# Identifying Depression and Suicidality in People with Post- Stroke Aphasia

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Year of Submission: 2021
Word Count: 36,596

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## Abstract

**Background:** Stroke is associated with increased risk of depression and suicidality. People with acquired communication disorder after stroke, or aphasia (PwA) are at even greater risk of low mood and suicidality. Screening mood after stroke with methods appropriate for use with PwA is recommended by clinical guidelines. Previous research found PwA were frequently excluded from studies assessing post-stroke depression however and it is unclear to what extent this exclusion is mirrored in staff screening practises.

**Method:** A systematic review was conducted on the level and method of inclusion of PwA in post-stroke depression (PSD) research to test if inclusivity has improved with the development of new measures. A Theory of Planned Behaviour (TPB) study of UK stroke professionals explored current rates, methods, and predictors of staff screening for mood and suicidality in PwA.

**Results:** Of 997 studies assessing post-stroke depression, only 70 did not exclude PwA and were included in the systematic review, demonstrating the continued exclusion of PwA from most research on PSD. When included, assessment practises frequently raised issues of accessibility or use of unvalidated measures. One hundred and eighteen stroke clinicians completed the TPB questionnaire. A striking discrepancy was found between high reported likelihood to screen PwA for low mood (Mode: 100%, M: 71%, SD: 34.54) but low likelihood to screen PwA for suicidality (Mode: 0%, M:43%, SD: 38.96). TPB variables accounted for 48% of variance in intention to screen for depression in PwA ($R^2$=.48, F (3,101) =30.60, p<.001) with normative beliefs found to be the only significant predictor (β= .62, p<.001).

**Conclusions:** More effort is needed to ensure PwA are included in post-stroke depression research and to help stroke professionals detect depression and suicidality in PwA. Screening rates may be improved by communicating a clear expectation that staff should screen all stroke survivors for depression and suicidality.

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## Acknowledgements

First, I would like to thank my research supervisors, Dr Cat Ford, Dr Niall Broomfield & Dr Ciara Shiggins, for their belief and commitment to in this project. This project began with one person with aphasia's expression of suicidal thoughts but without their help it may never have gone further than that.

I would like to acknowledge every stroke professional who took part in this research and thank them for the time they generously gave to this project. I would also like to thank the various organisations and professional bodies who helped to promote this project. And a special thanks to: Abbey Watson, Dr Annette Schwartz, Dr Ian Kneebone & Annie Bryant.

On a personal level, I would like to thank my friends, family and partner for their on-going support in life. Above all, I would like to thank Piers Lockhart, Ella & Derrin Schlesinger. A special thanks to Mike Woollard for coming out of retirement and for his unwavering commitment to spelling and grammar. I am fortunate and grateful to have them by my side.

Finally, I would like to acknowledge every person with aphasia.

# **Chapter 1-** General Introduction

## Introducing stroke, rehabilitation, post-stroke aphasia, post-stroke depression and theory of planned behaviour

# General Introduction

## Introducing stroke, rehabilitation, post-stroke aphasia, post-stroke depression and theory of planned behaviour

**Figure 1**

*Vincent Van Gogh (1980) Old Man in Sorrow (On the Threshold of Eternity)*

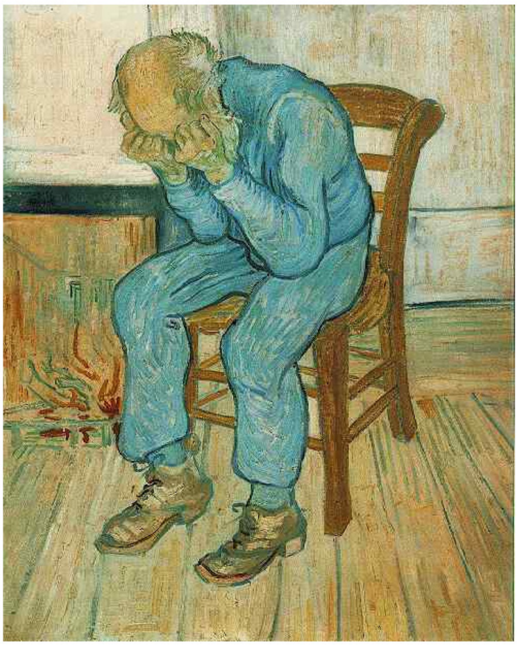


**Figure 2**

*Damien Hirst (2000) The Void*

**Figure 3**

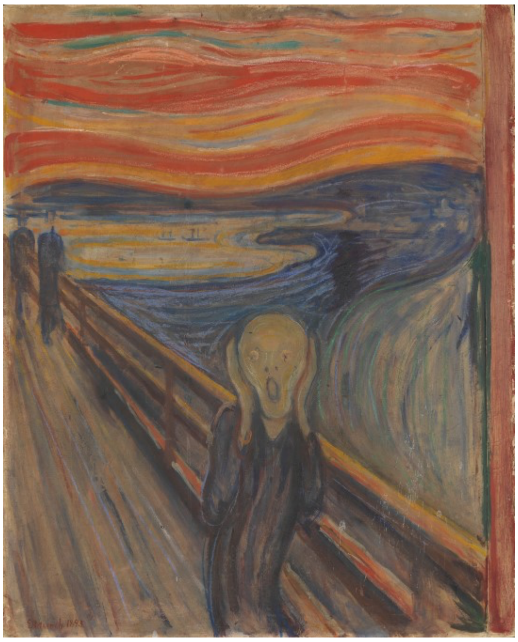
*Pablo Picasso (1903) The Old Guitarist*

**Figure 4**

*Tracey Emin (1998) My Bed*

**Figure 5**

*Edvard Munch (1893) The Scream*



Figures 1- 5 can be interpreted as conveying the depths of depression without words. This is a challenge faced not only by the artists of these works but also day by day for stroke survivors with both aphasia and post-stroke depression. The inspiration for this thesis on detecting post-stroke depression and suicidality in those with post-stroke aphasia came from working with a stroke survivor with severe expressive aphasia. As they navigated their way through the stroke rehabilitation pathway, they received extensive speech and language therapy and made significant improvements. Initially unable to utter any words, they progressed to producing several key words and phrases. Normally this would be heralded a great success, yet they chose to use their voice to express the depression they were suffering and their suicidal thoughts. A newly implemented standardised screening of low mood using a written self-report questionnaire proved inaccessible and the stroke team felt under-skilled and challenged by the need to assess and treat their low mood. One of the six founding values of the National Health Service is ‘everyone counts’, which highlights the importance of ensuring that everyone has access to the resources available in the NHS without discrimination (Department of Health & Social Care, 2021). It is this value that motivates this thesis.

## Stroke

Every two seconds, someone in the world will have a stroke (Stroke Association, 2017) resulting in 13 million people experiencing a stroke worldwide each year (Feigin et al., 2019). Stroke refers to an interruption of cerebral blood flow to an area of the brain, depriving that area of oxygen and causing cell death. The World Health Organisation (Aho et al., 1980) defined a stroke as, "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 h or leading to death, with no apparent cause other than of vascular origin". There are two main types of strokes: ischaemic (caused by a blood clot blocking a blood vessel in the brain) and haemorrhagic (due to a bleed in the brain resulting from a leaking or burst blood vessel). The majority of strokes are ischaemic, 85%, and a minority are haemorrhagic, 15% (Stroke Association, 2017). In the case of ischaemic strokes, blood clots typically form in brain areas where the arteries have become narrowed or blocked with plaques, a process called atherosclerosis. Atherosclerosis occurs naturally as a result of aging; however, this process can be accelerated as a result of several other health conditions and lifestyle factors including diabetes, atrial fibrillation, high cholesterol, high blood pressure, obesity, smoking and alcohol. In the case of haemorrhagic strokes, this is often caused by weakening of the arteries in the brain; the main cause being high blood pressure.

Stroke is a major cause of disability and death (Feigin et al., 2015; World Health Organisation, 2014) and roughly two-thirds of stroke survivors leave hospital with a disability (Adamson et al., 2004). The effects of a stroke are varied, depending on localisation in the brain, as well as the extent and severity of the damage (Stroke Association, 2017). Common consequences of a stroke include muscle weakness, visual difficulties, pain and fatigue, as well as changes to cognition, emotions and behaviour. These changes impact day-to-day living resulting in stroke survivors having a greater reliance on others to complete tasks of daily living (Sentinel Stroke National Audit Programme, 2019) increasing rates of unemployment, (Maaijwee et al., 2014) social restriction and avoidance and negative change in relationships with partners and negative impacts on family (McKevitt et al., 2011).

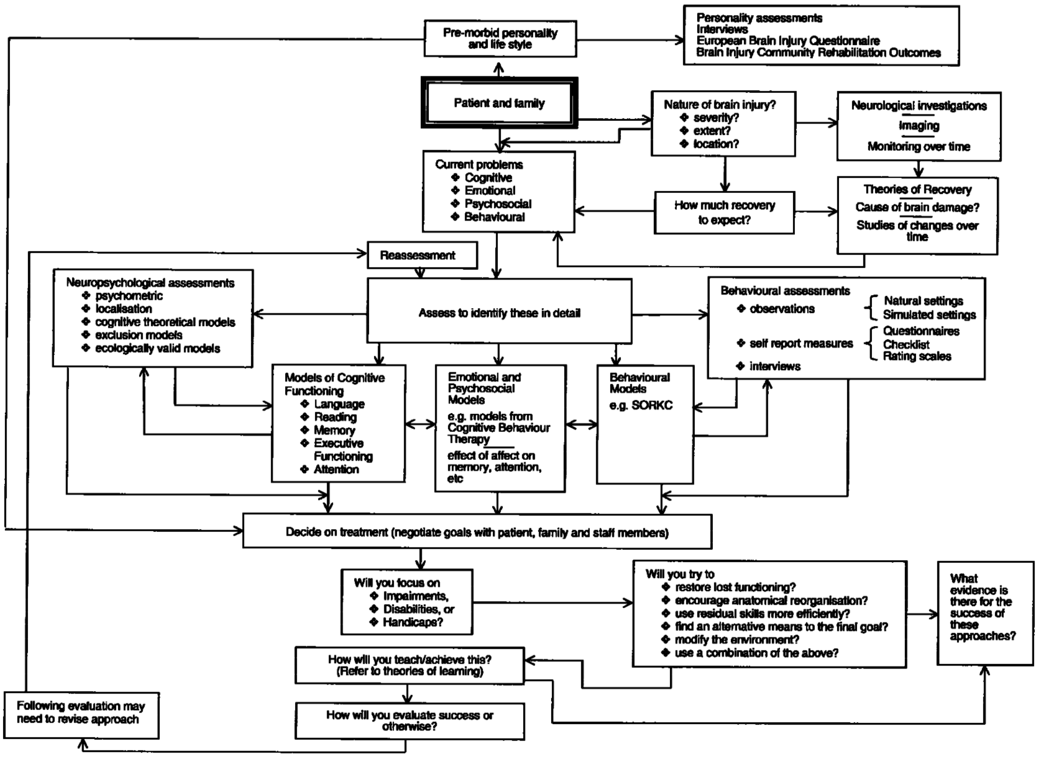
## Stroke Rehabilitation

The UK has approximately 1.2 million stroke survivors (Stroke Association, 2017). The Stroke Association estimate that the aggregate societal cost in the UK is between £18-43 billion, per annum (Patel et al., 2017). This makes effective stroke rehabilitation and management a key policy driver for the National Health Services Long Term Plan (2019). Rehabilitation is defined as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" (World Health Organisation, 2020). McLellan (1991) expands the definition, emphasising that rehabilitation is a two-way interactive process between survivors of brain injury and professionals and/or others to achieve survivors' optimum physical, psychological, social and vocational well-being.

There is a long history of rehabilitation within the context of brain injury, however modern neurorehabilitation began in west during the First World War following the increased number of injuries from gunshot wounds to the head. As a result, the first specialist brain injury rehabilitation centres were established (Boake, 1996). Kurt Goldstein's ideas during this time remain very influential in post- brain injury care. Goldstein published recommendations for therapy to mitigate impairments with speech, reading and writing (Goldstein, 1919, 1942; Boake, 1996), as well as establishing the practise of psychological assessment, and workshops for vocational skills for survivors of brain injury (Poser et al., 1996). Another influential figure in neurorehabilitation is Oliver Zangwill. Zangwill (1947) stipulated three main approaches to rehabilitation after brain injury: compensation, substitution and direct retraining. The latter approach to rehabilitation uses the mechanism of neuroplasticity (the brains natural ability to form and reorganise synaptic brain connections in response to learning or experience) to minimise disability. However, recent reviews of brain injury outcomes suggested that compensatory approaches are the most effective for memory and executive functioning deficits (Cicerone et al., 2005; Rohling et al., 2009). Wilson (2002) conceptualised a framework of cognitive rehabilitation aiming to bring together the models of cognition, assessment, recovery, behaviour, emotion, compensation, and learning. This highlights the complexity and holistic approach that is often taken in neurorehabilitation. This is further demonstrated in the 'Y-shaped' model of change (Gracey et al., 2009) and Wade's (2005) adaption of the WHO-ICF framework (World Health Organisation, 2002), alternative frameworks for conceptualising stroke survivors' needs and for guiding neurorehabilitation.

**Figure 6**

*Wilson's Model of Cognitive Rehabilitation*



In terms of rehabilitation post-stroke, NICE Clinical Guidelines for Stroke Rehabilitation were published in 2013 and updated in 2019. Evidence suggests that rehabilitation should commence as early as possible after stroke to be effective (Bernhardt et al., 2009) and is most effective when undertaken by a multidisciplinary team from different health backgrounds e.g., physiotherapists, occupational therapists, speech and language therapists, stroke physicians, nurses and psychologists (Stroke Unit Trialists' Collaboration, 2017). In acute stroke care, the focus is medical stabilisation, assessment and rehabilitation, (Lynch et al., 2019). Rehabilitation begins with "A comprehensive assessment of a person with stroke [which] should take into account: their previous functional abilities, impairment of psychological functioning (cognitive, emotional and communication), impairment of body functions, including pain, activity limitations and participation restrictions and environmental factors (social, physical and cultural)." (The National Institute of Clinical Excellence, 2019). As with all neurorehabilitation, stroke rehabilitation works through adaptation, restitution and neuroplasticity (Belagaje, 2017) and is strongly influenced by the above-mentioned work of Zangwill (1947). The focus of rehabilitation and recovery should be tailored to the individual, NICE recommended smart-goals to guide the recovery and these should be formed together with the stroke survivor and take into account severity, symptoms, an individual’s support system and function before stroke (NICE, 2019).

This thesis focuses on three common consequences of stroke: aphasia (a loss of the ability to use and understand language), depression (a mood disorder causing persistent feeling of sadness and loss of interest) and suicidality (the risk of killing oneself, usually preceded by thoughts of suicide, the presence of a well-elaborated suicidal plan or having intent to end one's life) and specifically, how staff assess when these conditions co-occur.

## Depression and Suicidality Post-Stroke

> “I would not wish what I’ve been through on my worst enemy. I’ve battled with depression and fatigue but I no longer consider suicide on a daily basis.” *Stroke survivor*

This quotation powerfully demonstrates how devastating and harrowing the experience of post-stroke depression can be for individuals. The Diagnostic and Statistical Manual (DSM- IV) defines post-stroke depression as “Mood disorder due to a general medical condition (i.e., stroke)” with the specifiers of depressive features, major depressive-like episodes, manic features, or mixed features.” Depression is defined by ICD-11 (World Health Organisation, 2018) as a common mental disorder, characterised by the presence of: persistent sadness and/or a loss of interest or pleasure and/or low energy or fatigue; most days, most of the time for at least two weeks. Additional associated symptoms include disturbed sleep, poor concentration or indecisiveness, low self-confidence, poor or increased appetite, suicidal thoughts or acts, agitation or slowing of movement and guilt or self-blame.

Depression following stroke is common. A systematic review found depression occurs in 31% of stroke survivors (Hackett & Pickles, 2014), making it more prevalent than in the general public (Evans et al., 2016). Post-stroke depression (PSD) has been negatively associated with survival (Williams et al., 2004), cost of medical care (Husaini et al., 2013), functional outcome (Žikić et al., 2014), resumption of social activities (Llorca et al., 2015) quality of life (Žikić et al., 2014) and suicide (Vyas et al., 2021).

Stroke survivors experience higher rates of suicide ideation, suicide attempts, and completed suicides than in the general population (Bartoli, et al. 2017; Eriksson et al., 2015; Pompili et al., 2012; Vyas et al., 2021). A meta-analysis of 13 samples, consisting of 10 400 subjects, reported a pooled proportion of suicidal ideation among stroke survivors of 11.8% (Bartoli, et al. 2017). An epidemiological study reported 7.2% of stroke participants died by suicide (Stenager et al., 1998), compared to 11.0 death per 100,000 in the UK general population, 1.1% (Office for National Statistics, 2020). A recent meta-analysis concluded that stroke should be considered as a risk factor for suicide and that a strategy to screen and treat depression and suicidal ideation in stroke survivors should be developed (Vyas et al., 2021). Although several risk factors are thought to play a role, depression appears to be the most important predictor of post-stroke suicide (Pohjasvaara et al., 2001; Forsstrom et al., 2010; Pompili et al., 2012; Eriksson et al., 2015). It should be noted that post-stroke suicide is significantly under researched in comparison to post-stroke depression.

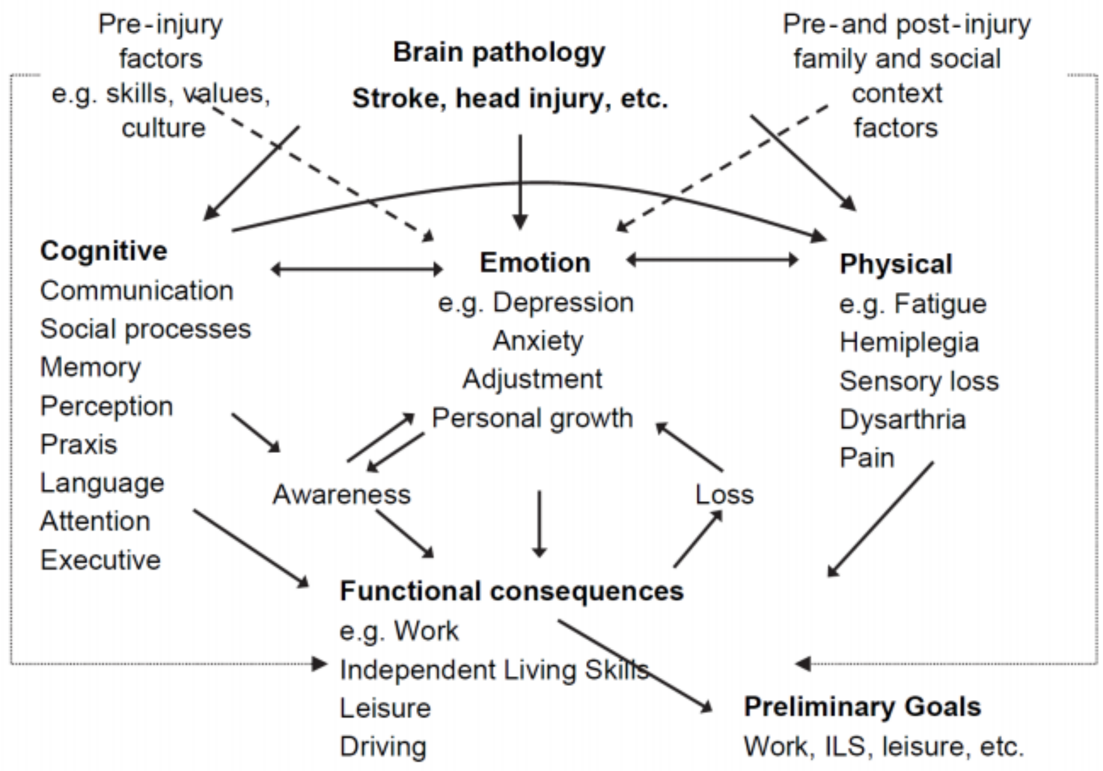
There are two main hypotheses concerning the cause of post-stroke depression: a biological hypothesis and psychological hypothesis. Fang and Cheng's (2009) review of the etiological mechanisms of post-stroke depression summarises the biological hypothesis as including four biological mechanisms: lesion location mechanism, neurotransmitters mechanism, inflammatory cytokines mechanism and gene polymorphism mechanism. The lesion location model first proposed by Robinson et al. (1984) stipulates that the specific location of a lesion (e.g., basal ganglia or left frontal lobe lesions) plays an important role in the etiology of PSD. The neurotransmitter theory first proposed by Robinson and Bloom in 1977 further suggests that a decrease in the neurotransmitters serotonin and norepinephrine produces PSD. Additionally, an increase in inflammatory cytokines (including interleukin (IL) 1β, IL-18, tumour necrosis factor α) after stroke has been found to be associated with depression and has been suggested as a biological cause (Spalletta et al., 2006). Finally, they reported that a significant association between serotonin transporter gene-linked promoter region short variant genotype and post-stroke major depression (Fang & Cheng, 2009).

The psychological hypothesis of PSD suggests that social and psychological stressors associated with stroke are the primary cause of depression. There are several different psychological models of depression, and each would conceptualise post-stroke depression slightly differently. For example, Broomfield et al. (2011) reviewed the evidence base for a cognitive behavioural therapy formulation of post-stroke depression. They proposed that PSD is a result of the physical consequences of stroke reducing activity and participation, and that stroke produces negative beliefs about oneself, the world and the future alongside cognitive deficits promoting processing biases that maintain depression. However, they concluded that the current evidence base was limited. Alternatively, the Social Cognitive Transition model (Brennan, 2001) highlights the importance of individuals' social context and applies theories of coping and traumatic stress to illness. This model has been applied to PSD (Taylor et al., 2011) this model stipulates the content and rigidity of an individual's “assumptive world” limits or prevents the processing of adjustment to stroke.

Fang and Cheng’s (2009) review concluded that based on the current evidence base “the neurobiological pathogenesis of PSD is far from clear... there is no definitive evidence to support or refute either a solely biological or solely psychosocial mechanism.”. However, these are not necessarily opposing hypotheses. George Engel (1977) first conceptualised the biopsychosocial model which stipulates that a medical condition cannot simply be understood through biological factors alone, but through understanding the psychological and social factors also. The biopsychosocial model is often used to understand PSD (Wilson et al., 2009).

**Figure 7**

*A biopsychosocial model of brain injury (Wilson et al., 2009)*



Despite the increased risk of depression following stroke, the National Audit Office (2010) highlighted a widespread lack of psychological care after stroke. As a result, there was a national push to change this with services asked to aim for 40% of stroke survivors to receive psychological support within six months of their stroke (NHS Improvement, 2011). Accordingly, the Stroke Association has made the psychological consequences of stroke one of their key priorities for research, stating “psychological effects of stroke often remain hidden, may go unrecognised by some healthcare professionals, with the true impact remaining unknown.” (Stroke Association, 2017, p. 35).

## Aphasia

> “At the beginning, I had no words in my mind but I felt calm and peaceful when I was meditating. I got very frustrated when my words started to return but I could not express them. Now I do what I can but people need to really listen.” *Stroke Survivor*

Aphasia is described as an acquired loss or impairment of the language system following brain damage affecting one's ability to comprehend or formulate language; and the ability to read or write (Benson & Ardila, 1996). Aphasia is often classified as "expressive" or "receptive", depending on whether there are difficulties with understanding or expressing language, or both. Expressive aphasia (also known as Broca's aphasia and dysfluent aphasia) is characterised by difficulties communicating thoughts and ideas to others; this may affect speech, writing, gestures or drawing (Sarno, 1998). Receptive aphasia (also known as Wernicke's aphasia) is characterised by difficulties understanding things that individuals hear or read and can impact people's ability to interpret gestures, drawings, numbers and pictures (Sarno, 1998). The severity of aphasia varies and is often characterised as mild, moderate or severe. In a mild case an individual might have a word-finding difficulty in a more severe case all modalities of language can be severely impaired producing a significant disability. Global aphasia results from damage to extensive portions of the language areas of the brain resulting in severe communication difficulties and significantly limits a person's ability to speak or comprehend language. Those with global aphasia may be unable to say even a few words or may repeat the same words or phrase or may have trouble understanding even simple words and sentences (National Institute of Health, 2017).

In most cases, aphasia is caused by strokes involving the left hemisphere, with more extensive damage typically being associated with more severe aphasia (Pedersen et al., 1995; Pedersen et al., 2004). Aphasia is most commonly the result of an occlusion within the middle cerebral artery (MCA) territory (Nogles & Galuska, 2020). The reason for this is thought to be due to the location of brain structures involved in language production. The areas traditionally believed to be involved in speech comprehension and production are in the left cerebral hemisphere known as Broca's area, Wernicke's area, and the arcuate fasciculus, a series of neuronal fibres that connect the two structures. Therefore, damage in either of these areas has been suggested to be responsible for aphasias. However, it should be noted that new advances in the study of language and language pathology, as well as advances in neuroimaging technology, have rendered the classical model somewhat inadequate in its explanation of language processing. For example, the more recently proposed neuroanatomical model of language, the dual stream model (Hickok & Poeppel, 2004).

Aphasia is a common and debilitating consequence of stroke. One in three stroke survivors has aphasia (Flowers et al., 2016), equating to a quarter of a million people in Great Britain (Engelter et al., 2006). Moreover, the presence of aphasia is negatively associated with quality of life (Hilari et al., 2012), social networks (Davidson et al., 2008) and self-identity (Shadden, 2005). However, public awareness of aphasia remains low (Jenkins, 2012). For example, Jenkins (2012) recruited public sector workers and found only 19% had heard of aphasia. Furthermore, there is converging evidence that those with aphasia receive poorer care in health services, due to barriers including inaccessible information, negative staff attitudes, lack of communication opportunities or unskilled communication partners (O'Halloran et al., 2008; Brown et al., 2006; Carragher et al., 2020). From a healthcare standpoint, communication problems between patients with aphasia and health professionals are also a serious concern, since they may be a source of error in diagnosis, management and treatment (Bartlett et al., 2008). Furthermore, there is evidence that those with aphasia receive poorer care in health services, due to "barriers" including inaccessible information, negative staff attitudes, or unskilled communication partners (O'Halloran et al., 2008). Although health professionals are likely to be educated in the symptoms of aphasia, they may not have received specific training in how to communicate with patients with aphasia (Burns et al., 2012; Finke et al., 2008). From a health care standpoint, communication problems between patients with aphasia and health professionals are a serious concern since they may be a source of error in diagnosis and treatment (Bartlett et al., 2008).

## Post- Stroke Depression in People with Aphasia

People with post-stroke aphasia are at greater risk of developing depression than not only the general public but also stroke survivors without aphasia (Evans et al., 2016; De Ryck et al., 2014; Shehata et al., 2015; Kauhanen et al., 2000). Family members of those with post-stroke aphasia are also at risk of experiencing depression (Grawburg et al., 2013). In terms of why PwA are at increased risk of PSD both the biological and CBT accounts of PSD can explain that frequent co-occurrence of aphasia and PSD. The Robinson's (1984) lesion theory of PSD links it to left frontal lobe damage which is also common region of damage for aphasia. Furthermore, the CBT model of PSD (Broomfield et al., 2011) would suggest that the loss of communication reduces activity and participation, thereby producing negative beliefs about oneself, the world and the future.

In terms of treatment, a Cochrane review has reported a small effect size of treating post-stroke depression with anti-depressants, although significant side effects were all highlighted and psychological approaches showed promise, but not enough evidence to demonstrate effectiveness (Allida et al., 2021). However, this review could not recommend these interventions for those with post-stroke aphasia because of too few studies including people with aphasia (PwA). A systematic review of rehabilitation interventions to prevent and treat depression in post-stroke aphasia analysed 45 studies and also concluded that more evidence is required to identify effective prevention and treatment interventions for depression in this population (Baker et al., 2017). There is evidence that PwA are frequently excluded from stroke research (Brady et al., 2013) and notably, from research on post-stroke depression (Townend et al., 2007), including randomised controlled trials (RCT) on PSD treatment (Li et al. 2018; Starkstein & Robinson 1988). Townsend et al.'s (2007) systematic review found that 71% of the 129 studies they analysed reported some exclusion of people with aphasia and less than half, 47%, of studies reported having participants with aphasia in their sample. Furthermore, currently there is no research on suicidality in post-stroke aphasia. Previous researchers have described that the exclusion of people with aphasia from research as systematic and discussed the fact that systematic exclusion of a group of people, even when inadvertent, because of disability is discriminatory (Brady et al., 2013). Furthermore, the lack of inclusion of those with aphasia will likely be limiting the validity of the knowledge base on post-stroke depression and is limiting evidence based clinical practice for those individuals with post-stroke depression and aphasia.

Furthermore, most psychological interventions are 'talking therapies' which limits their accessibility for those with communication difficulties. There is anecdotal evidence that PwA are often excluded from mental health interventions in the UK. An Australian qualitative research study of stroke professionals management of post-stroke depression in PwA, highlighted some barriers for PwA accessing evidence-based psychological treatment. They reported that approaches to treating depression were mainly ad hoc, psychologists reported feeling inexperienced in managing communication in aphasia and felt uncomfortable with how to provide psychological treatments and that staff reported a lot of unmet psychological need and lack of accessibility to psychological therapy and services for PwA (Baker et al., 2019). However, a behavioural therapy approach, which relies less on language to bring about positive change, can be adapted for people with aphasia (Grober et al., 1993). Behavioural approaches suggest depression occurs from a lack of positive response and social reinforcement from the environment and aims to increase activity level and frequency of pleasant events improve mood (Jacobsen et al., 1996). Thomas et al. (2013) demonstrated that behavioural approaches can be effective in improving mood in people with aphasia. This study and its approach is promising but its conclusions are limited; as highlighted by Baker and colleague's systematic review (2017) of rehabilitation interventions of post-stroke depression in PwA, the current evidence base is limited and more research is needed to evaluate effectiveness of possible treatment approaches.

## Screening for Depression and Suicidality

As a result of the increased risk of depression, multiple health guidelines recommend screening *all* stroke survivors (Duncan et al., 2005; Gooskens et al., 2009; Miller et al., 2010). Similarly, multiple national guidelines recommend screening for suicidality in those with suicide risk factors (Her Majesties Government Department of Health, 2012; Canadian Coalition for Seniors' Mental Health, 2006). Yet despite stroke being a well-documented risk factor, currently no stroke guidelines include a recommendation for suicidality screening in all stroke survivors. Screening is defined by the World Health Organisation as "the use of simple tests across an apparently healthy population in order to identify individuals who have risk factors or early stages of disease". In this context, the disease involved is depression and suicidality and the apparently healthy population is stroke survivors. Screening would be the first step in identifying those who would benefit from intervention and treatment (NHS Improvements, 2011). Screening for PSD is completed by staff in multiple professional disciplines, usually through a clinical interview or standardised screening measures (Duncan et al., 2005; Gooskens et al., 2009; Miller et al., 2010). The NHS Improvements stroke report recommends that "all patients should be assessed for mood disorder with a simple brief standardised measure e.g. GHQ12, BASDEC, HADS, PHQ9. Participatory measures such as the DISCs or observational measures such as the SAD-Q may be used in patients with more severe communication or cognitive difficulties." (NHS Improvements, 2011, p 10). Notably, this report does not recommend screening suicidality unless severe and persistent depression is identified. However, stroke without depression has been identified as a risk factor for suicidality (Bartoli, et al. 2017; Eriksson et al., 2015; Pompili et al., 2012). Depression plays a part but does not seem to be the whole story. Furthermore, it should be noted that only some standardised screening measures for depression include an assessment of suicidality.

A recent executive summary of PSD stated “one would assume that patients with stroke are routinely being screened for depression in our healthcare facilities. Sadly, however, this is not the case. Many patients with stroke are never screened for depression” (Rogers, 2017, p 66). According to the UK Sentinel Stroke National Audit Programme (SSNAP) (2019) 92% of patients received mood and cognition screening by discharge “if required”. However, this would not be consistent with the World Health Organisation’s definition of screening, which stipulates testing all in a particular population (WHO, 2012) but SSNAP does not provide data on screening rates in all stroke survivors. Additionally, SSNAP does not collect data on suicidality screening. A survey of stroke professionals in Scotland found that 72% of the 174 participants reported regularly screening mood (Lees et al., 2014). Another survey of stroke professionals found that a third of staff reported being very unlikely to screen mood (Hart & Morris, 2008). However, none of these studies explored suicidality screening rates. A survey of stroke survivors completed by the Stroke Association (2012) found that of their 2,700 responses, 59% reported feeling depressed, but over half of those did not receive any information, advice or support to help with depression.

## Screening for Depression and Suicidality in Aphasia

Despite multiple health guidelines recommending screening for depression in all stroke survivors, depression remains under assessed, diagnosed and treated in all stroke survivors (Rogers, 2017; Stroke Association, 2012). The assessment of depression is usually completed using a clinical interview or standardised written or verbal self-report measures (Duncan et al., 2005; Gooskens et al., 2009; Miller et al., 2010). This reliance on written or verbal assessment measures creates an additional barrier for those with aphasia. Specific instruments for the assessment of depression in aphasia have recently been developed (Stem et al., 1997; Turner-Stokes et al., 2005; Barrows & Thomas, 2018; Lincoln et al., 2000; Benaim et al., 2004) but the validity and frequencies with which they are used in clinical practice and research has been questioned (van Dijk et al., 2016; Bennett et al., 2006; Berg et al., 2009).

Despite this, several aphasia-friendly depression diagnosis methods are available, for example, an interview can be made accessible by using facilitated communication techniques, including: simplified questions, supplementary key written phrases or verbal rather than written material, repetition, personalising questions and use of pictorial material. Programmes that upskill partners and health professionals to become effective communication partner for those with aphasia have been shown to be effective (Legg et al., 2005; Simmons-Mackie et al., 2007; Simmons-Mackie et al., 2010). Furthermore, nonverbal self-report mood measures have been developed for example: The Visual Analog Mood Scales (VAMS), the Depression Intensity Scale Circles (DISCs) and the Dynamic Visual Analogue Mood Scales (D-VAMS) (Stem et al., 1997; Turner-Stokes et al., 2005; Barrows & Thomas, 2018). Finally, standardised observer rated measures have been developed and validated in individuals with post-stroke aphasia, for example the Stroke Aphasia Depression Questionnaire (SADQ) and The Aphasic Depression Rating Scale (ADRS) (Lincoln et al., 2000; Benaim et al., 2004).

However, questions have been raised about both the quality of methodology employed in the validation studies of the nonverbal self-report mood measures and the robustness of these measures as screening measure for depression (van Dijk et al., 2016; Bennett et al., 2006). Additionally, visual analogue scales are limited as they only measure one thing and therefore do not reflect the full picture of depression. Questions have also been raised regarding observer-rated approaches to screening, as the correlations between observer-rated and self-reported mood have proven to be unreliable (Berg et al., 2009) and observer rating measures removes the individual's voice and involvement in the assessment process. A recent systematic review of the reliability, validity and feasibility of available instruments for measure post-stroke depression in those with aphasia concluded that "none of the instruments available were found to be sufficiently investigated and most of the studies identified were of low methodological quality. Given the present evidence, the Stroke Aphasic Depression Questionnaire-10, the Stroke Aphasic Depression Questionnaire-H10 and the Signs of Depression Scale are the most feasible and can be recommended for clinical practice. " (van Dijk et al., 2016).

A systematic evaluation explored what methods research used to assess for depression in those studies that include those with post-stroke aphasia (Townend et al., 2007). They found that less than half of the studies (29/60; 48%) adapted their main depression diagnostic method for individuals with aphasia. It was found that 80% of studies conducted clinical interviews to diagnose depression, 10% used questionnaires and 10% used both methods combined.

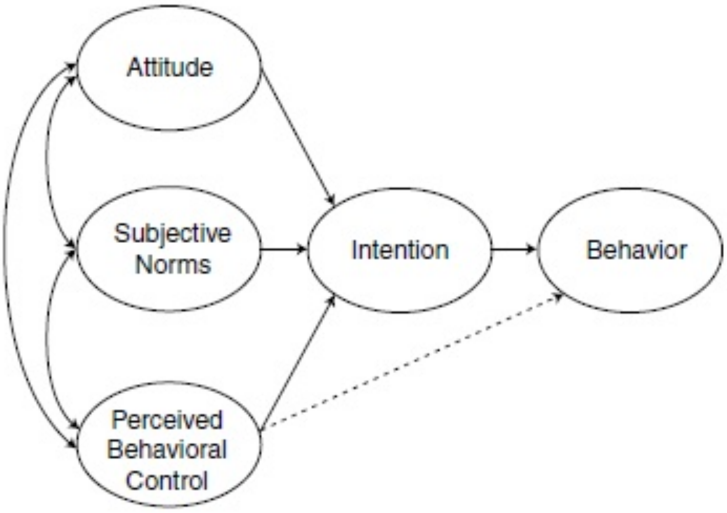
## The Theory of Planned Behaviour

There is a developing literature within the field of stroke rehabilitation using the Theory of Planned Behaviour (TPB) model (Ajzen, 1987) to explore staff intentions and behaviours to inform how best to facilitate service delivery.

TPB is one of the most frequently cited and influential models for the prediction of human social behaviour (Ajzen, 2011). The TPB postulates an association between personal beliefs and behaviours; namely that attitudes toward behaviour, subjective norms, and perceived behavioural control, together shape an individual's behavioural intentions and behaviours. Attitudes are defined as the degree to which a person has a favourable or unfavourable evaluation of the behaviour e.g., screening mood is useful. Subjective norms are defined as the perception that specific significant others have preferences about whether one should or should not engage in a behaviour e.g., my boss expects me to complete mood screens. Perceived behavioural control is defined as an individual's perception of the ease or difficulty of performing the particular behaviour (Ajzen, 1987), and is influenced by whether one has access to the necessary resources and opportunities to perform the behaviour successfully (Ajzen 1988, 1991).

**Figure 8**

*Visual Representation of the Theory of Planned Behaviour Model (Ajzen, 1989)*



Several studies have found that the TPB successfully predicts health-related behavioural intention (meta-analysis- Godin & Kok, 1996) as well as specific behaviours such as exercise (Blue, 1995; Hausenblas et al., 1997; Hagger et al.,

2002) and condom use (Sheeran & Taylor 1999). In the most comprehensive review to date, Armitage and Conner (2001) reported that the TPB accounted for 27% of variance for behaviour and 39% of intention across one hundred and eighty- five studies. Sheerans' (2002) meta-analysis reported a mean overall correlation of 0.53 between intention and behaviour. A meta-analysis conducted by McEachan and colleagues (2011) and Godin and Kok (1996) produced comparable results. Thus, there is evidence of a relationship between behavioural intentions and actions.

The TPB model has been effectively applied in studies of staff intentions and behaviours in stroke services (Hart & Morris, 2008; Gillespie et al., 2019). Hart and Morris (2008) applied the TPB to try to understand depression screening behaviour in stroke professionals; the aim of this study was to try to improve screening rates. They concluded that TBP was effective for understanding screening behaviours and that perceived behavioural control and subjective norms predicted screening intent. Hart and Morris (2008) concluded that "The theory of planned behaviour provides a framework for understanding screening intentions." Therefore, they suggested that "compliance may be enhanced by: training to increase knowledge and skills, providing evidence of the utility, increasing awareness of guidelines, support from colleagues and integrating mood assessment into job roles and routine assessment." (Hart & Morris, 2008, p69). TPB has also been successfully applied to understand intention to provide non-pharmacological interventions for emotionalism post-stroke (Gillespie et al., 2019). This was a survey of two hundred and twenty UK stroke clinicians which concluded that attitudes and subjective norms predicted intention to provide non-pharmacological approaches to help stroke survivors cope with and manage post-stroke emotionalism.

There has been criticism of the TPB, most notably summarised by Sniehotta and colleagues (2014) in their article, 'Time to retire the theory of planned behaviour' who questioned the predicative power of TPB on behaviour, it's validity and usefulness as a model. Some reject the hypothesis that consciousness is a causal agent suggesting that thoughts do not cause behaviours (Wegner & Wheatley, 1999). Others reject the view that human behaviour is driven by explicit attitudes (Greenwald & Banaji, 1995) and others dispute the unimportance of unconscious mental processes on behaviour (Aarts & Dijksterhuis, 2000; Brandstätter et al., 2001; Uhlmann & Swanson, 2004). Additionally, the theory has been criticised for its focus on rational reasoning, excluding unconscious influences on behaviour (Sheeran et al., 2013) and the role of emotions beyond anticipated affective outcomes (Conner et al., 2013). However, even Sniehotta et al. (2014) acknowledge that the TPB has been shown to consistently predict behaviour from intention and perceived behavioural control and that a large change in intentions is found to also produce changes in behaviour. Sniehotta et al.'s (2014) paper has also attracted a lot of countercriticism and commentary (Ajzen, 2015; Armitage, 2015; Connor, 2015; Ogden, 2015). There are alternative models of behaviour, for example the COM-B model of behaviour (Michie et al., 2014) which proposes that people need capability (C), opportunity (O) and motivation (M) to perform a behaviour (B). However, currently the TPB remains the model with the largest empirical support. Therefore, based on this and the fact that TPB has been applied successfully to staff intention in stroke rehabilitation research, the TPB was selected as the behavioural framework for the research paper in this thesis.

This thesis presents a systematic review of the inclusion of people with aphasia in current stroke research through investigating the methods and adaptations used to screen and assess depression in people with post-stroke aphasia. This is followed by the first TPB study of self-reported staff practices in screening for low mood and suicidality in people with post-stroke aphasia identifying factors that act as facilitators and barriers to screening. This research is in line with the agenda and values of both clinical practice and the research field. The Stroke Association (2017) named psychological support post-stroke as a key research agenda in stroke research. Furthermore, the value of 'everyone counts' is one of the six values in the NHS constitution; this sets out the importance of ensuring that everyone has access to the resources available in the NHS without discrimination. It is therefore hoped that this thesis provides a unique and rigorous contribution in an important area of stroke care.

# **Chapter 2**- Systematic Review

## Levels of Exclusion and the Methods of Inclusion of People with Aphasia in Post-Stroke Depression Research: A Systematic Review

Prepared for submission to Clinical Rehabilitation (guidelines outlined in Appendix A)

# Levels of Exclusion and the Methods of Inclusion of People with Aphasia in Post-Stroke Depression Research: A Systematic Review

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Word count excluding figures, tables and references: 5,325

## Abstract

### Introduction

One in three stroke survivors have aphasia and they are at a greater risk of developing depression compared to non-aphasic stroke survivors. Despite this, people with aphasia (PwA) are frequently excluded from stroke research, including post-stroke depression (PSD) research. This is despite the fact that several measures of depression have been validated in aphasia and clinical interview can be made accessible for PwA through the use of supportive communication adaption.

### Method

A systematic review was conducted to determine the inclusion of PwA in post-stroke depression research and methods used to assess mood in PwA, to determine if inclusion rates and the validity of assessment measures have improved. Three bibliographic databases (MEDLINE, CINAHL and EMBASE) were searched.

### Results

2,673 studies were generated. Of the 997 studies assessing PSD, only 70 (7.16%) studies did not exclude PwA and were included in the systematic review. Demonstrating the continued exclusion of PwA from most research on PSD. When included, assessment practices frequently raised issues of accessibility or use of unvalidated measures; resulting in PwA being excluded from the assessment of depression.

### Conclusion

In conclusion, more effort is needed to ensure PwA are included in PSD research and receive validated and accessible measures of mood.

## Introduction

One in three stroke survivors has aphasia, an impairment in language comprehension and expression[1], equating to a quarter of a million people in Great Britain[2]. Importantly, the presence of aphasia is negatively associated with quality of life[3], social networks[4] and self-identity[5]. However, public awareness of aphasia remains low[6] and there is converging evidence that those with aphasia receive poorer care in health services, due to barriers including inaccessible information, negative staff attitudes, lack of communication opportunities or unskilled communication partners[7-9]. From a healthcare standpoint, communication problems between patients with aphasia and health professionals are also a serious concern, since they may be a source of error in diagnosis, management and treatment[10].

Post-stroke depression is a common, serious consequence of stroke. An estimated 31% of all stroke survivors develop depression[11], making it more prevalent than in the general public[12]. Multiple research studies have found that those with aphasia are at even greater risk of developing depression compared to non-aphasic stroke survivors[13-16]. Post-stroke depression (PSD) has been negatively associated with survival[17,18], cost of medical care[19], functional outcome[20], resumption of social activities[21], and quality of life[20]. Furthermore, one review found stroke to be a significant risk factor for suicide and developing suicidal ideation[22]. An epidemiological study reported that 7.2% of stroke participants admitted to a hospital in Denmark died by suicide[23], greatly exceeding the suicide rate of the UK general population, which is 11.0 deaths per 100,000 population[24].

Despite the impact and prevalence of post-stroke aphasia, those affected are frequently excluded from stroke research[25-26] and notably, from research on post-stroke depression, despite being at a greater risk of developing it[13-16]. Townend et al.[26] review found that 71% of 129 studies evaluated reported either some people with aphasia (PwA) were being excluded from participation (e.g., those with severe and/ or moderate aphasia, or with impaired comprehension or who were deemed too aphasic to participate) or all participants with aphasia were excluded. Less than half (47%) of studies reported having participants with aphasia in their sample. Similarly, those with severe communication difficulties have often historically been omitted from randomised controlled trials (RCT) on PSD treatment[27]. This exclusion of PwA from stroke research is likely to skew research evidence on PSD, limiting effective clinical practice for people with post-stroke depression and aphasia. These studies explore the rates at which aphasia was named as an exclusion criterion for inclusion in the study sample; however, there are other types of more masked exclusion where PwA are included in the sample but are prevented from full participation in the study. For example, PwA may not be able to access the cognitive or depression assessment due to the heavy language load of the measure. The description of the exclusion of people with post-stroke aphasia as 'systematic' highlights the potential for inadvertent discrimination[25].

Several factors may underpin the exclusion of people with post-stroke aphasia from research on stroke and post-stroke depression[25,26]. One contributing factor may be that by convention, assessment of depression relies heavily on verbal procedures, such as clinical interviews or written self-report measures. This therefore creates a participation barrier for those with communication difficulties and may leave researchers unable to facilitate participation[28,29]. Stroke professionals will typically have received training concerning aphasia but may not have received specific training in how to communicate with patients with aphasia[30,31]. Another factor highlighted by Brady and colleagues[25] is the incorrect assumption of some researchers, that PwA necessarily lack the capacity to make decisions for themselves, including capacity to participate in research.

There are a range of ways in which depression can be assessed or screened for in an aphasia-friendly way. The World Health Organisation[32] defines screening as using a simple test across a particular population (e.g., stroke survivors) to allow early identification of a condition, in this case screening depression in people with post-stroke aphasia. By contrast a clinical assessment determines the presence of a specific condition and provides a fuller picture of a condition, its nature and severity. An interview can be made accessible by using communication support techniques, such as simplified questions, supplementary key written phrases, spoken rather than written material, repetition, personalising questions and use of pictorial material[33]. Programmes that upskill carers and health professionals to become effective communication partners for those with aphasia have been shown to be effective[34-36]. Furthermore, nonverbal self-report mood measures have been developed, such as the Visual Analog Mood Scales (VAMS)[37], the Depression Intensity Scale Circles (DISCs)[38] and the Dynamic Visual Analogue Mood Scales (D-VAMS)[39]. Standardised observer rated measures have also been developed and validated in individuals with post-stroke aphasia, for example the Stroke Aphasia Depression Questionnaire (SADQ)[40], Stroke Aphasic Depression Questionnaire Hospital Version (SADQ-H10)[40] and the Aphasic Depression Rating Scale (ADRS)[41].

The methodology of non-verbal self-report mood measures and the robustness of these measures in screening for depression after stroke has been questioned, however. For example, a recent systematic review by van Dijk et al.[42] highlighted that studies investigating internal consistency and reliability had small sample sizes[43,44] or excluded the target population[43,45] or had selection bias which meant that those with more severe aphasia were not included[46,47]. Van Dijk et al.[42(p9)] thus noted that "overall, the methodological quality of the studies was rated poor to fair, and the evidence for the psychometric properties of the instruments was limited.". Based on this van Dijk et al.[42] concluded that none of the instruments had been sufficiently investigated but that the Stroke Aphasic Depression Questionnaire-10[40], the Stroke Aphasic Depression Questionnaire-H10[40] and the Signs of Depression Scale[41] were the most feasible and therefore were recommended for use in clinical practice.

A systematic review by Townend et al.[49] of methods used to assess depression in research that included people with post-stroke aphasia found that fewer than half the studies (29/60; 48%) adapted the assessment method for participants with aphasia. Overall, 80% of studies identified conducted clinical interviews to diagnose depression, 10% used questionnaires and 10% used both methods combined. The limited use of observer-rated measures designed for use with PwA is noteworthy, especially considering the conclusion by van Dijk et al.[42] regarding the feasibility of these measures. Furthermore, limited use of communication support adaptations casts doubts on the validity of clinical interviews used to assess depression in PwA.

Given the prevalence of post-stroke aphasia and comorbid depression, it is important to ensure that inclusive assessment approaches are used in research on post-stroke depression. Psychological support post-stroke is currently a key research agenda in stroke research[50] and the value of 'everyone counts' is one of the six values in the NHS constitution[51]. 'Everyone counts' sets out the importance of ensuring that everyone has access to the resources available in the NHS, without discrimination. It is unclear, however, to what extent these have improved since the systematic reviews by Townend and colleagues[26] investigating the inclusion of people with aphasia in post-stroke depression research and by van Dijk and colleagues[42] on the reliability, validity and feasibility of measures to assess depression in people with post-stroke aphasia. The aim of the current systematic review is therefore to review the inclusion of PwA in post-stroke depression research and methods used to assess mood in PwA, to determine the inclusion rates and the validity of assessment measures used.

## Method

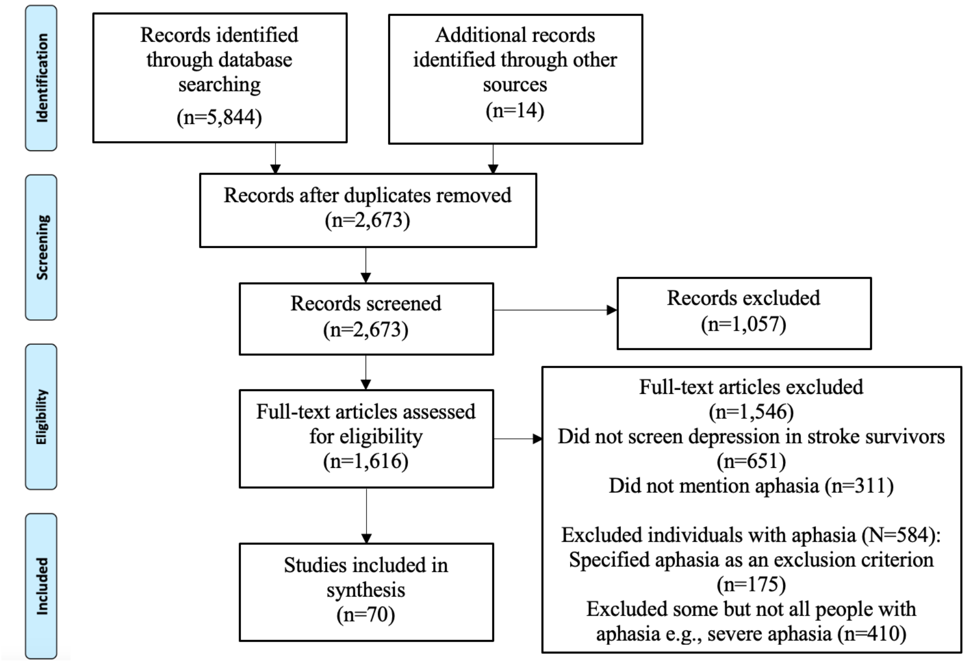
This systematic review was registered on the International Register of Prospective Systematic Reviews (PROSPERO) (registration number: CRD42020167364) and followed PRISMA guidelines[52]. Studies that assessed depression in adults with post-stroke aphasia were included. Stroke was defined as reference to stroke as an inclusion criterion or specific participants were reported to have had a stroke in the results or discussion. To determine that a depression assessment had been completed, a reference to a screening measure, assessment or diagnosis of depression or low mood (for example, a self-report measure or a clinical interview) was required. We excluded studies not published in English, studies of children or adolescents and studies of people with dementia or transient ischaemic attack. Studies were not excluded based on study design. To determine the inclusion of aphasia, the terms 'aphasia', 'dysphasia' or 'a language impairment of either comprehension or expressive nature', were required. The inclusion of aphasia was defined as: aphasia not being listed as an exclusion criterion, aphasia being listed as an inclusion criterion, or mention of participants with aphasia.

A predetermined search string of 'stroke' (cerebrovascular accident, CVA and thrombosis) and 'depression' (depressive disorder, low mood, post stroke depression and dysthymic disorder) and 'assessment' (screen and diagnose), and their synonyms, was used for this paper (Appendix B). This is a modified search strategy of previously published systematic review[49], to which the current review added the term 'assessment'. The search string was design with consolation from a specialist librarian. Three bibliographic databases (MEDLINE, CINAHL and EMBASE) were searched from January 2006 to July 2020. Reference lists of key publications[42] were also searched for additional research papers.

Titles and abstracts were screened to identify studies that assessed post-stroke depression in adults. Study exclusion and inclusion criteria were extracted and studies that assessed post-stroke depression and included PwA, were retained for full text review. Studies were then identified that did not reference excluding anyone with aphasia and administered a depression assessment, including to those with aphasia. The number of studies that excluded PwA, or specifically those with severe or moderate aphasia, or which did not reference aphasia in the description of the sample or method, was recorded. A second reviewer (CF) independently reviewed a random sample of 20% of studies included in the final synthesis, to confirm inclusion criteria were met. Any disagreements were resolved by a third reviewer (NB).

**Figure 1**

*Process of identifying, screening and assessing eligibility for inclusion of studies*



Data were extracted on sample source and size, participant demographics (sex and age), the number of participants with aphasia, the main depression assessment method (interview, observer-rated scales or self-report questionnaires), adaptations to this method for participants with aphasia and specific assessment tool used (e.g., Hospital Anxiety and Depression Scale[53] or Stroke Aphasic Depression Questionnaire [40]). We defined aphasia-specific measures as any measure designed to be suitable for use with an individual with aphasia e.g., Aphasia Depression Rating Scale. Adaptions were defined as established speech and language clinical practices used to ensure non-aphasia-specific measures are accessible for individuals with aphasia e.g., re-phrasing questions, using multiple choice or providing written information in alternative formats e.g., easy read. Information or comments regarding both the effectiveness of the main and adapted depression assessment methods in PwA and the validity and reliability of these methods, were extracted. One author was contacted to clarify an ambiguity.

There is no established quality appraisal tool for evaluating both the psychometric characteristics, quality of screening and assessment of depression with post-stroke aphasia; nor the extent of inclusive practice. A bespoke quality appraisal tool (Appendix C) was therefore developed and used by the researcher (HS) to evaluate the internal and external validity of the study methodology, including the validity of the assessment process, in the studies included. Studies were evaluated to determine whether the depression assessment used had been: validated for use in stroke and aphasia; administered by an appropriate professional; administered to all participants; any communication adaptions discussed in sufficient detail to be replicable and if the rationale or evidence base of any communication adaption were discussed. Studies were also evaluated to determine whether the study sample was representative of stroke survivors, a clear description of selection criteria was provided and whether information on study withdrawal was reported. The published 'Best Bets Critical Appraisal Worksheets for screening' was used to inform this appraisal tool[54]. A second reviewer (AB) independently reviewed a random sample of 25% papers using the same bespoke appraisal tool and consensus was reached.

### Analysis

Narrative synthesis was used to assess the inclusion of PwA in post-stroke depression research and methods used by researchers to assess depression in PwA, in terms of the current validity research. Guidance on conducting narrative synthesis was used to inform this analysis[55]. An evidence synthesis approach was taken by calculating a series of descriptive statistics on the variability of study methodology and population, to explore relationships between studies and to highlight general trends in the research. First, the relative frequency of use of each type of approach for assessing depression (clinical interview, standardised self-report questionnaire or observer rated measure) and each standardised measure was recorded. Second, the relative frequency of use of screens validated in stroke and in aphasia was recorded. Whether a measure was deemed to be validated for use in stroke and in aphasia was determined by whether a psychometric validation study is available for the use of this measure or adaption with aphasia and/ or stroke participants. As discussed in the introduction some authors have questioned the robustness of some of these studies[42]. It is acknowledged that this analysis is somewhat limited by the current limitation in the literature base. Third, the relative frequency of use of aphasia-specific measures of depression was noted. Additionally, the relative frequency of use of adaptions with individuals with aphasia by researchers when not using an aphasia specific measure was computed. Finally, the relative frequency of use of the different types of adaptions was assessed.

# Results

## Study Selection: Inclusion of People with Aphasia

A total of nine hundred and seventy- seven papers (36.55%) generated from the database searches were identified as having completed an assessment or screen of depression in a stroke survivor. Seventy studies (7.16%) reported not excluding those with aphasia and therefore met inclusion criteria for the systematic review.

The rest of the papers did not meet inclusion criteria for the systematic review. Over half (n= 584, 59.77%) reported the exclusion of PwA; one hundred and seventy-five of these papers (17.81%) specified aphasia as an explicit exclusion criterion and four hundred and ten papers (41.97%) excluded some, but not all, participants with aphasia (e.g., those with severe and/ or moderate aphasia, or with impaired comprehension or who were deemed too aphasic to participate). Additionally, a third of studies (n=311, 31.83%) that screened or assessed post-stroke depression, did not mention aphasia when describing exclusion and inclusion criteria, or when describing the participants.

Furthermore, the methods used to determine the presence, severity or subtype of aphasia varied between studies: some used a standardised aphasia diagnosis tool or language measure (e.g., Frenchay Aphasia Screening Test and Token test), others used medical records, some used self-report and some studies simply used researcher's judgement. A significant proportion of studies did not report how they assessed for the presence of aphasia to determine exclusion; phrases such as “were notably aphasic” or “unable to complete assessment” were common. This lack of standardisation made comparison between studies difficult and made it difficult to determine the true number of PwA excluded. Additionally, only a minority of studies reported the numbers of individuals with aphasia that were excluded, making it not possible to determine a true figure of how many individuals with aphasia were excluded. Finally, several studies reported an inclusion criterion relating to a participant being able to give written or verbal consent to participate; as some PwA struggle to give written or verbal consent without communication adaptions, it is therefore unclear how often this inclusion criteria resulted in the masked exclusion of PwA. Some studies did report the reasons why participants could not consent. Of the studies that did report this, the presence of aphasia was a common reason, but not the norm. Some studies reported allowing consent via proxy, however, this was relatively uncommon. The lack of specificity regarding exclusion criteria in terms of aphasia, combined with the lack of reference to aphasia in many papers, may mask the true level of exclusion.

## Quality Appraisal

Half of studies provided clear description of selection criteria (n=34, 48.57%). Many did not provide information on the proportion of eligible participants who agreed to participate (n=44, 62.86%) and less than half provided information on study attrition (n=32, 45.71%). In terms of whether samples were representative, two-thirds of study samples over-represented males (n=49, 70%) and almost half over-represented younger participants (n=32, 45.71%) as women are more likely to experience a stroke (53.5% of all strokes occur to women) and the median age of a stroke is 77 years[56].

Not all studies reported using a measure of depression validated for use in stroke in a standardised manner (n=62, 88.57%). Some studies either did not use a standardised measure for assessing depression (n=1, 1.43%), a measure not validated in stroke (n=1, 1.43%) or reported non-standard use of a measure (n=6, 8.57%) for example standardised self-report measures (e.g., the Patient Health Questionnaire[57] or Hospital Anxiety and Depression Scale[53]) were completed by informants and not participants with post-stroke aphasia. In contrast, only a minority of studies reported using a measure validated in aphasia (n=31, 44.29%). Of the studies that used measures not validated for use in aphasia, just over half reported adapting their method of assessment for individuals with aphasia (n=25, 52.08%).

Of the twenty-five studies that reported using supported communication adaptions, the majority reported these in sufficient detail to be replicable (n=17, 68%) but only half reported the evidence or rationale for the adaptions used (n=13, 52%). In twelve studies (17.14%) not all participants received a mood screen and in almost half of the studies (n=29, 41.43%), it was unclear whether all participants received a mood screen, potentially masking the true extent of exclusion of PwA.

Almost half the studies included, failed to report whether measures had been administered by an appropriate professional (n=32, 45.71%). Twenty-six studies

(37.14%) reported that the measure used was administered by a clinician. In seven studies, measures were administered by nurses (10%), in six by psychologists (8.57%), in five each by psychiatrists (7.14%) and neurologists (7.14%), and two each by physicians (2.86%), occupational therapists (2.86%), physiotherapists (2.86%) and speech and language therapists (2.86%). Seven studies (10%) did not report the professional background of the assessor but reported that they were trained to undertake the assessment. Although most studies reported that a clinician completed the assessment, only fourteen (20%) had a professional background in mental health and two (2.86%) had a professional background in supporting those with deficits in communication and language.

Table 1 summarises the quality assessment for each paper included in the synthesis.

**Table 1**

*Summary of Quality Assessment of Included Studies N=70*

| **Study ID** | **Were the studies' selection criteria clearly described?** | **Was information provided on the proportion of eligible participants who agree to participate?** | **Did all participants receive the depression screen?** | **Was Information Provided on Any Participant Withdrawals?** | **Is the Sample Representative?** | **Has the Depression Measure Been Validated for use in Stroke and used in a validated way?** | **Has the Depression Measure Been Validated for use in Aphasia?** | **Where those who administered the screen from an appropriate professional background?** | **Were the adaptions used to support communication clearly described enough to replicate?** | **Was the evidence base or rationale for the adaptions explained?** |
|---|---|---|---|---|---|---|---|---|---|---|
| *Self-report Measures* | | | | | | | | | | |
| 1. Morsund 2019[58] | 🟥 | 🟥 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 2. Glozier 2017[59] | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 🟥 | 🟥 | 🟨 | 🟩 | 🟥 |
| 3. Barra 2017[60] | 🟥 | 🟩 | 🟥 | 🟥 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 4. Arba 2016[61] | 🟥 | 🟥 | 🟥 | 🟥 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 5. McKenna 2012[62] | 🟥 | 🟩 | 🟥 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | 🟩 | 🟥 |
| 6. von Sarnowski 2012[63] | 🟥 | 🟩 | 🟩 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | 🟥 | 🟥 |
| 7. Hobson 2020[64] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 8. Heiberg 2018[65] | 🟥 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 9. Kielbergerová 2015[66] | 🟩 | 🟥 | 🟨 | 🟥 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 10. | Huenges Wajer 2017[67] | 🟥 | 🟥 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 11. | van Middelaar 2015[68] | 🟥 | 🟩 | 🟨 | 🟩 | 🟥 | 🟥 | 🟩 | 🟨 | 🟩 | 🟥 |
| 12. | Marshall 2014[69] | 🟥 | 🟥 | 🟩 | na[2] | 🟥 | 🟩 | 🟥 | 🟨 | 🟥 | 🟥 |
| 13. | Weaver 2013[70] | 🟩 | 🟥 | 🟥 | 🟥 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 14. | Mroczkowska 2019[71] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 15. | Benejam 2009[72] | 🟥 | 🟩 | 🟥 | 🟩 | 🟥 | 🟩 | 🟥 | 🟥 | na* | na* |
| 16. | Shehata 2015[15] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 17. | Ashaie 2019[73] | 🟩 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 |
| 18. | Pompon 2018[74] | 🟩 | 🟥 | 🟨 | na[2] | 🟥 | 🟩 | 🟥 | 🟨 | 🟩 | 🟩 |
| 19. | Pompon 2019[75] | 🟩 | 🟥 | 🟩 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | 🟩 | 🟩 |
| 20. | Lee 2015[76] | 🟩 | 🟥 | 🟥 | 🟨 | 🟥 | 🟩 | 🟥 | 🟥 | 🟩 | 🟩 |
| 21. | Graven 2016[77] | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 22. | Han 2019[78] | 🟥 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 23. | Trochimczyk 2017[79] | 🟥 | 🟥 | 🟨 | 🟥 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 24. | Wong 2013[80] | 🟩 | 🟥 | 🟩 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 25. | Deguchi 2013[81] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 26. | Hilari 2010[82] | 🟩 | 🟥 | 🟩 | 🟥 | 🟥 | 🟩 | 🟥 | 🟨 | 🟥 | 🟥 |
| 27. | Hoffmann 2013[83] | 🟩 | 🟥 | 🟩 | 🟨 | 🟥 | 🟥 | 🟥 | 🟩 | na* | na* |
| 28. | Barrows 2018[39] | 🟩 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 29. | Lees 2014[84] | 🟥 | 🟩 | 🟩 | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 |
| 30. | Dennis 2019[85] | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟥 | 🟥 | 🟨 | 🟥 | 🟥 |
| *Clinical Interview* | | | | | | | | | | | |
| 31. | Tse 2017[86] | 🟥 | 🟥 | 🟩 | 🟥 | 🟥 | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 |
| 32. | Pascoe 2015[87] | 🟩 | 🟥 | 🟩 | na[2] | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 33. | Hofmeijer 2013[88] | 🟥 | 🟩 | 🟥 | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 | na* | na* |
| 34. | Laska 2007[89] | 🟥 | 🟥 | 🟨 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 35. | Naess 2009[90] | 🟥 | 🟥 | 🟨 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 36. | Hofmeijer 2009[91] | 🟩 | 🟥 | 🟥 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 37. | Welmer 2007[92] | 🟥 | 🟥 | 🟨 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | na* | na* |
| 38. | Lundstörm 2020[93] | 🟩 | 🟩 | 🟩 | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 | na* | na* |
| 39. | Tse 2017[94] | 🟥 | 🟥 | 🟩 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 |
| 40. | Idiaquez 2015[95] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | 🟥 | 🟥 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 41. | Yuan 2014[96] | 🟩 | 🟥 | 🟥 | 🟥 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 42. | Pustokhanova 2013[97] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 43. | Guo 2017[98] | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟩 | na* | na* |
| 44. | Jerome 2009[99] | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | na* | na* |
| 45. | Hachioui 2014[100] | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 | 🟥 | 🟥 | 🟨 | na* | na* |
| *Observer-rated Measure* | | | | | | | | | | | |
| 46. | Laures-Gore 2013[101] | 🟩 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 47. | Kaur 2020[102] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟩 | 🟩 | na* | na* |
| 48. | Gyagenda 2015[103] | 🟩 | 🟥 | 🟩 | na[2] | 🟥 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 |
| 49. | Valiengo 2016[104] | 🟥 | 🟥 | 🟩 | 🟨 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 50. | Wang 2018[105] | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 51. | Koleck 2017[106] | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 | 🟩 | 🟩 | 🟨 | na* | na* |
| 52. | Maresca 2019[107] | 🟩 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟩 | 🟩 | na* | na* |
| 53. | Laurent 2011[108] | 🟥 | 🟩 | 🟥 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 54. | Klimiec 2017[109] | 🟩 | 🟥 | 🟥 | 🟨 | 🟩 | 🟩 | 🟥 | 🟨 | na* | na* |
| 55. | van Almenkerk 2015[110] | 🟥 | 🟥 | 🟨 | 🟨 | 🟥 | 🟩 | 🟥 | 🟩 | na* | na* |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 56. | Laures-Gore 2017[111] | 🟩 | 🟥 | 🟩 | na[2] | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| *Mixed Approach* | | | | | | | | | | | |
| 57. | van Dijk 2018[112] | 🟥 | 🟩 | 🟩 | 🟥 | 🟥 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 |
| 58. | Kontou 2012[46] | 🟥 | 🟩 | 🟥 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 59. | Cobley 2012[47] | 🟥 | 🟥 | 🟩 | 🟥 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 60. | Franzén- Dahlin 2008[113] | 🟥 | 🟥 | 🟨 | 🟨 | 🟩 | 🟥 | 🟩 | 🟨 | 🟥 | 🟥 |
| 61. | Tessier 2017[114] | 🟩 | 🟥 | 🟥 | 🟨 | 🟥 | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 |
| 62. | van Dijk 2017[115] | 🟥 | 🟩 | 🟩 | 🟨 | 🟥 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 |
| 63. | Lightbody 2007[116] | 🟩 | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟥 | 🟨 | 🟥 | 🟥 |
| 64. | De Ryck 2014[117] | 🟩 | 🟥 | 🟩 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | 🟥 | 🟥 |
| 65. | Benaim 2010[118] | 🟥 | 🟩 | 🟩 | 🟩 | 🟥 | 🟩 | 🟩 | 🟩 | 🟩 | 🟩 |
| 66. | Guiraud 2016[119] | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | 🟩 | 🟩 |
| 67. | Sackley 2008[120] | 🟩 | 🟩 | 🟨 | 🟩 | 🟥 | 🟩 | 🟥 | 🟨 | 🟩 | 🟥 |
| 68. | Lightbody 2007[121] | 🟩 | 🟥 | 🟩 | 🟩 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 69. | Berg 2008[122] | 🟩 | 🟥 | 🟨 | 🟥 | 🟥 | 🟩 | 🟩 | 🟨 | na* | na* |
| 70. | Buijck 2013[123] | 🟥 | 🟩 | 🟨 | 🟩 | 🟩 | 🟩 | 🟥 | 🟨 | na* | na* |

Red= no, Yellow= not clear or not reported and Green= yes.
* represents papers that did not report using supported communication adaptions.
$na^2$ = no withdrawals

### Synthesis

Most of these study samples were drawn from acute or rehabilitation hospitals (n=45, 64.29%) with a minority recruited from the community or outpatient clinics (n=25, 35.71%). A minority of studies recruited a purely aphasic sample (n=12, 17.14%); the majority were mixed samples of those with and without language difficulties. When reported, the pooled average age was 63.08 years (SD) and the pooled percentage of male participants was 57.45%. Sample sizes ranged from 4 to 3,127, with a combined total of 20,928 participants, of whom 4,090 (19.54%) had aphasia. However, it should be noted that sixteen (22.86%) studies did not report the number of PwA in their samples; again, highlighting a lack of clear information provided on PwA in research studies. Table 2 provides further information on specific demographic information for each study included in the synthesis.

### Masked Exclusion of People with Aphasia

Importantly, almost a third of the studies demonstrated masked exclusion of PwA. Despite not listing aphasia as an exclusion criterion, they excluded some PwA based on the methodology of the study (n=22, 31.43%). For example, authors reported that not all PwA received the depression screens (n=13, 18.57%). In most cases these mood measures were verbal measures and had not been validated in PwA. Additionally, PwA did not receive a cognitive screen (n=4, 5.71%). Some studies reported a very small proportion of their sample had aphasia (n=5, 5.71%) and some noted either few or no people with moderate or severe aphasia in the sample (n=5, 7.14%) suggesting possible masked exclusion. Finally, some studies had exclusion criteria with elements likely to exclude those with aphasia, for example the requirement of written or verbal consent (n=2, 2.86%), or the completion of all the subtests (n=2, 2.86%). In both cases these mood measures were language based, had not been validated in PwA and supported communication adaption was not reported. Without these, some PwA would struggle to give informed consent and therefore were likely excluded. Table 2 provides further information on the inclusion of PwA and specific comments made regarding the inclusion of PwA in the studies reviewed.

### Method of Screen or Assessment for Depression

In terms of the method used to screen for or assess depression, roughly half of the studies reviewed reported using a standardised self-report measure (n= 42, 60%), a third completed an observer rated measure (n=21, 30%), and a third a clinical interview (n=21, 30%). Roughly a fifth of papers reported using a mix of these approach to assess depression (n=14, 20%).

Twenty-one different mood measures were used. The most popular standardised self-report measure used was the Hospital Anxiety and Depression Scale[53] (n=16, 22.86%) followed by a Visual Analogue Scale[44] (VAS; n=8, 11.43%), Geriatric Depression Scale[124] (n=7, 10%) and then the Beck Depression Inventory (n=6, 8.57%). Only the VAS[44] has been validated for use with PwA and is not a written or verbal measure of mood. The most popular observer rated measure was the ADRS[41] (n=9, 12.86%) followed by the SAD-Q[40] (n=7, 10%); both have been validated for use with PwA[41,45]. The interview version of the Montgomery-Asberg Depression Rating Scale[125] (MADRS) was the most frequently used (n=12, 17.14%) followed by the Diagnostic and Statistical Manual of Mental Disorders[126] (DSM) (n=4, 5.71%). The MADRS and DSM have been validated for use in aphasia in the non-acute stage only [89].

The majority of studies used measures that had not been validated for use in aphasia (n=36, 51.14%) Of these, only ten reported using supported communication adaptions to make the assessment accessible for those with aphasia, and eleven studies chose instead to complete the self-report measure or interview with a proxy, usually a family member or carer. As mentioned above, the latter method has not been validated for the measures used. Studies that reported using adaptions to support communication, mentioned adaptions such as: larger font, reading questions aloud, repeating questions, supplementary visual analogue scales and printing key words in bold. The most commonly reported method used to support communication was the Communicative Support Hierarchy and Independence Rating Scale[128], used in two studies. Additionally, one study each reported using the adaption recommended by Townend et al[49] which recommended the use of simplified questions, supplementary key written phrases or verbal rather than written material; and Brennan et al.[129] who recommended 'aphasia friendly' writing e.g., shorter words, simple sentences, large print, large areas of white space and relevant pictures. Furthermore, only two studies reported using an aphasia specialist SLT to facilitate communication.

Table 2 provides further information on specific papers in terms of the screening methods used for those aphasia and any specific comments authors made in regard to the screening adaptions and feasibility.

**Table 2**

*Summary of Main Findings Regarding Inclusion and Assessment of Low Mood in People with Aphasia (PwA) for the Studies Reviewed (N=70)*

| Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| **Self-Report Measures** | | | | |
| *The Hospital Anxiety and Depression Scale (HADS)*<br>Validated for use in stroke[130] but not aphasia, or for use with a proxy. | | | | |
| 1. Morsund 2019 | Hospital<br>325 (not reported)<br>58.0 (10.0)<br>23.57% | No | No | No |
| 2. Glozier 2017 | Hospital<br>414 (not reported)<br>Not reported<br>68.21% | *"Participants with receptive aphasia, severe language disorder…were eligible to participate if their proxy provided consent and completed assessments on their behalf."* | No- proxy used | No |
| 3. Barra 2017 | Hospital<br>393 (not reported)<br>71.4<br>55.5% | No | No | No |
| 4. Arba 2016 | Not clear<br>4910 (27)<br>64.2 (± 11.9)<br>67% | No | No | 44% of the sample did not complete the HADS and *"had higher baseline neurological impairment*". |

| | Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| 5. | McKenna 2012 | Community<br>7(3)<br>35.8<br>60% | No | *“accepted yes and no answers… Participants and/or their main carer were also interviewed… Items and response options were presented visually and read aloud to participants… The authors therefore devised a visual analogue scale to aid responding, which consisted of black areas corresponding in size with the written response choices. For example, the response “most of the time” was shown by a large black area, while “never” was depicted by a very small black area. However, even with this addition these participants did not respond consistently.”* | *“assessment of mood was impossible in two cases due to aphasia. In such cases it might be preferable to use a reliable and valid pictorial scale devised for use with people with severe cognitive and communication difficulties, such as the Depression Intensity Circles Scale”* |
| 6. | von Sarnowski 2012 | Hospital<br>11 (4)<br>48 (5.8)<br>54.54% | Three participants were reported to have moderate aphasia and one severe aphasia. | “*All questions and statements… were read out aloud to all aphasic and non-aphasic patients by the same examiner, to minimize variability…the patients were asked to follow the examination by reading the questionnaires themselves for a better comprehension.”.* | *“Every aphasic patient was able to comprehend and complete all of his/her questionnaires with the help of the examiner.”.* |
| 7. | Hobson 2020 | Community<br>118 (Not reported)<br>73.14 (11.37)<br>53.39% | *“We also examined whether we could replicate previous reports… without the exclusion of patients with aphasia.”* | No | *“For the sample of patients with language problems, reliability was .75 and .75, for anxiety and depression,* |

| | Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| | | | | | *respectively. Thus, across the whole sample and for those patients with language problems, the HADS subscales had fair internal reliability.”.* |
| 8. | Heiberg 2018 | Hospital<br>125 (not reported)<br>70.5 (not reported)<br>62% | *“78% responded to the main questionnaire, despite the broad inclusion criteria and no exclusion of patients with aphasia”* | No | No |
| 9. | Kielbergerová 2015 | Community<br>341 (20)<br>69<br>58.9% | No | No | *“Presence of aphasia or cognitive impairment as consequence of stroke might also potentially influence the reliability of SF36 or HADS questionnaires (despite that real prevalence of these disorders was rather low in our sample).”.* |
| 10. | Huenges Wajer 2017 | Community<br>67 (not reported)<br>53.2<br>32.8% | *“patients… were not included in this study because of… missing… HADS scores (n = 5), incomplete neuropsychological examination due to (severe) aphasia (n = 1)”.* | No | No |

| | Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| 11. | van Middelaar 2015 | Community<br>25 (7)<br>48<br>76% | *"could not reliably administer the MMSE in aphasic patients"* | No<br>*"When the patient was not able to complete the interview alone (e.g. because of aphasia), he/she was interviewed in the presence of the caregiver... we could only interview the caregiver, because the patient had severe aphasia (n = 3)".* | No |
| *Beck Depression Inventory (BDI-II)*<br>Validated for use it stroke[130] but not in PwA, or when used with a proxy. | | | | | |
| 12. | Marshall 2014 | Not clear<br>11 (6)<br>52.4<br>81.82% | No | *"BDI were read to or with the patient, using compensatory methods necessary in order to maximize understanding."* | *"It is possible that... linguistic deficits precluded reliable responses from participants for some of the measures. In a review, Robinson and Spalletta concluded that there is currently no reliable method of assessing depression in post-stroke individuals with comprehension deficits. Individuals with aphasia are often excluded from studies investigating post-stroke depression, and in a review, Townend and colleague[49] found that many studies consider language-based methods of assessing* |

| | **Study ID** | **Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male** | **Inclusion of PwA Discussed?** | **Supported Communication Adaptions During Assessment Discussed?** | **Validity or Accessibility of Assessment for PWA Discussed?** |
|---|---|---|---|---|---|
| | | | | | *depression best for individuals with mild aphasia”* |
| 13. | Weaver 2013 | Community<br>121 (25)<br>Not reported<br>58.2% | No | No | 25 PwA couldn’t complete the BDI-II. |
| 14. | Mroczkowska 2019 | Hospital<br>42 (5)<br>Not reported<br>50% | No | No | No |
| 15. | Benejam 2009 | Hospital<br>20 (5)<br>48.84 (not reported)<br>68.42% | Range of aphasia severity, including four with global aphasia. | No | *“three patients, BDI could not be administered due to important language impairment.”.* |
| 16. | Shehata 2015 | Hospital<br>61 (31)<br>Not reported<br>39.34% | No | No | No |
| *Centre for Epidemiologic Studies Depression Scale*<br>Validated for use in stroke[131] but not in aphasia. | | | | | |
| 17. | Ashaie 2019 | Community<br>144 (114)<br>56.45 (±12.34)<br>58.30% | *“It is also essential that persons with aphasia be included in studies of poststroke depression, particularly treatment* | *“each question was written in large font on a single laminated card and read out loud to the participant. The speech-language pathologist repeated individual questions if requested by the* | *“Assessments such as the CESD should only be used in patients with aphasia who do not have severe linguistic deficits (eg. global aphasia* |

| | Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| | | | *studies... This will provide a better understanding of depression in aphasia so that effective treatments can be designed to reduce or control the depression and improve the quality of life of those with aphasia."* | *participant… (Townend et al., 2007[49])."* | *where individuals comprehend little to no language)…[and] may affect the results of different depression questionnaires."* |
| *Patient Health Questionnaire (PHQ)*<br>This has been validated for use in stroke[132] but not in PwA or for use with a proxy. | | | | | |
| 18. | Pompon 2018 | Community<br>75 (75)<br>64.53 (10.91)<br>59.27% | *"Inclusion of the Tucker Communicative Support Hierarchy and Independence Rating Scale allowed for more complete participation of PWA with more severe communication impairment".* | The use of the Communicative Support Hierarchy and Independence Rating Scale to support communication was reported. Evidence supporting these adaptions was also reported[62]. | No |
| 19. | Pompon 2019 | Community<br>57 (57)<br>65.32 (10.54)<br>70.18% | NA* | *"Each questionnaire was read silently by the participant and read aloud by the examiner. Questionnaires were administered using a communicative support hierarchy[62]".* | *"PHQ-8… [is a] widely used diagnostic measures of emotional disorders with rigorous psychometric evidence of validity from various clinical populations (though not specifically aphasia).".* |
| *Geriatric Depression Scale (GDS)*<br>Validated for use in stroke[133] but not in aphasia, or for use with a proxy. The GDS has previously not been recommended for use in stroke due to poor sensitivity and specificity[134]. | | | | | |

| | Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| 20. | Lee 2015 | Community<br>72 (30)<br>Not reported<br>43.05% | No | No<br>*"interviews in the present study were conducted by caregivers for 13 subjects in the aphasia group due to communication problems*". | *"the GDS is a useful screening tool for depression in elderly people, a study showed that it is suitable for the people with impaired cognitive function or expression since it is in a simple form of yes/no questions*" |
| 21. | Graven 2016 | Community<br>110 (not reported)<br>69.9 (14.2)<br>52% | "*Patients with communicative and cognitive deficits were included."* | No | No |
| 22. | Han 2019 | Community<br>193 (not reported)<br>Not reported<br>84.5% | No | No | No |
| 23. | Trochimczyk 2017 | Hospital<br>100 (66)<br>69 (±9.93)<br>60% | No | No | No |
| 24. | Wong 2013 | Hospital<br>120 (9)<br>51 (not reported)<br>68% | No | No | No |
| 25. | Deguchi 2013 | Community<br>142 (7)<br>Not reported<br>Not reported | No | No | No |

*General Health Questionnaire (GHQ)*

| Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| Recommended for use in stroke[43]but not in aphasia. | | | | |
| 26. Hilari 2010 | Hospital<br>87 (32)<br>69.7 (14.1)<br>60% | *"Those… classified as having severe receptive aphasia. We used proxy respondents for them and their results are not reported here."* | *"Each scale was reproduced and printed in an aphasia-friendly format: large font was used (minimum 14), key words were printed in bold, few items were presented per page, and where appropriate pre-prepared pictures were used. Participants were interviewed by an aphasia-specialist speech and language therapist able to facilitate the communication of people with aphasia. Practice items were introduced to ensure participants understood the format of each questionnaire and its response options; and respondents only had to point to their response option*" | No |
| *Carroll Depression Scale*<br>This has not been validated for use in stroke or aphasia. | | | | |
| 27. Hoffmann 2013 | Hospital<br>1796 (625)<br>Not reported<br>Not reported | The *"inability to complete all the subtests"* was an inclusion criterion | No | No |
| *HADS and the Dynamic Visual Mood Scale (D-VAMS)*<br>Both have been validated for use it stroke[130] and only the D-VAMS has been validated in aphasia[70]. | | | | |
| 28. Barrows 2018 | Community<br>46 (11)<br>63.8 | *"this validation study mostly comprised stroke patients without significant aphasia"* | No | *"Dynamic Visual Analogue Mood Scales used in people with stroke showed good* |

| Study ID | | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| | | 60.87% | | | *validity, internal consistency, and reliability… [this] study mostly comprised stroke patients without significant aphasia, which was necessary because participants had to be able to respond to questions on the HADS*" |
| *HADS and the Depression Intensity Scale Circles (DISCs)*<br>Both has been validated for use in stroke[130] but only the DISCs in aphasia[38]. | | | | | |
| 29. | Lees 2014 | Hospital<br>41 (not reported)<br>71<br>59% | *"We acknowledge limitations of this pilot study. The sample may not be entirely stroke-representative; more severe strokes were less likely to be included".* | No | *"We used two depression/anxiety screening tools… and one potentially suitable for patients with aphasia: Depression Intensity Scale Circles".* |
| *PHQ-2 and the Mental Health Inventory (MHI-5)*<br>PHQ-2 validated for use in stroke[72] but neither for aphasia, nor for use with a proxy. | | | | | |
| 30. | Dennis (2019) | Hospital<br>3127 (906)<br>71 (not reported)<br>61.46% | No | No- proxy report. | No |
| **Clinical Interviews** | | | | | |
| *Montgomery-Asberg Depression Rating Scale (MADRS)*<br>Validated for use in stroke[135] and in aphasia during the non-acute stage only[61]; less accurate for use with a proxy[61]. | | | | | |
| 31. | Tse 2017 | Hospital<br>100 (not reported)<br>66 (13) | No | Supported communication adaptions were reported and the evidence base | No |

| | Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| | | 72% | | for these adaptions was also reported; Townend et al[43] | |
| 32. | Pascoe 2015 | Hospital<br>149 (38)<br>Not reported<br>Not reported | No | No | No |
| 33. | Hofmeijer 2013 | Hospital<br>20 (12)<br>49 (9)<br>60% | *"Tasks were less often feasible in patients with than in those without aphasia"* | No | No |
| 34. | Laska 2007 | Hospital<br>77 (77)<br>74 (not reported)<br>56% | NA* | No | *"All 10 MADRS items could be completed by 76% of all patients at baseline and by 90% at 6 months… Twenty-six of the 89 patients lacked the 'yes/no' capability. Of these, 13 cases could be diagnosed according to DSM-IV at baseline, with help from relatives and staff".* |
| 35. | Naess 2009 | Community<br>195 (20)<br>Not reported<br>59% | Subtypes of aphasia were reported, including 6 people with global aphasia. | No | No |
| 36. | Hofmeijer 2009 | Hospital<br>64 (24)<br>Not reported | *"the small number of patients with aphasia suggests that there was some selection in the* | No | *"Two … patients had aphasia that was so severe that quality* |

| | **Study ID** | **Demographics**<br>**Sample Location**<br>**Sample Size (N of PwA)**<br>**Average Age (SD)**<br>**Percentage Male** | **Inclusion of PwA Discussed?** | **Supported Communication Adaptions During Assessment Discussed?** | **Validity or Accessibility of Assessment for PWA Discussed?** |
|---|---|---|---|---|---|
| | | 59.38% | *referral of patients for inclusion in this trial."* | | *of life and mood could not be assessed."* |
| 37. | Welmer 2007 | Hospital<br>115 (not reported)<br>81 (not reported)<br>45.22% | *"Subjects with interrupting aphasia or dysarthria were not assessed with the MMSE in the present study…* | No | No |
| 38. | Lundstörm 2020 | Hospital<br>1500 (268)<br>70.8 (10.9)<br>61.7% | *"consent from relatives was not accepted"* which may have excluded some PwA. | No | No |
| 39. | Tse 2017 | Hospital<br>92 (not reported)<br>65 (not reported)<br>74% | No | *"strategies for testing people with aphasia were developed based on aphasia-friendly principals[63]"* | No |
| *Hamilton Depression Rating Scale (HDRS)*<br>Validated for use in stroke[130] but not PwA or for use with a proxy. | | | | | |
| 40. | Idiaquez 2015 | Community<br>45 (not reported)<br>65.8 (±11.7)<br>62.2% | No | No<br>*"in patients with aphasia the answers were obtained from caregivers."*. | No |
| 41. | Yuan 2014 | Hospital<br>1,953 (260)<br>Not reported<br>66.9% | No | No | No |
| *Centre for Epidemiological Studies Depression Interview* | | | | | |

| | Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| Validated for use in stroke[131] and for proxy use[136] but not PwA. | | | | | |
| 42. | Pustokhanova 2013 | Hospital<br>129 (8 mild aphasia)<br>58.71(±10.32)<br>62.02% | No | No | *"The using of CES-D was caused by high specificity and sensitivity for the DSM-III diagnosis of depression… sufficient experience with CES-D as a screening tool for assessing depression in non-aphasic stroke patients"* |
| 43. | Guo 2017 | Community<br>94 (29)<br>63.7<br>70.2% | *"3 people had severe receptive aphasia and were unable to self-report excluded from analysis".* | No<br>*"individuals with severe receptive aphasia did not self-report during the interview and a proxy, usually their spouse or adult child, answered questions as they thought the person with aphasia (PWA) would have."* | No |
| *Diagnostic and Statistical Manual of Mental Disorders IV Revised*<br>Validated in stroke[136] and in aphasia during the non-acute stage only[61]. | | | | | |
| 44. | Jerome 2009 | Community<br>61 (23)<br>64 (8.5)<br>68.8% | No | No | No |
| 45. | Hachioui 2014 | Hospital<br>147 (147)<br>67 (±15)<br>47% | NA* | No, assessed via proxy. | *"It would have been better if we had been able to perform a thorough examination using the criteria of the Diagnostic* |

| Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| | | | | *and Statistical Manual of Mental Disorders.”.* |
| **Observer-Rated Measures** | | | | |
| *Stroke Aphasic Depression Questionnaire (SADQ)*<br>Validated for use in stroke[45] and PwA[45]. | | | | |
| 46. Laures-Gore 2013 | Hospital<br>31(31)<br>Not reported<br>Not reported | NA* | NA | The validity and feasibility of the measure was discussed. |
| 47. Kaur 2020 | Hospital<br>11 (11)<br>Not reported<br>90% | NA* | NA | No |
| *Aphasic Depression Rating Scale (ADRS)*<br>Validated for use in stroke[41] and PwA[41]. | | | | |
| 48. Gyagenda 2015 | Hospital<br>73 (12)<br>Not reported<br>41.1% | Discussed the impact of the inclusion of PwA on the higher depression rates compared to previous studies that excluded aphasia. | NA | No |
| 59. Valiengo 2016 | Hospital<br>4(4)<br>48.25<br>0% | NA* | NA | *“ADRS is a depression rating scale validated for the evaluation of PSD in aphasic patients”* |
| 50. Wang 2018 | Hospital<br>248(148) | An inclusion criterion of the *“ability to provide* | NA | *“As most depression scales cannot be used in stroke* |

| | Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| | | 57.3<br>71% | *informed consent"* may have excluded some PwA. | | *patients with aphasia…the severity of depressive symptoms … was measured using the 21-item Stroke Aphasic Depression Questionnaire (SADQ)"* |
| 51. | Koleck 2017 | Hospital and community<br>101 (101)<br>68.72 (± 13.28)<br>51.48% | NA* | NA | *"The ADRS has good psychometric properties"* |
| 52. | Maresca 2019 | Hospital<br>30 (30)<br>51<br>46.67% | NA* | NA | No |
| 53. | Laurent 2011 | Community<br>80 (25)<br>67.4<br>63.75% | *"The study's strong points are… did not exclude aphasic patients."* | NA | *"MADRS for aphasic people, as validated by Benaim et al."* |
| *Neuropsychiatric Inventory (NPI)*<br>Validated for use in stroke[137] but not in aphasia. | | | | | |
| 54. | Klimiec 2017 | Hospital<br>750 (doesn't report)<br>median age: 73<br>46.9% | Inclusion of severe aphasia | No | No |
| 55. | van Almenkerk 2015 | Hospital<br>271 (108) | No | NA | *"The use of observation instruments enabled us to* |

| Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| | Not reported<br>41.71% | | | *include also residents with severe cognitive and/or communicative impairments".* |
| *SADQ and ADRS*<br>Validated for use in stroke and PwA[41,45]. | | | | |
| 56. Laures-Gore 2017 | Community<br>25 (25)<br>48.69 (13.75)<br>64% | NA* | NA | *"The ADRS was developed in response to the SADQ series, as the authors of the ADRS point out the SADQ development was methodologically flawed because it was validated with depression measures standardized on non-aphasic patients… it is important that a "gold standard" for accurate depression diagnosis in adults with aphasia is developed".* |
| **Mixed Approaches** | | | | |
| *PHQ and the Signs of Depression Scale (SODS)*<br>Both validated for use in stroke[132,41] but only the SODS validated for use with PwA[41]. | | | | |
| 57. van Dijk 2018 | Hospital<br>58 (25)<br>59.3 (not reported)<br>53.45% | *"The inclusion of aphasic patients will improve the methodological quality of future studies"* | NA | *"evidence for the internal consistency and the interrater reliability of the SODS"* |
| *SADQ and the Visual Analogue Mood Scale (VAMS)*<br>Both validated for use in stroke[44,45] and PwA[44,45]. | | | | |

| | Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|---|
| 58. | Kontou 2012 | Community<br>121 (71)<br>69 (12.33)<br>54% | The authors noted that referrers *"may have not referred those with very severe communication problems".* | NA | The authors reported that *"five [participants were] unable to complete the VAMS-R, so the sample does not include people with very severe communication problems."* |
| *SADQ and the VAMS 'sad' item*<br>They have both been validated for use in stroke and PwA[44,45,47]. | | | | | |
| 59. | Cobley 2012 | Community and hospital<br>165 (165)<br>68.6 (12.1)<br>65% | NA* | NA | The validity of the measures for use with PwA was discussed. |
| *MADRS and the VAMS*<br>Both validated for use in stroke[44,135] and in aphasia[44,61] but not for proxy use[61]. | | | | | |
| 60. | Franzén- Dahlin 2008 | Community<br>148 (77)<br>Not reported<br>Not reported | No | No<br>*"completed by patients' significant other".* | No |
| *HADS, the Visual Analogue Scale (VAS) and the SADQ*<br>All validated for use in stroke[130,44] but only the VAS & SADQ-10 have been validated in aphasia[44,45]. | | | | | |
| 61. | Tessier 2017 | Hospital<br>54 (13)<br>51.7 (13)<br>68% | No | No | Originally selected the BDI-II but they concluded that *"this scale seems inappropriate within the first few days after stroke and was replaced… Missing HADS… scores were* |

| Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| | | | | *due to lack of feasibility in patients with aphasia”* |
| *Composite International Diagnostic Interview and the SODS*<br>Only the SODS validated for use in stroke and with PwA[41] but not via a proxy. | | | | |
| 62. van Dijk 2017 | Hospital<br>116(53)<br>70 (not reported)<br>58% | *“assumption on generalizability seems reasonable given … the inclusion of stroke patients with communicative impairment, which strengthens the methodological quality of our study.”* | No- assessment via proxy | *“to use the CIDI-relative with confidence, we compared ratings of patients without communicative impairment (CIDI-patient) and their relatives to check whether these rating sufficiently correlated…relatives provide a reliable diagnosis of patients depression using the CIDI.”* |
| *MADRS and the Geriatric Mental State*<br>Only the MADRS validated for use in stroke[135] and in aphasia during the non-acute stage only[61]. | | | | |
| 63. Lightbody[a] 2007 | Hospital<br>28 (23 had abnormal communication skills)<br>Median age: 72<br>50% | *“only two cases fell in the moderate or severe range [aphasia] and most cases were mild. Ideally, validation should include a range of severity”* | No- proxy if required | *“A number of studies have demonstrated good reliability and validity of the MADRS…but not in patients who have had a stroke, including those with communication … difficulties”* |
| *MADRS and the Cornell Scale of Depression*<br>Only the MADRS validated for use in stroke[135] and in aphasia during the non-acute stage only[61]. | | | | |
| 64. De Ryck 2014 | Hospital<br>125 (19) | *“we did not exclude patients with speech and language* | No | *“A potential limitation of this study is the nonpsychiatric* |

| Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| | 70.1 (12.7)<br>60.8% | *dysfunctions. Exclusion of the latter patients may result in selection bias… additionally ignore the predisposition to PSD of aphasic and severely impaired patients.”.* | | *assessment of depression… whereas a formal psychiatric assessment might not be feasible in… aphasia.”.* |
| *VAS and the ADRS*<br>Both validated for use in stroke[44] and aphasia[41, 44]. | | | | |
| 65. Benaim 2010 | Hospital<br>49 (23)<br>64 (±11)<br>63% | *“all stroke patients admitted… none of the previous clinical trials performed in post-stroke depression have included patients with communication deficiencies”.* | NA | *“only the ADRS has been validated in a sample of patients including those with aphasia…<br>Answers to VAMS were considered by the examiner to be doubtful in 9 patients (18%)”.* |
| 66. Guiraud 2016 | Hospital<br>251 (not reported)<br>61.2 (not reported)<br>40% | *“The strengths of our study were… the inclusion of patients with severe aphasia.”* | NA<br>*“proxies, in the case of patients with severe aphasia”* | No |
| *HADS and the SADQ*<br>Both validated for use in stroke but only the SADQ-10 has been validated for use in PwA[45,47]. | | | | |
| 67. Sackley 2008 | Hospital<br>122 (63)<br>76 (11) | *“our sample did not exclude patients with language…impairment... these* | No | No |

| Study ID | Demographics<br>Sample Location<br>Sample Size (N of PwA)<br>Average Age (SD)<br>Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| | 57% | *patients made up 60% of the study sample and would previously have been excluded by their inability to complete self-report measures of mood".* | | |
| *Diagnostic and Statistical Manual of Mental Disorders IV (DSM) and the SODS*<br>Both validated in stroke[136,41] and with PwA[41,61]. | | | | |
| 68. Lightbody[b] 2007 | Hospital<br>71 (35)<br>Median 70 (IQR: 59–76)<br>56.3% | No | No | No |
| *BDI, VAMS and the HDRS*<br>All validated for use in stroke[130,44] but only the VAMS has been validated for use in mild aphasia[44]. | | | | |
| 69. Berg 2008 | Hospital<br>100 (31)<br>55.2<br>68% | No | *"assisted when needed"* | *"Studies on the validity and reliability of common verbal tools among patients with aphasia are very rare. Use of the Visual Analogue Mood Scale (VAMS) in patients with stroke with impaired language function has only vague support in some studies…There was little variation in feasibility of the different measures of depression… predominant cause of not being able to* |

| Study ID | Demographics Sample Location Sample Size (N of PwA) Average Age (SD) Percentage Male | Inclusion of PwA Discussed? | Supported Communication Adaptions During Assessment Discussed? | Validity or Accessibility of Assessment for PWA Discussed? |
|---|---|---|---|---|
| | | | | *complete the measures was aphasia".* |
| *NPI and the GDS*<br>Both validated for use in stroke[137,133] but not in aphasia. However, the GDS has previously not been recommended for use in stroke due to poor sensitivity and specificity[68]. | | | | |
| 70. Buijck 2013 | Community<br>186 (not reported)<br>78 (not reported)<br>42.86% | No | No | No |

NA= observer- rated measure require no communication with PwA
NA*= Aphasia only sample.

## Discussion

The aim of the current systematic review is therefore to review the inclusion of PwA in post-stroke depression research and methods used to assess mood in PwA. It was found that less than one tenth of 977 studies that assessed depression in stroke survivors, report *not* excluding people with aphasia, in this comprehensive review of the inclusion and assessment of PwA in post-stroke depression research. Almost a third of these seventy studies demonstrated masked exclusion of PwA, for example, through use of assessment measures inaccessible for those with communication difficulties with no supportive communication adaptions reported. Our results bear striking similarities to those of the previous systematic review on this topic. Rates of exclusion found are similar to those found previously[26,49] suggesting that in the last decade there has been no significant improvement in the inclusion of PwA in post-stroke depression research. This long-term exclusion of those with aphasia from stroke research is likely to bias our knowledge of post-stroke depression. Townsend et al.[49] recommended an improvement in the reporting of exclusion and inclusion criteria and the use of standardised assessments of aphasia as the reporting across studies was either unclear or inconsistent. However, similar inconsistencies were observed in our analysis which reviewed papers published since Townsend et al.[49]. In this systematic review, a third of papers did not mention aphasia. Forty percent of papers excluded some individuals with aphasia, often those with moderate or severe aphasia, however the definition of these terms was often unreported or unstandardised; phrases such as “notably aphasic” were common.

The second key issue addressed by this systematic review concerns the methods used to assess depression in PwA and if these are validated and accessible. Most studies reviewed reported using self-report measures to assess depression. The joint second most common method of mood assessment was the use of observer rated measures and the use of a clinical interview.

Comparing our findings to those of the Townsend et al.[49] review highlights differences in our results. Townsend and colleagues reported clinical interviews to be the most commonly used method of mood assessment, with less than 10% of studies using self-report measures. No studies in the earlier review used the ADRS or SADQ observer rated measures. The ADRS and SADQ were very recently published at the time of the Townsend et al.[49] review. The increase in use of observer rated measures is promising, as both the ADRS and SADQ have been validated for use in aphasia[40,41,47] and the SADQ was recommended for its feasibility by a recent meta-analysis on the validity of mood measures for use with PwA[42]. The higher use of self-report than observer-rated measures is surprising, particularly given the large number of studies that used self-report measures with family members or carers, a use for which these measures have not been validated. The reduced popularity of clinical interviews to assess mood, often regarded as the gold standard assessment and in the case of the MADRS, validated for use in aphasia[61], was unexpected. It may reflect that, apart from two studies, speech and language therapists did not complete assessments and other professions may lack expertise to provide the supported communication adaptions required to make interviews accessible for PwA. Furthermore, two studies reported choosing to use an alternative approach due to an assumption that completing a clinical interview with individuals with aphasia would not be possible. This incorrect assumption may be held more widely and might explain the reduced possibility of clinical interview usage in these studies.

Strikingly, only a minority of studies used depression measures validated for use in aphasia and very few used measures recommended by NHS Improvement stroke guidelines[138], such as the DISCs or the SAD-Q for people with more severe communication or cognitive difficulties. Of those that did not use validated measures, only a minority reported using supported communication adaptions to make the assessments selected accessible for those with aphasia. The most commonly used measure was the HADS, a verbal self-report measure which is likely to be inaccessible for PwA and has not been validated for use in aphasia. A study by Lees et al.[84] found that 50% of stroke survivors in acute care needed support to complete HADS and they did not all have aphasia. These results suggest there is an over-reliance on language-based self-report measures in post-stroke depression research that contributes to the systematic exclusion of PwA. Most of those studies that reported that not all PwA received the mood screen had selected a verbal assessment measure like the HADS. There are self-report measures such as the VAMS[37], DISCs[38] and the D-VAMS[39] that carry less verbal load; are more accessible for PwA; and that have been validated for use in aphasia[44,70,38]. These findings would suggest even in studies that include those with aphasia the accessibility and validity of the mood screen for PwA is limited.

It was important to undertake this systematic review for two key reasons; there has been a recent growth in the number of publications on this topic, and although the inclusion of PwA in stroke research was previously reviewed by Townsend et al.[49], at the time observer-rated measures designed to assess low mood in those with aphasia, were still new and not yet commonly used in clinical research practice (e.g. ADRS & SADQ). This review used an inclusive search strategy and multiple databases, resulting in a broad dataset from across the globe. This large dataset reflects the recent growth in stroke research. The search strings used were informed by previous systematic reviews on this topic[49] and created with consultation with a specialist librarian. The PRISMA guidelines[52] were followed and a second rater checked a random sample of studies. A bespoke quality assessment tool was created to evaluate the internal and external validity of the assessment approach used to assess depression in people with post-stroke aphasia. It is hoped that our findings will prove relevant for both research and clinical practice. Psychological support post-stroke is a key topic for stroke research[50] and systematic reviews on this topic are important to evaluate and guide improvements of research evidence.

Limitations of this systemic review include the lack of details on aphasia, standardised measures of aphasia, or definitions of ‘moderate’ or ‘severe’ aphasia and unclear description of inclusion and exclusion criteria within the studies reviewed. This made determining the true extent of exclusion difficult and limited the ability to make comparisons between studies. These difficulties highlight the continued exclusion of PwA in stroke research and the continued need for greater consideration of PwA in this research field. Some other limitations include that only studies in the English language were included in this review which could create a western bias in the sample. Finally, an independent screening, extraction and quality assessment of all studies was beyond the remit of the current review.

In conclusion, it is a striking finding of this review that PwA continue to be systematically excluded from post-stroke depression research despite the availability of a range of accessible means to assess depression in this population. Furthermore, even when included in research PwA often experience masked exclusion from participation receiving depression measures that are inaccessible for those with communication difficulties and unvalidated in aphasia. These findings are not only important as aphasia is very common post-stroke[1], affecting an estimated third of stroke survivors, but also important as depression rates are known to be higher in those aphasia[13-16]. These findings are important as for several years now, there have been multiple assessment tools that are accessible, and valid for PwA yet this population continue to be excluded from research. Psychological support post-stroke is currently a key research agenda in stroke research[50] and the value of ‘everyone counts’ is one of the six values in the NHS constitution[51]. "Everyone counts" sets out the importance of ensuring that everyone has access to the resources available in the NHS without discrimination.

## Recommendation for Future Research

These findings highlight the need for a focused approach to future research that is inclusive of people with post-stroke aphasia. It is acknowledged that not all PwA will be able to be included in post-stroke depression research for example, if participants do not have capacity to consent or if significant cognitive impairment co-occurs. However, with reasonable adaptations more inclusion of PwA is possible. Post-stroke depression research needs to be representative to avoid the discrimination of key groups of stroke survivors and to ensure validity of the evidence base. To achieve this, it is recommended that research becomes less reliant on verbal and written mood measures, instead using mood assessments that are accessible and have been validated in aphasia. Furthermore, where possible a greater involvement of speech and language therapists in post-stroke research is recommended; to facilitate assessments and to inform study designs to ensure the inclusion of PwA. Additionally, this study’s findings highlight the need for more research evaluating the validity and accessibility of non-verbal self-report mood measures and of observer-rated measures. For example, research validation studies of mood measures in large samples of PwA, including those with moderate and severe aphasia, and qualitative research studies exploring how PwA and clinicians experience current depression assessment methods. The lack of representation in post-stroke depression research is likely to hamper the development of specific approaches for depression and suicidality in PwA. Finally, it is recommended that inclusion and exclusion criteria, including the presence of PwA, should be clearly reported in research studies.

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# **Chapter 3**- Main Paper

## Screening Mood and Suicidality in Post Stroke Aphasia: A Theory of Planned Behaviour Study

# Screening Mood and Suicidality in Post Stroke Aphasia: A Theory of Planned Behaviour Study

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Prepared for submission to Clinical Rehabilitation (see guidelines, Appendix A)

Word count excluding references, figures and tables: 5,583

## Abstract

Stroke is associated with increased risk of depression and suicidality and people with aphasia (PwA) are at even greater risk. Clinical guidelines recommend mood screening all stroke survivors, yet screening is not routinely provided across services and research has not investigated mood screening rates or practices in PwA. Therefore, we conducted an online survey of UK stroke professionals to explore the rates and methods of screening PwA for mood and suicidality. To determine what factors predict screening rates, the Theory of Planned Behaviour (TPB) model was applied to reported likelihood to screen for low mood. One hundred and eighteen UK stroke clinicians responded. A striking discrepancy was found between the high reported likelihood to screen for low mood (Mode: 100%, M: 71%, SD: 34.54) and the low likelihood to screen for suicidality (Mode: 0%, M:43%, SD: 38.96). TPB variables accounted for 48% of variance in intention to screen for depression ($R^2$=.48, F (3,101) =30.60, p<.001) with normative beliefs significantly predicting likelihood to screen for depression in PwA (β= .62, p<.001). Screening rates may be improved by communicating a clear expectation that staff should screen all stroke survivors for depression and suicidality by naming screening in job descriptions, sharing guidelines for depression and suicide screening, and auditing and publicising screening rates externally and internally. Respondents reported modifying screening methods for PwA, with more use of visual self-report measures and supported communication methods. These findings suggest that more support is needed to help stroke professionals detect depression and suicidality in PwA.

*Keywords:* stroke, aphasia, depression, suicidality, screening, theory of planned behaviour

# Screening Mood and Suicidality in Post Stroke Aphasia: A Theory of Planned Behaviour Study

## Introduction

Stroke is a major cause of disability and death; 13 million people suffer worldwide each year[1]. The UK has approximately 1.2 million stroke survivors[2]. The Stroke Association estimate that the aggregate societal cost in the UK is between £18-43 billion, per annum[3]. This makes effective stroke rehabilitation and management a key policy driver for health services. The current research focused on three common consequences of stroke: aphasia (a loss of the ability to use and understand language), depression (a mood disorder causing persistent feeling of sadness and loss of interest) and suicidality (the risk of killing oneself, usually preceded by thoughts of suicide, the presence of a well-elaborated suicidal plan or having intent to end one's life) and specifically, how staff detect when these conditions co-occur.

Depression after stroke is very common; an estimated 31% of stroke survivors develop depression[4], making it more prevalent than in the general public[5]. Post-stroke depression (PSD) has been negatively associated with survival[6], cost of medical care[7], functional outcome[8], resumption of social activities[9], and quality of life[8]. Accordingly, the Stroke Association has made the psychological consequences of stroke one of their key priorities for research, stating “psychological effects of stroke often remain hidden, may go unrecognised by some healthcare professionals, with the true impact remaining unknown.”[2(p35)].

Stroke survivors experience higher rates of suicide ideation, suicide attempts, and completed suicides than in the general population[10-12]. A meta-analysis of 13 samples, consisting of 10, 400 subjects, reported a pooled proportion of suicidal ideation among stroke survivors of 11.8%[10]. An epidemiological study reported 7.2% of stroke participants died by suicide[13], compared to 11.0 death per 100,000 in the UK general population, 1.1%[14]. A recent meta-analysis concluded that stroke should be considered as a risk factor for suicide and that a strategy to screen and treat depression and suicidal ideation in stroke survivors should be developed[15]. Although several risk factors are thought to play a role, depression appears to be the most important predictor of post-stroke suicide[11,12,16,17]. It should be noted that post-stroke suicide is significantly under researched in comparison to post-stroke depression.

Due to increased depression rates, multiple health guidelines recommend screening all stroke survivors[18-20]. Furthermore, multiple national guidelines recommend screening for suicidality in those with suicide risk factors[21,22]. Yet despite stroke being a well-documented risk factor, currently no stroke guidelines include a recommendation for suicidality screening post-stroke. Screening is defined by World Health Organisation[25] as "the use of simple tests across an apparently healthy population in order to identify individuals who have risk factors or early stages of disease". In this context, the disease involved is depression and suicidality and the apparently healthy population is stroke survivors. Screening for PSD is completed by staff in multiple professional disciplines, usually through a clinical interview or standardised screening measures[18-20]. Only some standardised screening measures for depression include an assessment of suicidality.

A recent executive summary of PSD stated "one would assume that patients with stroke are routinely being screened for depression in our healthcare facilities. Sadly, however, this is not the case. Many patients with stroke are never screened for depression"[23(p66)]. According to UK Sentinel Stroke National Audit Programme[24] (SSNAP) 92% of patients received mood and cognition screening by discharge "if required". However, this would not be consistent with the World Health Organisations[25] definition of screening, which stipulates testing all in a particular population but SSNAP does not provide data on screening rates in all stroke survivors. Additionally, SSNAP does not collect data on suicidality screening. A survey of stroke professionals in Scotland found that 72% of the 174 participants reported regularly screening mood[26]. Another survey of stroke professionals found that a third of staff reported being very unlikely to screen mood[27]. However, none of these studies explored suicidality screening rates. A survey of stroke survivors completed by the Stroke Association[28] found that of their 2,700 responses, 59% reported feeling depressed, but over half did not receive any information, advice or support to help with depression.

Research has started to make sense of barriers and aids to screening[27,29,30]. Hart and Morris[27] applied the Theory of Planned Behaviour (TPB)[31] to this issue; a model that predicts the intention to engage in a behaviour. TPB is one of the most frequently cited and influential models for the prediction of human social behaviour[32]. Several studies have found that the TPB successfully predicts health-related behavioural intention[33] and to a lesser extent specific behaviours[34-36]. A meta- analysis of 185 studies reported that TPB accounted for 39% intention and 27% of behavioural variance[37]. The TPB postulates an association between personal beliefs and behaviours; namely that attitudes toward behaviour, subjective norms, and perceived behavioural control, together shape an individual's behavioural intentions and behaviours. Hart and Morris[27(p69)] concluded that TPB can be applied to understanding screening intention and that "compliance may be enhanced by: training to increase knowledge and skills, providing evidence of the utility, increasing awareness of guidelines, support from colleagues and integrating mood assessment into job roles and routine assessment." TPB has been successfully applied to other staff intention studies, for example in interventions for emotionalism post-stroke[38]. There is a developing literature within the field of stroke rehabilitation using the TPB model to explore staff intentions and behaviours to inform how best to facilitate service delivery[27,38].

An estimated third of stroke survivors have aphasia[39] meaning a quarter of a million people in Great Britain have aphasia[40]. The presence of aphasia is negatively associated with quality of life[41], social networks[42] and self-identity[43]. Research suggests that those with aphasia are at even greater risk of developing depression[44-46]. Public awareness of aphasia, however, remains low[47]. Jenkins[47] recruited public sector workers and found only 19% had heard of aphasia. Furthermore, there is evidence that those with aphasia receive poorer care in health services, due to "barriers" including inaccessible information, negative staff attitudes, or unskilled communication partners[48]. Several techniques and programmes for staff are aimed at supporting people with aphasia (PwA) to engage in meaningful conversation[49]. These supported communication adaptions include spoken and written keywords, body language and gestures, hand drawings and detailed pictographs[50].

Despite the increased prevalence of depression in individuals with post-stroke aphasia, this topic remains under researched. None of the above-mentioned studies on post-stroke screening rates focused on PwA. Patients with severe communication difficulties are often omitted from randomised controlled trials (RCT) on PSD treatment[51,52]. A systematic review by Townend et al.[53] found of the 129 studies where stroke patients were screened for depression, 92 (71%) reported some exclusion of PwA. Often PwA are characterised as ‘inappropriate for screening’. In 80% of the studies reviewed, depression was evaluated by clinical interviews, 10% used questionnaires and 10% used both methods combined. This dependency on written and verbal screening tools made them unsuitable for PwA. More importantly, less than half of studies (48%) indicated having adapted their depression diagnostic method for participants with aphasia.[54] Many steps can be taken to support PwA to communicate, for example, using simplified questions, supplementary key written phrases, verbal rather than written material, repetition, personalising questions and use of pictorial material. Additionally, there are specific instruments designed for the assessment of depression in aphasic patients. These include observer rating measures that rely on staff or carers to rate behaviour (e.g., Stroke Aphasia Depression Questionnaire and the Aphasic Depression Rating Scale) and self-report measures (e.g., the Depression Intensity Scale Circles and the Visual Analogue Mood Scales). However, these tools have limitations, for example, observer rated measures remove the individual's voice and involvement in the assessment process. Additionally, visual analogue scales are limited, as they each measure only a single construct and therefore do not reflect the full picture of depression. Both the quality of methodology employed in the validation studies of the nonverbal self-report mood measures and the robustness of these measures as screening measure for depression has been criticised[55,56].

Research has begun to explore adherence to mood screening and the barriers and aids to screening[27,29,30]. The unique barriers highlighted in aphasia research are likely to influence screening for depression, but to date, no research has focussed on those with post-stroke aphasia. The current study sought to address this by investigating self-reported staff practices in screening for low mood and suicidality in individuals with post-stroke aphasia, and factors influencing staff screening intentions and behaviours that act as facilitators or barriers to screening. Based on previous applications of the TPB to understand staff intentions and behaviours regarding service delivery in stroke[27,38] we applied the TPB to an online staff survey of screening intentions and behaviours in PwA, within the UK. We examined how UK stroke staff describe mood and suicidality screening behaviours when working with PwA, and specifically: which healthcare disciplines report conducting mood and suicide screening in PwA; what proportion of

PwA on caseloads do staff estimate have had a mood screen, by themselves or another staff member; what proportion of PwA who report low mood on staff caseloads do staff estimate to have been asked about suicidal thoughts and intent, by themselves or another staff member; what approaches do staff report being used in their services to screen PwA for depression and suicidality in terms of measures and supported communication adaptations; and to what extent does the TPB, and its three factors of attitudes, subjective norms and perceived control, account for staff intentions to screen mood, in PwA.

## Method

### Design

An online survey was conducted using a cross-sectional, between- and within-participants, observational, design.

### Participants

The participants were UK stroke professionals for example: speech and language therapists, clinical psychologists and occupational therapists. The inclusion criteria were UK-based stroke professionals, working in the NHS and private health care, who would work with post-stroke aphasia. Professionals working in a service, or in a capacity that prevented them from working with PwA, stroke or outside the UK, were excluded.

### Measures

An online survey was developed by the research team which combines expertise in clinical neuropsychology, clinical psychology and speech and language therapy (SLT) with extensive experience of stroke and aphasia. Survey design was informed by the literature on TPB and screening, a previous service audit and professional advice on survey design and statistical analysis. The survey was piloted with a group of target users working in stroke; their feedback informed the development of the measure from the outset and throughout.

The survey had four parts: demographic information, screening behaviours, knowledge and training, and TPB questions. Demographic data on respondents' profession, the type of service they work for and the geographical region was collected. The survey aimed to collect data on how frequently stroke staff reported screening for low mood and suicidality in PwA and a estimate of the proportion of their aphasia caseload who had received a screen for low mood and suicidality, by themselves or a member of their team. Following statistical advice, respondents were asked to give their estimates as percentages, so parametric analysis could be applied. It is acknowledged that this self-reported estimate does not permit audit of actual staff practice. Additionally, data were collected on the method staff reported using to screen for low mood and suicidality in PwA, in terms of measures and use of supported communication adaptations. Research by Townend et al.[54] and van Dijk et al.[55] was used to establish a comprehensive list of screening behaviours: approaches, measures and adaptions. The list was further extended based on pilot feedback from target users. Staff were asked about their level of training and knowledge of depression, suicide, aphasia and stroke guidelines. Finally, a series of questions was designed to establish respondents' behavioural intent towards screening. These followed the theoretical framework of the TPB[31]. The design was guided by Francis et al.'s[57] published manual on constructing TPB questionnaires.

## Ethics

Ethical approval was received from the University of East Anglia Faculty of Medicine and Health Science Research Ethics Committee. Staff were asked to read an electronic participant information sheet to ensure informed consent, before being asked to complete an online consent form. Consent was required to access the questionnaire. Data were stored in accordance with the General Data Protection Regulation and UEA policy. Demographic information was collected on participants, but the combination of information was designed to avoid de-anonymisation.

## Procedure

An online snowballing campaign was conducted to recruit UK stroke professionals by sharing the study advertisement widely via two routes: 1. By asking relevant UK-based professional bodies and special interest groups to contact their consented members via email or social media post (e.g. British Psychological Society); 2. By using social media or email to advertise the study outside of professional organisations (e.g. via Twitter, Facebook, Email and ResearchGate). Participants were therefore either consenting members of professional groups contacted by direct email or social media post or non-members responding to an advertisement. Potential participants received no more than two emails inviting them to participate. Participants were asked to consent to completing the questionnaire on a second occasion, two weeks after the first, to determine the stability of the intention.

## Statistical Analysis

Descriptive statistics were calculated for demographic information, screening behaviours, knowledge and training, and TPB variables. The data on reported likelihood to screen for depression and suicidality were split by profession and an average per profession calculated, and data on which professions were reported to be completing mood screens in respondents' services were summarised. For the TPB statements, a series of visual analogue scales were used, consisting of a line anchored at either end by the extremes of the TBP variable being measured. Visual analogue scales are psychometric response scales used to measure subjective characteristics or attitudes and have been demonstrated to be valid for use in social science research[58-60]. The line was then divided up into 10 individual pieces, with no midpoint; after any required reverse scoring, the number the respondent mark fell on was used for statistical analysis. Answers relating to depression screening were sorted into the three TPB factors: attitudes, (Items:28,30,31,34,35,43,45,46,48,51), subjective norms (Items:37,39,41,44) and perceived behavioural control (Items:32,33,36,38,40,42,47,49,50&53) and the respondents' total score per factor was calculated and entered into a multiple regression. Answers relating to suicidality were not included in the total score for the TPB factors nor the multiple regression. A multiple regression analysis analysed how well TPB predicts respondent intention to screen for depression in aphasia. Based on Tabachnick and Fidell[61] it was estimated a sample size of 61 or larger ($N > 50 + 8x$ independent variables) would have significant power for a regression. Homoscedasticity and multicollinearity were analysed. The residuals (errors) were checked for approximately normal distribution. Significant outliers, high leverage points or highly influential points were analysed and removed where necessary. All statistical assumptions were checked before analysis and the appropriate parametric or non-parametric statistical test chosen. Finally, Cronbach's $\alpha$ coefficients were calculated to determine internal consistency and a repeated measure ANOVAs were completed to evaluate stability of responses over time by comparing data from those who completed the questionnaire twice.

## Results

One hundred and eighteen UK stroke professionals participated in the online survey. Table 1 presents the demographic details of the sample, including respondents' professions, geographical area of work and clinical setting. The respondents' demographics suggest a diverse sample from a variety of clinical settings, stroke professions and geographic regions within the UK. On average respondents reported spending roughly three quarters of their working hours with stroke survivors *(M=76%, SD=23)* and under half of their time with people with post-stroke aphasia *(M=40%, SD=26)*. Roughly a third of stroke survivors have aphasia so this suggests the sample had a high level of contact with post-stroke aphasia.

**Table 1**

*Sample Demographics (N = 118)*

| | n | % |
|---|---|---|
| *Geographical Location* | | |
| South of England | 41 | 35 |
| East of England | 37 | 31 |
| North of England | 16 | 14 |
| Scotland | 16 | 14 |
| West of England | 6 | 5 |
| Midlands | 1 | 1 |
| Wales | 1 | 1 |
| Northern Ireland | 0 | 0 |
| *Clinical Setting* | | |
| Hospital Stroke Unit | 51 | 43 |
| Community Neuro-rehabilitation Service | 16 | 14 |
| Early Supported Discharge | 14 | 12 |
| Community Stroke Service | 12 | 10 |
| Hospital Neuro-rehabilitation Unit | 9 | 8 |
| Hospital Ward (General) | 5 | 4 |
| Private Practice | 4 | 3 |
| Voluntary Sector | 4 | 3 |
| University Clinic | 2 | 2 |
| General Practice | 1 | 1 |
| *Clinical Profession* | | |
| Speech and Language Therapist | 40 | 34 |
| Occupational Therapist | 16 | 14 |
| Nurse | 16 | 14 |
| Clinical Psychologist | 12 | 10 |
| Stroke Physician | 10 | 8 |
| Clinical Neuropsychologist | 6 | 5 |
| Physiotherapist | 4 | 3 |
| Medical Doctor | 3 | 3 |
| Stroke Support Coordinator | 2 | 2 |
| Assistant Psychologist | 2 | 2 |
| Trainee Clinical Psychologist | 1 | 1 |
| Psychotherapist | 1 | 1 |
| Educational Psychologist | 1 | 1 |
| Senior Psychological Practitioner | 1 | 1 |
| Nursing Assistant | 1 | 1 |
| Occupational Therapy Assistant | 1 | 1 |
| Speech and Language Therapy Assistant | 1 | 1 |

## Screening Rates

Respondents reported that significantly more PwA on their caseload had received a mood screen completed by themselves or another member of their team than a suicidality screen, as shown in Table 2. Their own individual likelihood to screen for mood was also reported to be significantly more likely than for suicidality. Most respondents also reported a 100% likelihood to screen for low mood and 0% likelihood to screen for suicidality. Strikingly, most reported screening all PwA for low mood, yet screening no PwA for suicidality. The large standard deviations highlight a significant variability in responses however.

Table 2 also demonstrates the variation in individual likelihood to screen for both depression and suicidality between professions. Occupational therapists and psychologists reported a very high likelihood of screening for depression. In contrast, physiotherapists, speech and language therapists, nurses and doctors, reported lower likelihood to screen for depression. All professions reported themselves to be less likely to screen for suicidality than mood; for all professions except Psychologists, likelihood to screen for suicidality fell below 50%, suggesting a negative bias against screening suicidality in PwA. Most respondents reported psychologists (n=95), speech and language therapists (n=81) and occupational therapists (n=77) to be completing mood and suicide screens in their services; fewer reported nurses (n=58), doctors (n=46) and physiotherapist (n=46) to be screening PwA.

**Table 2**

*Individual Likelihood and Rates of Mood & Suicide Screen by Profession*

| Profession | Percentage of Aphasic Caseload Screened for Low Mood (%) | | | Individual Likelihood to Screen for Low Mood (%) | | | Percentage of Aphasic Caseload Screened for Suicide (%) | | | Individual Likelihood to Screen for Suicide (%) | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mode | Mean | SD | Mode | Mean | SD | Mode | Mean | SD | Mode | Mean | SD |
| Occupational Therapist | | | | 100 | 90 | 15.31 | | | | 30 | 42.06 | 33.59 |
| Psychologist | | | | 100 | 89.52 | 21.09 | | | | 100 | 71.43 | 33.06 |
| Physiotherapist | | | | 100 | 68.75 | 37.5 | | | | N/A* | 41.43 | 44.04 |
| Speech and Language Therapist | | | | 100 | 62.44 | 37.45 | | | | 0 | 33.12 | 35.75 |
| Nurse | | | | 100 | 58.67 | 35.39 | | | | 0 | 36.67 | 40.49 |
| Doctor | | | | 10 | 55.83 | 36.55 | | | | 10 | 24.58 | 35.96 |
| Total Sample (N=118) | 100 | 73.07 | 31.34 | 100 | 71.10 | 34.54 | 0 | 42.51 | 38.96 | 0 | 42.51 | 38.96 |

*no mode available as no repeated response

## Current screening practice

Table 3 demonstrates the reported approaches, methods and supported communication adaptions used to screen PwA for depression and suicidality. Most respondents reported using a combination of standardised measures and clinical interviews. Overall, approximately three quarters of all respondents reported using clinical interviews with patients, and the same proportion of respondents reported using standardised self-report measures. Approximately half of respondents reported interviewing family members, carers or staff and just under half reported using standardised self-report measures with a family member, carer or staff. In contrast, the use of observer-rated scales was reported less. Almost all respondents reported using supported communication adaptions to screen PwA for depression and suicidality. They reported a broad variety of self-report measures and observer rating scales, some designed to be accessible for those with communication difficulties and some not.

**Table 3**

*Approaches, Methods and Adaptions Used When Screening for Low Mood and Suicidality for People with Aphasia (N=118)*

| Screening Approaches Used | N | % (total of sample) |
|---|---|---|
| *Methods Used to Screen* | | |
| Standardised Self-Report Measure with Patient | 92 | 78 |
| Clinical Interview with Patient | 88 | 75 |
| Clinical Interview with a Family Member, Carer or Staff | 69 | 58 |
| Standardised Self-Report Measure with a Family Member, Carer or Staff | 49 | 42 |
| Observer Rating Scale | 36 | 31 |
| *Reported Frequency of Adaption During Clinical Interview* | | |
| Always | 68 | 58 |
| Routinely (>75%) | 25 | 21 |
| Often (>50%) | 6 | 5 |
| Occasionally (<25%) | 9 | 8 |
| None | 8 | 7 |
| *Adaptions Used to Support People with Aphasia* | | |
| Accepting Non-verbal Answers e.g. gesture | 110 | 93 |
| Checking Understanding | 109 | 92 |
| Additional Time | 105 | 89 |
| Provide Pictorial Support | 100 | 85 |
| Provide Options for Answers e.g. words or picture | 99 | 84 |
| Closed Questions | 97 | 82 |
| Use Short Sentences | 97 | 82 |
| Provide Pen & Paper | 96 | 81 |
| Repetition | 94 | 80 |
| Provide Written Support e.g. Key Words | 89 | 75 |
| Re-phrasing Questions | 87 | 74 |
| Use Only One Topic Per Sentence | 81 | 69 |
| Explain Written Material | 80 | 68 |
| Multiple Choice | 77 | 65 |
| Providing Written Information in an Alternative Formats e.g. Easy Read | 69 | 58 |
| Joint Session with a Speech & Language Therapist | 64 | 54 |
| Personalised Questions | 63 | 53 |
| Talking Mat | 44 | 37 |
| Joint Session with a Psychologist | 17 | 14 |
| *Standardised Self-Report Measures Used* | | |
| The Depression Intensity Scale Circles (DISCS)[62] | 62 | 53 |

| | | |
|---|---|---|
| Visual Analogue Mood Scale (VAMS)[63] | 47 | 40 |
| Hospital Anxiety and Depression Scale (HADS)[64] | 37 | 31 |
| Patient Health Questionnaire (PHQ)[65] | 31 | 26 |
| Distress Thermometer[66] | 24 | 20 |
| Aphasia Impact Questionnaire[67] | 19 | 16 |
| CORE 10[68] | 11 | 9 |
| Brief Assessment Schedule Depression Cards (BASDEC)[69] | 5 | 4 |
| Cornell Depression Scale[70] | 4 | 3 |
| *Standardised Observer Rating Scale Used* | | |
| Stroke Aphasic Depression Questionnaire (SADQ- 21)[71] | 24 | 20 |
| Stroke Aphasic Depression Questionnaire (SADQ-H10)[71] | 20 | 17 |
| Sign of Depression Scale (SODS)[72] | 15 | 13 |
| Aphasia Depression Rating Scale (ADRS)[73] | 5 | 4 |
| Hamilton Depression Rating Scale (HDRS)[74] | 2 | 2 |

## Level of Training and Awareness of Guidelines

Almost all respondents had received training on aphasia (n=114, 97%), over three-quarters had received training on depression (n=92, 79%) but less than two-thirds had received training on suicide (n=72, 62%). Additionally, a greater number of respondents (n=94, 80%) described their level of training on aphasia as more comprehensive, than described their level of training on screening for depression in post-stroke aphasia as comprehensive (n=63, 53.8%). Regarding awareness of relevant guidelines, most of the sample (n=85, 73.9%) reported having awareness of, or having read, official guidelines for depression and many respondents (n=65, 55.6%) reported awareness of, or having read, aphasia guidelines.

## Theory of Planned Behaviour (TPB)

Table 4 provides descriptive statistics for the TPB variables. All assumptions of multicollinearity, outliers, normality, linearity, homoscedasticity, independence of residuals were met. A multiple regression found that the TPB variables accounted for 48% of the variance in intention to screen for depression ($R^2$=.48, F (3,101) =30.60, p<.001). It was found that normative beliefs significantly predicted likelihood to screen for depression in post-stroke aphasia (β= .62, p<.001).

**Table 4**

*Descriptive Statistics for TPB Variables* (N=*105**)

| Theory of Planned Behaviour Component | Possible Range | Observed Range | Mean | SD |
|---|---|---|---|---|
| Attitudes | 13-130 | 62- 130 | 110.03 | 12.97 |
| Normative Beliefs | 4-40 | 7- 40 | 29.53 | 8.57 |
| Control Beliefs | 10-100 | 27- 89 | 58.77 | 12.97 |

* 13 (15%) respondents did not fully complete all TPB questions so only 105 respondents were included in the multiple regression

**Table 5**

*Summary of a Multiple Regression Analysis: TPB Predicting the Likelihood to Screen for Depression* (N=*105*)

| Variables | *B* | *SE B* | *β* |
|---|---|---|---|
| Attitudes | 0.15 | 0.21 | 0.05 |
| Normative Beliefs | 2.54 | 0.33 | 0.62** |
| Control Beliefs | 0.31 | 0.23 | 0.11 |
| $R^2$ | | .48 | |
| *F* | | 30.60** | |

**$p$<.001

### Internal Consistency

The attitudes (α = .83) and normative belief (α= .80) TPB variables had high internal consistencies with Cronbach's α >.8. The control beliefs TPB (α =.71) variable had good internal consistency with Cronbach's α >.7.

### Test-retest Reliability

Unfortunately, only thirteen (11%) respondents completed the questionnaire twice with at least two weeks between responses. Descriptive statistics indicated however, that the average change in scores for the TPB variable was consistently very small; the mean changes in Attitudes was an increase of 2.6 (SD=5.21), an increase of 0.8 (SD=3.83) for Normative Beliefs and an increase of 1.7 (SD=7.22) for Control Beliefs. Additionally, the mean change over the two weeks in the reported likelihood to screen was also small: for depression the average change was a decrease of 2.92% (SD=13.9). The average changes in reported likelihood to screen for suicidality was an increase of 13.13% (SD=6.25); which is still relatively small. Repeated measure ANOVAs were completed to evaluate stability of responses over time. A series of repeated measures ANOVAs with a Greenhouse-Geisser correction determined that the reported likelihood to screen for depression (F(1.00, 12.00)1.30 p=.277), the reported likelihood to screen for suicide (F(1.00, 12.00).17 p=.680), attitude beliefs (F(1.00, 9.00)2.36 p=.159), normative beliefs (F(1.00, 9.00).44 p=.525) and control beliefs (F(1.00, 9.00).55 p=.476) did not differ statistically significantly between time points; suggesting that responses were stable over time. In conclusion, reported likelihood to screen and TPB variables did not appear to vary greatly over time, although firm conclusion cannot be drawn as a result of the small sample size.

## Discussion

One hundred and eighteen stroke clinicians, across stroke professions, clinical settings and UK regions, supplied information on their screening practices in PwA. Some reported that everyone with aphasia on their caseload received mood and suicide screens, but this was inconsistent and large variations of practice were apparent. There were promising findings with respondents reporting a large percentage of PwA on their caseload to be screened for low mood and that they were highly likely to screen for low mood. Variation was seen between professions: occupational therapists and psychologists reported a high likelihood of screening for depression; physiotherapists, SLTs, nurses and doctors reported a lower likelihood to screen. We found a similar self-reported rate of poststroke depression screening to Lees et al.[26] but a higher rate than Hart and Morris[27], both of which examined screening of all stroke survivors rather than PwA. Encouragingly, mood screening rates were not markedly lower for PwA than stroke survivors as a whole.

Notably, this high screening rate was not echoed for suicidality screens, despite the severity of the risks involved. Respondents consistently reported themselves to be markedly less likely to screen for suicidality than low mood; the most commonly reported likelihood to screen for suicide in this sample was 0%. This was despite the high rates of positive attitudes about screening in the sample. All professions reported themselves to be less likely to screen for suicidality than mood; all professions except Psychology demonstrated a negative bias against screening PwA for suicidality. This finding was mirrored in the data on the percentage of PwA on their caseloads who had been screened for suicidality. No previous research has looked at self-reported suicidality screening rates. However, Kneebone et al.[29] created a protocol to support occupational therapists to screen for low mood and suicidality, in those with and without communication difficulties. In a follow up study, it was reported that the suicide question was not being asked or recorded on patient records[75].

Beyond the impact of profession on screening likelihood, the TPB regression model effectively predicted the likelihood of screening for depression in aphasia, specifically indicating that normative beliefs strongly predicted screening intent. Normative beliefs concern the extent to which the individual believes others think they should or should not perform a behaviour[32]. In this context, respondents' beliefs regarding whether their colleagues, others in their profession and their employer expect them screen for depression in post-stroke aphasia, effectively predicted screening intent. The results from this study further add to literature on TPB as an effective model of understanding behaviour. Hart and Morris[27] applied the TPB model to depression screening practices and concluded that despite its limitations, the TPB provided an effective framework for identifying factors that influence depression screening. Additionally, they similarly demonstrated that normative beliefs predicted screening intention, however in contrast, they reported that control beliefs also predicted intent. It should be noted that they used a correlational approach rather than multiple regression and did not specifically examine screening in post-stroke aphasia. Furthermore, Gillespie et al.[38] similarly concluded that the TPB model predicted stroke staff's intention to provide non-pharmacological approaches to post-stroke emotionalism; they found that attitudes and subjective norms predicted intent. Therefore, there is growing evidence that subjective norms predict behavioural intent of professionals working in stroke. Furthermore, a qualitative study exploring staff's experiences of providing intervention for low mood in PwA found that there was a lack of clarity in the roles and responsibilities for managing mood screening among a multidisciplinary stroke team[76].

In terms of screening practices, a mixed approach to PSD screening was common, using clinical interview and standardised self-report measures with PwA and family members. The most frequently reported method was combining standardised self-report measure with clinical interview with the PwA. Almost all respondents that reported completing a clinical interview with PwA, reported using supported communication adaptions; a range and high rate of total communication approaches were reported. This directly contrasts with a study examining use of adaptions for depression screens in PwA in research studies, which found less than half adapted screening approach[54]. Again, most respondents reported using visual self-report measures such as the Depression Intensity Scale Circles[62] and a smaller number reported using verbal self-report measures e.g. Hospital Anxiety and Depression Scale[64]. These findings greatly contrast to findings of Hart and Morris[27] who reported most respondents used verbal measures and less than 2% reported using visual mood scales. Finally, this study found that observer-rated measures were the least frequently used method of screening mood.

## Strengths and Limitations

This is the first study to examine screening practices for depression and suicidality in people with post-stroke aphasia and the first to examine suicidality screening rates post-stroke, despite stroke survivors dying by suicide at greater rates than the general population. Research on depression and suicide screening rates is fundamentally important as a third of stroke survivors develop aphasia[39] and post-stroke aphasia is associated with greater vulnerability to depression than stroke alone. Additionally, because the commonly used verbal and written screening measures of mood are often inaccessible for those with aphasia, screening approaches were likely different in this client group and furthermore may have acted as a barrier to screening altogether; however, till now this had not been researched. This study begins to fill that gap. It should be acknowledged though that this study used a self-report questionnaire, and it was not possible to audit actual staff practice. Additionally, it was not possible to statistically access stability of screening intent through test-retest analysis due to few respondents completing the questionnaire twice. However, descriptive statistics did not suggest marked changes in screening intent over time. However as those with post-stroke aphasia are frequently excluded from PSD research[52,53,77] and receive poorer care[48], this study contributes to efforts to right health and research inequalities affecting PwA.

Our findings reflect the reported screening practices of a large, diverse sample of respondents working in stroke from across the UK. Depression screening post-stroke is undertaken across the stroke pathway and by multiple professions, as reflected in the diversity of respondents across disciplines, working at different points in the stroke pathway. The choice to recruit via professional interest groups and social media rather than audit or pre-selected organisations, avoided narrowing our dataset. However, a notable limitation is that recruitment via professional bodies and social media may mean that our sample had a particular interest in screening and/or aphasia. The attitude towards screening tended to be positive, rather than distributed across the full range of this variable. More research is required to determine if this study's findings would be different if respondents held more negative attitudes. It should be acknowledged however that this study's sample had a significant proportion of SLTs and stroke staff working in acute settings. Additionally, data was collected online not via face-to-face sampling.

This research goes beyond just collecting data on screening rates and approaches to in addition predict staffs screening intent on the basis of a theoretical model of behaviour. Our research highlights both the challenges and potential solutions for stroke services wishing to improve their detection of post-stroke depression and risk of death by suicide in PwA. We hope this research facilitates and promotes healthcare improvement for a client group documented to experience poorer care[48]. The TPB used here to predict screening intention, is one of the most cited and influential models for the prediction of human social behaviour[32] and a meta-analysis found a significant pooled effect size for predicting intention[37]. Additionally, a systematic review found that self-reported intention predicts clinicians' behaviour[78]. Therefore, although this study only collected data on behavioural intent and did not audit screening behaviour, there is good grounds to believe these finding likely mirror actual staff practice. The TPB has been applied effectively to similar study designs and behaviours, in studies of staff intentions in stroke services[27,38]. However, it should be noted that there are critics of the TPB[79] and there are alternative models of behaviour, for example the COM-B model of behaviour[80], that could have been applied. Significant evidence supports the TPB and it has been successful applied to staff practice in stroke rehabilitation however[27,38] and our focus on self-reported behavioural intent (reported likelihood to screen) underpinned our use of the TPB. Human behaviour is notoriously difficult to predict, and no current theoretical model is without its limitations; however, the variance predicted by the TPB model in this study was significant and provides further support for the utility of this model.

Our study has a few notable strengths. First, previous research applying TPB relies on correlational analyses, rather than fully powered regression. Likert scales have been used previously in TBP research however our use of visual analogue scales permitted parametric analyses. The validity of visual analogue scales has been demonstrated in the social sciences[58-60] but it is acknowledged that both Likert and visual analogue scales, have strengths and weaknesses[80].

**Implications**

These findings are significant for clinical practice and stroke policy. Multiple guidelines recommend screening all stroke survivors for low mood and screening all individuals with suicidal risk factors, such as stroke, for suicidality[18-22]; therefore, our findings suggest more effort is required to support staff to meet these recommendations. It was promising to see that depression screening compliance was not markedly lower in this study focussing on PwA, compared to studies of stroke survivors in general[26,27] as previous research has demonstrated that PwA experience poorer health care[48]. However, as PwA have increased risk of PSD[44-46] we might expect a higher rate of mood screening corresponding to higher level of risk. This was not observed; more work is needed to support staff to screen all PwA for low mood. We provide important evidence that the risk of death from suicide is not being assessed for PwA in stroke services across the UK, by all professions. Screening all stroke survivors for depression and suicidality is important as depression is very common poststroke[4], has negative outcomes[82] and stroke survivors continue to die by suicide at greater rates than non-stroke survivors[13]. Without screening, individuals are unlikely to receive treatment or support, contrary to clinical guidance and these worrying statistics are likely to remain unchanged.

We found a detailed and thorough approach to screening PwA is being used in clinical practice across the UK, which captures the individual's and family's voices. These findings mirror what the NHS Improvements stroke guidelines recommended for mood assessments, which suggest “a simple brief standardised measure... followed up with an interview… about the patient’s view of their current emotional state.”[71(p10)]. Furthermore, this study demonstrated that stroke professionals are routinely adapting their approach to screening to make it accessible for PwA through routine use of supported communication adaptions and visual rather than verbal self-report measures. This is important in terms of validity as verbal self-report measures have been validated in stroke, but not PwA. Nonverbal self-report mood measures have been validated in stroke and aphasia; however, some have questioned the robustness of these measures and the methodology of these validation studies[55,56]. It should be noted that despite thorough screening methods and good use of total communication strategies, reported screening rates remained below 100%. Additionally, another important finding was the infrequent use of observer rated measures of mood. This is despite the NHS Improvements stroke guidelines[83] recommending using the SAD-Q in people with more severe communication difficulties and a recent meta-analysis by van Dijk et al.[55]

concluded that the Stroke Aphasic Depression Questionnaire-10 and the Signs of Depression Scale are the most feasible measures for PwA and recommended their use in clinical practice. This study clearly demonstrates the difference in approaches to screening PwA, compared to stroke survivors without aphasia. However, as the first study to document this, future studies should ensure inclusion of PwA in stroke research.

This study has clear implications for the improvement of depression and suicide screening in PwA. Steps should be taken by stroke services to communicate unambiguous normative beliefs regarding screening post-stroke depression and suicide risk in PwA. This can be implemented by naming screening in job descriptions, sharing guidelines for depression and suicide screening, and auditing and publicising screening rates externally and internally. We provide clear evidence that screening depression and suicide is completed by all stroke professions and an expression of distress can occur to any member of staff, so interventions must target all professions and levels. We found that some stroke professionals have not received training on depression and even fewer have received training on suicide; most staff reported their level of training on depression and suicide to be less than comprehensive. Our findings support the clear recommendation that services should provide training on depression and suicide risk for all staff working with stroke survivors. Stroke guidelines currently recommend screening mood but not suicide, despite other guidance to screen people with suicide risk factors, such as stroke or depression[11,12,16,17]. It is therefore recommended that stroke guidelines consider including a recommendation to screen suicide risk, to make expectations of services explicit for this aspect of clinical risk assessment.

## Recommendations

These findings warrant a series of recommendations for all services treating stroke survivors with aphasia. Firstly, it is recommended that training in depression and suicide is provided to all staff in contact with stroke survivors. Secondly, services are encouraged to use observer-rated measures of mood in clinical practice. To increase depression and suicidality screening rates in PwA the following is recommended: that screening be included in professionals working in stroke job descriptions, that services publicise guidelines that recommend post-stroke depression screening and guidelines recommending screening for suicide in those with risk factors including stroke, that screening rates be audited, shared with staff and published. Additionally, these findings highlight that more research is required to investigate post-stroke depression and suicidality in PwA, including: validation studies of self-report mood measures, the creation and validation of measures of suicidality and the creation of protocols to support staff to screen for suicidality. Finally, it is recommended that screening suicide risk be included into stroke guidelines and that national audits of stroke care consider auditing suicidality screening and adopting the WHO's definition of screening.

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# **Chapter 4-** Additional Methodology Chapter

## Additional Methodology

### Survey Design

A new Theory of Planned Behaviour (TPB) questionnaire was designed for this thesis. Several steps were taken to ensure the survey design was robust (Appendix I).

### Collaboration and Piloting

Both the questionnaire and study design were informed by a research panel made up of clinical psychologists and speech and language therapists (SLT), with extensive experience working in stroke and with aphasia. The motivation for using a multi-professional research panel was that screening for low mood in people with post-stroke aphasia spans the expertise of clinical psychology and speech and language therapy, and therefore co-creating this survey was important for empirical validity. One of the recommendations of the systemic review by Townsend et al. (2007) on the inclusion of PwA in post-stroke depression research was for depression experts to involve and collaborate with language experts. Additionally, a previous survey of 124 UK SLTs, regarding professional experience of supporting PwA with psychological needs poststroke, found the main facilitator reported to support addressing psychosocial well-being, was collaborative working between SLTs and stroke-specialist clinical psychologists (Northcott et al., 2017). This study also found less than half of SLTs felt confident to support psychological needs of clients and that one of the main barriers to referring PwA to mental health services, was concerns that mental health professionals lacked the skills to work PwA (Northcott et al., 2017). These studies highlight the need for collaboration in clinical practice and research.

The questionnaire was also benefited from pilot feedback from target users, professionals working in stroke (three speech & language therapists, one stroke nurse and three clinical psychologists). A draft copy of the questionnaire was sent to stroke professionals known to either myself or my supervisors and their feedback was collated and actioned. Feedback was gathered on whether the questionnaire captured the variety of ways in which mood and suicidality is screened in PwA and on the usability of the survey. For example, emphasis was placed on determining whether the completion time was appropriate and that the questions were comprehensible. Special focus was placed on the usability of the TPB questions as discussed below. The feedback gathered informed the development of the measure from the outset and throughout.

## Questionnaire Construction

To further ensure a robust survey design, a previous service audit on screening practice in those with post-stroke aphasia conducted in a UK community neuro-rehabilitation service and research by Townend et al. (2007a), Townend et al. (2007b), Hart and Morris (2008), Simmons-Mackie et al., (2013) and van Dijk et al. (2015) was used to inform the design and establish a comprehensive list of screening behaviours (approaches, measures and adaptions). The main research study within this thesis was a quantitative survey design where participants were asked to select their screening methods from a series of multiple-choice options, thereby ensuring an extensive list of screening practice which was crucial to ensure the dataset was unbiased. To further ensure this, all multiple-choice questions included an 'other' option with a free text box for respondents to freely describe alternative methods of screening not captured in the multiple- choice options.

### *Questionnaire Construction- Psychometric Properties*

To ensure the psychometric robustness of the questionnaire, guidance was taken from Braces et al.'s (2013) book on survey design and consultation on psychometrics was taken from an expert in questionnaire design based in the psychology department at the University of East Anglia. Based on this consultation, questions were written with both positive and negative items scored as "high" and "low" on the scale. Questions which use agree/disagree scales can be biased toward the "agree" side, so these were avoided and an odd numbers of response options was avoided as middle categories tend to attract disproportionate numbers of responses. Additionally, the BRUSO model (Peterson, 2000) guidelines for writing questionnaire items was used. The acronym, BRUSO stands for "brief", "relevant", "unambiguous", "specific", and "objective." was used to design question phrasing and content. Finally, counterbalancing was applied to the order of questions; this is deemed to be good practice to reduce response order effects (Miller & Krosnick, 1998).

### *Questionnaire Construction- Theory of Planned Behaviour*

To ensure the quality of the TPB questions, their design was guided by the theoretical framework of the TPB (Ajzen, 1985; 2002) and by Francis et al.'s (2004) published manual on constructing TPB questionnaires. For example, questions on respondents' beliefs about their level of training and education were included in the perceived control belief variable as recommended by Ajzen (2002, p13) because "when people believe that they have the required resources and opportunities (e.g., skills... they should have confidence in their ability to perform the behavior and this exhibit a high degree of perceived control.". Ajzen (2002) sights two studies were what factors influence perceived control were explored and lack of skills and knowledge were highlighted in both (Ajzen & Driver, 1991; Ajzen & Madden, 1986).

The following steps suggested by Francis et al. (2004) were taken: clearly defining the behaviour, deciding how best to measure intention, determining the perceived barriers or facilitating factors, determining the most frequently perceived advantages and disadvantages of performing the behaviour, determining the most important people or groups of people who would approve or disapprove of the behaviour, pilot testing the draft and rewording items if necessary and assessing the test-retest reliability of the indirect measures by administering the questionnaire twice to the same group of people, with an interval of at least two weeks. Francis et al. (2004) also suggests specific methods of question design, for example: to assess respondents' attitudes you should provide statements which clearly define the behaviour being investigated and then use bipolar adjectives or opposite pairs (e.g., bad and good) to determine attitude towards said behaviour. You should include items on whether the behaviour achieves something (e.g., useful–worthless) and experiential items on how it feels to perform the behaviour (e.g., pleasant – unpleasant). Advice is also given in terms of questionnaire structure, for example, arranging the items so that the ends of the scales are a mix of positive and negative endpoints (Francis et al., 2004).

### ***Questionnaire Construction- Statistical Analysis***

Additionally, to ensure a statistically robust questionnaire, statistical advice was sought from a consultant clinical psychologist with specific expertise in statistics. Following statistical advice, respondents were asked to represent their screening behavioural estimates as percentages, so parametric analysis could be applied. Additionally, a series of visual analogue scales were used, consisting of lines anchored at either end by bipolar adjectives or opposite pairs of the TBP variable, which were then coded and scored numerically. This is not only suggested by Francis et al (2004) but has additional psychometric and statistical benefits. Visual analogue scales are psychometric response scales used to measure subjective characteristics or attitudes and have been demonstrated to be valid for use in social science research (Wewer & Low, 1990; Svensson, 2000; van Dijk et al., 2002). Likert scales have more traditionally been used in social science questionnaires; however, these do not permit parametric statistical analysis. This method of survey design has the added benefit of being an interval scale, meaning parametric statistical analysis may be undertaken. A regression has advantages over correlation for example, it can demonstrate the direction and strength of the relationships between variables and can assess and compare amount of variance predicted. However, it is acknowledged that both Likert and visual analogue scales (VAS) have strengths and weaknesses (Hasson & Arnetz, 2005). Hasson and Arnetz (2005) described benefits of Likert scales, such as that they are easier to use and understand both for the researcher and the respondent, and that coding, as well as interpretation, is easier compared to the use of a VAS. They also outlined limitations of Likert scales, including that the wording of the categories is likely to affect responses and artificial categories might be insufficient to characterise a complex or more continuous phenomenon. Hasson and Arnetz (2005) described the benefits of using VAS; it has been suggested to be preferred by the raters, have a better ability to detect clinically significant change and might also be more reliable and valid. Based on these appraisals, the use of VAS was selected as VAS are preferred by raters and have been found to be more reliable and valid than Likert scales.

### ***Questionnaire Construction- Ethical Approval***

Ethical approval was received from the University of East Anglia Faculty of Medicine and Health Science Research Ethics Committee (Appendix D). A series of steps were taken to ensure the designed questionnaire was compatible with University of East Anglia research ethics standards. All data were stored in accordance with the General Data Protection Regulation and UEA policy. Demographic information was collected on participants, but the combination of information was designed to avoid de-anonymisation.

To ensure informed consent, an electronic participant information leaflet was created and given prior to taking part (Appendix G). This includes an explanation of the topic areas covered, a rationale for this study, pros and cons of taking part and information on how data was to be used and stored. Staff were asked to consent to take part using an online consent form (Appendix H). Only if consent was given were they able access to the questionnaire. Capacity to consent to participation was assumed in this study, as the participants were professionals working in stroke.

The other ethical consideration taken into account when designing this questionnaire was the possibility of causing distress. Discussing suicide can be emotionally difficult for some people; although this questionnaire did not discuss specific cases or personal experiences, it was acknowledged that participation could bring these to mind. Therefore, information on support services was provided on the debrief page (Appendix J) which was available for participants to access at any time while participating in this study. The possibility of distress was discussed in the participant information leaflet (Appendix G).

## Recruitment

After receiving UEA faculty research ethics committee (FMH REC) approval an online snowballing campaign was undertaken (see Appendices C and D for recruitment materials used). A convenience sampling method was used for recruitment. Snowball sampling is a recruitment method whereby the existing study subjects recruit future subjects among their acquaintances (Naderifar et al., 2016). The online nature of this recruitment approach meant that both participants' virtual and non-virtual networks were used. The hope of the snowballing campaign was that stroke professionals would then also share the questionnaire via their individual social media accounts, emails or via word of mouth to others that may be interested in taking part. This approach to sampling is called the "chained method" (Polit-O'Hara & Beck, 2013).

The methods used within the online campaign were two-fold. First, a series of UK-based professional bodies and stroke or aphasia special interest groups were contacted. The aim was to contact a diverse range of stroke professionals across the UK. The following societies or special interest groups agreed to share the questionnaire with their members or followers, via social media platforms or emails: National Stroke Nursing Forum, Royal Colleague of Speech and Language Therapist, Organisation for Psychological Research in Stroke, British Psychological Society, University of East Anglia School of Health Sciences, University of East Anglia School of Medicine, Aphasia Access, Stroke Rehabilitation Unit Leeds, UEA Nursing Society, AIA Aphasia International, Stroke Hub Wales, Unity Physiotherapy and Wellbeing, Collaboration of

Aphasia Trialists and British Association of Stroke Physicians. Some professional bodies and special interest groups contacted, such as Royal College of Occupational Therapists, British Medical Association and Stroke Association, declined to participate due to their policies of only sharing their own members' research with members. Secondly, the survey was advertised outside of professional organisations (e.g., by the Trainee Clinical Psychologist posting and asking others to repost the study advert via Twitter, LinkedIn, Email and ResearchGate).

Snowball sampling is often used when research is exploratory or the population under investigation is hard to reach, for example either due to low numbers of potential participants or because of the sensitivity of the topic or research (David & Sutton, 2011; Naderifar et al. 2016). This approach was selected for the TPB study in this thesis for three reasons. Firstly, reaching a broad range of stroke professional across the UK is challenging. Secondly, self-reporting lack of compliance with stroke guidelines had the potential to be a sensitive topic and anonymous recruitment via social media might therefore facilitate honest participation. Finally, this was exploratory research, as screening of depression and suicidality in PwA had not been researched prior to this study. However, online convenience sampling has some limitations. Data from convenience sampling can be prone to significant volunteer bias, because those who volunteer to take part may be different from those who choose not to participate. For example, this may mean that our sample had a particular interest in screening and/or aphasia. This could result in limited external validity. External validity is the extent to which the study results can be generalised to the population and depends on the characteristics of the sample and extent to which they represent the wider population. Furthermore, sampling from social networking site populations may skew participation to those individuals who have access to the necessary equipment and social media account. However, this approach also offered several benefits, by ensuring a broad picture of screening approaches, across the UK and across professions. This recruitment method allowed for a broader reach and larger sample; especially within the context of the COVID-19 pandemic and the busy, demanding working patterns of stroke professionals.

# **Chapter 5-** Discussion and Critical Evaluation

## Discussion and Critical Evaluation

The overall aim of this thesis was to determine both the level of exclusion and methods of inclusion of people with aphasia (PwA) in depression and suicidality screening post-stroke, in both research and UK clinical practice. The systematic review of 2,673 stroke research papers (Chapter 2) demonstrates that PwA continue to be excluded from the majority of research on post-stroke depression. Furthermore, even when included in research studies, they are often excluded from full participation, for example, not receiving a mood assessment because inaccessible verbal mood measures are too frequently being selected by researchers. This is despite the fact that several mood measures, which carry less or no language load, have been developed and validated in aphasia. Similarly, in the survey of 118 UK stroke professional (Chapter 3) respondents reported that not all PwA currently receive a mood and suicidality screen, as is recommended by multiple health guidelines, highlighting the need for further support for staff to meet these guidelines. The theory of planned behaviour analysis suggested that screening rates may be improved by communicating a clear expectation that staff should screen all stroke survivors for depression and suicidality; by naming screening in job descriptions, sharing guidelines for depression and suicide screening as well as auditing and publicising screening rates externally and internally. However, in contrast to the systematic review, respondents reported frequently modifying screening methods for people with post-stroke aphasia, using more visual self-report measures and supported communication methods. This is important in highlighting what is possible and that PwA are not therefore "inappropriate for screening" as has been suggested by some researchers (Karmachandani et al., 2015).

The pivotal strength of this thesis is that it expands the research base in an under-researched field within stroke. Aphasia and post-stroke suicidality have consistently been under-researched when compared to the body of research on stroke- survivors without aphasia and post-stroke depression (Brady et al., 2012; Dou et al., 2015; Chung et al., 2016; Lee et al., 2018; Townend et al., 2007). This is despite significant evidence to suggest that those with aphasia are at a greater risk of developing post-stroke depression (De Ryck et al., 2014; Kauhanen et al., 2000; Shehata, et al., 2015; Thomas & Lincoln, 2006) and that stroke survivors are at a greater risk of suicide than the general public (Bartoli, et al. 2017; Eriksson et al., 2015; Pompili et al., 2012; Vyas et al., 2021).

There is a growing research interest in the inclusion of those with aphasia in research and within clinical care. Effective stroke rehabilitation and management is a key policy driver for the National Health Services Long Term Plan (2019) and psychological support post-stroke is currently a key research agenda in stroke research (Stroke Association, 2017). The inclusion of PwA in depression and suicidality assessment, as well as more frequent use of accessible and valid measures, will be essential to achieving these goals. One of the six founding values in the NHS constitution is "Everyone counts". This sets out the importance of ensuring that everyone has access to the resources available in the NHS without discrimination. Previous researchers have described that the exclusion of PwA from research as systematic and discussed the fact that systematic exclusion of a group of people, even when inadvertent, because of disability, is discriminatory (Brady et al., 2012). Therefore, it is hoped the findings and recommendations from the body research set out in this thesis begins to right this fact.

The thesis portfolio makes a unique contribution by providing a systemic review of the current status in terms of inclusion of PwA in depression screening within stroke research and by capturing for the first time, screening practices for depression and suicidality in people with post-stroke aphasia, and suicidality screening rates post-stroke. Research on depression and suicide screening rates is fundamentally important, as a third of stroke survivors develop aphasia (Flowers et al., 2016) and post-stroke aphasia is associated with greater vulnerability to depression than stroke alone. Mood is traditionally assessed using verbal or written screening measures, which are often inaccessible for those with aphasia. Therefore, screening approaches were likely different in this client group and common use of verbal measures may have acted as a barrier to screening altogether in this client group. However, until now, this had not been researched. The research set out in this thesis begins to fill that gap and hopefully will inform and inspire further research in this field.

Additionally, this thesis also adds to the growing body of research that uses the theory of planned behaviour (TPB) model to understand staff's behaviour and inform service improvements in terms of clinical practice within stroke rehabilitation. In the past decade there has been a growth in the publication of clinical health guidelines, such as those published by the National Institute of Clinical Excellence (NICE), within stroke care and more widely. The aim of these clinical guidelines is to provide an independent assessment of the current evidence-base to help inform commissioners and front-line staff to increase effective treatment (NICE, 2021). For example, due to a significant amount of research demonstrating an increased risk of developing depression post-stroke (Hackett & Pickles, 2014), multiple health guidelines recommend screening all stroke survivors (Duncan et al., 2005; Gooskens et al., 2009; Miller et al., 2010). However, there is evidence within post-stroke psychological care, that front-line staff are not always able to meet the standard of care or deliver the recommendation mapped out in these guidelines. For example, not all stroke survivors currently receive a mood screen (SSNAP, 2019; Hart & Morris, 2008; Rogers, 2017; Lees et al., 2014; Stroke Association, 2013). Previous research has applied the TPB model to understand professional's working in stroke behaviour in terms of clinical practice and provide recommendations for services to improve compliance with guidelines (Hart & Morris, 2008; Gillespie et al., 2019). These studies and the TPB study within this thesis, all concluded that this behavioural model was effective in understanding staff's intention. Compliance with clinical health guidelines is becoming increasingly important in NHS services, both in terms of providing care in line with NHS values, such as commitment to quality of care, and in terms of the appraisal processes for the commissioning and funding of services (NHS Long Term Plan, 2019; NHS Commissioning Board, 2013). The application of the TPB model in this way provides an opportunity in terms of clinical research to provide empirically- based recommendations to increase compliance with clinical guidelines and improve patient care. This application of the TPB could be beneficial for other areas of healthcare research, within stroke and beyond. For example, the TPB could be applied to other recommended screening programs, (e.g., post-stroke cognitive screens) or to evaluate the inclusion of other groups of service users that historically received poorer care or experience exclusion (e.g., the oldest older adults).

### Strengths of the Systematic Review

There are several strengths of the systematic review that make it an important and robust contribution to stroke research. In regard to robustness, the review used an inclusive search strategy used and multiple databases, resulting in a broad dataset from across the globe. The search strings used were informed by previous systematic reviews on this topic (Townsend et al., 2007) and created with consultation with a specialist librarian at the University of East Anglia. Another important strength is that the PRISMA guidelines (Moher et al., 2009) were followed and two separate second raters independently checked 20% of a random sample of included studies to determine they met inclusion criteria and to independently evaluate the quality assessment. A bespoke quality assessment tool was created to evaluate the internal and external validity of the assessment approach used to assess depression in people with post-stroke aphasia. All of these ensure the robustness of the findings.

In terms of importance, the large dataset reflects the recent growth in stroke research. Psychological support post-stroke is a key topic for stroke research (Stroke Association, 2017) and systematic reviews on this topic are important to evaluate and guide improvements of research evidence. This growth in the number of publications on this topic meant that expanding the systematic review was important to determine whether inclusion rates have changed. The inclusion of PwA in stroke research was previously reviewed by Townsend et al. (2007). However, at the time, observer-rated measures designed to assess low mood in those with aphasia were still new and not yet commonly used in clinical research practice (e.g., ADRS & SADQ). Updating their systemic review was important to determine whether the development of these measures had improved the inclusion of PwA in research on post-stroke depression. This was found not to be the case; PwA are still routinely excluded from in post-stroke depression research. The exclusion of PwA reduces the validity of the current evidence regarding post-stroke depression and hinders evidence-base practice for PwA (Baker et al., 2017; Hackett et al., 2008; Allida et al., 2021). As mentioned above, effective stroke rehabilitation and management is a key policy driver for the National Health Services Long Term Plan (2019) and psychological support post-stroke is a key research agenda in stroke research (Stroke Association, 2017). The inclusion of PwA in depression research and the more frequent use of accessible and valid measures will be essential to achieving these goals. It is hoped that our findings will prove helpful in informing for both future research and clinical practice.

## Limitations of the Systematic Review

Limitations of this systemic review include the lack of details on aphasia, standardised measures of aphasia, or definitions of ‘moderate’ or ‘severe’ aphasia and unclear description of inclusion and exclusion criteria within the studies reviewed. This made determining the true extent of exclusion difficult and limited the ability to make comparisons between studies. These difficulties highlight the continued exclusion of PwA in stroke research and the continued need for greater consideration of PwA in this research field. Some other limitations include that only studies in the English language were included in this review which could create a western bias in the sample. Finally, an independent screening, extraction and quality assessment of all studies was beyond the remit of the current review.

## Strengths of the Theory of Planned Behaviour Study

Our study has a few notable strengths that speak to the robustness, importance and originality of this study. What makes this study original is that this is the first study to examine screening practices for depression and suicidality in people with post-stroke aphasia and the first to examine suicidality screening rates post-stroke, despite stroke survivors dying by suicide at greater rates than non-stroke survivors (Vyas et al., 2021) and despite the fact that those with post-stroke aphasia are at a greater risk of developing depression (De Ryck et al., 2014; Kauhanen et al., 2000; Shehata, et al., 2015; Thomas & Lincoln, 2006).

Another important strength of the empirical paper that demonstrates its robustness and importance is that the study goes beyond just collecting data on screening rates and approaches, to predict staff screening intent based on the basis of a theoretical model of behaviour. Our research highlights both the challenges and potential solutions for stroke services wishing to improve their detection of post-stroke depression and risk of death by suicide in PwA. We hope this research facilitates and promotes healthcare improvement for a client group documented to experience poorer care (O'Halloran et al., 2008). The TPB used here to predict screening intention, is one of the most cited and influential models for the prediction of human social behaviour (Ajzen, 2011) and a meta-analysis found a significant pooled effect size for predicting intent (Armitage & Conner, 2001). Additionally, a systematic review found that self-reported intention predicts clinicians' behaviour (Eccles et al., 2006). Therefore, although this study only collected data on behavioural intent and did not audit screening behaviour there is good grounds to believe these findings may mirror actual staff practice. The TPB has been applied effectively to similar study designs and behaviours, in studies of staff intentions in stroke services (Morris & Hart, 2008; Gillespie et al., 2019). Hart and Morris (2008) applied the TPB model to depression screening practices and concluded that despite its limitations, the TPB provided an effective framework for identifying factors that influence depressing screening. Additionally, they similarly demonstrated that normative beliefs predicted screening intention, however in contrast, they reported that control beliefs also predicted intent. It should be noted that they used a correlational approach rather than multiple regression and did not specifically examine screening in post-stroke aphasia. Furthermore, Gillespie et al. (2019) similarly concluded that the TPB model predicted professionals working in stroke's intention to provide non-pharmacological approaches to post-stroke emotionalism; they found that attitudes and subjective norms predicted intent. Therefore, there is growing evidence that normative beliefs predict professionals working in stroke's behavioural intent in terms of stroke care.

The methodological approach taken with this study has a series of notable strengths that speak to the robust design of this paper. Firstly, the questionnaire and study design were informed by a research of team of both language and psychological experts, with significant experience working with stroke rehabilitation and aphasia. Secondly, the questionnaire was both informed and piloted with multiple stroke professionals, including speech and language therapists, clinical psychologists, and nurses. Thirdly, to ensure a statistically robust survey, consultation on psychometrics was taken from an expert in questionnaire design based in the psychology department at the University of East Anglia; statistical advice was taken from a consultant clinical psychologist with specific expertise in statistics; and the design was guided by Francis et al.'s (2004) published manual on constructing TPB questionnaires. Additionally, to further ensure a robust survey design, the current literature-base and a previous service audit on screening practice in those with post-stroke aphasia conducted in a UK community neuro-rehabilitation service informed the design. Furthermore, previous research applying TPB to mood screening behaviours relied on correlational analyses, whereas this study used a more powerful design, a fully powered regression. Based on Tabachnick and Fidell (2007), it was estimated a sample size of 61 or larger ($N > 50 +$ 8x independent variables) would have significant power. A regression has advantages over correlation for example, it can demonstrate the direction and strength of the relationships between variables and can assess and compare amount of variance predicted. Furthermore, Likert scales have been used previously in TBP research, however our study used visual analogue scales which permitted parametric analyses methods. The validity of visual analogue scales has been demonstrated in the social sciences (Wewer & Low, 1990; Svensson, 2000; van Dijk et al., 2002) but it is acknowledged that both Likert and visual analogue scales have strengths and weaknesses (Hasson & Arnetz, 2005). Finally, our findings reflect the reported screening practices of a large, diverse sample of stroke professionals from across the UK. Depression screening post-stroke is undertaken across the stroke pathway and by multiple professions, as reflected in the diversity of respondents across disciplines, working at different points in the stroke pathway. The choice to recruit via professional interest groups and social media rather than audit or pre-selected organisations, avoided narrowing our dataset.

## Limitations of the Theory of Planned Behaviour Study

There are limitations of this study. The findings and recommendations in terms of screening behaviours were determined by designing a theory of planned questionnaire and applying that model to analysis in the form of a regression. However, it should be noted that there are critics of the TPB, most notably summarised by Sniehotta and colleagues (2014) in their article, ‘Time to retire the theory of planned behaviour’. Sniehotta et al. (2014) questioned the predictive power of TPB on behaviour, it’s validity and usefulness as a model. Some reject the hypothesis that consciousness is a causal agent suggesting that thoughts do not cause behaviours (Wegner & Wheatley, 1999), others reject the view that human behaviour is driven by explicit attitudes (Greenwald & Banaji, 1995) and others dispute the unimportance of unconscious mental processes on behaviour (Aarts & Dijksterhuis, 2000; Brandstätter et al., 2001; Uhlmann & Swanson, 2004). Additionally, the theory has been criticised for its focus on rational reasoning, excluding unconscious influences on behaviour (Sheeran et al., 2013) and the role of emotions beyond anticipated affective outcomes (Conner et al., 2013). However, even Sniehotta et al. (2014) acknowledge that the TPB has been shown to consistently predict behaviour from intention and perceived behavioural control and that a large change in intentions is found to also produce changes in behaviour. Sniehotta et al.’s (2014) paper has also attracted a lot of countercriticism and commentary (Ajzen, 2015; Armitage, 2015; Connor, 2015; Ogden, 2015). There are alternative models of behaviour, for example the COM-B model of behaviour (Michie et al., 2014), that could have been applied. The COM-B model has been applied to ensure services meet guidelines for aphasia (Shrubsole et al., 2019). However, as this study is seeking to understand staff screening intentions rather than ensure a particular service meets guidelines, the TPB seemed most appropriate. Additionally, currently the TPB remains the model with the largest empirical support (Ajzen, 2015). Furthermore, as noted above, it has successfully been applied to staff practice in stroke rehabilitation (Hart & Morris, 2008; Gillespie et al., 2019). Human behaviour is notoriously difficult to predict, and no current theoretical model is without its limitations; however, the variance predicted by the TPB model, or more specifically the normative belief variable, in this study was significant and provides further support for the utility of this model to understand stroke staff's clinical practice.

Additionally, it should be acknowledged that this study used a self-report questionnaire, and thus it was not possible to audit actual staff practice. The benefit of an audit is that real world behavioural data would have been collected, as opposed to data on behavioural intent. However, it would have limited the data to a few services and would not capture national trends limiting generalizability of the findings. Capturing a broad picture of screening approaches, across the UK and across professions, was a key priority of this research and therefore this methodology was chosen. Furthermore, in the light of the COVID-19 pandemic, the chance of securing the participation of a stroke service was unlikely, and if one had been found, the documentation of usual screening practice was unlikely during these unusual times. Furthermore, stroke practice, including mood screening, is currently audited in several NHS services through the Sentinel Stroke National Audit Programme (SSNAP). However, as mentioned previously, there are limitations to SSNAP as the definition of screening used is not reflective of the World Health Organisation's definitions of screening and data on suicidality screens is not collected. Another limitation was the small number of respondents who completed the questionnaire twice, thereby limiting the robustness of the test-retest analysis of stability of screening intent. Another limitation is that recruitment via professional bodies and social media may mean that our sample had a particular interest in screening and/or aphasia. The attitude towards screening tended to be positive, rather than distributed across the full range of this variable. More research is required to determine if this study's findings would be different if respondents held more negative attitudes. However, the choice to recruit via professional interest groups and social media rather than audit or pre-selected organisations, avoided narrowing our dataset. It should be acknowledged however that the study sample had a significant proportion of SLTs and staff working in acute stroke settings. Additionally, data were collected online not via face-to-face sampling, which however again allowed for a broader reach and larger sample; especially within the context of the COVID-19 pandemic and usual busy and demanding working patterns of stroke professionals.

There were alternative methodological approaches that could have been deployed to capture clinical practice which have their own advantages and disadvantages, for example, qualitative interviews. The benefit of a qualitative approach would be more detailed information on screening practices and a more open discussion around barriers and facilitators. However, qualitative research is often limited to a smaller sample size, limiting the ability to capture the national picture. Capturing a broad picture of screening approaches, across the UK and across professions, was a key priority of this research and therefore this methodology was chosen. Going forward, research studies applying these alternative methods would be recommended to further the evidence base.

## Implication and Recommendation for Research

This body of research demonstrates that PwA continue to be excluded from participation in stroke research and when included frequently receive inaccessible and unvalidated measures of mood, despite the creation of several aphasia-friendly assessment methods. It is acknowledged that not every PwA can be included in post-stroke depression research, for example, when someone lacks the capacity to consent or if significant cognitive impairment co-occurs. There is a balance to be struck between practicality and inclusion. However, with reasonable adaption more PwA can be included in research on post-stroke depression. Furthermore, the results from the main paper demonstrates how it is possible to screen for low mood and suicidality in PwA. The questionnaire revealed that significant numbers of stroke professionals are undertaking regular and in-depth screens of low mood that facilitates supported communication and include both the individual and their support network. These examples of good practice and the associated higher inclusion rates found in stroke staff compared to research studies, mean they can be used as an informative example for researchers on how to support the inclusion of PwA. However, despite these positives, consistent good practice was not reported by respondents, especially in terms of suicidality screening. Indeed, strikingly, the most commonly reported individual likelihood to screen for suicidality in PWA was 0%.

The research findings contained within this thesis warrants a series of recommendations for stroke research. Firstly, it is recommended that more people with aphasia should be included in stroke research on post-stroke depression. Furthermore, when PwA are included in research, accessible and validated measures of mood should be used. Secondly, additional validation studies are required for aphasia-friendly mood assessments, such as the SADQ, DISCS, VAS and ADRS, in large representative samples of people with aphasia. Thirdly, it is recommended that research be undertaken investigating rates of suicidality in PwA, including the creation and validation of measures and protocols to support staff to screen for suicidality. Finally, qualitative research studies are recommended to explore how PwA and clinicians experience current depression and suicidality assessment methods.

**Implication and Recommendation for Clinical Practice**

This body of research has important implications for clinical practice in the UK and it is hoped that these findings and the associated recommendation are timely as the Integrated Stroke Delivery Networks that focus on improving stroke outcomes have recently been launch, and the Intercollegiate Stroke Working Party, the NICE stroke guidelines and the Stroke Specific Education Framework are currently being reviewed. These findings demonstrate that at present, not all people with post-stroke aphasia receive a mood and suicidality screen in UK. This is despite the creation of several aphasia-friendly assessment methods. It did provide some positive and promising findings in terms of mood screens. It was demonstrated that a significant number of stroke professionals are undertaking regular and in-depth screens of low mood that facilitate supported communication including with both the individual and their support network. This highlights what is possible. It also demonstrated that a different approach to screening PwA is used in clinical practice compared to stroke survivors without aphasia; this is the first study to document this. However, this good practice was not universal, especially in terms of suicidality screening. This research provides important evidence therefore that the risk of death from suicide is not being assessed for PwA in stroke services across the UK, by all professions. This clearly demonstrates that more resources are needed to support staff to meet guidelines and screen all stroke survivors for low mood and suicidality. Screening all stroke survivors for depression and suicidality is important as depression is very common poststroke (Hackett & Pickles, 2014), is associated with multiple negative outcomes (Gaete & Bogousslavsky, 2008) and stroke survivors continue to die by suicide at greater rates than non-stroke survivors (Vyas et al., 2021). Without screening, individuals are unlikely to receive treatment or support, contrary to clinical guidance and these worrying statistics are likely to remain unchanged.

The research findings contained within this thesis warrant a series of recommendations for clinical practice, which should facilitate an increase in screening rates for depression and suicidality in those with post-stroke aphasia. Firstly, stroke guidelines should be updated to recommend screening for suicidality in all stroke survivors. Secondly, training should be provided on depression and suicidality to all staff in contact with stroke survivors. Thirdly, the use of observer-rated measure of mood should be encouraged in clinical practice. Fourthly, screening for depression and suicide risk should be included in the job descriptions for stroke professionals. Additionally, it is recommended that departments audit screening rates, share these with staff and publish these via articles, editorials and service audits. Finally, it is recommended that the SNAPP audit should include suicidality screening rates and use the WHO definition of screening, so data can be collected on the percentage of all stroke survivors receiving a mood and suicidality screen.

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# Appendices

## Appendix A - Guidelines of the Clinical Rehabilitation journal

### 1. What do we publish?

### 1.1 Aims & Scope

Before submitting your manuscript to Clinical Rehabilitation, please ensure you have read the Aims & Scope.

### 1.2 Article Types

The journal publishes original papers, systematic reviews, Rehabilitation in Practice and Rehabilitation in Theory articles and correspondence relating to published papers. Other article types should be discussed with the editor before submission. Classification is undertaken by the Editor, all artilces should be submitted as original articles.

For queries regarding the suitability of your submission please contact clinical.rehabilitation@sagepub.co.uk

### 1.2.1 Summary of manuscript structure (in order expected):

- A title page with names and contact details for all authors;
- A **structured** abstract of **no more than 250 words** (the website checks this);
- The text (usually Introduction, Methods, Results, Discussion);
- Clinical Messages (2-4 bullet points, 50 words or less);
- Acknowledgements, author contributions, competing interests and funding support;
- References (Vancouver style);
- Tables, each starting on a new page;
- Figures, each starting on a new page;
- Appendix (if any).

### Open Research Data Policy

For accepted papers, we also will place original (anonymised) data on the web associated with an article, as ‘Research Data’. **Please note** that this file type should **only** be uploaded when your submission is accepted. This file type refers **only** to the original, source data and not to any summarised data presented in the article (including supplementary data). Anything uploaded under this file type will **not be seen by reviewers.**

### 1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

### *1.3.1 Make your article discoverable*

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

## 2. Editorial policies

### 2.1 Peer review policy

The journal's policy is to obtain at least two independent reviews of each article. It operates a single-blind reviewing policy in which the reviewer’s name is always concealed from the submitting author. Referees are encouraged to provide substantive, constructive reviews that provide suggestions for improving the work.

All manuscripts accepted for publication are subject to editing for presentation, style and grammar. Any major redrafting is agreed with the author but the Editor's decision on the text is final.

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- Drafted the article or revised it critically for important intellectual content,
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Joe Bloggs, Department of Clinical Rehabilitation, Clinical Rehabilitation Hospital, Town, ST1 345, UK.
Email: JoeBloggs@email.com
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## 7. Further information

### 7.1 Important 'Instructions to Authors' – from the Editor

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**Click here for further information and advice on submitting to Clinical Rehabilitation.**

## Appendix B- Search Strategy

(“Stroke” OR “Cerebrovascular Accident” [MeSH] OR “CVA” [MeSH] OR “Thrombosis” [MeSH]) AND (“Depressive Disorder” [MeSH] OR “Depression” OR “Low Mood” OR “Dysthymic Disorder” [MeSH] OR “Post Stroke Depression”) AND (“Assess*” OR “Screen*” OR “Diagnos*”) AND (English[Language])

The same search terms were used for all database searches.

**Appendix C- Quality Appraisal Tool**

| **Paper** | **Were the study selection criteria clearly described?** (Y/N/Not Clear) | **Is information provided on the proportion of eligible participants who agreed to participate?** (Y/N/Not Clear) | **Did ALL participants receive the depression screening / assessment procedure?** (Y/N/Not Clear/NA) | **Is information provided on any participants that withdrew from the study?** (Y/N/Not Clear/NA) | **Is the sample representative of patients who will receive the screen in stroke services (e.g. in age, gender and proportion of patients with aphasia)** (Y/N/Not Clear) | **Have the screening / assessment measures used been validated for use in stroke?** (Y/N/Not Clear) | **Have the screening / assessment measures used been validated for use with adults with aphasia?** (Y/N/Not Clear) | **Were those who administered the screen from an appropriate professional background to administer the screen?** (Y/N/Not Clear) | **Were the adaptions used to support communication clearly described in enough detail to be replicated?** (Y/N/Not Clear/NA) | **Was the evidence base or rationale described for any adaptions used?** (Y/N/Not Clear/NA) |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | |
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## Appendix D- Ethical Approval

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

NORWICH MEDICAL SCHOOL
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Norwich NR4 7UQ

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Hope Schlesinger
Norwich Medical School
University of East Anglia
Norwich Research Park
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NR4 7TJ

23rd April 2020

Dear Hope

**Title: Screening Mood and Suicidality in Post-Stroke Aphasia - A Theory of Planned Behaviour Study**
**Reference: 2019/20 - 011**

Thank you for your email of 16th April 2020 notifying us of the amendments you would like to make to your above proposal. These have been considered and I can confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Ethics Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you arrange to send us a report once your project is completed.

Yours sincerely

Prof Alastair Forbes
Chair
FMH Research Ethics Committee

***COVID-19:*** *The FMH Research Ethics Committee procedures remain as normal. Please note that our decisions as to the ethics of your application take no account of Government measures and UEA guidelines relating to the coronavirus pandemic and all approvals granted are, of course, subject to these. If your research is COVID-19 related it will naturally be expedited. If the current situation means that you will have to alter your study, please submit an application for an amendment in the usual way.*

## Appendix E: Twitter Advert Material

Calling all UK #stroke Professionals! Have your Say! We invite you to complete this online questionnaire on screening for #depression and #suicide in people with #aphasia following a stroke https://t.co/7eQimGb1Lh?amp=1

We know those with aphasia are at an increased risk of developing depression but that in your day-to-day practice working to support these patients can be challenging.

It will only take 10-15 minutes of your time and will help to contribute to the continued improvement in services and care for this community.

## Appendix F: Email Advert Material

Calling all UK Stroke Professionals! Have your Say!

We invite you to complete this online questionnaire on screening for depression and suicide in people with aphasia following a stroke.

We know those with aphasia are at an increased risk of developing depression but that in your day-to-day practice working to support these patients can be challenging.

It will only take 10-15 minutes of your time and will help to contribute to the continued improvement in services and care for this community.

Click here to find out more and take part

## Appendix G: Electronic Participant Information Sheets

### ‘Have Your Say!’ Screening for Low Mood and Suicidality in Aphasia Post Stroke: Exploration of Current Staff Practice

Electronic Participant Information Sheets

Thank you for taking the time to consider taking part in this study. Before you decide to take part in this study it is important for you to understand why the research is being conducted and what it will involve. Please take the time to read the following information. A member of the team can be contacted if there is anything that is not clear or if you would like more information (Dr. Cat Ford: stroke.psyresearch@uea.ac.uk). Please take time to decide whether you wish to take part.

**Purpose of the study**

Because stroke survivors often have complex rehabilitation needs, the care provided by services can be complex and involves multiple professionals working together. In recent years there have been drivers for staff to screen for low mood in all stroke survivors due to the elevated risk of developing depression. However, research suggests that presently staff are struggling to meet these targets. Stroke survivors with communication difficulties post stroke (aphasia) are at a greater risk of developing depression than those without aphasia. Despite this, there is no current research exploring screening rates or practice in this client group in the UK. Anecdotally, it has been reported that working with those with aphasia can be challenging for professionals especially when discussing complex issues such as depression and suicide. We hope to explore with UK staff their current screening practices in aphasia and importantly explore what factors are helpful and unhelpful in screening. This study aims to give staff a voice to highlight barriers. This information can then be used to drive for change in services so targets can be met, so we as stroke professionals can continue to improve patient care and effectively support those with depression.

**Why have I been invited?**
You are invited to take part as a professional working in stroke care in the UK. However, taking part is entirely voluntary and refusal or withdrawal will involve no penalty or loss, now or in the future.

**What will happen to me if I take part?**
If you choose to take part, you will be asked to complete an online questionnaire that takes an estimated 15 minutes to complete. We have aimed to make this questionnaire as short and concise as possible, for your convenience. You can withdraw from the questionnaire at any time, simply exit the questionnaire and your data will not be included in the study. Once your responses are submitted you can no longer withdraw because as your data are anonymous, we cannot identify your responses to remove them.

After completing the questionnaire, you will be asked if you are prepared to complete the questionnaire on a second occasion, two weeks after the first, to determine the stability of the responses. If you consent to complete the questionnaire a second time you will be asked to provide your email address. All email addresses will be stored securely in compliance with UEA data management policies and General Data Protection Regulation (GDPR). Your email address will only be used to send you the website of the follow up questionnaire and linking your responses to the first and second questionnaires. Your email address will then be deleted. It will not be used for any other purpose.

**Are there possible disadvantages and/or risks in taking part?**
We would like to acknowledge that depression and suicide can be emotive topics. In this questionnaire, you will not be asked to discuss any specific cases or personal experiences of depression or suicide as we are only interested in general trends. However, we understand that this questionnaire has the potential of bringing to mind your own experiences. This potentially may cause some discomfort and therefore you may not wish to take part. Information regarding support services and resources on depression and suicide will be provided and made available at every point during your participation if you do feel you would like additional support or CPD around these topics.

**What are the possible benefits of taking part?**
Taking part in this study gives you the opportunity to voice your own experiences, opinions and be involved in working towards better stroke care and services. It may also give you a better understanding of the factors affecting your own screening practice; which can help to inform your work going forward. Finally, after completing the questionnaire we will provide informative and useful documents on aphasia and depression post-stroke that you may wish to read or bring back to your teams.

**Will my taking part in this project be kept confidential?**
All information collected in this study will be kept strictly confidential and anonymous. We will not ask you for your name or any combination of information that is identifiable but ask those happy to do the survey twice to provide an email address. Each returned questionnaire will be given a code and responses kept on a secure computer with access only by the immediate research team. Please see the following link to general information about how the University uses personal data: https://portal.uea.ac.uk/rin/open-access-and-research-data/research-data.

**What will happen to the results of the research project?**
It is planned that this study will be published in 2021 and presented at the Stroke Forum the same year. Additionally, we aim to circulate the published paper to the professional bodies that took part in the research.

**Who is organising and funding the research?**
This research is being undertaken as part of a Clinical Psychology Doctorate at the University of East Anglia by Miss Hope Schlesinger, under the supervision of Professor Niall Broomfield, Dr Catherine Ford & Dr Ciara Shiggins. The research is funded by University of East Anglia. The project has been reviewed by the University of East Anglia Research Ethics Committee.
Please contact Miss Hope Schlesinger at h.schlesinger@uea.ac.uk for further information. If you are unhappy with any aspect of this study, please contact Professor Niall Broomfield (Director of the Department of Clinical Psychology and Psychological Therapies, UEA).

**Appendix H: Consent Forms**

Please indicate you consent by selecting the box next to each statement.

I confirm that I have read and understand the Participant Information Sheet.

I understand that no personal information or identifiable data will be collected during this research.

I understand that I may be asked to provide my email address however that this is optional, and I can decline to do so.

If I do provide my email address, I understand it will be used solely for the purpose of sending me a weblink and that my data will be deleted once it has served this purpose. I understand that this data will be stored securely and in compliance with GDPR and University of East Anglia data management policies.

I agree that my data gathered in this study will be stored anonymously and securely and may be used for future research.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. However, I understand that once my data is submitted I can no longer withdraw as from this point my data is anonymous.

I understand that this research can be audited by the University of East Anglia or the regulatory authorities. I therefore give permission for these organisations to access my anonymous data.

I agree to take part in this study

## Appendix I- Online Theory of Planned Behaviour Questionnaire

Healthcare Professionals Screening for Depression and Suicidality in People with Post-Stroke Aphasia

University of East Anglia

Thank you very much for agreeing to complete this online questionnaire on how healthcare professionals screen for depression and suicidality in people with post-stroke aphasia. The questionnaire has 5 parts and should only take 15 minutes to complete. The following definitions may be helpful.

- Stroke is defined by the World Health Organisation (2014) as being caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. The effects of a stroke depend on which part of the brain is injured and how severely it is affected.

- Depression is defined by ICD-10 (2004) as a common mental disorder, characterised by the presence of: persistent sadness and/or a loss of interest or pleasure and/or low energy or fatigue; most days, most of the time for at least two weeks. Additional associated symptoms include: disturbed sleep, poor concentration or indecisiveness, low self-confidence, poor or increased appetite, suicidal thoughts or acts, agitation or slowing of movement and guilt or self-blame.

- Aphasia is defined by the Stroke Association as a communication disability that can affect the ability to understand, speak, read, write and use numbers. "The term aphasia (less commonly referred to as dysphasia) is used to describe an acquired loss or impairment of the language system following brain damage (Benson 1996). Usually associated specifically with language problems arising after a stroke, it excludes other communication difficulties attributed to sensory loss, confusion, dementia or speech difficulties due to muscular weakness or dysfunction, such as dysarthria" (Brady et al. 2016, p. 9).

- Screening is defined by the World Health Organisation (2012) as using a simple test across a particular population (e.g. stroke survivors) to allow early identification of a condition; in this case, we are focusing on screening for depression and suicidality in people with aphasia post-stroke aphasia.

Part 1- Demographic Information

1. Do you work in the UK?

Yes
No

2. During usual clinical practice, do you work with people with aphasia?

Yes
No

3. What is your professional title?

Clinical Psychologist
Stroke Physician
Speech and Language Therapist
Occupational Therapist
Physiotherapist
Clinical Neuropsychologist
Nurse
Assistant Practitioner
Health Care Assistant
Assistant Psychologist
Rehabilitation Consultant
Speech and Language Therapy Assistant
Occupational Therapy Assistant
Physiotherapy Assistant
Rehabilitation Assistant
Nursing Assistant
Social Worker
Other, please specify

4. During usual clinical practice, in which setting do you work?

Hospital Ward (General)
Hospital Neurorehabilitation Unit / Ward
Early Supported Discharge
Community Neuro-Rehabilitation Service
Private Practice
Older Peoples Hospital Unit/ Ward
Hospital Stroke Unit / Ward
Voluntary Sector
Community Stroke Service
Nursing Home
Residential Home
Other, please specify

5. In which country / region do you work?

Scotland
Northern Ireland
East of England
West of England
Wales
North of England
South of England
Other, please specify

In this part of the survey, there are 2 questions, we would be grateful if you would estimate some percentages, by typing a value between 0 -100, where 0 = none and 100 = all.

6. In your usual clinical setting, please estimate, what percentage of your time is spent working with people who have had a stroke? For example: working half time on a stroke ward you would put 50%.

7. In your usual clinical setting, please estimate, what percentage of your time is spent working with people with post-stroke aphasia? For example: if a third of the people you work with have aphasia you would put 33%.

## Part 2 - Screening Depression and Suicidality in People with Post-Stroke Aphasia

In this part of the survey, there are 2 questions, for which we would be grateful if you would estimate some percentages, by typing a value between 0 -100, where 0 = none and 100 = all.)

8. In your usual clinical setting, please estimate, what percentage of people with post- stroke aphasia are screened for depression? This could be using either a formal or informal assessment.

9. In your usual clinical setting, please estimate, what percentage of people with post- stroke aphasia are screened for suicidality? This could be using either a formal or informal assessment.

10. In your usual clinical setting, who usually screens depression and suicidality in patients with post-stroke aphasia, or whose role would it be? (You can tick multiple options)

Clinical Psychologist
Stroke Physician
Speech and Language Therapist
Occupational Therapist
Physiotherapist
Clinical Neuropsychologist
Stroke Nurse
Assistant Practitioner
Other, please specify

Assistant Psychologist
Rehabilitation Consultant
Speech and Language Therapy Assistant
Occupational Therapy Assistant
Physiotherapy Assistant
Rehabilitation Assistant
Nursing Assistant
Social Worker
Don't Know

In this part of the survey, there are 2 questions. Here we would be grateful if you would estimate using a percentage, how likely you think you are to complete a specific action by typing a value between 0 -100, where 0 = I am not likely to screen and 100 = I am very likely to screen.

11. During usual clinical practice, how likely would it be for <u>you</u> to screen a person with post-stroke aphasia, for depression? This could be a formal or informal assessment.

12. During usual clinical practice, how likely would it be for <u>you</u> to screen a person with post-stroke aphasia, for suicidal thoughts, intent or a plan? This could be a formal or informal assessment.

## <u>Part 3- Experience of Training and Guidelines for Depression, Suicidality and Aphasia</u>

13. Have you had any training on depression, either formally or informally?

    Yes
    No

14. Have you had any training on how to screen for depression, either formally or informally?

    Yes
    No

15. Have you had any training on suicide, either formally or informally?

    Yes
    No

16. Have you had any training on how to screen for suicidality, either formally or informally?

    Yes
    No

17. Have you had any training on aphasia (e.g. what it is and how it presents), either formally or informally?

    Yes
    No

18. Have you had any supported communication training for working with people with aphasia, either formally or informally?

    Yes
    No

19. Are you aware of or have you read any official guidelines for depression e.g. NICE Guidelines?

    Yes
    No

20. Are you aware of or have your read any official guidelines for aphasia e.g. Aphasia Rehabilitation Best Practice Statements 2014?

    Yes
    No

<u>Part 4 - Ways of Screening Depression in People with Aphasia</u>

21. During usual clinical practice, what methods do you use to screen for depression with patients with post- stroke aphasia? (You can tick multiple options)

Clinical interview with patient
Clinical interview with a family member, carer or staff
Standardised self-report measure (e.g. PHQ or HADS) with patient
Standardised self-report measure (e.g. SADQ) with family member or carer
Observer rating scale (e.g. Hamilton Rating Scale for Depression)

No screening used currently
Other please specify

22. During usual clinical practice, what methods do you use to screen for suicidality with patients with post- stroke aphasia? (You can tick multiple options)

Clinical interview with patient
Clinical interview with a family member, carer or staff
Standardised self-report measure (e.g. PHQ) with patient
Standardised self-report measure (e.g. SADQ) with family member or carer
Observer rating scale (e.g. Hamilton Rating Scale for Depression)
No screening used currently
Other please specify

23. During usual clinical practice, Do you use any standardised self-report measures to screen depression with patients with post- stroke aphasia, if so what? (You can tick multiple options)

Visual Analogue Mood Scales
The Depression Intensity Scale Circles (DISCS)
Patient Health Questionnaire (PHQ)
Hospital Anxiety and Depression Scale (HADS)
Distress Thermometer
Cornell Depression Scale
Structured Assessment of Depression in Brain Damage
Aphasia Impact Questionnaire
No screening used currently
I do not know
Other please specify

24. During usual clinical practice, do you use an observer rating scale and if so what? (You can tick multiple options)

Hamilton Rating Scale for Depression
Montgomery Åsberg Depression Rating Scale
Signs of Depression Scale
Stroke Aphasic Depression Questionnaire (SADQ-21)
Stroke Aphasic Depression Questionnaire- H10
Aphasia Depression Rating Scale (ADRS)
No screening used currently
I do not know
Other please specify

25. During usual clinical practice, do you make adaptations to clinical interviews to make them accessible for people with post-stroke aphasia?

Yes, I do this always
Yes, I do this routinely, more than 75% of the time
Yes, I do this more than 50% of the time
Yes, I have done this occasionally, less that 25% of the time

No, I haven't done this yet

26. During usual clinical practice, what adaptions do you use to support people with aphasia to understand questions? (you can tick multiple options)

Joint session with a Psychologist
Joint session with a Speech and Language Therapist
Explain written material
Provide pictorial support
Repetition
Closed questions
Use short sentences
Provide written support e.g. key words
Providing written information in an alternative formats e.g. easy read
Other please specify
Additional time
Talking Mat
Check understanding
Use only one topic per sentence
Personalised questions
Multiple choice
Re-phrasing questions
Provide pen & paper

27. During usual clinical practice, what adaptions do you use to support people with aphasia to express their responses? (you can tick multiple options)

Joint session with a Psychologist
Joint session with a Speech and Language Therapist
Providing options for answers - words
Accepting non-verbal answers e.g. gesture
Providing options for answers - pictures
Talking Mat
Multiple choice
Additional time
Closed questions
Other please specify

Part 5- Factors Affecting Screening

In this part of the survey, we will give you some statements about screening for depression and suicidality in people with post-stroke aphasia. We will give opposing opinions on each statement. Please move the bar to the position on the line to represent where you feel your opinion lies.

28. In terms of managing risk, screening for depression is …
Useful ____________________________________________Not Useful

29. Discussing suicidal thoughts and intent with people with post-stroke aphasia
Decreases risk of suicide_________________________ Increases risk of suicide

30. Screening for depression helps identify people with post-stroke aphasia who would benefit from psychological therapy
Definitely True_______________________________________Definitely False

31. In terms of treatment planning, screening for depression is:
Not beneficial __________________________________________Beneficial

32. Time pressures at work, affect how regularly I screen for depression in people with post-stroke aphasia

Definitely True________________________________________Definitely False

33. I would describe my methods of facilitating people with aphasia to communicate as
Limited__________________________________________________Effective

34. Screening for depression:
Increases risk of depression ____________________Decreases risk of depression

35. When discussing depression with people with post-stroke aphasia I feel:
Uncomfortable_________________________________________Comfortable

36. In terms of my skills in screening for depression with people with post-stroke aphasia, I feel:
Confident______________________________________________Unconfident

37. How routinely do others in my profession routinely screen for depression with people with post-stroke aphasia:
Never__________________________________________________Always

38. Standardised screening tools for depression with people with post-stroke aphasia are:
Effective_______________________________________________Ineffective

39. Screening for depression with people with post-stroke aphasia is:
Not part of my job role______________________________Part of my job role

40. I would describe the level of training I have received on aphasia as:
Comprehensive___________________________________________Absent

41. Assessing for suicidality in people who have depression is:
Part of my job role_______________________________Not part of my job role

42. I would describe the level of training I have received on screening for depression as:
Absent___________________________________________Comprehensive

43. In terms of optimising rehabilitation, screening for depression is:
Helpful________________________________________________Unhelpful

44. My colleagues expect me to screen for depression with people with post-stroke aphasia.
Definitely False________________________________________Definitely True

45. Treating depression effectively with psychological therapy in people with post-stroke aphasia is:
Possible______________________________________________Not possible

46. If a person with post-stroke aphasia is experiencing depression or suicidal ideation, there is a local service to support them:
Definitely False________________________________________Definitely True

47. I would describe recognising depression in people with post-stroke aphasia as:
Straightforward_________________________________________Challenging

48. Depression influences patients' engagement in rehabilitation:
Minimally_____________________________________________Significantly

49. I would describe my methods of facilitating people with post-stroke aphasia to understand me as
Effective ______________________________________________Limited

50. Using a standardised screening tools for depression with a person with post-stroke aphasia is:
Inaccurate ____________________________________________ Accurate

51. Following evidence based practice is:
Important_____________________________________________Unimportant

52. In terms of managing risk, discussing suicidality is:
Not Useful _____________________________________________Useful

53. I would describe the level of training I have received on screening for depression in those with post-stroke aphasia as:
Comprehensive__________________________________________Absent

54. In terms of managing risk, screening for suicidality is:
Not
Useful_________________________________________________Useful

55. Finally, we plan to check if responses vary over time by asking some respondents to complete the questionnaire again in a fortnight. Would you be willing to complete this questionnaire in two weeks? If you are happy to do so, please select yes and add your email address below. Please be aware that all email addresses will be kept securely and used only to send you the weblink of the questionnaire before being deleted.

Yes
No
Email address: ________________________________

Thank you for taking the time to complete this staff survey on screening for depression and suicidality in people with post-stroke aphasia.
If you have any questions or comments, please feel free to contact Miss Hope Schlesinger on h.schlesinger@uea.ac.uk.

## Appendix J: Debrief Page

Thank you for taking part in this study; your time and participation is greatly appreciated.

What was the aim of this study?

This research study aimed to build a better understanding of how UK healthcare staff screen for both depression and suicidality in people with post-stroke aphasia, as well as exploring possible barriers and facilitators to screening. The overarching aim of this study is to help inform clinical practice, by supporting services and individuals to continue to improve screening rates and care for stroke survivors.

Why is this important to study?

Previous research suggests that people with aphasia are at a greater risk of depression than the general stroke population. Post-stroke depression is associated with several negative outcomes: including increased mortality, increased distress, increased duration in hospital and reduced functional outcomes.

Due to the prevalence of post-stroke depression, several clinical guidelines recommend screening for depression after stroke. However, a recent executive summary stated that screening in clinical practices is sadly, not routine. Without screening there is the risk that people may not be receiving appropriate treatment.

Researchers have begun to identify barriers to screening for depression in the stroke population. The barriers highlighted include: lack of training; low confidence; negative attitudes towards the utility of screening; negative beliefs about following evidence-based practice; negative beliefs about the validity of screening tools and not feeling screening was part of their job role. Furthermore, researchers have applied a psychological model of behavioural intention, The Theory of Planned Behaviour (Ajzen, 1985) to try and predict an individual's intention to engage in screening for depression.

However, despite the increased prevalence of depression in people with aphasia, no specific research on screening appears to have been published. Furthermore, it has be documented that people with aphasia receive poorer healthcare, as a result of specific "barriers" including inaccessible information, negative staff attitudes, or unskilled communication partners. These documented barriers are unique to this population and will likely be impacting on screening rates and practices.

What if I want to know more?

If you are interested in learning more or have felt emotionally impacted by the topics discussed in this questionnaire, please explore the links and resources below. These third-party services aim to provide both information and support.

If you would like to be informed when this study is published or receive a summary of the findings, please add your email address below.

Thanks again for your participation.

## Suicide Prevention Guidance & Emotional Support

NICE Suicide Prevention Quality Standard- Draft for Consultation
Information on ways to reduce suicide and help people bereaved or affected by suicides.
https://www.nice.org.uk/guidance/qs189/documents/194

The National Suicide Prevention Alliance (NSPA)
An alliance of public, private, voluntary and community organisations in England working to reduce and prevent suicide and support those affected by suicide.
Website: https://www.nspa.org.uk/

Samaritans
Samaritans are available 24 hours a day for anyone struggling to cope and provide a safe place to talk where calls are completely confidential.
Phone: 116 123
Website: https://www.samaritans.org/

## Depression Guidance & Support

NICE Guidance- Depression in Adults with a Chronic Physical Health Problem
Information on the assessment and treatment of depression in adults with a chronic physical health condition.
Website: https://www.nice.org.uk/guidance/cg91

Depression After a Stroke Guidelines
Gooskens, F., de Man-van Ginkel, J., Schuurmans, M. J., & Hafsteinsdóttir, T. B. (2009). Depressie na een beroerte [Depression after stroke]. Verpleegkundige Revalidatierichtlijn Beroerte [Clinical Nursing Rehabilitation Guideline Stroke]; Hafsteinsdóttir, TB & Schuurmans, MJ.

Mind
A charity that provides specialist advice and support to empower anyone experiencing a mental health problem, including depression.

https://www.mind.org.uk/information-support/types-of-mental-health-problems/depression/#.XbltSWT7Tx4

## Stroke Guidance & Support

NICE Stroke Guidance
Information and guidance on stroke rehabilitation, including assessment of emotional functioning, support for emotional adjustment and management of depression and anxiety following a stroke.
https://www.nice.org.uk/guidance/cg162

Stroke Clinical Practice Guidelines
Duncan et al. (2005) Management of Adult Stroke Rehabilitation Care: a clinical practice guideline. *Stroke, 36*(9):e100-43.

Miller, E. L., Murray, L., Richards, L., Zorowitz, R. D., Bakas, T., Clark, P., & Billinger, S. A. (2010). Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. *Stroke, 41*(10), 2402-2448.

Stroke Association
A charity that provides specialist support, fund critical research and campaign to make sure people affected by stroke get the very best care and support to rebuild their lives.
Website: https://www.stroke.org.uk/