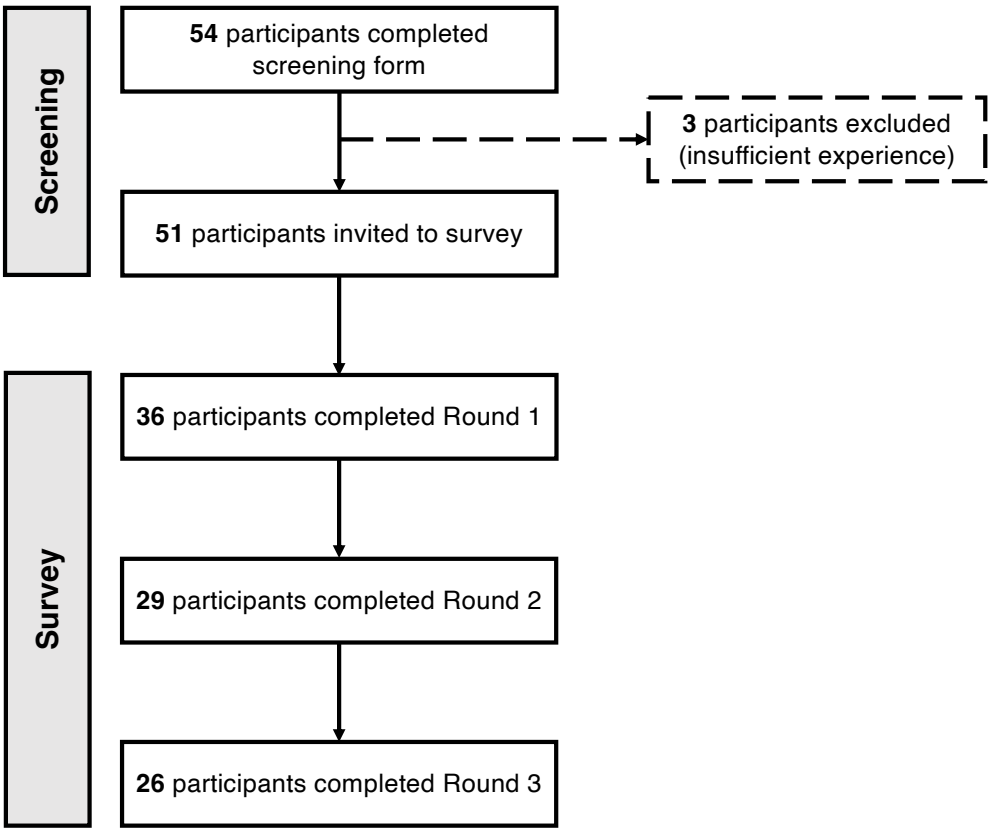


Figure 3.2. Flow diagram showing the number of participants included at each stage of the modified Delphi survey.

Demographics	Survey Round		
	1 (*N* = 36)	2 (*N* = 29)	3 (*N* = 26)
Gender			
Female	29	24	21
Male	7	5	5
Years of age			
25-34	4	3	3
35-44	21	17	15
45-54	10	8	7
55-64	1	1	1
Professional occupation*			
Occupational Therapist	15	12	11
Clinical Psychologist	6	5	4
Clinical Neuropsychologist	3	2	2
Speech and Language Therapist	2	2	2
Stroke Specialist Nurse	2	0	0
Physician	4	4	4
Professor or Associate Professor	1	1	1
Senior Lecturer or Lecturer	4	4	4
Postdoctoral Researcher	3	3	2
Doctoral Student	2	2	2
Geographical region working			
North East England	2	2	2
North West England	6	5	4
Yorkshire and the Humber	3	2	2
West Midlands	6	4	3
East of England	2	2	2
London	4	3	3
South East England	7	6	5
South West England	2	2	2
Scotland	4	3	3
Years of experience			
0-5	3	3	3
6-10	9	6	6
>10	24	20	17

Table 3.1. Demographic characteristics of the experts who participated in each modified Delphi survey round. ***** Participants were given the option to select more than one professional occupation.

Round 1

Of the 51 participants invited, 36 (70.59%) completed the first survey round, which included demographic questions and 30 survey items. Of the 36 participants who completed Round 1, 29 (80.56%) were female and 21 (58.33%) were aged between 35-44 years. 25 (69.44%) participants occupied a clinical role only, 5 (13.89%) occupied an academic role only, and 5 occupied both a clinical and academic role (13.89%), with one participant choosing not to respond. Participants reached consensus on 25 of the items, with no consensus reached on 5 items. Items that reached consensus in each round are summarised in Table 3.2.

In summary, the expert panel agreed that stroke survivors with (100.00%) and without (88.24%) cognitive impairment detected during acute hospital admission should be offered at least one cognitive review. They agreed that those with cognitive impairment should receive a review in the first weeks (85.71%), three months (92.59%), six-months (95.45%) and one-year (95.00%) after discharge. Whilst they agreed that those without cognitive impairment detected should receive a review in the first weeks (82.14%) and six-months (80.00%) after discharge, participants did not reach consensus on whether they should receive reviews at three-months (72.00% agree) and one-year (55.00% agree) after discharge.

Whilst the expert panel agreed that cognitive reviews should be conducted in person (86.67%), they failed to reach consensus on a separate item on whether stroke survivors should be given the choice of whether to attend a review in person or remotely (72.41% agree). Nevertheless, they agreed that a stroke specific cognitive

screen (96.97%), a depression screen (93.75%), and an anxiety screen (90.32%) should be administered during cognitive reviews, but they did not agree on whether the cognitive review should also include a dementia screen (e.g. MoCA) (56.52% agree) and a neuropsychological assessment (e.g. RBANS) (62.50% agree). They also agreed that self-report questionnaires about cognition for stroke survivors (97.06%) and family members (96.55%) should be included.

Participants agreed on the importance of information provision and psychoeducation during the cognitive reviews. Specifically, participants agreed that stroke survivors should be given information about their cognitive assessment results (93.75%), how these results compare to earlier cognitive testing (90.32%), potential cognitive trajectories (78.79%), the impact of cognitive problems on ADLs (100.00%), and information about services and support available (100.00%).

Participants also agreed that training for healthcare professionals administering cognitive reviews was important. They agreed healthcare professionals should be offered formal (100.00%) and informal (78.57%) training on administering cognitive assessments, as well as formal (97.06%) and informal (86.67%) training on discussing cognition with stroke survivors and their family members.

Analysis of free-text responses from the first survey round resulted in the addition of three further items to the second survey round (see starred items in Table 3.2). These represented three further candidate intervention features: fatigue measure, online training, in person training.

Statement	Consensus	Round Reached	Responses *(N)*		Agree *N* (%)	Disagree *N* (%)
			Total	Excl. no Opinion		
Stroke survivors **with a cognitive impairment** detected during acute hospital admission should have a **review** of their cognition **after discharge** from an acute inpatient setting.	Agree	1	36	36	36 (100.00)	0 (0.00)
Stroke survivors **with no cognitive impairment** detected during acute hospital admission should have a **review** of their cognition **after discharge** from an acute inpatient setting.	Agree	1	36	34	30 (88.24)	4 (11.76)
For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place in the **first few weeks** after discharge.	Agree	1	36	35	30 (85.71)	5 (14.29)
For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **3-months** after discharge.	Agree	1	31	27	25 (92.59)	2 (7.41)
For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **6-months** after discharge.	Agree	1	30	22	21 (95.45)	1 (4.55)
For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **1-year** after discharge.	Agree	1	29	20	19 (95.00)	1 (5.00)
For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place in the **first few weeks** after discharge.	Agree	1	32	28	23 (82.14)	5 (17.86)
For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **3-months after discharge**.	Agree	2	29	28	23 (82.14)	5 (17.86)

For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **6-months** after discharge.	Agree	1	29	20	16 (80.00)	4 (20.00)
Cognitive reviews should take place **in person**.	Agree	1	36	30	26 (86.67)	4 (13.33)
Cognitive reviews should include a **stroke-specific cognitive screen** (15-20 minutes) (e.g., Oxford Cognitive Screen; OCS).	Agree	1	36	33	32 (96.97)	1 (3.03)
Cognitive reviews should include a **questionnaire** for the **stroke survivor** about their post-stroke cognition.	Agree	1	36	34	33 (97.06)	1 (2.94)
Cognitive reviews should include a **questionnaire** for a **family member** about the stroke survivor's cognition.	Agree	1	36	29	28 (96.55)	1 (3.45)
Cognitive reviews should include a **depression screen** (e.g., Patient Health Questionnaire-9; PHQ-9).	Agree	1	36	32	30 (93.75)	2 (6.25)
Cognitive reviews should include an **anxiety screen** (e.g., Generalised Anxiety Disorder Assessment-7; GAD-7).	Agree	1	36	31	28 (90.32)	3 (8.33)
Cognitive reviews should include a **general discussion** with the stroke survivor about their **overall cognitive functioning**.	Agree	1	36	34	34 (100.00)	0 (0.00)
Cognitive reviews should include a **general discussion** with the stroke survivor about their **domain-specific cognitive functioning**.	Agree	1	36	28	27 (96.43)	1 (3.57)
Stroke survivors should be told the **results of the cognitive assessment** conducted during the review.	Agree	1	36	32	30 (93.75)	2 (6.25)
Stroke survivors should be told how their **cognitive assessment result compares to earlier cognitive assessment results** (e.g., in cognitive screen completed in acute inpatient setting).	Agree	1	35	31	28 (90.32)	3 (9.68)

Stroke survivors should be told about **potential cognitive trajectories** during the review.	Agree	1	36	33	26 (78.79)	7 (21.21)
Stroke survivors should be told about the potential **impact** of any cognitive impairments on **activities of daily living** during the review.	Agree	1	36	34	34 (100.00)	0 (0.00)
Stroke survivors should be **signposted** to available **support and services** during the review.	Agree	1	36	36	36 (100.00)	0 (0.00)
Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **formal training** (e.g., training videos) on **administering the cognitive assessment**.	Agree	1	36	35	35 (100.00)	0 (0.00)
Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **informal training** (e.g., training from colleague) on **administering the cognitive assessment**.	Agree	1	35	28	22 (78.57)	6 (21.43)
Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **formal training** (e.g., training videos) on **discussing cognition** with stroke survivors and family members.	Agree	1	36	34	33 (97.06)	1 (2.94)
Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **informal training** (e.g., training from colleague) on **discussing cognition** with stroke survivors and family members.	Agree	1	35	30	26 (86.67)	4 (13.33)
* Cognitive reviews should include a **fatigue measure** (e.g. Fatigue Severity Scale; FSS).	Agree	2	29	28	25 (89.29)	3 (10.71)
* **Online training** (e.g., training videos) should be offered to healthcare professionals administering cognitive reviews.	Agree	2	29	27	26 (96.30)	1 (3.70)
* **In person training** (e.g., training course) should be offered to healthcare professionals administering cognitive reviews.	Agree	2	29	25	21 (84.00)	4 (16.00)

Table 3.2. Items that reached consensus within the modified Delphi survey. *Item introduced in Round 2 of the modified Delphi survey.

Round 2

The second survey round was completed by 29 (80.56%) of the 36 participants invited. The second survey round included only 8 items, 4 (50%) of which reached consensus.

All three of the items developed from free-text responses to statements in the first survey round reached consensus: Participants agreed that the cognitive reviews should include a fatigue measure (89.29%), and that training for healthcare professionals should be offered online (96.30%) and in person (84.00%).

However, only one of the five items rolled over from the first round reached consensus in the second round. Participants agreed that stroke survivors with no cognitive impairment detected during acute hospital admission should receive a review of their cognition three-months after discharge (82.14%), but they were just shy of reaching consensus on whether these stroke survivors should receive a review one-year after discharge (74.07% disagree). Participants failed to reach consensus on whether stroke survivors should be given the option to complete reviews in person or remotely (62.07% agree) and whether the review should include a dementia screen (65.38% disagree) and/or a neuropsychological assessment battery (58.33% disagree).

Round 3

The third round of the survey was completed by 26 (89.66%) of the 29 participants invited. It included four items, none of which reached consensus. Compared to results of the second round, only one item moved closer to consensus (“Individual stroke survivors should choose whether they would prefer cognitive reviews to take place

either in person or remotely": 62.07% to 66.67% agreed). The level of consensus for one item remained the same in Round 3 compared to Round 2 ("Cognitive reviews should include a neuropsychological assessment battery (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS)": 58.33% disagree). Two items moved further away from consensus ("For stroke survivors with no cognitive impairment detected during acute hospital admission, a review of their cognition should take place 1-year after discharge": 74.07% to 68.00% disagree; "Cognitive reviews should include a dementia screen (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA)": 65.38% to 62.50% disagree). Table 3.3 presents a summary of results for these items from each survey round. Given that there was little indication that consensus would be reached on these items in the next round, the research team agreed to end the Delphi survey at this point.

Statement	Round	Responses *(N)*		Agree *N* (%)	Disagree *N* (%)
		Total	Excl. No Opinion		
For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **1-year** after discharge.	1	26	20	11 (55.00)	9 (45.00)
	2	29	27	7 (25.93)	20 (74.07)
	3	25	25	8 (32.00)	17 (68.00)
Individual stroke survivors should **choose** whether they would prefer cognitive reviews to take place either **in person or remotely** (i.e., telephone or videoconferencing).	1	36	29	21 (72.41)	8 (27.59)
	2	29	29	18 (62.07)	11 (37.93)
	3	26	24	16 (66.67)	8 (33.33)
Cognitive reviews should include a **dementia screen** (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA).	1	36	23	13 (56.52)	10 (43.48)
	2	29	26	9 (34.62)	17 (65.38)
	3	26	24	9 (37.50)	15 (62.50)
Cognitive reviews should include a **neuropsychological assessment battery** (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS).	1	35	24	15 (62.50)	9 (37.50)
	2	29	24	10 (41.67)	14 (58.33)
	3	26	24	10 (41.67)	14 (58.33)

Table 3.3. Items that did not reach consensus in the modified Delphi survey.

3.6.2. Qualitative results

Although consensus was not reached on four of the Delphi items by the end of the survey, qualitative analysis of free-text responses indicated that many participants shared similar viewpoints about potential risks, benefits, and caveats of including these candidate intervention features in the complex intervention. Table 3.4 presents a pragmatic summary of the final themes and subthemes developed from free-text responses to items that did not reach consensus with example quotations. Note quotations are presented verbatim with typographical errors uncorrected. A full description of themes and subthemes is presented in Appendix 1 due to space constraints.

Survey item		Theme	Example quotation
1	For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **1-year** after discharge.	Too late to be useful.	*"Should be earlier, as by a year post someone may have lost a job or relationships due to lack of support for cognitive changes by that point."* (P28, Speech and Language Therapist)
		Concerns about feasibility.	*"Given the evidence of the high prevalence of dementia post stroke, I think this would be a good opportunity to follow up on this. However, the resources needed would make it impossible and I do feel resources could be better allocated on those who really need the cognitive rehabilitation."* (P2, Occupational Therapist)
		It depends on earlier cognitive reviews.	*"I think if no cognitive deficits are indicated at 3 months there is no need to review again."* (P4, Occupational Therapist)

2	Individual stroke survivors should **choose** whether they would prefer cognitive reviews to take place either **in person or remotely** (i.e., telephone or videoconferencing).	Downsides of remote assessments.	*"Building rapport is so much easier in person (assuming they'd not previously met the assessor) and this is important for the person to do their best during the assessment. I think it's probably also more likely that higher level difficulties would be picked up if seen in person. Not saying that remote options don't have a place, I just don't think patient preference is the right way to decide."* (P19, Doctoral Student)
		Importance of choice and person-centredness.	*"I do think choice and accessibility is important therefore both videoconferencing and face to face should be offered. Not telephone consult. However the pros and cons of each should be clearly explained to the patient to enable them making an informed choice. My personal preference would be face to face but remote is better than a [Did Not Attend] DNA."* (P29, Occupational Therapist)
3	Cognitive reviews should include a **dementia screen** (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA).	Risk of misinterpretation in stroke populations.	*"Standard dementia screens can potentially be misleading because of all the confounds in a stroke population i.e. neglect, dysphasia, motor problems. Whatever training you put in place, there will still be some people who take the standard cut-off (e.g. 88/100 on ACE-III) and say, 'the score is below the cut-off and this suggests the person has dementia'."* (P1, Clinical Psychologist & Clinical Neuropsychologist)
		Situation- and person-specific approach.	*"A dementia screen would be very useful in certain situations: evidence of longitudinal cognitive decline either before stroke or months/years after the stroke; or a cognitive profile that doesn't match the stroke eg dense amnestic picture with a posterior stroke. Stroke and neurodegenerative disorders often co-exist particularly in the older patients. [...] So Dementia screen is important in some patients but not routinely in ALL patients."* (P7, Physician & Lecturer)

4	Cognitive reviews should include a **neuropsychological assessment battery** (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS).	Concerns about feasibility.	*"I don't think there will ever be enough people in stroke services to administer something that requires a more sophisticated understanding of psychometric assessment to make this workable - a 'review' will end up being too long and unwieldy."* (P1, Clinical Psychologist & Clinical Neuropsychologist)
		Importance of onwards referral.	*"A two tiered approach with initial screening/triage to select those needing more detailed assessment seems a better use of resource."* (P33, Physician)

Table 3.4. Summary of themes and subthemes developed from free-text responses to Delphi items that did not reach consensus by the end of the study.

In brief, some participants believed a one-year post-discharge cognitive review should be offered to those with no cognitive impairment detected in hospital depending on the results of cognitive reviews at later timepoints (i.e., is cognitive impairment present at e.g., six-months?) Others seemed to interpret the survey item to mean that *only* a one-year cognitive review would be provided. These participants generally agreed one-year was too late to be useful, should it be the only review point available. Some participants interpreted the survey to mean that reviews could – in theory – be offered at all four timepoints listed (first few weeks, three-months, six-months, one-year). Note that this was indeed how I intended the survey items to be interpreted. Many of these participants thought that providing reviews at four timepoints to all stroke survivors was overly ambitious, given constraints on clinical time and resources, and that the one-year review of those without cognitive impairment was the least important.

Participants generally agreed that providing stroke survivors the option to attend cognitive reviews either in person or remotely would be helpful for improving access. They noted online options to be particularly important for stroke survivors in remote areas or with caring/professional responsibilities. All participants seemed to agree that providing cognitive reviews in a person-centred way was pivotal, but many participants were worried about the downsides of conducting cognitive assessments remotely and practical problems (e.g., finding it more difficult to make observations online).

When considering whether cognitive reviews should include a dementia screen in addition to a stroke-specific cognitive screen, some participants were concerned that the results could be misinterpreted, given that performance may be confounded by stroke-specific deficits (e.g., aphasia). Nevertheless, many participants acknowledged the importance of conducting dementia screens where there is evidence of a clinical need, as long as healthcare professionals had the appropriate training. However, some participants made the point that an onwards referral (e.g., to a specialist memory clinic) may be a more appropriate and efficient use of limited clinical resources than conducting a dementia screen within the intervention itself.

Participants similarly acknowledged the potential benefit of conducting more detailed neuropsychological assessment batteries, recognising these assessments could provide more detailed insight into post-stroke cognitive changes. However, many participants were concerned about the feasibility of implementing these assessments routinely, given they require substantial time and specialist training to conduct and interpret. Again, some participants suggested the intervention should conclude with

onwards referral for a more detailed neuropsychology assessment where there is evidence of a specific clinical need.

3.7. Discussion

This modified Delphi survey sought to develop expert consensus on features of a UK-based monitoring and psychoeducational intervention for cognitive changes after stroke. Expert participants reached consensus on whether or not to include the majority (29/33: 87.88%) of intervention features identified from existing research and clinical guidelines. They agreed one-month, three-month, and six-month post-discharge cognitive reviews should be offered to those with and without cognitive impairments detected in hospital and that cognitive reviews should include a stroke-specific cognitive screen, additional measures of mood/anxiety and fatigue, and appropriate information on cognition. The importance of formal (e.g., training course) and informal training (e.g., training from colleague) for those responsible for conducting cognitive reviews was agreed. However, consensus was not reached on whether stroke survivors should be given the option to attend cognitive reviews online or in person, and whether reviews should also include a dementia screen or neuropsychological assessment battery, although rich qualitative feedback provided insights into important considerations and points of agreement with regards to these candidate intervention features.

Results from this study provide answers to key questions outlined by the JLA in their priority setting exercise, which identified post-stroke cognition as a top research priority (Hill et al., 2022; James Lind Alliance, 2022). With regards to assessing

cognition within the stroke pathway, participants agreed that a stroke-specific cognitive screen – like the OCS (Demeyere et al., 2015) – should be used as standard practice, recognising that the OCS offers advantages over other tools (Quinn et al., 2018). For example, the OCS was developed to be aphasia- and neglect-friendly and it can delineate impairments in multiple cognitive domains (memory, language, attention, executive function, number processing, praxis) (Iosa et al., 2022). Although a recent external psychometric validation indicated the OCS may lack sensitivity to impairments in memory (Murphy et al., 2023), results from our study suggest that supplementing the OCS with referral for additional tests where clinically indicated is a generally acceptable approach, in line with recommendations from clinical guidelines that cognitive support should be provided using a stepped- or matched- care model (Intercollegiate Stroke Working Party, 2023; NHS Improvement, 2011; Royal College of Physicians, 2016). Alongside cognitive screening, study results suggested the cognitive reviews should include brief screening for related post-stroke psychological sequalae – including mood, anxiety, and fatigue.

The JLA also asked in their set of key stroke research priorities how cognitive care interventions and services can be made accessible. Crucially, barriers to accessing healthcare exist at an individual level, as well as at structural and systemic levels (Tzenios, 2019). With regards to overcoming individual-level barriers, given the increasing provision of remote healthcare (Chapman et al., 2020; Fox-Fuller et al., 2022; Webb et al., 2022) and recent validation of cognitive screening tools – including the OCS – for remote use (e.g., Webb et al., 2023), survey participants were asked whether stroke survivors should be given the option to attend cognitive reviews

remotely, but they ultimately did not reach consensus on this item. While they acknowledged that offering remote reviews had the potential to improve access, there were concerns that conducting reviews remotely could lead to important behavioural and/or clinical information being missed and difficulty building rapport. Still, the modified Delphi survey shed some light on how systemic barriers to accessing post-stroke cognitive care might be addressed. Specifically, having been informed that the intervention would be administered by non-psychology specialist members of the stroke MDT, participants agreed that this approach should be feasible with appropriate training to conduct cognitive reviews. Ensuring non-psychology members of the stroke MDT are armed with skills and training to administer Level 1 cognitive care will be crucial to ensure the intervention is eventually widely accessible, given the substantial shortages in psychology specialist staff within the stroke care pathway (Gilburt & Mallorie, 2024).

Results from this study also support the provision of information about any cognitive impairments detected during reviews. Furthermore, given the well-evidenced association between post-stroke cognitive changes and later impairments in ADLs (Kwakkel & Kollen, 2013; Mole & Demeyere, 2018), participants agreed information on this relationship should be provided. Although research has suggested stroke survivors may not always reach full acceptance of and emotional adjustment to their impairments and that the adjustment process is complex and often non-linear (Smith et al., 2021), information provision is an important early step in developing awareness. According to the Y-shaped process model (Gracey et al., 2009), which builds on the self-discrepancy theory (Higgins, 1987), awareness of post-stroke changes is

intrinsically linked to later psychological outcomes (e.g., mood). Although an initial increase in awareness of cognitive impairment may threaten emotional wellbeing after brain injury (Boosman et al., 2014; Geytenbeek et al., 2017; Wheeler et al., 2022) – as recognising that 'who I am now is different to who I was' may be painful and stroke survivors may adopt maladaptive safety seeking and coping behaviours – onwards referral to Level 2 and 3 psychological interventions may help stroke survivors appraise cognitive changes in a less threatening way and practise compensatory strategies that enable them to engage in meaningful activities (Wheeler et al., 2022).

The study had several limitations. First, the survey was designed and submitted for ethical approval prior to the publication of the latest iteration of the National Clinical Guideline for Stroke in April 2023, meaning that survey items were informed by the earlier 2016 guideline. Nevertheless, our results remain in line with recommendations from the latest 2023 clinical guideline and provide important clarification on some points (Intercollegiate Stroke Working Party, 2023). For example, the most recent national clinical guideline has recommended that people with stroke should receive "appropriate supporting information and education regarding the findings [of the cognitive assessment], implications, and recommended approach to their cognitive problems" (p.114), with results of the present study highlighting the specific importance of providing information about potential cognitive trajectories, and support available, among other key topics. A second arguable limitation is that collaborative decision-making was boundaried to some extent, which may raise questions about the extent to which the approach can be accurately labelled as a co-productive one. Specifically, candidate intervention features were pre-selected to ensure the

intervention would be in line with recommendations for best clinical practice and would be firmly grounded in high-quality evidence and theory, as well as stakeholder perspectives. Nevertheless, this boundaried approach remained in line with the co-production definition endorsed in this thesis (Spencer et al., 2013: see Chapter 2 for full definition).

3.8. Reflections

Themes developed from qualitative data in this research project were largely descriptive, so analyses did not require overly deep interpretive engagement with the data. Nevertheless, reflexivity was still an essential part of the process. When analysing qualitative data from the first and final survey rounds, I made sure to turn the researcher lens regularly back onto myself (Berger, 2015), recognising that critical reflection about my own role in the research process would be crucial for promoting rigour wherever stakeholders were involved in the intervention design (Frauenberger et al., 2015).

When analysing qualitative data from the first survey round, I paid particular attention to my educational and occupational background in psychology. While participants had a diverse range of occupational backgrounds, early on in the data familiarisation process, I recognised my tendency to 'side' with psychological professionals, if and when participants shared contrasting views. When reading qualitative responses from healthcare professionals and researchers with a psychological background, their perspectives so often echoed my own thoughts about the intervention, so it was instinctive to assume they 'got it', to view their subsequent responses through a lens

of generosity, and to hold more space for their opinions. In contrast, where participants did not have a psychological background and their responses appeared to be coloured by a more medical mindset, I found myself interpreting their responses through a different lens, implicitly labelling their opinions as 'old fashioned' or discounting them as 'out of alignment' with the psychological approach being taken to develop this intervention. Having recognised this tendency, I was very conscious to remain open-minded and flexible to all ideas and opinions throughout the analysis to ensure the final results presented a faithful and comprehensive account of the data. To this end, I engaged in regular discussions with my supervisory team, with these non-judgemental conversations proving an invaluable space to share such reflections and consider the fullness and faithfulness of the theme structures before they were finalised.

3.9. Conclusions and chapter summary

Given the overarching aim of the research presented in this thesis was to develop an intervention providing Level 1 post-stroke cognitive care, the work presented in this chapter established expert consensus on features of the intervention. Experts reached consensus on most of the core design decisions addressed by the modified Delphi survey, including whether and when cognitive reviews should be offered to stroke survivors with and without cognitive impairment detected in hospital, what these reviews should include, and how training should be provided for healthcare professionals responsible for conducting cognitive reviews. Though the survey suffers from certain limitations, the results offer a crucially important and mutually agreed

minimum set of intervention features that builds on yet aligns with the initial intervention skeleton.

Chapter 4 Semi-structured interviews to explore the perspectives of stroke survivors and family members on core features of the complex intervention

4.1. Chapter overview

The previous thesis chapter presented a modified Delphi survey conducted to develop expert consensus on features of the intervention providing Level 1 post-stroke cognitive care. In line with the initial intervention skeleton, expert healthcare professionals and researchers who participated in the survey agreed the intervention should offer all stroke survivors cognitive reviews at multiple timepoints, and that the reviews should include – among other things – a stroke-specific cognitive screen and discussions about potential future cognitive trajectories.

As agreement was reached that the cognitive reviews should include a stroke-specific cognitive screen and discussions about potential future cognitive trajectories, this chapter presents two thematic analyses of semi-structured interviews conducted with stroke survivors and family members to explore their perspectives on these core intervention features (cognitive screening and cognitive trajectory discussions). These two analyses are presented in Part A and Part B of the chapter, which had the following more specific aims:

- **Part A:** To explore stroke survivor experiences of cognitive screening, with the hope that previous experiences may shed light on ways to improve the cognitive screening process within the complex intervention.

- **Part B:** To explore perceived advantages and disadvantages of discussing potential cognitive trajectories from the perspective of stroke survivors and family members to inform the extent to which the cognition trajectory guide outlined within the intervention skeleton would be helpful to develop.

Part A of this chapter begins with a recap of key background to the research question, a detailed summary of the methods used, the results and then a brief discussion. Part B also begins with a brief recap of key background, but the methods section is very brief, given that the data collection and analysis process were the same as for Part A. Results are presented, followed by a discussion. After presenting Parts A and B, I provide my own reflections on the process of data collection and analysis. Figure 4.1 shows the position of this research within the overall thesis.

4.2. Contribution

I contributed to the research presented in this thesis chapter by conceptualising the study, formulating the study aims and objectives, determining the study methodology, recruiting participants to the study, collecting data, transcribing data, analysing data, drafting the original research articles, editing drafts based on co-author feedback, and managing the submission processes. Prof Nele Demeyere was involved in conceptualising the study, formulating the study aims and objectives, advising on

study methodology, advising on results and evolving theme structure, and reviewing the original research article. Dr Eugene Tang was involved in conceptualising the study, advising on study methodology, advising on results and final theme structure, and reviewing the original research article. My PhD supervisors provided feedback on this chapter.

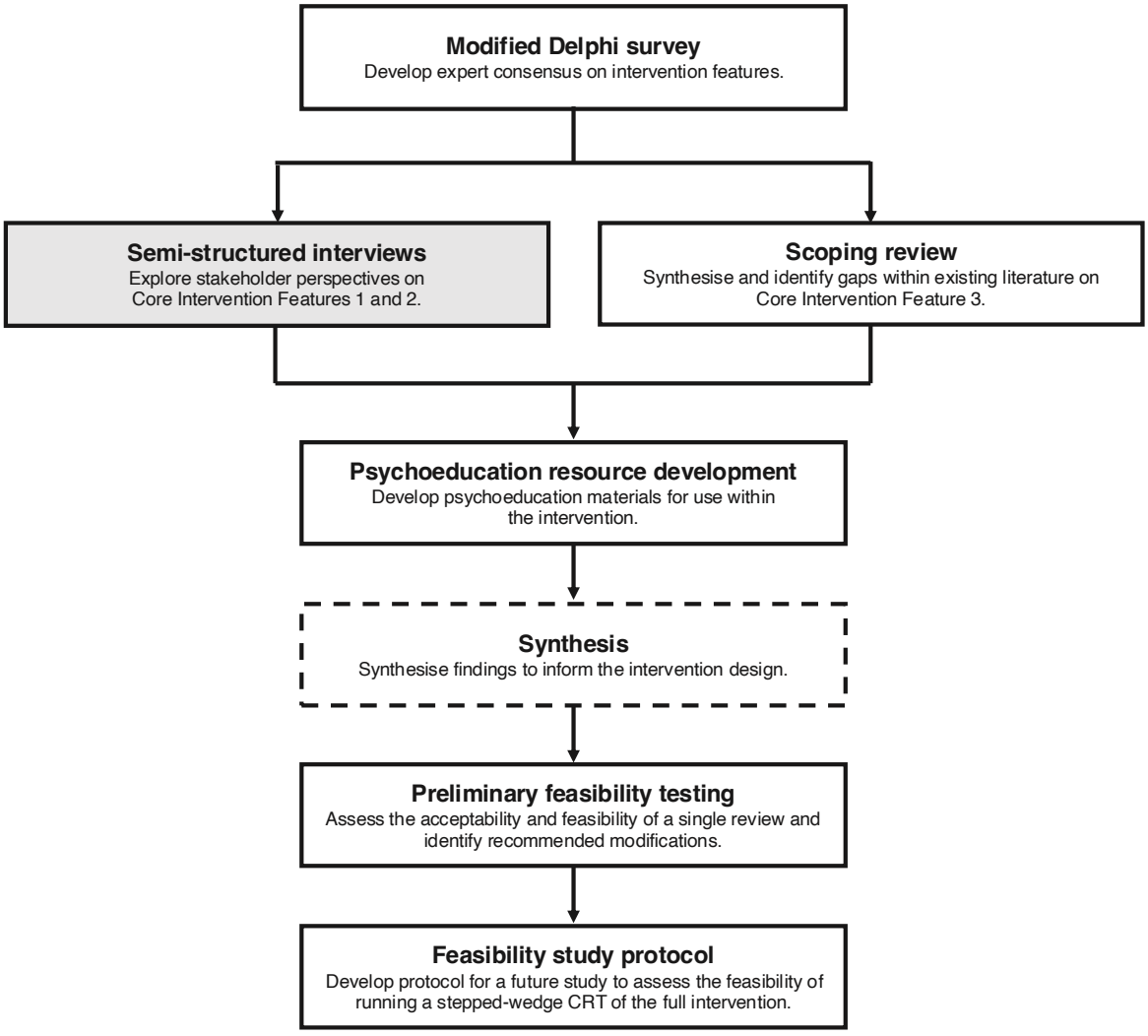


Figure 4.1. Position of semi-structured interviews (highlighted in grey) within the overall thesis.

4.3. Impact statement

Part A and Part B of this chapter have both been peer-reviewed and published separately:

- **Hobden, G.**, Tang, E.Y.H., & Demeyere, N. (2024). A qualitative study investigating the views of stroke survivors and their family members on discussing post-stroke cognitive trajectories. *Neuropsychological Rehabilitation*, 1-18.
- **Hobden, G.**, Tang, E.Y.H, & Demeyere, N. (2023). Cognitive assessment after stroke: A qualitative study of patients' experiences. *BMJ Open*, 13(6), e072501.

4.4. Part A: Experiences of cognitive screening

4.4.1. Background

Given the high prevalence of post-stroke cognitive impairment and its implications for recovery (Chapter 1), national and international clinical guidelines recommend that cognitive functioning should be assessed as soon as possible after stroke (Intercollegiate Stroke Working Party, 2023a; Royal College of Physicians, 2016; Stroke Foundation Australia, 2021; The European Stroke Organisation (ESO) Executive Committee and the ESO Writing Committee, 2008). Cognitive assessment tools designed specifically for stroke populations – such as the OCS (Demeyere et al., 2015) – are increasingly used for this purpose, as well as in community stroke settings (Ablewhite et al., 2019). These tools tend to be administered as a form of first-line screening for cognitive problems after stroke, with the idea that scores from these

assessments should inform tailored rehabilitation programmes (Ablewhite et al., 2019).

While national audit data confirm that over 90% of stroke survivors receive cognitive screening before discharge from inpatient settings (Intercollegiate Stroke Working Party, 2023), very little is known about stroke survivors' experiences of the cognitive screening process. This is despite increasing recognition of the value of person-centred care (Department of Health, 2013; NHS England, 2023a) and – correspondingly – patient-centred outcome research, which places emphasis on understanding patients' experiences, preferences, and needs to improve clinical practice (Bardes, 2012; Frank et al., 2014). Patient-centred outcome research in non-stroke populations (e.g., geriatric inpatients: Krohne et al., 2011; people with multiple sclerosis: Elwick et al., 2022) has indicated that some patients may not fully understand the purpose of cognitive assessments and that cognitive assessments may in some cases provoke intense emotions, like shame and irritation (Elwick et al., 2022; Krohne et al., 2011). It is critical to explore whether stroke survivors similarly struggle to understand the purpose of stroke-specific cognitive screening and whether the process also elicits strong emotional responses, in order to identify ways to protect stroke survivors' psychological and emotional wellbeing before, during, and after the cognitive screening process within the intervention.

The aim of this study was therefore to explore stroke survivors' experiences of the post-stroke cognitive screening process, through qualitative analysis of semi-structured interviews with stroke survivors and their family members. I hoped that

exploring past experiences would highlight aspects of 'good' and 'bad' clinical practice and thus shed light on ways to improve current and future practice, including within the intervention developed in this thesis. Indeed, in the context of this thesis, I saw this as a crucial question, given that the initial intervention skeleton highlighted cognitive screening as a core feature of cognitive reviews and modified Delphi survey participants agreed on the importance of stroke-specific cognitive screening within the cognitive reviews (see Chapter 3).

4.4.2. Methods

Ethics and research governance approval

The University of Oxford Medical Sciences Interdivisional REC provided ethical approval for this study (University of Oxford REC Reference: R80681/RE001).

Participant recruitment

Stroke survivors were recruited from a pool of research volunteers who had previously taken part in the OCS-Recovery study (NHS REC Reference: 18/SC/05501) and consented to being contacted for future ethically approved studies. The OCS-Recovery study originally recruited a sample of stroke survivors meeting the following eligibility criteria from the acute stroke inpatient unit at Oxford University Hospital (John Radcliffe), UK: at least 18 years old, clinical diagnosis of stroke, and ability to remain alert for at least 20 minutes (Milosevich et al., 2024).

Stroke survivors who had taken part in the OCS-Recovery study and consented to being contacted for future studies were purposively sampled and invited to take part

in this study. A purposive sampling approach was used to ensure the final sample included stroke survivors varying in the following characteristics: age, gender, stroke severity, cognitive profile (i.e., domain and severity of cognitive impairment, including those with no cognitive impairment). This approach was founded on the hypothesis that these stroke survivors may have different perspectives on the research questions (e.g., stroke survivors with no cognitive impairments may have had a less emotive cognitive screening experience). Purposive sampling based on these characteristics was conducted using data collected on entry to the OCS-Recovery study (see below for further detail on data collection procedures).

Potential participants were contacted by telephone and given a brief description of the study, as well as the opportunity to ask any questions. Stroke survivors who expressed initial interest were then sent a detailed information sheet and consent form by email or post, depending on their preference. They were invited to consider the information for as long as needed and to contact the research team if they had further questions or would like to participate. Those who said they would like to participate were asked to organise a date for the semi-structured interview and it was made clear that they could have a family member present if they preferred. Family members of purposively sampled stroke survivors were also invited to participate in the research. All participants provided written informed consent immediately before the semi-structured interview started.

Data collection

A topic guide was developed for the semi-structured interviews based on previous literature relevant to the research questions (e.g., Burton et al., 2021; Cheng et al., 2022; Elwick et al., 2022; Krohne et al., 2011; Tang et al., 2019) and research team input. The guide was designed to be iterative so that topics not originally identified could be pursued in later interviews. The topic guide comprised mostly open-ended questions to allow flexible dialogue and ad hoc questioning, and to encourage participants to share their thoughts without undue biasing. However, the questioning style was adapted for stroke survivors with cognitive impairments impacting their communicative abilities within the interview (e.g., aphasia limiting expression and/or understanding, memory impairments limiting recall) by using communication support strategies (e.g., probing, word offerings) (Luck & Rose, 2007). The topic guide included questions relevant to both Part A and Part B of this chapter but data from these questions were analysed and are presented separately. The final topic guide is presented in Appendix 2.

Within the interview, the term ‘thinking skills’ was used instead of ‘cognition’. The following explanation was given to introduce questions pertaining to cognitive trajectories (Part B): “We know from research that thinking skills change in the months after stroke. In some cases, thinking skills get better, although they may not go back to exactly where they were before the stroke. However, sometimes they don’t recover and sometimes they may even get worse. Sadly, people who have a stroke are more likely to develop dementia.”

Semi-structured interviews were conducted between May 2022 – September 2022. The interviews took place either at participants' homes or via telephone or videocall (Microsoft Teams), with interview locations determined by participants' preferences. Most interviews were conducted individually (i.e., researcher and one participant). However, participants were interviewed in pairs (i.e., researcher and two participants) if both the stroke survivor and their family member preferred to take part together. Interviews were audio recorded with participants' consent and transcribed verbatim using Jeffersonian Lite style (Potter & Hepburn, 2005). Though time consuming, I considered the transcription process to be an important part of the familiarisation stage of data analysis (Braun & Clarke, 2006, 2021a). All identifiable personal data (e.g., names) were removed from the transcripts and transcripts were labelled using unique participant identifiers to protect participants' anonymity.

Demographic and clinical data on stroke survivor age, gender, stroke severity, and cognitive profile were retrieved from previous research data collected for the OCS-Recovery study. Stroke severity was assessed by hospital staff during acute inpatient admission using the National Institute of Health Stroke Scale (NIHSS) (Brott et al., 1989) and cognitive profile was also determined acutely by hospital staff using the OCS (Demeyere et al., 2015). Cognitive profile was determined using normative data, with further detail on OCS administration and scoring provided elsewhere (Demeyere et al., 2015). I collected demographic information on family member relationship to the stroke survivor immediately before conducting the interview.

Data analysis

Two separate reflexive thematic analyses were conducted using the interview data (presented in Part A and Part B), with both analyses guided by the processes and principles outlined by Braun and Clarke (2006, 2013, 2019a). While recognising the availability of myriad thematic analysis approaches (Chapter 2), reflexive thematic analysis was selected for several reasons. First, as a method that is regularly employed within constructionist, interpretivist, critical realist frameworks (Braun & Clarke, 2019a, 2021a), reflexive thematic analysis was compatible with the philosophical positioning of this research (critical realism). Second, its emphasis on being a reflexive researcher and considering positionality, yet its conceptualisation of the interpretive role of the researcher as an asset rather than a threat, also seemed ideal for this project. Indeed, I recognised how challenging it would be to view individual experiences of cognitive screening objectively, particularly given my own clinical experience working on the hyperacute stroke unit at the John Radcliffe Hospital, where I regularly witnessed post-stroke cognitive screening, and my commitment to improving post-stroke cognitive care, which I considered to be falling below ideal standards. Acknowledging that we may unknowingly re-construct the stories of others based on our own subconscious frameworks formed through our unique lived experience, I considered how my own lived experiences might add colour and context to individual participants' stories, but I also recognised the importance of transparently 'owning' my interpretive and potentially also reconstructive role in the project. Finally, reflexive thematic analysis generally encourages an interpretive approach where the researcher goes beyond a descriptive level to identify broader meanings and implications (Braun & Clarke, 2006, 2013, 2019a). I considered how

this depth of engagement would be crucial to fully capture the significance of an individual's lived experience within broader clinical and personal contexts.

When collecting data, the topic guide was not followed rigidly but rather conceptualised as a loose framework to ensure key topics were addressed. Therefore, it was not possible to parse the transcripts cleanly into two sections addressing Part A and Part B of this research project. Instead, I familiarised myself with the interviews in their entirety by transcribing each of them, then reading and re-reading the transcripts, while making rough working notes. Then, I coded sections of the transcripts relevant to both Part A and Part B at a semantic level. Codes and accompanying data extracts were then parsed, such that codes and quotations deemed most relevant to Part A were kept separate from codes and quotations deemed most relevant to Part B. Henceforth, these sets of codes were considered and analysed entirely separate from one another, which I acknowledge to be a pragmatic decision yet suggestive of a somewhat false dichotomy, given the highly interrelated nature of the research questions.

Data were coded using the comment function in Microsoft Word, with coding taking place as the interviews progressed, rather than at the end of the data collection process. Coding was positioned more towards the semantic end of the spectrum, as I was keen in the early stages not to extrapolate too far beyond what participants themselves had said during interviews. Codes and accompanying data extracts were compiled in a Microsoft Excel file and, from this, I was able to start looking for larger patterns within the dataset, grouping related codes into initial themes. At the beginning, I tried to ensure theme development was mostly steered by the data but,

as I became increasingly familiar with the dataset, I allowed myself to take on a more interpretive role, moving beyond surface level descriptions in order to identify "patterns of meaning, underpinned by a central organising concept" (Braun & Clarke, 2017, p.297). Oftentimes, this meant revisiting data extracts and semantic codes to consider meanings that potentially lay beyond the surface. Rather than seeing this interpretive role as a threat to the reliability of the analysis, I considered it a crucial asset, particularly as participants often struggled to find words for their experiences, either because of post-stroke cognitive changes or – possibly – a limited emotional vocabulary or reluctance to disclose stigmatised emotions (e.g., shame). Throughout the analysis process, using and updating a single Microsoft Excel file allowed me to consider the evolving themes and subthemes at a glance and to establish the extent to which they were supported by data, enabling me to recognise where my interpretation had perhaps gone 'too far'. It was also straightforward to adjust theme titles, boundaries, and their order to ensure that they were both faithful to the data and comprehensive. My supervisor read a subset of eight transcripts to gain familiarity with the data. Regular discussions with my supervisor and other members of the research team provided useful alternative perspectives to consider and gave me confidence that important aspects of the data had not been overlooked.

Firmly rejecting the idea that data saturation – however defined – should determine the point at which data collection and analysis are stopped (Braun & Clarke, 2019b), I decided to stop data collection and analysis by weighing two factors: (1) Extent to which the themes and subthemes provided rich and nuanced insight into the research questions, and (2) Pragmatic constraints on time and resources, imposed by both my

PhD research programme and the timetable laid out within the NIHR fellowship by which this research was funded. Ultimately, the decision to stop data collection and analysis was an inevitably subjective one, which was considered carefully and discussed in depth with my supervisory team. In line with the reflexive thematic approach, the analysis and final theme structure are acknowledged to be situated, partial, and provisional and there was no ambition to generate a reliable and reproducible account of the data (Braun & Clarke, 2013, 2019a, 2021a). Nevertheless, research team agreement on the final theme structure gave me confidence that the results represented a faithful and informative account of the data. Still, writing was an integral part of the analysis that helped me reflect further on latent meanings and consider the interrelatedness of themes. These considerations informed final subtle revisions to theme and subtheme titles, as well as boundaries between them. Throughout the data collection, analysis, and writing process, it was crucial for me to bear in mind and 'own' any interpretations I was making based on my own assumptions and experiences. Any considerations along these lines were recorded in an electronic journal, with key reflections summarised in Section 4.6.

4.4.3. Results

A total of 37 participants were interviewed, including 26 stroke survivors and 11 family members. Of the 26 stroke survivors, 9 (34.62%) were female and the mean age was 74.11 years (*SD* = 7.58, range: 54.79-87.02). The mean cognitive impairment severity score (number of OCS tasks impaired at the acute/subacute stage of stroke) was 3.45 (*SD* = 3.02, range: 0-11). Across the sample, participants showed acute/subacute impairments affecting all of the cognitive domains assessed, including memory (*n* =

9), language (*n* = 6), visuospatial attention (*n* = 11), executive function (*n* = 3), praxis (*n* = 7), and number processing (*n* = 6). The mean stroke severity (NIHSS) was 7.05 (*SD* = 5.34, range: 0-18). Of the 11 family members interviewed, 9 (81.82%) were female, 9 (81.82%) were spouses and 2 (18.18%) were children. Table 4.1 reports demographic and clinical data for the stroke survivors and family members interviewed in the present study.

All participants completed one interview session, except one stroke survivor and their family member, who completed two interview sessions, as a technical error resulted in deletion of the first audio-recording. The mean time between stroke and interview was 345.46 days (*SD* = 187.36, range: 109-631). A total of 17 interviews were conducted in person and 11 interviews were conducted remotely via telephone. Interviews lasted on average 46.93 minutes (*SD* = 24.28, range: 14-119).

The following themes were identified: (1) Difficulty understanding the purpose of the cognitive assessment, (2) Variable but potentially intense emotional responses, and (3) The power of cognitive assessment feedback. Themes and subthemes are described in detail below.

Variable	Statistics
Stroke survivors, *N*	26
Age, range (*M, SD)*	54.79-87.02 (74.11, 7.58)
Gender, *N (%)*	
Female	9 (34.62)
Male	17 (65.38)
Cognitive impairment severity (OCS), range (*M, SD)*	0-11 (3.45, 3.02)
Domain-specific cognitive impairments (OCS), *N (%)*	
Memory	9 (34.62)
Language	6 (23.08)
Visuospatial attention	11 (42.31)
Executive function	3 (11.54)
Praxis	7 (26.92)
Number processing	6 (23.08)
Stroke severity (NIHSS), range (*M, SD)*	0-18 (7.05, 5.34)
+Family members, *N*	11
Gender, *N (%)*	
Female	9 (81.82)
Male	2 (18.18)
Relationship, *N (%)*	
Spouse	9 (81.82)
Child	2 (18.18)

Table 4.1. Demographic and clinical data characterising semi-structured interview participants. Stroke survivor participant data are presented first, followed by very basic family member participant data. Cognitive impairment severity was measured using the number of OCS tasks impaired (out of 12) during acute/subacute hospital admission as an imperfect proxy. A higher score reflects more severe cognitive impairment. Task impairment was binarized using cut-off scores derived from normative data. Domain-specific cognitive impairments were also determined using acute/subacute OCS data. Domain impairment was binarized, with impairment denoted by at least one task impairment in a task designed to tap the relevant domain. The following tasks corresponded to the following domain-specific impairments. Memory = Orientation, Verbal Recall and Recognition, Episodic Memory. Language = Picture Naming, Semantics, Sentence Reading. Executive Function = Trails Executive Score. Visuospatial Attention = Broken Hearts Allocentric Score, Broken Hearts Egocentric Score. Praxis = Imitation. Number processing = Number Writing, Calculation. Note that the OCS is a screening tool and is likely to have failed to detect more subtle impairments in these domains so the numbers presented here may be an underestimation of cognitive impairment prevalence within the sample. Stroke severity

was measured using the NIHSS (range: 0-42) during acute/subacute hospital admission, with a higher score denoting a more severe stroke. +Note the aim of the purposive sampling approach was to recruit a relatively diverse group of *stroke survivor* participants; the diversity of *family members* was not a consideration. This approach resulted in a seemingly homogeneous sample of family members according to the above demographic data.

Difficulty understanding the purpose of the cognitive assessment

Lack of explanation.

Stroke survivors generally showed a very limited understanding of the purpose behind cognitive assessments, which many participants attributed to the fact that the assessment administrator *"didn't explain much"* (Stroke Survivor 12) before beginning the assessment. When asked about their understanding of the purpose behind post-stroke cognitive screening, some participants failed to refer to cognition or thinking skills at all. For example, one participant stated that cognitive assessments are used *"just [to see] what your brain's like"* (Stroke Survivor 12). Others showed a very basic understanding of how cognitive assessments are used to detect problems in patients' thinking abilities after stroke. However, participants tended to describe this in vague and sometimes circular terms.

> *Basically, it's an assessment to see how you are and... I don't suppose they used the phrase 'what damage has been done' but to get an assessment of where you're at, what your cognitive state is really.* (Stroke Survivor 1)

In several interviews, participants referred to cognitive assessments as *"memory tests"* (Stroke Survivors 6 & 13, Family Members 4 & 5). These participants seemed to

recognise the role of post-stroke cognitive assessments in detecting memory problems, but not deficits in other cognitive domains. No participants mentioned the role of post-stroke cognitive assessments in detecting aphasia or visuospatial neglect, despite several participants having demonstrated these domain-specific cognitive impairments on cognitive screening tests according to their inpatient OCS results.

> *All she's had is a memory test. Nobody else, to my knowledge, has done anything with her.* (Family Member 5)

Some participants who claimed they received little explanation about the cognitive assessment and its purpose spoke as though they were simply doing the assessment administrator a favour. This was particularly true of stroke survivors with no cognitive impairment detected on the OCS as an inpatient, raising the possibility that their seemingly intact cognitive abilities led the assessment administrator to skim over the explanation.

> *[The cognitive assessments] were alright, you know. I persevered with 'em. Yeah, okay, you want me to do that, I'll do it. I don't really want to.* (Stroke Survivor 7)

Struggling to see the value.

The lack of explanation about the cognitive assessment meant that many participants failed to recognise the value of cognitive assessments – for example, for shaping their rehabilitation programmes and care packages. Some participants employed pejorative

expressions to describe them, such as *"stupid"* (Family Member 8) and *"pointless"* (Stroke Survivor 14).

> *She was like "Why am I doing these stupid things?" and all that.* (Family Member 8)

Viewing the cognitive assessments as useless was particularly common among participants who presented with cognitive impairments on the OCS whilst in hospital, raising the possibility that viewing the assessment as useless served as a psychological defence mechanism to deny the cognitive impact of stroke. One participant with impairments in six tasks on the OCS according to their inpatient data argued that cognitive assessments are pointless as they are too *"naïve"* (Stroke Survivor 20) to detect cognitive impairment. Another participant with impairments in four tasks and severe expressive aphasia continuing into the chronic stage post-stroke referred simply to the assessments as *"a load of old c***"* (Stroke Survivor 5) and described how this perspective was a barrier to engaging with the process.

> *The questions were naïve in their... You can't do a questionnaire like that when your audience is so varied, the people taking it. I don't think it works.* (Stroke Survivor 20)

> *I didn't really engage with [the cognitive assessment] anyway because I thought "oh, it's a load of old c***".* (Stroke Survivor 5)

Variable but potentially intense emotional responses.

When participants discussed their experiences completing the cognitive assessment, it seemed that the cognitive assessments had provoked a variety of emotional responses among stroke survivors. Whereas some participants appeared to enjoy the assessment, describing the experience as *"fun"* (Stroke Survivor 12) and a welcome *"break from the boredom of being in hospital"* (Stroke Survivor 21), other participants reported negative emotional responses to the assessment, including frustration, distress, and anxiety. Several factors appeared to moderate these emotional responses to the cognitive assessment process, predominantly those described below.

Emotional responses depend on perception of the assessment's purpose.

Stroke survivors' perception of the purpose behind the cognitive assessment seemed to influence their emotional response to it. One participant who reported enjoying the assessment referred to it benignly as *"a little challenge"* (Stroke Survivor 25), whereas several other participants perceived the assessment more threateningly as a test or exam, designed to pinpoint weaknesses in their cognitive abilities. Some participants drew comparisons between the cognitive assessment and their experiences of anxiety-provoking exams in childhood, speculating that their anxiety may have impeded their performance.

> *One thing that's happened here is I'm constantly worrying, just as I did at school, you know, if I got...say in Maths or Arithmetic, as it used to be called, you suddenly had a test in front of you, and I literally found myself thinking "No,*

no, I can't." And that made seeing it or focusing on it much more difficult. (Stroke Survivor 4)

If I've got a test coming towards me, I'll get "Oh Christ" because it gets back to school, back to tests kind of thing, so I'll get that...anxiousness...anxiety about it. (Stroke Survivor 5)

For some stroke survivors, perceiving the assessment as a test or exam tended to be *"kind of motivating but motivating in a negative way"* (Stroke Survivor 5), as they felt they had to prove something to themselves or to the assessment administrator.

*You were quite anxious beforehand about the assessment. You appeared very calm, but your concentration was ferocious in doing it. Almost I could see sort of a bubble coming out of your head saying "I'm b***** well going to show them and I'm going to get all these answers right."* (Family Member 7)

This feeling seemed to interact with patients' diminished self-confidence after stroke, as some stroke survivors described how performing poorly in the 'test' made them feel *"not good enough"* (Stroke Survivor 5). Others described more broadly their fear that the assessment would reflect their self-worth.

Oh my god! I'm being tested here. The result will reflect what I am. (Stroke Survivor 4)

Emotional responses depend on perception of cognitive impairment.

Stroke survivors' emotional responses to the cognitive assessment also seemed to be shaped by their perception of what it meant to be diagnosed with a post-stroke cognitive impairment. Recognising the potential to recover from cognitive impairment after stroke meant that patients were less likely to endorse cognitive impairment as a shameful element of their personal identity, and instead saw it as something that could be overcome with time. In turn, this seemed to reduce feelings of anxiety about the cognitive assessment itself. Similarly, by realising that stroke and cognitive impairment can affect anyone, stroke survivors seemed to be protected from feelings of shame and embarrassment while completing the tasks, as they identified cognitive impairment as a potential part of the *"human condition"* (Stroke Survivor 20), rather than as a problem exclusive to them.

> *I wasn't particularly concerned [when I got a question wrong]. I probably didn't realise the implications of it, and I just wanted to get onto the next part of the questionnaire or whatever it was we were engaged in. And I wasn't in any way embarrassed by it and that's actually been a part of the stroke all the way through. I mean, 'lots of people have strokes' was my sort of global rationale for this terrible thing that has happened to me. Lots of people have strokes and a lot of them get over these strokes, so that kept me going, even if I didn't know the answers to the next question. And I've never been...I've not been at all embarrassed by this. I just see it as part of the human condition.* (Stroke Survivor 20)

Similarly, several participants with cognitive impairments adopted a pragmatic problem-solving perspective, viewing post-stroke cognitive impairment as an issue to be addressed, rather than a stigmatising diagnostic label.

> *If you asked anybody who knew me, they would say, you know, my glass is definitely...it's not half full, it's three quarters full! I'm very positive about everything and if things aren't quite right, well, then you either change them or you make them right somehow.* (Stroke Survivor 16)

> *My way through this at that point was we have to fix this, and we have to come back out and get over the stroke, and I'll use any method I can to do that, so there was no soppiness.* (Stroke Survivor 20)

Emotional responses depend on confidence in cognitive abilities.

Emotional responses to the cognitive assessment also seemed to be moderated by patients' confidence in their own cognitive abilities after stroke. Stroke survivors who were confident that their stroke had not affected their cognitive skills seemed to be less anxious during the cognitive assessment, compared to stroke survivors who expected the assessment to detect weaknesses in their cognitive abilities.

> *Maybe if I had cognitive problems from the stroke, I might have felt different and more awkward about [the cognitive assessment].* (Stroke Survivor 3)

> *I feel actually quite nervous because I think "I'm not going to get this right, I'm going to get it wrong".* (Stroke Survivor 5)

Similarly, stroke survivors' emotional responses during the assessment seemed to reflect their perceptions of their performance in the assessment. Whereas stroke survivors described feelings of *"relief"* (Stroke Survivor 24) when they felt they had done well in the assessment, participants who felt they had done poorly described feelings of failure or shame.

> *I felt that I was failing it, you know, so it felt pretty lousy, to tell the truth. It felt pretty lousy.* (Stroke Survivor 17)

Emotional responses depend on assessment administration style.

Finally, stroke survivors' emotional responses during the cognitive assessment seemed to be influenced by external factors, such as how the cognitive assessment was administered. Several stroke survivors expressed gratitude for the *"gentleness"* (Stroke Survivor 4) and patience with which the therapist administered their cognitive assessment, as this approach made them feel more comfortable during the assessment and reduced feelings of anxiety. One stroke survivor highlighted the brutality of the hospital environment and explained how cognitive assessments – when administered with patience and gentleness – could provide an important counterpoint.

> *Really the thing about hospitals is how brutal they have to be in some ways and the thing that I, you know, once or twice thought about was but please be gentle*

too because we're lying here, not quite able to explain to you how we're feeling. (Stroke Survivor 4)

In direct contrast, one participant with aphasia described the negative emotional consequences of pressurised administration, explaining how perceived pressure to answer questions quickly compounded his frustration during the cognitive assessment.

I was so frustration...frustration...frustrated that I couldn't actually do this. A! B! I also felt under tremendous pressure to get answers quickly, kept going, and I found that quite tricky that, you know, I should be...I felt I should be doing 20 answers, for example, but would do only 3, so I was very frustrated. I felt a sense of pressure from the therapists that I needed to [do] things and get on and sort things. And...so...I didn't...Not only I was frustrated but I was also...I felt that I was failing it. (Stroke Survivor 17)

Similarly, several caregivers felt that the assessment administrator did not sufficiently account for the impact of post-stoke fatigue, pushing patients to continue with the assessment when they were tired, which affected both patients' test performance and emotional response during the assessment.

Sometimes the therapist didn't realise just how tired you feel after you've had a stroke and they would come in bright and breezy, all cheery, which was lovely, but they didn't always seem to know when that was enough and [the stroke

survivor] was actually getting very tired and therefore not getting so many answers right, which increased the frustration and the sense of him feeling that he was a failure because he couldn't get them. (Family Member 7)

The power of cognitive assessment feedback.

Stroke survivors reported receiving varying amounts and types of feedback after completing the cognitive assessments, suggesting a potential lack of consistency in the reporting of cognitive assessment results. Several participants described the encouraging effects of positive feedback (i.e., feedback highlighting intact cognitive abilities/cognitive strengths), whereas others referred to the feedback as vague and unhelpfully complicated by jargon, which had a demoralising impact in some cases.

Feedback can impact self-confidence and self-efficacy.

Several participants drew a contrast between the confidence-damaging nature of stroke and the potential for positive feedback after a cognitive assessment to restore diminished self-confidence. This was particularly common among participants with cognitive impairments detected on the OCS while in hospital, suggesting that encouragement may be especially important when patients are struggling with the tasks. Participants described how positive feedback after completing the cognitive assessment provided much needed reassurance, during a period of vulnerability that had arrived without warning or expectation.

For many of us, I guess we temporarily are, we're back in our childhood, where to get approval and to have to somebody say "Well, that is, you know, really

amazingly good!", even if it isn't, will make the world of difference, I think, because it brings back the confidence, which has been absolutely shattered by this [...] blow from above. (Stroke Survivor 4)

It's quite an experience having a stroke. I was really knocked for six because I didn't think I was in that category. [...] And to be able to complete well the tests, I was quite pleased really. [...] The person that came round was very reassuring that you were doing really well so that made me feel quite good. (Stroke Survivor 1)

Many stroke survivors seemed to adopt a critical perspective of their own performance in the cognitive assessment, assuming they had done poorly. These participants seemed to particularly appreciate positive feedback, as oftentimes it reassured them that their cognitive abilities were not as damaged by the stroke as they had assumed, which in turn promoted feelings of self-efficacy (i.e., confidence in their skills/abilities).

At first, when I completed the [cognitive assessment], I was a bit maybe disappointed, thinking "Oh, I didn't do very well on this. [...]" But when [the therapist] explained to me that this is absolutely quite normal and in fact I was at least average, if not better than average given my particular situation, it made me feel a lot...a lot...okay, and making decent progress, so it was quite positive. (Stroke Survivor 18)

One family member referred to her husband's self-critical tendencies after the stroke and speculated that professional feedback highlighting his cognitive strengths could have reminded him of his intact abilities and increased his sense of self-efficacy, but she was disappointed this had not happened in practice. Instead, she described how the small amount of feedback provided was biased towards the patient's weaknesses, rather than encapsulating areas in which he had performed well.

> *Possibly [the stroke survivor] is his own worst critic [...] Some objective outside discussion would be very, very helpful. [...] They've been terribly good at telling us how bad [the stroke survivor] is but they're not terribly good at telling us how good he is.* (Family Member 1)

Vague feedback and clinical jargon are unhelpful and potentially alienating.

Some stroke survivors and caregivers felt disappointed at the lack of concrete feedback provided after their cognitive assessment. Several participants described how the assessment administrator wrote down results, without communicating them directly. One participant reflected that such behaviour could leave patients with *"the vague feeling 'Oh dear, I made a right mess.'"* (Stroke Survivor 4), which she suggested could be damaging to patients' self-confidence.

> *There's a lot of stuff written but then that's not discussed with you. And that's actually...that aspect is not good.* (Family Member 1)

Several participants also discussed how the use of complex terminology and clinical jargon was a barrier to understanding feedback from the cognitive assessments, highlighting the need for feedback to be communicated to patients clearly using lay language.

> *[Reading from therapist report] "I get 13 out of 16. Not bad. Visuospatial." Well, I don't b***** hell what that means! 'Visuospatial'!* (Stroke Survivor 17)

Some participants felt so alienated and confused by clinical jargon that they resorted to seeking definitions themselves. One participant described how he consulted the dictionary to understand the meaning of the word 'cognition'.

> *I went out to the [...] dictionary about three months ago to ask one question – "What does that mean?" [...] 'Cognition' [...] [Reading from a typed sheet of paper] 'What are the eight cognitive skills? The eight core cognitive capacities. Sustained attention... Response...' Well, that's very helpful! I thought that was actually very useful, thank you very much, Mr Wikipedia or whoever you are! That's exactly what I wanted. I wanted to know what cognition meant.* (Stroke Survivor 17)

Some participants provided suggestions to improve the interpretability of feedback after cognitive assessments. For example, one family member suggested that visual feedback might be better than verbal feedback as this would help avoid clinical jargon.

Something visual is probably the easiest. Jargon-y words are probably not so helpful and a score that just says "You got 10 the first time and 40 the second", I don't think is that much help, but anything that is visual would be quite encouraging, I think. (Family Member 8)

Another participant suggested linking cognitive impairments to ADLs when providing feedback. She reflected that illustrating the impact of cognitive impairments on daily life would have made feedback more interpretable and meaningful.

You've always enjoyed cooking. It's got a bit better now but actually, if there's a menu, you have great difficulty trying transferring from reading – not great difficulty – but reading what it says and then sort of working out what you therefore do or what order. And again, that's a sort of tiny bit of one of cognition, probably one of those elements. But actually, somebody saying "Well, let's illustrate this with how you go about cooking" would be really helpful, I think. I think big words don't help. (Family Member 7)

4.4.4. Discussion

Results from the semi-structured interviews with stroke survivors and their family members suggested that the purpose of cognitive assessments was not always well understood, potentially due to a lack of explanation beforehand, and that lack of understanding – on some occasions – was a barrier to engagement. Cognitive assessments also seemed to have the potential to evoke strong but heterogeneous emotional responses, which seemed to depend on how patients perceived the

assessment, post-stroke cognitive impairment, their own cognitive abilities, and how the assessment was administered. Finally, analysis of the semi-structured interviews highlighted the power of feedback after cognitive assessments. While constructive feedback appeared to promote feelings of self-confidence and self-efficacy, vague or overcomplicated feedback seemed to have a potentially demoralising and alienating impact on stroke survivors and their family members. These results have important implications for conducting cognitive screening assessments in clinical practice, including within the intervention developed in this thesis. Specifically, they highlight the importance of sensitively communicating the purpose and significance of the post-stroke cognitive screening process, as well as results, and ensuring this information is understood by stroke survivors and their family members.

Stroke survivors and family members in the present study generally showed a very limited understanding of the purpose behind post-stroke cognitive screening and their role in guiding clinical care. While this echoes the results of previous studies in other clinical populations, which similarly found poor understanding of the cognitive assessment process among multiple sclerosis (Elwick et al., 2022) and geriatric patients (Krohne et al., 2011), the underlying cause of poor understanding among stroke survivors and family members here is unclear. Although participants often put their limited understanding down to a lack of explanation provided by the assessment administrator, it is also possible that they may have struggled to understand, interpret, retain, and/or communicate within the interview the information provided, a hypothesis also posited by Krohne et al. (2011). This alternative explanation is supported to some extent by the high prevalence of acute/subacute cognitive impairment within the stroke

survivor sample, which may have impeded understanding and/or retention of any explanation provided by a healthcare professional. Indeed, 23 out of 26 (88.50%) stroke survivor participants had at least one task-level impairment on the OCS while in hospital, a cognitive impairment rate that is towards the upper end of previous estimates of cognitive impairment prevalence in the first weeks after stroke (Demeyere et al., 2016; Hurford et al., 2013; Lesniak et al., 2008; Milosevich et al., 2024; Nijsse et al., 2017; Turunen et al., 2018). Difficulties retaining information about the cognitive assessment may have been further compounded by the substantial time that elapsed between the cognitive screen being administered while in hospital and the interview itself, which took place more than six-months after stroke. Still, should the results be explained by difficulties retaining the information, this highlights the potential value of additionally providing the information in written format within the intervention.

Cognitive assessments seemed to trigger various emotional responses for stroke survivors, which were moderated by several different factors. First, perceiving the assessment as a test seemed to trigger feelings of anxiety, in line with the psychological theory of test anxiety (Zeidner, 1998). Crucially, not only is test anxiety potentially detrimental to emotional wellbeing, it may also disrupt attention and memory function, potentially impacting the validity of cognitive screening results (Angelidis et al., 2019). It is worth considering, therefore, whether patient-facing language used within the intervention should be adapted so that terms such as ‘puzzles’ or ‘activities’ replace the anxiety-provoking clinical terminology of ‘tests’, ‘examinations’ and ‘screens’. Secondly, recognising the potential to recover from post-stroke cognitive impairment seemed to protect patients from feeling shame and

embarrassment, which suggests they may benefit from healthcare professionals outlining stroke recovery statistics for specific cognitive domain impairments (e.g., Demeyere et al., 2019; Nys et al., 2005) to support their understanding of 'what it means' to be diagnosed with a cognitive impairment, though the potential advantages and disadvantages of discussing potential cognitive trajectories – encompassing recovery, stability, and decline – will be addressed in further detail in Part B of this chapter. Finally, perceived pressure during assessment administration seemed to be detrimental to psychological wellbeing, highlighting the need for healthcare professionals to set aside sufficient time to complete cognitive screening, and to be mindful of being supportive and constructive during the assessment.

Stroke survivors reported receiving different amounts and types of feedback after the cognitive assessment. Here again, there are several potential reasons for this finding. Similar to the above posited explanation for the observed poor understanding of cognitive assessment purpose, cognitive impairment, psychological 'shock', and/or the length of time between inpatient cognitive screening and the semi-structured interviews may have limited participants' ability to understand, retain, and communicate accurately their clinical experience. This explanation supports the importance of repeating verbal feedback and accompanying it with visual supports within the intervention to aid understanding and retention of the information. The results also suggest a potential lack of consistency in the feedback provided in clinical practice, highlighting the need for clearer guidance through structured training to standardise the cognitive screening feedback provision process and ensure all stroke survivors receive high-quality information. Any training developed should consider the

potential psychological impact of cognitive assessment feedback, as the present study revealed how feedback can improve confidence and self-efficacy, both of which have been identified as important factors in promoting post-stroke recovery (Jones et al., 2008; Maujean et al., 2014). Training should also emphasise the importance of providing feedback using lay terminology, echoing the results of previous research on patient responses to jargon in other clinical populations (Raja et al., 2015)

The present study had several limitations. Firstly, as referenced briefly above, participants were interviewed several months or even years after their stroke and post-stroke cognitive assessment, so their memory of the process may have faded. Still, many participants reported intense emotional responses to the cognitive assessment, suggesting that – at least for some participants – the experience was salient and memorable. A further limitation is that very few participants engaged meaningfully in discussions about specific domain-level cognitive impairments during the interviews. Therefore, although the study aimed to understand similarities and differences in experiences depending on cognitive impairment type and severity, it was difficult to get rich data on this topic. Difficulty engaging in these discussions may reflect a language barrier, in that participants may have lacked sufficient cognitive lexicon to capture their precise experiences and impairments. Indeed, this hypothesis is potentially supported to some extent by participants' describing the cognitive screening process as a "memory test" and corresponding anecdotal evidence that many participants tended to describe their impairments as 'memory problems' or 'thinking problems', regardless of the specific cognitive domain affected.

Overall, analysis of these interviews highlighted the importance of communicating clearly, thoroughly, and constructively throughout the post-stroke cognitive screening process to promote engagement with cognitive screening and protect their psychological and emotional wellbeing. These results support the need for clearer guidance, training, and resources to standardise and promote information provision about the purpose and results of cognitive assessments after stroke within clinical practice. Given that cognitive screening will form a core part of cognitive reviews conducted within the complex intervention developed in this thesis, developing a resource to support information provision about cognition, including cognitive screening, will be a critical step in the intervention development (see Chapter 5 and Chapter 6).

4.5. Part B: Views on post-stroke cognitive trajectory discussions

4.5.1. Background

As described in the background to Part A of this chapter and within the general thesis introduction (Chapter 1), cognitive impairments are highly prevalent in the first weeks after stroke. However, over the longer term, post-stroke cognitive functioning follows highly complex and heterogeneous trajectories (del Ser et al., 2005; Demeyere et al., 2019; Kusec et al., 2023; Tang et al., 2018). A proportion of stroke survivors recover from early cognitive impairment (Demeyere et al., 2019; Kusec et al., 2023), but approximately half continue to experience cognitive impairment six-months post-stroke (Franklin et al., 2018; Jokinen et al., 2015; Lopes et al., 2021), with some

research suggesting an even higher long-term prevalence (Milosevich et al., 2024). Long-term cognitive impairment represents a stable impairment in some cases but, for others, early cognitive impairments become more severe over the months and years after stroke (e.g., Demeyere et al., 2019; Rost et al., 2022). Furthermore, stroke survivors are at a significantly increased risk of developing vascular and mixed dementia (e.g., Pendlebury & Rothwell, 2019), with a recent systematic review and meta-analysis concluding that approximately 20% of stroke survivors experience clinically defined dementia one-year after stroke (Craig et al., 2022). However, there is currently no reliable way to predict long-term outcomes on an individual level (Tang et al., 2020).

One of the main conclusions from Part A of this chapter was that informing stroke survivors and their family members about their cognitive screen results is an important first step after cognitive screening, which is emphasised as a critical element of early post-stroke care within UK clinical guidelines (Royal College of Physicians, 2016). Following this, it may also be beneficial to discuss possible long-term cognitive trajectories to facilitate future care planning and increase awareness of symptoms to monitor after discharge. Nevertheless, before incorporating prognostic discussions routinely into clinical practice, it is critical to explore the potential advantages and disadvantages of sharing complex information about recovery trajectories with stroke survivors and their family members, given the intricacy, complexity, and emotiveness. of post-stroke cognitive outcomes.

A recent systematic review synthesised twenty-eight qualitative studies on sharing information about recovery after acquired brain injury (Burton et al., 2021). Though this systematic review did not focus on stroke survivors nor cognitive recovery specifically, the authors found that participants across the studies wanted "the right information at the right time" (p.9), but this looked different depending on the specific patient group – for example, people with stroke were generally more receptive to prognostic information than those with tumours. Nevertheless, providing information about recovery brought challenges for both healthcare professionals and patients, and it was important for clinicians to tread carefully between providing hope and a realistic expectation for the future. The need for appropriate training in this area was stressed, with healthcare professionals recognising the complexity and emotive nature of prognostic discussions. Overall, the review provides valuable insight into recovery-related clinical conversations after brain injury, but only a minority of the included studies were related to stroke, and none focused on post-stroke cognition specifically.

Homing in on post-stroke cognitive recovery, Cheng et al. (2022) conducted a series of semi-structured interviews with stroke survivors and their caregivers to explore perspectives on sharing prognostic information about aphasia. Caregivers were generally receptive to this information, so long as it enhanced their ability to help their family member in recovery. Nevertheless, whereas non-partners tended to want both favourable and unfavourable predictions about recovery as early as possible, partners generally expressed a lesser desire for prognostic information, preferring information about maximising recovery. While Burton et al. (2021) highlighted the need for healthcare professionals to tread carefully between promoting hope and realistic

expectations, this finding from Cheng et al. (2022) very tentatively suggests that family members occupying different roles (i.e., partners versus non-partners) may weigh the importance of being hopeful versus realistic differently. Still, this study by Cheng et al. (2022) is limited by its narrow focus on post-stroke language impairments, given the diversity of post-stroke cognitive impairments affecting language, memory, attention, executive function, number processing, and praxis.

Moving beyond post-stroke language impairments but using a similar qualitative approach to Cheng et al. (2022), Tang et al. (2019) explored healthcare professional, stroke survivor, and family member perspectives on using dementia risk prediction tools to inform discussions about post-stroke dementia. Participants noted some potential advantages of discussing post-stroke dementia – for example, to help prepare for the future, to ensure a timely diagnosis, and for reassurance – but there were also disadvantages, including anxiety about a diagnosis and concerns about how such information might impact recovery. These disadvantages are potentially reflected by quantitative data from Ball et al. (2022), who surveyed sixty UK healthcare professionals and found that, although 57% of participants thought acute stroke patients would benefit from knowing if they were at high risk of dementia, 89% never or rarely discussed dementia with their patients.

The above articles offer valuable insight into perspectives on delivering information about post-stroke cognitive trajectories, but none of them fully captured the complexity of post-stroke cognitive impairment as a problem that affects multiple domains (e.g., language, memory, attention, executive function, number processing, praxis)

(Demeyere et al., 2015) and follows varying trajectories (del Ser et al., 2005; Kusec et al., 2023). The aim of this study was therefore to explore the potential advantages and disadvantages of discussing post-stroke cognitive trajectories – encompassing cognitive recovery, stability, decline, and dementia – from the perspective of stroke survivors and their family members. This has important implications for the intervention being developed in this thesis, in terms of determining whether, to what extent, and how information about potential post-stroke cognitive trajectories should be shared with stroke survivors and family members during cognitive reviews.

4.5.2. Methods

The methodological approach taken matched the approach outlined in Part A of this chapter. Specifically, I conducted a reflexive thematic analysis of semi-structured interviews from the same participant sample.

4.5.3. Results

Characteristics of the stroke survivors and family members interviewed in the present study are described in Part A of this chapter. One overarching theme and three related subthemes pertaining to the advantages and disadvantages of discussing potential cognitive recovery trajectories with stroke survivors and their family members were identified. The overarching theme was: One size does not fit all. The related subthemes were: (1) Hearing about potential cognitive trajectories may help to develop realistic expectations; (2) Discussions about cognitive trajectories may be motivating; (3) Cognitive decline and post-stroke dementia discussions may be

anxiety-provoking and demoralising. These are described below with illustrative quotes.

One size does not fit all.

Discussions about potential cognitive trajectories seemed to be viewed very differently by individual stroke survivors and family members, with person-specific factors (e.g., perspectives on cognitive impairment and dementia) and timing of information provision appearing to have a substantial – and potentially interactive – impact on how the information was perceived. For example, participants who described themselves as optimistic were generally positive about cognitive trajectory discussions and said they would be particularly keen to receive this information in the early stages after stroke, so that they could develop realistic expectations. In contrast, some participants who reported a proclivity towards worrying thought that only positive information should be provided, as information about dementia and cognitive decline could be anxiety-provoking, particularly should it be provided in the early stages after stroke. In this sense, participants seemed to weigh the advantages and disadvantages differently, depending on individual perspectives and time since stroke, but there was nevertheless overlap in the specific advantages and disadvantages identified by participants. Commonly identified advantages and disadvantages are described by the subthemes below.

Hearing about potential cognitive trajectories may help to develop realistic expectations.

Several stroke survivor participants described feeling uncertain about how their cognitive functioning would evolve over time and how any cognitive impairments might impact their daily lives. These participants believed that learning about potential cognitive trajectories in the early stages after stroke would have helped them develop realistic expectations for the future, attenuating feelings of uncertainty and accompanying anxiety.

> *I think that information is really useful. Either it's motivating, which is sort of a positive scenario, or it makes the patient more realistic about the potential outcomes.* (Stroke Survivor 20)

Most participants who spoke about the importance of developing realistic expectations about cognitive recovery experienced cognitive impairments affecting multiple domains in the early stages after stroke. However, one stroke survivor with cognitive impairment affecting only one domain also thought it would have been helpful to discuss cognitive trajectories in order to develop realistic expectations for the future, but he particularly stressed the importance of promoting awareness without generating fear.

> *I think it might have been useful for me to have been more aware that [cognitive decline] was a possibility and therefore, possibly if I'd been more aware of it, I would have looked out for it more, you know, when I recovered. [...] I think*

awareness is the issue, isn't it? Not being totally in the dark about it but not being too frightened about it at the same time. I didn't want to be scared about it. I didn't want to be scared about the future. I wanted to be positive about the future and I wanted to get on with my life. (Stroke Survivor 18)

Some participants stressed the importance of developing realistic expectations in the very early stages after stroke in particular, emphasising the potential importance of providing information about cognitive trajectories in the very early stages. Being discharged from hospital was seen as a particularly challenging point, so some participants felt it was important to receive information about potential cognitive trajectories prior to this. Indeed, one participant commented on the disorientating experience of leaving hospital without knowing what to expect over the long-term, and he explained that a discussion about cognitive trajectories may have helped to alleviate these uncomfortable feelings of uncertainty.

It would have been helpful, I think, just to have a little bit more information [about post-stroke cognitive trajectories] and to maybe have had that discussion briefly, just to be aware of – or more aware of – what might be the, you know, the progression afterwards. I didn't know what to expect coming out. I was out so quickly. I wasn't quite sure how quickly I should be improving, what difference it should have made to my day-to-day living – very little, as it happened. But I didn't have that conversation. (Stroke Survivor 18)

Nevertheless, many participants described how they had not received any information about cognitive functioning (see also Part A of this chapter) or cognitive trajectories in the early stages after stroke and this lack of information had led some of them to generate overly optimistic expectations for future cognitive recovery. In the early stages after stroke, optimism and positivity about cognitive recovery seemed to serve a useful function, helping participants to cope emotionally with their – or their family member's – cognitive impairment. However, participants acknowledged the value of having *"known facts"* (Family Member 1) about cognitive trajectories to temper their expectations and to balance their idealism with realism.

> *We're people of faith and hope, rather than 'glass half empty' kind of people, I think. I think I always looked forward with hope and trust because I was seeing improvements every time – every single time – I visited. My hope was always there that [the stroke survivor] was going to get a lot better than he was. But to have that discussion [about cognitive trajectories] I think could have been helpful to have a basis for our thinking.* (Family Member 6)

Some participants' optimistic expectations and goals for cognitive recovery persisted many months after stroke, as they still had not received information about cognitive trajectories to temper these expectations. For example, one stroke survivor with severe expressive aphasia, which had persisted six-months after his stroke, still hoped and believed that his language abilities would return to pre-stroke levels at some point.

We still don't know the future. I mean, we have certain goals, but nobody's actually talked to us about what the future is, other than what we've read and we don't know whether that applies to [the stroke survivor] specifically. [...] [The stroke survivor's] hope is that he will be 100% back. I'm a little bit more moderate. I think 99. But nobody has actually discussed that with us. (Family Member 1)

When such optimistic expectations and goals for cognitive recovery were not met, stroke survivors and their family members described feelings of disappointment and frustration. Discussing cognitive trajectories early after stroke may have helped participants temper their expectations and, in turn, helped them to avoid such negative emotional responses when these expectations were not met.

Aphasia – it's different [...] for every person, I think. I was always very clear that I was going to get much better than I was and I'm not sure I've done it at the rate at which I thought, initially. (Stroke Survivor 15)

[Responding] Yeah, you thought you'd be all better by now. (Family Member 6)

Nobody ever talked to me about the progress through the stroke itself. I never talked to a doctor, so I had an expectation of more...speedier...more speedy recovery. I now realise that was a wrong expectation. (Stroke Survivor 20)

Nevertheless, a minority of participants did not even mention the potential advantage that information about cognitive trajectories would have helped them develop realistic

expectations. Instead, they discussed the importance of providing *"only encouraging"* (Stroke Survivor 25) information that would help stroke survivors and their family members retain hope and optimism for the future. In other words, whereas some participants preferred to temper optimism with factual information, others seemed to purely value hopefulness, especially in the early stages after stroke.

Discussions about cognitive trajectories may be motivating.

In addition to helping develop realistic expectations, several participants described how information about post-stroke cognitive trajectories could be motivating for stroke survivors and their family members. Information about cognitive recovery in particular was seen as potentially beneficial, as participants believed discussing future recovery may help motivate stroke survivors to engage with rehabilitation exercises, which were often perceived as tedious.

> *I think what could have been good, do the [cognitive] assessment, go back a week later, and go through it with the [occupational therapist], who can say "This means..." and "It's likely that this will improve if you use this sort of exercise" or [...] "There's always opportunity. Keep doing those boring exercises because actually, even if it's five years down the line, the brain will have adapted and learned. Don't give up!" But it needs somebody to say that.* (Family Member 7)

Some participants felt that discussing cognitive decline and post-stroke dementia could also be motivating for stroke survivors, although this sentiment was less

common among participants and there was some discrepancy in opinions. Generally, these differences in opinion seemed to be driven by individual perspectives and outlooks on post-stroke recovery. One stroke survivor, who described himself as *"very positive about everything"* (Stroke Survivor 15), explained that information about post-stroke dementia would have motivated him to reduce his risk of developing it. Similarly, another stroke survivor believed that his competitive nature would have compelled him to *"[fight] against"* (Stroke Survivor 5) the possibility of cognitive decline, had this been discussed with him in the early stages after stroke.

> *[Information about post-stroke dementia] wouldn't upset me. I'd just say "Right, okay, that's... What do I need to do to try and reduce that risk?"* (Stroke Survivor 15)

> *If someone had said "Oh, you're going to go down", or "You're going to flatline", I'd have fought against it.* (Stroke Survivor 5)

One stroke survivor believed that information about cognitive trajectories would have been neither motivating nor demotivating for him, as his personal determination had already led him to decide and declare that he would recover from post-stroke cognitive impairment. As such, he thought information about post-stroke cognitive trajectories would have served little useful purpose in motivating him to recover, but he acknowledged the information may have a motivating impact on stroke survivors less determined than him.

> *My mind was made up – I was going to get better. If there'd have been a doctor that was saying "Well, these are all the problems," you know "This is what we can do maybe", then it wouldn't have helped me, but it might have helped some people in my position.* (Stroke Survivor 16)

The sentiment that information about cognitive trajectories may be motivating for some but not for others was echoed by participants who highlighted the importance of healthcare professionals adopting an individualised approach when discussing cognitive trajectories. In particular, before providing information about cognitive trajectories, participants felt it was important for health professionals to determine whether or not stroke survivors would be *"egged on"* (Family Member 8) by information about cognitive decline.

> *I think you almost have to determine the person's sort of 'glass half full' versus 'glass half empty' status before you decide what to say and what not to say, don't you? Because if they're the ones that are egged on by it, then yeah, I can absolutely see why [cognitive trajectories are] something to talk about.* (Family Member 8)

Cognitive decline and post-stroke dementia discussions may be anxiety-provoking and demoralising.

Despite these potential benefits, several participants felt that information about post-stroke cognitive decline and post-stroke dementia would increase feelings of anxiety and low mood among stroke survivors and their family members. Some participants

reasoned that stroke survivors have little control over whether their cognition deteriorates, due to the lack of interventions available to prevent post-stroke cognitive decline or dementia. They believed that hearing about post-stroke cognitive decline/dementia, without being able to do anything to prevent it, would accentuate negative emotions for stroke survivors and their family members.

> *Having a stroke is bad enough without having additional worries piled on, basically. You know, you worry about getting better but if somebody said to you, you know, you might get an awful lot worse or you might get dementia, you'd feel like giving up.* (Stroke Survivor 25)

> *It would make them depressed and worried, I think, because I don't think there's much you can do to prevent things getting worse. I mean, obviously, you can try but if it's going to happen and you go down the road and develop dementia, then I don't think you'd want to know about it beforehand really. It would make your life one big worry.* (Stroke Survivor 25)

However, some participants argued that discussing post-stroke cognitive decline and dementia would not have made them *"any more worried than [they were] anyway"* (Stroke Survivor 7). For one stroke survivor, his lack of agency and control over post-stroke cognitive decline and dementia in fact buffered him against feelings of anxiety. This stroke survivor and his family member adopted a pragmatic attitude about potential cognitive decline and dementia, acknowledging that feeling anxious or

depressed would serve no useful purpose and that living in the present moment was a preferrable alternative.

> *It's not good being worried about [post-stroke dementia]. If it's going to happen, it's going to happen.* (Stroke Survivor 7)

How participants perceived dementia as a condition seemed to be an important factor in determining whether they felt that information about cognitive decline and dementia would trigger negative emotional responses or not. For one stroke survivor, discussing potential post-stroke cognitive decline and dementia was a frightening prospect, as dementia posed a threat to his independence, which was important to him, yet had already been threatened to some extent by his stroke. However, another participant commented that dementia is *"so common now"* (Stroke Survivor 10) and more challenging for family members than for the person with dementia themselves. He thought that information about post-stroke dementia would not necessarily be anxiety-provoking for the stroke survivor, but more so for their family members.

> *Because I live on my own, I think if I ended up with dementia, I'd probably have to go into a care home.* (Stroke Survivor 21)

> *To be quite honest, if you develop dementia and you completely lose your memory, in a way, you're in a fortunate position in that you don't know that you're ill.* (Stroke Survivor 10)

Nevertheless, some participants acknowledged that it could be useful for family members to receive information about post-stroke cognitive decline and dementia, as this information – although potentially anxiety-provoking – could help them monitor cognitive symptoms. One family member recognised she now had substantial caring responsibilities for her husband since his stroke, which affected his memory and attention. She readily acknowledged her duty to monitor his cognitive symptoms and felt that information about post-stroke cognitive decline and dementia would help her fulfil this role, despite its potentially anxiety-provoking effect.

> *They need to relay the information to the next of kin, you know. It needs...lots of things need to be made, you know, sort of for the person to be made aware of. Because as his carer now, I need to know what kind of signs to look out for and things.* (Family Member 11)

Furthermore, whereas some participants believed information about post-stroke cognitive decline and dementia would be anxiety-provoking for family members, others believed this information would in fact reduce their anxiety about potential outcomes. The family member described above who saw herself as *"that sort of person who deals better with known facts"* (Family Member 1) believed that information about cognitive decline and cognitive recovery would have reduced her anxiety in the early stages after stroke, as it would have allowed her to work with facts rather than fantasies. However, she acknowledged this information may not be beneficial in the early stages after stroke for family members who deal less well with objective data or for stroke survivors themselves.

> *I think [the stroke survivor] at this stage can hear that sort of statistical information. I don't think it would have been useful for him to have heard that say a couple of months ago, three, four months ago, but I think it would have been useful for me to hear it. [...] I certainly would have benefitted from it. I can tell you right now, that's what I was looking for.* (Family Member 1)

Nevertheless, one family member who acknowledged the anxiety-provoking impact of information about post-stroke cognitive decline and dementia, but simultaneously recognised the potential benefits of providing this information to family members, referred to the ethical dilemma of providing information to a family member but not to the stroke survivor themselves.

> *You can sort of imagine having that conversation with the family – but is it fair to not involve the patient – saying "Well, realistically, things are going to decline." Well, they are, aren't they, for everyone a little bit, but how soon and how fast is impossible [to know]. But it's not motivating and not something to strive for the next level of betterness, if you know what I mean.* (Family Member 8)

While there was substantial individual variability in terms of whether information about cognitive decline and dementia was perceived as potentially anxiety-provoking or demoralising, participants seemed to be generally more open to receiving this information in the later stages after stroke, rather than the very early stages after

stroke. For example, one family member recognised that having these discussions later on may help stroke survivors and their family members come to terms with and accept that their cognitive skills might not fully recover, if their recovery had plateaued.

> *I would certainly, at the beginning, would rather not know if the outlook is poor because I think that would be a demotivator. I think maybe after a year, it could be helpful because if you're going on and on trying and it doesn't seem to be getting much better, there could be something to be said for saying "Well, I think maybe you've got to settle for this." It doesn't mean you can't stop trying but you wouldn't perhaps be so frustrated if you felt all your efforts weren't bearing fruit.* (Family Member 7)

4.5.4. Discussion

Analysis of the semi-structured interviews revealed the complexity of discussing post-stroke cognitive trajectories – encompassing cognitive recovery, stability, decline, and dementia – with stroke survivors and their family members. Stroke survivors and family members seemed to recognise similar advantages (developing realistic expectations and motivating recovery) and disadvantages (increased anxiety and low mood) of discussing potential post-stroke cognitive trajectories in clinical practice, but they weighed these factors differently and ultimately reached very different conclusions about whether, when, and how this information should be shared with stroke survivors and their family members. These results support a person-centred approach to delivering information about post-stroke cognitive trajectories within the intervention being developed and in clinical practice more broadly, as well as highlighting the need

for training to support healthcare professionals to navigate this complex and emotive area.

The finding that participants reached different conclusions about whether, when, and how information about cognitive trajectories should be provided in clinical practice broadly aligns with Burton et al.'s (2021) conclusion that patients want the "right information at the right time" (p.9), but that this looks very different from case to case. However, whereas Burton and colleagues concluded based on results of a study by Becker and Kaufman (1995) that stroke survivors were generally receptive to prognostic information, the present study found substantial heterogeneity in viewpoints among this patient population, at least where *cognitive* recovery is concerned. Here, individual perspectives (e.g., on cognitive impairment and dementia) appeared to be important in determining participants' ultimate conclusions, as did the timing of information provision. Ball et al. (2022) found in their survey that healthcare professionals were generally more in favour of providing information about dementia between one to six-months after stroke, compared to the first weeks after stroke. Likewise in this study, participants generally appeared to be more supportive of discussing dementia later down the line but – crucially – some participants in the present study believed this information should *never* be discussed. Echoing results from Tang et al. (2019), these participants generally saw information about post-stroke dementia to be needlessly anxiety-provoking and preferred information that helped them maintain hope and optimism. Ultimately, our findings suggest a very nuanced picture, where stroke survivors hold varying views on whether, when, and how

information about post-stroke cognitive recovery should be incorporated into clinical care, including within the intervention developed in this thesis.

In line with findings from Burton et al. (2021), our results suggested the importance of being optimistic and having realistic expectations for the future. However, here again, there was substantial variability in terms of the ideal balance across participants – whereas some participants described a desire for both hopeful information and information to promote realistic expectations, others favoured optimism over and above all else. Ultimately, discussing the possibility of cognitive stability, decline, and dementia may support stroke survivors and their family members to develop realistic expectations for the future, but there is indeed a risk that this information may be seen as 'bad news'. Quite rightly, healthcare professionals in previous studies have recognised that such 'bad news' about potential limited recovery after brain injury may negatively impact hope, mood, and motivation to participate in rehabilitation activities (Becker & Kaufman, 1995; Peel et al., 2020; Phillips et al., 2013; Sexton, 2013; Soundy et al., 2010), a concern that has also been expressed by patients and caregivers (Maddern & Kneebone, 2019). Recognising this risk and the substantial heterogeneity in viewpoints within this study, the decision was made at this stage in the research not to proceed with the cognition trajectory guide outlined within the initial intervention skeleton, given the evident need for a more thoroughly person-centred approach.

Lessons on providing information about post-stroke cognitive trajectories in a thoroughly person-centred way may be learned from research in other health

conditions, such as cancer and multiple sclerosis, where healthcare professionals often face a similar challenge in terms of maintaining hope while providing 'bad news'. Extensive research has shown that delivering such information can result in emotional distress for both healthcare professionals and patients (Bousquet et al., 2015), so it is critical to establish a delivery method that minimises negative emotional sequelae on both ends (Dean & Willis, 2016). Various strategies have been established to support best practice in this regard, including the SPIKES protocol (Baile et al., 2000) and Kaye's 10 step approach (Kaye, 1996), with Royal College of Nursing guidance recognising that most strategies have a similar overarching structure, involving preparation, communication, planning and follow-up (Royal College of Nursing, 2013). Healthcare professionals responsible for delivering the intervention developed through this research will be trained to adopt a similar approach when broaching the complex and sensitive topic of potential post-stroke cognitive trajectories (e.g., assess the person's perception of the topic, obtain their invitation to discuss it, share knowledge and information, address emotions with empathy, and revisit the conversation at a later point if and when appropriate).

The present study has several limitations. Firstly, as discussions about post-stroke cognitive trajectories tend not to be integrated routinely into clinical care for stroke (Ball et al., 2022), participants were asked to consider how these discussions *would* have affected them. The hypothetical nature of this line of questioning is a limitation, as stroke survivors and their family members may have responded differently to information about cognitive trajectories in reality. Secondly, although the meaning of post-stroke cognitive trajectories was clearly defined during the interviews,

participants may not have understood the concept fully, nor recognised the incredible complexity and heterogeneity of post-stroke cognitive trajectories (Demeyere et al., 2019; Kusec et al., 2023). Nevertheless, the interviews provided nuanced and meaningful insight into this topic, suggesting that participants sufficiently understood the concept for the purposes of this study. Still, similar to in Part A of this chapter, it was challenging to acquire rich data on certain aspects of the topic, including whether opinions varied depending on the cognitive domain in question.

Overall, results presented here have highlighted the complexity and emotive nature of post-stroke cognitive trajectory discussions and suggested that adopting a person-centred approach will be critical when discussing potential cognitive trajectories in the intervention developed in this thesis and clinical practice more broadly. Ultimately, discussions will likely need to be tailored to individual needs and preferences, with information related to cognitive decline and dementia in particular shared with utmost selectivity and sensitivity. Providing appropriate training to healthcare professionals responsible for conducting cognitive reviews in the intervention will be critical to help them navigate these complex and sensitive discussions.

4.6. Reflections

While conducting the research presented in this chapter, I critically and continually examined my different identities and roles, including being a relatively young female, a PhD student at the University of Oxford, and an Assistant Psychologist at an acquired brain injury service. Reflections were recorded in an electronic journal, with

key considerations about my role and impact on the research process summarised below.

In terms of data collection, working as an Assistant Psychologist at an acquired brain injury service provided me with skills necessary to communicate empathetically within the interview setting. This potentially helped participants to feel comfortable sharing openly about their experiences and perspectives. Nevertheless, my relative youth may have been interpreted by some participants as indicative of naivety and lack of 'life experience', and I wondered whether participants were in some cases inhibited from sharing because of this. Furthermore, although I did not disclose during interviews anything about my own personal or medical history, I wondered whether participants may have 'jumped to conclusions' and assumed – potentially due to my age and physical ableness – that I had not experienced any 'major' health challenges, like a stroke. Again, this assumption may have affected the depth of their sharing.

My positionality as an *academic* investigating *clinical* topics also presented some challenges during the interviews. While all stroke survivor participants had received a cognitive screen during their inpatient treatment at the John Radcliffe Hospital, they had also completed cognitive tests as research participants in the OCS-Recovery study. Though my goal in Part A of this chapter was to investigate *clinical* experiences of cognitive screening, I wondered whether participants assumed I was more interested in their *research* experiences, given my role as a PhD student. When I emphasised my curiosity in their symptoms and clinical experiences, rather than their research with the Translational Neuropsychology Group, this led some participants to

focus more heavily on their *physical* – rather than cognitive – symptoms and their experiences receiving physiotherapy. When this happened, I tried to allow space for discussions about the physical symptoms of stroke, recognising the courage it took participants to share their struggle with this important aspect of post-stroke life, but I also attempted to redirect participants sensitively back to the cognitive consequences of stroke (namely, post-stroke cognitive impairment). This situation was navigated more effectively on some occasions than others, meaning that the richness of interviews varied substantially. As a result, I found myself questioning regularly whether I should have 'pushed harder' to steer the interviews back on track, but my naturally empathetic tendency and dual identify as both a researcher and healthcare professional made this challenging, as I preferred to offer a 'listening ear'. Ultimately, however, it remains possible that this more flexible and person-centred approach may have enhanced the richness of interviews. I reflected on the importance of the therapeutic relationship in clinical psychology settings and recognised how listening curiously and non-judgementally, while allowing space for what participants themselves wanted to discuss, enabled a strong 'research relationship' to develop in many interviews.

In terms of the analytic process, being a PhD student at the very start of my academic career likely influenced the way in which I engaged with the data. Working within a field that values publications and evidence of impact as necessary prerequisites for career progression, I was keen to ensure that meaningful output from this project (e.g., publications, conference presentations) was delivered in a timely fashion. Braun and Clarke (2021b) have argued that "good qualitative research needs time" (p.31),

claiming that their analyses usually take years from data collection to journal submission. I concur with their view that 'good' reflexive thematic analysis requires thoughtful, considered, and reflective engagement with the data and research question, which often takes substantial time, and I regret that I did not feel able to 'mull' over the data presented in this chapter for longer. Indeed, Braun and Clarke (2021b) have noted from their own experience that putting a project aside and returning to it many months later has often resulted in a new 'spark' of insight and, subsequently, a total shift in how the final analysis is presented.

Indeed, my view on the data and analysis has shifted since submitting Part A and Part B of this chapter for publication in February 2023 and July 2023, respectively. As described above, the analysis was produced at the intersection of the data, the analytic context, and the interpretations and assumptions I brought to the analysis. Whilst the data have been stable and constant, the context and my own perspectives have evolved substantially in the months since submitting these manuscripts. In particular, I have become even more conscious of my interpretive role and, consequently, my cautiousness not to jump to conclusions about the clinical reality has increased. Therefore, in this chapter, I have tried to provide more space and place greater emphasis on the difficulty of truly 'knowing' the clinical reality and the existence of infinite simultaneously 'true' clinical realities – not only is clinical practice highly heterogeneous within the UK, one 'instance' of clinical practice is inevitably viewed differently by individuals. This research project presents merely an attempt to summarise meaningfully one possible interpretation of each stroke survivor's reality; extrapolating this to make assumptions about what happens in practice is not only

impossible but potentially dangerous. Therefore, I have tried to hedge my claims carefully in this chapter. Certainly, I believe the research has implications for clinical practice, but these implications are drawn from my interpretation of patients' realities and certainly not a knowingness of the clinical reality. Ultimately, as I endorse the 'Big Q' perspective that qualitative research is not meant to be reliable nor reproducible, but rather to provide nuanced yet situated insight into the questions, I see this shift in perspective and framing not as a 'problem', but as an inevitability.

4.7. Conclusions and chapter summary

To recap, the intervention skeleton described in Chapter 1 included three core intervention features: cognitive reviews involving cognitive screening, a cognition trajectory guide to support discussions around prognosis, and psychoeducation about cognition. With expert healthcare professionals and researchers having agreed through consensus on the importance of these features (Chapter 3), this chapter explored stroke survivor and family member experiences of cognitive screening (Part A) and perspectives on cognitive trajectory discussions (Part B). Results confirmed the importance of providing information within the intervention about the purpose and results of post-stroke cognitive screening. However, the need for a highly person-centred approach to cognitive trajectory discussions was highlighted, leading to the decision that the cognition trajectory guide should be substituted with carefully structured training focused on these conversations. The next empirical thesis chapters – Chapter 5 and Chapter 6 – will focus on the third and final core feature outlined within the initial intervention skeleton: psychoeducation about cognition.

Chapter 5 A scoping review of previous articles describing cognition-related psychoeducation needs of stroke survivors and their family members

5.1. Chapter overview

Having established consensus on the intervention features among healthcare professionals and researchers (Chapter 3) and explored stroke survivors' experiences of and perspectives on cognitive screening and cognition trajectory discussions (Chapter 4), this chapter addresses the third and final core feature outlined in the initial intervention skeleton: psychoeducation about cognition. A scoping review was conducted to map and identify gaps within existing literature describing cognition-related psychoeducation topics deemed acceptable by stroke survivors and their family members. The primary aim was to establish 'what is out there' and a secondary aim was to develop a very tentative understanding of key topics that should be addressed within a tangible cognition-related psychoeducation resource to be used within the intervention. To this end, results of this scoping review were used to inform the development of an initial prototype cognition-focused psychoeducation resource, which was then evaluated and revised through an iterative co-production process, presented in the next chapter (Chapter 6). Figure 5.1 shows the position of this chapter within the thesis.

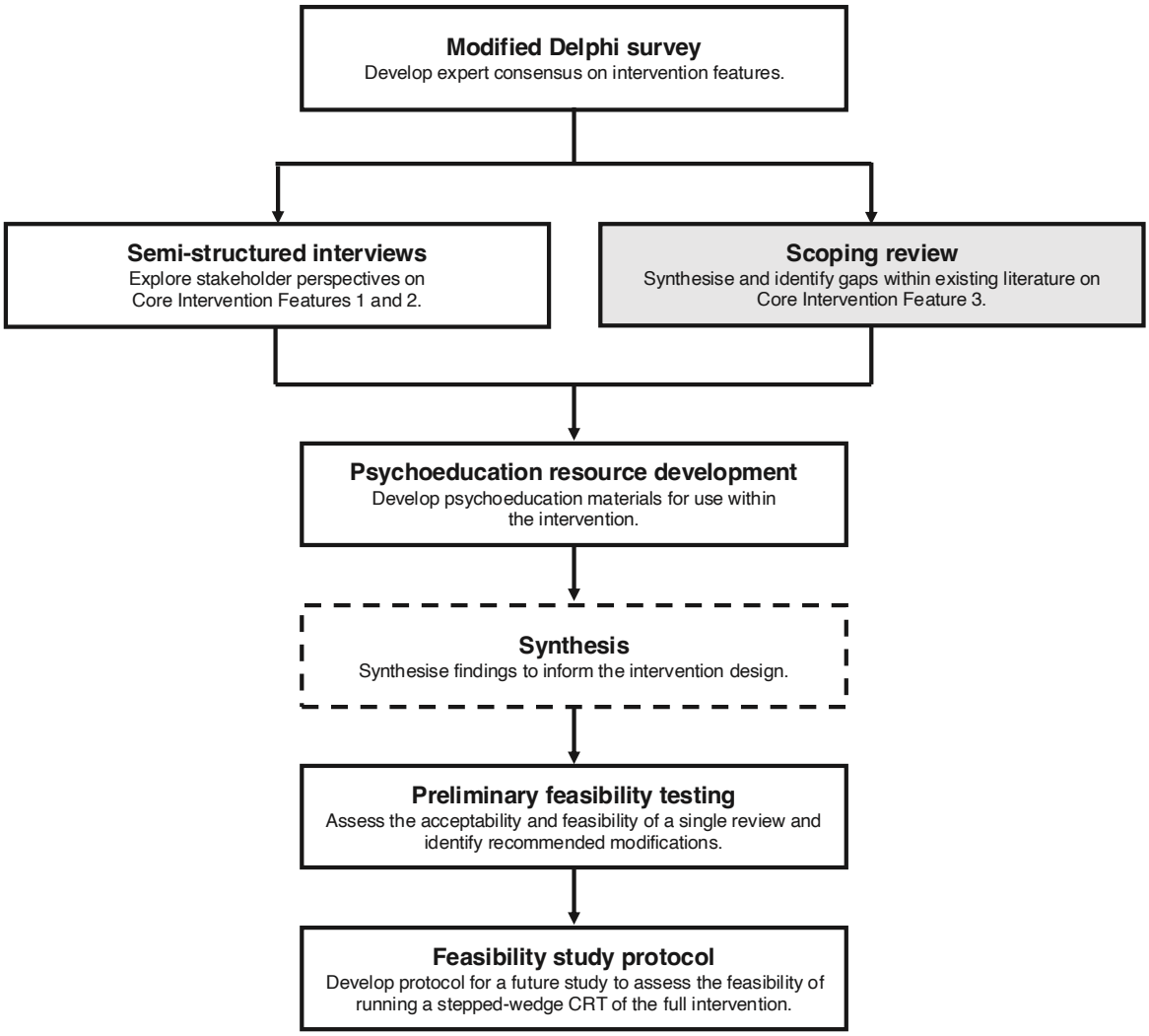


Figure 5.1. Position of the scoping review (highlighted in grey) within the overall thesis.

5.2. Contribution

I contributed to the research presented in this thesis chapter by conceptualising the study, formulating the study aims and objectives, determining the study methodology, developing the search strategy, drafting the original protocol and managing the submission process, searching databases, screening retrieved records, extracting data from included records, synthesising results, tabulating and visualising results, drafting the manuscript, editing drafts based on co-author feedback, and managing

the submission process. Prof Nele Demeyere was involved in conceptualising the study, formulating the study aims and objectives, advising on study methodology, reviewing and editing the protocol, advising on study inclusion, advising on the data synthesis, and reviewing and editing the final manuscript. Miss Faye Tabone was involved in screening retrieved records, verifying extracted data, and reviewing the final manuscript. I would like to thank librarians at the Bodleian Library for reviewing and advising on the systematic search strategy. I would also like to thank peer reviewers of the scoping review protocol who provided important and valuable suggestions for improving the review design. My PhD supervisors provided feedback on this chapter.

5.3. Impact statement

The protocol for this scoping review has been published and the final scoping review is currently in review.

- **Hobden, G.**, & Demeyere, N. (2023). Information needs of stroke survivors and their family members regarding post-stroke cognition: a scoping review protocol. *JBI Evidence Synthesis*, 10-11124.
- **Hobden, G.**, Tabone, F., & Demeyere, N. (In review). A scoping review of research investigating patient and carer psychoeducation needs regarding post-stroke cognition. *BMJ Open.*

5.4. Background

As described in Chapter 1, there is currently no strong evidence to support interventions that aim to directly improve cognitive outcomes after stroke (Bowen et al., 2013; Chung et al., 2013; das Nair & Lincoln, 2007; Gillespie et al., 2015; Mijajlović et al., 2017). Recently developed cognitive rehabilitation interventions for patients with acquired brain injury, including stroke, have therefore tended to focus on psychoeducation to help patients and their family members psychologically adjust to and manage cognitive impairments so that their detrimental impact on daily life is limited (e.g., Merriman et al., 2021; Rasquin et al., 2010).

Psychoeducation is a broad and multifaceted concept that has been variously defined. In this thesis, it is recognised to be a process of providing education and information about psychological topics that is designed to empower individuals with knowledge and skills to manage their own specific challenges (Lukens & McFarlane, 2004). Crucially, this is different to information provision, where factual information about psychological changes may be disseminated but without specifically addressing individual needs or questions.

Despite growing recognition that psychoeducation may be a valuable approach to help stroke survivors adjust to cognitive and broader psychological changes, there is currently limited high-quality evidence evaluating its impact on long-term outcomes. Cheng et al. (2014) conducted a systematic review and meta-analysis to evaluate the effectiveness of post-stroke psychosocial interventions, most of which included psychoeducation as a core component alongside social support. Overall, evidence for

the effectiveness of psychosocial interventions was limited but pooled analysis of two studies that included *only* psychoeducation showed a positive impact on long-term healthcare resource usage (Gräsel et al., 2006; Shyu et al., 2010). Specifically, stroke survivors who received individual psychoeducation had significantly fewer placements in residential/nursing homes eleven-months (Shyu et al., 2010) and two years (Gräsel et al., 2006) after the intervention, compared to those receiving a control. Nevertheless, the focus of both interventions seemed to be on secondary prevention and managing physical symptoms and the extent to which the interventions addressed post-stroke cognitive changes is unclear. In a more recent scoping review characterising previously developed psychoeducation interventions for transient ischaemic attack (TIA) and minor stroke patients that had been evaluated in an RCT, Kontou et al. (2021) similarly found that many interventions in the 15 included RCTs focused on understanding general TIA/minor stroke symptoms, secondary prevention, and stroke warning signs, and it was unclear to what extent and how the interventions addressed cognitive changes specifically.

While rigorous RCT evidence supporting the effectiveness of post-stroke psychoeducation about cognitive changes is currently limited, there are theoretical justifications for including it within the cognitive care intervention being developed in this thesis. The "Y-shaped" process model (henceforth referred to as the Y-shaped model) is a dominant theoretical model of the 'change processes' that underpin effective neuropsychological rehabilitation (Gracey et al., 2009). Founded on seminal psychological theories – including the interacting cognitive subsystems model (Barnard & Teasdale, 1993), self-discrepancy theory (Higgins, 1987), and models of

psychological growth (Ryff & Keyes, 1995) and development (Vygotsky, 1968) – the Y-shaped model posits that individuals experience social, interpersonal, and personal discrepancies after brain injury. Awareness of these discrepancies leads to psychological threat, automatic negative emotional reactions, and safety-seeking behaviours. While safety-seeking behaviours are helpful in reducing distress over the short-term, long-term outcomes are improved when the individual resolves discrepancies, a process that often requires clinical intervention.

Drawing on this model, Gracey et al. (2009) outlined a number of rehabilitation activities that may be particularly helpful in supporting psychological adjustment after brain injury. Providing information about brain injury, including cognitive impairment, was highlighted as a potential way to transform maladaptive narratives and resolve social and interpersonal discrepancies in particular. Gracey et al. suggested that, by learning about cognitive impairment, individuals may move away from unhelpful (and inaccurate) explanations involving fundamental personality change and towards more accurate explanations that facilitate discrepancy resolution. Resolving intrapersonal discrepancies was implicitly suggested to be hindered by cognitive impairment, as cognitive processes – including aspects of executive functioning (switching, working memory) and memory (autobiographical retrieval) – facilitate reframing of catastrophic and traumatic meanings and identification of pre-injury values that may still be viable in the context of brain injury. Still, with skilful clinical intervention, appropriate adjustments, and potential collaboration with willing family members/friends, I would argue that engaging in these change processes absolutely remains a possibility for those with cognitive impairment.

Given this empirical and theoretical justification for including psychoeducation in the cognitive care intervention being developed in this thesis, the aim of the research presented in this chapter and the following chapter (Chapter 6) was to establish stroke survivor and family member psychoeducation needs related to post-stroke cognition, with the ultimate goal of developing a tangible cognition-focused psychoeducation resource to be used within the cognitive care intervention. This chapter presents a scoping review, the primary aim of which was to map and identify gaps within existing peer-reviewed articles describing self-reported cognition-related psychoeducation needs of stroke survivors and family members. The idea was that this would provide crucial 'food for thought' with regards to my own methodological approach for the research presented in Chapter 6 and other empirical chapters, as well as a tentative understanding of key topics that should be addressed by the psychoeducation resource. Specific questions addressed by this scoping review were:

1. What study designs and research methods have been used in previous peer-reviewed articles describing cognition-related psychoeducation topics deemed acceptable by stroke survivors and their family members?

2. What timepoints after stroke have been investigated in previous studies?

3. What are the characteristics of stroke survivors and family members included in previous studies?

4. What psychoeducation needs related to post-stroke cognition have been reported in previous studies?

5. What factors have been suggested to impact psychoeducation needs in previous studies?

6. What key gaps exist within the current evidence base?

5.5. Methods

5.51. Review protocol

This review was conducted in accordance with the Johanna Briggs Institute (JBI) methodology for scoping reviews (Peters et al., 2020) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist. The protocol for this review underwent a rigorous peer-review process for publication (Hobden & Demeyere, 2023) and has been made openly available (https://osf.io/fmz9t). Any divergences from the protocol are justified and provided in Appendix 3.

5.5.2. Search strategy

The search strategy was developed in consultation with an expert librarian at the University of Oxford. The search strategy for MEDLINE (PubMed) was then peer-reviewed and edited based on reviewer feedback. Then, it was adapted to search additional electronic databases using the Polyglot tool (Kung, 2022) provided by

Systematic Review Accelerator software (https://sr-accelerator.com/). Appendix 3 documents the final strategies used to systematically search each of the following electronic databases on August 25th, 2023: MEDLINE (PubMed), PsycINFO (Ovid), Embase (Elsevier), CINAHL (Ebsco), and Scopus (Elsevier). The search strategy was limited to English, but it was not limited by year.

Although grey literature is regularly included in scoping reviews (Peters et al., 2020), the aim of the review was to use relevant findings to inform the development of a psychoeducation resource that would be firmly rooted in high-quality evidence, as well as stakeholder perspectives and theory, in line with the overarching intervention development approach (Chapter 2). As such, the decision was made to include only articles that had been through a rigorous peer review process and not to include grey literature.

5.5.3. Inclusion criteria

Inclusion criteria were based on the JBI Population, Concept, Context (PCC) framework (Peters et al., 2020). Articles were eligible for inclusion in this review if they met the following criteria:

Participants

- Stroke survivors and/or family members of stroke survivors. Stroke survivors were defined as a person who has experienced a stroke of any type (but not TIA). Family members were defined as a person who identifies as related to a stroke survivor by blood, marriage, or with other familial involvement.

- Stroke survivors and/or family members of stroke survivors comprising at least 50% of the study population, in line with cut-offs used in previous scoping reviews (Fletcher et al., 2022; Theou et al., 2018).
- Stroke survivors and family members aged 18 years and over.

Concept

- Cognition-related psychoeducation topics deemed acceptable according to self-report. Cognition was defined as thinking skills related to any of the following domains: memory, language, attention, executive function, praxis, number processing (Demeyere et al., 2015). I decided to include only articles that involved stroke survivor/family member *self-report* as I was keen not to extrapolate too far beyond what stroke survivors/family members themselves had stated, in order to capture their views most accurately.

Context

- Studies conducted in the UK and other high-income countries, defined using the most recent World Bank country classifications (2022). Articles were constrained to these countries as the aim was to inform a UK-based complex intervention, so I considered data to be most relevant where it came from countries with a broadly comparable national economy.
- Participants based either in a clinical setting or the community.

Types of sources

Published peer-reviewed articles that used quantitative, qualitative, or mixed methods designs were included. Review articles, peer-reviewed commentaries, and opinion pieces were excluded.

5.5.4. Study selection process

Identified records were collated and uploaded into EndNote v.X9 (Clarivate Analytics, PA, USA). Duplicates were removed using Systematic Review Accelerator Deduplicator (Rathbone et al., 2015). Following deduplication and after two members of the research team had conducted a pilot screening round, records were screened against eligibility criteria by title, abstract, then full text. Discrepancies were settled by a third research team member. Reference lists of the final included articles were screened to identify further relevant records.

5.5.5. Data extraction

A data extraction tool was developed and revised iteratively, with the final tool (Appendix 3) used to extract relevant data from the included articles by one member of the research team. A second research team member independently reviewed the extracted data for accuracy.

5.5.6. Data analysis

Descriptive frequency counts were calculated to characterise the included articles, in terms of key article characteristics (year of publication, location) and factors relevant

to Research Questions 1-3 (e.g., study sample characteristics, timepoints under investigation).

To identify specific cognition-related psychoeducation needs and factors potentially impacting them (Research Questions 4 and 5), template analysis was selected for several reasons (King, 1998, 2024). First, Peters et al. (2020) have recommended that qualitative analyses, where included in scoping reviews, should be purely descriptive in nature in order for the analyses to be in keeping with the purpose of a scoping review – namely, to map the data, rather than to interpret or critically analyse them in depth. In contrast to reflexive thematic analysis, which focuses on identifying patterns of shared meaning united by a central organising concept (Braun & Clarke, 2019a), 'medium Q' approaches like template analysis allow for themes to be organised in topics summaries, which may reflect the research questions themselves and may be developed very early during the analysis process (King, 1998, 2024). Developing topic summaries rather than broader interpretive themes was seen as a way to ensure the analysis would remain firmly at the descriptive level, as recommended in JBI guidance (Peters et al., 2020), and directly translational in terms of informing a prototype psychoeducation resource (Chapter 6). Additionally, the philosophical flexibility of template analysis meant it was compatible with the critical realist positioning of this work, and its systematic yet flexible approach was hoped to facilitate efficient delivery of a pragmatic analysis to inform the next research project (Chapter 6).

The analysis began with initial data familiarisation, which involved reading and re-reading the included articles while making rough notes. Then, relevant sections of text

within the first ten included articles (i.e., any text describing psychoeducation needs and factors impacting them) were coded at a semantic level. Codes and accompanying text were recorded in the 'relevant findings' section of the Microsoft Excel data extraction table shown in Appendix 3 and were used to inform an initial template comprising candidate themes. This template, stored as a separate Microsoft Excel sheet, was iteratively revised and added to while coding the remaining articles. By including themes, codes, and accompanying text in the template, I was able to consider its fit to the data and its structure at a glance, and it was straightforward to adapt theme titles and boundaries. Once I was confident that the theme structure was faithful to the data from the included articles, a second member of the research team considered them against the original source articles. Rather than promoting reliability or reproducibility, the aim of this cross-checking was to gain a second perspective and ensure relevant findings were not missed or misinterpreted. To ensure the analysis remained at the descriptive level, as recommended in JBI guidance (Peters et al., 2020), the final themes discussed and agreed by the research team resembled topic summaries, rather than broader interpretive units of meaning.

The aim was to generate a situated theme structure with translational value, rather than a reliable and reproducible one. Indeed, the research team recognised that the analysis and themes would inevitably be shaped by their own expertise (i.e., clinical neuropsychology, clinical psychology), experiences (e.g., working on hyperacute stroke units and in community brain injury rehabilitation settings), and values (e.g., importance of addressing cognitive changes after stroke during rehabilitation). Rather than seeing these factors as threats to the reliability of the analysis, however, they

were considered an asset that would mitigate the risk of relevant findings from included articles being overlooked.

5.6. Results

5.6.1. Selection of evidence sources

A total of 8,112 records were retrieved from database searching. This was reduced to 6,726 records after deduplication and 27 records were retained after screening. A further 3 records were identified from reference lists. This resulted in a total of 30 articles being selected for inclusion in the scoping review. Figure 5.2 documents the selection process.

The included articles were published between 1996 – 2023. Most studies (*N* = 20) were published between 2001-2020, with 14 published in the last ten years (2013-2023). Studies were conducted in Australia (*N* = 7), United States of America (*N* = 6), UK (*N* = 5), Canada (*N* = 3), New Zealand (*N* = 3), Ireland (*N* = 2), the Netherlands (*N* = 2), South Korea (*N* = 1) and Sweden (*N* = 1). Each included article was given a number to facilitate concise collation and reporting. Table 5.1 documents the numbers corresponding to each article and a summary of extracted data.

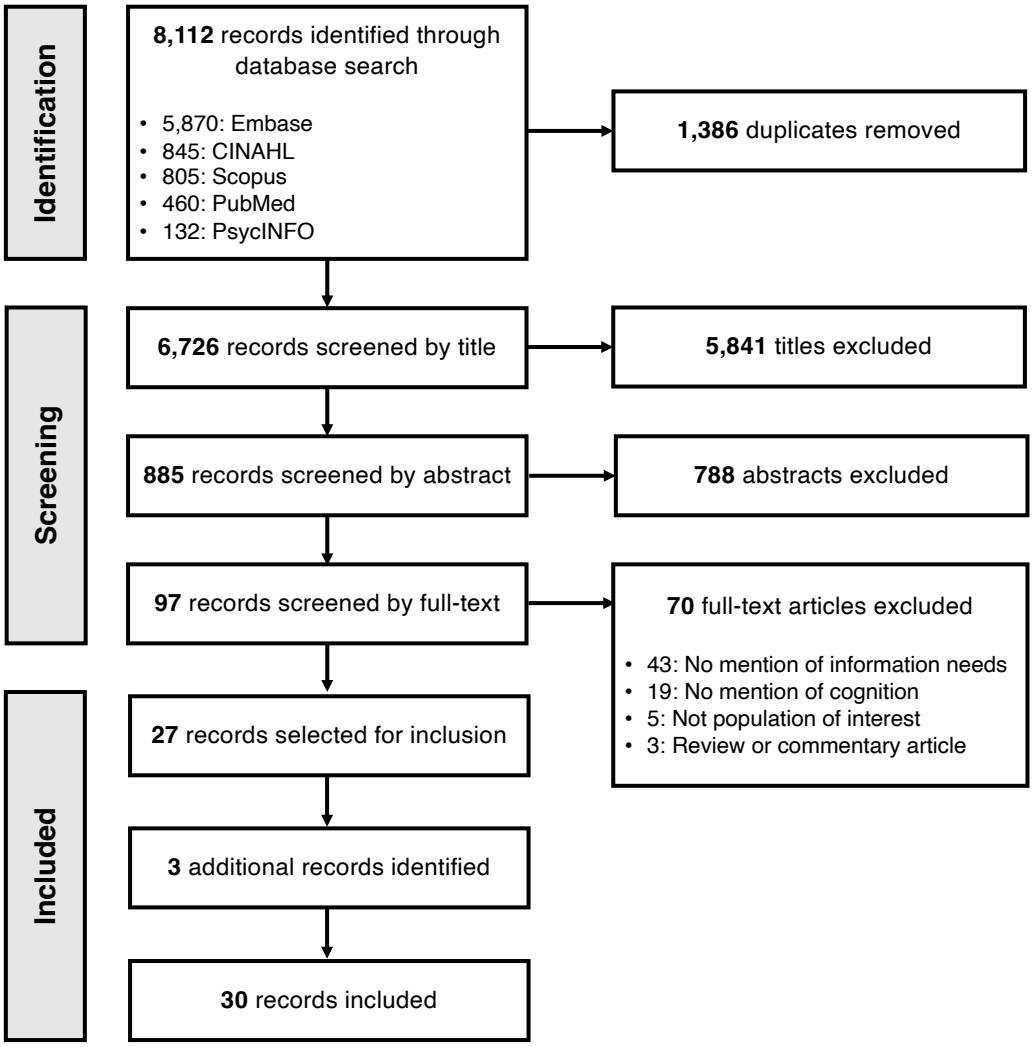


Figure 5.2. Flow diagram illustrating numbers of articles screened, assessed for eligibility, and included in the scoping review.

Reference number	Authors, Year, Country	Study aims	Study methodology	Participant sample	Participant demographics	Timepoint(s) investigated	Psychoeducation need(s) identified
[1]	Avent et al., 2005, USA	To identify information needed by family members at different phases after onset of aphasia.	Qualitative methods. Focus groups, analysis using five-stage framework approach.	16 family members.	Age: Not reported. Gender: 15 female, 1 male. Relationship: 12 spouses, 2 children, 1 parent, 1 long-term partner. Average time since stroke: 5.5 years (range: 1.10-13).	Onset of aphasia (hospitalisation). Initial rehabilitation. Chronic phases of aphasia.	• General information. • Specific time-based aphasia information. • Information about psychosocial support and counselling. • Hopeful information. • Information about coexisting behavioural and medical conditions, including depression, impaired judgement, fatigue, personality changes. • Information about aspects of treatment. • Information about maximising communicative effectiveness. • Information about how to access available resources. • Information about financial aid. • Information about volunteer opportunities. • Information about support groups. • Information about alternative therapies. • Information about job retraining.

							• Information on recovery trajectory
[2]	Cheng et al., 2022, Australia	To explore the perspectives of significant others of people with aphasia on receiving information about prognosis.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis.	7 significant others.	Age: 64.71 years (range: 35-76). Gender: 5 female, 2 male. Relationship: 3 partners, 2 parents, 1 child, 1 friend. Time since stroke: 7.29 months (range: 3-12).	3-12 months post-stroke.	• Information on expected outcomes (impairment-level improvement and process of recovery). • Information to help family member recover. • Information on how to maximise the outcome of recovery (optimal practice stimuli and techniques). • Information on treatment efficacy. • Information about practical aspects of recovery (arranging suitable accommodation, planning supports for daily activities). • Information about aphasia • Information about cognitive comorbidities.
[3]	Davidson & Wallace, 2022, USA	To explore information needs of carers of right hemisphere stroke survivors at different phases after stroke.	Qualitative methods. Semi-structured interviews, analysis using phenomenological approach using a modified five-step process.	4 carers.	Age: 65.5 years (range: 59-70). Gender: 3 female, 1 male. Relationship: 2 spouses, 1 brother, 1 parent. Time since stroke: 6.11 years (range: 3-10.5).	Onset. Rehabilitation. Chronic.	• Information about the rehabilitation timeline. • Information about symptoms. • Information about the roles of medical professionals. • Information about treatment rationales.

							• Information about treatment progress. • Information about techniques and compensatory strategies. • Information on support for carers and patients (e.g., support groups). • Information on home practice activities. • Information on supplementary treatments (e.g., vision, music, water therapies). • Hopeful information.
[4]	Davoody et al., 2016, Sweden	To explore stroke survivors' information needs after discharge in order to inform the development of an eHealth service.	Qualitative methods. Focus groups, content analysis.	12 stroke survivors.	Age: Mean not reported (range: 30-85 years). Sex: 7 female, 5 male. Time since stroke: Not reported.	After discharge.	• Simple description of invisible difficulties (e.g., chronic fatigue, cognitive impairments, and personality changes) to share with family and friends. • Information to track recovery (motor and cognitive) progress.
[5]	De Simoni et al., 2016, UK	To describe the characteristics of participants of an online stroke forum, *their reasons for posting in the forum*, and whether the responses	Qualitative and quantitative methods. Descriptive statistical analysis of forum user population, thematic analysis of posts from representative subsample of forum users.	2,348 forum users overall. 59 representative users selected for subsample thematic analysis, representing 26 stroke survivors and 33 stroke	Subsample age: Not reported. Subsample gender: 27 female, 30 male, 2 NA. Subsample time since stroke: Not reported.	Not specified.	• Information about stroke physical symptoms (communication impairments, cognition). • Information on potential for recovery (timeline, age influence, recovery of functioning, reading, memory, communication).

		addressed these needs.		survivors mentioned by third party.			• Information on invisible stroke impairments
[6]	Denman, 1998, UK	*To identify needs of spouses caring for someone with communication difficulties due to stroke* and to identify solutions they felt would alleviate the difficulties described.	Qualitative methods. Semi-structured interviews, identification of common themes.	9 carers.	Age: Not reported. Gender: 6 female, 3 male. Relationship: 9 spouses. Time since stroke: At least 12 months (mean and range not reported).	Not specified.	• Information about symptoms and their recovery (e.g., aphasia). • Information about financial entitlements. • Information about services available locally.
[7]	Donovan-Kicken & Bute, 2008, USA	*To investigate sources of uncertainty for significant others of patients with communication-debilitating illness (CDI) or injury* and how uncertainty is managed.	Qualitative methods. Semi-structured interviews, analysis using constant comparative technique.	31 significant others of individuals with CDIs, including 18 significant others of individuals with CDI due to stroke. Other CDIs were brain injury (*n* = 3), brain tumour (*n* = 3), autism (*n* = 2), Alzheimer's disease (*n* = 2), AIDS (*n* = 1), dementia (*n* = 1),	Age: 42.6 years (range: 25-75). Gender: 23 female, 8 male. Relationship: 18 children, 2 spouses, 3 close friends, 2 grandchildren, 3 aunts/uncles, 1 child-in-law. Time since CDI: 4.2 years (range: 6 months-12 hears). *Note.* Demographic details for stroke subsample not available.	Not specified.	• Information about diagnosis. • Information about the extent of damage caused by illness or injury. • Information about cause of communication debilitating illnesses. • Information about long-term prognosis (possibility for and extent of physical and mental recovery). • Information about quality of life.

				throat cancer (*n* = 1).			
[8]	Grohn et al., 2012, Australia	To describe the experience of the first three months after stroke in order *to identify factors which facilitate successfully living with aphasia after stroke.*	Qualitative methods. Semi-structured interviews, thematic analysis.	15 stroke survivors.	Age: 66.3 years (range: 47-90). Gender: 7 female, 8 male. Time since stroke: Not reported.	First 3-months after stroke.	• Information from other people with aphasia about how they make adjustments. • Information on completing activities of daily living (write shopping list, cheques, use a computer)
[9]	Hanger et al., 1998, New Zealand	*To identify what type of questions are asked by stroke survivors and their caregivers and how the nature of questions asked changes with increasing time after stroke.*	Qualitative and quantitative methods. Longitudinal, semi-structured interviews conducted at three timepoints (two-weeks, six-months, two-years after stroke), descriptive and inferential statistical analyses.	Subsample 1 (two-weeks after stroke): 60 participants. Subsample 2 (six-months after stroke): 111 participants. Subsample 3 (two-years after stroke): 72 participants. *Note*. Number of stroke survivors versus caregivers not reported.	Subsample 1. Age: 71.5 years (range: 42-99). Gender: 26 female, 34 male. Time since stroke: Not reported. Subsample 2. Age: 72.3 years (range: 23-100). Gender: 48 female, 63 male. Time since stroke: Not reported. Subsample 3. Age: 71.8 years (range: 24-101). Gender: 35 female, 37 male.	Two-weeks after stroke. Six-months after stroke. Two-years after stroke.	• Information about communication difficulties. • Information about memory problems. • Information about poor memory/concentration.

					Time since stroke: Not reported. *Note.* Demographic details for stroke survivors versus caregivers not reported.		
[10]	Hersh & Armstrong, 2021, Australia	To explore how the wife of a man with aphasia managed his discharge from hospital in the acute stage after stroke.	Qualitative methods. Single case study, narrative analysis of semi-structured interview collected as part of a large multisite study, systemic functional linguistics analysis of two complaint letters.	1 significant other.	Age: 63 years. Gender: Female. Relationship: Spouse. Time since stroke: 4 years.	Stroke onset and following days.	• Information about aphasia, including definition of term. • Information about what might happen in the future.
[11]	Hinojosa et al., 2012, USA	*To identify information needs of stroke caregivers with regard to managing recovery process at home;* to explore whether and how information needs vary by race, ethnicity and place; to explore how the information needs	Quantitative methods. Survey, descriptive and inferential statistical analyses.	276 stroke survivor-caregiver dyads.	Caregivers: Age: 59.36 years (range not reported). Gender: Not reported. Relationship: Not reported. *Note.* Stroke survivor demographics not reported.	Not specified.	• Information about knowing how to help others communicate with patient due to speech.

		are associated with caregiver characteristics (depression, coping, social support etc.).					
[12]	Howe et al., 2012, New Zealand	To identify rehabilitation goals of family members of stroke survivors with aphasia.	Qualitative methods. Semi-structured interviews, content analysis.	48 family members.	Age: 60.92 years (range: 24-83). Gender: 36 female, 12 male. Relationship: 28 spouses or de facto partners, 7 children, 5 siblings, 2 parents, 6 other relatives (e.g., sister-in-law). Time since stroke: Not reported.	Not specified.	• Information about aphasia. • Information about future recovery prospects. • Information about available services. • Information about therapy. • Information about progress. • Information that is hopeful and positive.
[13]	Oh et al., 2017, South Korea	To develop a home-based, online cognitive rehabilitation program that can be easily and repeatedly implemented and integrates cognitive training into daily activities.	Mixed methods. Three stage process involving analysis, design, and development. Analysis stage involved literature reviews and two-phase participant needs assessment (Phase 1: cognitive assessment; Phase 2: semi-structured interviews).	Analysis Stage Phase 1 (cognitive assessment): 60 stroke patients. Analysis Stage Phase 2 (semi-structured interviews): 5 stroke patients. 5 family members. Design Stage: Number of panel	Analysis Stage Phase 1: Gender: 12 female, 48 male. Age: 61.4 years (range not reported). Time since stroke: Not reported. Analysis Stage Phase 2: Gender: Not reported. Age: 69 years (range not reported). Relationship: Not reported.	Not specified.	• Information on cognitive impairment. • Information on rehabilitation.

			Design stage involved feedback on intervention design from expert panel. Development stage involved validity testing with questionnaire measures.	members not reported. Development Stage: 4 patients. 6 family members. 10 healthcare professionals.	*Note.* Subsample demographics for patients versus family members not reported. Design Stage: No demographic details reported. Development Stage: No demographic details reported.		
[14]	Kerr et al., 2010, UK	*To determine what information stroke survivors would like to see on a website about living with stroke;* to determine how to structure the information; to identify differences between stroke survivors with and without aphasia.	Qualitative and quantitative methods. Focus groups, modified card sorting task, content analysis of focus groups, descriptive statistical analysis of modified card sorting task.	12 stroke survivors.	Age: 67.8 years (range: 45-86). Gender: 7 female, 5 male. Time since stroke: 11 months (range: 6-15).	Not specified.	• Information about aphasia/communication problems.

[15]	Le Dorze & Signori, 2010, Canada	To explore needs of family members of people with aphasia and barriers/facilitators to meeting these needs.	Qualitative methods. Focus groups, custom analytic approach.	11 family members, including 10 family members of individuals with aphasia due to stroke and 1 family member of an individual with aphasia due to brain tumour resection.	Age: 60.5 years (range: 51-68). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since aphasia onset: 6.66 years (range: 3-15).	Not specified.	• Information about aphasia. • Information about available resources.
[16]	Le Dorze et al., 2009, Canada	To describe a daughter's adaptation process to her father's stroke and aphasia.	Qualitative methods. Longitudinal, single case study, semi-structured interviews (four-months, seven-months, and eleven-months after stroke), content analysis.	1 family member.	Age: 31 years. Gender: Female. Relationship: Daughter. Time since stroke: 4-11 months.	Four-months after stroke. Seven-months after stroke. Eleven-months after stroke	• Information about aphasia. • Information about services and resources available. • Information about therapy. • Information about other people who have suffered from aphasia to maintain hope and optimism.
[17]	Manning et al., 2022, Ireland	To explore the perspectives of working-aged adults with post-stroke aphasia toward what has or would help them in living well with aphasia.	Qualitative methods. Semi-structured interviews, reflexive thematic analysis.	14 individuals with aphasia as a result of stroke.	Age: 51 years (range: 33-62). Gender: 6 female, 8 male. Time since stroke: 7 years (range: 14 months-14 years).	Not specified.	• Information about aphasia. • Information about services available. • Information relevant to younger people with aphasia. • Information to help relatives understand aphasia.

[18]	Merriman et al., 2019, Ireland	To examine the perspectives and preferences of stroke survivors, carers, and healthcare professionals to inform the design of a cognitive rehabilitation intervention.	Qualitative methods. Semi-structured interviews, thematic analysis.	14 stroke survivors. 11 informal carers. 19 healthcare professionals.	Stroke survivors: Age: Mean not reported (range: 35-40 to 80-85). Gender: 8 female, 6 male. Time since stroke: Mean not reported (range: <1 year–17 years). Informal carers: Age: Mean not reported (range: 40-45 to 80-85). Gender: 9 female, 2 male. Relationship: 11 spouses. Time since stroke: Mean not reported (range: <1 year–17 years). *Note.* Age was reported categorically.	Not specified.	• Information about consequences of stroke. • Information about rehabilitation. • Information on purpose of activities instructed to undertake. • Information about impact of stroke on memory.
[19]	Paul & Sanders, 2010, USA	To explore education experiences and needs of communication partners of individuals with aphasia.	Qualitative methods. Semi-structured interviews, constant comparative analysis.	9 communication partners.	Age: 58 years (range: 37-78). Gender: 7 female, 2 male. Relationship: 5 spouses/significant others, 3 children, 1 friend. Time since stroke: 11 months (0.5-24).	Not specified.	• Information that fosters hope for improvement. • Information on how to support transition to independence. • Information that is tailored to needs of dyad. • Information about employment, disability, and return to work.

							• Information about communicating with the person with aphasia.
[20]	Rochette et al., 2008, Canada	To identify information on the internet regarding rehabilitation intended for those who have experienced a stroke and their families and *to assess the usability of a newly created website on stroke rehabilitation for laypersons.*	Quantitative methods. Questionnaire.	4 stroke survivors. 3 family members.	Stroke survivors: Age: 53.5 years (range: 47-68). Gender: Not reported. Time since stroke: 11 years (range: 4-19 years). Family members: Age: 49 years (range: 42-62). Gender: Not reported. Relationship: 1 spouse, 2 children. Time since stroke: 113.67 months (range: 2 months–28 years).	Not specified.	• Information about cognitive changes.
[21]	Rose et al., 2010, Australia	*To determine whether stroke survivors with aphasia consider it important to receive written stroke and aphasia information; to examine preferences for*	Qualitative and quantitative methods. Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content analysis of audio recorded interviews.	40 stroke survivors.	Age: 65.9 years (range: 32-84). Gender: 16 female, 24 male. Time since stroke: Not reported.	Admission. Day after stroke. Within first week after stroke. Within first month after stroke. Six-months after stroke. Twelve-months after stroke.	• Information about aphasia.

		timing and modality of this information provision.				More than twelve-months after stroke.	
[22]	Rose et al., 2019, Australia	To explore family members' experiences and preferences for receiving aphasia information.	Qualitative and quantitative methods. Survey administered during interview, descriptive and inferential statistical analyses of survey responses, content analysis of audio-recorded interviews.	65 family members.	Age: Not reported. Gender: 48 female, 17 male. Relationship: 53 spouses/partners, 12 NA. Time since stroke: 3.7 years (range: 1-16).	First days after stroke through to settled at home.	• Information about what aphasia is. • Information about causes of aphasia. • Information about purpose of communication assessment. • Information about communication progress to expect. • Information about ways to facilitate communication. • Information about coping strategies and living successfully with aphasia. • Information about aphasia therapy. • Personal experience stories from people with aphasia. • Personal experience stories from family members/friends of people with aphasia. • Information about support groups for people with aphasia. • Information about support groups for family members.

							• Information about community services for people living with aphasia. • Information about aphasia associations. • Information about aphasia research (ways to be informed about or involved in research).
[23]	Rotherham et al., 2015, New Zealand	To explore the benefits for adults with aphasia of all the groups they had chosen to participate in post-stroke.	Qualitative methods. Semi-structured interview, content analysis.	10 people with aphasia. 6 family members.	People with aphasia: Age: 69 years (range: 51-83). Gender: 2 female, 8 male. Time since stroke: 55.1 months (range: 7 months–8 years). Family members: Age: 63 years (range: 51-78). Gender: 6 female, 0 male. Relationship: 6 spouses/partners. Time since stroke: Not reported.	Not specified.	• Information about aphasia. • Information about shared experiences of others with aphasia. • Information about strategies. • Information about resources.
[24]	Shafer et al., 2022, USA	*To explore how care partners of stroke survivors with aphasia accessed*	Qualitative methods. Longitudinal, semi-structured interviews at up to five stages post-stroke	Stage 1/2 (event/stabilisation: 13 care partners.	Age: 64.18 years (range: 49-75). Gender: 9 female, 4 male. Relationship: 7 spouses, 5 children, 1 relative.	Stroke onset through to six-months after stroke.	• Information about aphasia. • Information about recovery prospects. • Information about how to help during rehabilitation.

		information and adapted to the caregiver role at different stages of recovery during COVID-19 pandemic.	(event, stabilisation, one-two weeks after stroke, one-month after stroke, six-months after stroke), thematic analysis using codebook approach.	Stage 3 (one-two weeks after stroke): 11 care partners. Stage 4 (one-month after stroke): 9 care partners. Stage 5 (six-months after stroke): 7 care partners.	Time since stroke: Not reported. *Note.* Demographic details for subsamples at each interview stage are not provided.		
[25]	Tomkins et al., 2013, Australia	To explore the factors influencing the satisfaction and dissatisfaction of people with aphasia with regards to their health care.	Qualitative methods. Semi-structured interviews, content analysis.	50 people with aphasia.	Age: 63.9 years (range not reported). Gender: 26 female, 24 male. Time since stroke: 54.9 months (range not reported).	Not specified.	• Information about aphasia.
[26]	Tyson et al., 2014, UK	To investigate stroke survivors' and caregivers' experiences and views of rehabilitation	Qualitative methods. Focus groups, content analysis.	17 stroke survivors. 6 caregivers.	Stroke survivors: Age: 58 years (range: 19-84). Gender: 6 female, 11 male. Time since stroke: Not reported.	Within the first year after stroke.	• Information about psychological assessments (cognition and mood).

		assessment process.			Caregivers: Age: Not reported. Gender: 4 female, 2 male. Relationship: 5 spouses/partners, 1 parent. Time since stroke: Not reported.		
[27]	van Rijssen et al., 2023, Netherlands	To explore the experiences, needs, and wishes of people with aphasia and their relatives to inform development of communication training for healthcare professionals.	Qualitative methods. Semi-structured interviews, thematic analysis.	20 people with aphasia. 12 relatives.	People with aphasia: Age: 59 years (range: 46-93). Gender: 11 female, 9 male. Time since stroke: 82.5 months (range: 9 months–31 years). Relatives: Age: 67 years (range: 39-96). Gender: 5 female, 7 male. Relationship: 10 spouses/partners, 2 children. Time since stroke: 105.25 months (range: 9 months–31 years).	Not specified.	• Information about aphasia. • Information about emotional consequences of living with someone with aphasia. • Information about what to expect for the future.
[28]	van Veenendaal et al., 1996, Netherlands	To investigate informational needs of stroke survivors	Quantitative methods.	35 stroke survivors. 39 family members.	Stroke survivors: Age: 61 years (range: 36-79). Gender: Not reported.	Not specified.	• Information about talking difficulties. • Information about problems with concentration.

		and their family members.	Questionnaires, descriptive statistical analysis.	43 health professionals.	Time since stroke: 18 months (range not reported). Family members: Age: 62 years (range: 36-84). Gender: Not reported. Relationship: Not reported. Time since stroke: 16 months (range not reported). Health professionals: Age: 41 years (range not reported). Gender: Not reported. Professional role: 11 nurses, 10 physiotherapists, 9 social workers, 13 not reported.		
[29]	Wiles et al., 1998, UK	To identify information needs of stroke patients and their informal carers at various stages after stroke.	Qualitative methods. Semi-structured interviews at three time-points after stroke (during hospitalisation, up to one-month after discharge, two-twelve months after discharge), thematic analysis.	Stage 1 (during hospitalisation): 6 patients. 1 carer. Stage 2 (up to one-month after discharge): 5 patients. 3 carers.	*Note.* Demographics for subsamples of participants included at each stage not reported. Demographics for carers not reported. Demographics for stroke survivors interviewed/referred to during interviews (n = 21): Age: Mean not reported (range: 50-85).	During hospitalisation. Up to one-month after discharge. Two-twelve months after discharge.	• Information about significance of symptoms (including memory loss and speech difficulties). • Information about how symptoms (including memory loss and speech difficulties) should be managed. • Information about how long symptoms (including memory loss and speech difficulties) might last.

				Stage 3 (two-twelve months after discharge): 8 patients. 8 carers.	Gender: 10 female, 11 male. Time since stroke: Not reported.		
[30]	Worrall et al., 2011, Australia	*To describe the goals of people with aphasia after stroke* and to code the goals according to the International Classification of Functioning, Disability and Health.	Qualitative methods. Semi-structured interviews, content analysis, coding of subsample of goals according to ICF.	50 participants with aphasia.	Age: 63.9 years (range not reported). Gender: 26 female, 24 male. Time since stroke: 54.9 months (range not reported).	Not specified.	• Information about terms used to describe communication difficulties. • Information about aphasia. • Information about prognosis and what to expect at different stages after stroke. • Information about aphasia services. • Information about how to explain difficulties to friends or people in community. • Information about aphasia therapy.

Table 5.1. Summary of extracted data from articles included in the scoping review. Where the article had multiple aims, all study aims are presented with the aim most relevant to this scoping review highlighted in italics. Terminology and results are quoted verbatim from included articles where they align sufficiently with the table headings, leading to variation in terminology used across the table (e.g., stroke survivor, patient, person). Psychoeducation needs are presented in the order listed within the articles.

5.6.2. Research questions

What research methods have been used?

Twenty-one articles used an exclusively qualitative approach to data collection and analysis [1, 2, 3, 4, 6, 7, 8, 10, 12, 15, 16, 17, 18, 19, 23, 24, 25, 26, 27, 29, 30] and six further articles used qualitative methods combined with quantitative methods [5, 9, 13, 14, 21, 22]. Most studies that used a qualitative data collection approach conducted semi-structured interviews [2, 3, 6, 7, 8, 9, 10, 12, 13, 16, 17, 18, 19, 23, 24, 25, 27, 29, 30] but five studies conducted focus groups [1, 4, 14, 15, 26]. Participant sample sizes in qualitative studies varied substantially. Two articles presented a case study involving a single family member [10, 16]. The maximum sample size among the articles using exclusively qualitative methods was 50 participants with aphasia [25, 30]. Focus group sizes varied between two-four participants [15] and six-ten participants [26].

Articles that used qualitative data collection methods employed different analytic approaches and frameworks. Eight articles used a version of thematic analysis [1, 2, 8, 17, 18, 24, 27, 29], eight articles used a version of content analysis [4, 12, 14, 16, 23, 25, 26, 30], two used the constant comparative method [7, 19]. Other approaches were narrative analysis [10] and a modified referenced five-step process [3]. One article described an approach that resembled thematic analysis but did not label it as such [6]. Two articles did not describe how semi-structured interview data were analysed [9, 13]. Most studies that used qualitative methods did not mention how they dealt with important qualitative concepts, such as positionality, in their data collection

and analysis processes [1, 3, 4, 6, 7, 8, 10, 13, 14, 15, 16, 18, 19, 21, 22, 25, 26, 27, 29, 30].

Five of the included articles used surveys or questionnaires [11, 20, 21, 22, 28]. All of these articles used custom measures rather than validated standard questionnaires. Questionnaires were administered remotely in three studies [11, 20, 28] and face-to-face in the other two studies [21, 22]. Face-to-face administrations were audio-recorded and analysed qualitatively to complement quantitative questionnaire data [21, 22].

What timepoints after stroke have been investigated?

Ten articles explicitly stated their investigation pertained to the first six-months after stroke (acute/subacute stage) [1, 3, 8, 9, 10, 16, 21, 22, 24, 29]. Specific timepoints investigated included stroke onset/first days after stroke [1, 3, 10, 21, 22], first week after stroke [21], two-weeks after stroke [9], first month after stroke [21], first three-months after stroke [8], and four-months after stroke [16].

Three articles explicitly stated their investigation pertained to the period at least six-months after stroke (chronic stage) [9, 16, 21]. Specific timepoints investigated were six-months [9, 21], seven-months [16], eleven-months [16], twelve-months [21], more than twelve-months [21], and two-years after stroke [9].

Eight articles investigated information needs at multiple timepoints after stroke [1, 3, 9, 16, 21, 22, 24, 29]. However, many articles did not specify the timepoint under

investigation [2, 5, 6, 7, 11, 12, 13, 14, 15, 17, 18, 19, 20, 23, 25, 27, 28, 30] and some articles used ambiguous terminology. Temporally ambiguous terms used to describe the timepoint under investigation included initial rehabilitation [1], rehabilitation [3], starting to recover [22], preparing to leave hospital [22], just returned home [22], settled at home [22], and stroke survivor returning home [1, 3].

What are the characteristics of participants?

Seven studies recruited stroke survivors only [4, 8, 14, 17, 21, 25, 30] and eleven articles included both stroke survivors and family members [5, 9, 11, 13, 18, 20, 23, 26, 27, 28, 29]. Some studies did not report the mean age of stroke survivor participants [4, 11, 18, 29] or the mean time since stroke [4, 5, 8, 9, 11, 13, 18, 21, 26, 29]. The mean age of stroke survivors was less than 70 years in all studies that reported this variable [8, 13, 14, 17, 20, 21, 23, 25, 26, 27, 28, 30]. The mean time since stroke for stroke survivor participants was between eleven months [14] and seven years [17] but these studies did not describe how stroke date was established (e.g., self-report, medical records).

With regards to the cognitive status of stroke survivors, 18 articles focused on stroke survivors with or family members of stroke survivors with aphasia [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 30]. The presence of any other cognitive impairment (including dementia) was listed as part of the inclusion/exclusion criteria in eight studies [2, 8, 17, 19, 21, 22, 25, 30], whilst the other ten articles did not report whether stroke survivors had cognitive impairments affecting domains other than language [1, 6, 7, 10, 12, 15, 16, 23, 24, 27].

One article described participants as affected by “mild physical, cognitive, and/or psychosocial disabilities” (p.2) but did not specify the precise nature of these difficulties [4]. One article assessed cognitive functioning in non-language domains using Raven’s Coloured Progressive Matrices [14]. Only one article reported in detail the cognitive status of stroke survivors in domains other than language [3]. In this study, family members reported that their relative with stroke experienced problems with memory (*n* = 4/4), executive function (*n* = 4/4), attention (*n* = 3/4) and neglect (*n* = 2/4) but there was no behavioural measure of cognition to confirm these reports [3].

Twelve studies recruited family members but not stroke survivors [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Two of these articles were case studies involving only one family member each [10, 16]. Most family members were described as spouses/partners/significant others (*n* = 134 across these twelve articles) [1, 2, 3, 6, 7, 10, 12, 15, 16, 19, 22, 24]. Some articles also included children (*n* = 37) [1, 2, 7, 12, 16, 19, 24], parents (*n* = 6) [1, 2, 3, 12], and siblings (*n* = 6) [3, 12]. Other family members were relatives-in-law (*n* = 4) [7, 12], aunts/uncles (*n* = 3) [7], and grandchildren (*n* = 2) [7]. Two studies included one friend alongside other family member participants [2,19] and one study included three friends [7]. One study included ex-family members (*n* = 3) as well as current family members (*n* = 45) [12].

Note that different terminology was used to describe stroke survivors in the articles, including stroke survivors [5, 9, 11, 14, 18, 21, 26, 28], patients [8,13, 29], individuals/people/participants with aphasia due to stroke [17, 15, 23, 25, 27, 30], and individuals with communication-debilitating illness or injury due to stroke [7]. The

following terms were used to refer to family member participants: family members [1, 12, 13, 15, 16, 20, 22, 23, 28], significant others [2, 7, 10], carers [3, 6, 29], caregivers [9, 11, 26], informal carers [18], relatives [27], communication partners [19], and care partners [24].

What psychoeducation needs have been reported?

Participants across the included studies reported psychoeducation needs regarding cognitive difficulties after stroke [1, 2, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 27, 28, 29, 30]. Psychoeducation needs mentioned within the articles were most often described in the context of aphasia [1, 2, 6, 7, 8, 9, 10, 11, 12, 14, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 28, 29, 30] but participants also described a need for psychoeducation about memory problems [9, 18, 29], concentration problems [9, 28], and general cognitive changes [13, 20].

When describing psychoeducation needs related to aphasia, participants reported a desire for general information, including definitions and information about symptoms [1, 5, 6, 7, 9, 10, 12, 14, 15, 16, 17, 21, 22, 23, 24, 25, 27, 28, 29, 30], and participants in two studies wanted information about psychological comorbidities [1,2]. With regards to recovering from aphasia, participants wanted information about what to expect in the future [1, 2, 5, 6, 7, 10, 12, 22, 24, 27, 29, 30], treatments for aphasia and their efficacy [1, 2, 12, 16, 30], as well as ways to maximise recovery [2]. The following information about living with aphasia was also sought: compensatory strategies [8, 22, 23, 29], maximising communicative effectiveness [1,11,22], available support and services [1, 6, 12, 15, 16, 17, 22, 23, 30], psychosocial support

and counselling [1], support for family members [2,17], support groups [1, 22], employment [1, 19], financial aid [1, 6], and information to help maintain hope and optimism [1, 12, 16, 19].

Though far fewer studies considered non-language cognitive impairments, participants in these studies similarly described a need for general information about symptoms and definitions [3, 4, 5, 9, 13, 20, 28, 29]. Some participants also wanted information about recovering, including what to expect in the future [3, 5, 29], treatments and rehabilitation available [3, 13, 18], and information to track recovery progress [3, 4]. Finally, in terms of living with cognitive impairments, some participants wanted information about compensatory strategies [3, 29], support for family members [3], and information to help maintain hope and optimism [3]. Themes and subthemes are summarised in Table 5.2.

Domain	Theme	Subtheme	Articles
Aphasia psychoeducation topics	General information	Symptoms and definitions	[1, 5, 6, 7, 9, 10, 12, 14, 15, 16, 17, 21, 22, 23, 24, 25, 27, 28, 29, 30]
		Psychological comorbidities	[1,2]
	Recovering from aphasia	What to expect in the future	[1, 2, 5, 6, 7, 10, 12, 22, 24, 27, 29, 30]
		Treatment and its efficacy	[1, 2, 12, 16, 30]
		Maximising recovery	[2]
	Living with aphasia	Compensatory strategies	[8, 22, 23, 29]

		Maximising communicative effectiveness	[1,11,22]
		Available support and services	[1, 6, 12, 15, 16, 17, 22, 23, 30]
		Psychosocial support	[1]
		Family member support	[2,17]
		Support groups	[1, 22]
		Employment, return to work, and job retraining	[1, 19]
		Financial aid	[1, 6]
		Maintaining hope and optimism	[1, 12, 16, 19]
Domain-general psychoeducation topics	General information	Symptoms and definitions	[3, 4, 5, 9, 13, 20, 28, 29]
	Recovering from cognitive impairment	What to expect in the future	[3, 5, 29]
		Treatments and rehabilitation	[3, 13, 18]
		Information to track recovery	[3, 4]
	Living with cognitive impairment	Compensatory strategies	[3, 29]
		Support for family members	[3]
		Maintaining hope and optimism	[3]
Influencing factors	Time since stroke	Psychoeducation needs become more prevalent over time	[9, 21]

Table 5.2. Summary of theme structure developed to capture cognition-related psychoeducation needs and influencing factors mentioned in articles included in the scoping review. Note that themes were developed to resemble domain summaries in order to enhance their actionable translational value for the next stage of the research (Chapter 6).

What factors impact psychoeducation needs?

Cognition-related psychoeducation needs were reported in articles investigating both the acute/sub-acute stage [1, 3, 8, 9, 10, 16, 21, 22, 24, 29] and chronic stage after stroke [9, 16, 21], but the prevalence and content of these information needs varied depending on the timepoint under investigation.

Two of the articles that investigated cognition-related information needs at multiple timepoints found that prevalence increased over time [9, 21] but other articles that claimed to have investigated multiple time points did not comment on the temporal evolution of psychoeducation needs. Hanger et al. [9] reported that only 4 out of 60 (7%) participants asked questions about poor memory/concentration in the first two-weeks after stroke, whereas 25 out of 111 (32%) asked these questions two-years after stroke. Similarly, whereas 3 out of 60 (5%) participants asked questions about communication difficulties in the first two-weeks after stroke, 7 out of 72 (10%) participants asked these questions two-years after stroke [9]. Rose et al. [21] similarly found that only 9% of stroke survivors considered it helpful to receive written stroke and aphasia information on the day of admission but 91% of participants considered this information helpful more than twelve-months after stroke. Nevertheless, it appeared that information needs around aphasia may have peaked before this, as 97% of stroke survivors considered it helpful to receive written stroke and aphasia information six-months after stroke [21].

Only one article provided insight into how the content of cognition-related information needs evolved over time [22]. Family members in this study considered some

information more useful to receive in the first days after stroke and other information more useful once they were settled at home. For example, 93.8% considered it useful to receive information about what aphasia is in the first days after stroke, compared to 75% who considered this information useful once settled at home. On the other hand, only 52.3% of participants considered it useful to receive information about support groups for people with aphasia in the first days after stroke but 90.4% considered this information useful once settled at home.

There were no obvious differences in the information needs reported in articles that included stroke survivors only versus family members only but results from one article tentatively suggested that information needs may vary depending on the specific relationship of the family member to the stroke survivor [2]. Cheng et al. [2] reported that non-partners tended to want information about aphasia prognosis, regardless of whether the prognosis was 'good or bad'. However, partners tended to favour information about rehabilitation over prognostic information and they felt that the delivery of prognostic information should be dictated by the preference of the stroke survivor.

What key gaps exist across the included articles?

The majority of articles focused on stroke survivors with or family members of stroke survivors with aphasia [1, 2, 6, 7, 8, 10, 12, 15, 16, 17, 19, 21, 22, 23, 24, 25, 27, 30]. Psychoeducation needs related to other cognitive domains (e.g., memory, visuospatial attention, executive function, praxis, and number processing) were rarely mentioned. Figure 5.3 shows the number of times cognitive terms included in the systematic

search strategy were used in included articles. Furthermore, most studies investigating aphasia did not report cognitive status in other domains, making it difficult to determine whether non-language cognitive impairments were also present within the sample.

Relatively few studies considered psychoeducation needs at multiple timepoints after stroke [1, 3, 9, 16, 21, 22, 24, 29] and only two of these articles [9, 21] explicitly described how the prevalence and content of cognitive-related information needs evolve over time.

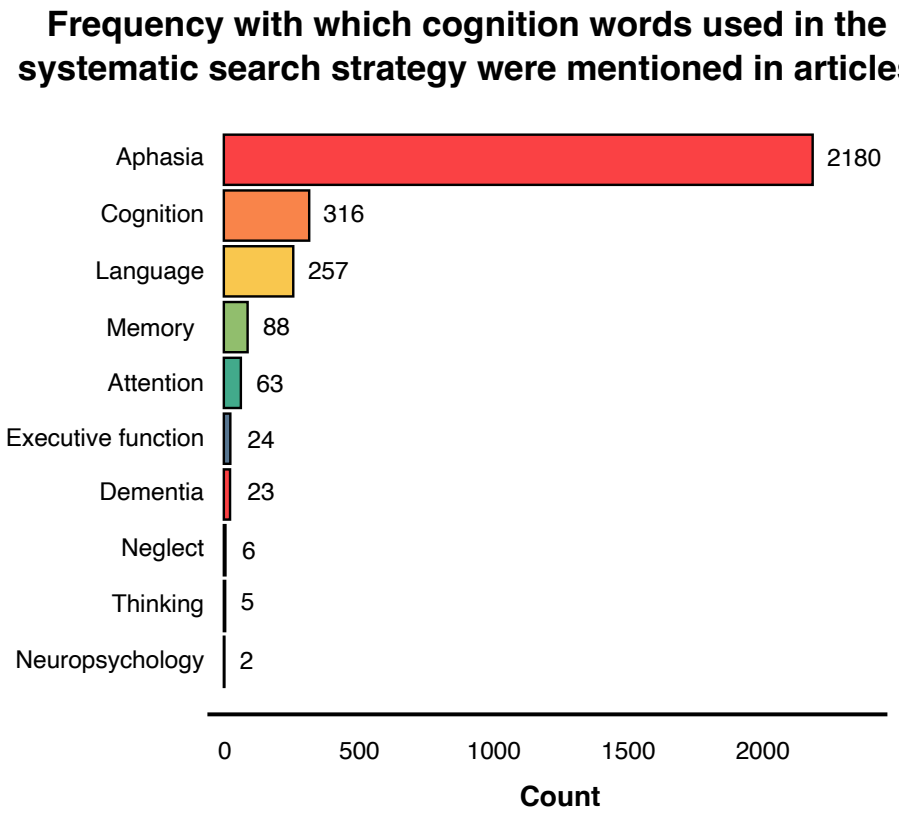


Figure 5.3. Bar chart showing the frequency with which cognition words used in the systematic search strategy were mentioned within articles included in the scoping review. The frequency counts (x-axis) for individual search terms (y-axis) are presented. Note that words included in the search strategy with an asterisk (e.g., cogniti*) were searched in full text articles using their stem but they are represented in the figure as full words (e.g., cognition) for interpretability.

5.7. Discussion

This scoping review mapped and identified gaps in 30 published articles describing cognition-related psychoeducation topics deemed acceptable to stroke survivors and family members, with the goal of informing a prototype cognition-focused psychoeducation resource to be used within intervention (Chapter 6). According to the included articles, both stroke survivors and family members reported cognition-related psychoeducation needs and these were present at all timepoints investigated by the included articles. Specific psychoeducation topics mentioned were related to expected cognitive recovery, treatment/therapy options, services/resources available, and hopeful information. Although I sought to understand (tentatively) whether time since stroke and family member relationship impacted the prevalence and content of cognition-related psychoeducation needs, very few studies investigated multiple timepoints or considered different relationship statuses separately. Another gap identified was that very few articles considered psychoeducation topics related to non-language cognitive domains commonly affected by stroke.

The articles in this scoping review – which included both stroke survivors and family members and addressed multiple timepoints after stroke – found that participants wanted psychoeducation about cognitive impairment diagnosis, prognosis, treatment, and available services. These key topics broadly align with results of the modified Delphi survey (Chapter 3), which found that healthcare professionals were in favour of providing psychoeducation about overall cognitive functioning, domain-specific cognitive functioning, potential cognitive trajectories, and support/services available, within the cognitive care intervention developed in this thesis. Together, these results

provide important insight into the topics that a successful psychoeducation resource should address in the cognitive care intervention, and it is encouraging to see that resources addressing some of these topics already exist (for examples, see websites from the Stroke Association, American Heart Association, and Stroke Foundation Australia). For example, the Stroke Association – most relevant as a UK-based charitable organisation – provides open-access leaflets, which contain rich and valuable information about post-stroke cognition, including information on different domain-specific impairments (e.g., Stroke Association, 2021a, 2021b). Having been developed based on aphasia-friendly design principles (e.g., large text, key words highlighted) (Stroke Association, 2012), these resources are accessible to stroke survivors with language impairments. However, whilst undoubtedly valuable, Chapter 6 will justify the need for a novel cognition-focused psychoeducation resource to be used within the cognitive care intervention developed in this thesis.

Cognition-related psychoeducation needs were apparent throughout the post-stroke care continuum, according to articles included in this scoping review. Although very few articles explicitly commented on the evolution of cognition-related psychoeducation needs over time, two articles included in this scoping review found cognition-related psychoeducation needs became more prevalent over time (Hanger et al., 1998; Rose et al., 2010). The reason for this is unclear but the increased needs over time may reflect the early focus on and potential preoccupation with medical management and physical recovery after stroke (Clarke & Forster, 2015); cognitive concerns may emerge later in the post-stroke recovery period once medical care and physiotherapy have been provided and stroke survivors begin to pay more attention

to invisible difficulties, including cognitive changes. Another possible explanation for the continuation of cognition-related psychoeducation needs into the later post-stroke period, and one posited by Hanger et al. (1998) to explain their findings, is that information about post-stroke cognition is not sufficiently processed, understood, and/or retained when provided in the days and weeks after stroke, potentially due to psychological and/or cognitive challenges. However, it is worth noting that this explanation is unlikely to explain the *rise* in cognitive concerns over the longer term, merely their continuation. Commenting on their clinical practice, Hanger et al. (1998) described their policy of providing written psychoeducation resources alongside verbal information to support processing, comprehension, and retention. However, given that relatively 'simple' questions emerged despite the provision of a physical resource, there are questions about the extent to which stroke survivors engaged with the resource independently. In other words, it is unclear the extent to which information provision – rather than more active approaches to psychoeducation – is effective. In the intervention developed in this thesis, providing multiple cognitive reviews to revisit key topics, as well as a tangible psychoeducation resource, may help to cement understanding and facilitate retention of cognition-related psychoeducation, while also providing an opportunity for stroke survivors (and their family members) to discuss, adjust to, and manage any cognitive changes (and potentially also psychological discrepancies).

Over half the included articles focused exclusively on aphasia, with very few articles considering other commonly affected cognitive domains and only one study reporting the prevalence of non-language cognitive impairments in their stroke survivor sample

(Davidson & Wallace, 2022). Understanding psychoeducation needs related to other domains is crucial as non-language impairments may be even more prevalent than language impairments in the years after stroke (Kusec et al., 2023) and domain-specific impairments vary substantially in their underlying aetiologies and likely trajectories (Mijajlović et al., 2017; Milosevich et al., 2024; Moore & Demeyere, 2022; Tang et al., 2018). To address this identified gap, future research should aim to include stroke survivor samples with cognitive profiles that better reflect the clinical reality (i.e., stroke survivors with impairments affecting different cognitive domains) to ensure any cognition-focused psychoeducation materials are tailored appropriately. Indeed, it is worth noting that, while existing psychoeducation resources from the Stroke Association have been designed to support understanding among those with aphasia, their length (upwards of 30 pages) and informational density may present barriers for patients with attentional difficulties (see Chapter 6 for further discussion).

This scoping review has several potential limitations. First, in contrast to systematic reviews that aim to provide definitive answers to a clearly delineated question, scoping reviews are more exploratory in nature. In line with scoping review guidance (Peters et al., 2020), this review included heterogeneous study designs and no systematic assessment of study quality, meaning that any findings related to Research Question 4 and Research Question 5 should in particular be interpreted with caution. Another limitation of this scoping review is that – by not searching grey literature and by including studies with participant samples comprising at least 50% stroke survivors and/or family members – valuable sources of information may have been missed. For example, the review may have missed co-developed resources that implicitly

document the cognition-related psychoeducation topics deemed acceptable by stroke survivors and/or family members, as well as stroke survivor/family member psychoeducation needs as perceived by healthcare professionals. Nonetheless, these decisions were justified based on the goals of including high-quality peer-reviewed evidence and not extrapolating too far beyond what stroke survivors and family members themselves have reported.

Overall, as stroke mortality rates continue to decline and the number of patients experiencing cognitive impairment in the months and years after stroke correspondingly rises (Seminog et al., 2019), it is critical to consider how best to prepare stroke survivors and their family members to manage and adjust to life with potential cognitive changes. Psychoeducation was proposed to be a key element of the post-stroke cognitive care intervention, with a strong theoretical basis for its inclusion. This scoping review demonstrates that stroke survivors and their family members are generally keen to receive psychoeducation about cognition throughout the post-stroke care continuum and key topics deemed acceptable were identified. Nevertheless, by focusing predominantly on psychoeducation in the context of aphasia, further research is required to capture perspectives on psychoeducation related to and among stroke survivors with non-language cognitive impairments.

5.8. Impact on the research

While all research activities documented in this thesis had a critical impact on the cognitive care intervention developed, the scoping review presented in this chapter also had a substantial impact on the research itself, an impact which is challenging to

convey in a ‘typical’ discussion section, like the one above. The above discussion focuses predominantly on scoping review findings in the context of the cognitive care intervention: What do the findings mean in terms of psychoeducation provision? Which cognition-related psychoeducation topics are deemed acceptable and when in the post-stroke period is it seen as acceptable to provide such psychoeducation? What gaps in the literature do we need to consider when interpreting the findings and planning future research? Here, I am keen to emphasise the broader impact of the scoping review findings on my overall approach to the research documented in this thesis.

The methodological aspect of the synthesis (Research Questions 1-3 and Research Question 6) in particular had a substantial impact on my approach to recruitment and data collection throughout the research projects presented in this thesis, which – as emphasised previously – were conducted in tandem. Recognising that the vast majority of included articles focused exclusively on stroke survivors with aphasia, I became more conscious of the need to incorporate perspectives from stroke survivors with heterogeneous cognitive impairment profiles in the research (particularly relevant to Chapter 4 and Chapter 6 recruitment). I also became aware of the potential need to steer research interviews and focus group discussions carefully to ensure perspectives on non-language related cognitive domains were being captured in sufficient depth (particularly relevant to Chapter 4 and Chapter 6).

In addition, the scoping review findings helped me to embrace the qualitative nature of the overall research programme, while motivating me to engage in a continual

process of critical reflection on my methodological approach. My academic 'upbringing' in the Psychology Departments at Durham University and the University of Oxford had instilled a sense that traditional EBM evidence hierarchies are valid and justified, that psychology researchers should strive to design rigorously controlled experimental studies, and that qualitative research is 'less than' quantitative research. While instinctively sensing these assertions to be lacking in nuance, I struggled in the early stages of my PhD to see my largely qualitative research as sufficiently valuable or rigorous. However, by recognising the prevalence of qualitative methods within the field and – crucially – the important insights they provided, I was reassured that qualitative methods are neither more nor less than quantitative methods, but rather they have the potential to offer fundamentally different yet equally valuable insight into fundamentally different yet equally valuable questions.

However, considering the conduct of qualitative studies included in this scoping review – albeit unsystematically – alerted me to problematic practice in the field (e.g., failure to consider key qualitative concepts, such as positionality, and use of incompatible methods). When trying to understand why problematic practice prevailed, I reflected on the challenge of bringing qualitative research and associated principles into a discipline dominated by a more positivist philosophical ideology. Are researchers uncomfortable 'owning' their qualitative approach, preferring instead to couch it in (neo)positivist terms that fit more neatly with the dominant quantitative mindset? Or is there simply a lack of 'good practice' on which applied health researchers can model their own work, given the historic dominance of quantitative approaches? Though the reason for problematic practice is likely multifaceted, these reflections provided further

motivation for me to reflect critically on the methods used in my own research and avoid 'falling into the same traps' I had identified in articles included in this scoping review.

5.9. Conclusions and chapter summary

Having established expert consensus on the cognitive care intervention features (Chapter 3) and explored important considerations relevant to two of the core intervention features outlined in the initial intervention skeleton (Chapter 4), research presented in this chapter sought to gain insight into the third and final core feature: psychoeducation about cognition. By conducting a scoping review of previous studies investigating cognition-related psychoeducation topics deemed acceptable by stroke survivors and family members, I gained insight into 'what has been done?' and, tentatively, 'what has been found?'. Understanding 'what has been done?' had a fundamental impact on my own methodological approach within this research programme, while understanding tentatively 'what has been found?' provided an initial indication of specific psychoeducation topics that – according to stroke survivors and family members – should be addressed in the cognitive care intervention developed in this thesis. This provided the foundation for the research presented in Chapter 6, where I used insights from research presented in this chapter and Chapter 4 to develop a prototype cognition-focused psychoeducation resource, and then used an iterative co-production approach to evaluate and revise it.

Chapter 6 Developing a novel cognition-focused psychoeducation resource to be used within the intervention

6.1. Chapter overview

By establishing 'what has been done?' and, tentatively, 'what has been found?', the scoping review presented in the previous chapter provided important insight to inform the psychoeducation component of the cognitive care intervention. This chapter builds on the foundational insight gained from Chapter 5, as well as semi-structured interviews analysed in Chapter 4, and presents the research conducted to develop a novel psychoeducation resource to be used within the cognitive care intervention.

The chapter begins by explaining why it was considered necessary to develop a novel cognition-focused psychoeducation resource, given that freely available resources already exist (for examples, see websites from the Stroke Association, American Heart Association, and Stroke Foundation Australia). In line with the overall methodological approach used in this thesis (see Chapter 2), the justification is based on interdisciplinary considerations rooted in the fields of clinical neuropsychology and educational psychology. Having outlined the rationale for the resource, the iterative approach taken to develop it is described. Results of each iterative research stage are presented in sequence and then discussed together towards the end of this chapter. The chapter concludes with my reflections on the process and a brief conclusion. Figure 6.1 shows the position of this chapter within the thesis.

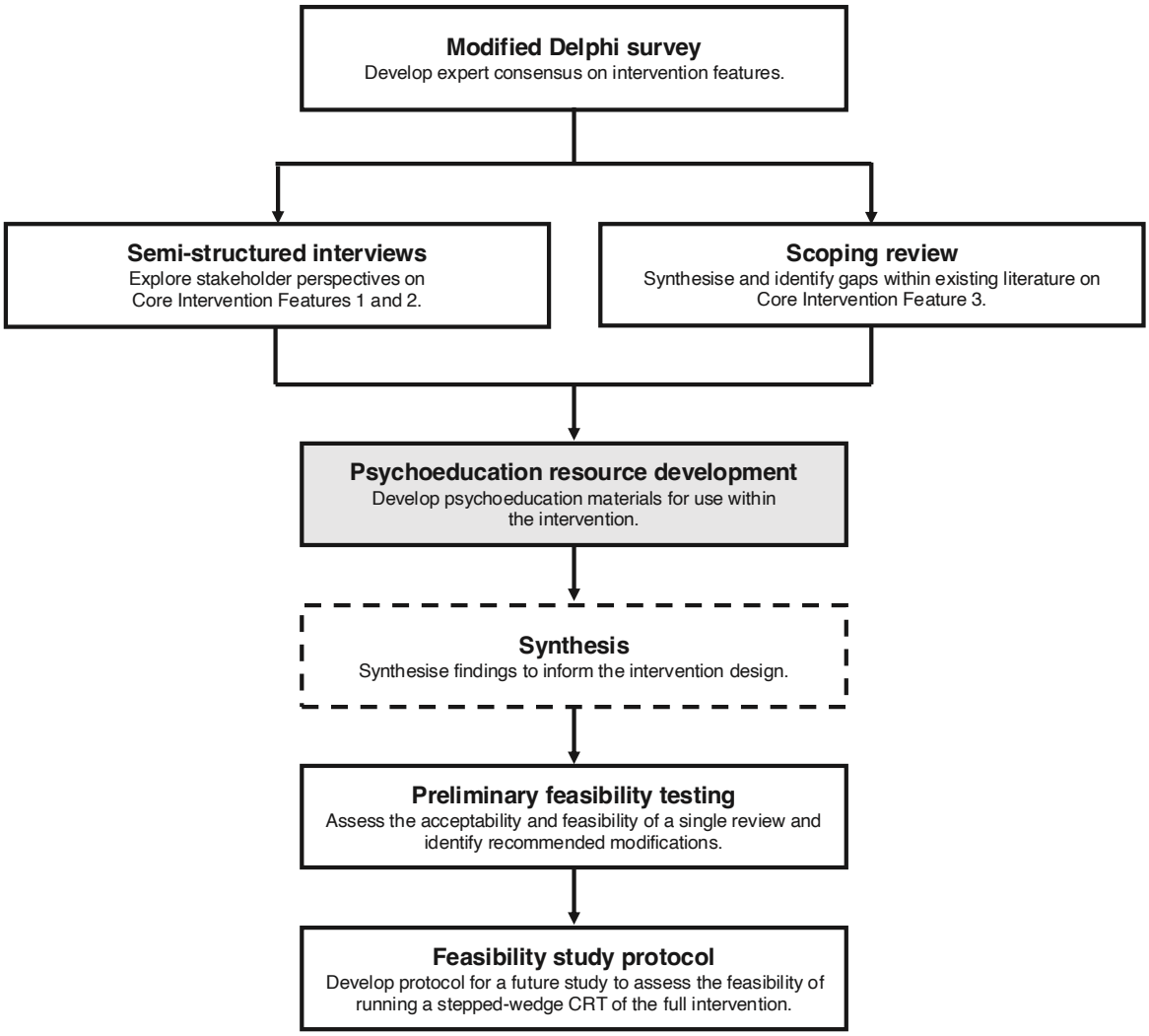


Figure 6.1. Position of the research conducted to develop psychoeducation resources (highlighted in grey) within the overall thesis.

6.2. Contribution

I contributed to the research presented in this thesis chapter by conceptualising the study, formulating the study aims and objectives, determining the study methodology, recruiting participants, coordinating workshops, collecting data, analysing data, revising psychoeducation resources based on data, and drafting the manuscript. Prof Nele Demeyere was involved in conceptualising the study, formulating the study aims and objectives, advising on study methodology, supporting workshops, collecting data,

consulting on psychoeducation resource revision, and reviewing and editing the manuscript. Dr Andrea Kusec was involved in supporting workshops, collecting data, consulting on psychoeducation resource revision, and reviewing and editing the manuscript. Mr Sam Webb was involved in supporting workshops.

6.3. Background

Despite the general emphasis on physical changes and secondary prevention within previously developed post-stroke psychoeducation interventions (see reviews by Cheng et al., 2014; Kontou et al., 2021), the work presented thus far in this thesis has confirmed the importance of cognition-related psychoeducation after stroke. Nevertheless, findings from previous chapters predominantly speak to *what* psychoeducation should be provided and, at this point in the research, it remained unclear *how* this psychoeducation should be provided to stroke survivors (and family members) receiving the cognitive care intervention. Given the high prevalence of cognitive impairment likely hindering 'normal' learning processes (Demeyere et al., 2016; Hurford et al., 2013; Lesniak et al., 2008; Milosevich et al., 2024; Nijsse et al., 2017; Turunen et al., 2018), it would be crucial to identify a psychoeducation provision approach that would support understanding and retention of the material among those receiving the cognitive care intervention.

Educational psychology theories suggest how learning and retention may be supported among student populations. The Interactive, Constructive, Active, Passive (ICAP) framework (Chi & Wylie, 2014) – also known as the Differentiated Overt

Learning Activities (DOLA) framework (Chi, 2009; Menekse et al., 2013) – is one such theory that has thus far been considered almost exclusively in an educational context but may have important implications for the intervention developed in this thesis. The framework defines four distinct learning modes: passive (receiving), active (manipulating), constructive (generating), and interactive (dialoguing). In many respects, these learning modes bear resemblance to the active versus passive psychoeducation distinction drawn in clinical research with neurological (Pinquart & Sörensen, 2006; Tang et al., 2018) and psychiatric populations (Sarkhel et al., 2020) – whereas active psychoeducation generally engages individuals in interactive and participatory learning processes, passive psychoeducation requires less participation and is akin to mere information provision, as defined in the previous chapter. Each learning mode is said to be underpinned by a different set of theoretically based and hierarchically structured knowledge change processes (Chi, 2009), with different knowledge change processes supporting relatively shallower or deeper encoding of information and subsequent retention.

Evidence from educational psychology has offered support for the ICAP framework by showing that passive learning activities result in the shallowest encoding and poorest retention, whereas interactive learning activities lead to the strongest encoding and retention and the best educational performance (Menekse et al., 2013). Though not yet investigated empirically, it stands to reason that just as deeper engagement modes facilitate *students'* understanding and retention of educational materials in experimental setups (Menekse et al., 2013), so too might deeper engagement modes facilitate stroke *patients'* understanding and retention of cognition-related

psychoeducational materials in the cognitive care intervention. Table 6.1 briefly summarises the ICAP framework and explores how it may be applied to the psychoeducation component of the post-stroke cognitive care intervention developed in this thesis.

Mode of engagement	Knowledge change process	Example learning activity	Example post-stroke psychoeducation activity
Passive (Receiving)	Store: Information is stored in an isolated way, without embedding it within a relevant schema.	Listening to explanations.	SS listens to or reads psychoeducation provided by HCP without doing anything else.
Active (Manipulating)	Integrate: Information activates prior knowledge and schema and new information is assimilated into the activated schema.	Taking verbatim notes; Highlighting sentences.	SS takes verbatim notes while HCP provides verbal psychoeducation; SS highlights or underlines written psychoeducation provided by HCP.
Constructive (Generating)	Infer: Information is assimilated into activated schema(ta) and, from this, the learner infers new knowledge by connecting, comparing, and contrasting aspects of information.	Self-explaining.	SS takes notes in their own words on psychoeducation provided by HCP.
Interactive (Dialoguing)	Co-infer: Turns taken to mutually infer new knowledge; mutuality provides opportunity to incorporate feedback ('new new knowledge') and to entertain new ideas and directions as well as alternative perspectives.	Discussing with a peer.	SS and HCP collaboratively ask and answer questions about psychoeducation topics covered in text.

Table 6.1. Summary of the ICAP framework as described by (Chi & Wylie, 2014) and applied to the post-stroke cognitive care intervention developed in this thesis. SS = Stroke survivor. HCP = Healthcare professional.

While cognition-specific psychoeducation resources are freely available from a number of charitable organisations (see Stroke Association, American Stroke

Association, and Stroke Foundation Australia websites for examples), the extent to which they are able to support an interactive mode of psychoeducation delivery as defined by the ICAP framework is questionable. Resources provided by the Stroke Association, a UK-based charitable organisation, are extensive but provide little room for personalisation and ad hoc questioning. Though a skilled healthcare professional may be able to deliver the information dialogically, there is a risk that information might be recited, particularly should it be delivered by more junior healthcare professionals, as planned for the cognitive care intervention developed in this thesis. Furthermore, certain psychoeducation topics deemed important according to results presented in previous thesis chapters are not easily addressed using these resources (e.g., no space to document cognitive assessment results) and their length and informational density present particular barriers for stroke survivors with attentional difficulties and fatigue.

Recognising the limitations of currently available psychoeducation resources addressing post-stroke cognition, the aim of the research presented in this chapter was to develop a novel cognition-focused psychoeducation resource to be used within the cognitive care intervention. To ensure the final psychoeducation resource(s) was firmly grounded in evidence and theory, with stakeholder perspectives integrated, an initial prototype was developed based on results from chapters that were complete at the point of study commencement (Chapter 4 and Chapter 5). Then, key stakeholders (stroke survivors, family members, and healthcare professionals) participated in a series of focus groups to provide feedback on the prototype. Given the non-linear and

highly iterative nature of the thesis, with each chapter informing all others, final modifications to the resource were made once all studies were complete.

6.4. Methods

6.4.1. Ethics and research governance approval

The study protocol and participant-facing materials, including participant information sheets and consent forms, were reviewed by the University of Oxford Medical Sciences Interdivisional REC, who determined that the research did not require ethical approval. A copy of the letter received from the REC confirming this decision is provided in Appendix 4. Best practice ethical conduct was adhered to throughout the research, with participants receiving detailed information sheets and completing written consent forms at each stage of the research.

6.4.2. Participant recruitment

The research presented in this chapter involved two iterative stages: (1) Prototype Development; and (2) Prototype Evaluation and Revision (two rounds). Stroke survivors, family members, and healthcare professionals were recruited for the second stage of the research. Stroke survivors and healthcare professionals were recruited from existing databases that included the contact details of participants who had taken part in previous research and consented to being contacted about future ethically approved research (Stroke survivors: NHS REC reference 18/SC/05501; Healthcare professionals: University of Oxford REC reference: R83766/RE001).

Purposive sampling was used to ensure a diverse group of participants were included to stimulate discussion and promote cross-pollination of ideas during the focus groups. The aim was to include: (a) stroke survivors with different ages, genders, time since stroke, and cognitive abilities; and (b) healthcare professionals with different occupations and geographical locations; and (c) participants who were naïve and experienced with regards to the cognitive care intervention research programme. Potential participants were contacted by email or telephone, provided with detailed information about the research, and offered the chance to ask questions. Those who decided to participate provided written informed consent before each focus group.

6.4.3. Research procedure

The following sections provide further detail on the two iterative stages involved in developing the cognition-focused psychoeducation resource: (1) Prototype Development, (2) Prototype Evaluation and Revision.

Prototype Development

As the research presented in this thesis was guided by the MRC framework for complex intervention development, which advocates that evidence and theory should be prioritised, the initial prototype psychoeducation resource was developed based on findings from research activities that were complete at the point at which this study began (Chapter 4 and Chapter 5). Findings were operationalised as discrete evidence statements and then synthesised to develop a set of candidate intervention requirements, defined as evidence-based, concrete, pragmatic, and actionable statements detailing 'ideal' features of the prototype psychoeducation resource.

Candidate intervention features were evaluated and revised using a quasi-systematic approach, whereby each requirement was considered against the following criteria, adapted to suit the purpose of this study from the criteria used by Curtis et al. (2015): (a) Relevance to the target outcome; (b) Ease of implementation within the scope and scale of the project; (c) Ease of implementation within clinical practice. Candidate intervention requirements were accepted if they met all three criteria, otherwise they were adapted or rejected. Initial evidence statements, candidate intervention requirements, and final intervention requirements are presented in Appendix 4.

The final set of intervention requirements informed the initial prototype psychoeducation resource, which was developed using Microsoft PowerPoint. The following considerations guided the decision to present stakeholders with an initial prototype to be evaluated and revised within focus groups, rather than asking them to collaboratively design a prototype 'from scratch'. First, it was hoped that the focus on feedback rather than prototype generation would reduce participation barriers for those with more severe cognitive impairment, who may have found it challenging to generate abstract ideas and link them to execution. Second, by developing an initial prototype based on empirical evidence, the approach remained in line with the overall methodological approach taken in this thesis, where empirical evidence, theory and stakeholder feedback were prioritised (see Chapter 2).

Prototype Evaluation and Revision

Having developed an initial prototype based on existing evidence and informed by relevant theory (i.e., ICAP framework), key stakeholders were invited to evaluate and

provide feedback by completing a custom survey and attending a focus group. Data were analysed and results used to inform prototype revisions and revisions to the intervention requirements. This process of evaluation and revision was repeated, with the plan to stop this iterative evaluation and revision process when qualitative participant feedback indicated no major revisions needed to be made to the prototype for it to be deemed acceptable.

Custom surveys

The aim of the custom surveys was to gauge the extent to which the prototype resources met the intervention requirements established in the initial Prototype Development stage of the research. The surveys comprised a series of statements reflecting the intervention requirements. For example, the intervention requirement "Clinical jargon should be avoided when possible and explained if used" was used to develop the following survey item: "The resource avoids clinical jargon when possible and explains any jargon used." For each item, participants were asked to indicate using a Likert scale the extent to which they agreed or disagreed with the statement (response options for all items: Strongly disagree, disagree, neither disagree nor agree, agree, strongly agree). The surveys were distributed and completed online (Microsoft Forms) prior to the focus groups. Survey responses were anonymous to encourage honest sharing of opinions, so it was not possible to follow-up non-responders.

Focus groups and semi-structured interviews

The initial plan was to run focus groups in order to gather qualitative feedback on the prototypes, including positive feedback, negative feedback, and recommended modifications. After the initial round of prototype evaluation and revision, the decision was made to offer one-to-one semi-structured interviews as an alternative to focus groups in order to encourage participation from a more diverse sample of participants. Focus groups with stroke survivors and family members were run in-person at the University of Oxford to facilitate rapport building, collaboration, and cross-pollination of ideas. Separate focus groups with healthcare professionals were run online (Microsoft Teams) to allow participants of geographically diverse participants who could not travel to the University of Oxford. Semi-structured interviews were conducted either in-person at participants' homes or online, depending on participant preference.

Focus groups and interviews began with a brief introduction to the research, including the aims and objectives of the session. Topic guides were then used to lead discussion on the prototype resources and encourage participants to provide feedback. Focus groups and semi-structured interviews were audio recorded with participants' consent and transcribed verbatim, ensuring that identifiable information (e.g., participant names) was redacted from the transcripts.

6.4.5. Data analysis

Custom surveys

R-Studio version 4.3.1 was used to calculate descriptive statistics from quantitative survey data and to visualise data. The aim of the descriptive statistical analysis was

to calculate the proportion of participants who strongly agreed, agreed, neither agreed nor disagreed, disagreed, or strongly disagreed the prototypes met each intervention requirement. When more than one survey item pertained to the intervention requirement, responses were aggregated across each relevant item to calculate proportion agreement/disagreement to the intervention requirement overall. I analysed proportions relative to the intervention requirements, rather than individual survey items, to facilitate comparison between prototype iterations (i.e., to gauge whether subsequent prototype iterations were more successful in meeting intervention requirements compared to previous iterations). However, the analysis was not powered for formal hypothesis testing, so it was not possible to determine at a statistical level whether the extent to which the final prototype met the intervention requirements was significantly different from earlier iterations.

Focus groups and semi-structured interviews

Qualitative data from the focus groups and individual interviews were analysed using template analysis (King, 1998, 2024). As in research projects presented within previous thesis chapters, this approach was selected as its philosophical flexibility meant it was compatible with the critical realist positioning of the research and its systematic coding style enabled efficient delivery of the analysis. While efficient delivery was crucial in all research presented in this thesis, it was particularly important in this study, as the aim was to minimise temporal gaps between rounds of prototype evaluation to limit participant attrition and ensure the previous prototype would remain 'fresh' in participants' minds.

The overarching objective of the thematic analysis was to identify pragmatic and actionable feedback to inform prototype revisions. The following a priori themes were therefore developed and held in mind during each analysis: (a) Positive feedback; (b) Negative feedback; or (c) Suggested modification. After running the focus groups and interviews, I transcribed the audio-recordings myself as a crucial part of the data familiarisation process, then read and re-read them to increase my familiarity while making rough notes. Having familiarised myself with the data, transcripts were coded at a semantic level using the comment function in Microsoft Word while holding in mind a priori themes. Codes and accompanying text were compiled in a Microsoft Excel file that already contained a priori themes. This enabled me to see at a glance how the data fitted (or did not fit) with these themes and make appropriate revisions to the theme titles and boundaries. While I was the only member of the research team to read the transcripts in their entirety, other team members were involved in the data collection process and thus had some familiarity with the data. Regular discussions with other members of the research team provided useful alternative perspectives on the data, highlighted important points that I had initially overlooked, and provided reassurance that any subjective interpretations of the data had not gone 'too far'. Ultimately, I acknowledged that the data collection, analysis and results would inevitably be coloured by my own assumptions and values, but the aim was still for the final themes and subthemes to be firmly rooted in the data (i.e., predominantly inductive approach). An electronic journal helped me document pertinent considerations and reflections about my role as a researcher, with key reflections summarised in Section 6.7.

Design response

Results of the custom survey and focus group/interview data analysis from each round were used to inform prototype revisions. As the aim of the survey was to gain a 'snapshot' of the extent to which intervention requirements were being met, rather than to inform specific changes to the prototype, revisions were mostly based on qualitative data. When considering qualitative data to make prototype revisions, it was critical to distinguish between recommendations that reflected subjective preferences and those that would enhance the prototype for the wider stroke survivor, family members and healthcare professional population. To achieve this, a quasi-systematic approach was used, where the decision to accept or reject preferences was guided by the following criteria, again adapted from those used by Curtis et al. (2015): (1) Alignment with intervention requirements; (2) Supported by theoretical findings and/or evidence (including evidence from research presented in other chapters of this thesis); (3) Scope within project; (4) Ease of implementation. Throughout this process, my own opinions and those of other members of the research team shaped revisions to the prototype, given that the approach used in this research project was decidedly collaborative. However, I aimed to ensure revisions were predominantly grounded in stakeholder feedback.

6.5. Results

The following sections present the results from each stage of the research in turn, in order to make clear how the prototype evolved over time based on participant input. Each prototype iteration is described briefly but only the final resource is presented in full (Appendix 4) due to space constraints in the thesis.

6.5.1. Intervention requirements

Six intervention requirements (nine including sub-requirements) were developed. These are presented below, with further detail on how these intervention requirements evolved from initial candidate requirements presented in Appendix 4.

1. The prototype should have the potential to provide accurate information about cognition in the acute and chronic stages after stroke.

2. The prototype should provide information on:
    (a) cognition (e.g., definitions),
    (b) cognitive assessments,
    (c) potential cognitive trajectories,
    (d) services and support available.

3. The prototype should provide comprehensive and honest information within a positive framework.

4. The prototype should provide information that is personalised and specific to individual stroke survivors where possible.

5. The prototype should communicate information clearly and concisely, avoiding clinical jargon where possible and explaining any jargon used.

6. The prototype should not include highly emotive language.

6.5.2. Prototype Version A

Initial prototype psychoeducation resources were:

- **OCS Feedback Form:** One-page document describing the purpose of cognitive screening, defining specific cognitive domains, and providing a summary of the individual stroke survivor's performance on the OCS, including a visual snapshot and written description of performance to be filled in by the healthcare professional conducting the cognitive review within the cognitive care intervention.

- **OCS Domain Information Sheets:** Collection of one-page summary sheets providing further information on impairments affecting the following specific cognitive domains, selected to be compatible with the OCS: memory, language, number processing, executive function, visuospatial attention, and praxis. Each sheet included an introduction describing the prevalence of post-stroke cognitive impairment, a description of the specific cognitive domain and how it may be affected by stroke, including how changes may evolve over time, and a list of online and local resources and services available for support. In the cognitive reviews, it was envisaged that sheets would be distributed to stroke survivors and their family members where the cognitive screen indicated a potential impairment affecting the relevant domain. Thus, stroke survivors

receiving a cognitive review may receive none, one, several, or all the OCS Domain Information Sheets, depending on their cognitive screen performance.

Participants

The initial prototype (Prototype Version A) – including the OCS Feedback Form and OCS Domain Information Sheets – was reviewed by 12 participants. This included 4 stroke survivors, 3 family members, and 5 healthcare professionals. The mean age of stroke survivors was 65.80 years (*SD* = 6.35, range: 61.31-70.29) and the average age of family members was 65.00 years (*SD* = 4.58, range: 61.00-70.00). The mean time since stroke was 2.37 years (*SD* = 0.04, range: 2.34-2.40). Due to the high rates of missing cognitive (OCS) data from the acute and subacute stage of stroke, participants were asked to self-report on cognitive changes since their stroke. All stroke survivors and family members reported they/their family member had experienced changes in cognition since their stroke, with domains affected including language (*n* = 2), memory (*n* = 3), visuospatial attention (*n* = 3), and processing speed (*n* = 1). All healthcare professionals were occupational therapists due to short-notice cancellations from clinical neuropsychologists and speech and language therapists. Demographic characteristics are summarised in Table 6.2.

Variable	Prototype Version A	Prototype Version B
Stroke survivors, *N*	**4**	**9**
Years of age, range (*M, SD)*	61.31-70.29 (65.80, 6.35)	34.80-73.80 (60.91, 13.68)
Gender, *N*		
Female	1	2
Male	3	7
Ethnicity, *N*		
White-British	4	7
Black-African	0	1
White-Other	0	1
Years since stroke and participation, range *(M, SD)*	2.34-2.40 (2.37, 0.04)	0.89-2.13 (1.39, 0.40)
Cognitive changes, *N*		
None	0	1
Language	2	2
Memory	3	6
Visuospatial attention	3	1
Processing speed	1	1
Executive function	0	1
Family members, *N*	**3**	**3**
Years of age, range (*M, SD)*	61.00-70.00 (65.00, 4.58)	61.00-70.00 (65.00, 4.58)
Gender, *N*		
Female	3	3
Male	0	0
Ethnicity		
White-British	3	3
Relationship, *N*		
Spouse or partner	3	3
Time since relative's stroke, *N*		
Six-twelve months	0	0
One-three years	2	2
More than three years	1	1
Relative's cognitive changes, *N*		
None	0	0
Language	1	1
Memory	3	3
Attention	1	1
Processing speed	1	1
Executive function	0	0

Healthcare professionals, *N*	**5**	**4**
Gender, *N*		
Female	5	3
Male	0	1
Professional occupation, *N*		
Occupational Therapist	5	0
Clinical Neuropsychologist	0	2
Clinical Psychologist	0	1
Speech and Language Therapist	0	1

Table 6.2. Demographic and clinical characteristics of participants involved in co-production activities to develop cognition-focused psychoeducation resources. Cognitive changes were self-reported due to high rates of missing OCS data from the acute/subacute stage of stroke.

Custom survey

A total of 11 (91.67%) participants completed the custom survey to evaluate Prototype Version A. Responses to the custom survey are summarised in Table 6.3. Overall, aggregating responses across all survey items, 52.12% (n = 86) responses indicated participants agreed the prototype met the intervention requirements and 20.00% (n = 33) strongly agreed.

Intervention requirement		Prototype meets intervention requirement, *N (%)*				
		Strongly agree	**Agree**	**Neither**	**Disagree**	**Strongly disagree**
1	Useful information for the acute and chronic stages after stroke.	**4 (36.36)**	**4 (36.36)**	3 (27.27)		
2a	Information about general aspects of cognition (e.g., definitions).	3 (27.27)	**5 (45.45)**	3 (27.27)		
2b	Information about purpose and outcomes of cognitive assessment.		**8 (72.73)**	3 (27.27)		
2c	Information about potential cognitive trajectories.	2 (18.18)	**6 (54.55)**	1 (9.09)	1 (9.09)	1 (9.09)
2d	Information about services and support available.	**6 (54.55)**	4 (36.36)	1 (9.09)		
3	Comprehensive and honest information provided within a positive framework.	8 (18.18)	**24 (54.55)**	9 (20.45)	3 (6.82)	
4	Information personalised and specific to individual patients where possible.	1 (9.09)	**8 (72.73)**	2 (18.18)		
5	Information communicated clearly and concisely with clinical jargon avoided when possible and explained if used.	7 (15.91)	**24 (54.55)**	8 (18.18)	5 (11.36)	
6	Highly emotive language avoided.	2 (18.18)	**3 (27.27)**	**3 (27.27)**	2 (18.18)	1 (9.09)
	Overall	33 (20.00)	**86 (52.12)**	33 (20.00)	11 (6.67)	2 (1.21)

Table 6.3. Number and percentage of survey responses indicating the extent to which participants (n = 11) considered intervention requirements to be met by Prototype Version A. Participants were asked to indicate whether they strongly agreed, agreed, neither agreed nor disagreed, disagreed, or strongly disagreed that the prototype met the intervention requirement. The most common response (mode) for each intervention requirement is highlighted in bold. Survey responses do not sum to eleven in all cases due to some non-responses and aggregation of results where there were multiple questions tapping the same intervention requirement.

Focus groups

Themes and subthemes developed from the qualitative analysis of focus group data are summarised in Table 6.4 and described in more detail below. A priori themes (positive feedback, negative feedback, recommended modifications) were adapted, as negative feedback was often intricately tied to a recommended modification.

Theme	Subtheme Level 1	Subtheme Level 2
Positive feedback	Potential positive impact on stroke survivors and family members	• Normalise cognitive impairment. • Increase awareness and understanding. • Motivate rehabilitation. • Visualise areas of strength. • Reduce feelings of abandonment.
	Potential positive impact on healthcare professionals and services	• Standardise services nationally. • Improve quality of information provision. • Increase confidence.
Negative feedback and recommended modifications	Issues with design.	• Too much text. • Insufficient space for personalisation. • Professional-centred. • Different dissemination options required.
	Issues with wording.	• Lacking nuance in places. • Overly emotive in places.
	Risk of use by healthcare professionals without requisite qualifications and experience	• Clarify for whom resources are designed.

Table 6.4. Summary of theme structure developed from focus group data evaluating Prototype A.

Positive feedback

Participants generally agreed the resources would be valuable for stroke survivors and their family members. Specific advantages were identified at both an individual stroke survivor and healthcare professional-level, as well as a more systemic service-level.

Potential positive impact on stroke survivors and family members

Participants suggested the resources could help normalise post-stroke cognitive impairment and increase awareness. Statistics referencing the high prevalence of post-stroke cognitive impairment were described as *"a real keeper"* (Healthcare Professional 1), with participants speculating that they may help those with cognitive impairment feel less alone. The *"soundbites"* (Healthcare Professional 1) were also perceived as valuable for this reason, and because they were concise and understandable summaries of domain-specific cognitive impairments that effectively consolidated the most important information provided.

> *"I think having those patient words there are really powerful because that's what [language] is – it's listening, writing, and understanding. It's just so eloquently put so I think that's really nice to have that for clarity in each thing."* (Healthcare Professional 5)

The resources were also seen as potentially motivating. In particular, stroke survivors and family members reflected that being able to see different levels of impairment severity within the cognitive assessment feedback visualisation

could motivate stroke survivors and encourage optimism by highlighting the potential for natural recovery from impairments. Some healthcare professionals also suggested the graded severity levels would be helpful for feeding back on areas of strength, where stroke survivors had impairments affecting the majority of cognitive domains.

> *"The person I am, I would go "Right, okay, I'm severe at the moment. Let's head to moderate and see if I can get close to moderate." That's the way I would look at it."* (Stroke Survivor 2)

> *"The cognitive wheel with the different levels of impairment, I really really like that because I think that is something that, you know, sometimes you'll fill that out and actually someone's got an impairment in absolutely every part of that and that's really challenging to feedback but then actually, as a clinician, you know that, you know, they still have a strength in that area or, you know, this is a little bit stronger than that. So I think that was really valuable."* (Healthcare Professional 5)

Participants also felt that listing available support was beneficial, as stroke survivors and family members would have somewhere to turn after receiving preliminary information about their cognitive abilities through the intervention. One family member described feeling unsure about where to find support for cognitive changes, which eventually led to a feeling of *"research fatigue"* (Family Member 1). Stroke survivors and family members suggested local

support groups should also be listed in this section, as they recognised the potential power of support groups for reducing feelings of isolation. Indeed, one family members spoke about how attending a local support group for people with aphasia helped her husband – himself a stroke survivor with expressive aphasia – feel less alone.

> *"I think how you [stroke survivor] felt [...] very isolated, and it took a lot to get you, for instance, to go to the aphasia group. You were very very reluctant to go but it's actually been really helpful. You don't feel so alone."* (Family Member 2)

While healthcare professionals agreed the section providing detail on available support and resources was useful, they identified minor improvements to make it easier for patients with cognitive impairment to access and navigate the resources, such as providing links to specific website sections rather than homepages.

> *"I followed that link that was there just for myself to see, okay, where does this take me to? And it takes you to the Stroke Association page and then you've got to go in there to find the specific thing so, you know, that relies on a certain amount of cognition, so I did think, if you have links, it might be that you link straight to the – say it's the memory information sheet, it doesn't go to the general page, it goes straight to*

memory. It's just one less step for someone to have to navigate." (Healthcare Professional 5)

Stroke survivors and family members also suggested including guidance on how to access private therapy, given the lengthy waiting lists for public sector stroke services, though they acknowledged that it may not be appropriate for an NHS-based intervention to be seen endorsing specific private practitioners.

"[Private therapy is] a very expensive way to go. However, if you choose to spend your resources in that way, sometimes you need assistance to make sure you're going in the right direction and I know it's not something the NHS likes to do and I hesitate to say it, but some help directing people to how they might find something outside the NHS. [...] I don't want to say that because the NHS is really important, and I feel strongly that it is a wonderful creation, and we need to support it in every way. However, at the moment, it is failing, and it has failed us." (Family Member 2)

"Because of the fact that I was so undirected in what [private therapy] I was looking for, you find your way expensively, so some help with that might be a good thing." (Family Member 1)

Potential positive impact on healthcare professionals and services

Healthcare professionals identified potential positive impacts the resources could have at a more systemic level. Should they be made freely available, participants suggested the resources could help standardise and improve the quality of information provision across stroke services in the UK. Participants reflected that services are often left to develop their own resources to meet patient needs and the quality of these resources can vary depending on the expertise of those working within the specific service, leading to potential inequalities in healthcare provision nationally. They stressed that having a single evidence- and theory-based resource developed in consultation with key stakeholders would be ideal to reduce these disparities and ensure stroke survivor needs are better met nationally.

> *"They're great steps to make in terms of having resources that can be, if you like, benchmarked and used across all organisations. I think it's really really positive from that perspective."* (Healthcare Professional 1)

Participants also noted how many non-psychology-specialist healthcare professionals lack knowledge and confidence in cognitive screening and rehabilitation, which can lead them to shy away from discussing cognition with patients and their family members. This, they suggested, leads to even greater inequalities in healthcare provision nationally, as cognition may not be addressed with every patient. Participants suggested that having verified

information in printed format could help healthcare professionals feel more prepared and confident engaging in these discussions.

> *"If you have a tool that you had in your hand, you explain things to patients one million times better than you would without one. It's just a prompt but it makes you feel safe, especially as a junior member of staff. You can open up to some of those questions that the patients want to ask you. You've got something to keep you safe and have a bit of an answer."* (Healthcare Professional 4)

Negative feedback and recommended modifications

Despite the generally positive feedback on the prototype resources from participants, concerns were expressed about some aspects of the design and textual content. One potential risk was also identified, should the resource encourage healthcare professionals without the requisite qualifications and experience to undertake cognitive screening and provide feedback and psychoeducation.

Issues with design.

With regards to the design of the resources, participants expressed concern that the resources were too wordy and informationally dense in places. These design issues raised concerns about how accessible the resources would be for stroke survivors with visual, attentional, and language impairments. Although participants agreed the information included within the resources was valuable, several participants suggested it could be more concise in places and

that the text should be spread over more pages. One participant suggested readability could be further enhanced by bolding key words, as well as headings.

> *"I would have thought this is a lot for somebody with hemianopia, hemineglect, attention problems to be able to take on board. I mean, we can take it on with a glance but there might be some people who can't so it's a bit overwhelming to have that much."* (Family Member 3)

> *"I thought that the key words might benefit from being highlighted on the feedback form so when you put in those – I can't remember now having read them earlier – I think when you've said a word, 'attention' or 'concentration', maybe bold those so they stand out more."* (Healthcare Professional 1)

Participants – particularly healthcare professionals – also stressed the need for additional space to personalise and tailor the resources. Whilst they appreciated the ability to personalise cognitive screening feedback using the visualisation tool provided, participants suggested it would be valuable to have additional space to highlight individual cognitive strengths, as the visual snapshot was felt to be heavily impairment focused. Providing space for personalised strategies to manage cognitive changes in day-to-day life was also suggested.

"It's still quite impairment-based. I'm not sure whether there's a way just to also highlight those strengths. I'm just thinking about kind of the positive way that I think, you know, we're wanting it to come across." (Healthcare Professional 1)

"The danger with having pre-set [strategies] is if you have someone who's very high-functioning, you know, and they see 'use Post-It notes to remind yourself', well, that would be like so insulting and they would kind of think you haven't got it. You know, for them, it might be something around, you know, using their work calendar and having something a bit more high level, so you could personalise and not have that kind of broad brush thing, which I think alienates people, whichever end of the spectrum they fall." (Healthcare Professional 5)

Personalisation was also important to stroke survivors and family members, who stressed that both the content of the psychoeducation resources and the process of providing it should be tailored to individual stroke survivors.

"I think sometimes people like to be asked "How do you like your feedback? Shall we focus on the things that you seem to have performed strongly on first or shall we comment on the ones that weren't so strong and what we can do about that?" Because some people like the bad news out the way first and some people like to be eased in gently with the good news first." (Family Member 3)

Still, healthcare professionals acknowledged the challenge of training junior members of staff to personalise psychoeducation about post-stroke cognitive impairment, given the complexity of cognitive screening and rehabilitation, as well as the heterogeneity of patient needs and preferences. One healthcare professional acknowledged how difficult it would be to get the resource and training to be "*perfect and simple when [cognitive screening and rehabilitation] is so complex and so varied in different contexts with different patients"* (Healthcare Professional 4).

Participants also considered the heterogeneity of stroke survivor needs and preferences in terms of the resource modality. Whilst stroke survivors and family members generally agreed patients should be given a physical copy of the resource, some healthcare professionals wondered whether emailing resources may be more appropriate in some cases. Nevertheless, one healthcare professional highlighted potential issues with this, reflecting that *"to have a laptop or a normal computer is actually a luxury"* (Healthcare Professional 5). As such, there was general agreement that stroke survivors and their family members should be given the option of receiving a physical or digital version of the resources within the intervention.

> *"Most people don't have laptops or computers. They're doing it all on their phone so therefore [...] if you've got something printed, it makes it*

easier to read than sort of scrolling up and down on your phone." (Healthcare Professional 5)

Issues with wording.

The resources were said to be too *"black and white"* (Healthcare Professional 3) in places and some participants were concerned that the complexity of post-stroke cognitive impairment was not always fully conveyed. In particular, one participant highlighted the information about potential cognitive recovery and future changes as being *"too blunt"* (Stroke Survivor 3). They suggested this section could be rephrased to be more motivating and hopeful, whilst remaining accurate in the context of current evidence.

"The one sentence about 'most recovery happens in the first months after stroke' [...], I just think for language, that's not really the case so I feel it's quite negative. [...] We know that we see a lot of change acutely but we don't really know what happens after that because people aren't being followed up. [...] For me, that sentence makes me feel uncomfortable." (Healthcare Professional 5)

"The point needs to be made that, if we find something that has been affected by your stroke, we hope to be able to point you in the right direction and that this is a moveable...it will change over time." (Family Member 1)

Nevertheless, while motivating and hopeful information was emphasised as important, participants also stressed the need to balance this with honest information in order to foster realistic expectations, echoing the intervention requirements developed from previous research.

> *"I think you have to be careful about aiming for positive when realistic might be a better term. I know when my husband had his stroke [...], there was a problem with some of the staff being too positive because he had expectations about going back to work and doing all sorts of things and he really needed to have a realistic and constructive perspective."* (Family Member 3)

Healthcare professionals were also concerned the resources did not sufficiently convey how cognitive screening fits into the broader picture of the post-stroke assessment process, given that functional assessments and conversations with stroke survivors and family members are often also important in informing judgements about cognitive status. As such, healthcare professionals were keen that the resource should explain cognitive screens are informative as a first-line approach, rather than *"the be all and end all"* (Healthcare Professional 3).

> *"It very much felt like that [cognitive screen] was the thing that was going to tell you about that person's cognitive profile or how they're getting on. My experience in reality is that's just one part of the puzzle. I wonder if*

you need to say "This is one thing that we're using to help us understand so that we can help you but there are lots of other things too that are important." (Healthcare Professional 3)

Finally, while the resources were generally perceived as having an encouraging tone, participants worried some words were potentially anxiety-provoking, with 'performance' and 'ability' highlighted as two key examples.

"Performance almost indicates a judgement. So if you were on the stage and you were doing a performance, people would judge whether you were good or bad at it and it's kind of the same thing here – "you've performed." (Stroke Survivor 4)

"When I read the word 'ability', it kind of has like 'testing' connotations to me, so it means 'your ability to do this is not as good as...your ability to –' so the word 'ability' is a bit of a difficult word for me because when you've just had a stroke, you know that your abilities are lower than what they used to be but I don't know if another word could be used other than 'ability'." (Stroke Survivor 4)

Risk of use by healthcare professionals without requisite qualifications and experience

Participants generally agreed the resources were potentially beneficial for healthcare professionals and clinical services, but healthcare professionals

also identified a potential risk. Referencing recent updates to the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2023a), one participant noted that healthcare professionals must have appropriate qualifications and experience to undertake cognitive screening and provide accompanying feedback and psychoeducation. She expressed concern that the resources may be used by those without these requirements and suggested it should be made clear in any accompanying training by whom the resources should be used.

> *"Thinking about what we said in the guidelines, people shouldn't even be undertaking screening unless they've got this sort of knowledge to be able to do it properly and that worries me a bit. [...] What I would be nervous about is people being able to access the resources – maybe assistant staff, for example, who we now say shouldn't be conducting screens – and thinking "Well, that's okay then because everything's written down for me and I can now do it." [...] That doesn't mean we shouldn't have the resources, but I think we do need to be clear who they're for."* (Healthcare Professional 4)

Design response

Prototype Version A was revised based on the above feedback. The major revisions were:

- Streamlining to create a single workbook.

- Addition of blank sections to highlight cognitive strengths and challenges for individual stroke survivors and to list personalised strategies.
- Reductions in text density and bolding of key words.
- Rephrasing and rewording.

6.5.3. Prototype Version B

The above revisions resulted in a single prototype psychoeducation resource:

- **OCS Workbook**. The workbook began with a title page and a contents page, followed by a one-page introduction with basic definitions and statistics related to post-stroke cognitive impairment. Then, the workbook included two pages where healthcare professionals could personalise a cognitive screening wheel, alongside 'strengths' and 'challenges' boxes, based on the individual stroke survivor's performance in the cognitive screen conducted as part of the intervention. This section was followed by a page on cognitive strategies, with space for the healthcare professional, stroke survivor, and family member to identify and record personalised strategies collaboratively. Places to find support were then documented. The book concluded with several pages providing further information on domain-specific cognitive impairments. A supplementary page was developed for follow-up cognitive reviews to allow performance in cognitive screens conducted at different time points (i.e., one-month, three-month and six-month cognitive reviews) to be easily compared and contrasted.

Participants

Prototype Version B was reviewed by 16 participants, including 9 stroke survivors, 3 family members, and 4 healthcare professionals. 4 of the stroke survivors and all three family members had taken part in the first round of evaluation. The mean age of stroke survivors was 60.91 years (*SD* = 13.68, range: 34.80-73.80) and the average age of family members was 65.00 years (*SD* = 4.58, range: 61.00-70.00). The mean time since stroke was 1.39 years (*SD* = 0.40, range: 0.89-2.13). Due to the high rates of missing cognitive (OCS) data from the acute and subacute stage of stroke, participants were asked to self-report on cognitive changes since their stroke. A total of 8 stroke survivors reported noticing cognitive changes since their stroke, with specific changes affecting language (*n* = 2), memory (*n* = 6), visuospatial attention (*n* = 1), processing speed (*n* = 1), and executive function (*n* = 1). Healthcare professionals included 2 Clinical Neuropsychologists, 1 Clinical Psychologist and 1 Speech and Language Therapist. Table 6.2 above summarises demographic characteristics.

Custom survey

The survey evaluating Prototype Version B was completed by 10 (62.50%) participants, including 4 stroke survivors, 1 family member, and 5 healthcare professionals. Responses to the custom survey are summarised in Table 6.5. Overall, aggregating responses across all survey items, 59.32% of responses indicated agreement the prototype met the intervention requirements, and 26.27% of responses indicated strong agreement. Descriptive statistics showed an increase in the percentage strong agreement/agreement for 7 out of 9 intervention requirements (sub-requirements counted separately) for Prototype Version B, compared to Version A,

though the survey was not powered to determine whether these differences were statistically significant. Figure 6.2 visually depicts survey responses to show the difference in responses for Prototype Version A versus Prototype Version B.

Intervention requirement		Prototype meets intervention requirement, *N (%)*				
		Strongly agree	**Agree**	**Neither**	**Disagree**	**Strongly disagree**
*1	Useful information for the acute and chronic stages after stroke.	2 (20.00)	**6 (60.00)**	2 (20.00)		
*2a	Information about general aspects of cognition (e.g., definitions).	3 (30.00)	**6 (60.00)**	1 (10.00)		
2b	Information about purpose and outcomes of cognitive assessment.	5 (25.00)	**9 (45.00)**	5 (25.00)	1 (5.00)	
*2c	Information about potential cognitive trajectories.	2 (20.00)	**7 (70.00)**	1 (10.00)		
2d	Information about services and support available.	1 (10.00)	**6 (60.00)**	3 (30.00)		
*3	Comprehensive and honest information provided within a positive framework.	6 (30.00)	**12 (60.00)**	2 (10.00)		
*4	Information personalised and specific to individual patients where possible.	3 (30.00)	**6 (60.00)**	1 (10.00)		
*5	Information communicated clearly and concisely with clinical jargon avoided when possible and explained if used.	5 (25.00)	**13 (65.00)**	1 (5.00)	1 (5.00)	
*6	Highly emotive language avoided.	4 (40.00)	**5 (50.00)**	1 (10.00)		
*	Overall	31 (26.27)	**70 (59.32)**	17 (14.41)		

Table 6.5. Number and percentage of survey responses indicating the extent to which participants (n = 10) considered intervention requirements to be met by Prototype Version B. *Percentage increase in the number of responses indicating strong agreement/agreement the prototype met the intervention requirements compared to the first round of prototype evaluation.

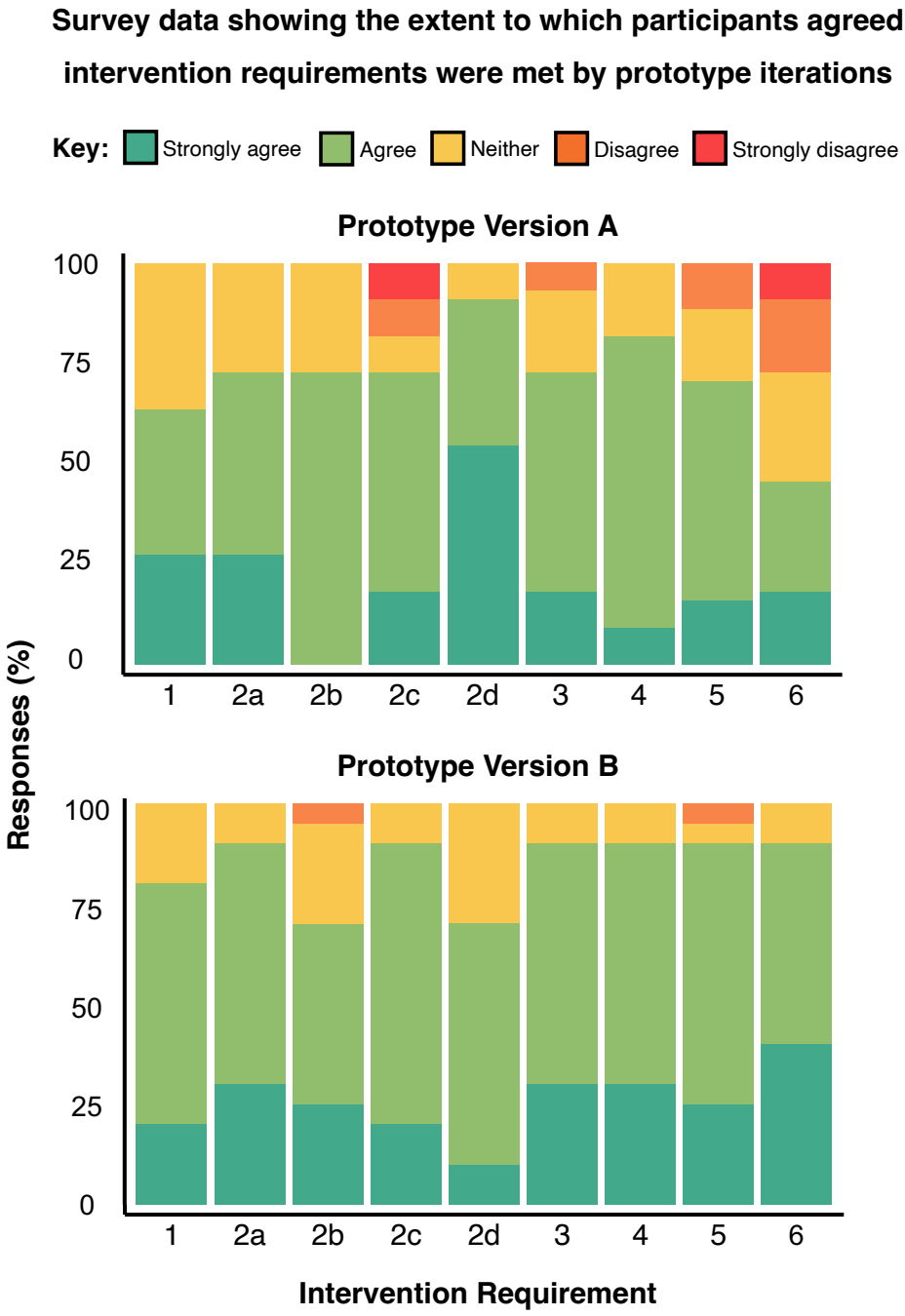


Figure 6.2. Visualisation of the extent to which participants considered the intervention requirements to be met successfully by Prototype Version A (survey respondents: $n = 11$) and Prototype Version B (survey respondents: $n = 10$). Participants were asked to indicate whether they strongly agreed, agreed, neither agreed nor disagreed, disagreed, or strongly disagreed the prototype met the intervention requirements. Responses were aggregated where more than one question corresponded to an intervention requirement. Percentage of responses (x-axis) corresponding to each of these options are plotted for each intervention requirement (y-axis). Colours correspond to specific response options.

Focus group and semi-structured interview data

Themes and subthemes developed from the qualitative analysis of focus group and semi-structured interview data are summarised in Table 6.6. A priori themes (positive feedback, negative feedback, recommended modifications) were adapted, as there was no explicitly negative feedback on this iteration of the prototype. Positive feedback was largely similar to the feedback on Prototype Version A; only 'new' subthemes (labelled with an asterisk) are described in detail below due to space constraints in the thesis.

Theme	Subtheme Level 1	Subtheme Level 2
Positive feedback	Design and content	• *Easy to navigate. • *Accessible length and language.
	Positive impact at a stroke survivor- and family member-level	• *Empowering for patients. • Increase awareness of cognitive impairment. • Normalise cognitive impairment.
	Positive impact at a healthcare professional- and service-level	• *Feasible for use by junior staff. • Increase confidence among staff. • *Potential to plug gap in services. • Standardise services nationally. • Improve quality of information provision.
Recommended modifications	Optional additional content	• *Additional topics could be included. • *Additional detail could be provided in places.

Table 6.6. Summary of theme structure developed from qualitative data evaluating Prototype B. * Subthemes not identified in evaluation of Prototype A.

Positive feedback

Those who participated in both rounds of prototype evaluation and revision agreed qualitatively that Prototype Version B was an improvement on Prototype Version A. Previously provided positive feedback was echoed and several additional positive features and potential advantages were identified.

Design and content

The design and layout of Prototype Version B was said to be much improved, with participants commenting that the prototype was easier to navigate, now that it was structured as a single workbook with content following a logical order. Participants generally agreed the booklet was accessible for stroke survivors in terms of its length, layout, and language, including those with visual impairments and cognitive impairment (reduced attention, visuospatial neglect). While many participants drew comparisons between the two iterations of the prototype, one participant also compared Prototype Version B to other freely available resources providing information on cognitive impairment after stroke. She believed the conciseness of the prototype in particular rendered it a substantial improvement on existing resources.

> *"We often feel like the 35 pages of some lovely leaflets from some of our charity partners is just probably not very accessible. [...] This seems to me ideal compared to what we've got."* (Healthcare Professional 7)

Healthcare professionals acknowledged the impossibility of developing a single resource to meet the needs and preferences of every stroke survivor and family member, but believed the prototype struck a useful balance between providing informational *insight* while avoiding information *overload*, with one participant commenting that it would be a useful *"starting point"* (Healthcare Professional 7) for providing psychoeducation about post-stroke cognitive changes.

> *"The language, the terminology is accessible and easy to read so I think in terms of how it's presented is really really good. It's something I would use in my practice. [...] I think your terminology wasn't too difficult and also I like how big the resource was. It was kind of like big enough – not too short and not too long that maybe clients might disengage."* (Healthcare Professional 8)

Positive impact at a stroke survivor- and family member-level

In addition to helping increase awareness of post-stroke cognitive impairment and normalise the experience of noticing changes in cognitive abilities, participants thought the psychoeducation resource could empower stroke survivors to take ownership of their recovery journey. The workbook-style layout was seen to promote this, as it gave stroke survivors the opportunity to look at and add to sections in their own time after healthcare professionals had provided preliminary information.

> *"It's quite empowering, you know, isn't it, to have something that's yours and you can hold on and perhaps it's something that doesn't just belong to a service and a clinician."* (Healthcare Professional 7)

Positive impact at a healthcare professional and service- level

Participants stressed the importance of upskilling more junior members of the MDT to provide information on post-stroke cognitive changes, given increasing pressures on NHS services and the limited availability of highly specialist clinical psychologists and neuropsychologists. Although they again stressed the importance of ensuring cognitive screening and subsequent psychoeducation is only provided by those with the requisite qualifications and training, healthcare professionals believed the resource would be feasible for use by more junior members of the team, as planned for the intervention. Furthermore, one participant thought that having a tangible resource could also increase confidence among more senior healthcare professionals responsible for delivering complex information about cognitive changes after stroke.

Participants further reflected that the resource could help plug an important gap in current service provision – namely, the lack of support provided to stroke survivors with subtle cognitive impairments that may be overlooked in acute settings. One participant emphasised that changes in cognition are not always picked up when they are more subtle but stroke survivors with milder cognitive changes may still struggle once discharged. The psychoeducation resource, he speculated, could be important in these instances.

> *"I think [the resource] would fill a really important need for some of those patients who have a hospital admission of a matter of days and are quite well at the point they're then discharged home and they don't even refer them onto community stroke services but that is the group that I'm concerned we're missing things and then three months, six months down the line, you know, their life is slowly falling apart because they've lost their job because they can't cope with the work demands or their relationships are failing and they don't understand and nobody around them understands why that is and it might be that there are some psychological sequalae of their stroke that just haven't been picked up. And this would alert them potentially to some changes, even if immediately on discharge and returning home, they weren't kind of invested in that. But if they found that they struggled, they might look back to something like this that they had in their notes and think "Oh actually..."* (Healthcare professional 9)

Recommended modifications

While there was no overtly negative feedback on Prototype Version B, several modifications were suggested. These were framed by participants as ideas and suggestions, rather than required modifications.

Additional content

Participants suggested additional topics could be briefly addressed within the prototype. One stroke survivor acknowledged the resource was helpful in explaining short-term and working memory problems, but he argued long-term memory problems, such that he had experienced, were *"not getting picked up"* (Stroke Survivor 7). Recognising the link between cognition and other sequelae of stroke, one healthcare professional suggested the resource could address mood and fatigue, as well as post-stroke cognitive changes. She reflected that explaining associations between cognition and mood/fatigue may help patients understand why their cognitive problems were worse some days compared to others, and it would help to emphasise that recovery after stroke is not linear.

> *"If you're very anxious because you just had a stroke, maybe there are some residual cognitive changes, those would be exacerbated if you are in an anxious state. And similarly, you can say at the same time if you're forgetting things or if you struggle to watch a movie because now focusing is more difficult, that will make you feel sadder or will make you feel more anxious so you can see how the two things are parallel, they work together. So the more you become aware about your mood and your mental health state impact on cognition and vice versa, how maybe the difficulties in cognition can maybe impact how you feel, the more you have awareness that can help you to cope with those changes and can put you in a better place for that adjustment process and in general to*

be more prone to use skills to help you to cope with the changes." (Healthcare Professional 8)

Other participants suggested minor content expansions in relation to the cognitive trajectories aspect, as well as caveating the cognitive screening results to make clear that the cognitive screen is not always sensitive to subtle cognitive changes, particularly among individuals with high premorbid cognitive abilities. This was seen as an important way to encourage stroke survivors to seek support if they notice cognition-related challenges in daily life, even if the cognitive screen picked up no overt impairments.

"Your thinking skills will also change over time." How long? What are you talking about? Are you talking about years, months, weeks, days?" (Stroke Survivor 9)

"It might be good to put something on there that says "Our screen might not have highlighted any problems and actually the screen might not be sensitive enough to highlight in somebody who's very very intelligent pre-morbidly". So just something on there that says if you feel that you're [...] struggling, if there are some problems in these areas, then don't hesitate to share." (Healthcare Professional 9)

Design response

The above stakeholder feedback led to minor revisions, which mostly comprised subtle rephrasing. After discussion about the results and recommended revisions, the decision was made that these revisions were not substantial enough to warrant a further stage of formal evaluation and revision. Minor revisions were made at this point. Later, additional content on mood, anxiety, and fatigue were added based on results of other research projects documented in this thesis (Chapter 3). The final revised psychoeducation resource was presented to our PPI group. PPI members provided positive feedback and agreed the psychoeducation resource would be a valuable component of the cognitive reviews provided to all stroke survivors as part of the intervention. The final psychoeducation resource is presented in Appendix 4.

6.6. Discussion

A novel cognition-focused psychoeducation workbook to be used within the cognitive care intervention was developed through a rigorous process of evidence synthesis and iterative evaluation with stroke survivors, family members, and healthcare professionals. Survey data indicated the interactive workbook-style resource successfully met key intervention requirements and qualitative feedback highlighted specific ways in which the workbook may have a positive impact on individual stroke survivors, family members, and healthcare professionals. Should the resource be made freely available in future, participants also described potential positive impacts at a system-level, in terms of improving standardisation and quality of psychoeducation about post-stroke cognitive changes.

Survey data confirmed the final cognition-focused psychoeducation workbook met key intervention requirements developed from research presented in previous thesis chapters (Chapter 4 and Chapter 5). Specifically, participants agreed the workbook provided accurate, comprehensive, and personalisable information about cognition, cognitive assessment, potential cognitive trajectories, and services/support available within a positive framework, while avoiding emotive language and clinical jargon. While national audit data on post-stroke care have confirmed over 90% of stroke survivors receive a cognitive screening assessment before discharge from inpatient settings, provision of follow-up cognitive reviews falls below recommended standards (Intercollegiate Stroke Working Party, 2023b) and very little is known about what happens *after* the cognitive screening process, if and when a cognitive screen is conducted acutely and at follow-up points. Still, many stroke survivors and family members who participated in semi-structured interviews presented in Chapter 4 expressed disappointment that the results of their cognitive assessment had not been clearly explained, raising the possibility that relevant psychoeducation may not always be provided in clinical practice, nor potentially understood or retained by stroke survivors and their family members. The workbook developed here offers a way to address these challenges. In contrast to existing cognition-focused materials that provide detailed yet depersonalised information (see Stroke Associations, American Stroke Association, and Stroke Foundation Australia websites for examples), this workbook may support healthcare professionals to deliver individualised cognition-related psychoeducation in a thoroughly interactive way, which – according to the ICAP learning model (Chi & Wylie, 2014) – is likely to support understanding and retention of the information by stroke survivors, an important consideration given the

high prevalence of cognitive impairment within this population (e.g., Demeyere et al., 2016; Hurford et al., 2013; Lesniak et al., 2008; Milosevich et al., 2024; Nijsse et al., 2017; Turunen et al., 2018). Furthermore, by supporting healthcare professionals to work *with* stroke survivors (and their family members) to discuss cognitive changes and identify personally appropriate compensatory strategies, the psychoeducation workbook may go some way towards helping stroke survivors manage the impact of cognitive changes in their daily life over the long term, one of the most commonly reported unmet needs among stroke survivors according to recent systematic reviews (Chen et al., 2019; Guo et al., 2021; Lin et al., 2021).

Qualitative data from focus groups and semi-structured interviews with key stakeholders indeed suggested the workbook, when implemented within the intervention, could have a positive impact for stroke survivors, their family members, and healthcare professionals, as well as healthcare services more broadly, should the workbook be made freely available in future. According to participants, the workbook had the potential to increase awareness and understanding of cognitive impairment, a crucial first step in post-stroke cognitive rehabilitation according to previous research that used a similar evidence-, theory-, and user-based approach to develop a more intensive cognitive rehabilitation intervention (Merriman et al., 2021). Nevertheless, whereas the intervention developed by Merriman et al. is deliverable by clinical psychologists and clinical neuropsychologists, the cognitive care intervention developed in this thesis is hoped to be implementable by less specialist healthcare professionals (e.g., Band 4-5 Assistant Psychologists, Band 6 Occupational Therapists). While developing an intervention that is implementable by less specialist

healthcare professionals is hoped to encourage and facilitate eventual broader implementation of the cognitive care intervention across the NHS, previous qualitative research has suggested these healthcare professionals may lack confidence around post-stroke cognitive screening and cognitive rehabilitation (Ablewhite et al., 2019). Participants in this study suggested the workbook developed here could improve competence among healthcare professionals responsible for delivering psychoeducation in the intervention and, eventually potentially also in broader clinical practice, although participants stressed the importance of emphasising that cognitive screens should be administered, interpreted, and fed back only by registered healthcare professionals with the necessary training and skills, in line with recent updates to the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2023a).

Finally, qualitative data suggested the psychoeducation workbook may have a positive impact at a more systemic level by facilitating standardisation of post-stroke cognitive care across the UK healthcare system. Although by no means specific to post-stroke care, the NHS Long Term Plan has highlighted reducing healthcare inequalities across the UK as a top priority (NHS, 2019), with researchers noting the importance of standardising treatment approaches, care processes, and documentation of clinical practice in particular (McLachlan et al., 2020). Eventually, after establishing the feasibility and clinical effectiveness of the intervention, it is hoped the overall cognitive care intervention developed in this thesis will improve standardisation of post-stroke cognitive care by outlining a clearly delineated evidence-, theory- and stakeholder perspective-based approach for Level 1 cognitive care. Within this overarching

programme of research, the workbook developed here offers a way to better standardise the provision of psychoeducation specifically.

Nevertheless, the research documented in this chapter suffers from several limitations. First, it was not possible to evaluate whether there were statistically significant differences in the extent to which the first and final prototype iterations met the intervention requirements, as the survey was not powered for this purpose, nor for any other formal hypothesis testing. While descriptive data indicated an improvement in the extent to which the majority of intervention requirements were met by the final compared to the first prototype iteration, these figures should be interpreted with caution, given differences in the size and demographic characteristics of participant samples evaluating the prototype iterations. A further limitation, related to the qualitative data, is that focus groups were held separately for stroke survivors and family members (predominantly in-person) versus healthcare professionals (online). This approach was selected to enhance collaboration and cooperation where possible through in-person interaction, while recognising the geographic dispersion of healthcare professional participants, which was a barrier to in-person research participation for these stakeholders. However, conducting separate stroke survivor/family member and healthcare professional focus groups meant these stakeholder groups were not able to share and reflect together upon their different perspectives as service providers versus service users. Such reflections may have opened up different avenues to consider. Finally, given that the cognitive care intervention developed in this thesis was originally envisaged to be provided as a standard part of follow-up care to all stroke survivors and modified Delphi survey

participants agreed this should be the case (Chapter 3), the goal was to include a clinically, cognitively, and sociodemographically diverse sample of stroke survivors in this study. Although substantial efforts were made to encourage and facilitate participation (e.g., flexibility in the data collection procedure), the representativeness of the sample is likely affected to some extent by a self-selection bias and basic descriptive analysis suggested some skewedness (e.g., towards male stroke survivors). With regards to self-selection bias, a particular concern is the likely overrepresentation of stroke survivors for whom cognitive changes are a key consideration or interest, as stroke survivors who are less interested or concerned about cognitive changes may have been less willing to commit time and energy to cognition-focused research. As such, the sample may have been skewed towards stroke survivors with a particular 'thirst' for psychoeducation about cognitive changes.

6.7. Reflections

Given my commitment to fostering cooperation and collaboration throughout the intervention development process, I thought proactively about how I could effectively transition from acting as a facilitator for the sharing of experiences and opinions (Chapter 4) to a mediator responsible for bridging diverse perspectives among group members. Often, I expected to find myself in the role of the 'middleman', negotiating compromises between stroke survivors and family members who were thirsty for psychoeducation, with healthcare professionals who were hyperaware of time constraints within clinical practice. However, I was pleasantly surprised by the extent to which healthcare professionals and stroke survivors/family members seemed to be 'singing from the same hymn sheet', often suggesting very similar modifications to the

resources and praising the same aspects. This provided optimism that the prototypes were effectively striking a reasonable balance between clinical utility for stroke survivors/family members and feasibility for delivery by healthcare professionals.

Nevertheless, there were occasions when opinions were not shared by stroke survivors and healthcare professionals (e.g., signposting to private practitioners and services). In these situations, I felt the weight of responsibility in ensuring that no voice was marginalised. Furthermore, though we held collaborative discussions as a research team before deciding how to update the prototypes based on stakeholder feedback, being the person responsible for implementing the final decisions occasionally felt isolating and uncomfortable. Being a young female researcher in this position added layers of complexity, as I grappled with my own internal biases about whether I had sufficient authority to implement changes in the face of conflicting evidence.

In cases where recommended modifications were not made, it was important to recognise and respond intentionally to the power dynamic that existed between myself as a researcher and stroke survivors/family members as experts by lived experience. I made a conscious effort when introducing the updated prototype to explain the rationale for not following a recommendation, and to reinforce that the feedback was gratefully received, valuable, and insightful. On reflection, this was critical in ensuring participants remained fully invested, committed, and comfortable during the research process and that there continued to be a sense of shared ownership over the psychoeducation resource.

6.8. Conclusions and chapter summary

Research documented in Chapter 5 led to a tentative identification of key topics to be addressed by a novel cognition-focused psychoeducation resource, and research documented in Chapter 4 highlighted further key topics to be addressed (e.g., cognitive screen purpose and results) and overarching design principles (e.g., importance of using accessible terminology). This foundational insight facilitated the development of an evidence- and theory-based prototype cognition-focused psychoeducation resource to be used in the intervention. To ensure stakeholder perspectives were also fully captured, stroke survivors, family members, and healthcare professionals contributed their feedback in a series of iterative prototype evaluation and revision rounds. This resulted in a psychoeducation resource that appeared to meet key intervention requirements and that, according to participants, had several potential benefits for stroke survivors, family members, and healthcare professionals.

At this point in the thesis, having established expert consensus on the key features of the cognitive care intervention (Chapter 3) and explored important considerations related to all three core features outlined in the initial intervention skeleton (Chapter 4, Chapter 5, Chapter 6), the crucial 'next step' was to draw together key findings to inform the design of the 'final' intervention that will be taken forwards into the feasibility stage of the research. The next chapter, Chapter 7, documents this synthesis process and presents the 'final' intervention design, alongside its formal programme theory.

Chapter 7 Synthesising the evidence to design the 'final' intervention

7.1. Chapter overview

Having developed consensus on the intervention features (Chapter 3), gained insight into stakeholder perspectives on the core features outlined within the initial intervention skeleton (Chapter 4 and Chapter 5), and co-produced a psychoeducation resource to be used within the intervention (Chapter 6), this brief synthesis chapter brings together key findings to design the 'final' intervention, which will be taken into the feasibility testing stage of the complex intervention (Chapter 8). The intervention design is considered 'final' in the sense that no further development work will be conducted. However, recognising MRC recommendations that complex interventions should be continually revised and updated as new insight is gleaned from subsequent research stages (Skivington et al., 2021), furthers revisions are anticipated as the feasibility testing, evaluation, and implementation stages of the research progress.

As the conceptual, empirical, and theoretical background to the cognitive care intervention has been thoroughly addressed throughout the thesis, the background section of this chapter will provide a pragmatic overview of the methodological approach used to synthesise key findings, including its rationale. In line with the thoroughly interdisciplinary approach taken in this thesis, this section of the chapter draws predominantly from *digital* health literature, where there has been substantial and highly relevant previous research turning 'data into design'. The goal is not to

provide an exhaustive review of the literature, but to outline several previously used approaches that fundamentally informed the specific methodological approach integrated with the MRC intervention development framework (O'Cathain et al., 2019).

The methods section delineates more precisely the iterative process by which the 'final' intervention was designed. The components of the 'final' intervention are then summarised alongside a formalised programme theory and corresponding logic model. As the focus of this chapter is on synthesising findings, rather than developing novel insight, the chapter concludes with reflections on the process of synthesis and intervention design, rather than a more traditional discussion of findings. Figure 7.1 shows the position of this chapter within the thesis.

7.2. Contribution

I contributed to the research presented in this thesis chapter by reviewing previous literature to inform the study methodology, synthesising key findings, designing the final intervention, delineating the programme theory, and developing the accompanying logic model. Prof Nele Demeyere advised on study methodology and was involved in designing the final intervention, programme theory, and logic model. Dr Andrea Kusec was involved in designing the final intervention. My PhD supervisors provided feedback on this chapter.

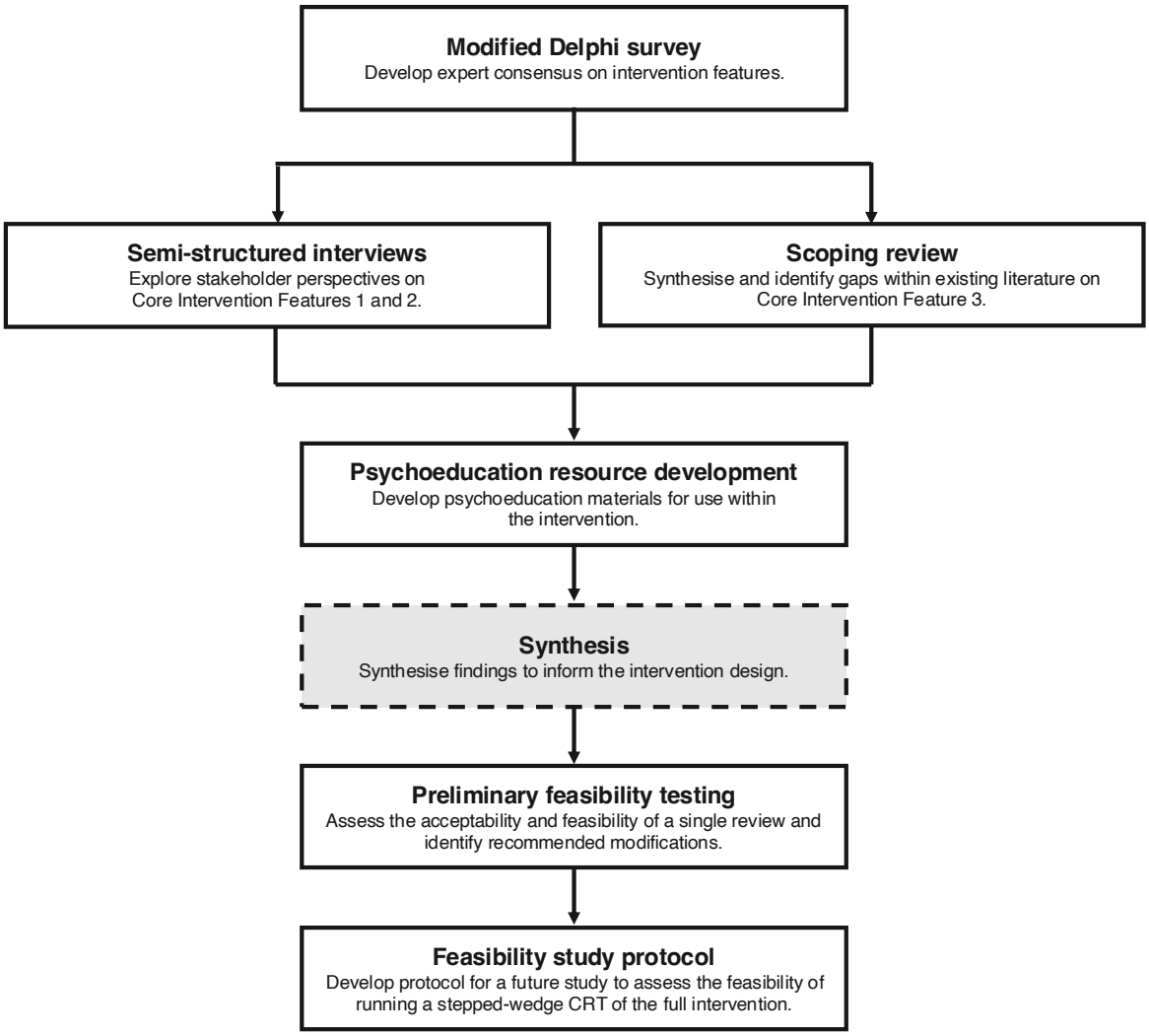


Figure 7.1. Position of the synthesis chapter (highlighted in grey) within the overall thesis.

7.3. Methodological background

In order to open the 'black box' of intervention development (Blandford et al., 2016; Danaher et al., 2015), it is crucial to document transparently the process by which key findings are converted to design elements. Nevertheless, opening the 'black box' is challenging, as there are few systematic frameworks for converting data into design, particularly when data are both qualitative and quantitative in nature. Despite this,

there are a number of cases where researchers have found rigorous ways to navigate this challenge.

First, O'Brien et al. (2016) developed a web-based lifestyle intervention for retirees using a multistage approach that integrated scientific evidence, expert input, and user perspectives. O'Brien et al. transparently documented their method for abstracting and operationalising primary quantitative and qualitative data from systematic reviews, qualitative research, and other sources (e.g., relevant experts, wider evidence base), with key findings converted into a series of evidence statements. After assessing the face validity of the evidence statements through consultation with key stakeholders, they translated the evidence statements into a design specification, which guided the development of a functioning prototype.

While the highly collaborative nature of co-production supports research team members as crucial contributors to the design process, there are questions about the extent to which O'Brien et al. (2016) made clear the research team input at this key stage of the intervention development process. This is in direct contrast to research presented by Curtis et al. (2015), where a co-productive approach was used to develop a theory-driven and user-centred mobile app to support parents in managing their children's weight. Having explored user perspectives on the app and its design in a series of focus groups, core findings were operationalised and evaluated against carefully delineated and pre-specified criteria: (1) Relevance to the target behaviour, (2) Availability online, (3) Ease of implementation, (4) Alignment with usability and user experience recommendations, and (5) Supported by theoretical findings and/or

evidence. This approach permitted research team members to use their expertise and exercise decision-making power within the design process, without overshadowing the user voice, unless just cause was established and transparently documented.

When reviewing previous literature, I noticed fundamental similarities between the data acquired by O'Brien et al. (2016) and the data acquired in this thesis – namely, their diverse sources and natures. Adopting their method of distilling and drawing together key findings by developing a set of concrete statements seemed ideal in the context of this research. However, given my commitment to transparency and rigour, it felt uncomfortable to make a similar 'jump' from evidence statements to intervention design without clearly documenting the rationale for accepting or rejecting each statement. As such, the approach used by Curtis et al. (2015) was also integrated, such that evidence statements were converted into actionable intervention requirements and then evaluated against a clear set of criteria to ensure their relevance, feasibility, and fit with the intervention. After establishing a final set of intervention requirements, these were used to inform the 'final' intervention, as well as the overarching programme theory and a logic model specifying how intervention inputs and activities are expected to contribute to individual-level and system-level outcomes (O'Cathain et al., 2019; Skivington et al., 2021). In this sense, the goal of this synthesis chapter was not only to open the 'black box' of intervention development, but also the 'black box' of the intervention itself by specifying mechanisms and processes by which the intervention is anticipated to impact outcomes.

7.4. Methods

7.4.1. Developing intervention requirements

First, findings from research activities presented in previous thesis chapters (Chapter 3, Chapter 4, Chapter 5, and Chapter 6) were converted into a set of concrete and discrete evidence statements. Evidence statements directly informed a set of candidate intervention requirements, with each intervention requirement constituting a necessarily evidence-based, concrete, pragmatic, and actionable feature of the cognitive care intervention. Candidate intervention features were evaluated and revised using a quasi-systematic approach, where they were considered against the following criteria, adapted to suit the purpose of this study from those used by Curtis et al. (2015): (a) Relevance to the target outcome; (b) Ease of implementation within the scope and scale of the project; (c) Ease of implementation within clinical practice. Candidate intervention requirements were accepted if they met all three criteria, whereas they were adapted or rejected if they met only one or two of these three criteria. This evaluation and revision process resulted in a 'final' set of intervention requirements.

7.4.2. Designing the 'final' intervention and logic model

The 'final' set of intervention requirements was used to inform the design of the 'final' intervention to be taken forwards into the feasibility testing stage of the research (Chapter 8). In line with the overarching methodological approach taken in this thesis, the intervention design process was highly iterative, as I went back and forth between the intervention requirements and the primary data whenever additional clarification seemed important.

Once the ‘final’ intervention was designed, the overarching programme theory was delineated and summarised diagrammatically using a Type 2 logic model (Mills et al., 2019). While recognising the heterogeneity and varying complicatedness of logic models developed in previous complex intervention research (see Chapter 2 for a full discussion), the decision was made to expand on the initially developed problem-intervention-outcome model (see Figure 1.2) by developing a formal Type 2 logic model, as this typology was seen to offer a pragmatic middle ground between simplicity and complexity. Again, developing the programme theory and logic model involved a highly iterative process, during which I drew flexibly on a range of resources and guidance (Better Evaluation, 2022; Midlands and Lancashire Commissioning Support Unit, 2016; Wilder Research, 2009), given that there is no single agreed development approach.

As described in Chapter 2, the programme theory was conceptualised as a uniting theory that describes how intervention inputs and activities contribute to a chain of hypothesised outcomes (Rogers, 2008; Rogers et al., 2000). As such, mechanisms of action are elucidated within the programme theory and accompanying logic model. The results section also elaborates on the theoretical foundation of these proposed mechanisms of action.

Finally, consideration was given to the possible points of failure of the intervention. This included potential barriers that could affect training, intervention delivery, stroke survivor engagement, and healthcare system integration. Anticipating potential points

of failure was considered crucial for mitigating future challenges that could undermine subsequent feasibility, evaluation, and implementation stages of the research.

7.5. Results

7.5.1. Intervention requirements

The following sections present the 'final' intervention requirements. Initial evidence statements, candidate intervention features, and evaluation outcomes are presented in Appendix 5. The following codes are used to indicate the chapter(s) from which key findings informing the intervention requirements derived: Chapter 3 (C3), Chapter 4 (C4), Chapter 5 (C5), Chapter 6 (C6), Expert Input (EI). EI refers to any input from the research team or study collaborators acquired after initial consultation to develop the fellowship grant, but not acquired within the research activities presented in this thesis.

1. Psychological reviews should be offered to stroke survivors with and without cognitive impairment detected during hospital admission. (C3)

2. Psychological reviews should be offered:

    a. One-month after stroke. (C3)
    b. Three-months after stroke. (C3)
    c. Six-months after stroke. (C3)

3. Psychological reviews should take place in person. (C3, EI)

4. Psychological reviews should include the following:

    a. Assessments: (C3, EI)
        i. Stroke-specific cognitive screen.
        ii. Questionnaire about cognition for stroke survivor.
        iii. Questionnaire about cognition for family member.
        iv. Depression and anxiety screen.
        v. Fatigue measure.

    b. Personalised and interactively delivered psychoeducation addressing:
        i. Results of stroke-specific cognitive screen, addressing each cognitive domain (C3, C4, C6).
        ii. Results of mood and anxiety screen (EI).
        iii. Results of fatigue measure (EI).
        iv. Summary of personal ‘strengths’ and ‘challenges’ (C6).
        v. Personalised strategies to address identified challenges (C6).
        vi. Comparison of results at different timepoints, where relevant (C6).

    c. Further information addressing:
        i. Potential cognitive trajectories, where deemed to be of benefit to the individual stroke survivor and/or family member (C4, C5, C6).

ii. Potential impact of cognitive changes on ADLs (C3, C4).

iii. Signposting to support and services available (C3, C5, C6).

5. Within each psychological review, accessible language and terminology should be used whenever possible and any specialist terminology used should be carefully explained. (C4, C6)

6. Within each psychological review, healthcare professionals should strive to support stroke survivors and their family members to maintain hope and optimism while providing accurate information. (C4, C5, C6)

7. Within each psychological review, healthcare professionals should strive to act with the utmost compassion and sensitivity. (C4, C6)

8. The final psychological review should conclude with onwards referral to specialist neuropsychology services, memory clinics, and/or mental health services where this is clinically indicated by assessment results and/or deemed to be of substantial clinical benefit to patients. (C3, EI)

9. Healthcare professionals responsible for administering psychological reviews should be offered:

a. Formal (training videos) and informal (training from colleague) training on administering, interpreting, and discussing assessments. (C3, C6, EI)

b. The option to attend training online and/or in-person. (C3)

7.5.2. Psychological care intervention

After synthesising findings from previous thesis chapters, the decision was made to expand the scope of the intervention to address psychological changes encompassing low mood, anxiety, and fatigue, in addition to cognitive changes. The 'final' psychological care intervention is illustrated graphically in Figure 7.2 and henceforth referred to as the **En**hanced **R**eviews of Psycholog**i**cal **Ch**anges (ENRICH) programme. The intervention includes three enhanced psychological reviews provided to all stroke survivors one-month, three-months, and six-months after stroke. Each review includes the following assessments to determine the presence and severity of any post-stroke psychological changes, as well as psychoeducation and signposting facilitated by the ENRICH workbook (Chapter 6, Appendix 4):

- **Oxford Cognitive Screen (OCS):** The OCS is a stroke-specific behavioural assessment of cognitive functioning, containing twelve tasks that tap the following six cognitive domains: memory, language, visuospatial attention, executive function, praxis, number processing. Tasks are scored based on standardised criteria and scores are evaluated against cut-off scores deriving from normative data to determine the presence of absence of a task impairment

(Demeyere et al., 2015). Given the finding that psychological reviews should include a stroke-specific cognitive screen (Chapter 3), the OCS was selected from alternatives as it is freely available, domain-specific, brief, validated for both acute and chronic stroke, and already widely used within research and clinical practice (currently over 2500 licensed users), potentially facilitating future widespread implementation of the intervention

- **Patient Reported Evaluation of Cognitive State for Stroke (PRECiS):** A 27-item self-report measures of everyday difficulties with cognition following stroke. The measure was developed specifically for use in stroke (Patchick et al., 2016). As experts agreed the psychological reviews should include a self-reported measure of cognitive changes (Chapter 3), the PRECiS was selected from alternatives as it is freely available and was co-produced with stakeholders, which provides grounds for optimism that it will be feasible and acceptable within the intervention.

- **Depression Anxiety and Stress Scale-21 (DASS-21):** A 21 item self-report measure of depression, anxiety, and stress (Henry & Crawford, 2005). The DASS-21 has good psychometric evidence for use with acquired brain injury populations (Rose et al., 2023). The DASS-21 was selected for use within the intervention as it is freely available and taps both low mood and anxiety, which were agreed to be important by stakeholders (Chapter 3, Chapter 6).

- **Fatigue Severity Scale (FSS):** A 9-item self-report measure assessing everyday fatigue. It was selected as it has good psychometric evidence in stroke populations (Krupp et al., 1989), and it is freely available and brief to administer.

Where clinically indicated, the intervention concludes with onwards referral to clinical services providing ongoing and specialist psychological support. Training provided to those responsible for administering ENRICH reviews will advise healthcare professionals to use their clinical judgement alongside key principles (e.g., declining cognitive profile over reviews, reported difficulty managing daily life and/or employment responsibilities) to inform onwards referral decisions. Note that, at the point of thesis submission, these training materials are currently being developed by the research team.

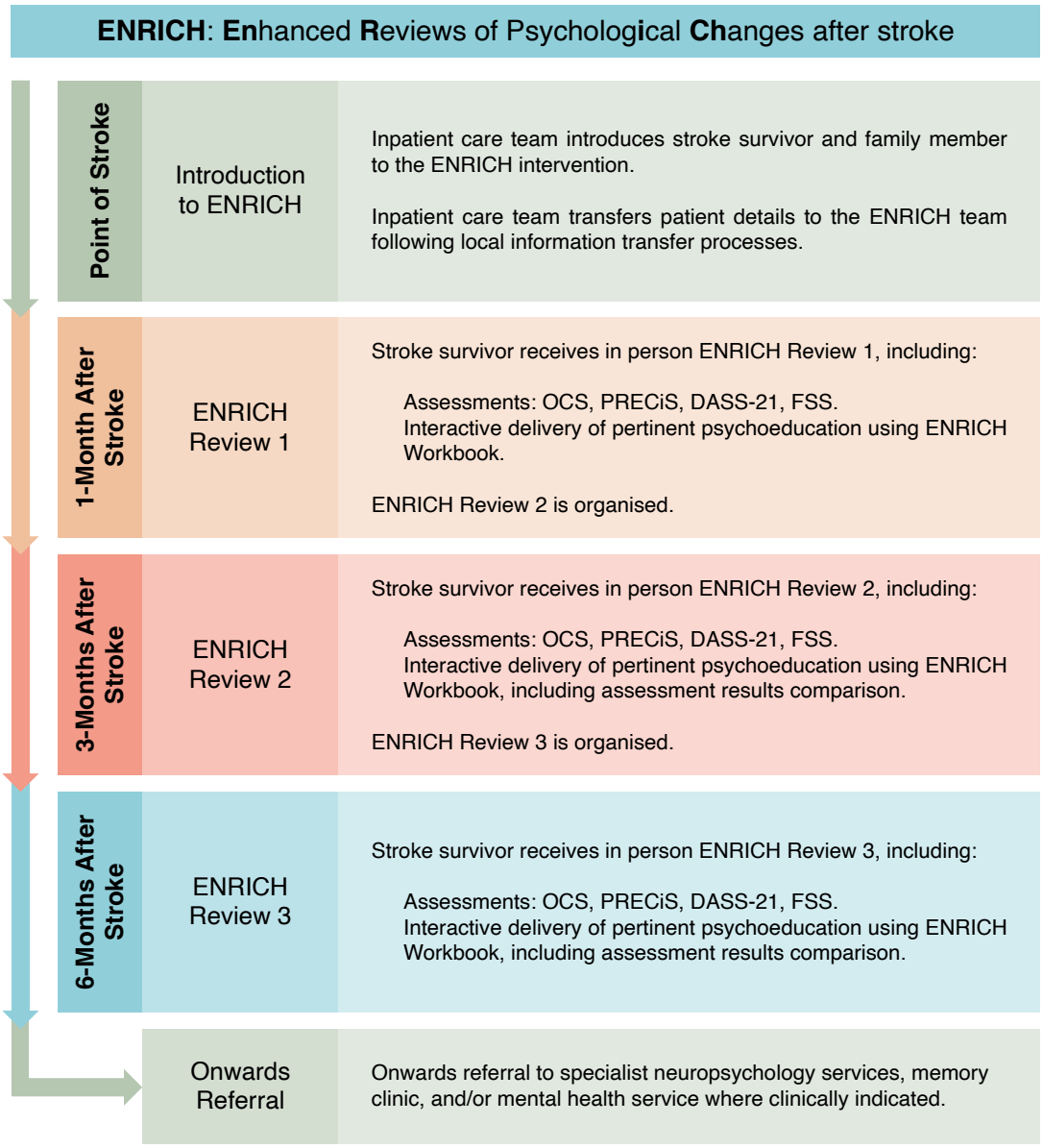


Figure 7.2. The 'final' psychological care intervention developed from research presented in this thesis.

7.5.3. Programme theory

The ENRICH programme offers a pragmatic and scalable intervention that provides Level 1 psychological care after stroke that is deliverable by non-psychology specialist members of stroke MDTs. In line with recommended models of post-stroke psychological care provision, the intervention aims to address mild and transitory

psychological symptoms by focusing on monitoring, improving awareness, and developing compensatory strategies to manage psychological changes. This is achieved through active listening, normalising rather than minimising issues, providing advice and information, and signposting for informal support and further professional support where required.

Screening for post-stroke psychological changes at multiple timepoints after discharge will increase awareness of psychological changes, reduce feelings of abandonment, and provide stroke survivors with a sense of reassurance that they are being appropriately monitored. Psychoeducation about psychological changes will improve stroke survivors' ability to manage any mild psychological changes detected and reduce feelings of uncertainty stemming from lack of understanding and awareness about psychological changes, resulting in a reduced impact of psychological changes on ADLs and participation. Onwards referral for those with more complex and persistent psychological changes will further reduce feelings of abandonment and improve hopefulness in this subgroup of stroke survivors. These proximal outcomes will result overall in medium- to long-term improvements in quality of life and psychological wellbeing (i.e., improved mood, reduced anxiety).

At a system-level, there will be reduced time, resource and hence financial demand on primary care services over the medium- to long-term as stroke survivors with mild psychological changes will be more aware of and better able to self-manage these changes. Better understanding psychological changes, being better able to manage them independently, and being more aware of how and where to find further

information and non-clinical support will also result in reduced time, resource and financial demand on services providing specialist psychological and neuropsychological support. By providing Level 1 support to those with mild psychological changes and referring only those with complex and persistent psychological changes, the appropriateness of referrals to services providing specialist psychological support will also be improved. This programme theory is summarised diagrammatically in Figure 7.3.

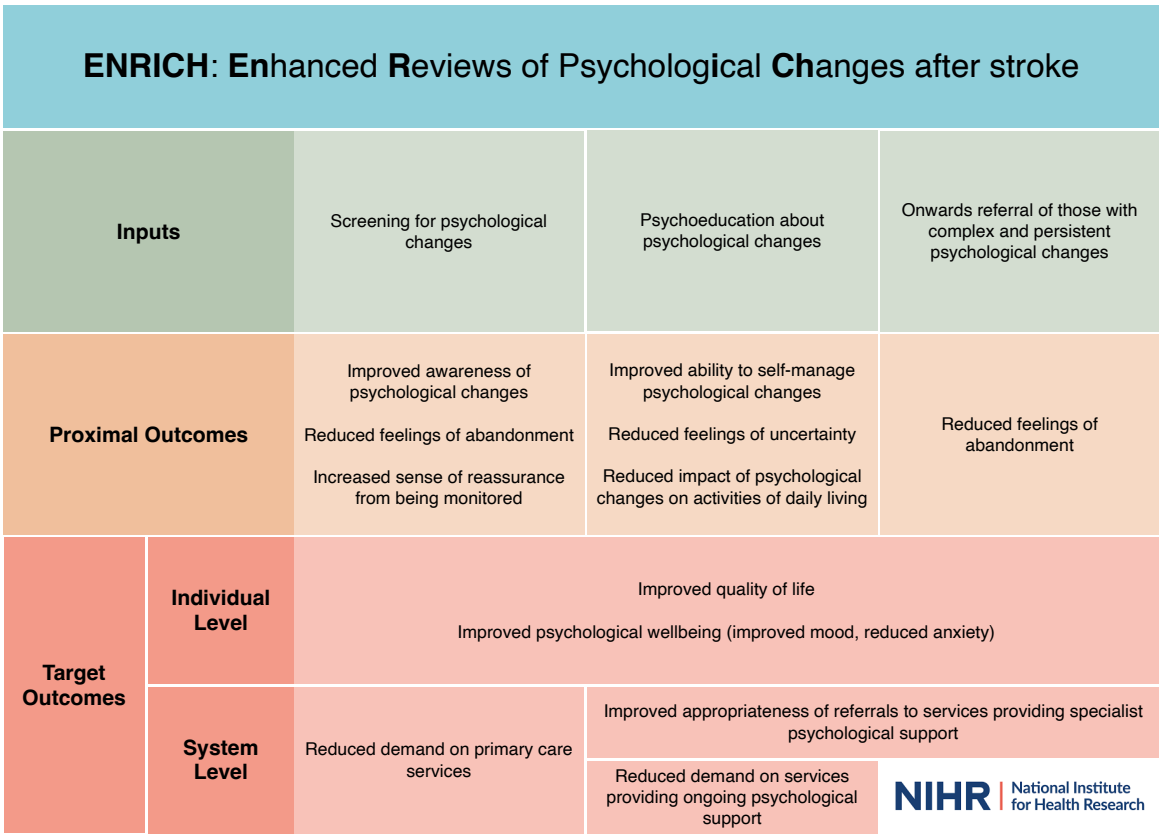


Figure 7.3. Logic model for the 'final' psychological care intervention developed from research presented in this thesis.

7.5.4. Mechanisms of action

The hypothesised relationships between intervention inputs, proximal outcomes, and target outcomes are underpinned by theoretical considerations that predominantly derive from the Y-shaped model of neuropsychological rehabilitation (Gracey et al., 2009), which itself reflects a synthesis and elaboration of earlier psychological theories (e.g., self-discrepancy theory: Higgins, 1987; models of psychological growth: Ryff & Keyes, 1995; models of psychological development: Vygotsky, 1968).

As described in previous thesis chapters (see Chapter 2, Chapter 3, and Chapter 5), the model proposes that individuals experience social, interpersonal, and personal discrepancies after brain injury, with these discrepancies leading to psychological threat, automatic negative emotional reactions, and maladaptive safety-seeking behaviours. Broadly, rehabilitation is thought to promote resolution of these discrepancies by supporting individuals to adjust to brain injury-related limitations, while simultaneously working to restore and rebuild a more adaptive sense of self.

Within the above-described intervention more specifically, screening for psychological changes and providing comprehensive feedback encompassing psychological ‘strengths’ and ‘challenges' is hypothesised to be a crucial first step in awareness-building. Based on the Y-shaped model, it is hypothesised that increased awareness of psychological challenges may be associated with initial decreases in psychological wellbeing (e.g., reduced mood, increased anxiety) due to an increased discrepancy between conceptualisations of ‘present’ and ‘ideal’ self. However, short-term decreases in psychological wellbeing may be partially offset by a sense of reassurance

from being monitored and, over the medium to long-term, psychological wellbeing is hypothesised to improve above pre-intervention levels as a result of the psychoeducation component of the intervention. Crucially, the psychoeducation component will support stroke survivors to develop and practise strategies to live well with any identified psychological changes. In line with the Y-shaped model, effective strategy usage is hypothesised to resolve maladaptive discrepancies between conceptualisations of 'present' and 'ideal' self, hence reducing psychological threat and improving psychological wellbeing. Additionally, strategy usage is hypothesised to reduce the impact of post-stroke psychological changes on ADLs, in turn promoting participation and autonomy, which will further resolve maladaptive discrepancies, according to the Y-shaped model. Cumulatively, these changes are anticipated to contribute to overall improved quality of life.

7.5.5. Potential points of failure

The following potential points of failure were identified. These potential points of failure will be held in mind throughout subsequent stages of intervention feasibility testing, evaluation, and implementation with the aim of mitigating potential barriers to success.

- Training for healthcare professionals administering ENRICH reviews
    - There may be limited uptake. Those who attend may show limited engagement.
    - The training may be ineffective in providing sufficient skills, confidence, or understanding of the 'spirit' of the intervention.

- Retention of key aspects of training (e.g., procedures, understanding of the ‘spirit’ of the intervention) may be limited.

- Intervention delivery
  - Workload and time constraints may limit the time available for healthcare professionals to administer ENRICH reviews in line with recommended standards.
  - Healthcare professionals may feel that delivering psychological care falls outside their professional role or expertise, creating resistance to delivering the intervention.

- Stroke survivor engagement
  - Some stroke survivors may not engage with the psychological care intervention, potentially due to limited insight into psychological needs or sociocultural barriers (e.g., taboo of experiencing psychological challenges).
  - Stroke survivors with severe communication challenges may have limited ability to engage in some aspects of the intervention, particularly those that place a higher cognitive burden on patients (e.g., cooperative strategy development).
  - Stroke survivors with cognitive impairments, particularly those affecting memory, may have limited ability to retain psychoeducation provided within ENRICH reviews, resulting in limited integration of ENRICH principles in daily life.

- Limited resources within the stroke care pathway
    - The proposed onwards referral pathway may have limited utility in geographical areas where Level 2 and Level 3 post-stroke psychological care provision is sparse.

7.6. Reflections on the process

At the outset of the synthesis process, I had some confidence in my ability to open the 'black box' of intervention development, by adopting a systematic and rigorous approach based on previous research (Curtis et al., 2015; O'Brien et al., 2016) and transparently documenting methodological choices and design decisions. Nonetheless, and despite my commitment to rigour and transparency, I found myself struggling to justify and document key decisions that came from distinctly untransparent interactions – those where we debated key issues as a research team, largely without external influence. Below are the two most fundamental design decisions that came from independent research team discussions during the synthesis process documented in this chapter.

- **Framing the intervention as a *psychological* care intervention:** The intervention had originally been framed as a post-stroke *cognitive* care intervention, with reviews designed to monitor and provide psychoeducation on post-stroke cognitive changes, which are known to be prevalent and important to stroke survivors over the long term. Research presented in previous thesis

chapters thus focused heavily on cognition, with other psychological changes – like low mood and anxiety – considered only tangentially. Nevertheless, while synthesising results and developing the 'final' intervention, it became apparent that stakeholders thought broader psychological changes encompassing low mood, anxiety and fatigue should be addressed in tandem (see in particular Chapter 3 and Chapter 6). As such, the decision was made to broaden the scope of the intervention, so it shifted at this point from being a *cognitive* care intervention to a *psychological* care intervention.

- **Adjusting the timepoint of psychological reviews:** The timepoint at which reviews should be offered was a key decision and one with the potential to impact stroke survivor outcomes substantially, given that psychological changes are more or less of a focus for patients at different stages in their recovery timeline. Though consensus had been reached within the modified Delphi survey (Chapter 3) that reviews should be conducted in the first few weeks after discharge, three-months after discharge, and six-months after discharge, concerns emerged when we – as a research team – gave further thought to future evaluation of the intervention. Specifically, we queried whether cognitive reviews should be offered at a certain point after *discharge*, as agreed in the modified Delphi survey, or at a certain point after *stroke*, having recognised the potential importance within a future CRT of ensuring the timepoint of the final cognitive review aligns with the existing six-month review of health and social care needs recommended in clinical guidelines (Intercollegiate Stroke Working Party, 2023; Royal College of Physicians,

2016), so that the effect of the intervention could be more validly compared against care-as-usual. Ultimately, the decision was made to adjust the timepoint of reviews, such that they would occur in the first few weeks, three-months, and six-months *after stroke*.

Making these key decisions as a research team without consulting stakeholders sat uncomfortably, given my commitment to integrating stakeholder perspectives and working collaboratively throughout the research. We considered whether further co-production sessions should be run, but the costs and benefits seemed not to balance: further co-production work would require substantial time from both the research team and stakeholders, and the design decisions we needed to address were important but also relatively narrow in scope (in essence, 'should we extend the psychoeducation intervention component to address low mood, anxiety, and fatigue?' and 'are we justified in offering reviews at a certain point post-stroke, rather than a certain point post-discharge?')

As a 'compromise', these design decisions were run past our PPI group, comprising five stroke survivors and three family members, who agreed these changes were well-justified and unlikely in their opinion to negatively impact intervention feasibility, acceptability, or effectiveness. The iterative nature of complex intervention research also provided grounds for optimism that any 'mistakes' introduced at this stage of the research could be rectified in future feasibility testing, by remaining wholly welcoming of and receptive to stakeholder feedback. Indeed, though this chapter marks the end of the development stage of the research programme, the subsequent feasibility stage

(Chapter 8) is characterised by a similar commitment to collaboration, receptiveness, flexibleness, and iterative improvement.

Ultimately, the intervention presented in this chapter represents a substantial elaboration on the initial intervention skeleton presented in Chapter 1. Whereas the initial skeleton essentially presented three well-justified 'hunches' as to what should be included, the components outlined in this chapter are based on a solid grounding of evidence, theory, and stakeholder perspectives. It was encouraging to see two of the initially proposed core features (cognitive screening, psychoeducation) broadly supported by research presented in this thesis, and the research provided important further elaboration on what these and other features should look like. Nevertheless, it was crucial to remain fully open to the possibility that the initially proposed features might not be fully supported by evidence, theory, and stakeholder perspectives. Indeed, based on research presented in Chapter 4 that revealed the incredible heterogeneity of opinions about whether cognitive trajectory discussions would be acceptable to stroke survivors and family members, the decision was made not to proceed with the third core intervention feature – the cognition trajectory guide. The sunk cost fallacy reared its head as this decision was evolving. I noticed myself working hard to look for data within the semi-structured interviews that might support the cognition trajectory guide, given that time and effort had already been invested in its planning and development. At this point, it was critical to recognise where this desire to 'hang on' to the cognition trajectory guide came from and to acknowledge that it might not be in the best interests of the people for whom the intervention is designed.

7.7. Conclusions and chapter summary

This chapter has bridged the gap between the complex intervention development and feasibility testing stages of research, as defined by the MRC framework (Craig et al., 2008; Skivington et al., 2021). Findings from the four interrelated research projects presented thus far in this thesis were synthesised using a rigorous quasi-systematic approach and an outline of the 'final' intervention was presented, alongside its formalised programme theory. While the focus of the thesis is predominantly on the intervention development stage of research, the next chapter presents data from preliminary feasibility testing (Chapter 8 Part A), which is ongoing at the point of thesis submission, as well as the protocol for a larger scale study to determine the feasibility and acceptability of a future full scale stepped-wedge cluster randomised controlled trial (SWCRT) to evaluate the clinical effectiveness of the intervention (Chapter 8 Part B).

Chapter 8 Using a two-stage approach to assess the acceptability and feasibility of the Enhanced Reviews of Psychological Changes after stroke (ENRICH) programme and a future evaluative trial

8.1. Chapter overview

The previous chapter synthesised key findings from research presented in earlier thesis chapters and outlined the overall intervention requirements, the 'final' intervention design, the programme theory, and an accompanying logic model. Henceforth, the 'final' intervention will be referred to as the **En**hanced **R**eviews of Psycholog**i**cal **Ch**anges after stroke (ENRICH) programme.

Having established the design of the ENRICH programme, the next step according to the MRC framework is to evaluate its acceptability and feasibility. While the focus of this thesis is predominantly on the development stage of complex intervention research, this chapter briefly documents the two-stage approach being used to assess feasibility of the intervention and a future effectiveness trial. The introduction focuses on the importance of assessing feasibility, but also discusses the challenges of designing a feasibility and/or pilot study, given the definitional ambiguity of these terms and heterogeneous guidance on their methodological conduct. Recognising the importance of minimising resource waste, it justifies the two-stage feasibility testing approach taken here to establish first the feasibility/acceptability of the intervention

itself, then the feasibility/acceptability of running a full-scale SWCRT to establish the clinical effectiveness of the intervention.

Part A of the chapter presents preliminary results from the first stage of feasibility testing, which is underway at the point of thesis submission. Part B then presents the protocol for a future larger scale two-site study designed to assess the acceptability and feasibility of running a summative SWCRT of the ENRICH programme. Figure 8.1 shows the position of these research projects within the thesis.

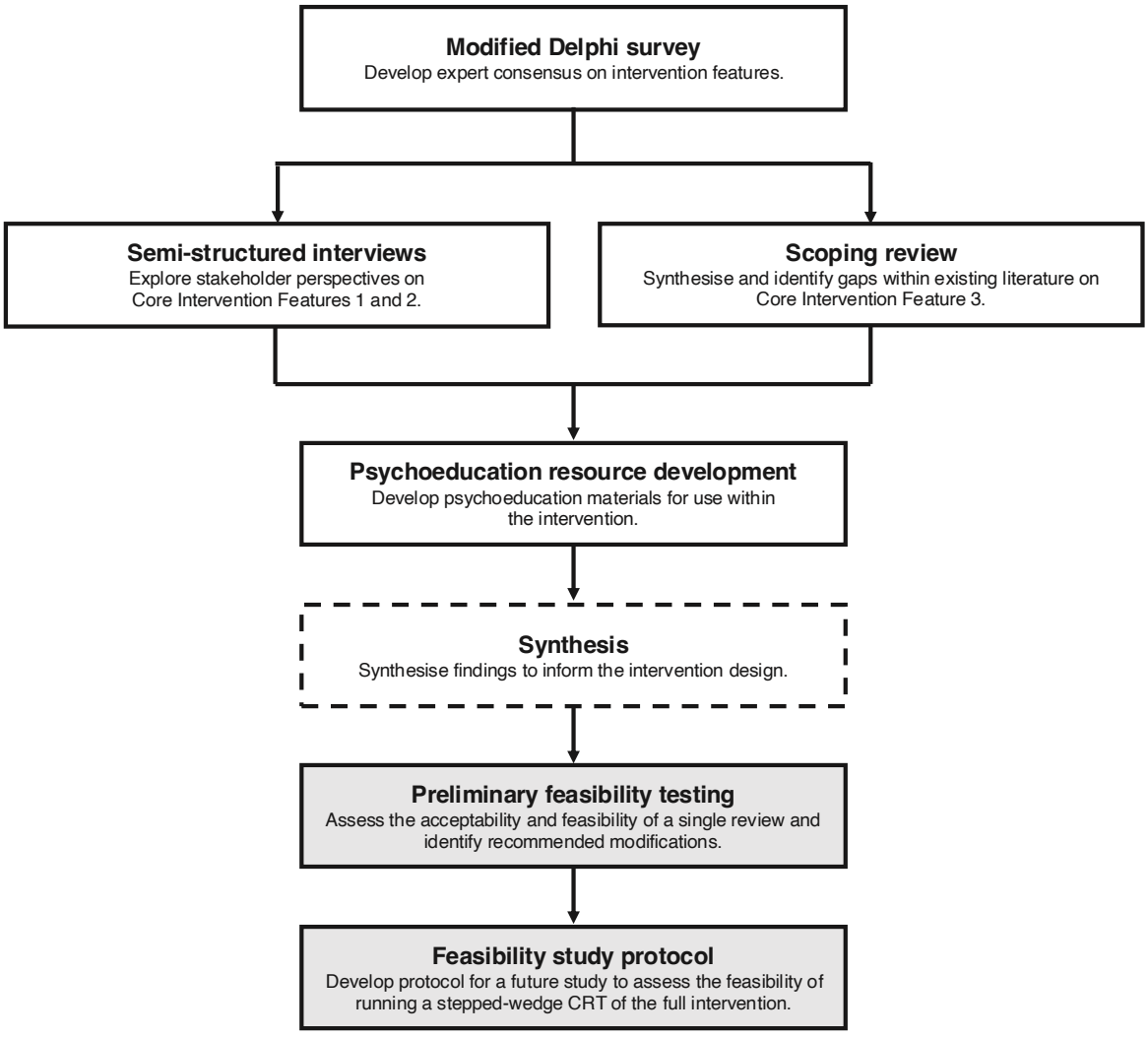


Figure 8.1. Position of the feasibility research projects (highlighted in grey) within the overall thesis.

8.2. Contribution

I contributed to Part A of the research presented in this thesis chapter by conceptualising the study, formulating the study aims and objectives, determining the study methodology, recruiting participants, running ENRICH reviews, collecting data, and conducting preliminary data analysis for the purpose of this thesis chapter. Prof Nele Demeyere was involved in conceptualising the study, formulating the study aims and objectives, advising on study methodology, running ENRICH reviews, and consulting on preliminary results. Dr Andrea Kusec consulted on preliminary results.

I contributed to Part B of the research presented in this thesis chapter by advising on the study methodology, drafting the original study protocol, drafting participant-facing materials, and assisting with co-ordination of the application for Sponsorship and NHS ethical approval. Prof Nele Demeyere conceptualised the study, led the study design process, edited and reviewed the protocol and participant-facing materials. Dr Andrea Kusec advised on the study methodology, reviewed and edited the protocol and accompanying participant-facing materials, and co-ordinated the application for Sponsorship and NHS ethical approval. My PhD supervisors provided feedback on this chapter.

8.3. Introduction

Though feasibility testing has not always been prioritised, particularly in psychology research (Gadke et al., 2021), the value and potential benefits of assessing feasibility are increasingly recognised (Eldridge, Chan, et al., 2016; Giangregorio & Thabane,

2015; Richards & Hallberg, 2015; Skivington et al., 2021; Thabane et al., 2010). Crucially, this stage of research enables exploration in a 'real world' context of the acceptability and feasibility of both the intervention and evaluation design, which in turn facilitates identification of important issues that may need to be addressed before a costly multisite study is undertaken to determine intervention effectiveness (Gadke et al., 2021; Skivington et al., 2021). Among other factors, feasibility testing may highlight issues related to intervention delivery, compliance, integrity, or acceptability, as well as issues with recruitment, retention, and randomization that may fundamentally undermine a future effectiveness study (Gadke et al., 2021; Skivington et al., 2021). They thus offer an important means to limit resource waste from commissioning costly large scale evaluation trials that may be undermined by fundamental but preventable issues with the intervention itself or the evaluation design (Gadke et al., 2021; Moore et al., 2018; Skivington et al., 2021).

The volume of feasibility studies has increased markedly since the initial publication of the MRC framework for complex intervention research (Arain et al., 2010; Lancaster, 2015), which recommended feasibility testing as a crucial 'next step' after intervention development (Craig et al., 2008). Nevertheless, there is conflicting guidance about what feasibility testing should ultimately involve, the methods that should be employed, as well as how results should be used to determine whether progression to a larger scale effectiveness study is warranted (Arain et al., 2010; Hallingberg et al., 2018).

Even attempts to define feasibility testing have been controversial, with particular debate about the similarities and differences between feasibility studies and pilot studies (Arain et al., 2010; Eldridge, Lancaster, et al., 2016; Hallingberg et al., 2018). Recognising definitional discrepancies and fearing their potential detrimental impact on feasibility/pilot study quality, Eldridge, Lancaster, et al., (2016) conducted an extensive systematic review and Delphi survey exercise that aimed to achieve definitional clarity on the terms 'feasibility study' and 'pilot study'. Ultimately, they concluded that "A feasibility study asks whether something can be done, should we proceed with it, and if so, how. A pilot study asks the same questions but also has a specific design feature: in a pilot study a future study, or part of a future study, is conducted on a smaller scale." (Eldridge, Lancaster, et al., 2016, p.1). Though these definitions are by no means universally agreed within the research community, they were endorsed in this thesis, given their use by a number of funding bodies, including the NIHR who supported the research presented in this thesis.

What constitutes good methodological practice in feasibility and pilot studies has also been debated, with a recent systematic review identifying 25 unique sets of guidance (Hallingberg et al., 2018). The existence of inadequately delineated and oftentimes conflicting guidance presents challenges for researchers in designing and conducting feasibility/pilot studies, as well as for peer reviewers and funders responsible for evaluating their potential merit (Hallingberg et al., 2018; Moore et al., 2018). As such, researchers have called for clarity and consensus to bring order to this so-called chaotic area of complex intervention research (Hallingberg et al., 2018; Moore et al., 2018). In their systematic review, Hallingberg et al. (2018) paved the way for this by

identifying broad areas of agreement and disagreement across published guidance. A subsequent consensus-building Delphi survey involving expert complex intervention research methodologists similarly identified many aspects of agreement in terms of feasibility study methodology, but consensus was not reached on aspects related to terminology, how feasibility data should inform decisions about sample size, how progression criteria should be set, and how progression decisions should be made (Craig et al., 2018). Ultimately, much like complex intervention development work, this suggests there is no 'one size fits all' approach, but rather a number of study designs and methods may be appropriate for feasibility testing.

Having designed a complex intervention providing enhanced psychological care for stroke survivors within the UK (Chapter 7), the crucial next step is to evaluate the feasibility of both the intervention and running a full-scale SWCRT to establish the clinical effectiveness of the intervention. Given inconsistency in recommendations and the potential value of a number of study designs, determining a methodological approach was not straightforward. Ultimately, in order for the methodological approach to be fully aligned with the intervention development research presented earlier in this thesis, the decision was made to broadly follow MRC recommendations for feasibility testing (Campbell et al., 2000; Craig et al., 2008; Skivington et al., 2021). Nevertheless, recognising the predominant focus of MRC guidance on assessing *trial* feasibility and the lesser focus on *intervention* acceptability, a two-stage approach was designed:

- **Part A:** The first stage of feasibility testing uses a highly iterative approach that prioritises qualitative data to establish the feasibility and acceptability of the ENRICH reviews. Resembling the approach used in Chapter 6, the study involves iterative rounds of feasibility testing, with modifications made to the intervention design in between rounds based on results of data analysis. The study aims to acquire feasibility and acceptability data from stroke survivors receiving an ENRICH review at the roughly appropriate post-stroke stage in an ecologically valid setting. The study also aims to establish the extent to which healthcare professionals working within an NHS ESD stroke service deem ENRICH reviews feasible and acceptable to run as part of their clinical practice. At the point of thesis submission, the first round of iterative feasibility testing has been completed with the second round planned to commence in late July 2024.

- **Part B:** The second stage of feasibility testing will involve a pilot study to assess the feasibility of evaluating the full ENRICH programme (i.e., three ENRICH reviews administered one-month, three-months, and six-months after stroke) in a full-scale SWCRT to establish the clinical effectiveness of the intervention. In this pilot study, the ENRICH programme will be run within two existing NHS stroke care pathways and quantitative data will be collected on a number of factors predominantly related to trial design (e.g., recruitment, retention). Though quantitative data will be prioritised, the study will also involve a nested qualitative evaluation to gain further nuanced insight into stroke survivor, family member, and healthcare professional perspectives on the intervention. This

study has recently received Sponsorship and NHS ethical approval. It will commence once Part A has concluded and is anticipated to run between December 2024 – December 2026.

The following thesis sections present preliminary data from the first stage of intervention feasibility testing (Part A) and the protocol for the second stage of trial feasibility testing (Part B).

8.4. Part A: Determining the feasibility and acceptability of the ENRICH reviews

8.4.1. Methodological background

Recognising that qualitative research can make a fundamentally important contribution to the feasibility testing stage of complex intervention research, O'Cathain et al. (2015) provided guidance on how researchers can maximise its contribution at this stage in the research process. Resembling the MRC guidance on developing complex interventions (see Chapter 2), this guidance comprises a series of options rather than a clearly delineated list of required research activities, as O'Cathain et al. recognised that a key strength of qualitative research lies in its flexibility and adaptiveness. Key guidance that fundamentally informed the methodological approach taken in this first stage of feasibility testing is summarised in Table 8.1 and elaborated in relevant sections below.

Feasibility aspects	Factors to consider	This study
Research questions	Identify key uncertainties to determine the initial research question(s).	Unclear the extent to which ENRICH reviews are acceptable to stroke survivors receiving them at the appropriate post-stage unclear. Unclear the extent to which ENRICH reviews are acceptable and feasible to healthcare professionals administering them as part of their standard clinical practice.
Design and data collection	Be explicit about the rationale for selecting particular qualitative methods.	Remote (online/telephone) semi-structured interviews with stroke survivors and family members receiving ENRICH reviews to facilitate open and honest sharing around sensitive topics and recognise practical constraints around travelling to stroke survivors' homes multiple times.
	Pay attention to diversity when sampling participants, groups, or sites.	Clinical and demographic data were collected and regularly reviewed, with the goal of including a sociodemographically, clinically, and cognitively diverse stroke survivor sample.
	Recognise key differences between qualitative research versus patient and public involvement.	PPI group consulted on the conduct of the feasibility studies.
Analysis	Be open to many different analysis methods.	Template analysis was selected as a pragmatic approach that would enable identification of positive feedback, negative feedback, and recommended modifications.
	Be open to investigating a breadth of issues in the data or focusing on a few key issues.	The main goal of the analysis was to establish aspects of positive feedback, negative feedback, and recommended modifications whilst also attending to data suggesting the intervention may be more or less acceptable or feasible to subgroups of stroke survivors.
Teamworking	Establish who will be responsible for making changes to the intervention or trial based on qualitative data.	The core research team were responsible for making changes to the intervention. Changes to the trial design will be considered after the second stage of feasibility testing.

Reporting	Describe any qualitative analysis and findings in detail.	See below.
	Be explicit about the implications of qualitative findings for the intervention and/or future trial.	See below.

Table 8.1. MRC framework guidance on using a qualitative approach in the feasibility testing stage of complex intervention research.

Note the original plan was for healthcare professionals within Oxford University Hospitals (OUH) NHS Trust ESD stroke team to conduct ENRICH reviews for the first and subsequent rounds of iterative feasibility testing, but unforeseen delays in the Sponsorship and NHS ethics approval process for this study meant that it had not been possible for the ESD team to commence ENRICH reviews at the point of thesis submission. Therefore, this thesis presents data from ENRICH reviews run by the research team through the University of Oxford Medical Sciences Interdivisional REC approval process. The current aim is for the OUH ESD team to begin running ENRICH reviews for this study in late July 2024, as Sponsorship and NHS ethics approval has very recently been received (NHS REC Reference: 24/LO/0341).

8.4.2. Methods

Ethics and research governance approval

The University of Oxford Medical Sciences Interdivisional REC provided ethical approval for the first round of iterative feasibility testing (University of Oxford REC Reference: R80681/RE001). Sponsorship and NHS ethics approval has very recently been received for subsequent iterative feasibility testing rounds that will involve the

OUH NHS ESD team and stroke survivors under their care (NHS REC Reference: 24/LO/0341).

Participants

Stroke survivors were recruited for the first round of iterative feasibility testing through a pool of research volunteers who had previously taken part in the OCS-Recovery study (NHS REC reference: 18/SC/05501) and consented to being contacted for future ethically approved studies. Chapter 4 provides further detail on the OCS-Recovery study, including eligibility criteria. Stroke survivors were eligible to take part in this study if they had their stroke no more than ten-months ago. This threshold was set because ENRICH reviews are designed to be provided at one-month, three-months, and six-months post-stroke (see Chapter 7), but there were very few stroke survivors within the research volunteer pool who had their stroke within this time window. The relatively limited pool of research volunteers also precluded any purposive sampling, so all research volunteers meeting the eligibility criterion were invited to participate. Where a family member was present at the ENRICH review, family members were invited to complete a semi-structured interview and custom survey, where the stroke survivor also consented to this. All participants provided written informed consent to participate in the study.

Procedure

Eligible stroke survivors were contacted by telephone and invited to receive a single in-person ENRICH review at their home. In line with the 'final' intervention design (Chapter 7), the ENRICH review included the following components: stroke-specific

cognitive screen (OCS), self-reported cognition measure (PRECiS), low mood and anxiety screen (DASS-21), fatigue measure (FSS), psychoeducation and signposting (ENRICH Workbook). Participants completed a remote (telephone or Microsoft Teams) follow-up research session with a member of the research team within five-days of receiving an ENRICH review. During this research session, they were invited to complete a custom survey and semi-structured interview in order to provide feedback on the feasibility and acceptability of the ENRICH review.

Data collection

Basic participant demographic and clinical data were recorded as part of the OCS-Recovery study and participants gave consent for these data to be accessed for the purpose of this study. Demographic variables recorded were: age at stroke, gender, ethnicity. Clinical variables recorded were: stroke date, stroke type, stroke lateralisation, stroke severity (NIHSS recorded during inpatient hospital admission by the clinical team), acute cognitive impairment severity (number of OCS task impairments during inpatient hospital admission), acute domain-specific cognitive impairments (binarised OCS domain impairments during inpatient hospital admission).

The following measures were completed as part of the ENRICH review and these data were used to further describe the participant sample in terms of the prevalence and severity of psychological changes at the point of receiving an ENRICH review: OCS (number of task impairments, binarised domain impairments), PRECiS (total score), DASS-21 (depression score, anxiety score, stress score), FSS (total score). Further

detail on these measures and references to psychometric validations are provided in Chapter 7.

Data to characterise the fidelity of ENRICH review completion were recorded by the review administrator immediately after the review had finished. The following variables were recorded: review length (minutes), review components completed, reason(s) for non-completion or partial completion of any review components, personally relevant strategies to manage psychological changes discussed.

During the follow-up research session, participants completed an orally administered custom survey and semi-structured interview to provide data on the perceived acceptability and feasibility of the ENRICH review. The custom survey (Appendix 6) was designed to gauge the extent to which each of the 'final' intervention requirements outlined in Chapter 7 were deemed helpful. Interviews were structured around a topic guide (Appendix 6) that was developed prior to the interviews with the aim of elucidating which components of the ENRICH review were acceptable, to whom, why, and under what circumstances. Participants were also encouraged to make suggestions about any modifications to the ENRICH review. The topic guide was designed to allow flexible dialogue and was continually adapted as data collection progressed to enable additional topics to be explored. Communication support strategies (e.g., probing, word offerings) were used for stroke survivors with cognitive impairments impacting their communicative abilities.

Data analysis

Quantitative analysis

R-Studio version 4.3.1 facilitated descriptive statistical analysis of data collected by June 7th, 2024. Descriptive statistics were calculated from demographic and clinical data to characterise the sample. Feasibility was assessed in part by calculating the average ENRICH review length and the proportion of stroke survivors completing each component of the review. Acceptability was assessed in part by calculating from custom survey data descriptive statistics to establish the proportion of participants who believed each aspect of the ENRICH review to be very helpful, helpful, neither helpful nor unhelpful, unhelpful, or very unhelpful. As with quantitative data presented in previous thesis chapters (e.g., Chapter 6), these data are purely descriptive and not powered for any formal hypothesis testing.

Qualitative analysis

Qualitative data from the semi-structured interviews were analysed using template analysis (King, 1998, 2024). As in previous research projects (see Chapter 3, Chapter 5 and Chapter 6), template analysis was selected based on its philosophical flexibility and its suitability for a pragmatic analysis that aimed to achieve a balance between providing descriptive insight and delivering actionable feedback efficiently, given the research deadlines laid out in the NIHR fellowship outline by which this work was funded.

As the primary aim of the qualitative analysis was to identify actionable feedback informing any modifications to the intervention prior to larger scale feasibility testing,

the following a priori themes were developed: (a) Positive feedback; (b) Negative feedback; and (c) Suggested modifications. After familiarising myself with the data in its entirety by transcribing audio-recordings then reading and re-reading them while making notes, I coded an initial set of three transcripts at a semantic level using the comment function in Microsoft Word while holding in mind a priori themes. After coding these initial transcripts, codes and accompanying data were compiled in a Microsoft Excel file that already contained a priori themes, enabling me to consider how the data did or did not fit with them. I revised theme titles and boundaries to create an initial template comprising candidate themes and subthemes, which I stored as a separate Microsoft Excel sheet. I added to, updated and revised this template while coding the remaining transcripts, with the goal that the final themes and subthemes would be faithful to the data and offer both actionable feedback and nuanced insight into positive aspects of the intervention. Using a single Microsoft Excel file enabled me to view the evolving themes, codes and data together at a glance and to consider any deeper meanings and relationships between the themes.

While the goal was that the themes and subthemes would be firmly rooted in the data, I allowed myself to play an interpretive role to some extent, considering this role to be particularly important where participants did not fully elaborate on their explanations, either due to communicative difficulties or – possibly – reluctance to appear critical of the intervention (i.e., social desirability bias). My own assumptions about the intervention were also highly salient during the analysis, given my first-hand experience delivering it as part of the research. However, rather than attempting to limit the impact my own perspectives had on the interpretation of the data and final

results presented, I saw my first-hand experience delivering the intervention – as well as the first-hand experience of other members of the research team – as an asset with the potential to add richness and further insight that may inform critically important intervention modifications. Regular research team discussions played a pivotal role in that multiple perspectives on the intervention were shared and we were able to identify intervention modifications that had been either implicitly mentioned by participants or recognised as problematic from an administrator perspective. Still, I recognised the importance of interrogating my own perspectives, as well as transparently documenting how the analysis and results were shaped by my perspectives and those of the research team. Pertinent considerations were recorded in an electronic journal, with key reflections from the first round of feasibility testing summarised in Section 8.4.4.

The decision to stop data collection and analysis was a pragmatic yet inevitability subjective one that was determined based on in-depth discussions as a research team that involved weighing the following factors: (1) Extent to which the themes and subthemes provided actionable insight into recommended modifications and nuanced perspectives on positive aspects of the intervention; (2) Availability within research database of potential participants at the appropriate post-stroke stage to receive an ENRICH review; and (3) Temporal targets imposed by the NIHR fellowship outline (i.e., original target was to begin feasibility testing Part B in September 2024).

Design response

Modifications to the intervention were based predominantly on semi-structured interview data, as well as reflections from research team members responsible for delivering ENRICH reviews as part of this study. When considering whether to modify the intervention design, a quasi-systematic approach was used in order to delineate between recommendations reflecting subjective preferences versus those that would enhance the intervention for a wider population. This involved considering recommendations against the following criteria (Curtis et al., 2015): (1) Alignment with intervention requirements; (2) Supported by theoretical findings and/or evidence (including evidence from research presented in previous thesis chapters); (3) Scope within project; (4) Ease of implementation. In this respect, the research team made the final decision on whether intervention modifications would be made but a deeply reflective approach was taken to ensure stakeholder preferences were held in mind and prioritised during this decision-making process.

8.4.3. Preliminary results

Participant characteristics

At the point of thesis submission, ENRICH reviews had been completed by 10 stroke survivors, of which 5 (50%) were female and all 10 (100%) were White-British. The mean age at stroke was 70.23 years (*SD* = 13.32, range: 55.13-88.79) and mean stroke severity (NIHSS) was 7.71 (*SD* = 5.02, range: 3-15). Ischaemic strokes were more prevalent in the sample (*n* = 7; 70%) compared to haemorrhagic strokes (*n* = 2; 20%) and one participant was diagnosed with both an ischaemic and haemorrhagic stroke.

On average, participants were impaired on 3.14 OCS tasks acutely (*SD* = 1.68, range: 0-5), with impairments spanning every domain assessed (memory, language, visuospatial attention, executive function, praxis, number processing), compared to 1.30 OCS tasks at the time of the ENRICH review (*SD* = 1.83, range: 0-6), with impairments again spanning all domains assessed. This is in line with previous findings of cognitive impairments showing domain-specific recovery at six-months after stroke (Milosevich et al., 2024).

Low mood, anxiety, and fatigue assessments were conducted at the time of the ENRICH review but data on these variables were not available from the acute/subacute stage of stroke. For the 8 stroke survivors who completed questionnaires assessing these factors during the ENRICH reviews, scores on the DASS-21 and FSS were interpreted using standard cut-off scores. A total of 3 stroke survivors scored in the mild range (score 10-13) for symptoms of depression and 1 stroke survivor scored in the moderate range (score 14-20), with 4 stroke survivors scoring in the non-clinical range (score 0-9). For anxiety, all 8 stroke survivors scored in the non-clinical range (score 0-7). Only 1 stroke survivor scored in the mild range (score 15-18) for symptoms of stress and the other 7 scored in the non-clinical range (score 0-14). Fatigue was binarised as clinically significant (score ≥36) for 4 stroke survivors and not clinically significant for the other 4 stroke survivors (score <36). Table 8.2 summarises demographic and clinical characteristics for stroke survivor participants.

3 family members were present for an ENRICH review and agreed to participate in the research, of which 2 (66.67%) were female and all 3 (100%) were White-British. The mean age at the ENRICH review was 63.30 (*SD* = 10.18, range: 56.31-74.99).

ENRICH review completion

ENRICH reviews were completed on average 211 days after stroke (*SD* = 61.12, range: 129-292) and lasted on average 72.90 minutes (*SD* = 18.14, range: 45-100). All 10 stroke survivors completed the OCS, 8 completed the PRECiS, 8 completed the DASS, 8 completed the FSS, and 8 completed the ENRICH workbook. In all other cases, components were only partially completed/attempted. Reasons for non-completion were: limited time (PRECiS: *n* = 1, ENRICH Workbook: *n* = 1), stroke survivor becoming distressed (PRECiS: *n* = 1, DASS: *n* = 1), stroke survivor becoming fatigued (DASS-21: *n* = 1, FSS: *n* = 1), and lack of perceived relevance (FSS: *n* = 1, ENRICH Workbook: *n* = 1).

Variable	Statistics	
Demographic characteristics		
Age at stroke, range *(M, SD)*	55.13-88.79 (70.23, 13.32)	
Gender, *N (%)*		
Female	5 (50.00)	
Male	5 (50.00)	
Ethnicity, *N (%)*		
White-British	10 (100.00)	
Stroke characteristics		
Stroke type, *N (%)*		
Ischaemic	7 (70.00)	
Haemorrhagic	2 (20.00)	
Both	1 (10.00)	
Stroke lateralisation, *N (%)*		
Left	6 (60.00)	
Right	4 (40.00)	
Stroke severity (NIHSS), range (*M, SD)*	3-15 (7.71, 5.02)	
Psychological changes	**Acute**	**ENRICH review**
Cognitive impairment severity (OCS), range *(M, SD)*	0-5 (3.14, 1.68)	0-6 (1.30, 1.83)
*Domain-specific cognitive impairments (OCS), *N (%)*		
Memory	2 (28.57)	3 (30.00)
Language	2 (28.57)	1 (10.00)
Visuospatial attention	6 (85.71)	1 (10.00)
Executive function	3 (42.86)	1 (10.00)
Praxis	2 (28.57)	1 (10.00)
Number processing	2 (28.57)	1 (10.00)
Difficulties with cognition (PRECiS), range *(M, SD)*		0-81 (34.63, 31.73)
Emotional changes (DASS-21), range *(M, SD)*		
Depression		0-18 (8.75, 5.85)
Anxiety		0-6 (2.13, 2.30)
Stress		1-15 (6.75, 4.50)
Fatigue (FSS), range *(M, SD)*		25-54 (38.13, 10.96)

Table 8.2. Demographic and clinical characteristics of stroke survivors who received an ENRICH review as part of the first stage of feasibility testing. Cognitive impairment severity was measured using the

number of OCS tasks impaired (out of 12) as an imperfect proxy. A higher score reflects more severe cognitive impairment. Task impairment was binarised using cut-off scores derived from normative data. Domain-specific cognitive impairments were also determined using OCS data. Domain impairment was binarised, with impairment denoted by at least one task impairment in a task designed to tap the relevant domain. The following tasks corresponded to the following domain-specific impairments. Memory = Orientation, Verbal Recall and Recognition, Episodic Memory. Language = Picture Naming, Semantics, Sentence Reading. Executive Function = Trails Executive Score. Visuospatial Attention = Broken Hearts Allocentric Score, Broken Hearts Egocentric Score. Praxis = Imitation. Number processing = Number Writing, Calculation. *OCS data from the acute/subacute post-stroke stage were available for only 7 participants so proportions are out of 7.

Custom survey data

All 10 stroke survivors completed the custom survey and semi-structured interview on average 1.40 days (*SD* = 0.52, range: 1-2) after receiving an ENRICH review. The custom survey and semi-structured interview were also completed by two of the family members who were present for the ENRICH review and consented to participating in the research. Custom survey data are summarised in Table 8.3 and visualised in Figure 8.2.

Intervention requirement		Extent to which intervention requirement deemed helpful, *N (%)*				
		Very helpful	**Helpful**	**Neither**	**Unhelpful**	**Very unhelpful**
1	ENRICH review offered to stroke survivors with and without cognitive impairment detected during hospital admission.	Not evaluated in survey				
2	ENRICH review offered about one-six months after stroke.	5 (41.67)	**6 (50.00)**		1 (8.33)	
3	ENRICH review conducted in person.	**10 (83.33)**	2 (16.67)			
4ai	Stroke-specific cognitive screen administered.	**7 (58.33)**	2 (16.67)	3 (25.00)		
4aii	Self-report questionnaire about cognition administered to stroke survivor.	**4 (33.33)**	**4 (33.33)**	3 (25.00)	1 (8.33)	
4aiii	Self-report questionnaire about cognition administered to family member.*	2 (40.00)	**3 (60.00)**			
4aiv	Self-report questionnaire about depression and anxiety administered.	**6 (50.00)**	**6 (50.00)**			
4av	Self-report questionnaire about fatigue administered.	4 (33.33)	**7 (58.33)**		1 (8.33)	
4bi	Personalised information about stroke-specific cognitive screen results delivered interactively.	**8 (66.67)**	2 (16.67)	2 (16.67)		
4bii	Personalised information about mood and anxiety delivered interactively.	5 (41.67)	**6 (50.00)**	1 (8.33)		
4biii	Personalised information about fatigue delivered interactively.+	**4 (33.33)**	**4 (33.33)**	2 (16.67)	1 (8.33)	
4biv	Personalised information about psychological strengths and challenges delivered interactively.	4 (33.33)	**6 (50.00)**	2 (16.67)		
4bv	Personalised information about strategies to manage psychological challenges delivered interactively.	**5 (41.67)**	**5 (41.67)**	2 (16.67)		
4bvi	Personalised information about cognition at different timepoints delivered interactively.	Not evaluated in survey				

4ci	Further information about potential future cognitive trajectories delivered.	**6 (50.00)**	5 (41.67)	1 (8.33)	
4cii	Further information about potential impact of cognitive changes on ADLs delivered.	**5 (41.67)**	**5 (41.67)**	2 (16.67)	
4ciii	Further information on support and services available delivered.	2 (16.67)	**9 (75.00)**		1 (8.33)
5	Accessible language and terminology used.	**7 (58.33)**	4 (33.33)		1 (8.33)
6	Encouraged to maintain hope and optimism.	**8 (66.67)**	4 (33.33)		
7	ENRICH review delivered with compassion and sensitivity.	**11 (91.67)**	1 (8.33)		
	Overall	**103 (49.52)**	81 (38.94)	18 (8.65)	6 (2.88)

Table 8.3. Number and percentage of survey responses indicating the extent to which stroke survivor (*n* = 10) and family member (*n* = 2) participants considered each aspect of the ENRICH review helpful according to custom survey data from the first stage of feasibility testing. Participants were asked to indicate whether they found each aspect of the intervention very unhelpful, unhelpful, neither unhelpful nor helpful, helpful, or very helpful. The most common response (mode) for each intervention requirement is highlighted in bold. Note that intervention requirements 1 and 4bvi were not evaluated in the survey due to their lacking relevance in this study. Intervention requirements pertaining to onwards referral and healthcare professional training were also not evaluated in this round of iterative testing. *Only a subset (*n* = 5) of participants responded to this survey item as family members were not present in other ENRICH reviews. ⁺Missing data for one participant.

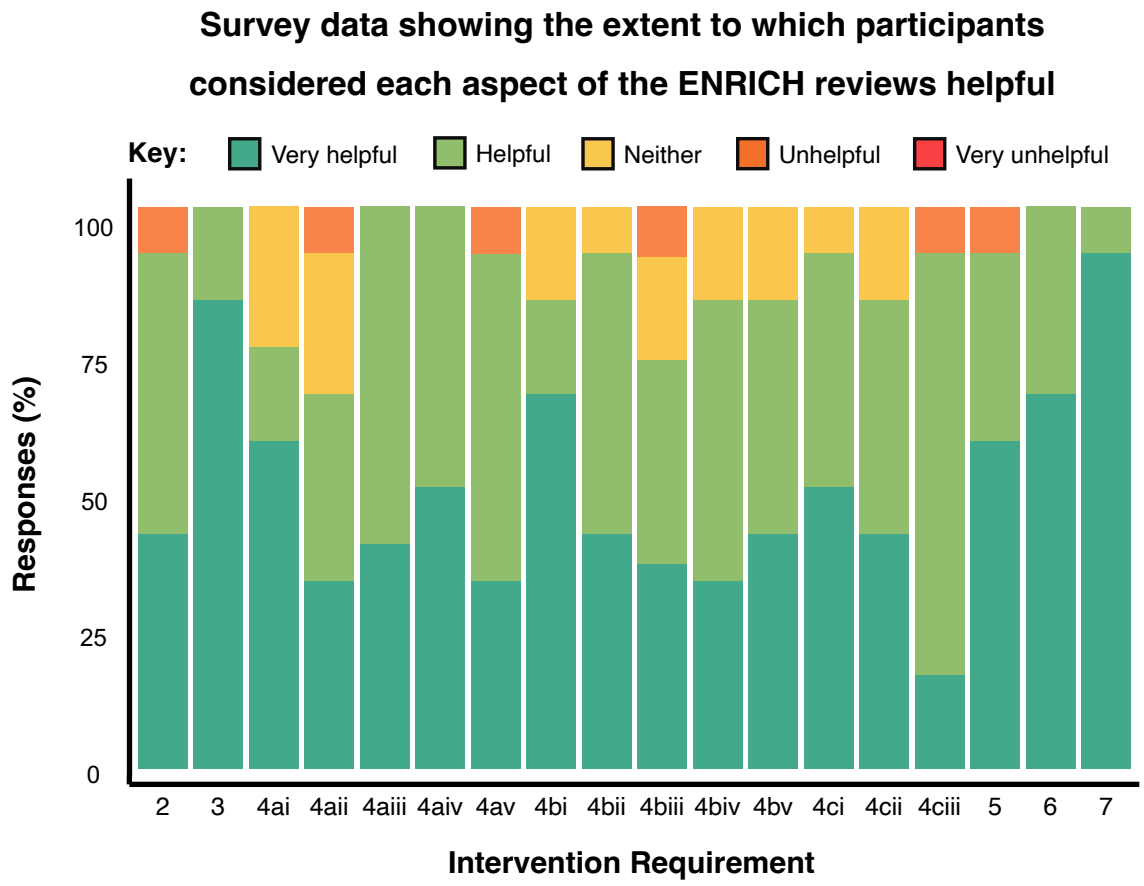


Figure 8.2. Visualisation of the extent to which stroke survivor (*n* = 10) and family member (*n* = 2) participants considered each aspect of the ENRICH reviews helpful according to custom survey data from the first stage of feasibility testing. Participants were asked to indicate whether they found each aspect very unhelpful, unhelpful, neither unhelpful nor helpful, helpful, or very helpful. Percentage of responses (y-axis) corresponding to each of these options are plotted for each intervention requirement (x-axis). Colours correspond to specific response options. Note that intervention requirements 1 and 4bvi were not evaluated in the survey due to their lacking relevance in this study. Intervention requirements pertaining to onwards referral and healthcare professional training were also not evaluated in this round of iterative testing.

Semi-structured interview data

Qualitative analysis resulted in a priori themes (positive feedback, negative feedback, recommended modifications) being replaced with the following two themes that were thought to better capture the data: (1) Therapeutic benefit, and (2) Person-centredness. Themes and subthemes are described in further detail below.

Therapeutic benefit

A number of participants described some form of therapeutic benefit coming from the ENRICH review. Several participants described feeling a sense of relief from discussing post-stroke psychological changes they had previously been *"bottling up"* (Stroke Survivor 8).

> *Speaking to you, I suppose helped. [...] I think maybe talking to somebody, even though I get upset, does help me a little bit because I don't bottle it all up, if you know what I mean. [...] I sort of felt relieved once I'd spoken to you about the things I spoke to you about.* (Stroke Survivor 8)

Seeing or sensing an improvement in aspects of psychological functioning since the first days and weeks after stroke also provided some participants with a sense of reassurance and increased optimism that some natural recovery had occurred.

> *[The cognitive assessment and discussion afterwards] actually made me feel a bit better, because when I came away from the hospital, I thought "Oh my god. I'm sort of definitely losing my mind!" But when I did a little bit better on that one, yeah, it gave me a little bit of hope.* (Stroke Survivor 8).

With regards to cognition specifically, participants described the benefit of discussing cognitive abilities in a domain-specific way, as it enabled them to recognise areas of strength, where they had previously only noticed and potentially overgeneralised domain-specific challenges.

It's useful to know those different areas of cognition because people think of memory and they think of recall and then they get very upset because they can't, you know, their short-term recall can sometimes be affected. You know, I'm thinking of dementia here. They only think of memory or of cognition only being about memory, you know, so it's useful to be able to breakdown those things and actually, you know, there isn't a deficit in all areas. There is, you know, some deficits in some areas and this is what you can do to address that, you know, and that's really, really helpful. (Family Member 1).

Specific strategies to manage psychological changes that were discussed during ENRICH reviews were also described as helpful and a number of participants explained that they would take them forwards to manage psychological changes in the future.

I'm a bit more aware about my left side, my left side attention is weaker than my right side so when I'm crossing the road and stuff, I'll pay a lot of attention to my left...oncoming traffic that's coming from the left, and stuff like that. (Stroke Survivor 6)

The different ways of using...you know, with the traffic light system, and the different ways of thinking about fatigue and how to manage fatigue. I think that they're very useful concepts that we'll take forward. (Family Member 1)

Although participants recognised the ‘one off’ nature of the ENRICH review, several participants described how it had sparked their curiosity and desire to learn more about psychological changes. They displayed enthusiasm to continue learning about post-stroke psychological changes and how to manage them, and referenced the workbook as an invaluable tool for supporting ongoing learning.

> *The workbook is really handy to look at, you know, and identifying those areas to keep working on. And I notice in the workbook as well, you know, it gives you [...] things that you can do for praxia and, you know, sort of executive functioning and that sort of thing, you know, memory, games and, you know, those sorts of word games that would be helpful to continue.* (Family Member 1)

Person-centredness

Participants generally seemed to agree that the most valuable aspects of the ENRICH review were person-centred and tailored to their individual needs. Indeed, participants recognised the ENRICH workbook as a valuable starting point for learning about post-stroke psychological changes that provided a useful base level of information, but it seemed to be most appreciated when the discussion focused on personally relevant needs.

> *Everything that was personalised was good, yeah, because you can't generalise. We're all different and we all react different to situations, like what's affecting me...what's affecting me in the stroke psychologically could affect*

> *someone else differently. [...] Some of your responses were helpful because they were tailored to my, you know, to my needs, to my questions. [...] I think towards the end where I could talk about some of my, you know, personal issues. You were very informative and helpful with your answers.* (Stroke Survivor 6)

It was also appreciated when the delivery of information was highly person-centred and conversational, as this allowed the stroke survivor to feel more like a conversational partner rather than a recipient of information. One participant explained how this approach helped to reduce the uncomfortable power imbalance that sometimes exists during healthcare consultations and speculated that this would in turn promote openness and disclosure of sensitive information about post-stroke psychological changes.

> *Sometimes when you're a professional, you can come across sort of...yeah, you know, because you're the master of what you do, the thing is the power balance can feel a little bit, you know. But it wasn't like that with you. You were really personable and really inclusive and, you know, you go along with people rather than tell people what they're doing, so, you know, that's absolutely fantastic. Your delivery is fantastic.* (Family Member 1)

However, there was a sense from some stroke survivors that aspects of the ENRICH review were not sufficiently person-centred. In particular, participants referenced how certain questionnaires seemed to lack specific relevance to them, if they believed the

stroke had not affected them in that way. One suggestion to address this was to ask broad questions and progress to the questionnaires if and when stroke survivors indicated the topic was personally relevant and important to them.

> *A lot of your questions, they were not directed enough at that individual. You'd have to find out...like a lot of your questions were about fatigue. You have to find out what that particular person's problems are [...] and then you can focus your questions on that, that area because if it's about the patient, then asking them loads of questions about fatigue when he's not really fatigued is not the...I don't think...for the patient, it's not the best way. You're wasting his time really.* (Stroke Survivor 7)

Design response

Semi-structured interview data and reflections from research team members responsible for administering ENRICH reviews led to the following modifications to the ENRICH review design:

- **Addition of initial screening questions:** ENRICH reviews will begin with an initial set of screening questions to identify psychological changes that are personally relevant to the individual stroke survivor. Where a psychological change is deemed not personally relevant, the accompanying questionnaire will not be administered. Nevertheless, the OCS will be administered in all ENRICH reviews, regardless of self-reported personal relevance of cognitive changes, given that awareness of cognitive changes may be limited after stroke.

- **Replacement of PRECiS:** The PRECiS will be replaced by the Checklist for Cognitive and Emotional Consequences following stroke (CLCE-24), a 24-item self-report measure used to identify cognitive and emotional stroke sequelae (van Heugten et al., 2007). The decision was made to replace the PRECiS as it was lengthy to administer, items often required substantial clarification and were regularly misinterpreted.

- **Replacement of DASS-21:** The DASS-21 will be replaced by the Patient Health Questionnaire (PHQ-9), a nine-item self-report depression screening tool (Kroenke et al., 2001), and the General Anxiety Disorder (GAD-7) scale, a seven-item self-report anxiety screening tool (Spitzer et al., 2006). Like the DASS-21, these tools have good psychometric validity for acquired brain injury populations and are freely available (Rose et al., 2023). The decision was made to replace the DASS-21 as it was lengthy to administer and challenging to score rapidly during the review, given the intermixed nature of items generating depression, anxiety, and stress scores.

In line with the highly iterative approach taken throughout this thesis, the above modifications have been implemented and the next step – commencing in July 2024 – will be for the OUH ESD team to administer a revised version of the ENRICH reviews. The research team will then collect further semi-structured interview and custom survey data from stroke survivors and family members receiving these

reviews, to gauge the acceptability and feasibility of the updated ENRICH reviews and to inform any further modifications, as well as from healthcare professionals delivering their reviews, to establish the extent to which they consider it acceptable and feasible to integrate ENRICH review delivery within their existing clinical practice. NHS ethical approval has very recently been received for this stage of the research. However, unexpected delays to the Sponsorship and NHS ethical approval process meant it has unfortunately not been possible to proceed to this stage of research at the point of thesis submission. Iterative evaluation and revision will continue until no further major modifications are recommended, at which point Part B of the research will commence.

8.4.4. Reflections

Conducting feasibility testing presented a unique set of challenges, as I was both the creator of the intervention and coordinator of the evaluative process. Early on in the research process, I recognised inherent personal biases stemming from my creator role. Particularly problematic was my psychological investment in the intervention being successful, which conflicted with the critical detachment necessary to make constructive use of negative feedback to improve the intervention design. A careful process of introspection led me to reflect on what negative feedback meant in the context of this study, which was crucial in helping me shift my conceptualisation of negative feedback as being a direct criticism of the intervention and instead come to see it as valuable insight that could enhance the intervention design. Adopting this mindset relatively early in the research process was highly beneficial, as it meant I was comfortable actively eliciting negative feedback during much of the data collection process and, as the negative feedback no longer posed a psychological threat, I was

able to spend time considering it and carefully integrating it into the analysis and theme structure.

8.5. Part B: Determining the feasibility and acceptability of a future full-scale stepped-wedge cluster randomised controlled trial evaluating the clinical effectiveness of the ENRICH programme

8.5.1. Methodological background

As described in the introduction to this chapter, the MRC framework recommends that the feasibility and acceptability of the planned evaluative trial design should be assessed, so that any issues with the design can be identified and addressed before a costly evaluative trial is undertaken (Skivington et al., 2021). More often than not, to assess the feasibility of a trial design, the trial is run on a smaller scale (Thabane et al., 2010). Although the most recent revision of the MRC framework for complex intervention research has acknowledged that a number of trial designs may be appropriate for establishing intervention effectiveness, including non-randomised designs (Skivington et al., 2021), RCTs have long since been positioned at the top of traditional evidence hierarchies, as randomisation aims to ensure that any differences in clinical outcomes for those receiving the intervention versus those receiving a control are due to the intervention itself rather than any extraneous variables.

Randomisation in RCTs often occurs at the level of the individual, with individuals being randomly allocated to receive either the intervention or a control, but individual

randomisation may not be possible when interventions are delivered at the level of a service or site (Hemming et al., 2011), as is the case for the ENRICH programme. Instead, CRTs – where clusters of individuals are randomised to either the intervention or control condition – may be conducted, in order to avoid contamination across groups, as well as for logistical and economic reasons (Hemming et al., 2011).

Hemming et al. (2015) outlined three broad types of CRTs, each with relative merits and drawbacks: parallel CRT, parallel CRT with a baseline period, and SWCRT. In parallel CRTs, clusters are randomised to either the intervention or control at the outset of the main trial and they remain in that arm throughout the study. To minimise the risk that outcomes are influenced by differences between the clusters at the outset of the trial, a baseline period may be added. While this design is broadly similar to the parallel CRT design, making observations during a set period before any cluster is randomised to receive the intervention enables researchers to measure and adjust for any pre-existing differences between clusters. Still, with this design, some clusters (those receiving the control) may not receive the intervention at all, which raises ethical questions given that there is often reasonable expectation that the intervention will offer some clinical benefit over the control. The SWCRT design overcomes this challenge, as each cluster is eventually exposed to the intervention but the point at which they are exposed is randomised. There is sometimes a transition period built into the design to allow time for the intervention to become fully embedded before data from the treatment period are collected.

In a systematic review of SWCRTs, Mdege et al. (2011) found that the use of this design has been increasing, which they attribute to an "increased acknowledgement of the usefulness of the design in evaluating the effectiveness of interventions in routine practice" (p.945). Indeed, recent estimates suggest there are 30-40 published protocols using the SWCRT design per year (Grayling et al., 2017; Taljaard et al., 2017). In addition to the ethical advantage outlined above, there are multiple reasons why SWCRTs may be beneficial for evaluating complex health interventions (Keriel-Gascou et al., 2014) but the design is not without drawbacks (Kotz et al., 2012). Hemming and Taljaard (2020) have thus powerfully argued that "The mere popularity and novelty of the [SWCRT design] should not be a factor in its adoption. In situations when a conventional parallel [CRT] is feasible, it is likely to be the preferred design." (p.1043) and the Consolidated Standards of Reporting Trials (CONSORT) extension for SWCRT requires that investigators provide a well-justified explanation for using this design over more parsimonious alternatives. The following section briefly summarises key advantages and disadvantages of the SWCRT design and outlines the rationale for its use in the study protocol presented below.

First, Woertman et al. (2013) have provided evidence that SWCRTs are substantially more efficient than parallel CRTs in terms of the number of clusters that need to be recruited, as the intervention effect can be estimated using both between- and within-cluster comparisons where the study involves a closed cohort (i.e., participants recruited at the start of the study with no new participants recruited later). Nevertheless, some researchers have argued this increased power stems from the large number of measurements of the outcome variable, rather than being an inherent

characteristic of the design itself (Hussey & Hughes, 2007; Kotz et al., 2012). As such, the same amount of power would be achieved simply adding an equivalent number of pre- and post-intervention measurements in the classic CRT (Kotz et al., 2012).

A second potential advantage of the SWCRT design is the logistical benefit in terms of cluster recruitment that derives from ensuring all clusters eventually receive the intervention. Specifically, Hemming and Taljaard (2020) have argued that gatekeepers (those who can facilitate cluster participation in a trial) may be reluctant to participate if they are not guaranteed to receive the intervention, as the substantial time and resources required to participate in a trial may only be logically justifiable if there is a reasonable expectation that participation will improve the local clinical service (i.e., through delivery of a more clinically effective treatment). While it has also been argued that it is more ethically justifiable to deliver the intervention to all clusters by using the SWCRT design, this is debatable (Binik, 2019; Hemming & Taljaard, 2020; Taljaard et al., 2017), as discussed in the quote below:

> *"If the intervention is known to be effective, then there is no ethical justification for withholding the intervention from some clusters or some individuals. Consequently, if it is argued that there is an ethical imperative for all clusters to receive the intervention, the same argument should mean that there is an ethical imperative for all individuals to receive the intervention without delay. Yet, in a [SWCRT], only half of participants (in a cross-sectional design) will receive the intervention and for many there will be a delay before receiving it.*

There is thus no ethical benefit of using the [SWCRT], although its use can be ethical in situations of clinical equipoise." (Hemming & Taljaard, 2020, p.1048)

In terms of disadvantages to the SWCRT design versus parallel CRTs (with baseline period), perhaps the most concerning is that SWCRTs introduce a substantial confounder by nature of their design, as observations from the control condition are collected at a systematically earlier time period compared to those from the intervention condition (Hemming & Taljaard, 2020). As a result of this, the intervention effect may be confounded by secular trends (i.e., the underlying tendency of an observation to increase, decrease, or remain stable over an extended period of time) (Hemming & Taljaard, 2020). Complex mathematical models are required to unpick changes in outcomes due to the intervention versus secular trends (Hemming et al., 2017) but these models often make the assumption that secular trends are homogeneous across all clusters, an assumption that may not always be met (Hussey & Hughes, 2007). Ultimately, analyses that do not adjust appropriately for secular trends are at risk of providing biased treatment effect estimates (Kasza & Forbes, 2019; Thompson et al., 2017).

The research team agreed that a cluster approach would be required for this study, as healthcare professionals responsible for delivering ENRICH reviews would need to receive appropriate training and this training would likely lead to contamination should participants be randomised at an individual level (i.e., principles learned during training applied advertently or inadvertently in the control condition). Weighing the above advantages and disadvantages of the SWCRT design versus other CRT designs,

while holding in mind the rule of thumb that a conventional parallel CRT should be conducted rather than a SWCRT where is it feasible to do so (Hemming & Taljaard, 2020), my preference was to run a pilot study of a full-scale *parallel CRT* evaluating the clinical and cost effectiveness of the ENRICH programme. Nevertheless, I recognised that the heterogeneity of post-stroke care across the UK rendered large cluster effects likely, and thus recognised the need for a stratified randomisation procedure to account for this. Nevertheless, other members of the research team ultimately preferred the SWCRT design, given the recruitment advantages offered. Specifically, it was anticipated that recruitment would be facilitated by guaranteeing that all sites would receive the intervention at some stage. Furthermore, as each site would provide both control and intervention data, fewer sites would be required, thus offering further pragmatic recruitment advantages.

The below thesis section presents a study protocol. The aim of the study will be to assess the feasibility and acceptability of running a full-scale SWCRT evaluating the clinical and cost effectiveness of the ENRICH programme. Crucially, qualitative data are prioritised in this study in order to assess the feasibility and acceptability of the ENRICH intervention, SWCRT trial design, data collection procedures and measures, and ENRICH training. This qualitative study will use the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework (Greenhalgh & Abimbola, 2019) as an interpretive lens to enable a systematic examination of acceptability and feasibility that acknowledges the complexity of the intervention delivery environment. The study is anticipated to run between December 2024 – December 2026.

8.5.2. Planned methods

Ethics and research governance approval

Sponsorship and NHS ethics approval has recently been received for this feasibility and acceptability study (NHS REC Reference: 24/LO/0341).

Site identification and recruitment

This feasibility and acceptability study will use a SWCRT design with two clusters (i.e., units of randomisation). Each cluster will include one study site (i.e., integrated stroke care pathway). Given the distributed nature of stroke services in the UK, sites may or may not comprise more than one service (e.g., ESD, ESD plus community stroke service). The number of services constituting the local stroke care pathway will not affect site eligibility. Eligibility criteria for sites are: (1) Local stroke care pathway currently includes the recommended six-month health and social care review offered to all stroke patients (henceforth referred to as usual care reviews); (2) Capacity for research activity within the clinical team(s) as determined by the clinical leads for the service(s) (i.e., capacity to recruit participants and pass relevant data to research team, capacity to conduct three enhanced reviews per participant recruited during the intervention period).

Study design

The SWCRT design consists of a control period, where data will be collected from each site before exposure to the intervention. Sites are then exposed to the intervention in randomised sequences or ‘steps’ so that the intervention is implemented across all sites by the end of the study timeline. In this study, the two

clusters will be exposed to the intervention sequentially in a randomised two-step approach with steps separated by a two-month interval. The overall feasibility and acceptability study design is summarised schematically in Figure 8.3.

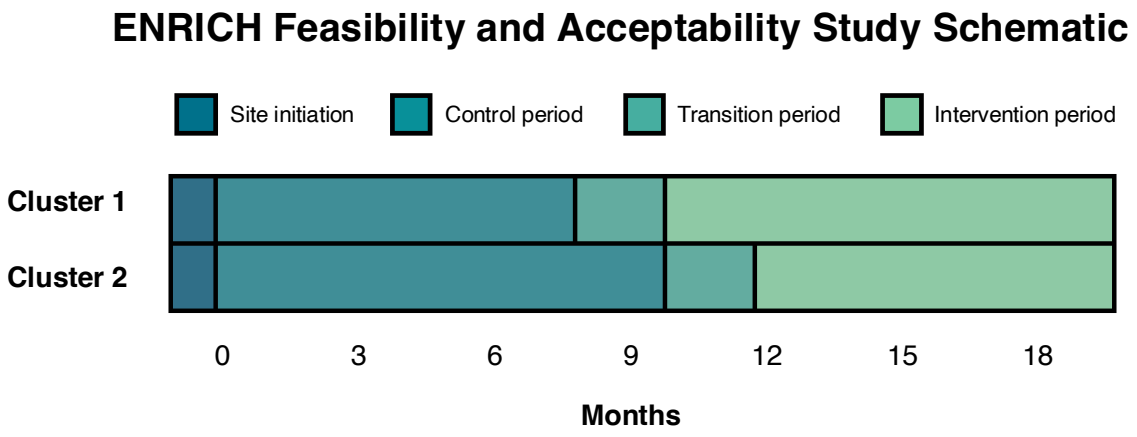


Figure 8.3. Schematic overview of the ENRICH feasibility and acceptability study design.

Participant identification and recruitment

Stroke survivor participants

Stroke survivors seen by the participating sites for usual care reviews or ENRICH reviews during the control and intervention periods, respectively, will be invited to provide study data. For stroke survivors to be eligible to provide study data, they must meet the following inclusion criteria: (1) Aged at least 18 years old; (2) Within four-weeks of a confirmed clinical diagnosis of stroke (first ever or recurrent) at the point of consent; (3) Sufficient English language proficiency to comprehend requirements of participation and components of ENRICH intervention, as determined by person taking consent. Note that the intervention is designed for English speakers, so this level of English language proficiency is necessitated for study inclusion. It is a potential

limitation of the intervention itself that it has been designed for fluent English speakers only. Stroke survivors will be excluded if they are unable to concentrate for at least 10 minutes, as determined by the person taking consent.

Stroke survivors seen by participating sites for usual care reviews or ENRICH reviews (i.e., during control and intervention periods) will be screened against these eligibility criteria by a healthcare professional (e.g., research nurse) within the participating site. Stroke survivors meeting eligibility criteria will be offered the participant information sheet by the healthcare professional, alongside a verbal summary of the research. They will be offered the chance to ask any questions about the research at this point. Those who agree to participate will be taken through the informed consent procedure. A copy of the signed consent form will be given to the participant and a separate copy will be filed in their clinical notes. The original signed form will be retained at the study site.

Inclusion of stroke survivor participants with cognitive impairment in the study is crucial, given that the overarching goal of the ENRICH programme is to enhance post-stroke psychological care, including for those with cognitive impairment. However, cognitive impairment may limit a stroke survivor's ability to consent to participation within the research. Principles outlined by the Mental Capacity Act (2005) will inform standard consent procedures. Specifically, capacity will be assumed in all cases and the onus will be on the recruiting person to demonstrate a lack of capacity to consent to participating in the research. If the stroke survivor is deemed not to have capacity

to consent to participating in the research after the capacity assessment, the consultee advice on consent process will be followed.

All those who are responsible within the trial for conducting eligibility screening and acquiring informed consent or consultee advice will have completed mandatory Good Clinical Practice Training during the site initiation period. The Chief Investigator and Principal Investigator will officially authorise these individuals to conduct screening and consent procedures for the trial.

Family members/carers

Stroke survivors will be asked at the point of recruitment whether they consent to a family member or carer being invited to participate in the research. They will be asked to provide the name and contact details of the nominated family member or carer where they consent to this. These family members/carers will be contacted by the research team at the end of the intervention period and invited to participate in the research. They will be eligible to participate if they meet the following criteria: (1) Aged at least 18 years; (2) Cohabiting with the stroke survivor participant.

Healthcare professionals

The clinical lead of each participating service will advise on healthcare professionals who will be participating in the intervention by providing usual care reviews and ENRICH reviews. Healthcare professionals participating in this capacity will be invited to provide qualitative data on acceptability and feasibility at the end of the intervention period at their site. Healthcare professionals will be eligible to provide these data if

they meet the following inclusion criteria: (1) Currently working within participating stroke pathway service; (2) Allocated responsibility by service clinical lead for recruiting stroke survivor participants to the study and/or delivering usual care and ENRICH reviews.

Data collection

Semi-structured interviews

Participants will be invited to take part in a remote (telephone or Microsoft Teams) semi-structured interview. A topic guide will be used to explore feasibility and acceptability of the ENRICH intervention, SWCRT trial design, data collection procedures, data collection measures, and ENRICH training (healthcare professionals only). The topic guide will be revised iteratively as the work progresses, but the initial guide will be based on the NASSS framework (Greenhalgh & Abimbola, 2019) to facilitate a systematic examination of acceptability and feasibility that acknowledges the complexity of the intervention delivery environment. As such, it will include questions that tap acceptability and feasibility in relation to the following seven domains of complexity: Condition (e.g., To what extent does the ENRICH intervention address the needs of stroke survivors with different stroke-related sequelae?), Technology (e.g., How user-friendly was the ENRICH intervention and associated resources?), Value Proposition (e.g., What benefits or challenges have stakeholders experienced as a result of the ENRICH intervention?), Adopters (e.g., How easy was it for healthcare professionals to integrate the intervention into their existing clinical practice, and for stroke survivors to integrate the intervention principles into their daily lives?), Organisation (e.g., What organisational factors promoted or hindered the

implementation of the intervention within clinical practice?), Wider System (e.g., How have external factors such as healthcare policies and clinical commissioning influenced the ability to integrate the intervention into clinical practice?), Embedding and Adaptation over Time (e.g., How sustainable do you think this intervention is, and what changes could improve its long-term success?). Interviews will be audio recorded with consent and transcribed verbatim.

Questionnaire measures

Stroke survivor participants will be invited to complete the following questionnaires within two-weeks of receiving a usual care review (control period) or their six-months ENRICH review (intervention period) as part of the feasibility and acceptability study: Quality of Life Brain after Brain Injury scale (QOLIBRI: von Steinbüchel et al., 2010); Depression Anxiety and Stress Scale-21 (DASS-21: Henry & Crawford, 2005); Institute for Medical Technology Assessment Medical Consumption Questionnaire (iMCQ: Erasmus University Rotterdam, 2018). These questionnaires were selected based on the intervention logic model, which predicts individual-level improvements in quality of life (QOLIBRI) and psychological wellbeing (DASS-21) and system-level improvements in healthcare usage (iMCQ). Our PPI Group also reviewed the questionnaires. Note that the goal of questionnaire administration is to elucidate whether the planned data collection procedures (telephone questionnaire administration) and measures are acceptable and feasible to use within the full-scale definitive SWCRT.

Demographic and clinical data

To characterise the participant sample, data will be collected from stroke survivor medical records on: date of birth, gender, years of education, ethnicity, confirmation of diagnosis of stroke/TIA, date of stroke, stroke severity (NIHSS), length of stay in acute care, pre-stroke disability level (pre-morbid modified Rankin scale: mRS), pre-stroke dementia status, discharge destination, discharge date. Any available data on acute post-stroke cognitive functioning (e.g., OCS or MoCA) will also be collected. The following clinical data from usual care reviews or ENRICH reviews will also be recorded to further contextualise the participant sample in terms of their psychological profiles: OCS performance, PHQ-9 scores, GAD-7 scores, and FSS scores.

Family members and healthcare professionals will be asked to provide self-report data on the following demographic variables: date of birth, gender, and ethnicity. Family members will also be asked to report their relationship to the participating stroke survivor. Healthcare professionals will be asked to report their length of time employed at the participating site and their professional occupation within the site.

Data analysis plan

Qualitative data analysis

A thematic analysis will be conducted, with the NASSS framework (Greenhalgh & Abimbola, 2019) used as an interpretive lens to shed light on the complex dynamics affecting intervention acceptability and feasibility. One member of the research team will first familiarise themselves with the interview transcripts by reading through all data and noting initial impressions. Data will then be coded at a semantic level using a

mostly deductive approach, whereby the NASSS framework is held in mind and used to partially inform coding. Related codes will be grouped, and initial themes will be identified through an iterative process involving regular research team discussions. Once an initial set of themes is established, they will be reviewed for internal coherence (i.e., codes within a theme are meaningfully related) and external distinction (i.e., themes are clearly distinct from each other). Themes will be refined by collapsing those that are similar and splitting broad themes into sub-themes. For instance, the theme of Organisation may split into "organisational readiness" and "resource limitations". Finally, a cross-theme analysis will be conducted to explore any interconnections between the seven NASSS domains and to understand how challenges in one domain (e.g., organisational support) may impact another (e.g., long-term sustainability).

Quantitative data analysis

The following descriptive measures will be calculated at both a site-level and overall study-level for both the control and intervention periods to assess the feasibility and acceptability of running a definitive full-scale SWCRT of the intervention:

- Number of stroke survivors screened for eligibility.
- Number of eligible stroke survivors.
- Number of recruited stroke survivors.
- Rate of recruitment of stroke survivor participants (i.e., average number of stroke survivors recruited per month).

- Participant attrition rates by study time point (i.e., percentage attrition of control participants at six-month usual care review; percentage attrition of intervention participants at first, second and third ENRICH reviews).
- Outcome measure completion rates (i.e., rates of data missingness per outcome measure collected at the end of the control/intervention period and at follow-up).
- Duration of outcome assessment sessions (i.e., mean, standard deviation, range in minutes).
- Number of sites screened for eligibility.
- Number of eligible sites.
- Proportion of healthcare professionals responsible for delivering usual care and ENRICH reviews who attend ENRICH intervention training (online and in person per site).
- Number of usual care reviews completed during control period and reasons for missed reviews.
- Number of ENRICH reviews completed during intervention period and reasons for missed reviews.
- Average number of ENRICH reviews completed during the intervention period per stroke survivor participant (i.e., mean, standard deviation).
- Duration of usual care and ENRICH reviews (i.e., mean, standard deviation, range in minutes).
- Proportion of fidelity checklists completed and returned.
- Proportion of fidelity checklists partially completed and returned.
- Proportion of prespecified ENRICH sessions audio-recorded and returned.

These measures will be compared against prespecified progression criteria to determine whether progression to a full-scale SWCRT is warranted. Progression criteria are summarised in Figure 8.4 below and were based on feasibility objectives, clinical assumptions, and pragmatic expectations, rather than being statistically derived. Progression to a full-scale SWCRT will be deemed to be warranted where all feasibility factors meet either green or orange progression criteria, and appropriate adjustments are made for factors meeting orange criteria.

ENRICH Feasibility Trial Progression Criteria

	Proceed to RCT	Proceed to RCT after modification	Do not proceed to RCT
Site recruitment	2 sites recruited within 6-months of study opening (R&D approval in place).	2 sites recruited but it takes longer than expected (e.g., 3-6 months).	Unable to recruit sites.
Site retention	2 sites retained until intervention period ends.	1 site retained until intervention period ends.	0 sites retained until intervention period ends.
Intervention training	>50% eligible HCPs complete training during transition period.	20-50% eligible HCPs complete training during transition period.	<20% eligible HCPs complete training during transition period.
Participant recruitment	≥5 stroke survivors recruited per month by retained site(s) across both study periods on average.	3-4 stroke survivors recruited per month by retained site(s) across both study periods on average.	<3 stroke survivors recruited per month by retained site(s) across at least one study period on average.
Participant retention	≥50% recruited stroke survivors retained in study until outcome data collection point.	30-50% recruited stroke survivors retained in study until outcome data collection point.	<30% recruited stroke survivors retained in study until outcome data collection point.
Review completion	≥50% recruited stroke survivors completed more than one ENRICH review.	≥50% recruited stroke survivors completed one ENRICH review.	<50% recruited stroke survivors completed one ENRICH review.
Outcome completion	≥75% stroke survivors retained until outcome data collection point complete outcome measures.	50-74% stroke survivors retained until outcome data collection point complete outcome measures.	<50% stroke survivors retained until outcome data collection point complete outcome measures.
Nested qualitative study	≥50% recruited stroke survivors consent to contact for nested qualitative evaluation.	20-49% recruited stroke survivors consent to contact for nested qualitative evaluation.	<20% recruited stroke survivors consent to contact for nested qualitative evaluation.
Intervention acceptability	Qualitative data supports intervention acceptability as it stands.	Qualitative data supports intervention acceptability with minor modifications.	Qualitative data does not support intervention acceptability or suggests major modifications.
Trial acceptability	Qualitative data supports trial acceptability as trial design stands.	Qualitative data supports trial acceptability with minor modifications.	Qualitative data does not support trial acceptability or suggests major modifications.

Figure 8.4. Criteria that will be used to determine whether progression to a full-scale SWCRT is warranted based on data from the ENRICH feasibility trial. HCPs = Healthcare professionals.

As the aim of this study is to determine the feasibility of running a full-scale SWCRT, it is not formally powered to detect a statistically significant difference in questionnaire measures for participants recruited to the control and intervention condition (QOLIBRI, DASS-21, EQ-5D-5L, mRS). Instead, the primary aim of administering these questionnaires is to assess the feasibility and acceptability of the data collection procedures and measures. Additionally, questionnaire data will be used to conduct a cautious investigation of whether there is *signal* to detect an effect of the intervention on outcome measures in a formally powered full-scale SWCRT. Intention-to-treat analyses will be performed to determine this. Where there is no more than 20% missing data on a scale across the sample and data are determined to be missing at random, multiple imputation procedures will be used to handle missing data (Peyre et al., 2011). Multiple linear regression analyses will be used to determine whether there are significant differences in outcome measures between participants in the control versus intervention condition. Age, gender, years of education, stroke severity (NIHSS), pre-stroke disability level (mRS recorded at recruitment), and time since stroke (at outcome measure completion) will be included as covariates in these analyses. The required sample size for a large scale definitive SWRCT will be calculated based on effect size estimates on the primary outcome measure. Sample size estimates will be adjusted with intra-cluster correlation coefficient estimates by trial site via mixed-effects models adjusted for a secular trend in time.

8.6. Conclusions and chapter summary

While the primary focus of this thesis has been on developing an intervention to provide enhanced cognitive care for stroke survivors in the UK, this chapter introduced the feasibility testing stage of research that follows on from the initial development work. The chapter outlined the importance of feasibility testing and justified the two-stage approach being used to gauge the feasibility and acceptability of the ENRICH intervention and running a full-scale SWCRT. Then, preliminary feasibility data from the first stage of testing was presented, followed by the protocol for the second stage of testing, which has received Sponsorship and NHS ethical approval and is anticipated to run between December 2024 – December 2026. Ultimately, this chapter demonstrates that the work presented in this thesis has made a crucial contribution to an ongoing programme of research that has the ambitious goal of improving post-stroke psychological care within the UK.

9. General discussion

9.1. Chapter overview

The research presented in this thesis took an interdisciplinary approach – guided by the MRC framework and integrating co-production principles – to develop an intervention providing Level 1 post-stroke cognitive care. By addressing each of the specific objectives outlined in Chapter 1 and reiterated below, the research culminated in a clearly delineated Level 1 complex intervention focused on monitoring post-stroke psychological changes and providing psychoeducation (Chapter 7). Crucially, development work resulted in the scope of the intervention being extended to encompass not only post-stroke cognitive care, but also psychological support for low mood, anxiety, and fatigue. Chapter 8 presented preliminary results from the first intervention feasibility testing stage of the research, which is currently underway at the point of thesis submission, alongside the protocol for a future study assessing the feasibility of running a full-scale SWCRT to establish clinical effectiveness.

This final thesis chapter discusses key findings related to each research objective, drawing links with previous research and theory, though being mindful not to replicate discussions presented in the empirical chapters themselves. The implications for clinical and research practice are laid out, before the strengths and limitations of the research are discussed. The chapter concludes by outlining planned future research. It is worth noting briefly that this chapter predominantly focuses on cognition after stroke, even though the intervention was ultimately broadened to address not only cognitive changes, but also low mood, anxiety, and fatigue (see Chapter 7). The focus

here on cognition reflects the initially narrower scope of the intervention as providing post-stroke *cognitive* care and the fact that most empirical work presented in this thesis therefore generated findings pertinent to this topic specifically.

9.2. Overview of key findings

9.2.1. Objective 1: To establish expert healthcare professional and researcher consensus on the complex intervention features.

The modified Delphi survey (Chapter 3) resulted in a minimum set of features to include within the complex intervention, as agreed by expert UK-based healthcare professionals and researchers. Participants agreed overwhelmingly that the intervention should provide structured post-discharge reviews of psychological changes to all stroke survivors, regardless of whether cognitive changes were detected during inpatient hospital admission, in line with national clinical guidelines recommending that all stroke survivors should receive a comprehensive and structured needs reassessment after discharge in the months after stroke, encompassing psychological changes (Intercollegiate Stroke Working Party, 2023a; Royal College of Physicians, 2016). Monitoring and providing support for psychological factors in the months after stroke is crucial in light of evidence that subtle cognitive impairments are easily missed when assessed (sub)acutely using brief screening tools (Abzhandadze et al., 2021; Jaillard et al., 2009), some of which are not appropriately sensitive (Chan et al., 2014; Lees et al., 2014). False negatives are a largely inevitable consequence of using brief cognitive screening tools (Nelson et al., 1986) and so they are also likely to occur in later psychological reviews conducted within the intervention. The inclusion of a self-reported measure of cognitive concerns

– as agreed by participants – will provide an important opportunity for stroke survivors to voice any subjective cognitive complaints and receive appropriate psychoeducation and/or onwards referral, even in cases where performance-based cognitive screens detect no impairment.

Monitoring psychological changes and providing psychoeducation in the months after stroke within the intervention is also critical in light of mounting empirical evidence that managing psychological changes is among the most commonly reported unmet needs over the long-term after stroke (Chen et al., 2019; Guo et al., 2021; Lin et al., 2021). Indeed, although clinical guidelines quite rightly emphasise the importance of assessing psychological changes in the first six-weeks after stroke (Intercollegiate Stroke Working Party, 2023a; Royal College of Physicians, 2016), clinical anecdotal evidence suggests these factors may in some cases become more important to stroke survivors and their family members in later months. Though cognitive impairments are highly prevalent in the first days and weeks after stroke (Demeyere et al., 2016; Hurford et al., 2013; Lesniak et al., 2008; Milosevich et al., 2024; Nijsse et al., 2017; Turunen et al., 2018), stroke survivors may initially be more preoccupied with visible impairments affecting mobility and independence, potentially due to their perceptibility and/or enhanced salience stemming from the tendency to focus in hyperacute and acute stroke units on visible impairments (Clarke, 2013). The detrimental impact of cognitive impairment on ADLs may only become readily apparent once stroke survivors return home and it may be at this point that the importance of cognition is recognised and support readily accepted. There was indeed tentative evidence from two studies included within the scoping review (Chapter 5) that cognition becomes

more subjectively important or at least more salient over time, as both studies reported that the number of cognition-related questions asked by stroke survivors increased in the months after stroke (Hanger et al., 1998; Rose et al., 2010). In terms of experiencing low mood and anxiety after stroke, though symptoms may emerge immediately after stroke as a direct response to an unexpected and potentially life-changing stressor (Ferro et al., 2016; Morris et al., 2017), a proportion of stroke survivors demonstrate remarkable psychological resilience in the early stages and only later experience low mood and anxiety when they are forced to confront the contrast between 'who I was then' and 'who I am now', as well as anxiety about 'who I might be in the future' (Gracey et al., 2009), highlighting the need for ongoing psychological monitoring in the months after stroke, in line with the intervention design.

There was some discrepancy in views among modified Delphi survey participants about the optimal approach to assess cognition within the intervention, however, echoing ongoing discourse and debate within the literature (Quinn et al., 2018, 2021). Identifying the most appropriate cognitive assessment approach (i.e., screening versus neuropsychological assessment) and the specific tool to use within the intervention was a crucial yet highly challenging question, as the ideal method needed to strike a pragmatic balance between being implementable within time- and resource-constrained clinical environments, while also providing data that are rich enough to be clinically meaningful. Though these questions arguably bear more relevance to the evaluation and implementation stages of complex intervention research, as defined within the MRC framework (Craig et al., 2008; Skivington et al., 2021), and though the research presented in this thesis was firmly situated within the development stage

(O'Cathain et al., 2019), recent revisions to the MRC framework have emphasised the importance of holding in mind implementation and evaluation considerations as early as possible in the complex intervention research process to mitigate challenges later down the road (Skivington et al., 2021). Ultimately, modified Delphi survey participants did not reach consensus on whether dementia screening and neuropsychological assessments should form a standard part of the intervention, but an overwhelming majority (97% of participants) agreed that a stroke-specific cognitive screening tool should be used within the post-discharge Level 1 psychological care intervention.

There are a range of potential tools that have been psychometrically validated to screen for these post-stroke cognitive changes, low mood, anxiety, and fatigue (see reviews by Bennett & Lincoln, 2006; Burton & Tyson, 2015a; Burton & Tyson, 2015b; Nadarajah & Goh, 2015; Rose et al., 2023) and, though the modified Delphi survey concluded *that* screening tools should be used within the intervention, it did not go so far as to ask *which* screening tools should be used. This 'boundaried-ness' of the survey – and indeed the intervention development process as a whole – is arguably a further limitation of the research that will be discussed further in Section 9.4. In brief, boundaries were put in place where it was felt the research team and collaborators had extensive expertise, while recognising that the iterative nature of the research would enable stakeholders to provide feedback on these design decisions in later feasibility testing (Chapter 8). While recognising the availability of a number of psychometrically valid stroke-specific cognitive screening tools (Benaim et al., 2022; Bickerton et al., 2015; Brookes et al., 2015; Lunardelli et al., 2009; Williams et al., 2016), once modified Delphi survey participants agreed the intervention should include

a stroke-specific cognitive screening tool, the OCS was selected by the research team as it is freely available, domain-specific, brief, validated for both acute and chronic stroke, and already widely used within research and clinical practice (currently over 2500 licensed users), potentially facilitating future widespread implementation of the intervention. Encouragingly, preliminary feasibility testing data (Chapter 8) supported the OCS as an appropriate cognitive screening tool within the intervention, as 9 out of 12 (75%) participants agreed the OCS was either helpful or very helpful, and there was support for the acceptability of the OCS from qualitative data, in which some participants even described a therapeutic benefit of sorts. To assess low mood/anxiety and fatigue, respectively, the DASS-21 and FSS were selected over possible alternatives (see reviews by Bennett & Lincoln, 2006; Burton & Tyson, 2015a; Nadarajah & Goh, 2015; Rose et al., 2023), given that they are freely available, brief, and have good psychometric evidence in acquired brain injury (FSS: Krupp et al., 1989; DASS-21: Rose et al., 2023). Though the FSS was observed in preliminary feasibility testing to be broadly acceptable to stroke survivors, pragmatic concerns emerged about the suitability of the DASS-21. In particular, the need to generate three sub-scores capturing depression, anxiety, and stress, respectively, proved time-consuming and questionnaire items capturing stress seemed to have only limited relevance to the overarching aims of the intervention. As such, the decision was made to replace the DASS-21 with the PHQ-9 and GAD-7 for subsequent feasibility testing stages, given that these tools are similarly well validated for acquired brain injury, freely available, and brief (Rose et al., 2023). Whether these tools are acceptable to stakeholders and feasible for use in the intervention will be addressed in the second iterative round of feasibility testing.

No consensus was reached by the end of the three-round survey on whether or not to include dementia screening and neuropsychological assessments as standard within the intervention. In what is arguably a quite accurate depiction that has been loosely implied in previous research (Quinn et al., 2018), modified Delphi survey participants painted stroke-specific cognitive screening and neuropsychological assessment as polarities – whereas screening was seen as 'quick but dirty', neuropsychological assessments were considered 'rich but time-consuming'. The tension between participants' preferences to provide more and a healthcare system that is affording less due to financial constraints and staffing shortages was palpable, and the different ways in which participants reconciled this tension perhaps explains why no consensus was reached on this design decision. Still, we tentatively inferred from the qualitative data that participants agreed the intervention should be situated within the recommended matched care model of post-stroke psychological support (Intercollegiate Stroke Working Party, 2023a; NHS Improvement, 2011; Royal College of Physicians, 2016), with stroke-specific cognitive screening conducted as standard and dementia screening and neuropsychological assessments – which often require more careful interpretation and hence expertise and training – reserved for those with more complex needs. The need for an onwards referral pathway thus became a clear and important component of the intervention.

Holding in mind this proposed onwards referral pathway and recognising the intervention as firmly situated within the Level 1 tier of post-stroke psychological care (NHS Improvement, 2011) is important for establishing how the intervention might eventually fit with other previously developed complex interventions providing

enhanced post-stroke psychological care (see reviews by Cheng et al., 2014; Hickey et al., 2019; Kontou et al., 2021; Merriman et al., 2019). Though it is worth noting that none of these interventions – to our knowledge – have been widely implemented within national healthcare systems, they were consulted and considered regularly throughout this thesis and many of them (or at least the evidence and/or theory underpinning them) served as important sources of evidence and inspiration for the intervention ultimately proposed here. In particular, the StrokeCog intervention – a cognition-focused five-week group-based programme – struck me as likely to deliver substantial clinical benefit and its rootedness in high-quality empirical evidence, psychological theory, and stakeholder input bore distinct resemblance to the methodological approach taken in this thesis (Merriman et al., 2021). However, with five sessions comprising thirty-six clinical activities delivered by three healthcare professionals (including a highly skilled clinical neuropsychologist), its 'hungriness' for both clinical time and expertise introduces concerns about its suitability for widespread implementation within the stroke care pathway, concerns that are indeed readily acknowledged by the intervention developers themselves (Merriman et al., 2021). In particular, the need for psychological specialist staff is potentially problematic in light of the substantial shortage of such professionals within the NHS (Gilburt & Mallorie, 2024). Although recent calls have been made to expand the psychology specialist workforce within the UK stroke care pathway (Division of Neuropsychology, 2023), the broader political and economic landscape within the UK make it impossible to predict whether and when this personnel gap might be filled.

Once again highlighting how considerations pertinent to eventual implementation were held in mind throughout the intervention development process, in line with MRC recommendations (Skivington et al., 2021), the intervention developed in this thesis was envisaged from the outset to be deliverable by non-psychology specialist members of the NHS workforce in order to side-step this limitation and propose a more pragmatic and scalable approach for providing Level 1 psychological support within the UK stroke care pathway. As agreed by modified Delphi survey participants, it will be essential to upskill those tasked with administering the intervention through a structured training programme. At the point of thesis submission, a training programme is being developed by the research team and establishing its feasibility and acceptability, as well as identifying ways to improve it, will be a fundamental part of the second feasibility testing study (Chapter 8 Part B). In an eventual and ideal world, where it is shown that the training and intervention developed here are feasible and clinically effective, the intervention may be delivered widely by non-psychology specialists and the proposed onwards referral pathway may allow it to dovetail with other more intensive approaches, like the StrokeCog intervention, designed to provide more specialist support for those who need it.

9.2.2. Objective 2: To explore stroke survivor and family member experiences of cognitive screening and perspectives on discussing future cognitive trajectories.

The second objective aimed to inform two core features of the intervention outlined in the initial intervention 'skeleton' – cognitive screening and discussions about future cognitive trajectories. Findings from research presented in Chapter 4 had key

implications for these aspects of the intervention design. First, by sharing their past experiences of cognitive screening within the early stages of stroke – which is recommended by national and international clinical guidelines (Intercollegiate Stroke Working Party, 2023a; Royal College of Physicians, 2016; Stroke Foundation Australia, 2021; The European Stroke Organisation (ESO) Executive Committee and the ESO Writing Committee, 2008) and carried out before discharge in the vast majority of cases according to national audit data (Intercollegiate Stroke Working Party, 2023b) – stroke survivors and family members in this study revealed the importance of clearly explaining the purpose and results of screening within the intervention, in order to support psychological wellbeing and adjustment. As it is relatively brief and non-invasive, cognitive screening is often seen as a benign procedure in clinical practice, but there are in fact inherent risks involved (Ismail et al., 2010). Indeed, echoing research in non-stroke clinical populations (Elwick et al., 2022; Krohne et al., 2011), research presented in this thesis suggested that poor understanding of the purpose of cognitive screening may limit engagement in the process, with potential detrimental implications for both validity of results and psychological wellbeing.

Merely 'ticking the box' by administering a cognitive screen without adequately explaining it nor discussing results may be an unfortunate consequence of the limited time and resources available in hyperacute and acute stroke units, reflecting the systemic pressures facing the UK healthcare system. Nevertheless, the research presented in Chapter 4 highlighted the potential beneficial impact of providing clear and easily interpretable feedback on stroke survivors' confidence and self-efficacy.

Given that both self-efficacy and confidence have been identified as important factors in promoting post-stroke recovery (Jones et al., 2008; Maujean et al., 2014), there may be subtle clinical benefits to providing such feedback. Furthermore, and drawing on the Y-shaped model of psychological adjustment after brain injury (Gracey et al., 2009), helping stroke survivors understand cognitive impairment and perceive it accurately as a prevalent psychological consequence of stroke that can be effectively managed through behavioural strategies may be important for adjusting maladaptive narratives that may contribute to problematic social and interpersonal discrepancies. Indeed, even in this empirical chapter, perceptions of what it meant to have a cognitive impairment appeared to impact emotional responses to testing, further highlighting the importance of ensuring strike survivors have an accurate conceptualisation to support adjustment.

Since publishing the above-described research in 2023 (Hobden et al., 2023), a further study has broadly confirmed and extended the above key findings (McMahon et al., 2024). After conducting interviews with 13 stroke survivors about their experience of cognitive screening and analysing data using framework analysis, McMahon et al. similarly identified the importance of information provision to ensure stroke survivors have a firm grasp of the purpose and results of cognitive screening. Though the aim of the qualitative research presented in Chapter 4 was not to generate findings that replicate across populations but rather to provide a rich yet inevitably partial, provisional, and situated account of the data, seeing similar sentiments echoed in a separate stroke survivor sample provides optimism that key principles incorporated within the intervention will be applicable to a broad stroke population, which is in line

with the vision that the intervention may one day be more widely implemented within the UK stroke care pathway, if it is proven to be feasible, acceptable, and clinically effective.

Expanding on these key findings from Chapter 4, results from McMahon et al. (2024) also suggested potential benefits of developing and delivering a complex intervention focused on monitoring (and providing psychoeducation about) psychological changes after stroke, like the one developed in this thesis. While healthcare professionals have recognised the importance of post-stroke cognitive screening for informing rehabilitation programmes (Ablewhite et al., 2019), McMahon et al. suggested the benefit of post-stroke cognitive screening may derive not only from the clinical utility of the data, but also that cognitive screening may have a subtle therapeutic benefit. Specifically, some stroke survivors in their study described how cognitive screening provided them with a sense of reassurance that they were being listened to and monitored, which may potentially reduce anxiety and feelings of abandonment after stroke. Similarly, and as described briefly above, preliminary feasibility data presented in this thesis (Chapter 8) highlighted a potential therapeutic benefit of post-discharge cognitive screening, as evidencing improvement in cognitive functioning helped to allay one stroke survivor's fear that she was "losing [her] mind". Nevertheless, cognitive screening appeared to be a double-edged sword in the study by McMahon et al., as frequent screening was associated with perceived burden. This raises questions about the extent to which it will be clinically beneficial and in stroke survivors' best interests to offer multiple post-discharge psychological reviews involving stroke-specific cognitive screening within the intervention developed in this thesis, as is

currently planned. As such and given the increased clinical and economic burden of providing multiple psychological reviews within the intervention, the extent to which stakeholders consider multiple reviews to be 'worth it' will need to be considered carefully in the second feasibility study (Chapter 8 Part B). Though these considerations raise questions about the clinical and cost effectiveness of the intervention versus usual care, they ultimately provide the equipoise that will be critical for any future CRT to be ethically justifiable (Braakhekke et al., 2017).

Compared to progressive neurological conditions where abilities might be reasonably expected to decline over time, stroke is perceived by some as a condition that affords more hope for at least a partial recovery and existing evidence has thus highlighted the relative acceptability of discussing prognosis with stroke survivors compared to other brain injury populations (Burton et al., 2021). Nevertheless, by investigating perspectives on discussing potential cognitive trajectories specifically, the research presented in Chapter 4 provided important insight for the complex intervention and added crucial nuance to this earlier conclusion (Burton et al., 2021). Specifically, it highlighted the importance of adopting a person-centred approach to conversations about post-stroke cognitive trajectories within the intervention – potentially by drawing on frameworks like the SPIKES protocol (Baile et al., 2000) or Kaye's 10 step approach (Kaye, 1996) – to support adjustment while encouraging optimism. In this respect, just as person-centredness is a fundamental principle within the broader NHS constitution (Department of Health and Social Care, 2012), so too does it form a central tenet of the intervention developed in this thesis.

The simultaneous emphasis within the 'final' intervention design (Chapter 7) on both personalisation and standardisation appears in some respects paradoxical. However, while standardisation and personalisation have often been conceived as opposite poles, they are not in reality intrinsically opposing imperatives (Lasalvia & Merges, 2020). Rather, striving for both standardisation and personalisation is at the crux of delivering effective person-centred healthcare, as thoughtful and strategic application of both principles allows the strengths of each to be harnessed and the weaknesses offset. Indeed, in many respects, clinical guidelines themselves illustrate the possibility and desirability of delivering simultaneously standardised and personalised care, as they call on healthcare professionals to use their clinical judgement in the context of delivering consistent high-quality care. Ultimately, while the modified Delphi survey (Chapter 3) in many respects resulted in the development of a minimum set of 'standard' features to be included in the intervention, semi-structured interviews revealed the importance of adopting a thoroughly personalised approach to intervention delivery, with the importance of person-centredness clearly echoed later in Chapter 6. As such, the 'final' intervention outlined in Chapter 7 is conceptualised more as a guiding framework than a rigid and prescriptive manual, as clinicians will be encouraged to utilise their expertise and clinical instincts to tailor it appropriately. Though this was challenging to capture within the final intervention outline and corresponding logic model (Chapter 7), training being developed for healthcare professionals tasked with administering the intervention will emphasise this point emphatically.

9.2.3. Objective 3 and Objective 4: To map and identify gaps within the current literature describing stroke survivor and family member psychoeducation needs about cognition and to develop a novel psychoeducation resource about cognition to be used within the complex intervention.

These objectives are combined here for discussion as they both addressed the psychoeducation component of the intervention, the third core feature highlighted within the initial intervention skeleton. Crucially, the scoping review (Chapter 5) highlighted gaps in existing research – in particular, a lack of research investigating non-language psychoeducation needs and including cognitively diverse stroke survivor samples – and provided tentative evidence for specific psychoeducation needs, which laid the foundation for developing a novel cognition-focused psychoeducation resource to be used within the intervention (Chapter 6). Having developed an initial prototype psychoeducation resource by integrating key findings from previous chapters, a purposive sampling approach was used to recruit a cognitively diverse stroke survivor sample to evaluate and iteratively revise the resource, alongside family members and healthcare professionals. Co-production work culminated in a psychoeducation resource that appeared to meet key a priori developed intervention requirements and addressed the gamut of post-stroke cognitive impairments. Once the decision had been made to expand the intervention scope (Chapter 7), the psychoeducation resource was further revised with input from our PPI group to address low mood, anxiety, and fatigue, in addition to cognitive changes.

Key findings from the scoping review (Chapter 5) were that stroke survivors and family members appeared to have cognition-related psychoeducation needs at all timepoints investigated but there was a clear emphasis in previous studies on language impairments specifically. Stroke survivors with non-language cognitive impairments were excluded from some studies and very few articles explicitly described psychoeducation needs related to non-language domains, despite a long neuropsychological tradition recognising the potential for post-stroke cognitive impairments to affect memory, visuospatial attention, executive function, number processing, and praxis domains. In some respects, the emphasis on aphasia within these studies may be seen as a positive contrast to the historic underrepresentation of stroke survivors with language impairments in previous research (Shiggins et al., 2022, 2024). Indeed, substantial efforts have been made in recent years to improve inclusivity in stroke research by drawing attention to the fact that, although aphasia may introduce research participation challenges given the high language demands of many research processes (Shiggins et al., 2022), meaningful participation is possible with appropriate and carefully considered adaptations and accommodations (e.g., supported communication techniques) (Kagan, 1998; Luck & Rose, 2007). While it was positive to see research within the scoping review that strove to investigate perspectives of a historically underrepresented subgroup of stroke survivors, just as it has been argued that truly inclusive research requires recruitment of stroke survivors with aphasia (Shiggins et al., 2024), so too does this argument apply to stroke survivors with other cognitive impairments.

The purposive sampling approach used in Chapter 4 and Chapter 6 meant that – in contrast to most language-focused articles included in the scoping review – we were able to capture perspectives on psychoeducation, and the intervention more broadly, from a cognitively diverse sample of stroke survivors. Although there was no indication from either of these research projects that stroke survivors had fundamentally different perspectives on psychoeducation, cognitive screening, or discussing cognitive trajectories depending on their specific cognitive profile, by showing that it was possible to collect meaningful and insightful data from a cognitively diverse sample, the research makes a fundamentally important point about inclusivity and diversity in stroke research more broadly, which will be further discussed in Section 9.3.3.

In addition, actively probing psychoeducation needs related to non-language cognitive domains in the research presented in Chapter 6 meant we were able to build on findings from the scoping review, which were generally reported in the context of aphasia. This ultimately culminated in the development of a novel psychoeducation resource that addresses a variety of cognitive domains – encompassing language impairment as well as memory, number processing, executive function, visuospatial attention, and praxis – with design principles incorporated to ensure they are accessible to stroke survivors with aphasia, and impairments affecting visuospatial attention, concentration, and vision. Providing brief information on each cognitive domain and signposting to sources of further information, the 'final' psychoeducation resource (Appendix 4) stands in contrast to already available resources that have tended to target single domains in extensive detail (see for examples websites from the Stroke Association, American Stroke Association, and Stroke Foundation

Australia). Ultimately, the resource captures the multifacetedness of post-stroke cognition and aligns neatly with the OCS (Demeyere et al., 2015), which is already widely used in clinical practice and will also be used in the intervention, potentially facilitating future uptake and clinical usage of the psychoeducation resource.

Essentially replicating in miniature, the overall methodological approach taken to intervention development (Chapter 2), the psychoeducation resource was developed by integrating evidence (i.e., from scoping review), holding in mind theory (Chi, 2009; Chi & Wylie, 2014; Menekse et al., 2013), and incorporating stakeholder perspectives. This affords some optimism that the final resource will be clinically useful, in that it addresses evidenced psychoeducation needs and theoretically supports processing, understanding, and retention of the information among stroke survivors with a diverse range of cognitive impairments that potentially hinder 'normal' learning processes. Still, future feasibility and evaluative research may benefit from considering the extent to which the resource is acceptable and clinically useful to those with more severe cognitive impairments, who may have only limited ability to engage with this relatively more cognitively demanding component of the intervention. Indeed, researchers have acknowledged the importance of probing not only whether the intervention works, but specifically for whom and under what circumstances it works (Fletcher et al., 2016; Pawson, 2013), so that interventions can be better targeted to those who need and will benefit from it most, ensuring optimal use of limited clinical and financial resources.

9.2.4. Objective 5: To gauge the feasibility and acceptability of a single intervention review according to stroke survivors and healthcare professionals, and to develop the protocol for a future study to assess the feasibility of running a full-scale evaluative trial of the final intervention.

Although the research presented in this thesis is predominantly situated in the development stage of complex intervention research, as defined within the MRC framework (O'Cathain et al., 2019; Skivington et al., 2021), the final empirical chapter (Chapter 8) presented preliminary data on feasibility and acceptability of ENRICH reviews from a small sample of stroke survivors who have received a single enhanced psychological review at the appropriate post-stroke stage in an ecologically valid setting. Though it was hoped that healthcare professionals would administer these reviews in order to provide additional insight into the feasibility of incorporating intervention delivery into their existing clinical practice, unforeseen delays to the NHS ethics application and approval processes meant this was not possible by the thesis submission deadline. Nevertheless, with NHS ethics approval now in place, healthcare professionals at OUH ESD stroke service will begin administering enhanced psychological reviews in July 2024 for the next iterative round of feasibility testing. Feasibility and acceptability data from these healthcare professionals and further stroke survivors will inform final modifications to the intervention design, before a larger scale study is conducted between December 2024 – December 2026 to assess the feasibility and acceptability of running a full-scale SWCRT to establish the clinical effectiveness of the intervention (Chapter 8 Part B).

According to the overarching MRC framework that fundamentally guided the research presented in this thesis, determining the feasibility and acceptability of an intervention is a pivotal step prior to evaluation, as it affords the opportunity to identify potential barriers and facilitators before running a costly larger scale trial to establish clinical effectiveness (Skivington et al., 2021). Preliminary custom survey data from a small sample of stroke survivors broadly confirmed the acceptability of each intervention component, and qualitative data from semi-structured interviews shed light on several potential benefits of the intervention (Chapter 8). Nevertheless, there were also areas for improvement according to both stroke survivors who received the reviews and members of the research team responsible for administering them. Aligning with evidence from previous research projects presented in this thesis (Chapter 4 and Chapter 6), there was a strong sense that person-centredness was crucial, but some stroke survivors believed the approach originally agreed in the modified Delphi survey (Chapter 3) of administering each questionnaire to every stroke survivor came across as insufficiently person-centred. Furthermore, detailed qualitative feedback and first-hand experience administering reviews raised concerns about the extent to which the optimal screening tools had been selected. Finally, preliminary fidelity data indicated the reviews took on average 72.38 minutes to administer, compared to the target 60 minutes. Though the margin of difference is relatively moderate, in a healthcare system that is already overstretched to the point of breaking, such added time pressures could tip services over the edge, potentially resulting in poor intervention completion rates and fidelity should a full-scale SWCRT be conducted in the future.

As outlined in Chapter 8 Part B, a larger scale feasibility study involving two existing NHS stroke care pathways, will determine more conclusively whether it is indeed feasible and acceptable to run such a definitive SWCRT of the intervention. While this research will be essential before broader implementation of the intervention can be considered, preliminary results from a very recent large-scale multicentre CRT of a similar Level 1 post-stroke psychological monitoring and psychoeducation intervention in the Netherlands affords some optimism that the intervention may have some clinical benefit (Slenders et al., 2024; Slenders et al., 2020). In this trial, patients with very mild stroke who were discharged immediately after presenting at hospital received either usual care or enhanced psychological care, which bore a striking resemblance to the intervention developed in this thesis in that it comprised screening for post-stroke emotional and cognitive changes, screening for participation restrictions, educational support, and onwards referral to rehabilitation services at six-weeks post-stroke, where clinically indicated (Slenders et al., 2020). Although there was no significant difference in societal participation at one-year post-stroke (primary outcome), those receiving the intervention showed subtle but statistically significant improvements in anxiety and quality of life at three-months post-stroke compared to those receiving usual care (Slenders et al., 2024). This tentatively suggests that low intensity screening and psychoeducation for post-stroke psychological changes may improve some aspects of wellbeing in the months after stroke.

Nevertheless, it is by no means guaranteed that the intervention developed in this thesis will similarly improve stroke survivor outcomes compared to usual care, given important differences in the intervention components (e.g., measures used, depth of

psychoeducation provided, and intervention dosage), populations targeted (mild stroke versus all stroke survivors), and contexts in which the interventions are situated (Netherlands versus UK: potentially more or less efficient referral pathways, differences in systemic pressures contributing to differences in waiting lists), and considerations documented in Section 9.2.2 that provide equipoise with usual care. Indeed, recent revisions to the MRC framework strongly emphasised the importance of recognising the situatedness of complex interventions within equally complex systems and interrogating contextual interactions within large scale evaluations to facilitate later implementation (Skivington et al., 2021). This will need to be carefully considered within any future definitive trial of the intervention developed in this thesis to support widespread implementation.

9.3. Clinical practice and research implications

9.3.1. Informing local service improvements

Moving from intervention development to widespread implementation is a lengthy process and there is no guarantee that even meticulously designed interventions will reach the implementation stage of research (O'Cathain et al., 2019; Skivington et al., 2021; Turner et al., 2019). Determining the exact proportion of complex interventions developed using the MRC framework that are eventually widely implemented in clinical practice is made challenging by the variability in reporting, but it is generally acknowledged that only a very small fraction – possibly less than 10% – of complex interventions developed are implemented successfully (O'Cathain et al., 2019; Turner et al., 2019). Ultimately, rigorous feasibility testing (Chapter 8) and evaluation will be required before widespread implementation of the intervention developed in this thesis

should even be considered. Nevertheless, in the meantime while this work is underway, key findings from research presented in this thesis may usefully inform smaller scale local service improvements.

Specifically, although the modified Delphi survey (Chapter 3) was conducted to inform the design of a very specific intervention, rather than to expand on clinical guidelines and recommendations for post-stroke psychological care provision, clinical services tasked with providing Level 1 post-stroke psychological care may wish to consider how their practice aligns (or does not align) with the agreed upon intervention features. Furthermore, and on an individual level, healthcare professionals who routinely conduct post-stroke cognitive screens may wish to reflect on the extent to which findings from the semi-structured interviews (Chapter 4) are mirrored in their own clinical practice. Where healthcare professionals find themselves 'skimming over' explanations or cognitive screening results, they may find it helpful to recognise that clear and thorough information may support engagement, psychological well-being, and adjustment. Finally, discussions are underway about whether the psychoeducation resource developed in Chapter 6 should be made openly available. Though there are concerns that making it widely available may risk contamination of control clusters should a future definitive SWCRT be conducted, healthcare professionals may wish to integrate it into their current post-stroke psychological care practice to ensure they are providing well-evidenced and acceptable psychoeducation about post-stroke psychological changes so that stroke survivors' needs in this area are better met.

9.3.2. Addressing key research priorities

As stroke is a multifaceted condition with the potential to cause heterogeneous chronic sequalae, post-stroke *psychological* changes have not always been given the specific attention and resources they arguably deserve in research (Broussy et al., 2019). Nevertheless, substantial momentum has been building in this area in recent years, with the JLA identifying cognition and mood as the top two research priorities in long-term stroke care during a collaborative priority setting exercise involving stroke survivors, carers, and professionals (Hill et al., 2022; James Lind Alliance, 2022). To reiterate the quote featured at the beginning of this thesis, the JLA specifically called for researchers to investigate the following:

> *What is the best way to assess for, understand the impacts of and track progression in all areas of cognition – including using standardised measures - across the stroke pathway; what and how can interventions and services involving multidisciplinary teams and families be made accessible, and how can information on these problems be provided? (James Lind Alliance, 2022)*

Though substantially more research will be required to address these broad questions conclusively, the research presented in this thesis provides preliminary insight and thus has important implications in terms of addressing key research priorities. Key insights related to these priority research questions are presented in Table 9.1 for concision. Again, it is worth emphasising that research presented in this thesis focused on developing a specific intervention rather than generating a standard set of

guidelines, but results may be tentatively interpreted as offering suggestions for good clinical practice.

Priority Research Question	Key Findings
What is the best way to assess all areas of cognition?	• A stroke-specific cognitive screen should be used as standard (C3), with some preliminary evidence that the OCS is acceptable to stroke survivors (C8). • A self-report measure of everyday difficulties with cognition should be used as standard for stroke survivors and family members (C3). • Dementia screens and neuropsychological assessments should be reserved for those with more complex needs (C3).
What is the best way to track progression in all areas of cognition?	• Cognition should be reviewed using a stroke-specific cognitive screen (e.g., OCS) as standard after discharge at multiple stages (C3) • Cognition should be tracked for all stroke survivors, regardless of their in-hospital cognitive profile (C3).
How can information on cognitive problems be provided?	• Information on cognitive screening purpose and results – encompassing both strengths and challenges – should be provided (C4, C6). • Information on future changes in cognition should be provided only where deemed of benefit to the individual stroke survivor or family member (C4). • Information on managing cognitive problems (i.e., strategies) should be provided (C5, C6). • Information on changes in cognitive problems from one timepoint to another should be provided where possible (C6). • Further information on cognitive problems, including where to find support, should be signposted (C5, C6). • Use of accessible language to provide information on cognitive problems (C4, C6). • Co-produced workbook may prove helpful for providing information on cognitive problems in clinical practice (C6), should it be made openly available.
How can cognitive care interventions involving MDTs and families be made accessible?	• Appropriate training may enable non-psychology-specialist members of the MDT to provide Level 1 cognitive care (C3*).

Table 9.1. Key findings from research presented in this thesis that provide insight into priority stroke research questions identified by the JLA. The following codes are used to indicate the chapter(s) from which key findings derived: Chapter 3 (C3), Chapter 4 (C4), Chapter 5 (C5), Chapter 6 (C6), Chapter 8 (8). *Tentative evidence from modified Delphi survey but feasibility testing data ultimately required.

9.3.3. Inclusivity and diversity in stroke research

While equality, diversity, and inclusion are firmly on the agenda of major UK research councils (Economic and Social Research Council, 2023; National Institute for Health and Care Excellence, 2022; UK Research and Innovation, 2023b; Wellcome Trust, 2023), underrepresentation of stroke survivors with certain sociodemographic and clinical traits has long been recognised (e.g., Acton et al., 2022; Boden-Albala et al., 2015; Carcel & Reeves, 2021; Shiggins et al., 2024). Not only does such underrepresentation have grave ethical implications, it also has serious consequences for our scientific understanding of stroke-related phenomena. Many barriers to recruitment and retention in research that extend beyond the stroke population specifically are economic and attitudinal (e.g., competing demands on time, distrust of researchers) (Corbie-Smith et al., 2002), and strategies have been proposed to minimise the impact of such factors on research participation (Bower et al., 2014; Heller et al., 2014). However, even when such positive steps are taken in stroke research, the perception that research places heavy cognitive demands on participants has led to underrepresentation of stroke survivors with cognitive impairment (Shiggins et al., 2022, 2024).

Adding to existing examples of qualitative research involving stroke survivors with cognitive impairment (e.g., Cheng et al., 2022; Davidson & Wallace, 2022; Tang et al., 2020), the research presented in this thesis makes a fundamentally important point about inclusivity and diversity in stroke research by showing the value that a cognitively diverse sample of stroke survivors can bring to complex intervention development. Specifically, stroke survivors with cognitive impairments that varied in

domain and severity participated in the research presented in Chapter 4, Chapter 6, and Chapter 8 and provided valuable insight into topics that varied in complexity and depth, affording confidence that the intervention ultimately developed will be acceptable to a similarly diverse stroke survivor population. Communication support strategies (e.g., probing and word offerings) proved invaluable for facilitating involvement of stroke survivors with cognitive impairments and these participants were often joined in the research by family members, who provided both moral and interpretive support. Furthermore, we carefully considered ways to reduce the cognitive load of key intervention development activities (e.g., Chapter 6: participants were asked to evaluate an existing prototype, rather than designing one 'from scratch', to reduce load on cognitive abilities). Having shown the possibility of including cognitively diverse stroke survivors in qualitative research and the value they can bring to complex intervention development, we echo recent calls to increase representation of aphasic stroke survivors in research (Shiggins et al., 2022) and extend this call to encompass stroke survivors with any and all types of cognitive impairment.

9.4. Future research

9.4.1. Ongoing research

Initial feasibility testing of the intervention, the recommended 'next step' in complex intervention research according to the MRC framework (Craig et al., 2008; Skivington et al., 2021), is currently ongoing and a multisite feasibility study to inform a future full-scale SWCRT is planned for December 2024 – December 2026. If these data show progression to the evaluation stage of research is warranted (i.e., progression criteria

are met), the clinical and cost effectiveness of the intervention will be evaluated in a full-scale definitive SWCRT.

9.4.2. Future research

Any future evaluative research will benefit from considering not only whether the intervention is clinically effective, but also for whom and under what circumstances. While the dominant approach to complex intervention evaluation has been to generate aggregate estimates of intervention effectiveness versus a carefully considered control condition (Minary et al., 2019), researchers have stressed that this approach risks over-privileging parsimony and over-simplifying causality (Fletcher et al., 2016; Pawson, 2013). While 'traditional' RCTs have been widely used to evaluate complex interventions (Minary et al., 2019), further aspects that render them suboptimal for complex intervention research include their successionist approach to causation and their conceptualisation of contextual variables as confounders and intervention users as passive recipients (Blamey & Mackenzie, 2007). Realist evaluation seeks to overcome these limitations by taking a more nuanced approach that focuses on the mechanisms of an intervention (i.e., what makes it work?) and the specific context in which these mechanisms may be triggered to bring about certain outcomes, with these relationships captured and tested in context-mechanism-outcome configurations (Pawson, 2013; Pawson & Tilley, 1997). Though realist evaluation is not yet formally planned for the intervention developed in this thesis, it will likely be critically important should progression to a full-scale SWCRT be warranted by feasibility data.

Having developed the intervention and its programme theory (see Chapter 7), preliminary hypotheses about the extent to which the intervention may or may not be clinically effective for certain subgroups of stroke survivors have indeed been informally identified and these should be tested in any future realist evaluation. For example, the intervention was designed for all stroke survivors in line with clinical guidelines recommending that "services for people with stroke should offer psychological support to all patients regardless of whether they exhibit specific mental health or cognitive difficulties" (Royal College of Physicians, 2016, p.26). However – as a Level 1 psychological care approach that focuses on active listening, normalising, psychoeducation, and signposting – the intervention is likely to have relatively limited benefit for stroke survivors experiencing more severe or complex psychological changes and requiring ongoing and more specialist psychological support. Although the onwards referral pathway integrated into the intervention design aims to ensure these stroke survivors receive an appropriate level of psychological support, whether it makes fiscal sense to offer three low intensity psychological reviews prior to referral is heavily debatable, particularly as this approach is somewhat more in line with a stepped- rather than matched-care model of psychological support.

Determining for whom the intervention is effective and thus whether it should be targeted more specifically towards certain subgroups has critically important implications for future implementation in terms of establishing precisely where in the stroke care pathway the intervention should be situated. Indeed, although the intervention development process began within the context of a national effort to increase integration across stroke services through the development of ISDNs (NHS

England and NHS Improvement, 2021), the level of integration remains suboptimal at the point of thesis submission. Feasibility data may thus reveal a need to situate the intervention within a specific stroke service (e.g., ESD services) in order to enhance the extent to which it is clinically implementable, in contrast to the original goal which was for the intervention to span ISDNs.

9.5. Limitations

Limitations specific to individual research projects are discussed in the relevant empirical thesis chapters, but several limitations of the overarching research programme should also be noted. First, while the scope of the complex intervention was initially narrower and focused on post-stroke cognitive changes specifically, synthesis of the research led us to recognise the potential benefit of broadening its scope to encompass additional psychological changes (low mood, anxiety, fatigue). Still, given that the parameters of the intervention were expanded at a relatively late stage in the intervention development process, the vast majority of development work had already been completed. As such, although the research provides important insight into post-stroke cognition and cognitive care, the insight provided into broader psychological changes is much more limited. As a research team, we considered conducting additional development work to shed further light on ways to address low mood, anxiety, and fatigue within the intervention, but there were reasonable grounds to believe the broad principles identified in the context of cognition would extend to these other psychological changes (e.g., the importance of providing accessible feedback after screening) and we trusted that any over- or mis-extension of findings would be identified and rectified within the feasibility testing stage of research.

A second potential limitation of the research is that theory was applied unsystematically throughout the intervention development process. Indeed, although intervention development followed a distinctly evidence- and theory-based approach, the lack of specific guidance in the MRC framework on how to select and incorporate theory (O'Cathain et al., 2019; Skivington et al., 2021) and the substantial debate within the literature on this topic (e.g., Michie & Prestwich, 2010; Moore & Evans, 2017; Ogden, 2016) made it challenging to choose a theory integration approach. Recognising the multiple facets of the intervention and its operation at both individual- and system-levels, I decided to move away from popular approaches to theory integration like the BCW (Michie et al., 2011), which have been criticised for focusing predominantly on individual-level behaviour and attempting to systematise it without allowing sufficient space for inevitable variability and complexity (Ogden, 2016). Instead, at the outset of the research programme, the decision was made to hold in mind and draw flexibly upon a selection of relevant psychological theories throughout the intervention development process (e.g., Y-shaped process model: Gracey et al., 2009; self-discrepancy theory: Higgins, 1987; models of psychological growth: Ryff & Keyes, 1995; models of psychological development: Vygotsky, 1968; learning models: Chi & Wylie, 2014). In this respect, the research falls foul of previous criticisms that theory has been integrated only loosely within complex interventions (Prestwich et al., 2014), but by dint of being relatively unconstrained by theory, the research was able to capture the fundamental variability between stroke survivors and thus the importance of individuation and personalisation within the intervention.

Furthermore, although the research programme was motivated by a firm commitment to integrating stakeholder perspectives in the intervention design (O'Cathain et al., 2019; Skivington et al., 2021), an arguable limitation is that co-operative design decisions remained boundaried. Though it was thought to be optimal for the research team to retain some independent decision-making ability where this was thoroughly and carefully justified (e.g., substantial and internationally recognised expertise in post-stroke psychological screening tool validity leading to independent selection of stroke-specific cognitive screen, mood and anxiety screen, and fatigue measure), some might argue about the validity of labelling this approach as a co-productive one. Indeed, while the approach used in this thesis aligned with the relatively broad definition of co-production provided by Spencer et al. (2013) – "an approach to public services which involves citizens, communities, and the professionals who support them, pooling their expertise to deliver more effective and sustainable outcomes and an improved experience for all involved" (p.7) – it may not align with other definitions that invoke full power sharing and truly equal partnership at each and every stage of intervention design (e.g., Usher, 2023).

Relatedly, stroke survivors were not involved in all research projects, with a key gap being the modified Delphi survey presented in Chapter 3. As the aim of the modified Delphi survey was to develop consensus on structural aspects of the intervention, it was important for participants to have a firm understanding of the stroke care pathway composition and the role of ESD teams within this care pathway. Though this information could arguably have been communicated to stroke survivor participants, the lived experience of healthcare professionals with experience working in these and

closely related teams was seen as critically valuable, so the decision was made to prioritise their input. Though the decision not to include stroke survivors in this stage of the research was carefully considered, their lack of involvement in this key decision-making stage of research is indeed a limitation of the research.

Finally, while the goal of the research was to include a clinically, cognitively, and sociodemographically diverse sample of stroke survivors, the extent to which we captured sociodemographic diversity – including cultural and ethnic diversity – is limited. In part, lack of sociodemographic diversity stemmed from our recruitment approach, as stroke survivors were purposively sampled from a single existing research database that comprised stroke survivors based in Oxfordshire and the surrounding counties. Indeed, the proportion of White-British participants within our stroke survivor samples closely resembles the locality, where 76.8% Oxfordshire residents are White-British according to recent census data (Oxfordshire County Council, 2021). While there were advantages to recruiting from an existing database (e.g., ability to characterise cognitive profiles objectively using pre-collected screening data, ability to build rapport through in person data collection approaches facilitated by geographic proximity), broadening our recruitment approach (e.g., using social media) would have increased diversity of the participant samples. Relatedly, the intervention was designed for fluent English speakers, meaning that stroke survivors who are less proficient in the English language yet reside within the UK may not benefit from the intervention to the same extent. A key aim of future feasibility and evaluation research will be to gauge for whom the intervention works and under what circumstances. Better understanding subgroup differences in intervention feasibility,

acceptability, and effectiveness may facilitate tailoring of the intervention to better meet the needs and preferences of minority groups.

9.6. Conclusion

Findings from four interrelated research projects culminated in the development of a Level 1 psychological care intervention designed to monitor and provide psychoeducation about post-stroke cognitive changes, low mood, anxiety, and fatigue. There is some room for optimism that the intervention will be feasible for use in clinical practice, acceptable to stakeholders, and of clinical benefit to stroke survivors, as development involved rigorous integration of evidence, theory, and stakeholder perspectives. While preliminary data indeed seemed to support the acceptability and feasibility of the intervention with appropriate revisions, empirically investigating whether such views are shared by healthcare professionals is a crucial 'next step' and further research is planned to investigate the extent to which it is feasible to run a full-scale SWCRT to establish definitively the clinical and cost-effectiveness of the intervention. This work will hopefully pave the way for future more widespread implementation of the intervention in the UK stroke care pathway.

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Appendices

Appendix 1 Chapter 3

Appendix 1.1. Example participant feedback from the first round of the modified Delphi survey. Qualitative comments are presented verbatim with typographical errors uncorrected.

Name: [Redacted]

1. Introduction

Thank you for taking part in the first round of our Delphi survey to develop consensus on the structure and content of an improved post-stroke cognitive care pathway.

The first round of the survey presented a number of statements, and you were asked whether you agreed, disagreed, or had no opinion about each statement. Participants in the survey reached consensus on many of these statements, which means that at least 75% of respondents either agreed or disagreed with the statements (excluding those who had no opinion).

However, participants did not reach consensus on **5 statements**. This document provides an overview of results for these statements. Please consider the information in this document carefully before completing the second survey round, which will ask you to reconsider these statements.

2. Summary of results

The statements that did not reach consensus in the first round of the survey are presented below with:

- Your response.
- Percentage of participants who agreed/disagreed.
- Free-text comments from participants (copy and pasted verbatim).

We encourage you to reflect on this information before responding to the second survey round here: [Microsoft Forms hyperlink]

Statement 1

For stroke survivors with **no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **3-months** after discharge.

Your response: No response

Group response: 72% agree; 28% disagree

Comments:

- I think a brief review a few weeks after discharge would help pick up those who are having cognitive changes which were missed.
- I think cognitive review at three to six months is really important.
- In line with my other comments. This review should start with detailed questioning, as we know many people only begin to be aware of cognitive changes once they are starting to resume more cognitively demanding aspects of their daily life back at home. Testing should then follow if any changes are reported but I feel all stroke survivors need the opportunity to be reviewed regularly during their recovery so that things can be readily picked up and support offered if needed.
- Important to assess after discharge to see if change of environment means any higher level difficulties have come to light. If no difficulties highlighted then, could check at 6 months when doing 6-month review. Probably unnecessary at 3 months or a year if no difficulties identified.
- Unless a specific need is identified eg through functional assessment or to support return to driving, vocational rehab.
- No clinical basis for repeating screen for pts with no cognitive deficits
- It really depends on an individual basis as I said above - if risk factors for cognitive impairment, age , location of stroke, symptoms reported…
- Ideally a service would be available for patients or their relatives with concerns about cognitive decline prior to the 6 month review. Especially for those working and high functioning at baseline.
- Only if concerns raised with resumption of life and maybe for certain individuals following review of stroke aetiology...e.g would you expect cog impairments with type of stroke...how reliable would this be also?
- I think it could be helpful to assess this slightly later when they have had a chance to return to more complex tasks which might highlight higher level impairments.
- difficulties emerge with return to normality - some aspects were reported by patients to only emerge a year on, when they return to work (e.g., difficulties processing numerical information)
- Again, I think this should probably happen at an early stage to put the right management in place for that individual, ideally as they are starting to get back to their normal activities when they might realise something is different about memory and thinking skills.

Statement 2

For stroke survivors with **no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **1-year** after discharge.

Your response: No response

Group response: 55% agree; 45% disagree

Comments:

- See comments in response to Statement 1 (above).

Statement 3

Individual stroke survivors should **choose** whether they would prefer cognitive reviews to take place either **in person or remotely** (i.e., telephone or videoconferencing).

Your response: Agree

Group response: 72% agree; 28% disagree

Comments:

- Do agree with this as may be difficult to get to review, however would suggest video call rather than telephone call
- Choice is important.
- They also need to have it explained that were they to wish to have testing completed remotely that it would limit what tests can be completed and so may not be as meaningful so that they can make an informed decision.
- Great to give patients choice! But I think you can get a better sense of difficulties in person. Might end up with duplication of effort if done online/ by phone and the person is struggling or you have a sense that there are difficulties - increases the possibility you might miss something.
- i think the default should be inperson
- Contrary to the above, if the person has no option to have a cognitive review in person then a remote one is better than none at all.
- Difficult to reliably conduct screens remotely
- Yes, where someone has the ability (or suitable support) to enable them to get the most from the appointment
- Agree with giving them the possibility to choose as above, acknowledging the limitations
- Initial screening should be remote to avoid over burdening clinical services
- For those who are more familiar with technology and where deficits are more higher level, executive functioning then the patient may be happy with virtual.
- As stated above face to face or remote reviewing depends on the patients circumstances and their preference should be taken into account
- Its easier to pick up cognitive impairment face to face, things would be missed over virtual calls
- as long as their given accessible information about what it would entail and the pros/cons of each
- If someone lacks insight into their cognitive challenges this may pose as a difficulty.

Statement 4

Cognitive reviews should include a **dementia screen** (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA).

Your response: Disagree

Group response: 57% agree; 43% disagree

Comments:

- Often these are not appropriate due to changes to language or attentional neglect
- Unless there is a preexisting history having a test set up as a dementia screen could be misinterpreted by the teams (given that we know stroke survivors will fail due to new acquired cognitive impairments) and could lead to inappropriate management (e.g. referral on to memory clinic inappropriately).
- Ummed and ahhed about this one. It would be important to identify if someone was at risk for dementia as its not uncommon post-stroke. What would you do with the info - refer to GP? I suspect this would just pick up someone with post-stroke cognitive difficulties, rather than dementia. And despite its disadvantages, I wouldn't see the MoCA as just a dementia screen, with careful interpretation it can give you much more information about which aspects of cognition the patient is struggling with.
- This is universally understood across disciplines, dementia more common than we think in stroke survivors (1 in 5)
- I think it would depend on the circumstances of the person as to whether this would be appropriate. If it is their first stroke and they were functioning well before then I would think no. If they have had several strokes and/or they were experiencing some cognitive difficulties prior to the stroke then perhaps this would be appropriate.
- I wouldn't normally do this unless there was concerns around dementia in which case I would normally request referral to the memory hub. Given the high association of stroke patients going on to develop a dementia though this may be useful.
- Assessment should be sensitive to abi changes and include ax for cognitive communication disorder
- Often used in hospital so good to repeat
- I don't think a dementia screen should be used as a blanket tool. Again the assessment tool used should be based on the individuals presentation.
- Good screening tool, and more sensitive to executive dysfunction than MMSE ; in highly educated individuals be aware of recency effect
- We see a large population of stroke patients with no formal dementia diagnosis but whose families reveal a significant cognitive decline in the months/ years prior to admission which suggests a very likely underlying dementia.
- Is not uncommon that a stroke triggers a cognitive deficit more globalise than expected for a stroke. Some patients were probably having cog deficits pre morbidly and the stroke takes away the cognitive reserve that allowed them to compensate.
- In my daily practice I use dementia screens for this type of patients as it captures better than a stroke specific cog assessment the cog profile of the patient
- if warranted then yes
- Not sure what is meant with dementia screen (via MoCA for instance) here?
- For most stroke survivors the MoCA will identify cognitive issues in at least some domains.
- The score will possibly be in the impaired range, but the interpretation of this is of course very different than if the same score was obtained from a community-dwelling individual.

- I don't think the cognitive review should routinely be aimed at screening for dementia. This will require a separate assessment/referral, and only when relevant for the survivor/family
- Depends on the patient age co morbidity etc. And clinical reasoning
- Dementia screen will not pick up a lot of stroke specific impairments.
- Any pre existing cognitive decline should have been highlighted from social/ family history of the persons memory and thinking therefore this would be taken into account when stroke specific assessment is completed.
- I think we should stay well away from this and stick to trying to understand the person's stroke-specific deficits.
- A decision to assess for possible dementia should be determined in the first instance by establishing the trajectory of symptoms over time in the clinical context.
- Even when there is a high degree of suspicion for dementia in the weeks or months after a stroke, commonly used dementia screens may have limited utility due to neglect, dysphasia, problems with motor control etc. The exception to this might be when there is already a baseline cognitive screen on file to compare against.

Statement 5

Cognitive reviews should include a **neuropsychological assessment battery** (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS).

Your response: Agree

Group response: 63% agree; 37% disagree

Comments:

- No experience in this therefore cannot comment
- a cognitive review could be shorter screen such as the OCS, with a full RBANS if the clinician then decides it is required.
- I don't feel I have the expertise to comment
- This would be my typical practice for anyone seen by neuropsychology who reports any cognitive changes.
- Depends if its appropriate for the patient! If someone is struggling with a simpler assessment, it wouldn't be appropriate to give them something more detailed and therefore challenging as you don't want to cause distress. But you'd want something sensitive enough to identify higher level difficulties for someone who sailed through the simpler screening tools. So you'd probably want a stepped model - start with basic screens and move up if they pass.
- Also important for the assessment battery used to have been validated for use with stroke survivors.
- Not sure this is needed for all and starts to have major resource implications, a two step approach with initial brief testing that triages those who need more detailed assessment
- But only if cognitive problems have been identified, on other rounds of screening.
- I think a little later down the line post-injury this could be more appropriate, or if the person is in a situation whereby they may only be experiencing very subtle cognitive difficulties post-stroke and they are planning to return to work very soon and want the assessment to inform reasonable adjustments etc.
- I'm not familiar with what this would add to the assessment so unable to comment
- Depends on whether the initial screens detect any problems
- only if clinically indicated from presentation that this might be beneficial (see answer above)
- If difficulties self reported; or difficulties evident on cognitive screen. For pts returning to cognitively demanding activities incl work and driving
- Where indicated this can be included.
- Not familiar but perhaps indiscriminately very long tests will not add much and patients will have difficulty engaging especially if remotely
- I think it is important to move to specific assessment and not stay at a screening level.
- Not practical for every one
- In an ideal world then maybe. But the time and lack of neuropsychology means maybe it should be reserved for those where there are concerns.
- Not used this test
- particularly if we're talking about post-discharge reviews. I think assessment batteries should only be done by professionals who are in need of a detailed / nuanced picture of impairment in order to inform treatment. If reviews are ever to be implementable on a large scale, they would likely be done by 'on the ground' staff who wouldn't need to conduct a battery like this

- That's a different appointment - only if cognitive difficulties are identified on review AND if the survivor finds they limit their day to day life and are keen to explore this in more detail
- I do not think these should be completed routinely. However, I think these can be helpful for some patients where we want to get a deeper understanding of cognition (e.g. younger patients hoping to return to work).
- this should be done at least once- i.e., weeks after release, and spending on outcomes, should be considered to be performed again.
- The vast majority of the people we work with need neuropsychological input post stroke. We use a variety of measures and discussion with the person to decide if this follow-up is needed. A single 'battery' would be helpful, though the main issue for us is having a very small neuropsychological resources available (ie long waiting times for neuropsych support)
- It can be indicated, but not in all cases
- I think this is possibly a 'step 2' of the cognitive review or pathway and would not be offered routinely because there will be many cases where 'step 1' yields sufficient information to address the person's needs and only when this is not the case, or the presentation is complex or atypical, might you progress to the next step and involve the team psychologist.
- There is not enough time or funding to do this in all

Supplementary Information

Please read the below information at your leisure. It provides a summary of results for statements that reached consensus in the first round of the survey.

We would like to thank all participants who took part in the first round of the survey for contributing to these valuable results.

We would in particular like to thank participants who provided detailed and insightful comments in response to the statements. These comments have provided us with a nuanced understanding of potentially important factors to consider when designing the improved cognitive care pathway.

1. Stroke survivors **with a cognitive impairment** detected during acute hospital admission should have a **review** of their cognition **after discharge** from an acute inpatient setting.
   Consensus: **Agree** (100%)

2. Stroke survivors **with no cognitive impairment** detected during acute hospital admission should have a **review** of their cognition **after discharge** from an acute inpatient setting.
   Consensus: **Agree** (88%)

3. For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place in the first few weeks after discharge.
   Consensus: **Agree** (86%)

4. For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place 3-months after discharge.
   Consensus: **Agree** (93%)

5. For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place 6-months after discharge.
   Consensus: **Agree** (95%)

6. For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place 1-year after discharge.
   Consensus: **Agree** (95%)

7. For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place in the first few weeks after discharge.
   Consensus: **Agree** (82%)

8. For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place 6-months after discharge.
   Consensus: **Agree** (80%)

9. Cognitive reviews should take place **in person**.
   Consensus: **Agree** (87%)

10. Cognitive reviews should include a **stroke-specific cognitive screen** (15-20 minutes) (e.g., Oxford Cognitive Screen; OCS).
    Consensus: **Agree** (97%)

11. Cognitive reviews should include a **questionnaire** for the **stroke survivor** about their post-stroke cognition.
    Consensus: **Agree** (97%)

12. Cognitive reviews should include a **questionnaire** for a **family member** about the stroke survivor's cognition.
    Consensus: **Agree** (97%)

13. Cognitive reviews should include a **depression screen** (e.g., Patient Health Questionnaire-9; PHQ-9).
    Consensus: **Agree** (94%)

14. Cognitive reviews should include an **anxiety screen** (e.g., Generalised Anxiety Disorder Assessment-7; GAD-7)
    Consensus: **Agree** (90%)

15. Cognitive reviews should include a **general discussion** with the stroke survivor about their **overall cognitive functioning.**
    Consensus: **Agree** (100%)

16. Cognitive reviews should include a **general discussion** with the stroke survivor about their **domain-specific cognitive functioning.**
    Consensus: **Agree** (96%)

17. Stroke survivors should be told the **results of the cognitive assessment** conducted during the review.
    Consensus: **Agree** (94%)

18. Stroke survivors should be told how their **cognitive assessment result compares to earlier cognitive assessment results** (e.g., in cognitive screen completed in acute inpatient setting).
    Consensus: **Agree** (90%)

19. Stroke survivors should be told about **potential cognitive trajectories** during the review.
    Consensus: **Agree** (79%)

20. Stroke survivors should be told about the potential **impact** of any cognitive impairments on **activities of daily living** during the review.
    Consensus: **Agree** (100%)

21. Stroke survivors should be **signposted** to available **support and services** during the review.
    Consensus: **Agree** (100%)

22. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **formal training** (e.g., training videos) on **administering the cognitive assessment**.
    Consensus: **Agree** (100%)

23. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **informal training** (e.g., training from colleague) on **administering the cognitive assessment**.
    Consensus: **Agree** (79%)

24. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **formal training** (e.g., training videos) on **discussing cognition** with stroke survivors and family members.
    Consensus: **Agree** (97%)

25. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **informal training** (e.g., training from colleague) on **discussing cognition** with stroke survivors and family members.
    Consensus: **Agree** (87%)

Appendix 1.2. Survey items presented in each round of the of the modified Delphi survey.

Round One

*The cognitive care pathway will include **at least one post-stroke review of cognition** conducted by **Early Supported Discharge** stroke services in the UK.*

*We want to **establish consensus** on **who** should be offered these reviews, **when** reviews should take place, **where** they should be conducted, **what** they should include, and what **training** should be offered to healthcare professionals conducting the reviews.*

*Please respond to the **demographic** questions. Then, please read each statement and indicate whether you **agree** or **disagree** and provide any **further comments** you have about the statements.*

1. What is your **gender**?
☐Male
☐Female
☐Nonbinary
☐Prefer not to say

2. What is your current **age**?
☐18-24 years
☐25-34 years
☐35-44 years
☐45-54 years
☐55-64 years
☐65 years and over
☐Prefer not to say

3. What is your **professional occupation**? You may select any that apply.
☐Occupational Therapist
☐Clinical Psychologist
☐Clinical Neuropsychologist
☐Trainee Clinical Psychologist
☐Speech and Language Therapist

☐Stroke Specialist Nurse
☐Physiotherapist
☐Physician (e.g., Neurologist, Stroke Doctor, GP)
☐Professor or Associate Professor
☐Senior Lecturer or Lecturer
☐Clinical Research Fellow
☐Postdoctoral Researcher
☐Doctoral Student
☐Other _____
☐Prefer not to say

4. In which **region** of the **United Kingdom** are you based **professionally**?
☐North East England
☐North West England
☐Yorkshire and the Humber
☐East Midlands
☐West Midlands
☐East of England
☐London
☐South East England
☐South West England
☐Wales
☐Scotland
☐Northern Ireland
☐Prefer not to say

5. How many **years of experience** do you have working clinically with and/or researching **stroke**?
☐0-5 years
☐6-10 years
☐>10 years
☐Prefer not to say

6. Please select the **option** that best describes your **professional role** and **responsibilities**.
☐I **oversee** and/or **conduct** cognitive screening after stroke in clinical practice.
☐I have **professional expertise** in cognition after stroke but I am not responsible for overseeing and/or conducting cognitive screening after stroke in clinical practice.
☐Prefer not to say

7. Stroke survivors **with a cognitive impairment** detected during acute hospital admission should have a **review** of their cognition **after discharge** from an acute inpatient setting.
☐Agree
☐Disagree
☐No opinion

8. Please enter any **further comments** about the above statement.
_____

9. Stroke survivors **with no cognitive impairment** detected during acute hospital admission should have a **review** of their cognition **after discharge** from an acute inpatient setting.
☐Agree
☐Disagree
☐No opinion

10. Please enter any **further comments** about the above statement.
_____

11. For stroke survivors **with a cognitive impairment** detected during acute hospital admission, a review of their cognition should take place:

a. In the **first few weeks** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

b. **3-months** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

c. **6-months** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

d. 1**-year** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

12. Please enter any **further comments** about the above statements.

_____

13. For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place:

a. In the **first few weeks** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

b. **3-months** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

c. **6-months** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

d. 1**-year** after discharge.
   ☐Agree
   ☐Disagree
   ☐No opinion

14. Please enter any **further comments** about the above statements.

_____

15. Cognitive reviews should take place **in person**.
☐Agree
☐Disagree
☐No opinion

16. Please enter any **further comments** about the above statement.

_____

17. Individual stroke survivors should **choose** whether they would prefer cognitive reviews to take place either **in person or remotely** (i.e., telephone or videoconferencing).
☐Agree

☐Disagree
☐No opinion

18. Please enter any **further comments** about the above statement.
_____

19. Cognitive reviews should include a **dementia screen** (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA).
☐Agree
☐Disagree
☐No opinion

20. Please enter any **further comments** about the above statement.
_____

21. Cognitive reviews should include a **stroke-specific cognitive screen** (15-20 minutes) (e.g., Oxford Cognitive Screen; OCS).
☐Agree
☐Disagree
☐No opinion

22. Please enter any **further comments** about the above statement.
_____

23. Cognitive reviews should include a **neuropsychological assessment battery** (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS).
☐Agree
☐Disagree
☐No opinion

24. Please enter any **further comments** about the above statement.
_____

25. Cognitive reviews should include a **questionnaire** for the **stroke survivor** about their post-stroke cognition.
☐Agree
☐Disagree
☐No opinion

26. Please enter any **further comments** about the above statement.
_____

27. Cognitive reviews should include a **questionnaire** for a **family member** about the stroke survivor's cognition.
☐Agree
☐Disagree
☐No opinion

28. Please enter any **further comments** about the above statement.
_____

29. Cognitive reviews should include a **depression screen** (e.g., Patient Health Questionnaire-9; PHQ-9).
☐Agree
☐Disagree
☐No opinion

30. Please enter any **further comments** about the above statement.
_____

31. Cognitive reviews should include an **anxiety screen** (e.g., Generalised Anxiety Disorder Assessment-7; GAD-7).
☐Agree
☐Disagree
☐No opinion

32. Please enter any **further comments** about the above statement.
_____

33. Cognitive reviews should include a **general discussion** with the stroke survivor about their **overall cognitive functioning.**
☐Agree
☐Disagree
☐No opinion

34. Please enter any **further comments** about the above statement.
_____

35. Cognitive reviews should include a **general discussion** with the stroke survivor about their **domain-specific cognitive functioning.**
☐Agree
☐Disagree
☐No opinion

36. Please enter any **further comments** about the above statement.

_____

37. Stroke survivors should be told the **results of the cognitive assessment** conducted during the review.

☐Agree
☐Disagree
☐No opinion

38. Please enter any **further comments** about the above statement.

_____

39. Stroke survivors should be told how their **cognitive assessment result compares to earlier cognitive assessment results** (e.g., in cognitive screen completed in acute inpatient setting).

☐Agree
☐Disagree
☐No opinion

40. Please enter any **further comments** about the above statement.

_____

41. Stroke survivors should be told about **potential cognitive trajectories** during the review.

☐Agree
☐Disagree
☐No opinion

42. Please enter any **further comments** about the above statement.

_____

43. Stroke survivors should be told about the potential **impact** of any cognitive impairments on **activities of daily living** during the review.

☐Agree
☐Disagree
☐No opinion

44. Please enter any **further comments** about the above statement.

_____

45. Stroke survivors should be **signposted** to available **support and services** during the review.
☐Agree
☐Disagree
☐No opinion

46. Please enter any **further comments** about the above statement.
_____

47. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **formal training** (e.g., training videos) on **administering the cognitive assessment**.
☐Agree
☐Disagree
☐No opinion

48. Please enter any **further comments** about the above statement.
_____

49. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **informal training** (e.g., training from colleague) on **administering the cognitive assessment**.
☐Agree
☐Disagree
☐No opinion

50. Please enter any **further comments** about the above statement.
_____

51. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **formal training** (e.g., training videos) on **discussing cognition** with stroke survivors and family members.
☐Agree
☐Disagree
☐No opinion

52. Please enter any **further comments** about the above statement.
_____

53. Healthcare professionals responsible for conducting cognitive reviews after stroke should receive **informal training** (e.g., training from colleague) on **discussing cognition** with stroke survivors and family members.

☐Agree
☐Disagree
☐No opinion

54. Please enter any **further comments** about the above statement.

_____

55. Please provide **any further thoughts** about follow-up reviews of cognition after stroke.

_____

Round Two

*The cognitive care pathway will include **at least one post-stroke review of cognition** conducted by **Early Supported Discharge** stroke services in the UK.*

*We want to **establish consensus** on **who** should be offered these reviews, **when** reviews should take place, **where** they should be conducted, **what** they should include, and what **training** should be offered to healthcare professionals conducting the reviews.*

*Please read the **personalised feedback sheet** that has been emailed to you and reflect on the information provided before responding to this survey round.*

*Then, please read each statement below and indicate whether you **agree** or **disagree** and provide any **further comments** you have about the statements.*

1. For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **3-months after discharge**.
☐Agree
☐Disagree
☐No opinion

2. Please enter any **further comments** about the above statement.

_____

3. For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **1-year after discharge**.
☐Agree
☐Disagree

☐No opinion

4. Please enter any **further comments** about the above statement.

_____

5. Individual stroke survivors should **choose** whether they would prefer cognitive reviews to take place either **in person or remotely** (i.e., telephone or videoconferencing).
☐Agree
☐Disagree
☐No opinion

6. Please enter any **further comments** about the above statement.

_____

7. Cognitive reviews should include a **dementia screen** (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA).
☐Agree
☐Disagree
☐No opinion

8. Please enter any **further comments** about the above statement.

_____

9. Cognitive reviews should include a **neuropsychological assessment battery** (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS).
☐Agree
☐Disagree
☐No opinion

10. Please enter any **further comments** about the above statement.

_____

11. Cognitive reviews should include a **fatigue measure** (e.g. Fatigue Severity Scale; FSS).
☐Agree
☐Disagree
☐No opinion

12. Please enter any **further comments** about the above statement.

_____

13. **Online training** (e.g., training videos) should be offered to healthcare professionals administering cognitive reviews.
☐Agree
☐Disagree
☐No opinion

14. Please enter any **further comments** about the above statement.
_____

15. **In person training** (e.g., training course) should be offered to healthcare professionals administering cognitive reviews.
☐Agree
☐Disagree
☐No opinion

16. Please enter any **further comments** about the above statement.
_____

17. Please provide any **further thoughts** about follow-up reviews of cognition after stroke.
_____

Round Three

*The cognitive care pathway will include **at least one post-stroke review of cognition** conducted by **Early Supported Discharge** stroke services in the UK.*

*We want to **establish consensus** on **who** should be offered these reviews, **when** reviews should take place, **where** they should be conducted, **what** they should include, and what **training** should be offered to healthcare professionals conducting the reviews.*

*Please read the **personalised feedback sheet** that has been emailed to you and reflect on the information provided before responding to this survey round.*

*Then, please read each statement below and indicate whether you **agree** or **disagree** and provide any **further comments** you have about the statements.*

1. For stroke survivors **with no cognitive impairment** detected during acute hospital admission, a review of their cognition should take place **1-year after discharge**.
☐Agree
☐Disagree
☐No opinion

2. Please enter any **further comments** about the above statement.
_____

3. Individual stroke survivors should **choose** whether they would prefer cognitive reviews to take place either **in person or remotely** (i.e., telephone or videoconferencing).
☐Agree
☐Disagree
☐No opinion

4. Please enter any **further comments** about the above statement.
_____

5. Cognitive reviews should include a **dementia screen** (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA).
☐Agree
☐Disagree
☐No opinion

6. Please enter any **further comments** about the above statement.
_____

7. Cognitive reviews should include a **neuropsychological assessment battery** (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS).
☐Agree
☐Disagree
☐No opinion

8. Please enter any **further comments** about the above statement.
_____

9. Please provide **any further thoughts** about follow-up reviews of cognition after stroke.
_____

Appendix 1.3. Full description of themes developed from template analysis of free-text responses to items in the third and final modified Delphi survey round. Note quotes are copied verbatim from participant responses with typographical errors uncorrected.

Statement 1: For stroke survivors with no cognitive impairment detected during acute hospital admission, a review of their cognition should take place 1-year after discharge.

Too late to be useful.

A common concern among participants was that conducting a cognitive review one-year after stroke would be too late to have a meaningful impact and that it would be more beneficial for patients to receive a review at an earlier timepoint. One participant highlighted the importance of conducting a review earlier so that appropriate support can be provided, with another participant arguing that *"a lot of harm can happen in somebody's life in 12 months with unrecognised cognitive problems"* (Clinical Psychologist & Clinical Neuropsychologist).

> *I feel this should be earlier within the 3-6 month mark to ensure difficulties are picked up earlier and support can be provided as needed. (Occupational Therapist)*

> *Should be earlier, as by a year post someone may have lost a job or relationships due to lack of support for cognitive changes by that point. (Speech and Language Therapist)*

Concerns about feasibility.

Another concern was that it would not be clinically feasible to conduct follow-up reviews at one-year for all stroke survivors without cognitive impairment detected during acute hospital admission. Lack of clinical resources – including staff and time – was cited as a key challenge in implementing such reviews and one participant highlighted the *"opportunity costs"* (Physician) associated with conducting these reviews. Similarly, one participant argued that, if and when clinical resources are limited, cognitive rehabilitation should take priority over late-stage reviews for those without cognitive impairment detected acutely (Occupational Therapist).

> *Screening at one year in an ideal world, but do we enough about the economic and opportunity costs associated. If someone has absolutely no cognitive issues during acute admission (unusual) and develops no new symptoms, the yield from the one year screening is likely to be low. (Physician)*

> *Given the evidence of the high prevalence of dementia post stroke, I think this would be a good opportunity to follow up on this. However, the resources needed would make it impossible and I do feel resources could be better allocated on those who really need the cognitive rehabilitation. (Occupational Therapist)*

It depends on earlier cognitive reviews.

The survey instructions explained that "The cognitive care pathway will include at least one review of cognition a by Early Supported Discharge stroke specialist services."

Some participants argued that, if the care pathway included only one review, a review at one-year would be *"better than nothing"* (Lecturer).

> *This would be too late. If only one screen is being conducted in ESD this would need to be earlier to support assessment, intervention, education and therefore return to desired ADLS. (Occupational Therapist)*

Several participants implied that the value of a cognitive review at one-year depended on cognitive status at earlier follow-up reviews at three- and/or six-months after stroke. Specifically, these participants felt that a one-year follow-up review would not be needed, so long as no cognitive impairment was detected during these earlier reviews.

> *I think if no cognitive deficits are indicated at 3 months there is no need to review again. (Occupational Therapist)*

> *Providing the patient has had rehab and there has not been any evidence of cognitive deficits and neither the patient nor the family has raised any concerns, I do not think a cognitive assessment should be done. (Occupational Therapist)*

Statement 2: Individual stroke survivors should choose whether they would prefer cognitive reviews to take place either in person or remotely (i.e., telephone or videoconferencing).

Downsides of remote assessments.

Several participants highlighted the potential downsides of conducting cognitive reviews remotely, rather than in person. A frequently cited concern was that important behavioural and/or clinical information would be missed by conducting cognitive assessments remotely. Some participants worried that this could lead to either inaccurate or less informative conclusions being drawn about stroke survivors' cognitive abilities.

> *This remains a difficult question to answer as there is so much contextual information that we don't know. Interviewing someone about their cognitive abilities is certainly fine to be done by phone but I would want to see the person in order to complete any cognitive testing in order to get as much information as possible from the assessment and I think valuable clinical information is more likely to get missed remotely. (Clinical Psychologist)*

Another participant argued that building rapport is easier in person and that rapport is essential to support stroke survivors in performing optimally during any cognitive assessments.

> *I still think this needs to be according to clinical need rather than patient preference - sorry! Building rapport is so much easier in person (assuming they'd not previously met the assessor) and this is important for the person to do their best during the assessment. I think it's probably also more likely that higher level difficulties would be picked up if seen in person. Not saying that*

remote options don't have a place, I just don't think patient preference is the right way to decide. (Doctoral Student)

One participant expressed additional concern that, although services may start out by giving stroke survivors the choice to conduct assessments in person or remotely, the remote option may become the default, despite the downsides of this approach compared to in person testing.

All for promoting person centred care and stroke survivors should have remote as an option. However, I fear that services may lead to remote becoming the default; and remote is not as good as in-person (Physician)

Importance of choice and person-centredness.

Nevertheless, some participants cited the concept of person-centred care as a reason why options should be given to conduct cognitive assessments either remotely or in person. Some participants highlighted the importance of tailoring care to individual needs, whilst acknowledging the downsides of remote testing.

Any intervention has to be patient centred (Physician & Professor)

choice is important and that remote is better than nothing, but there is a risk that potentially things will be missed in remote assessments. (Occupational Therapist)

Alongside person-centredness, the concept of informed decision-making was felt to be important. Participants suggested that healthcare professionals should offer stroke survivors the choice to receive either an in person or remote cognitive review, after clearly explaining the advantages and disadvantages of each option. In this way, it was felt that care would be person-centred but that stroke survivors would be fully informed about the costs and benefits of different approaches.

> *It should be an informed choice - e.g. patients should be presented with pros and cons. (Clinical Psychologist & Lecturer)*

> *I do think choice and accessibility is important therefore both videoconferencing and face to face should be offered. Not telephone consult. However the pros and cons of each should be clearly explained to the patient to enable them making an informed choice. My personal preference would be face to face but remote is better than a DNA. (Occupational Therapist)*

Several participants argued that providing choice and a person-centred approach to cognitive reviews was important to improve access to these reviews. In particular, participants felt that a remote option would improve access for stroke survivors with work and/or caring responsibilities and those living in remote areas with little access to transport.

> *I am keen to ensure that access to this review is as universal as possible. For young, working age patients, or for patients living in remote areas with no*

access to transport, remote assessment may be the best, or indeed the only option. So, although the default option should be face to face, I strongly feel there should be other options for remote assessment (videoconference better than telephone) (Clinical Psychologist & Lecturer)

Stroke survivors need to be provided with options for follow-up to increase the likelihood of them engaging with this. This also avoids discriminating against those that can't get time off work or caring responsibilities. (Occupational Therapist & Doctoral Student)

Statement 3: Cognitive reviews should include a dementia screen (10-15 minutes) (e.g., Montreal Cognitive Assessment; MoCA).

Risk of misinterpretation in stroke populations.

Participants who disagreed with the statement that cognitive reviews should include a dementia screen expressed concern that performance on these screens could be confounded by certain post-stroke impairments, such as neglect and aphasia.

Standard dementia screens can potentially be misleading because of all the confounds in a stroke population i.e. neglect, dysphasia, motor problems. Whatever training you put in place, there will still be some people who take the standard cut-off (e.g. 88/100 on ACE-III) and say, 'the score is below the cut-off and this suggests the person has dementia' (Clinical Psychologist & Clinical Neuropsychologist)

For this reason, some participants explicitly stated that a stroke-specific screen would be better.

> *I don't feel it that a dementia screen is necessarily a routinely helpful element to include in the review and the results could be used inappropriately if new post-stroke changes are misinterpreted. Inclusion of a stroke-specific screen, such as the OCS, would be better. (Clinical Psychologist)*

Situation- and person-specific approach.

Some participants agreed that a dementia screen should not be administered by default, due to the potential risk of misinterpretation, but that it could be used as an adjunct in cases where dementia was suspected to be contributing to post-stroke cognitive functioning.

> *I feel that if the specialist clinician feels that dementia could be playing a role then this could be explored further, but not as default due to risk of misinterpretation etc. by others. (Clinical Psychologist)*

In line with this, some participants argued that healthcare professionals should consider the precise profile and/or longitudinal course of the person's cognitive impairment to determine whether a dementia-type syndrome could explain it. They argued that, if the profile/course of symptoms suggested a dementia-type syndrome, administering a dementia screen could be beneficial.

I changed my response to Disagree with a lot of reservation. I think the question is not definitive. A dementia screen would be very useful in certain situations: evidence of longitudinal cognitive decline either before stroke or months/years after the stroke; or a cognitive profile that doesn't match the stroke eg dense amnestic picture with a posterior stroke. Stroke and neurodegenerative disorders often co-exist particularly in the older patients. [...] So Dementia screen is important in some patients but not routinely in ALL patients. (Physician & Lecturer)

One participant also suggested that healthcare professionals should consider key risk factors for dementia, implying that a dementia screen may be useful in cases where stroke survivors are at high risk for dementia.

This depends on other factors e.g. age, risk factors for dementia etc. (Clinical Neuropsychologist)

Making an accurate differential diagnosis between stroke-specific cognitive impairment and a dementia-type syndrome was felt to be important so that stroke survivors could be provided with appropriate rehabilitation, education, and potentially also medication, given encouraging results from recent trials of pharmacological treatments for dementia.

If a patient has had a stroke specific cog assessment and his/her cog profile is well establish, a dementia screen could be redundant. However, for a patient with suspected or establish global cog deficits who may have had previos dementia screen, a dementia assessment a few months down the line could show a cognitive trajectory that could be useful for her/his rehab plan and family education. (Occupational Therapist)

It is becoming increasingly important to diagnose conditions such as Alzheimer's with the new drugs that are likely to change practice in the future. So acurate pathological diagnosis of the cognitive difficulties in these patients is going to become even more important. (Physician & Lecturer)

Statement 4: Cognitive reviews should include a neuropsychological assessment battery (>30 minutes) (e.g., Repeatable Battery for the Assessment of Neuropsychological Status; RBANS).

Concerns about feasibility.

A key concern among participants who disagreed with this statement was lack of clinical resources to administer neuropsychological assessments during cognitive reviews. Participants highlighted lack of both time and trained staff as key reasons why it may not be feasible to administer neuropsychological assessments during cognitive reviews.

I don't think there will ever be enough people in stroke services to administer something that requires a more sophisticated understanding of psychometric assessment to make this workable - a 'review' will end up being too long and unwieldy. (Clinical Psychologist & Clinical Neuropsychologist)

I fear this would make it too long and we do not have sufficiently trained neuropsychological staff to provide it. (Occupational Therapist)

Given the potentially big numbers of people needing assessed, offering a neuropsych battery like this to all would need major investment - investment that is unlikely. (Physician)

One participant suggested that, rather than conducting a neuropsychological assessment, information from other sources could be used to support a formulation.

I would rather we do a small amount of testing and put just as much (or more) emphasis on other sources of information to support a formulation e.g. clinical interview, collateral information, functional assessment. (Clinical Psychologist & Clinical Neuropsychologist)

Importance of onwards referral.

Some participants acknowledged the limited clinical resources available for neuropsychological assessment, but suggested a stepped approach should be offered, whereby neuropsychological assessments are offered to stroke survivors as

and when there is a clinically indicated need (e.g., according to results on a shorter screen, clinical observations, and/or self-reported problems).

> *I don't think so as a standard procedure, rather a shorter screen such as the OCS should be used in the first instance. A Neuropsychological battery could be an additional step if the need is indicated by other tests or functional observations/client or relative reported problems. (Occupational Therapist)*

> *A two tiered approach with initial screening/triage to select those needing more detailed assessment seems a better use of resource. (Physician)*

> *I've said agree but only if clinically indicated. Not for everyone on the first appointment, it should be used if an initial screen or report indicates difficulties. It depends if you mean it should 'always include a neuropsychological assessment battery' - in which case, no but that's not to say they shouldn't ever be used. (Lecturer)*

Some participants agreed that neuropsychological assessments should be administered on a needs-led basis, but that the decision should consider personal circumstances, as well as cognitive concerns and/or performance. Whether the stroke survivor would be returning to work or education was felt to be a particularly important consideration for one participant.

This needs to be need-led. If cognitive difficulties are being reported, or a stroke survivor is trying to return to work/college then the information from this testing can be invaluable. In other cases however it may not be needed. It should certainly be something that is available and easily accessible within the service. (Clinical Psychologist)

ONLY if below cut off for cognitive screen OR patient reports difficulties and is returning to cognitively demanding tasks. (Occupational Therapist)

Appendix 2 Chapter 4

Appendix 4.1. Iteratively revised topic guide used in semi-structured interviews with stroke survivors and their family members.

Introduction

Thank you for agreeing to participate in this interview. The purpose of the interview is to find out about your experiences since your stroke. Specifically, I'm interested in any changes in your thinking skills – like your memory, language, and attention – that you may have noticed and what you thought about the care you received for your thinking skills. I'm also interested in your views about how we can improve the way we care for and talk about these changes after stroke.

I am going to ask you some questions about this topic but there are no right or wrong answers. I am simply interested in your own experiences, thoughts, and opinions. The interview should take no more than one hour. You may choose not to answer any of my questions or stop the interview at any time for any reason.

I would like to audio record the interview, if you're happy with that. This is so I can go over your responses and analyse them in detail. The recording will only be shared with research team members, and we will make sure that any information included in our final report does not identify you personally. Is that okay?

Do you have any questions about what I've just explained? May I turn on the digital recorder?

1. I'd like to start by asking whether you've noticed any changes in your thinking skills.

- Probe to explore cognitive domains.
- When did you first notice them? To what extent do they affect you in daily life?

2. I wonder if you remember completing any tests to look at your thinking skills when you were in hospital after your stroke?

- Prompt if no: The tests might have involved looking at pictures, reading some words, writing some numbers, connecting some shapes, remembering some words, and so on?

3. How did you find the test?

- Probe: What did you think was the purpose of the test? How was it explained to you?
- Probe: How did you find completing the test?

4. What happened next when you finished the test?

- Prompt: What were you told about how you did in the test? How did this make you feel?
- Prompt: What were you told about how to manage any changes in your thinking skills identified in the test? How did you find this conversation?

6. What would you have changed about the testing process?

- Probe: What would you like to have happened before/during/after the test in an ideal world?

7. Can you tell me what you know about how thinking skills may change over time after stroke?

- If limited knowledge demonstrated: We know from research that thinking skills change in the months after stroke. In some cases, thinking skills get better, although they may not go back to exactly where they were before the stroke. However, sometimes they don't recover and sometimes they may even get worse. Sadly, people who have a stroke are more likely to develop dementia.

8. What did people tell you about how your thinking skills might change over time after your stroke?

- Prompt: How much of the earlier information I mentioned did they tell you?

9. What would you have liked people to tell you about how your thinking skills might change over time after your stroke?

- Prompt: Would any of the information I mentioned earlier have been useful?

10. How would you have felt if someone had told you the earlier information I mentioned?

- Probe: Different parts of the information (i.e., recovery, stability, decline, dementia).
- Clarify reasons.
- Probe: How would you have felt had you been given this information at different times after your stroke?
- Probe: How do you think other people would feel?
- If indication that information is desirable: How do you think the information should be delivered?

9. Before we finish, do you want to add anything about what we've talked about?

you shared with me.

Appendix 3 Chapter 5

Appendix 3.1. Description and justification of divergences from peer-reviewed scoping review protocol.

The scoping review protocol stated that "Data will be analysed using a grounded theory approach based on the principles of textual narrative synthesis, in line with the procedure outlined by Lucas et al." (Hobden & Demeyere, 2023, p.3). However, after further consideration of JBI guidelines supporting the use of qualitative analysis only when it is descriptive in nature (Peters et al., 2020), we opted to conduct a more pragmatic template analysis. In line with guidance from (Peters et al., 2020), the goal of this analysis was purely descriptive in nature.

Appendix 3.2. Example search conducted on MEDLINE (PubMed) on 7th July, 2023. Note that this search strategy was developed in consultation with an expert university librarian and was peer-reviewed.

Search	Query	Records retrieved
#1	"Stroke" [Mesh] OR stroke*[tiab] OR "cerebral infarct*"[tiab] OR "cerebrovascular infarct*"[tiab] OR "cerebrovascular accident*"[tiab]	369,044
#2	"Patients" [Mesh] OR "Caregivers" [Mesh] OR patient*[tiab] OR survivor*[tiab] OR victim*[tiab] OR carer*[tiab] OR caregiver*[tiab]	8,296,534
#3	"Education" [Mesh] OR "information need*"[tiab] OR "education need*"[tiab] OR "knowledge need*"[tiab]	907,499
#4	"Cognition"[Mesh] OR "Memory"[Mesh] OR "Executive Function"[Mesh] OR cogniti*[tiab] OR thinking[tiab] OR memory[tiab] OR attention[tiab] OR "executive function*"[tiab] OR aphasia*[tiab] OR dementia*[tiab] OR language[tiab] OR neglect[tiab] OR neuropsych*[tiab]	1,719,882
#5	#1 AND #2 AND #3 AND #4	434

Appendix 3.3. Search strategies used to search the following electronic databases on 25th August, 2023: PsycINFO, Embase, CINAHL and Scopus. Note that these search strategies were developed by inputting the above peer-reviewed search strategy into the Polyglot tool provided by Systematic Review Accelerator software (https://sr-accelerator.com/).

	PsychInfo (Ovid)
#1	exp Stroke/ OR stroke*.ti,ab. OR "cerebral infarct*".ti,ab. OR "cerebrovascular infarct*".ti,ab. OR "cerebrovascular accident*".ti,ab.
#2	exp Patients/ OR exp Caregivers/ OR patient*.ti,ab. OR survivor*.ti,ab. OR victim*.ti,ab. OR carer*.ti,ab. OR caregiver*.ti,ab. OR famil*.ti,ab.
#3	exp Education/ OR "information need*".ti,ab. OR "education need*".ti,ab. OR "knowledge need*".ti,ab. OR psychoeducation*.ti,ab.
#4	exp Cognition/ OR exp Memory/ OR exp "Executive Function"/ OR cogniti*.ti,ab. OR thinking.ti,ab. OR memory.ti,ab. OR attention.ti,ab. OR "executive function*".ti,ab. OR aphasia*.ti,ab. OR dementia*.ti,ab. OR language.ti,ab. OR neglect.ti,ab. OR neuropsych*.ti,ab.
#5	#1 AND #2 AND #3 AND #4
	Embase
#1	Stroke/exp OR stroke*:ti,ab OR 'cerebral infarct*':ti,ab OR 'cerebrovascular infarct*':ti,ab OR 'cerebrovascular accident*':ti,ab
#2	Patients/exp OR Caregivers/exp OR patient*:ti,ab OR survivor*:ti,ab OR victim*:ti,ab OR carer*:ti,ab OR caregiver*:ti,ab OR famil*:ti,ab
#3	Education/exp OR 'information need*':ti,ab OR 'education need*':ti,ab OR 'knowledge need*':ti,ab OR psychoeducation*:ti,ab
#4	Cognition/exp OR Memory/exp OR 'Executive Function'/exp OR cogniti*:ti,ab OR thinking:ti,ab OR memory:ti,ab OR attention:ti,ab OR 'executive function*':ti,ab OR aphasia*:ti,ab OR dementia*:ti,ab OR language:ti,ab OR neglect:ti,ab OR neuropsych*:ti,ab
#5	#1 AND #2 AND #3 AND #4
	CINAHL
#1	(MH Stroke+) OR (TI stroke* OR AB stroke*) OR (TI "cerebral infarct*" OR AB "cerebral infarct*") OR (TI "cerebrovascular infarct*" OR AB "cerebrovascular infarct*") OR (TI "cerebrovascular accident*" OR AB "cerebrovascular accident*")

#2	(MH Patients+) OR (MH Caregivers+) OR (TI patient* OR AB patient*) OR (TI survivor* OR AB survivor*) OR (TI victim* OR AB victim*) OR (TI carer* OR AB carer*) OR (TI caregiver* OR AB caregiver*) OR (TI famil* OR AB famil*)
#3	(MH Education+) OR (TI "information need*" OR AB "information need*") OR (TI "education need*" OR AB "education need*") OR (TI "knowledge need*" OR AB "knowledge need*") OR (TI psychoeducation* OR AB psychoeducation*)
#4	(MH Cognition+) OR (MH Memory+) OR (MH "Executive Function+") OR (TI cogniti* OR AB cogniti*) OR (TI thinking OR AB thinking) OR (TI memory OR AB memory) OR (TI attention OR AB attention) OR (TI "executive function*" OR AB "executive function*") OR (TI aphasia* OR AB aphasia*) OR (TI dementia* OR AB dementia*) OR (TI language OR AB language) OR (TI neglect OR AB neglect) OR (TI neuropsych* OR AB neuropsych*)
#5	#1 AND #2 AND #3 AND #4

Scopus

#1	INDEXTERMS(Stroke) OR TITLE-ABS(stroke*) OR TITLE-ABS("cerebral infarct*") OR TITLE-ABS("cerebrovascular infarct*") OR TITLE-ABS("cerebrovascular accident*")
#2	INDEXTERMS(Patients) OR INDEXTERMS(Caregivers) OR TITLE-ABS(patient*) OR TITLE-ABS(survivor*) OR TITLE-ABS(victim*) OR TITLE-ABS(carer*) OR TITLE-ABS(caregiver*) OR TITLE-ABS(famil*)
#3	INDEXTERMS(Education) OR TITLE-ABS("information need*") OR TITLE-ABS("education need*") OR TITLE-ABS("knowledge need*") OR TITLE-ABS(psychoeducation*)
#4	INDEXTERMS(Cognition) OR INDEXTERMS(Memory) OR INDEXTERMS("Executive Function") OR TITLE-ABS(cogniti*) OR TITLE-ABS(thinking) OR TITLE-ABS(memory) OR TITLE-ABS(attention) OR TITLE-ABS("executive function*") OR TITLE-ABS(aphasia*) OR TITLE-ABS(dementia*) OR TITLE-ABS(language) OR TITLE-ABS(neglect) OR TITLE-ABS(neuropsych*)
#5	#1 AND #2 AND #3 AND #4

Appendix 3.3. Final iteratively revised tool used to extract data from included articles.

Author, Year, Country	Title	Aims, Research questions	Research design (eg longitudinal)	Research methods (eg survey, interviews)	Time since stroke	Participants	Relevant findings

Appendix 4 Chapter 6

Appendix 4.1. Copy of letter received from the University of Oxford Medical Sciences Interdivisional REC confirming their decision that the co-production research conducted to develop a novel psychoeducation resource for the intervention did not require ethical approval.

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
Tel: +44(0)1865 616575
ethics@medsci.ox.ac.uk



Professor Nele Demeyere and Georgina Hobden
Department of Experimental Psychology
Anna Watts Building
Radcliffe Observatory Quarter
Oxford
OX2 6GG

13 February 2023

Dear Professor Demeyere,

Designing information resources about cognition after stroke for stroke survivors and their caregivers

Reference: R85529/RE001

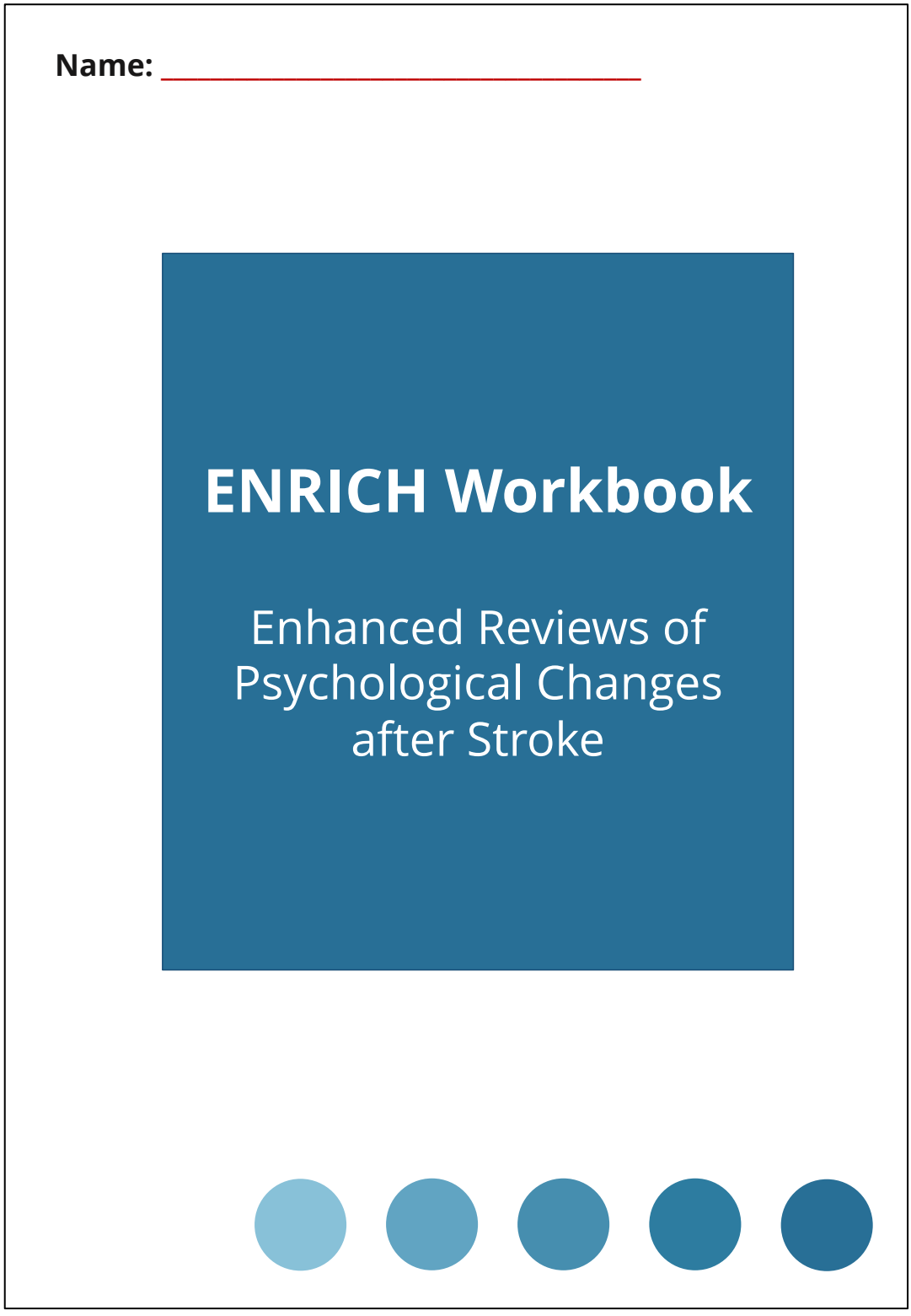
I am writing to confirm that this application has been reviewed by the Officer of the University of Oxford Medical Sciences Interdivisional Research Ethics Committee (MS IDREC), with reference to formally approved process. It has been determined that the study is not classified as research, therefore does not require ethics review.

Yours Sincerely

DocuSigned by:
H. Barnby-Porritt
045C0A3BF8234FD...

Dr. Helen Barnby-Porritt
Research Ethics Manager

Appendix 4.2. Psychoeducation resource developed from co-production research and with additional input from our Patient and Public Involvement Group to expand the resource to address low mood, anxiety, and fatigue, in addition to cognitive changes after stroke.



Introduction

Psychological changes after stroke are **very common**. The ENRICH programme reviews psychological changes after stroke at three timepoints. We look at your **thinking skills**, **mood and anxiety**, and **fatigue**. You completed ENRICH reviews on:

- ENRICH Review 1: _____*[DATE]*_____
- ENRICH Review 2: _____*[DATE]*_____
- ENRICH Review 3: _____*[DATE]*_____

Thinking Skills

- Lots of people experience changes in their thinking skills (cognition) after stroke, including their memory, language, and attention skills.
- It may be important to find ways to **manage** changes in thinking skills in your everyday life.



7 in 10 people have problems with cognition after stroke.

Mood and Anxiety

- It is very common to feel low in mood and anxious after stroke.
- It may be important to get **support** if your mood/anxiety is stopping you from doing things you want or causing you distress.

Fatigue

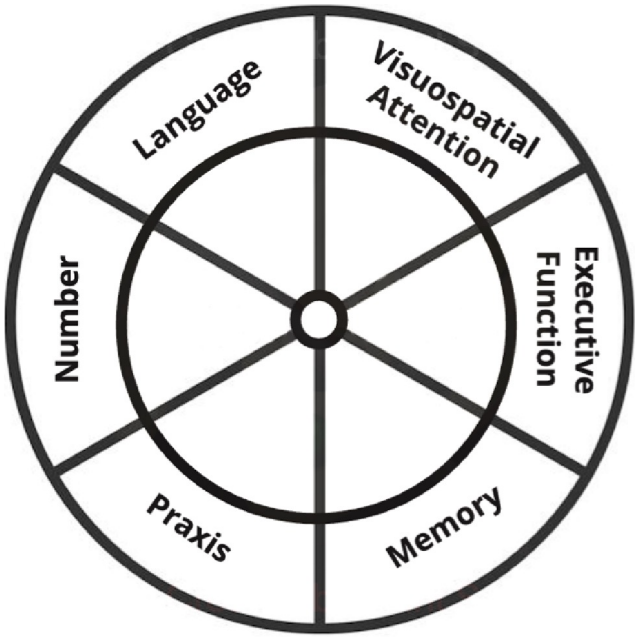
- Lots of people feel physical, mental, or emotional **exhaustion** after stroke.
- This can make it harder do things that are important to you, so it is important to find ways to **manage** fatigue.

My Thinking Skills

7 in 10 people experience changes in their thinking skills after stroke.

You completed some **activities** to see how your **stroke** has affected your **thinking skills**.

This **wheel** shows how you did in the **activities.** Most people do well in some activities and find other activities more difficult.



Key

- Not affected
- Mildly affected
- Moderately affected
- Severely affected

Glossary

- **Language:** Understand and communicate.
- **Visuospatial attention:** Pay attention to things around you.
- **Executive function:** Plan and execute complicated tasks.
- **Memory:** Remember things.
- **Praxis:** Plan physical movements.
- **Number processing:** Use numbers.

It is important to remember that:

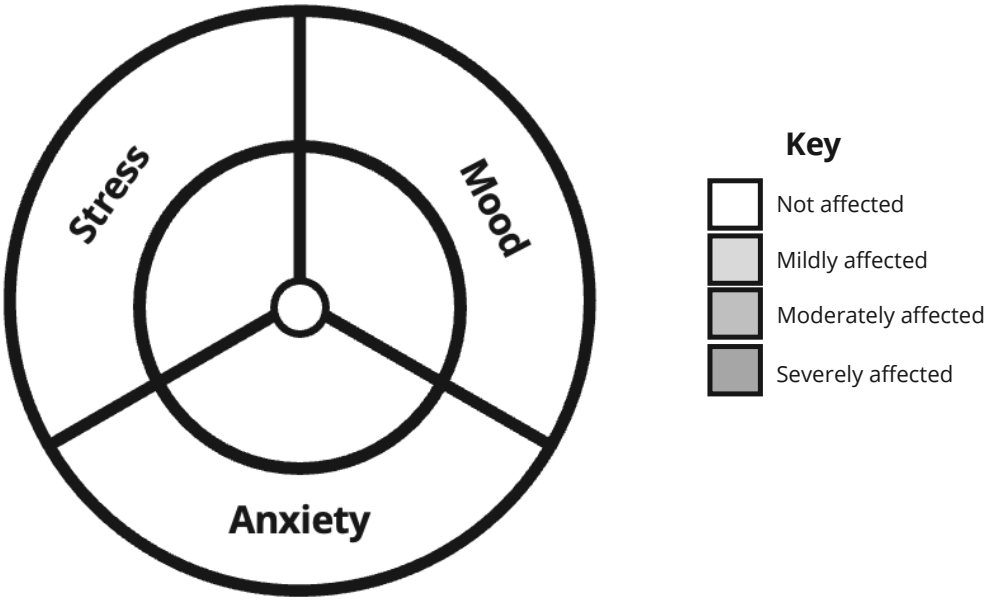
- Your thinking skills will **change**. This wheel may look very different in a few weeks or months.
- The activities do not always detect **subtle changes** in thinking skills.
- Your thinking skills may be affected by your **mood** or feeling very tired (**fatigue**).

My Mood and Anxiety

1 in 3 people experience low mood and depression after stroke.
1 in 4 people experience anxiety.

You completed a **questionnaire** to see how your **stroke** has affected your **mood, anxiety,** and **stress** levels.

This **wheel** shows how your mood, anxiety, and stress levels seem to be.



It is important to remember that:

- Your mood, anxiety, and stress levels will **change**. They may look very different in a few weeks or months.
- Your mood, anxiety, and stress levels may **impact** your **thinking skills** after stroke.
- You can find **more information** on low mood and anxiety, including where to find support, towards the back of this book.

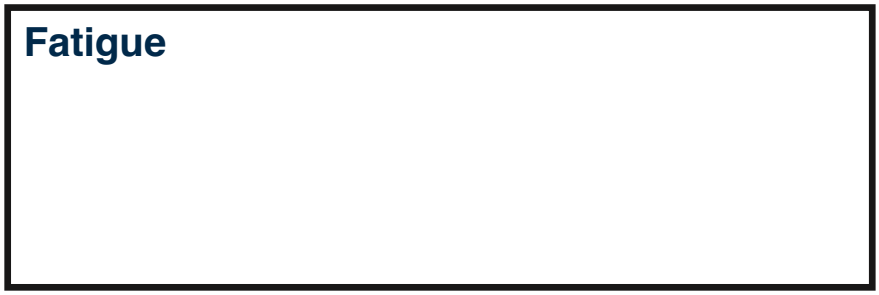
My Fatigue

1 in 2 people experience fatigue after stroke.

You completed a **questionnaire** to see how your **stroke** has affected your fatigue (feelings of exhaustion).

Fatigue may affect you mainly in a **physical**, **emotional**, or **mental** way.

The box below shows how your fatigue level seems to be.



0
Minimum fatigue score

63
Maximum fatigue score

This score suggests your fatigue level IS / IS NOT clinically significant.

It is important to remember that:

- Your fatigue levels will **change**. They may look very different in a few weeks or months.
- Your fatigue levels may **impact** your **thinking skills** after stroke.
- You can find **more information** on fatigue, including where to find support, towards the back of this book.

My Thinking Skills, Mood, Anxiety & Fatigue

Most people continue to do well in lots of things after their stroke (**strengths**), but they may find some things more difficult (**challenges**).

My strengths	My challenges

Here are some **things you can do** to make it easier to live with these challenges.

What can I do to manage these challenges?

Finding Support

There are places to find more **support** for your thinking skills, mood, anxiety, and fatigue.

1. Make an appointment to see your GP.
Your doctor can give you information and refer you for specialist treatment through the NHS.

2. Find local and online support in your area
You can find support in your local area by entering your postcode online. This was also show you whether there are peer support groups in your area.
Website: www.stroke.org.uk/finding-support/support-services

3. Stroke Association Here for You Service
This service provides eight weeks of one-to-one phone calls to provide support following stroke. You can sign up online or by telephone:
Website: www.stroke.org.uk/finding-support/here-for-you
Telephone: 0303 3033 100

4. Online resources
There are free resources for many different problems after stroke online. You can find information about different thinking skills, mood, and fatigue after stroke here:
Website: www.mystrokeguide.com
Website: www.bridgesselfmanagement.org.uk/csh-resources

Section 2: More information

More information about memory



"I sometimes have trouble **remembering things** after my stroke."

What are memory problems?

Problems with **short-term memory** (remembering things for a short time) and **working memory** (holding information in mind and using it whilst doing a task) are common after stroke. Some people may experience changes in their **long-term memory** (remembering things for a long time).

- It may be difficult to **remember** something you have been **told** very **recently**.
- It may be difficult to **remember** what you are supposed to be doing when completing an **activity**.
- It may be difficult to **remember** names of **people** and **places**.

What if you notice memory problems?

It may be helpful to play **memory games** to keep **exercising** your memory skills.

It may also be useful to **write things down** or **schedule digital reminders** for important events.

You can find more information here:
www.stroke.org.uk/effects-of-stroke/memory-problems

More information about language



"I sometimes have trouble **speaking, writing, and understanding things** after my stroke."

What are language problems?

Problems with **language** are common after stroke. This is sometimes called **aphasia** or **dysphasia**.

- It may be difficult to **find the words** to say something, despite knowing what you want to say.
- It may be difficult to **understand** what people are saying and to say things that make sense.

What if you notice language problems?

It may be helpful to play **games**, like naming as many things as you can in a certain category, to keep **exercising** your **language** skills.

It may be helpful to use different ways of communicating that don't involve language, like drawing **pictures** or **diagrams** or using a **mobile phone** or **tablet** to show things.

You can find more information here:
www.stroke.org.uk/what-is-aphasia

More information about number processing



"I sometimes have trouble **using numbers** after my stroke."

What are number processing problems?

Many people have problems **using numbers** after stroke. This is sometimes called **dyscalculia**.

- It may be difficult to **understand** and use written numbers ('eight') and/or digits ('8').
- It may be difficult to do **sums**, like adding and subtracting.
- It may be difficult to pay in cash notes and coins or to tell the time.

What if you notice number processing problems?

It may be helpful to play **games**, like completing sudokus, to keep **exercising** your **number processing** skills.

It may be helpful to pay with a **card** and to keep a **calculator** with you if you think you may need to do sums.

It may be useful ask for **support** with important financial tasks.

You can find more information here:
www.stroke.org.uk/effects-of-stroke/memory-and-thinking

More information about executive function



"I sometimes have trouble **planning** and **completing the steps** for **complicated tasks** after my stroke."

What are executive function problems?

Executive functions help people **plan steps** to complete **complicated tasks.**

- It may be difficult to do **more than one thing** at a time and to **switch** between different tasks.
- It may be difficult to **plan** things because it is hard to think of all the steps or put them in the right **order**.
- It may be difficult to **solve problems** and work out what to do when something goes wrong.

What if you notice executive function problems?

It may be helpful to play **keep challenging yourself** to complete **complicated activities**.

It may be **break down the steps** you need to take to complete an activity and **write them down** before you start doing it.

You can find more information here:
www.stroke.org.uk/effects-of-stroke/planning-and-problem-solving-problems

More information about visuospatial attention



"I sometimes have trouble **noticing things** on **one side** after my stroke."

What are visuospatial attention problems?

Visuospatial attention helps you **notice** and **pay attention** to things around you. Problems with visuospatial attention are sometimes called visuospatial **neglect**, spatial neglect, or neglect. If you have neglect:

- You may find it difficult to **notice** things on one side of you.
- You may **ignore people** or **bump into things** without realising they are there.
- You may not **read** one side of a book, page, sentence, or word without realising it.

What if you notice visuospatial attention problems?

You may find it useful to wear something that draws your attention to the side that you struggle to notice.

You can find more information here:
www.stroke.org.uk/effects-of-stroke/problems-noticing-things-on-one-side-spatial-neglect

More information about praxis



"I sometimes have trouble **carrying out actions** or **using tools** correctly after my stroke."

What are praxis problems?

Praxis helps you **plan** and **carry out physical movements**. Problems with praxis are sometimes called **apraxia** or **dyspraxia**. If you have apraxia:

- You may **hesitate** before doing things or do them very **slowly**.
- You may do things with the **wrong amount of force**.
- You may move in the **wrong way**, like waving their hand forwards and backwards instead of side to side to say goodbye.

What if you notice praxis problems?

It is important to **keep challenging yourself** to complete **difficult tasks**, like using cutlery and buttoning shirts.

You can find more information here:
www.stroke.org.uk/effects-of-stroke/problems-moving-or-controlling-your-body-apraxia

More information about depression and low mood



"I sometimes **do not feel interested in my usual activities** and feel **hopeless**."

What are depression and low mood problems?

Depression and low mood often causes you to feel **down, low, or sad** more days than not. If you have depression:

- You may find it **more effortful** to complete complex tasks and get **less pleasure from usual activities**.
- You may find yourself **less motivated** for activities that would normally be enjoyable.
- You may feel a sense of **hopelessness** or **guilt.**
- You may have **negative thoughts** that you would be better off dead or of **hurting yourself** in some way.

What if you notice depression or low mood?

Low mood can happen to anyone, but if it affects you more days than not it is worth **finding support.** It is important to **keep taking part in valuable and enjoyable activities**, even small tasks like contacting a friend, listening to music, or sitting in the garden. Talking therapies may be helpful for you.

You can find more information here:
www.stroke.org.uk/stroke/effects/emotional-changes

More information about anxiety



"I sometimes find myself **over worrying about things** and have a **hard time managing uncertainty** in my future."

What are anxiety problems?

Anxiety can cause increases in **worry** about your future, especially over things you cannot fully control. If you have anxiety:

- You may find yourself **feeling restless** or "butterflies" in your stomach.
- You may feel a **sense of dread** for the future or feel more **irritable** than normal.
- You may feel on edge as if in **"fight or flight"** mode often.

What if you notice anxiety?

Feeling anxious is more common in early stroke, but if it stopping you from your daily activities it is worth **finding support.**

You might find it useful to do **deep** breathing if you feel very anxious or worried. **Scheduling "worry time" in your day** might help stop worry from interfering with the rest of your day. Talking therapies may also be helpful for you.

You can find more information here:
www.stroke.org.uk/stroke/effects/emotional-changes

More information about fatigue



"I sometimes find myself **exhausted** even though I have rested enough."

What are fatigue problems?

Fatigue is a feeling of **exhaustion and tiredness** that doesn't get better with rest. Fatigue can be **mental, physical, or emotional**. Fatigue may be sudden or get worse throughout the day. If you have fatigue:

- You may **need more sleep** than before your stroke to feel alert.
- You may find you need **more mental effort** to complete challenging tasks.
- You may find it tiring to be around **loud noises and bright lights**.

What if you notice fatigue problems?

You may find it helpful to use the 3 Ps – **Plan** activities that are fatiguing throughout your week, **Prioritise** activities that are important to you, and **Pace** yourself with regular rest breaks.

You can find more information here:
https://www.stroke.org.uk/stroke/effects/physical/tiredness-and-fatigue

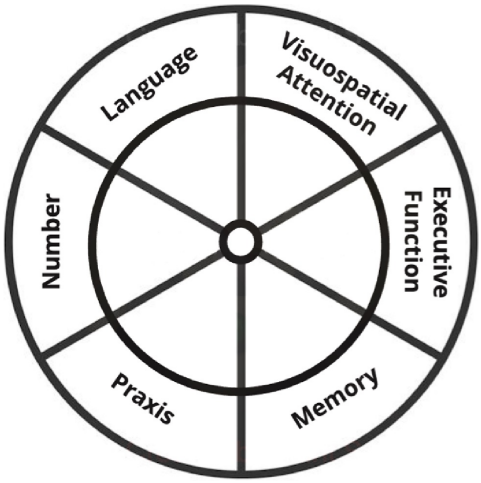
Section 3: Follow-up ENRICH Reviews

Review of your thinking skills

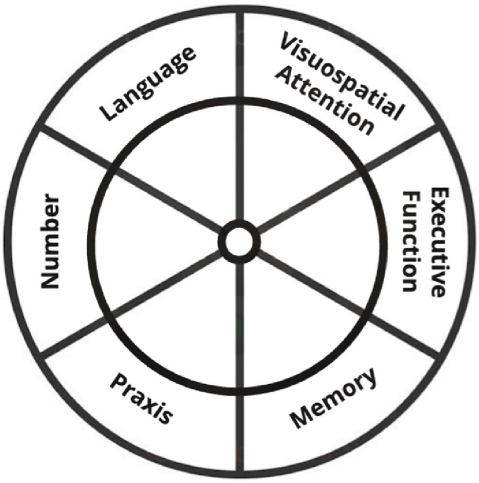
These **wheels** show how you did in all the **thinking skills** and how your thinking skills have **changed** over time.

Remember it is normal to have **strengths** in some areas and experience **challenges** in others.

_____DATE 1_____



_____DATE 2_____



- **Language:** Understand and communicate.
- **Visuospatial attention:** Pay attention to things around you.
- **Executive function:** Plan and execute complicated tasks.
- **Memory:** Remember things.
- **Praxis:** Plan physical movements.
- **Number processing:** Use numbers.

Key

- Not affected
- Mildly affected
- Moderately affected
- Severely affected

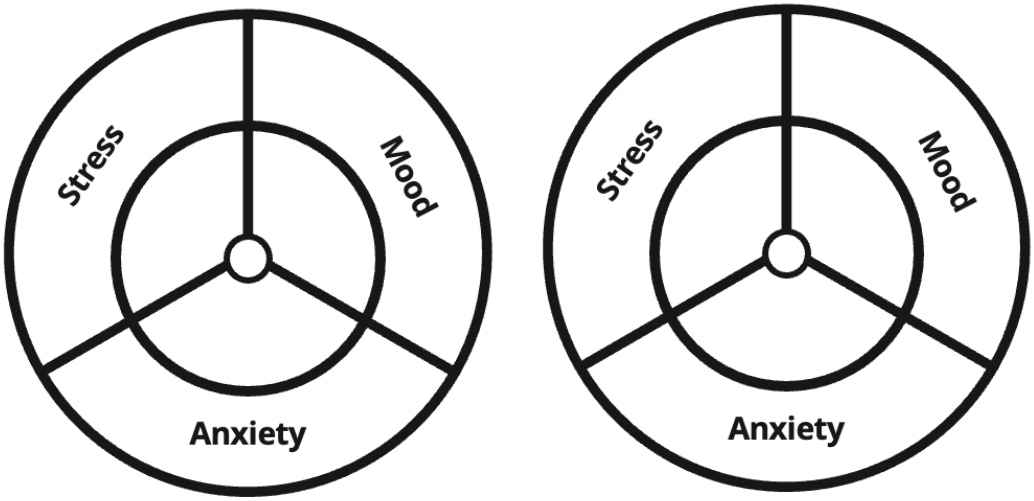
Review of mood, anxiety and stress

These **wheels** show how you rated your **mood, anxiety,** and **stress** levels and how they have **changed** over time.

Remember it is normal for there to be a **link** between your stress, mood, and anxiety.

These feelings may also affect your **thinking skills** and feelings of exhaustion (**fatigue**).

_____DATE 1_____ _____DATE 2_____



Key

- Not affected
- Mildly affected
- Moderately affected
- Severely affected

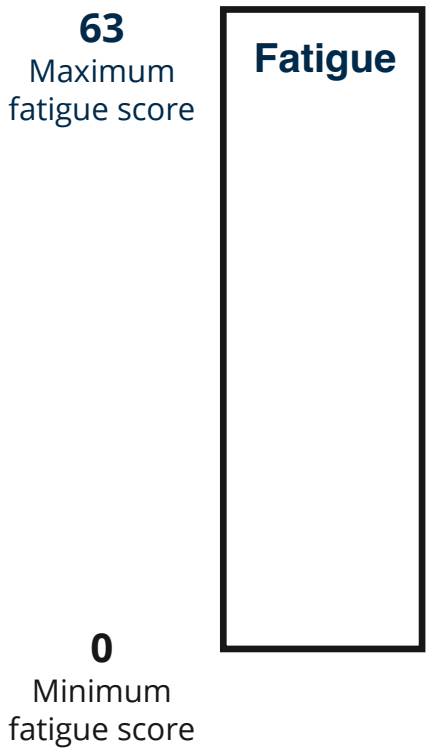
My Fatigue

1 in 2 people experience fatigue after stroke.

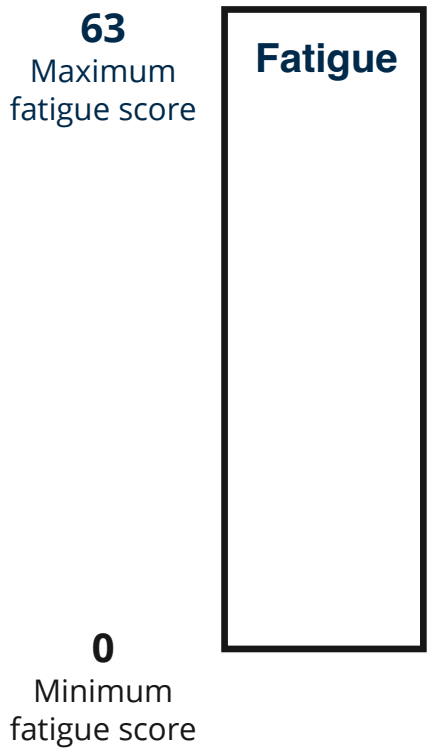
These **boxes** show how you rated your levels of exhaustion (**fatigue**) and how they have **changed** over time.

Remember your fatigue may also affect your **thinking skills** and your **mood**, **anxiety**, and **stress** levels.

_____DATE 1_____



_____DATE 2_____



Your score on _____DATE 2_____ suggests your fatigue level IS / IS NOT clinically significant.

Appendix 4.3. Development of intervention requirements for the prototype psychoeducation resource to be used in the cognitive care intervention. I developed the intervention requirements using a quasi-systematic approach to evidence synthesis. First, I converted findings from research presented in Chapter 4 and Chapter 5 of this thesis into a series of evidence statements. Then, I converted each evidence statement into a concrete and actionable intervention requirement, a statement detailing an 'ideal' feature of the prototype psychoeducation resource. I accepted, rejected, or refined each intervention requirements based on the following criteria: (a) Relevance to the target outcome; (b) Ease of implementation within the scope and scale of the project; (c) Ease of implementation within clinical practice. The following section presents the initial evidence statements, initial intervention requirements including their 'status' (accepted, rejected, revised), and then the final intervention requirements used to inform the initial prototype.

Evidence statements

Chapter 4 Semi-structured interviews

Part A

Qualitative data suggested that stroke survivors and family members:

- Had difficulty understanding the purpose of the cognitive assessment.
- Struggled to see the value of the cognitive assessment.
- Had difficulty engaging with the cognitive assessment due to a lack of understanding about its purpose.
- Experienced strong emotional responses to the cognitive assessment.

- Felt very anxious about the cognitive assessment because of perceiving it as a test.
- Felt very engaged with the cognitive assessment because of perceiving it as a challenge.
- Felt relatively little anxiety about the cognitive assessment as they recognised that post-stroke cognitive impairments are very common.
- Felt relatively little anxiety about the cognitive assessment as they believed their cognitive abilities had not been impacted by their stroke.
- Felt relieved when they perceived themselves to have performed well in the cognitive assessment.
- Felt comfortable when the cognitive assessment was administered with patience and gentleness.
- Felt uncomfortable when they perceived pressure to answer quickly during the cognitive assessment.
- Valued positive feedback after the cognitive assessment, even when results indicated some level of cognitive impairment.
- Felt disappointed that their performance in the cognitive assessment was not fed back to them.
- Found it difficult to understand explanations of their performance in the cognitive assessment due to the use of complex terminology and clinical jargon.
- Thought it could be helpful to link discussions of cognitive impairments to activities of daily living.

Part B

Qualitative data suggested that stroke survivors and family members:

- Had very different thoughts about whether cognitive trajectory discussions should be incorporated in the post-stroke care pathway.
- Recognised that cognitive trajectory discussions may help stroke survivors and their family members develop realistic expectations for the future.
- Recognised that not discussing cognitive trajectories may lead to the development of unrealistic expectations and disappointment when expectations were not met.
- Believed that discussing cognitive trajectories may be less important in many cases than helping stroke survivors and family members maintain hope and optimism.
- Recognised that cognitive trajectory discussions may be motivating for stroke survivors and their family members.
- Believed that discussing potential cognitive recovery would be motivating for a greater proportion of stroke survivors and family members compared to discussing potential cognitive stability, decline, or dementia.
- Believed that discussing potential cognitive decline and dementia would be anxiety-provoking and depressing for some stroke survivors and family members.
- Believed that discussing potential cognitive decline and dementia with family members was important to increase awareness of key symptoms to monitor.

- Believed that discussing potential cognitive stability, decline and dementia in the later stages after stroke may be important for helping stroke survivors and family members come to terms with stagnation in or lack of cognitive recovery.

Chapter 5 Scoping review.

- Predominantly used qualitative methods, with a range of data collection and analysis approaches.
- Investigated the early (acute/sub-acute: <6-months) and later (chronic: >6-months) stages after stroke.
- Rarely investigated multiple timepoints after stroke.
- Included stroke survivors and/or family members.
- Predominantly reported only language-related cognitive impairments of stroke survivors.
- Sometimes excluded stroke survivors with non-language cognitive impairments.
- Predominantly investigated psychoeducation needs specific to language-related cognitive impairments.
- Identified the presence of cognition-related psychoeducation needs at all timepoints after stroke investigated.
- Identified a range of specific cognition-related psychoeducation needs, including information about cognitive difficulties, cognitive assessments, future outcomes (prognosis and rehabilitation timeline), treatment and therapy options, services and support available, psychosocial support and counselling available.

- Emphasised the importance of supporting stroke survivors and their family members to remain hopeful and optimistic in the context of psychoeducation provision.
- Suggested the prevalence of cognition-related psychoeducation needs may increase over time after stroke.
- Suggested the content of cognition-related psychoeducation needs may evolve over time after stroke.

Intervention requirements

Candidate intervention requirements

1. The psychoeducation resource should provide accurate information about cognition at 'all' stages after stroke.
2. The psychoeducation resource should provide information about:
    a. Cognition (e.g., definitions)
    b. Purpose and outcomes of cognitive assessment
    c. Potential cognitive trajectories
    d. Services and support available
    e. Strategies to live with cognitive difficulties
3. The psychoeducation resource should provide information that helps stroke survivors and their family members maintain hope.
4. The psychoeducation resource should provide information that is personalised and specific to individual stroke survivors.

5. The psychoeducation resource should provide information clearly, concisely, and without using clinical jargon.
6. The psychoeducation resource should provide information in a sensitive and compassion manner.
7. The psychoeducation resource should provide information without using highly emotive language.

Evaluation and revision of intervention requirements

Intervention requirement	Decision	Reason for decision	Detail
The psychoeducation resource should provide accurate information about cognition at 'all' stages after stroke.	Adapt	Outside scope and scale of the project	The cognitive care intervention will provide follow-up care to stroke survivors in the first six-months after discharge from inpatient services. The psychoeducation resource will be implemented in this temporal context.
The psychoeducation resource should provide information about: • Cognition (eg definitions). • Purpose and outcomes of cognitive assessment. • Potential cognitive trajectories. • Services and support available. • Strategies to live with cognitive difficulties.	Accept		
The psychoeducation resource should provide information that helps stroke survivors and their family members maintain hope.	Accept		
The psychoeducation resource should provide information that is personalised and specific to individual stroke survivors.	Adapt	Outside scope and scale of the project.	It will only be possible to provide personalised information related to specific topics. For example, although participants in the articles included in the scoping review wanted information about their prognosis, predicting long-term outcomes on an individual level is not currently possible (see Chapter 4 for more detail).

The psychoeducation resource should provide information clearly, concisely, and without using clinical jargon.	Accept
The psychoeducation resource should provide information in a sensitive and compassion manner.	Accept
The psychoeducation resource should provide information without using highly emotive language.	Accept

Final intervention requirements

1. The psychoeducation resource should have the potential to provide accurate information about cognition in the acute and chronic stages after stroke.
2. The psychoeducation resource should provide information on:
    (a) cognition (e.g., definitions),
    (b) cognitive assessments,
    (c) potential cognitive trajectories,
    (d) services and support available.
3. The psychoeducation resource should provide comprehensive and honest information within a positive framework.
4. The psychoeducation resource should provide information that is personalised and specific to individual stroke survivors where possible.
5. The psychoeducation resource should communicate information clearly and concisely, avoiding clinical jargon where possible and explaining any jargon used.
6. The psychoeducation resource should avoid highly emotive language.

Appendix 5 Chapter 7

Appendix 5.1. Documentation of the multistage process by which key findings from previous chapters (Chapter 3, Chapter 5, and Chapter 5) were converted into a set of intervention requirements used to inform the 'final' intervention design.

Step 1. Evidence Statements

Chapter 3 Modified Delphi survey

Participants agreed that:

- Stroke survivors with a cognitive impairment detected during acute hospital admission should have a review of their cognition after discharge from an acute inpatient setting.
- Stroke survivors with no cognitive impairment detected during acute hospital admission should have a review of their cognition after discharge from an acute inpatient setting.
- For stroke survivors with a cognitive impairment detected during acute hospital admission, a review of their cognition should take place in the first few weeks after discharge.
- For stroke survivors with a cognitive impairment detected during acute hospital admission, a review of their cognition should take place 3-months after discharge.
- For stroke survivors with a cognitive impairment detected during acute hospital admission, a review of their cognition should take place 6-months after discharge.

- For stroke survivors with a cognitive impairment detected during acute hospital admission, a review of their cognition should take place 1-year after discharge.
- For stroke survivors with no cognitive impairment detected during acute hospital admission, a review of their cognition should take place in the first few weeks after discharge.
- For stroke survivors with no cognitive impairment detected during acute hospital admission, a review of their cognition should take place 3-months after discharge.
- For stroke survivors with no cognitive impairment detected during acute hospital admission, a review of their cognition should take place 6-months after discharge.
- Cognitive reviews should take place in person.
- Cognitive reviews should include a stroke-specific cognitive screen (15-20 minutes) (e.g., Oxford Cognitive Screen; OCS).
- Cognitive reviews should include a questionnaire for the stroke survivor about their post-stroke cognition.
- Cognitive reviews should include a questionnaire for a family member about the stroke survivor's cognition.
- Cognitive reviews should include a depression screen (e.g., Patient Health Questionnaire-9; PHQ-9).
- Cognitive reviews should include an anxiety screen (e.g., Generalised Anxiety Disorder Assessment-7; GAD-7).
- Cognitive reviews should include a fatigue measure (e.g. Fatigue Severity Scale; FSS).

- Cognitive reviews should include a general discussion with the stroke survivor about their overall cognitive functioning.
- Cognitive reviews should include a general discussion with the stroke survivor about their domain-specific cognitive functioning.
- Stroke survivors should be told the results of the cognitive assessment conducted during the review.
- Stroke survivors should be told how their cognitive assessment result compares to earlier cognitive assessment results (e.g., in cognitive screen completed in acute inpatient setting).
- Stroke survivors should be told about potential cognitive trajectories during the review.
- Stroke survivors should be told about the potential impact of any cognitive impairments on activities of daily living during the review.
- Stroke survivors should be signposted to available support and services during the review.
- Healthcare professionals responsible for conducting cognitive reviews after stroke should receive formal training (e.g., training videos) on administering the cognitive assessment.
- Healthcare professionals responsible for conducting cognitive reviews after stroke should receive informal training (e.g., training from colleague) on administering the cognitive assessment.
- Healthcare professionals responsible for conducting cognitive reviews after stroke should receive formal training (e.g., training videos) on discussing cognition with stroke survivors and family members.

- Healthcare professionals responsible for conducting cognitive reviews after stroke should receive informal training (e.g., training from colleague) on discussing cognition with stroke survivors and family members.
- Online training (e.g., training videos) should be offered to healthcare professionals administering cognitive reviews.
- In person training (e.g., training course) should be offered to healthcare professionals administering cognitive reviews.

Qualitative data suggested participants thought:

- Conducting cognitive reviews remotely is less ideal than conducting them in person.
- Conducting cognitive reviews remotely may help to increase access to the cognitive care intervention for those with substantial work and/or caring commitments, and those living in remote geographic locations.
- Screening for dementia within cognitive reviews present risks where professionals are not fully trained to administer them and interpret the results.
- Screening for dementia may help to ensure patients access appropriate care if and when their cognitive abilities show a declining trajectory over time.

Appendix 6 Chapter 8

Appendix 6.1. Custom survey administered in the first stage of intervention feasibility testing (Part A) to gauge the extent to which aspects of the ENRICH reviews were deemed helpful.

To what extent do you agree with the following statements?

1	2	3	4	5
Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

___ It was helpful to receive a follow-up psychological review ~6-months after stroke.

___ It was helpful to receive a follow-up psychological review in person.

___ It was helpful to complete a test of my thinking skills during the follow-up psychological review.

___ It was helpful to be asked to report on my thinking skills during the follow-up psychological review.

___ It was helpful for my family member to be asked to report on my thinking skills during the follow-up psychological review.

___ It was helpful to be asked about my mood and anxiety during the follow-up psychological review.

___ It was helpful to be asked about fatigue during the follow-up psychological review.

___ It was helpful to receive personalised information about my thinking skills in different areas during the follow-up psychological review.

___ It was helpful to receive personalised information about my mood and anxiety levels during the follow-up psychological review.

___ It was helpful to receive personalised information about my fatigue levels during the follow-up psychological review.

___ It was helpful to receive personalised information about strengths and challenges I may be facing, in terms of psychological changes after my stroke, during the follow-up psychological review.

___ It was helpful to receive personalised information about strategies to manage challenges I may be facing, in terms of psychological changes after my stroke, during the follow-up psychological review.

___ It was helpful to receive information about potential changes in my thinking skills over time during the follow-up psychological review.

___ It was helpful to receive further information about the potential impact of changes in my thinking skills on daily life activities during the follow-up psychological review.

___ It was helpful to receive further information about support and services available to me during the follow-up psychological review.

___ I understood the language used and any explanations of specialist terms within the follow-up psychological review.

___ I was encouraged to maintain hope and optimism within the follow-up psychological review.

___ The person providing the follow-up psychological review acted with compassion and sensitivity.

Appendix 8.2. Iteratively revised topic guide used in semi-structured interviews with stroke survivors and their family members to obtain feedback on the acceptability and feasibility of the ENRICH intervention and any recommended modifications.

Introduction

Thank you for agreeing to participate in this interview. The purpose of the interview is to find out what you thought about the review of psychological changes you received recently from our research team. These reviews were developed to monitor and help people learn about psychological changes they may be experiencing since their stroke. We want to make sure these reviews are positive for people so I would like to hear any feedback you have about the review you received – positive or negative – and how you think they could be made better.

I am going to ask you some questions about the review you received but there are no right or wrong answers. I am simply interested in your own experiences, thoughts, and opinions. The interview should take approximately twenty minutes. You may decline to answer any of my questions or stop the interview at any time for any reason.

I would like to audio record the interview because I don't want to forget any of your responses, if you're happy with that. All your responses will be kept completely confidential, and they will not affect the care you currently receive. Your comments will only be shared with research team members, and we will make sure that any information included in our report does not identify you personally.

Do you have any questions about what I've just explained? May I turn on the digital recorder?

1. I'd like to start by asking you how you found the follow-up review of psychological changes.

2. What aspects of the review did you find particularly helpful/useful/beneficial?

- Probe to explore reasons
- Clarify if necessary

3. What aspects of the review did you find less helpful/useful/beneficial?

- Probe to explore reasons
- Clarify if necessary

4. How did you find the experience of completing an assessment to look at your thinking skills/mood/anxiety/fatigue since your stroke?

- Probe to explore reasons for feelings expressed.
- How did feelings change when healthcare professional provided feedback and/or explanation?

5. What did you think of the workbook you were given with information about psychological changes since your stroke?

- Probe to explore reasons
- Clarify if necessary
- Have they used workbook in between/since reviews?

6. Have you noticed any changes in yourself or ability to manage psychological changes since the follow-up review?

- If interviewee is hesitant, reassure them that they may not have noticed changes and that is fine.
- Probe if necessary: reasons behind any changes, whether changes are perceived as generally positive or negative.
- Any further impacts on eg work, relationships, managing daily life activities, social functioning.

7. If you could make any changes to the follow-up review you received, what would these be?

- Probe reasons
- Ask for concrete examples

8. Before we finish, do you want to add anything about what we've talked about?