The feasibility of a novel group self-management intervention for stroke

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I, Ella Clark confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abbreviations

ANCOVA - Analysis of Covariance

CI - Confidence Interval

CONSORT- Consolidated Standards for Reporting Trials

CRD - Centre for research dissemination

CRN - Clinical Research Network

HADS - Hospital Anxiety and Depression Scale

HASU - Hyper Acute Stroke Unit

MeSH - Medical Subject Headings

MRC - Medical Research Council

NEADL - Nottingham Activities of Daily Living

NHS - National Health Service

NIHR - National Institute for Health Research

NIHSS - National Institutes of Health Stroke Scale

PPI - Patient and Public Involvement

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PTC - Permission To Contact

RfPB - Research for Patient Benefit

SAQOL-39 - Stroke and Aphasia Quality Of Life (39 item measure)

SSES - Stroke Self-Efficacy Scale

TiDiER - Template for Intervention Description and Replication

UCL - University College London

UK - United Kingdom

WHO - World Health Organisation

Abstract

Background: Stroke survivors consistently report long term unmet needs. Unlike other chronic conditions stroke self-management programmes have been slow to emerge. Bridges self-management is a one-to one approach used by some UK NHS stroke services and aims to increase self-efficacy and confidence to manage long term needs post stroke. However, a one-to-one delivery does not facilitate peer support, which stroke survivors report as being valuable to the self-management process. In order to evaluate the potential for a one-one programme such as Bridges to be delivered in a group setting important parameters need to be explored, such as, acceptability, fidelity and outcome measure effect sizes. The MRC calls this type of research 'feasibility', and labels it an essential part of complex intervention development.

The aim of this thesis was to explore the feasibility of delivering a one-to-one stroke self-management intervention (Bridges) in a group setting.

Method: Feasibility was explored across three phases: (1) the development phase included patient involvement activities, stroke survivor interviews, and a systematic review to inform the design of a four-week self-management intervention, (2) the implementation phase monitored intervention delivery, 60 stroke survivors were randomised to the intervention or waitlist condition, (3) the evaluation phase used a mixed methods approach to explore acceptability and potential mechanisms of change as well as the effect of the intervention on mood, self-efficacy, quality of life and activities of daily living.

Results: Overall it was feasible to adapt Bridges for group delivery. The intervention had high fidelity to the protocol. Recruitment occurred at a mean rate of 6.6 per month with a 21.667% drop out rate. The intervention was found to be acceptable to stroke survivors and carers. Potential mechanisms of change included vicarious learning and supported goal setting. At six-months post-baseline, outcomes had improved in favour of the intervention group. A number of recommendations were made to further develop the intervention, and for subsequent research on this topic.

Conclusion: The thesis concludes that delivering a group self-management intervention for stroke may offer some benefits to stroke survivors and suggests research progress to a definitive trial.

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1 Chapter one: Introduction

1.1 The rise and rise of chronic conditions

The World Health Organisation (WHO) state a condition is defined as long-term or chronic if it lasts a number of years and needs continuing management[1]. In the United Kingdom (UK) chronic conditions already account for 1/2 of General Practitioner appointments, and just under 3/4 of inpatient stays and health and social care expenditure[2]. One of the biggest risk factors for developing a chronic condition is growing older. By the age of 50, 1/2 of the population have a chronic condition, which rises to 4/5 by the age of 65[3]. As the life expectancy in the UK continues to rise so too will the prevalence of chronic conditions, making "the treatment and management of long-term conditions the most important challenge facing the National Health Service (NHS)" (pg.2)[3].

In addition to the rise in life expectancy, chronic conditions have increased due to the improvements in acute medical services. As more people are surviving conditions such as stroke that used to be fatal[4], the residual symptoms have become more prevalent. For example, nearly 3/4 of survivors aged 45 or over experienced a score of 3-5 on the Oxford Handicap Scale which suggests dependence on others for activities of daily living[5]. These levels of dependence support the idea that stroke is really a chronic condition that starts with an acute event[6].

A stroke can be caused by either cerebral ischemia or haemorrhage, resulting in damage to numerous areas of the brain[4]. Consequently, it causes a greater range of disability that any other chronic condition[7]. Over 3/4 of survivors experience arm and leg weakness, half experience high levels of fatigue and a third describe speech difficulties[4]. Stroke also has a psychological impact on survivors, with three quarters reporting they lack confidence since their stroke[8], half reporting anxiety, and a third experiencing depression[9]. When describing their experiences since stroke, one survivor said, "I would not wish what I've been through on my worst enemy" (pg.11) [8].

There are a number factors that increase the risk of stroke including, high blood pressure, smoking, and diabetes[4]. Being older, overweight or living in a socioeconomically deprived area, are also associated with increased stroke risk[4]. The wide range of risk factors and residual symptoms makes stroke complex, and 54% of survivors feel they

lack the necessary information to better understand their condition and reduce their risk of having another stroke[10].

These heterogeneous risk factors and residual symptoms make managing stroke long-term challenging. However, doing so is vital. Over half of the survivors report unmet needs, 4/10 felt abandoned by support services once they were discharged from hospital[10,8], and many are left feeling unprepared to cope with the challenges ahead[10]. It is clear that current services do not effectively support stroke survivors to manage their condition long-term. Thus, this should be addressed as a priority in stroke service development.

1.2 The lack of long-term support for stroke

The lack of appropriate support for the chronic management of stroke may reflect recent investment in stroke services which have been weighted towards prevention and acute care[11]. For example, there has been a re-structuring of services in the NHS which now offers specialised Hyper Acute Stroke Units (HASUs) delivering lifesaving treatments in the first few hours post-stroke[12]. Chronic services need to catch-up as now the unmet needs of survivors relate to the long-term management of their condition[10]. Unfortunately, the best way to meet these needs and better support stroke survivors long-term is unknown.

In order to improve chronic services, the Kings Fund has suggested we should "abandon traditional ways of thinking" such as neoliberal philosophies (which place responsibility on individuals as opposed to the government)[3]. For example, although patients should "be encouraged to play a central role in managing their own care" (pg. 2), they should not feel like they are managing alone[3]. Insight into what this might entail comes from more established chronic conditions which suggest effective support is person-centred, inclusive of support networks, and integrated within a whole systems approach[3,6,13,14]. More specifically, conditions such as heart disease, diabetes, arthritis and lung disease have been successfully supported through the implementation of self-management programs[15–17]. As a result of their success, in 2015 the Kings Fund made self-management one of its top 10 priorities for the NHS[18]. It may be that a similar approach could be useful for the long-term management of stroke.

1.3 Self-management

The definition of self-management is constantly evolving as new evidence in the field emerges. For the purpose of this thesis, self-management can be defined as supporting individuals to manage the medical, behavioural and emotional aspects of their condition in a way which enables them to feel confident doing so[19,20]. Self-management can be conceptualised as a boundary object, meaning it may have different implications in different contexts[21], or result in different practices for each individual. For example, how one person manages the medical aspects of their condition may vary from one day to the next and from person to person.

Self-management is unique in that it combines, "the high individualization of the clinical approach with the large-scale applicability of the public health approach" (pg.12)[22]. When implemented correctly, a review of 550 studies suggests self-management interventions can positively impact quality of life, self-efficacy, self-care and clinical outcomes for a variety of chronic conditions[23]. Self-management interventions have also been praised for facilitating the co-ordination of care[3], and for their ease of use; the interventions are not constrained by time and place and do not require any special equipment[22]. In addition, they have a strong link to theory which mean they are "more likely to result in an effective intervention than a purely empirical or pragmatic approach" (pg. 9)[24].

1.3.1 Theoretical underpinnings

Self-management interventions are commonly underpinned by Social Cognition Theory (SCT), which was developed by Bandura in 1986[14]. Before outlining the components of SCT, it should be acknowledged that the context in which health behaviours are operating today has changed substantially compared to when SCT was first developed. As previously discussed, the nature of disease itself has shifted from predominantly acute to more chronic disorders[22]. However, SCT remains valuable as it focuses on how behaviours can be maintained over time which is particularly important for the management of chronic conditions. SCT also specifies the different ways behaviour change can be enabled and offers insight into what an intervention based on the theory might look like in practice. Facilitating the process of translation is advantageous as currently only 50% of interventions are utilised in practice[25]. Therefore, despite being developed at a time when health care was facing different challenges, SCT is still relevant in the current health care climate.

SCT was pioneering in the world of behaviour change as it suggested behaviour is underpinned by social cognitions. This discredited the widely held view at the time that behaviour was the result of unidirectional causation in which behaviours with positive outcomes were reinforced, and those with negative outcomes were not[26]. Crucially, Bandura stated that humans were not simply products of their environment, but that they were also 'actors' in their environment. This is known as the model of triadic reciprocal causation[27,28], conceptualised as "cognitive, affective and biological events, behavioural patterns, and environmental events, [which] all operate as interacting determinants that influence one another bi-directionally" (pg.14)[29]. The development of SCT led researchers to shift their focus to include the cognitions underlying behaviours as well as the behaviours themselves[26]. In particular, self-efficacy continues to be an essential component of numerous behaviour change theories[26,30–32].

1.3.2 Components of Social Cognition Theory

SCT has a number of components which work together to facilitate behaviour change. Figure 1 illustrates how these combine to form the whole theory and each component is then discussed below.

Figure 1. Illustration of Social Cognition Theory
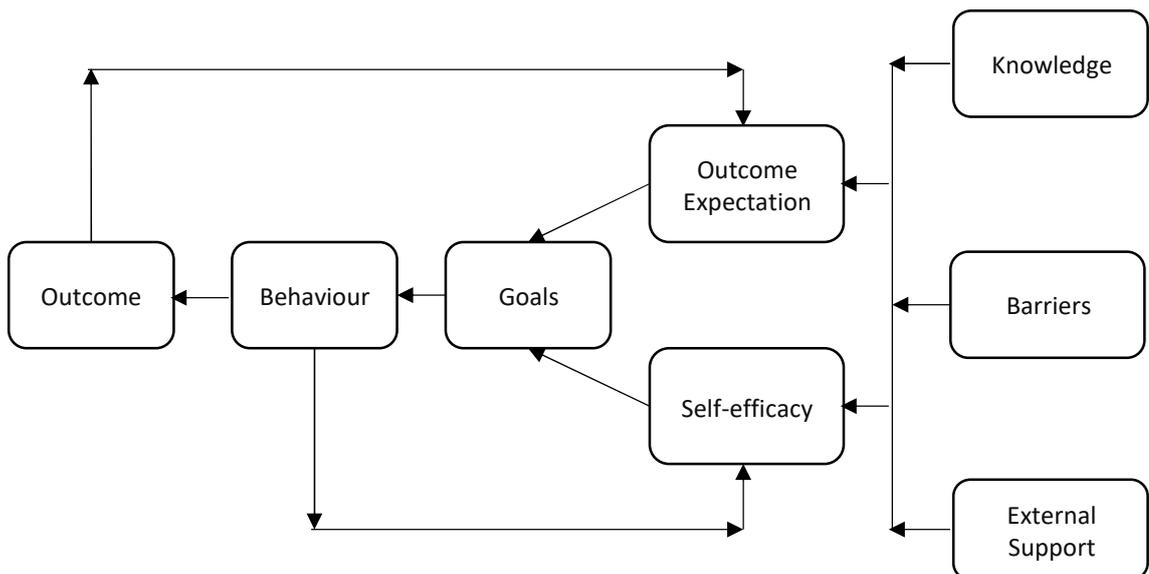
1.3.2.1.1 Self-efficacy

Self-efficacy can be defined as the belief an individual has in their ability to perform a specific task[33]. As the core concept of SCT, it is unsurprising that in a synthesis of 550 self-management interventions, self-efficacy was found to be the most commonly used

construct. In addition, it was more likely to be used in programmes that had successful outcomes[23]. Self-efficacy is particularly important post stroke as it has been found to positively correlate to quality of life[34] and functional ability, and to negatively correlate with fatigue[35]. Self-management interventions that can increase self-efficacy may therefore offer a range of benefits to stroke survivors.

Bandura proposes a number of different ways to increase self-efficacy: through physiological response, vicarious learning and mastery[33]. The latter two in particular, have informed the design of the intervention explored in this thesis. Vicarious learning suggests social role models (such as peers) influence behaviour change. The concept was discovered in the infamous BOBO doll experiment which showed that children were significantly more likely to display aggressive behaviour towards an inflatable doll after observing someone else display the same type of behaviour[27,28]. Mastery refers to the feeling of personal success an individual gets when they complete a task, for example, running a marathon. Since SCT was developed, subsequent research looking specifically at stroke self-management interventions has found additional techniques which could increase self-efficacy, including decision making, problem solving, self-discovery, reflection and collaboration[36].

1.3.2.1.2 Knowledge, barriers and external support

Figure one shows three factors that can influence self-efficacy before a behaviour has been attempted: knowledge, barriers and external support. Knowledge refers to what an individual knows about their condition, themselves, and also the health beliefs that they hold. Bandura states, "if people lack knowledge about how their lifestyle habits affect their health, they have little reason to put themselves through the travail of changing the detrimental habits they enjoy" (pg. 144)[22]. Barriers are detrimental to behaviour change. Considering them is crucial so that they can be overcome, for example, if a stroke survivor is unable to walk to a medical appointment then transportation is a perceived barrier. To overcome this, a car could be arranged to come and collect them. However, this does lead to a potential flaw when applying SCT as interventions may end up treating the symptoms (no transport) as opposed to the true cause (perhaps a lack of confidence in the individual to use public transport)[37]. The third factor related to self-efficacy is external support, which may include friends, family, health care practitioners and peers. Social support has been found to facilitate effective condition management[38], perhaps because it can be a catalyst for action, offer empathy and provide a platform for problem

solving and decision making[13,39,40]. It is also described by stroke survivors as being valuable to their recovery[41].

1.3.2.1.3 Outcome Expectations

Knowledge, barriers and external support also relate to an individual's outcome expectation (see figure 1), which refers to what an individual thinks will happen when they perform a behaviour. Bandura identifies three types of outcomes: physical, social and self-evaluative. Physical outcomes include pleasurable and adverse effects as well as material losses that occur as a result of the behaviour. Social approval (or disapproval) refers to the effect a behaviour has on an individual's social network. Finally, self-evaluative outcomes are those which shape how an individual sees their health status and is determined by the personal standards to which each individual holds themselves accountable.

1.3.2.1.4 Goals

Goals refer to the specific activities or behaviours that individual's want to work towards and are often used as a marker of progress. A distinction is made in SCT between distal and proximal goals. Distal goals can 'set the course of change', and proximal goals can guide step by step actions that can be completed in the short term. As a result, the latter offer more immediate feedback to individuals than distal goals, which are longer-term projects completed on a larger scale. Goal setting is a well-established technique that is known to facilitate behaviours in a range of settings including stroke rehabilitation. SCT hypothesises that goal setting, and self-efficacy are linked, and this is supported by research which shows the goals set by individuals vary in difficultly depending on levels of self-efficacy, with more difficult goals requiring higher levels of self-efficacy[22].

In summary, as the above components are so clearly mapped out, SCT lends itself to intervention design. Accordingly, it has been translated into a large number of self-management interventions, some of which were designed to include stroke survivors.

1.3.3 Evidence base for stroke self-management interventions

Three recent reviews have been conducted which summarise the evidence surrounding self-management interventions for stroke. Firstly, a meta review of 101 individual studies found high quality evidence that self-management interventions delivered within a year of stroke onset could result in improvements in activities of daily living, and a reduction

in poor outcomes (dependence/death)[42]. The review also suggested that interventions incorporating problem solving could facilitate the reintegration of stroke survivors into the community. The second systematic review focussed on functional ability and participation after stroke and found that self-management interventions could significantly improve both [20].

The third review was published in the Cochrane database in 2016 and focussed specifically on community living stroke survivors. The review included 14 trials and explored the effect of self-management interventions on 1863 stroke survivors[43]. The results provided medium-quality evidence suggesting such interventions can increase quality of life (P=0.02), and low-quality evidence that they increase self-efficacy (P=0.03) when compared with standard care. The review also found individual studies reported improvements in smoking, alcohol intake, diet, attitude and health care use. As a result of the growing evidence base, the 2016 National Clinical Guidelines for Stroke suggest all stroke survivors, "should be supported and involved in a self-management approach" (Pg. 24)[44].

1.3.4   An existing stroke self-management intervention – Bridges

The evidence base for self-management interventions is growing, but many health interventions which prove effective in research settings are not translated into practice[45]. One self-management intervention which has been implemented within the UK's NHS is Bridges[36]. Bridges has been shown to increase self-efficacy, locus of control, and measures of functional capacity[46]. It is a one-to-one intervention which aims to build self-efficacy in stroke survivors using nine self-management techniques: collaboration, taking action, goal setting, reflection, self-discovery, decision making, accessing resources, knowledge and problem solving. Although the techniques can be used individually they often overlap in practice, for example, a stroke survivor may have a go at a new task (self-discovery). Based on how it has gone (reflection and mastery) they may decide whether to have another go (decision making) but may approach the task differently next time (problem solving).

Each individual that takes part in the intervention receives their own hand-held Bridges workbook which they can keep. The workbook provides the space to record goals, reflect on past success, learn about the causes of stroke and see what other survivors do to help them manage on a day-to-day basis (see appendix 1 for some example pages from the workbook). It is important to note here that the workbook should not be used in in isolation as it does not, "negate the need for professionals to use language and techniques, which facilitate self-management in a non-directive way" (pg. 473)[21].

There are a number of other self-management interventions that exist, but Bridges has distinct advantages over these. Firstly, the Chronic Disease Self-Management Program (CDSMP) should be discussed as it is the most widely used intervention of this type in research (see chapter four). It can be critiqued as it advocates a didactic approach to delivery with pre-determined topics of discussion. In contrast Bridges encourages a flexible approach to delivery. This enables the self-management intervention to remain tailored to each individual. For example, if a stroke survivor was suffering from low mood but not fatigue then only the former would be incorporated into a Bridges session. Secondly, the CDSMP if often used in a format which means anyone with a chronic condition can attend[15,47–49]. However, some have argued that disease specific interventions (such as Bridges) are more effective[50]. Thirdly, although the CDSMP has included service users in the development process, it has not included stroke survivors. Bridges has been co-created with stroke survivors who offered input to the content of the intervention and the workbook which incorporates real survivor stories. As a result, the acceptability of the intervention is maximised.

Finally, Bridges has already been implemented within the UK's NHS. To date, it is delivered in approximately 120 multi-professional stroke teams[21]. There is no other published work detailing a stroke self-management intervention that has successfully achieved this. Only one study has been published which details the failed attempt to translate the Whole Systems Informing Self-Management Engagement (WISE) intervention to a primary care setting[51]. The successful implementation of Bridges may be the result of the extensive research completed during the intervention's development, exploring barriers to implementation with health care professionals[52,53].

1.3.5 How does Bridges relate to Social Cognition Theory?

SCT provides the theoretical foundations of Bridges. The theory states that mastery can increase self-efficacy and thus it is incorporated "into every rehabilitation session to help patients understand their own contribution to progress and self-management"(pg. 473). In turn, this may help stroke survivors continue to self-manage once they are no-longer engaging with health care professionals[21]. The concept of goal setting is important for mastery. Similarly to SCT, Bridges distinguishes between 'future hopes' (which parallel distal goals) and small steps (which represent proximal goals)[36]. SCT suggests the likelihood of achieving a goal is enhanced if someone understands why it is beneficial to do so and if it is important to them. This is why individualised goal setting that prioritises personally driven goals is advocated in Bridges[54].

However, Bridges challenges currently accepted goal setting practice by critiquing the commonly used SMART goal model that advocates for goals to be realistic[55]. This is because "an environment in which professionals protect patients from making what they perceive as irrational and irresponsible choices or prioritise 'realistic' goals runs the risk of creating an imbalanced relationship from the start, rather than good care which is jointly shaped by reciprocal and open interactions" (pg. 473). The setting of unrealistic goals would, in turn, enable self-discovery which has been found to improve self-efficacy, the core concept of SCT[36] and is thus encouraged by Bridges.

Bridges has also expanded on the traditional sense of patient engagement which suggests the responsibility for decision making lies solely between the patient and healthcare professional. In keeping with the SCT approach, Bridges suggests a more practice-based approach should be used, which "takes the social context in which the individual is managing into account" (pg. 474)[54], and has led to discussions around how to create a shared space within which individuals can self-manage[54,56].

The workbook that participants receive also incorporates elements of SCT, for example, it has pages to record past successes which can facilitate mastery, and spaces to record goals (see appendix one for example pages). SCT suggests that vicarious learning can also increase self-efficacy. However, this concept is utilised only once in Bridges - in the workbook which provides written experiences from other stroke survivors. Other self-management interventions such as the CDSMP utilise vicarious learning in every session as the group format allows for face-to-face interactions with peers[13]. This is a limitation of Bridges as the one-to-one delivery does not incorporate face-to-face interactions with peers. Therefore, it may not be the best delivery mechanism to facilitate vicarious learning.

In summary, it is clear that SCT is incorporated in numerous ways to the existing Bridges self-management intervention. However, some elements of SCT such as vicarious learning may not be being used to their full potential. Thus, there is call to explore alternative delivery mechanisms for the intervention, as the optimum approach is currently unknown[19].

1.3.6   Delivery mechanisms

At present, there are two main delivery mechanisms available to stroke self-management interventions: one-to-one and group-based interventions. Interestingly, although Bridges is delivered in a one-to-one setting, other established chronic disease self-management interventions tend to use a group delivery mechanism, which has been found have a number of benefits. The Chronic Disease Self-Management Programme (CDSMP) was

delivered in a group setting and resulted in significant improvements at six-months post intervention in weekly minutes of exercise, cognitive symptom management, communication with health care professionals, self-reported health distress, fatigue, disability and social/role activity limitations[15]. It was also found to reduce hospital admissions which in turn has the potential to save health services money[57]. A systematic review that explored both delivery mechanisms within the stroke population, found that group interventions used on average two more self-management techniques than one-to-one interventions (five compared to three), and were more likely to have a stroke survivor co-faciliating[20].

Another advantage of group delivery over a one-to-one delivery is that it offers the opportunity for social support. Not only is social support a component of SCT, but it has been highlighted as valuable to the recovery process by stroke survivors themselves[41]. Previous research suggests that "maximising the possibilities for social engagement [is] a way of increasing the effectiveness of individual and network effects for chronic illness management"(pg.719)[58]. Peer support in particular is important as peers can facilitate problem solving and sharing experiences[39]. It can also offer emotional assistance which can help validate stroke survivors feelings[20] and be a source of social contact and comparison from which stroke survivors can gain knowledge about stroke[13]. Despite all the benefits of peer support, the role it plays within self-management interventions is not widely studied and potentially underutilised which had led to calls for this to be explored in future work[20].

1.4 Moving the field forward

Self-management interventions can facilitate the management of chronic conditions including stroke, and Bridges provides a number of advantages over other interventions. However, Bridges it is not currently delivered in a way which maximises vicarious learning or peer support. Research suggests group delivery (as opposed to one-to-one) may provide a platform for vicarious learning and social support, and facilitate the use of more self-management techniques. A reasonable question then, is whether the Bridges self-management intervention can be adapted for use in a group setting. Before a definitive trial can be run, it is important to explore the feasibility of the intervention. Research that does not do so can be costly in terms of time, money and the quality of research[24,59]. It is for this reason that the Medical Research Council (MRC) suggest all complex interventions are subject to in depth feasibility testing prior to conducting a definitive trial[25].

1.5 Thesis Aim

The aim of this thesis was to explore the feasibility of delivering a one-to-one stroke self-management intervention (Bridges) in a group setting. The following seven questions will be answered with specific research questions listed in the relevant chapters:

1. How acceptable to stroke survivors is it to deliver self-management in a group setting?
2. What would the protocol for a group self-management intervention based on Bridges look like?
3. Can a group self-management intervention be implemented in practice?
4. What mechanisms of change are occurring within the intervention?
5. How acceptable to stroke survivors is it to deliver Bridges in a group setting?
6. How acceptable to family/friends/carers is it to deliver Bridges in a group setting?
7. Does the intervention have any effect on stroke survivors on quality of life, mood, activities of daily living, or self-efficacy?

2 Chapter two: Methodology

Here, I present an overview of the methodology used in the wider thesis and describe how it was developed. The current chapter is split into four sections, (1) methodological considerations (2) the thesis methodology, (3) stakeholder contributions, and (4) the thesis structure.

2.1 Methodological considerations

The first section presents four concepts which had implications for the thesis methodology: complex interventions, feasibility studies, patient and public involvement and mixed methods.

2.1.1 Complex interventions

The intervention explored in the wider thesis is complex in nature. The Medical Research Council (MRC) outline five core concepts that make an intervention complex[24], each of which are discussed below in relation to a group self-management intervention.

(1) The number of components within the experimental and control interventions and potential interactions between them.

Although the guidelines do not define how many components or interactions are needed to become complex, it is assumed that as these rise so too does the intervention complexity. In a group self-management intervention there are many components that may influence the intervention. For example, self-efficacy[19], depression[19], ethnicity[60], socioeconomic status and stroke severity[61] have all been shown to influence the outcome of self-management interventions. These components may also interact with each other. A systematic review of 104 studies found that self-efficacy alone was associated with multiple outcomes including quality of life, activities of daily living and depression[19]. It is also important to consider the facilitators of the intervention as their ability to deliver the intervention may impact the outcomes. In a self-management setting it is well documented that achieving truly collaborative goal setting is a challenge and a lack of it may impact intervention efficacy[53,62]. Therefore, because of the large number of components, group self-management interventions can be labelled as complex according to the first criteria.

(2) The number and difficulty of behaviours required by those delivering or receiving the intervention.

As with the number of components, the MRC guidelines offer neither a threshold for the number of behaviours that would make an intervention complex nor guidance on how to define a 'difficult' behaviour. However, they do specify that as these two variables increase, so too does an intervention's complexity. The behaviours required by those delivering a group self-management intervention include: delivering and tailoring content, managing a complex group dynamic, facilitating emotive discussions, and resolving unpredictable situations that arise during the group sessions, as well as ensuring that the individual needs of participants are met. The behaviours required by those receiving the intervention include goal setting, setting small steps, reflection and decision making, but also the ability to engage with other group members and discuss potentially emotive topics such as stroke. It is also worth noting that the small steps that are set will vary from person to person depending on the goal they are trying to reach. For example, someone with the goal of getting to the supermarket may set their first step as, 'call and check opening hours', but someone who has the goal of walking a mile, may set their first step as, 'walk five steps a day for a week'. In addition, each of these individuals may have more than one goal they wish to achieve which adds to the number of behaviours required. It is clear there are a large number of behaviours required by a group self-management intervention and they may range in difficulty. As a result, according to the MRC's second criteria, a group self-management intervention would be deemed complex.

(3) The number of groups targeted by the intervention (e.g. stroke survivors, family/friends/carers, health care professionals, and funders) and their organisational levels (service-user, social support, primary/secondary care and clinical commissioning groups)

At present, the group self-management intervention only targets one group: stroke survivors. However, within the stroke population, there are a number of sub groups such as varying levels of stroke severity, different residual symptoms and a wide age range which increases complexity. In addition , family, friends and carers who attend the group should also be considered as although they were not the target population of this work previous research suggests that they may gain some benefit from the group[13].

It is also important to keep in mind the future of the intervention when considering target populations. The thesis only explores feasibility but if the intervention progressed into a fully powered randomised controlled trial or was routinely delivered as part of the UK's NHS then the intervention would have to target a larger number of organisational levels to facilitate implementation (e.g. policy makers, commissioners and individual organisations). Thus, although the intervention is not highly complex at present in terms

of the number of groups targeted by the intervention, if the project grows to become a larger trial, so too would the intervention complexity.

(4) The number and variability of outcomes used

Group self-management interventions often explore a high number of varied outcomes. For example, mood, activities of daily living, self-efficacy and quality of life[15,47,63]. In addition, if a process evaluation is conducted additional outcomes such as recruitment, adherence, attendance and fidelity would also be collected. In some cases, qualitative outcomes are also used to explore acceptability and experiences of stroke survivors during the group self-management intervention[13]. Consequently, group self-management interventions can be deemed complex in nature according to the MRC's fourth criteria.

(5) The degree of flexibility permitted in tailoring the intervention to an individual.

The final criteria for determining the complexity of an intervention relates to how flexible it can be in delivery. Group self-management interventions must be flexible in order to remain tailored to each individual as different techniques would be used for different challenges. For example, a stroke survivor who wants to choose a new general practitioner might have already set small steps to find their top three services but now require support with decision making to choose the final one. In contrast, a stroke survivor who wants to apply for benefits may have decided which stream to apply for but require support setting small steps to help them work towards this goal. In keeping with guidelines, the group self-management intervention is flexible enough to allow these adaptations, and in turn, this increases the complexity of the intervention.

It is evident that group self-management interventions for stroke are complex interventions as they meet (or have the potential to meet) all five of the MRC's criteria. As a result, there are a unique set of methodological considerations for researchers.

2.1.2   Methodological considerations for complex interventions

In 2006 the MRC published guidance for researchers exploring the development, implementation and evaluation of complex interventions[24]. Accordingly, this guidance was the primary influence for the methodology used in this thesis. The MRC emphasise the importance of three stages when designing a complex intervention: development, implementation and evaluation. The guidelines state that "all of the stages are important, and too strong a focus on the main evaluation, to the neglect of adequate development and piloting work, or proper consideration of the practical issues of implementation, will result in weaker interventions, that are harder to evaluate, less likely to be implemented

and less likely to be worth implementing" (pg.4). Each of the three stages come with their own methodological implications which are discussed in turn below.

2.1.2.1 The development phase

The MRC guidelines recommend that the development of a complex intervention should start with the identification of existing evidence in the field of interest, and more specifically, recommend conducting a systematic review. Although for group self-management interventions this may be challenging due to the heterogeneity of outcomes and intervention delivery[20], systematic reviews are beneficial as they consolidate current evidence into a coherent whole. It is important this information is available in the development phase as the review can then help researchers make informed decisions about the direction of research[64]. As a systematic review exploring the key features and role of peer support within group self-management interventions for stroke has not previously been conducted, it was decided I would conduct one as part of this thesis (see chapter four).

The MRC guidelines also recommend that the acceptability of the intervention be explored during the development phase. It is important to do this early on as if the intervention is not acceptable the researchers can adapt it through feedback[65]. An example of this is given by a study which explored the theoretically driven sex education intervention for schools called SHARE[66]. Initially, teachers were reluctant to use the intervention as they did not want to provide condom demonstrations in class. When the researchers explored this in more detail, they realised this was due to the lack of guidance provided on how to give the demonstrations. Accordingly, the protocol was amended to offer a structure for the demonstration and then teachers were much more willing to take part in the intervention. Exploring acceptability also offers a chance for the target population to have a voice, and provides novel insight which may inform changes to the intervention design. It was thus decided issues of acceptability surrounding a group self-management intervention in general would be explored prior to intervention design (chapter three). The intervention acceptability post-delivery is also explored in the evaluation phase (chapter seven).

The third factor emphasised as an important part of the development phase in the MRC guidelines is determining the theoretical underpinning of the intervention. Theory is important as it suggests the mechanisms of change that may be at work during an intervention, which in turn influences what data is captured in the evaluation. Thus, after speaking to the relevant stakeholders (see the section 2.3 within this chapter) SCT was identified as the most appropriate theory to underpin the intervention.

Finally, the MRC make suggestions for the research design which should be conceptualised in the development phase. The guidelines suggest randomisation is the 'most robust' way to reduce the risk of selection bias in complex interventions and create reliable results at evaluation. Gaining reliable results at evaluation is important for this thesis as the size of potential effects and when they may become apparent is unknown. As a result, the research design used in this thesis incorporated randomisation (see section 2.2.6 for more detail).

2.1.2.2 The implementation phase

The implementation phase is the second phase described by the MRC as essential for the design of novel complex interventions. As the National Clinical Guidelines for Stroke have called for self-management to be available to all stroke survivors, it is imperative that such interventions can be effectively implemented in practice[67]. The MRC guidelines suggest that conducting a process evaluation can greatly facilitate this process as they can: help explain differences between expected and observed events, offer insight into how context influences outcomes, and help future implementation by highlighting potential implementation barriers. In the past, research into complex interventions has overlooked these processes, and researchers are left wondering why an intervention has failed unexpectedly, or why they have resulted in unexpected consequences (see case studies 10 and 13 in the MRC guidelines).

One example of this in the UK comes from the implementation of a one-to-one self-management intervention delivered across 43 general practices with 55 chronic disease patients[59]. The results showed no significant difference between the intervention and control group in self-efficacy, shared decision making, general health, self-care activity, psychological well-being or quality of life. However, because there was a lack of implementation data it was not clear whether the results were due to intervention or implementation failure. In order to decipher this, the implementation processes were evaluated, revealing that the intervention had not been delivered as intended[51]. For example, the guidebooks were being used but shared decision making was not embedded in practice. In addition, it became more apparent that self-management was not prioritised or considered different enough to standard care to warrant investment. The research highlights the number of variables that could impact the efficacy of a self-management intervention and therefore the importance of capturing the processes at work.

As well as the processes involved, the MRC suggest consideration needs to be given to local context during the implementation phase and how an intervention may adapt to it.

Context is important to consider as it can impact how an intervention is delivered and how it creates change[68]. As discussed previously, adaptation may be necessary to ensure that an intervention is working to its full potential in different contexts so "strict fidelity to a protocol may be inappropriate" (Pg. 7)[24]. Detailing the level of adaptation is also important for future stakeholders as a lack of standardisation can be a barrier to health care commissioners who are less likely to fund an intervention that cannot be 'bottled'[69].

In line with recommendations from the MRC guidelines, it was decided that a process evaluation would be conducted (see chapter six). Doing so would enable sufficient understanding of the implementation process and distinguish (if needed) between intervention and implementation failure. In order to facilitate best practice, the specific parameters explored in the process evaluation were partly drawn from the National Institute for Health Research's (NIHR) feasibility guidelines[70], and partly drawn from the MRC guidelines for complex interventions[24].

2.1.2.3 The evaluation phase

The MRC makes three recommendations for the evaluation phase. Firstly, that complex evaluations should use a mixed methods approach to ensure data is captured from multiple angles, minimizing the chance something important is missed (see section 2.1.5 in the current chapter for a more in-depth discussion on mixed methods). Accordingly, in this thesis, a mixed methods approach was used.

Secondly, the guidelines recommend that evaluations are reported in line with established guidelines, so the Consolidated Standards for Reporting Trials (CONSORT) guidelines were used which provide a gold standard for reporting work using randomised control designs.

The third recommendation concerns outcome selection. Capturing outcomes is an important part of any research study. However, it is difficult to know how to capture these outcomes at evaluation if they are unexpected. For example, a novel complex intervention may be expected to increase self-efficacy, but in practice may also increase mood. If the study was not designed to capture mood an opportunity to collect change in a key variable may be lost. Thus, the MRC guidelines suggest, "identifying a single primary outcome may not make best use of the data; a range of measures will be needed […which in turn allows…] unintended consequences [to be] picked up where possible" (pg.7). As a result of the above, no primary outcome was specified for this work. Instead it was decided that a number of outcomes should be explored (see chapter nine, section 9.2.3).

In summary, multiple methodological considerations are needed in the development, implementation and evaluation of group self-management interventions. These have been incorporated in this thesis where possible to ensure best practice. However, intervention complexity is not the only factor impacting the methodology. The fact that this thesis explores feasibility should also be considered.

2.1.3 Feasibility

The decision was made to explore feasibility as the MRC highlight this is essential when designing novel complex interventions. Evaluations which have not explored feasibility lack essential information[24], which in turn, makes future implementation more challenging, and may result in a waste of time and resources[59]. For the purpose of this thesis feasibility studies are defined as, "research done before a main study in order to answer the question "Can this study be done?" They are used to estimate important parameters that are needed to design the main study"(pg.1)[70]. The NIHR offer clear guidelines on the types of parameters that should be investigated when conducting a feasibility study: For example, the practicalities of intervention delivery, acceptability of the intervention to the target population, opportunities for patient and public involvement and the return rate for follow-up questionnaires[70], all of which are explored in the current thesis.

In addition to principles that could be explored in feasibility studies, the NIHR provide a list of parameters which do not necessarily need to be explored such as power calculations. Drawing from Julious et al[71], the NIHR suggest no power calculation is required as the sample need only be adequate in size for its purpose which in this case is to assess feasibility and not statistical significance. The advice is compounded by the fact the feasibility stage is often lacking in the necessary information (e.g. effect size) to determine a power calculation. Similarly to the MRC guidelines for complex interventions, the NIHR also states that primary outcomes are not required when exploring feasibility. The advice is given because often in feasibility studies there is a lack of information about what the outcomes of interest might be, but also because outcomes are not the most important output: "if a feasibility study involves carrying out a small randomised controlled trial it is for the purpose of evaluating/testing trial processes, not the intervention [itself]" (pg. 2). Accordingly, the decision was made not to specify a primary outcome or conduct a formal power calculation in the present study.

2.1.3.1 Feasibility and pilot studies

Despite the above guidelines, feasibility studies are often overlooked, perhaps because the research community lacks knowledge regarding the difference between 'pilot' and 'feasibility' studies. The problem is compounded by the ambiguity and contradiction found in the literature. For example, the established guidelines for complex interventions by the MRC fail to define 'feasibility' or 'pilot' studies and use the terms interchangeably: "piloting and feasibility questions to ask yourself include…" (pg. 4), and "the feasibility and piloting stage includes…." (pg. 10). The lack of clarity encourages different uses of these concepts in practice, as well as different opinions about their true meaning[72]. In order to move forward, the differences between pilot and feasibility studies must be established.

Despite some claims that 'pilot' and 'feasibility' are synonymous, as they both guide future research[73], clear distinctions can be made between the two concepts in terms of when they are used in the research pipeline. The NIHR guidance states that feasibility studies are conducted earlier in the design pipeline than pilot studies. This is because their purpose is to assess variables such as acceptability, eligibility, adherence, and information to inform future power calculations[70,74]. Only once these parameters have been determined are pilot studies used, which in contrast to a feasibility study would contain a small-scale replica of the methodology to be used in future research. Differences between pilot and feasibility studies are also found in practice. A review of published feasibility and pilot studies from medical journals found that pilot studies were significantly more likely to include sample size calculations, randomisation, control groups and a recommendation of further study[75].

In summary, the terms 'pilot' and 'feasibility' should not be seen as interchangeable. The thesis should be considered as a feasibility study, and judged accordingly.

2.1.4   Stakeholder involvement

The third methodological consideration for this thesis is stakeholder involvement, which can be defined as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (pg. 6)[76]. The NIHR argues that the public should be able to have a say in how research is carried out, especially when it is government funded. Doing so can also bring a number of benefits to research. To ensure that the voices of stakeholders were heard and incorporated into the current work, a number of groups were approached: (i) stroke survivors, (ii) a multidisciplinary management panel, and (iii) Bridges, the social enterprise that developed the one-to-one self-management intervention this thesis builds on. How each of these groups contributed to the research

design is presented in section 2.3, but why stakeholder involvement is valuable is presented below alongside ways to facilitate this process.

2.1.4.1 Why are stakeholder views important?

It was important to incorporate stakeholder views in this research for a number of reasons. Firstly, stakeholders will have a lived experience that differs to the researchers, for example, they may be living in a community that is being studied, or living with a condition of interest. This is advantageous as it may generate ideas and information that had not previously been thought of[77]. An example comes from the PROUD study which explored HIV transmissions[78]. Stakeholders informed the research team that clinicians would be unable to sterilise the equipment in the location specified in the protocol. This information enabled the research team to adapt the protocol so that disposable medical equipment could be used instead, and thus avoid the problem. By highlighting the potential implementation issues, the stakeholder's input may also have saved the researchers time and money[79].

Secondly, research shows that the goals and understanding between health care practitioners and patients may differ[80]. For example, when reflecting on the delivery of a self-management intervention, one therapist spoke about how their chosen goal for the patient was different to what the patient actually wanted to do[80].

> "*It's very easy to set goals with someone that are not necessarily the most important to them. The lady was able to achieve climbing up and down the stairs, but for her the most important thing was that she would be able to look in her own wardrobe and choose her clothes to wear downstairs — this would have been a far more meaningful target for her*" (pg. 95)[80].

Thirdly, stakeholders can help identify the most appropriate theory for the research. Doing so is important as interventions built on appropriate theory are more likely to result in an effective intervention than a purely pragmatic one[24]. The MRC suggest experts in the field are the most appropriate stakeholder group to identify relevant theory as they have an in depth knowledge of the evidence base[24]. Finally, stakeholder involvement in research may also offer benefits to those contributing their views, as patients have reported feeling empowered by the opportunity to help create change[81].

2.1.4.2 How to incorporate stakeholders in research.

The MRC recommends that stakeholders are involved in the development, implementation and evaluation of complex interventions, "as this is likely to result in better, more relevant science and a higher chance of producing implementable data" (pg. 15). However, these guidelines offer little advice on which mechanism of engagement to use. More detail on how to involve stakeholders in research was sought from the NIHR's INVOLVE briefing notes which were published in 2012[82], and their handbook for researchers published in 2014[77]. Similarly to the MRC guidelines for complex interventions, the INVOLVE handbook suggests patient and public involvement (PPI) can be incorporated into research at multiple stages but INVOLVE also offer advice on what this might look like. For example, in the development phase, researchers could have a patient or member of the public as a co-applicant on grant applications, and ask them for advice on study documentation. PPI could also be encouraged by certain research methods such as interviews or focus groups that give participants a voice. In keeping with best practice and to gain the associate benefits, stakeholder involvement was incorporated in the thesis using a range of techniques (see section 2.3).

2.1.5   A mixed methods approach

The final methodological consideration for this thesis is the choice of a mixed methods approach. Defined as the collection, analysis, and synthesis of both qualitative and quantitative data, mixed methods is widely advocated for use in health research and complex interventions[1,83,84]. As the School of Social Care states, mixed methods "can enhance our understanding of how an intervention works (or not)" (pg. 13)[84]. Part of assessing feasibility involves exploring the processes at work during the intervention which the MRC state should be done using both qualitative and quantitative outcomes so unexpected processes have a higher chance of being captured[65]. In addition, using a combination of methods enables the investigation of difference aspects of a phenomena, broadening understanding of the intervention, for example, what potential barriers to implementation might be[85].

Qualitative and quantitative approaches both offer distinct advantages. The former offers a richness of detail, while the latter can offer statistical objectivity. However, both also have the inverse weaknesses, quantitative work lacks a richness of detail while qualitative work lacks statistical objectivity. Mixed methods allows researchers "to capitalise on the strengths of each paradigm whilst offsetting their weaknesses" (pg.1)[86]. Both data sources are often collected across numerous studies with the aim of understanding one channel of investigation and combined post analysis[83]. In this thesis,

the channel of investigation was feasibility, and multiple studies contributed to the exploration e.g. a systematic review, two interview studies and a quantitative exploration of pre-post intervention scores.

Mixed methods can benefit feasibility studies in a number of ways. Firstly, each methodology can "inform the design of subsequent studies" (pg. 13)[84], as results from one approach can inform the development of another[85]. For example, qualitative discussions may help reveal that in future work quantitative outcome measures are not capturing aspects considered important to service users. Based on this feedback the researcher could adapt the outcome measures for subsequent trials accordingly.

Secondly, a mixed methods approach can create a divergence in findings, which can generate new avenues of exploration. This is referred to in the literature as 'initiation'[85]. The MRC highlight the importance of these discoveries happening during the feasibility stages of research as the researcher has the ability to act on them, even if this involves changing the scope or design of research[24].

Thirdly, a mixed methods approach can facilitate the translation of research into practice by engaging key stakeholders from multidisciplinary backgrounds. For example, commissioners may be more likely to engage with quantitative outcomes as this provides a more objective approach, while service users may prefer a qualitative approach that provides insight into how an intervention would change their day-to-day experiences[84].

It is evident from the above that a mixed methods approach offers health care research, complex interventions and feasibility studies numerous advantages. Without this approach, novel complex interventions may not be fully understood[65]. However, by combing the approaches one is also suggesting the underlying philosophies can be combined.

2.1.5.1 Reconciling different philosophies

Mixed methods brings together two philosophical approaches: Interpretivist and positivist. Traditionally, qualitative data is underpinned by an interpretivists belief that reality can only be understood through social constructs (e.g. language and shared meaning), while quantitative data takes a positivists approach which suggests access to reality is objective[84]. Publications in support of mixed methods can be found as early as 1959[87], but historically, there has been much debate about whether these two inherently different philosophies can be combined.

Debating the former in full is beyond the scope of this thesis (for more detail see Symonds et al[86]). In brief, the SAGE handbook summarises the case against mixed

methods with a quote from Holmes, "can we really have one part of the research which takes a certain view about reality nested alongside another which takes a contradictory view?" (pg. 5)[88]. The counter argument suggests that determining methodology based on a philosophical view point is not best practice, especially in health care settings where a pragmatic approach is favoured. Instead, researchers are encouraged to focus on the question as the driver for methodology[85], which enables the use of methodologies that are true to the research aims and objectives. The latter also reduces the risk of poor quality research being conducted which may lead to inconclusive outputs[85].

Finally, as the field of mixed methods has developed, the advantages of using qualitative and quantitative methods within the opposing philosophical frameworks have become more apparent[89]: In addition to the benefits discussed previously, qualitative data can benefit a quantitative framework as it may detect causal mechanisms that were missed and dispel a positive publication bias. The reverse is also true; quantitative data may offer benefits to a qualitative framework through the categorisation of large amounts of data and the ability conduct meta-analysis which would give an overview of a specific topic. Other literature has echoed these views particularly within the realm of public health and health promotion[90] and it is now widely believed that mixed methods "can lead to a multidimensional understanding of complex health issues" (pg. 378)[91]. However, the issue of combining such different methodologies in a coherent manner remains, and researchers should consider the different options carefully to find the most appropriate.

2.1.5.2 Combining the different methods

The approach used in the wider thesis to combine quantitative and qualitative results is triangulation. The purpose of triangulation is to 'enhance validity' through exploring convergence, complementary and dissonant analysis[92,93]. In contrast to other techniques, triangulation allows some data sources to be 'silent' in the formation of meta-themes. This means if a theme arises from one source and not another it can still be included[90], allowing answers that differ from the majority to be heard and ensuring stakeholders have all the available information. Triangulation can involve a number of data collection techniques and methods[91], in the thesis these include post intervention interviews, a process evaluation, focus groups, and between group comparisons of four quantitative outcome measures.

Limited literature exists which details the process of applying triangulation to health care setting. However, through reading the following two publications, the process of triangulation becomes clearer: One reports work from The Canadian Heart Dissemination Project[91] and the second reports health care research undertaken in the

UK[90]. There are three key features of triangulation. Firstly, researchers must seek similarities and discrepancies in the data as this deepens understanding and may open new lines of enquiry. In order to seek discrepancies and similarities, O'Cathain et al. recommend that researchers,

> *"List findings from each component of a study on the same page and consider where findings from each method agree (convergence), offer complementary info on the same issue (complementary), or appear to contradict each other (discrepancy or dissonance." (pg. 1147)*

Secondly, meta-themes are formed, providing an overview of key findings from both data sources to be presented, offering a richer and more detailed account of the results. Finally, data is combined post analysis. Thus, separate studies in this thesis will be combined in the discussion section, pulling individual studies together to form a clearer understanding of the bigger picture: the feasibility of a group self-management intervention for stroke.

Despite clear guidelines, triangulation of mixed methods data can be a lengthy and challenging process[3,44], so it is recommended that a research protocol is written prior to work commencing[65,94]. Doing so encourages researchers to consider how the qualitative and quantitative data will fit together, maximising the chance the data will complement each other. A multi-disciplinary team can greatly facilitate this process, ensuring expert insight for both qualitative and quantitative data sources. Thus, prior to the commencement this thesis, and with input from a multidisciplinary management panel (described in 2.3), an overview of what the project may look like was considered.

2.1.6 Summary

The current chapter considered the methodological implications of complex interventions, feasibility studies, stakeholder involvement and mixed methods. The thesis methodology was designed with these considerations in mind. For example, the MRC suggested that multiple outcomes should be used when exploring novel complex interventions and thus this was the case for the thesis. However, these considerations are general and do not offer specific advice, for example, what the outcomes used to explore the intervention effects (if any) should be. Consequently, it is necessary to detail the specific aspects of the thesis design which is done below.

2.2 Thesis methodology - The group self-management after stroke study (GUSTO)

The current section describes the methodologies used to implement the intervention. The specific methodology for each individual study conducted as part of the thesis is described in the relevant chapters.

2.2.1 Approvals, registration and funding.

Ethical approval was obtained from the NHS (5/NE/0341, see appendix 2). Any additional approvals required are referenced in the relevant sections. For example, the interview study conducted in chapter three has separate ethical approval, and the systematic review in chapter five was registered in the Centre for Research Dissemination (CRD) database and given a unique registration number. In order to maximise transparency, the study was registered on the on 20.12.2016 on the ISRCTN registry (ISRCTN19867168) as recommended by the World Health Organisation.

2.2.2 Management

2.2.2.1 Study management

I (EC), was responsible for all aspects of the study management, including budget handling and stakeholder liaison. The study was overseen by a seven-person multi-disciplinary management panel (see section 2.3.2), who met to discuss the research progress and any issues that arose. The panel enabled input from medical, psychological, statistical, and physiotherapy backgrounds. In addition, the panel included a stroke survivor (HK) who has been involved with the study from its conception. NW and FJ were members of the management panel and were also the primary and secondary supervisors of this thesis.

2.2.2.2 Data management

Data entry occurred via electronic devices where possible, through the on-line platform 'RedCap'. All data transfer and storage were in line with the Data Protection Act (1998). Identifiable information collected manually was stored securely in a locked cupboard within a secure building and will continue to be kept securely in the UK for ten years by UCL. A collection log was created to ensure all data was accounted for, and to act as a prompt for follow up data collection. All data collected as part of this thesis was analysed in the UK.

2.2.3   Research design

A flowchart illustrating the research design is presented in figure 2. The study was designed in accordance with MRC guidelines for complex interventions[24] to determine whether it is feasible to deliver the Bridges self-management intervention in a group setting. As recommended, the study used a mixed methods approach and a randomised waitlist control design. The design allowed comparisons between the intervention and waitlist groups (between subjects) and between pre and post intervention measures (within subjects). Ethically, a waitlist group is preferred as it enables all participants to gain the potential benefits of the intervention[95]. Outcome measures were collected at four-time points for both groups. The intervention group completed them at baseline, end of intervention, two-weeks, and six-months post intervention. The waitlist group completed the measures at baseline, the end of the six-month waiting period, the end of the intervention and two-weeks post intervention. Any changes to the research design were discussed with the relevant stakeholders (funders, ethics committee and management panel). Participants were able to withdraw from the study at any time.

Figure 2. CONSORT diagram illustrating the study recruitment process and design.

Enrolment

Assessed for eligibility

Excluded n=342

- Did not meet inclusion criteria n=40
- Declined to participate n=111
- Could not contact n=171
- Maybe in future n=20

Randomized

Intervention and baseline assessment n=30

Waitlist and baseline assessment n=30

Did not take part n=2

- Out of country n=1
- Unavailable on dates n=1

Enrolled in intervention

n-28

Did not complete intervention n=4

- Difficult to travel n=1
- Other commitments n=1
- Unwell n=1
- Aphasia too severe n=1

End of the intervention

Lost to follow up n=1

- But participant did complete subsequent 6m measure

2 week follow up n=23

Lost to follow up n=0

Lost to follow up n=2

//

//

Figure 2 continued: CONSORT diagram illustrating the study recruitment process
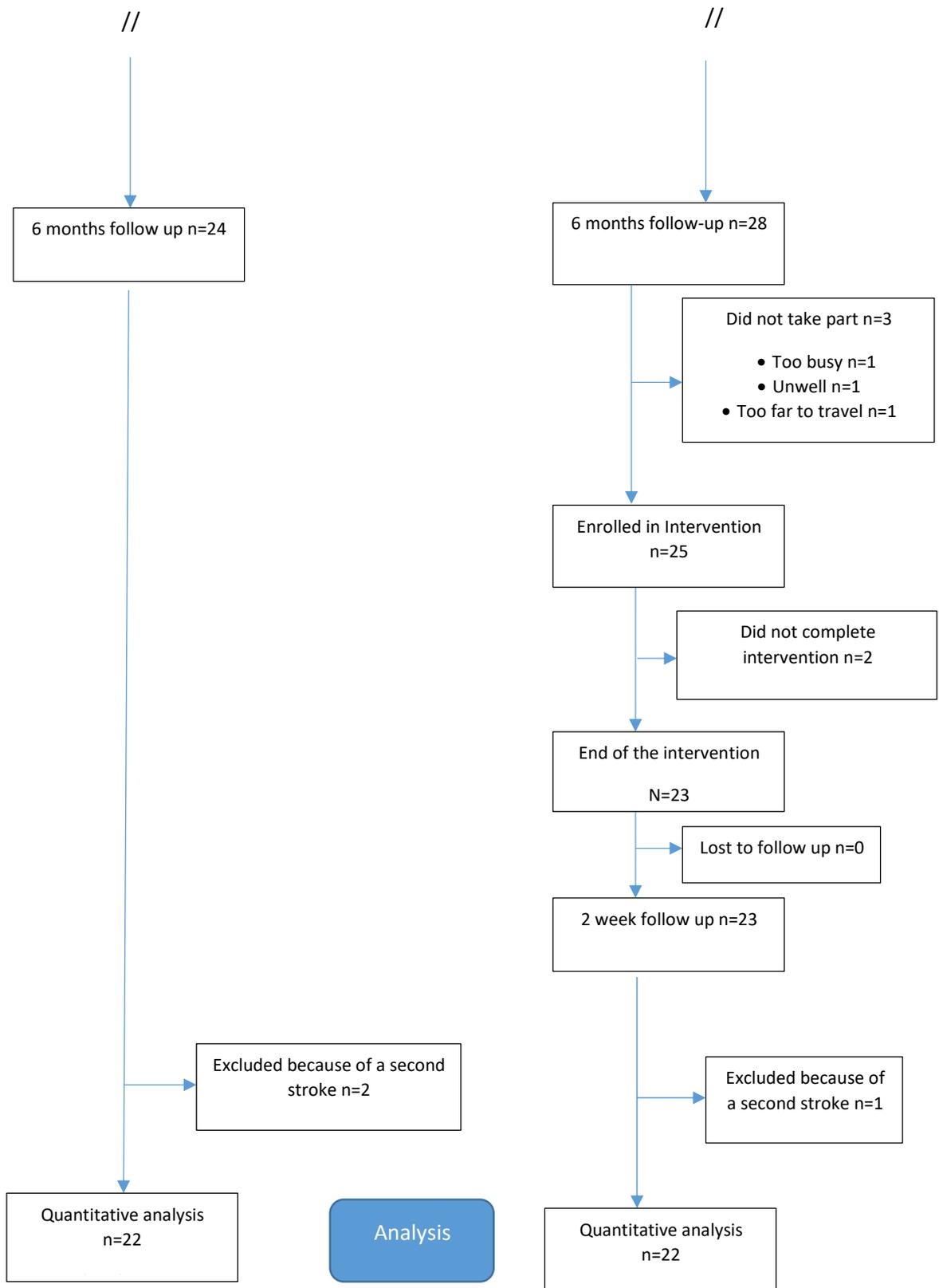
2.2.4 Recruitment process

Recruitment of stroke survivors was overseen by the Clinical Research Network (CRN). Stroke survivors were recruited from a Hyper Acute Stroke Unit (HASU) in University College London Hospitals (UCLH) NHS Trust. The intense nature of the HASU meant potential participants were often emotionally drained and tired so it was difficult to fully consent them in this setting. Instead, patients were only given a brief overview of the study and the information sheet while in the HASU. If interested, they were consented to a Permission To Contact register (PTC). The PTC is a list of those willing to be contacted by researchers in the future. It enabled access to a naturally occurring sample within the stroke population. This minimised the risk of selection bias and maximised the chance the sample would be representative of the target population. The current study began in 2015 and the PTC was set up in 2013 so at the point of use it also included individuals who had their stroke up to 2 years ago, giving the sample a larger range of time post stroke than recruiting from the start of this research would have (March 2015). However, this PTC only had patients on it who could consent for themselves during their stay in HASU, meaning those who did not have capacity to consent were not given the opportunity to take part. To overcome this, the PTC was adapted to become the PTC+ in December 2015. This enabled a family member or friend to consent on a stroke survivor's behalf. Recruitment started from the first entry on the PTC/PTC+ and continued in chronological order until the target sample size was reached. There is no published documentation regarding the uptake levels to stroke rehabilitation studies from the UCLH PTC. However, previous research conducted using the PTC suggests that the level of uptake may be around 40%.

2.2.5 Sample size

The NIHR guidelines state no formal power calculation is needed for feasibility studies[74] (as discussed in section 2.1.3). The sample size used in this thesis is based on published guidance that suggests a feasibility study should have at least 24 participants in order to inform a future sample size calculation[71]. In contrast, others suggest work conducted prior to an RCT should have at least 50 participants[96]. We have based our sample size on the most conservative estimate for group size (N≥50). Dropout rates from group Bridges are currently unknown but adherence to Bridges on a one-to-one level has been reported at 100%[46]. After discussion with the management panel a conservative estimate of 10 drop outs was decided on resulting in a total sample size of 60 stroke survivors.

2.2.5.1 Inclusion and exclusion criteria

As this work addresses feasibility, the exclusion criteria were kept broad to gain insight into who the group self-management intervention may be appropriate for.

Inclusion criteria

- Confirmed diagnosis of stroke from a medical professional
- Able to hold a conversation in English as judged by the researcher enrolling the participants (no interpreter was available, but participants were encouraged to come with a family or friend supporter who could assist with interpretation. The same was true for those with communication disorders such as aphasia).
- At least 18 years old
- Discharged from NHS services

Exclusion criteria

- Any previous access to, or support from, Bridges self-management programme
- A clinical diagnosis of depression from a medical professional
- Severe co-morbidities, such as other neurological conditions that would prevent the individual attending the group intervention.

2.2.6 Randomisation and research conditions

Once participants were enrolled in the study they were randomised by a member of the research team using a blocked randomisation chart that was created by the statistician on the management panel (GB). Blocked randomisation was chosen as it ensured balanced numbers were allocated to the intervention and the control group[97]. Once a participant had consented to participate in the research a member of the research team (EC or KE) would reveal the next line on the chart which would indicate the intervention allocation using a 'C' for control or 'I' for intervention.

2.2.7 Intervention and waitlist groups

Figure 2 includes the different research activities for the waitlist and intervention groups. Individuals randomised to the intervention group completed the intervention as soon as possible. The waitlist control group experienced a six-month wait period during which they did not have any interaction with the research team. They continued to engage with standard practice as if not taking part in the research. Outcome measures were completed at the time points described in section 2.2.9.

2.2.8 Intervention

The intervention protocol is described in full in chapter five. Briefly, the intervention is a four-week group self-management intervention which had one session a week lasting two hours. The groups were facilitated by a self-management practitioner, a speech and language practitioner and a stroke survivor. As transport to the venue has been reported as a potential barrier to attendance (either due to difficulty travelling post stroke, or cost[39]), all participants were offered a taxi to the venue or were reimbursed for their expenses. A register was taken to record which participants, facilitators and carers attended each session.

2.2.9 Outcomes

As this is a feasibility study, no primary outcome was specified in accordance with guidelines70. Stroke survivors completed four quantitative outcomes measures: the 39 item Stroke and Aphasia Quality of Life Scale (SAQOL-39), the Hospital Anxiety and Depression Scale (HADS), the Nottingham Activities of Daily Living Scale (NEADLS) and the Stroke Self-Efficacy Scale (SSES). The reasons each of these outcomes was chosen is detailed in chapter nine. In addition, post intervention interviews with a subset of stroke survivors (chapter three) and focus groups with family, friends and carers who attended the groups (chapter four) enabled the collection of qualitative outcomes. The outcomes were collected at for time points. Both the intervention and waitlist group completed the measures at the start of the intervention, the end of the intervention and at two-weeks follow up. In addition, the control group completed the measures at the start of the waitlist period, and the intervention group at six-months post intervention.

Summary

In summary, a mixed methods randomised control design was used to explore the group self-management intervention for stroke. The research design was informed by best practice guidelines from both the MRC and NIHR, and a range of stakeholders which are described in more detail below.

2.3 Stakeholder contributions to the research design

Three stakeholder groups contributed to the research design: stroke survivors, the Bridges team, and a multidiscipline management panel. The key discussion points from each of these groups, and how these impacted the research design are presented in chronological order as follows: (i) a meeting with the Bridges team (ii) a meeting with the

multidisciplinary management panel, (iii) a stroke survivor focus group and (iv) a second multidisciplinary management meeting.

2.3.1 A meeting with Bridges

A meeting was held on the 11/05/2017 with two senior members of the Bridges team: FJ -the founder of Bridges and LB-the director of innovation and training. EC (thesis author) was also present. Five topics were discussed which informed the research design:

1. **Theory:** It was decided that the most appropriate theory to underpin the group delivery of Bridges was Social Cognition Theory as it underpins the one-to-one delivery of the intervention and centres around self-efficacy.

2. **Core principles:** All nine of the core Bridges principles should be included in the adaptation of the intervention to maximise fidelity to the original design.

3. **Facilitators:** The Bridges team felt three people should facilitate the intervention: a stroke survivor (as they offer a shared experience of stroke and insight to what day-to-day life with stroke is like), a speech and language therapist (as they can offer support to participants with communication disorders), and finally a self-management practitioner (to ensure the intervention delivery is in keeping with a self-management approach).

4. **Session Structure:** It was decided that sessions would be one and a half hours in length and that they would run once a week for four-weeks. A 15-minute ice breaker was suggested at the start of each session which would be facilitated by refreshments. In addition, in keeping with the belief that self-management is 'boundary object'[21], as well as MRC guidelines it was decided that the intervention should be able to adapt to the context when required.

5. **Recruitment:** It was felt that it was important for the friends and family of stroke survivors to have the option to attend the intervention as self-management is a collective process[58]. In addition, it was felt that stroke survivors with mild aphasia should be included as it was unknown whether the intervention was appropriate for delivery with this population. In terms of recruiting participants, it was felt the ambiguity of the term 'self-management' could be a barrier so the importance of having clear information sheets was stressed. Finally, form an ethical perspective it was felt that holding the groups in hospital settings may coerce stroke survivors to take part as they may feel non-attendance would impact the standard of care they receive. Therefore, it was decided that all the groups would be held in non-NHS settings.

2.3.2 The first multidisciplinary management panel meeting

The second stakeholder group who contributed to research design was the management panel, made up of the grant co-applicants who secured funding for this research:

- Ella Clark – *PhD student and trainee health psychologist, University College London Hospital*
- Dr Nick Ward- *Reader in Clinical Neurology and honorary consultant University College London*
- Professor Fiona Jones – *Professor of rehabilitation research, Kingston University and St George's University of London*
- Professor Diane Playford – *Professor of Neurological Rehabilitation, Warwick University*
- Dr Catherine Doogan –*Clinical Psychologist, University College London Hospital*
- Dr Gianluca Baio – *Reader in statistics and health economics, University College London*
- Helen Kelly - *Stroke survivor and physiotherapist*

The first meeting took place on 01/05/2015. Everyone on the management panel bar GB was present. In addition, three individuals from the stroke research network were also present. The meeting was facilitated by EC. The recruitment approach was discussed at length which informed the research design as follows: Different ways to meet the recruitment target (N=60) in eight-months were considered. The CRN suggested using the Permission To Contact (PTC) register which has a list of stroke survivors that have agreed to be contacted about future research projects. In addition, the inclusion criteria were discussed. One inclusion criterion was changed from 'discharged from standard care' to 'discharged from NHS services' as the wording of 'standard care' was considered too vague. There was discussion around whether stroke survivors should be excluded if they took part in additional groups such as Stroke Association's social groups. However, it was deemed unethical to ask individuals to choose between two potentially beneficial interventions, especially during the feasibility stages of research.

2.3.3 A stroke survivor focus group

A focus group consisting of eight stroke survivors was run on the 17/05/2017 (see appendix 3 for demographics). Two facilitators were present (FJ and EC). FJ led the focus group using a pre-decided topic guide as shown in appendix 4. The group was run in a non-clinical building in a University in order to minimise the risk of attendees feeling what they say may impact their care. Discussion during the focus group informed the following changes:

1. The structure of the group, for example, breaks and length of session was changed as stroke survivors felt one and a half hours was too long without a break, so this was changed to two hours with a 25-minute break in the middle.

2. Some stroke survivors were concerned that the group may become 'another social group', and suggested a designated social time at the start of sessions as well as a break. The focus group all agreed that this would help to compartmentalise social time.

3. Discussions about the impact helping others would have on the stroke survivors offered insight into both how the content should be structured and framed, but also how the group self-management intervention should be 'advertised'. For example, the information sheet was re-written with greater emphasis on the reciprocal nature of relationships that the group may offer. In addition, it was important that when recruiting individuals to state it is OK if you feel very well recovered or not at all as there is a role for everyone.

4. Due to the ambiguity of the term 'self-management', stroke survivors felt it was important to convey at the start of the intervention what self-management is and what the group would look like in practice.

2.3.4 The second multidisciplinary management meeting

The second management meeting happened on the 06/10/2015. The management panel were all in attendance except for HK (who had work commitments) and the statistician GB (as the meeting was not focussing on statistics). EC facilitated the meeting. The following considerations informed the research design:

- It was unanimously agreed that the groups could be two hours in length with designated times to socialise as suggested by the stroke survivor focus group.
- Disruptive participants were discussed as this was of concern, and the team thought of different ways to manage this. In particular, having a senior member of the team on call. The issue of defining disruptive was also explored and how the facilitator's judgement alongside feedback from other attendees could be used as a tool. It was agreed that at the start of each group the facilitator would make it clear that if anyone is perceived as disruptive or behaving inappropriately they would be asked to leave.
- One individual suggested creating a community once the sessions had finished in order to extend the group dynamic. For example, if people want to keep in touch or want to connect with others who have done Bridges. It was noted that it would be more in keeping with the self-management ethos if such a community

were run by the stroke survivors themselves and not researchers. From a practical perspective, having a researcher run this group would not be feasible at this stage as it would be a full-time job.

2.3.5 Conclusion

Stakeholders were invaluable to the development of the intervention and research design. Involving stroke survivors in the research design maximised the likelihood the study would be seen as acceptable, relevant and helpful[76,98]. This was complemented by the involvement of the multidiscipline team who offered clinical insight, and the Bridges team who offered a wealth of experience with self-management interventions. All three sources gave insight into the feasibility of delivering the intervention in a group setting.

2.4 Thesis structure

The final section of the methodology chapter presents the thesis structure. The thesis is organised according to the three main phases, development, implementation and evaluation. It ends with the triangulation of the quantitative and qualitative findings from all three phases. Across these phases all seven of the research questions (listed at the end of the introduction section 1.5) were answered.

2.4.1 The development phase

The development phase is reported in chapters three, four and five. This phase addressed both the acceptability of delivering self-management in a group setting, and explored what the protocol for a group self-management intervention based on Bridges would look like. A brief summary of the work conducted during the development phase is presented below in relation to the research questions they answer.

The first research question asked: How acceptable to stroke survivors is it to deliver self-management in a group setting? Fourteen one-to-one interviews were conducted to answer this question, which is presented in chapter three. The second question asked, 'what would a group self-management intervention based on Bridges look like?' The existing one-to-one Bridges self-management intervention was adapted for use in a group setting using the interviews listed above and two additional sources.

(1) A systematic review: In accordance with the MRC guidelines for developing complex interventions, relevant literature was collated as a systematic review exploring the key features and role of peer support in existing group self-management interventions (chapter 4).

(2) Stakeholder views: Stakeholder views were captured from stroke survivors, the Bridges team, and a multidisciplinary management panel. These are presented in section 2.3, but also contributed to the development phase.

Findings from each of these studies contributed to the design of the group self-management intervention presented in chapter five. Once the development phase had finished the implementation phase took place.

2.4.2 The implementation phase

The implementation phase involved delivering the novel complex intervention and is reported in chapter six. The third and fourth research questions were answered in the implementation phase: Can a group self-management intervention be implemented in

practice? And, what processes are at work in the intervention? Both were answered using a process evaluation which answered a number of sub-questions, including: who will be recruited and how quickly can they be recruited? And, is the intervention being delivered as intended (fidelity)? Once the intervention had been implemented, it could be evaluated as described below.

2.4.3   The evaluation phase

The final phase was the evaluation of the group self-management intervention. The evaluation phase answered the fifth, sixth and seventh research questions: how acceptable to stroke survivors is it to deliver self-management in a group setting? How acceptable to family/friends/carers is it to deliver Bridges in a group setting? And finally, does delivering Bridges in a group setting have any impact on the lives of stroke survivors? Three individual studies were conducted during the evaluation phase, an interview with stroke survivors who took part in the intervention, a focus group with family/friends/carers who attended the group, and finally a quantitative analysis of the outcomes collected.

2.4.4   Conclusion

The thesis is organised according to the three phases: development, implementation and evaluation. In keeping with MRC guidelines, all three phases are given equal weight in terms of importance as all contribute to creating a full picture of feasibility. The findings from all three phases were triangulated in the discussion (see chapter 10) to make final conclusions about the feasibility of delivering Bridges in a group setting.

2.5   Discussion

Interest is growing in group self-management interventions as they may facilitate the long-term management of stroke, an area which is currently understudied. However, before group self-management interventions can be evaluated as part of a fully powered trial, their feasibility needs to be assessed. The current chapter explored the methodological considerations for such research and detailed the specific methodology that will be used in this thesis.

2.5.1   General methodological considerations

When designing this thesis, care was taken to use methodology advocated by current research guidelines including the MRC guidelines for complex interventions, and the NIHR's advice on feasibility studies. It is vital that the methodological considerations

raised in this chapter are considered within the context of feasibility, as the work is not designed to create robust statistical outcomes, but to answer, 'can this research be done?' However, having said this, many considerations raised in this chapter will be relevant for future work, should a definitive trial be conducted. For example, the implications for research exploring complex interventions, such as the use of a mixed methods approach, and mechanisms through which one can maximise patient and public involvement will both be relevant to future work.

Although there are a number of limitations with the specific methodologies used (discussed in detail below), it is rare for researchers to conduct feasibility studies on such a detailed scale when developing complex interventions. Doing so is a strength of the methodology and increases the credibility of the current work as well as subsequent iterations of the intervention.

2.5.2 Thesis methodology

The specific methodology used to explore the feasibility of a group self-management intervention was designed following best practice guidelines, and input from a number of stakeholders. Despite this, there are some limitations that should be addressed. The chosen recruitment strategy means that participants will be recruited from only one hospital, limiting the geographical reach of recruitment and thus minimising how representative the sample is of the stroke population in general. However, it is important to remember that the current study is assessing feasibility. Thus the aim was to decipher if the research could be done, and not to generate representative results at this stage. A future trial could overcome this issue by recruiting from a range of hospitals across the United Kingdom.

A second limitation is inherent to all non-telehealth group self-management interventions, as by definition individuals have to be able to attend the sessions somewhere other than their own homes. As a result, the sample will be biased to stroke survivors who are able to the travel to the venue[39]. Previous research has shown some success with telehealth interventions[99], and although these have not been trialled in the UK yet, they should be considered for use in future work as they may enable those who cannot travel to take part.

The third limitation comes from type of control group used. It has been argued that bias may be inherent to wait list control groups as those waiting have 'a sense of expectancy' in that they know they will receive the intervention in the future[100]. Simply knowing that you are on a wait list may provide comfort to individuals and in some cases can actually improve clinical outcomes. For example, tinnitus patients experienced a 3-8% reduction

in tinnitus measures over a wait period of 6-12 weeks that involved only standard care[101]. However, as mentioned in response to the first limitation, the aim of the thesis is to assess feasibility and not to robustly asses the clinical outcomes. Therefore, the fact that all stroke survivors could access the intervention and gain any associated benefits, was deemed to outweigh the potential research costs of using a waitlist control group.

It should also be highlighted that the quantitative outcome measures used to capture any change as a result of the intervention all use pre-defined questions and answers. This could be seen as being at odds with the self-management philosophy: For example, self-management practitioners are encouraged to be collaborative in their practice[21], and to create 'democracy' as opposed to a 'dictatorship'[62], but this may be more challenging when outcome measures pre-determine how an individual can express their views. The problem is in part addressed through the use of qualitative data capture in the thesis, but future work should consider this when deciding which outcome measures to use in a group self-management setting.

Finally, it is hoped this thesis will inform the design of future work assessing the efficacy of a group self-management intervention in a definitive trial. The methodology used reflects this and care has been taken to adhere to best practice guidelines.

2.5.3   Conclusion

This chapter has provided an overview of the methodological considerations required for the thesis, including, complex interventions, feasibility, stakeholder involvement and mixed methods. It has also presented the research design, and the structure that this thesis will follow. The next section presents the first phase of the research: The Development phase.

Development Phase

The first phase of the thesis is the development phase, during which question one (how acceptable to stroke survivors is it to deliver self-management in a group setting?) and question two (what would the protocol for a group self-management intervention based on Bridges look like?) are addressed.

The development phase ran from February 2015 until February 2016. Before the project began it was important to make sure the concept of the group self-management intervention was acceptable to the target population so question one was explored using interviews with stroke survivors (how acceptable to stroke survivors is it to deliver self-management in a group setting?). The interviews are presented first in this section (chapter three). As delivering Bridges in a group setting had not been done before, the intervention had to be adapted for use in this context. Question two (what would the protocol for a group self-management intervention based on Bridges look like?) was explored using three sources: A systematic review (chapter four), stakeholder views (presented in the previous methodology chapter), and interviews with stroke survivors. Finally, the resulting protocol for the four-week group self-management intervention for stroke for which the protocol is presented (chapter five).

Chapter Three

3 Chapter three: Stroke survivor views on a group self-management intervention for stroke: It's not a one size fits all problem.

This chapter is based on the following publication: Clark, E., Bennett, K., Ward, N. & Jones, F. One size does not fit all – Stroke survivor's views on group self-management interventions. *Disabil. Rehabil.* **0,** 1–8 (2016).

3.1 Introduction

It is important that studies are carried out in line with the MRC guidelines, which suggest the design of any complex intervention should be tested for acceptability among its target population[24]. In addition, when developing such an intervention within the context of stroke rehabilitation is important that the intervention reflects the needs of those who would use the service, as self-management interventions may profess to be patient centred, but can often be professionally led[53]. Both of these considerations could be achieved through involving the target population in research.

It is important to capture the views of the target population as early as possible when developing a complex intervention as this means there is scope to incorporate any findings into subsequent designs. This reduces the likelihood that valuable time and recourses are wasted on aspects of interventions that are not acceptable to those using it. Another example of how insights from the target population can facilitate intervention design comes from work exploring stroke survivor's perceptions of self-management in general[102]. Interviews found that stroke survivors saw self-management as a complex and personal learning process and suggested that self-management interventions would need to be tailored to those taking part. In addition, stroke survivors expressed views that they were not ready to self-manage when they were first discharged form hospital, which has important implications for intervention delivery. However, to date this is the only study that has explored when the 'right time' to self-manage is and the findings have not been replicated.

Similarly, there has been no work which explores the acceptability of group self-management interventions in general. Previous work has sought stroke survivor feedback about an existing Chronic Disease Self-Management Program (CDSMP), but only after they had participated in the intervention[13]. The findings revealed participants valued social contact and comparison, and felt they gained knowledge about stroke.

Crucially for a self-management intervention, participants felt they had experienced an increase in self-efficacy as a result of the intervention. However, the results offer little insight into how the CDSMP could be improved in terms of intervention design. In addition, as the was research completed post intervention it may be at risk of the Hawthorne bias as participants may feel an obligation to please the individuals who ran the intervention[103].

At present, there is no work exploring the acceptability of group self-management interventions in general, or corroborating findings about when the 'right time' for implementation is. Furthermore, there is no work exploring the anticipated barriers and benefits of a group self-management intervention specifically designed for stroke. It is vital for the thesis that these gaps in knowledge are addressed. Therefore, the aims of the current research were to explore the acceptability of a group self-management intervention, and more specifically stroke survivor's insights on 1) possible benefits of a group self-management intervention 2) possible challenges of a group self-management intervention and 3) when/where to implement a group self-management intervention in an individual's stroke journey.

3.2 Method

Semi-structured interviews enabled researchers to gain an insight into what stroke survivors thought of a group self-management intervention and how it could be delivered. Inductive thematic analysis was used which is recommended for preliminary health service research, and when key themes reflecting variations in the data need to be identified[104,105]. Recruitment, interviews and data analysis were carried out concurrently over six-months. This allowed data saturation (defined as when all members of the research team agreed no new categories were emerging from the data) to be considered contributing to rigour[106].

The work was informed by the NIHR guidelines which encourage patient and public engagement in health and social care research[77], and the MRC guidelines for the development of complex interventions[24]. A favourable ethical opinion was given for this study from the NRES Queen Square committee (13/LO/1412).

3.2.1 Recruitment

The researchers had an initial aim of interviewing at least 12 participants as this is suggested for applied research with narrow questions[107]. Participants were recruited from the Sobell Stroke Database at Queen Square. The database contains contact

information for individuals who have previously expressed an interested in research. Researchers can access the database if they work in the Sobell department and have ethical approval for the proposed work. Individuals were initially added to this database through NHS services, the Stroke Research Network, or other research studies conducted within the Sobell Department.

Stroke survivors were approached consecutively about taking part in the study using their preferred method of contact. The majority stated they preferred telephone so where a preference was not listed telephone was used. All potential participants were assured taking part was completely voluntary and would not affect their standard of care within the NHS. Reasons that stroke survivors declined to take part in the study were documented and allowed the researchers to see if any patterns of decline were emerging. It also provided a clear context for the sample which reduces the likelihood of making unsupported statements about overall findings.

The inclusion criteria were designed to ensure as wide a sample as possible. Stroke survivors were included if they had: (1) one or more stroke(s), (2) were able to verbally complete an interview (this included people with aphasia who could understand a two-step command and express thoughts and ideas) and (3) received their care in a UK stroke care pathway.

3.2.2 Interviews

All of the semi-structured interviews were conducted by EC (thesis author). Interviews were conducted in a university research department in a room with minimal distraction. A university room was chosen as it offered a non-clinical environment and emphasised that the interviews had no impact on clinical care. However, the chosen location meant that participants would need be able to travel to the venue for the interviews. Prior to each interview the room was set up in the same way (chairs facing each other and a low round table in the middle and the curtains open). Each interview was recorded using a Dictaphone. Participants had the option to bring a friend or family member with them.

Two researchers (EC and KB) developed the topic guide and research questions which were informed by guidelines for developing interview schedules in health research[104]. The topics themselves were informed by the research questions as well as relevant research. For example, Satink's work drew attention to the time that stroke survivors felt ready for self-management[108]. As a result, a question surrounding when to implement a group self-management intervention was included in the interview guide. The transcript was piloted in a practice interview and discussed by EC and KB. Some questions were

removed after the pilot as they were off topic and did not facilitate full exploration of the research questions. The full topic guide can be found in appendix five.

At the start of the interview participants were read a paragraph about what self-management means as the term is somewhat ambiguous. They were also given the opportunity to ask questions. The interviews were carried out in two parts. The first part explored participant experiences of self-management in their own stroke journey which gave insight into the third aim of the study (when/where to implement a self-management intervention in the stroke pathway/ stroke survivor's recovery). The second part of the interview explored the idea of group self-management interventions and the barriers and gains associated with them. This gave insight into the first and second study aims (possible benefits of a group self-management intervention and possible challenges). An example of the types of questions asked is found in box 3.1.

Box 3.1. Example of questions used in the interview guide.

- How do you think it would have made a difference to your current life if you had experienced self-management, if at all?
- How would self-management make a difference to your life if you were practicing it now?
- What do you think about the idea of group self-management programmes? What would the barriers/benefits be?

3.2.3   Data analysis

Data were interpreted using inductive thematic analysis with codes drawn directly from the data. Codes were phrases or words which were then grouped to develop categories and themes. In the first instance the raw data were interpreted as codes (e.g. learning from others and new ideas from peers) which were then combined to create collections of codes (e.g. collective problem solving). These collections were then combined to produce sub-themes (e.g. peer support), which were again combined to produce the main themes of the study (e.g. a space to share support).

In keeping with guidance on qualitative research[105], themes were formed iteratively which meant data analysis and interviews were done simultaneously. The process involved exploring which themes were identified across the data set as it grew and re-reading interview transcripts to find illustrative examples and adjusting themes to reflect the new data gathered. This process continued until no new themes were identified.

To minimise researcher's preconceptions influencing data analysis, and to offer a broader understanding of the data, three researchers coded data for two interviews (EC,

FJ, KB). Each researcher then wrote a summary of their interpretations and these were discussed as a group, including codes and their descriptive groupings. No substantial differences in interpretation were found and all the remaining interviews were coded separately by two of the researchers (EC with either FJ or KB) in keeping with published recommendations[105]. Data management was performed using Nvivo 10.

3.3 Results

Fourteen participants were interviewed (see table one). The interviews lasted from 12 to 54 minutes, with a mean average of 30 minutes. The mean age of participants was 58 (with a range of 47-78). The mean time since stroke was 30 months and ranged from 4 to 174 months. Eight of the interviewees were female, and six were male. Similarly, in the UK, three out of five strokes are in women[109]. Eleven of the interviewees were white British, one was Chinese, and one was white Irish, one not wish to disclose their ethnicity. In the UK, people of black and south Asian origin are at a higher risk of stroke compared to white people[110]. The limited ethnic diversity of this research should be considered in terms of transferability of the data. Four of the interviewees were unemployed, three were retired, three were employed (one of the three was self-employed), which is similar to the national statistics which show 69% of stroke survivors were unable to return to work[110]. One participant (8) had mild expressive aphasia. Residuals symptoms reported included: Aphasia, motor impairment, motor weakness, fatigue, low mood, and poor balance. No one else was present at participant interviews 1-12 apart from EC and the participant. Participant 13 brought her husband to the interview, as did participant 14. Five stroke survivors who were approached declined to take part in the study, three as they were too unwell, and two as they were too busy.

Table 1. Demographics of participants who were interviewed prior to intervention development.

Participant Number	Gender	Age	Ethnicity	Employment status	Time since stroke (months)	Living situation
1	M	48	White British	Employed	33	Living alone
2	F	50	White Irish	Employed	57	Living alone
3	M	47	White British	Self-employed	16	Living alone
4	F	73	Not given	Not given	4	Living with partner
5	M	78	White British	Retired	174	Living with partner
6	M	51	White British	Unemployed	9	Living alone
7	F	50	Not given	Not given	61	Living with partner
8	F	57	White British	Unemployed	31	Living alone
9	F	66	Chinese	Volunteer	24	Living alone
10	M	53	White British	retired	40	Living with partner
11	F	54	White British	Volunteer and student	4	Living with partner
12	M	51	White British	Unemployed	34	Living with partner and daughter
13	F	76	White British	Unemployed	23	Living with partner and daughter
14	F	69	White British	Retired	26	Living with partner

The research was conducted with the aims to explore 1) possible benefits of a group self-management intervention, 2) possible challenges of a group self-management intervention and 3) when/where to implement a self-management intervention in an individual's stroke journey. The aims are discussed within the context of the three main themes that were identified in the data. The first theme, 'A space to share support' illustrates the challenges and benefits of a shared space that would be created as part

of a group self-management intervention. An example of the sub-themes that made up this theme is found in figure three. The second theme, 'It's not a one size fits all problem' illustrates the view that a group approach needs to be able to address the heterogeneity of stroke. The third theme, 'How's it all going to happen?' was identified in discussions around the logistical aspects of a group self-management intervention, for example transportation and facilitators.

Figure 3. Example of theme formation 'a space to share support'
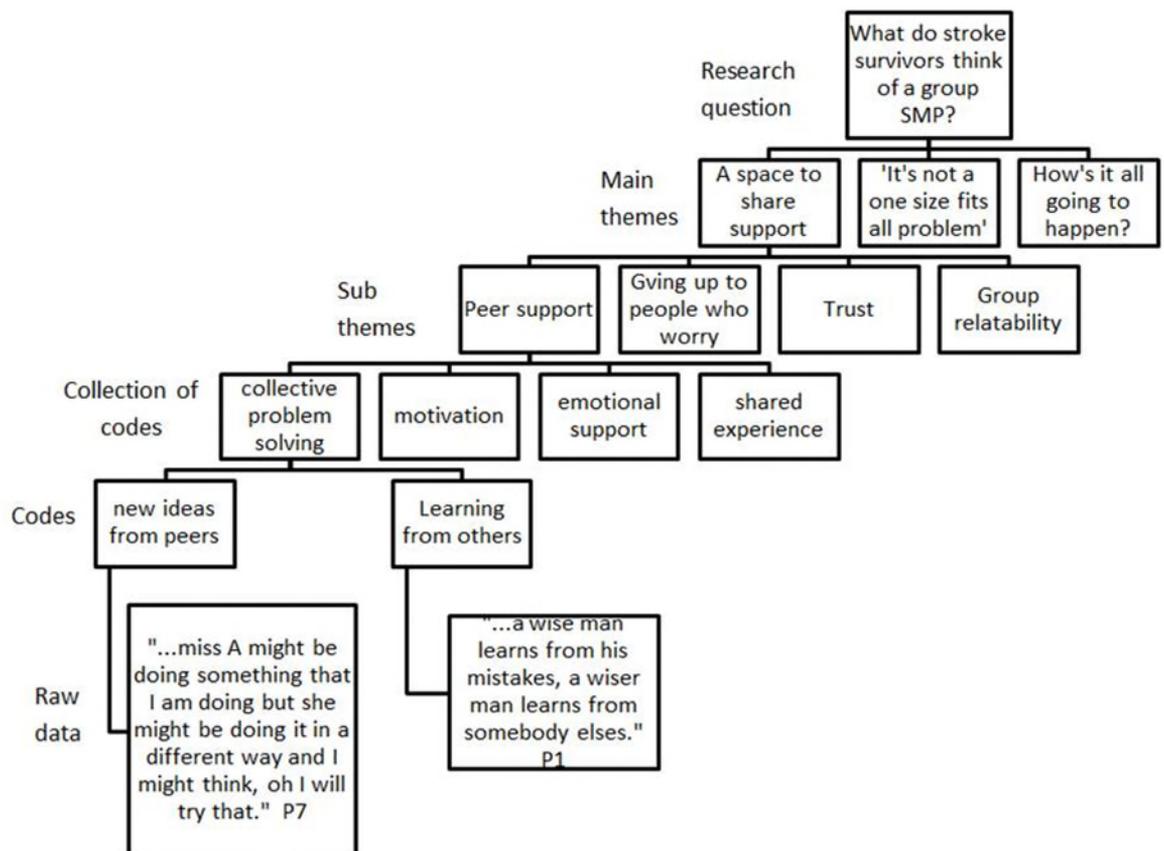
3.3.1 Theme 1: A space to share support

'A space to share support' represents how participants felt about the social aspects inherent to a group self-management intervention, in particular, the challenges and benefits of a shared space. Four sub-themes contributed to this overarching theme as follows: peer support, giving up to people who worry, group relatability, and trust.

Peer support within a group setting

The value of peer support was referenced by nine participants, and included reflections on the value from both a practical and emotional stance. Many participants described

how they had faced new challenges after their stroke and highlighted the potential benefit that could be gained through peers by collectively problem solving:

> *"I do think [one-to-one] would limit me. You know, cos I think it is good to have other people around* (researcher in bold) **Why would it be limiting?** *Well because it is just one person and she, there is only her or his ideas, I just think with other people's ideas you get more of an all-round idea you know…. Miss A might be doing something that I am doing but she might be doing it in a different way and I might think, oh I will try that. you just don't know." (Jess)*

Participants felt others who had experienced a stroke would have a greater understanding of where they are coming from. Linda explains this may be in part because you are 'working towards the same goals'. In addition, discussions around this shared experience may reduce feelings of loneliness as Paul illustrates:

> "*That is good if you know there are others in the same position as you. Going, going through the same thing as you. So you don't think you are the only one… It's good talking to other stroke survivors because with their experiences you know you are not alone then. Because it is very demoralising once you have had your stroke." (Paul)*

Motivation from peers was mentioned by a number of participants. It was spoken about in relation to vicarious experience or learning from others. Seeing others succeed could be particularly motivating:

> *"Sometimes it is peer pressure. You see someone doing well and you want to get better as well so it spurs you on a bit".* (Paul)

Peer support was seen as a positive thing by the majority of participants due to the potential for shared problem solving, increased motivation, and a reduction in loneliness.

The ripple effect- A group just for stroke survivors?

'The ripple effect' depicts the effect stroke can have on family and friends and also the impact family and friends can have on a stroke survivor's self-management. Participants described the need for those caring for them, as well as themselves, to understand what is going on. A shared understanding was felt to be important as those caring for stroke survivors can then offer a 'nudge' in the right direction. This was illustrated by Henry who said:

> *"I think erm a carer, even if they are just there to nudge*
> *support, is important. So, I think the carer needs to be*
> *involved in the management program, so they know what*
> *is going on."*

Similarly, Liz felt that a group self-management intervention might help her husband better understand how to encourage her to self-manage:

> *"If my husband is there I would use him…..Like you know [if I ask], 'can you*
> *do this, and can you do that?'. Then they would be trained to say, 'oh you*
> *know, let's see if you can do it yourself'…I know I can do it, as I have done it*
> *myself. But you give up to people who worry about you."*

Overall, participants felt family and friends were involved with the process of self-management. For this reason, it was felt important that a stroke survivor could share the group self-management sessions with family and friends if they chose to.

Group Relatability – 'I might not fit in'

'Group relatability' describes the importance of relating to others in a group self-management intervention. There was some overlap in the factors participants found relatable, but the importance of these factors varied from person to person. Mukesh suggested that a similar age was what he would relate to in a group. He says this because age may alter the challenges you face. For example, younger people he had met were all keen to get to the gym, but he felt older people would not have the energy for this. Thomas agreed with Mukesh that age was significant but also mentioned gender:

> *'I think really if I was going to sit down with a bunch of men my*
> *age I would probably be, you are more likely to be more open*
> *and you are going to relate to them more.'*

Thomas's view on gender was held by the majority; all but one participant stated they would feel more comfortable around people of the same gender as them. However, Patricia recalled a group she attended that was all women in which she felt like she 'just didn't fit in'. Similarly, Jane reflected on a recent group programme she had attended for neurological psychological impacts of stroke. She suggests that gender was less important to her than circumstance:

> *'It is helpful to meet other people in the same circumstances*
> *to you and actually I felt more in common with the 2 guys in*
> *that.'*

Helping people feel that they fit in and can relate to others in a group may be linked to creating an environment in which people feel able to share personal information. George emphasises why this is important when he says he may not be 'able *to open up about personal things in front of a group of strangers'*.

These results demonstrate that a range of factors can make stroke survivors feel like they could fit in with a self-management group. Age and gender were mentioned most often followed by personal circumstances. In addition, this highlights that some participants may not feel comfortable opening up and 'being themselves' in a group setting if they do not know the people in it.

'A space to share support' explores peer support, the role of family and friends in self-management, and factors that impact whether a stroke survivor would feel they 'fitted in'. A number of benefits of peer support were highlighted and included collective problem solving. The shared education of best practice with carers was also seen as a positive outcome. Finally, participants emphasised the importance of creating a space they would feel comfortable in.

3.3.2 Theme 2: It's not a one size fits all problem

'It's not a one size fits all problem' illustrates the inevitable heterogeneity and variation in long-term needs after stroke that may present in a group self-management intervention. It is made up of three categories: the importance of being individualised, ability to cope emotionally, and when to implement a group self-management intervention.

The importance of being individualised

Eight of the participants discussed the need for a group self-management intervention to be individualised or tailored to the person. Stroke can cause a huge range of residual symptoms and the symptoms themselves may be managed differently by different people.

> *"It depends on how the stroke has affected you. Every stroke is different, so you need to have it tailored to individual need."* Paul

Linda expands on this, stating that when an intervention is tailored to someone it is more relevant to their personal situation. For example, she suggests that the programmecontent should be tailored to different levels of cognition:

> *'I suppose like any group things, if people are different*
> *levels. Erm, if you have a clever kid and a stupid kid, that's*
> *mean but you know what I mean. If you have too many*
> *levels and you teach to many people, then people say, 'it's*
> *not relevant to me''. (Linda)*

Emma talks about the mechanism used to deliver self-management intervention as opposed to the content. She suggests that the delivery mechanism of a group self-management intervention could be tailored to your personality as opposed your post stroke symptoms:

> *'If someone is shy then you would do one-to-one [as opposed to a group]'.*

The importance of having an individualised self-management intervention is clear. Participants said they would be less likely to attend if they felt the self-management intervention is not relevant to them. Perception of relevance may be based on residual stroke symptoms, cognition, or personality.

Ability to cope emotionally – 'Perhaps not everyone can cope'

The ability of each individual to cope with the potential emotional demands of a group self-management intervention was discussed by participants. Some aspects of a group may be emotive such as, discussing experiences of stroke. Five stroke survivors spoke about how they would cope emotionally when hearing and talking about stroke. Thomas reflects on times he has had to hear about stroke, such as in the paper. He says he does not like it as he finds it both 'difficult' and 'distressing' to hear. Other participants expressed concerns at how they would feel attending a group self-management intervention. For example, Liz mentioned attending a group may scare her as she would have a greater insight into the medical factors surrounding stroke. James said he would not want to put himself in a situation in which he might get stressed as he worries it would aggravate his atrial fibrillation. Margaret, whilst more certain about how she might react emotionally, also sees the experience as challenging:

> *"I have found I have got more emotional, I will cry at the*
> *drop of a hat, you know, happy times, or sad times. And*
> *erm, if I had somebody who was in a group who was*
> *reduced to tears I would be too. ….it is not a nice feeling*
> *I suppose."*

The concern that all these participants share is summarised by Ben, who talks about emotional management in relation to group programs:

> *'I suppose the danger with rolling it out to everyone, is*
> *perhaps not everyone can cope. Because it's not very*
> *good news this stuff you are being told.'*

Discussion around how people may cope with the emotional demands of a group self-management intervention emphasised the need for a space in which people feel able to share they are not always coping. It also highlighted the importance of a skilled facilitator to manage complex group dynamics.

When is the right time?

Participants were asked at what time they would have liked a group self-management intervention in their personal stroke journey. Opinion varied but five participants suggested, 'the sooner the better'. Margaret explains why she would like to have access to a group self-management intervention as soon as possible:

> *"Because I felt so down and so…traumatised by the stroke*
> *that I didn't understand why I had it…so I would have liked*
> *someone to have come in and talked to me about it."*

However, other participants felt that the time immediately after their stroke could be too soon:

> *"For the first month of so I don't think I would have*
> *taken it In. For the first month everything was too much*
> *for me."* (Jess)

Ben expressed similar views as Jess:

> *"You need a bit of time to calm down, to err, get a little bit*
> *more empathy to say everybody's different yet we are all*
> *the same."*

The transition home was mentioned by six participants as the time they would like a group self-management intervention to be on offer. This was a time many felt support was lacking:

> *"I would say once [I] got home. I think then would have been*
> *a good time, the third stage, so after the six-weeks of*
> *community rehab. Because that's when we feel it all*
> *disappeared. It all stopped.'(Liz)*

This period is perhaps one of the most important for strengthening self-efficacy as individuals are often starting to do more things for themselves:

> *"It would be best here cos then you've gone from being in*
> *a caring environment and then to being in your own home*
> *or flat, and I moved cos of this yeah, so, (pauses). I think*
> *it would just help people deal with the outside world."*
> *(Patricia)*

Some participants mentioned ways in which they were already self-managing. Paul had his stroke 40 months before the interview; he felt that it was 'too late for him now'. He says this is because he created his own support network earlier on his stroke pathway:

> *"I have got things in place that I do. I have created*
> *strategies that I was taught by [group name] and that.*
> *Different strategies so I did things to remind me and that. I*
> *am also part of different strokes on Facebook and I talk to*
> *loads of other stroke survivors that way as well. I have got*
> *a network from that."*

Although Paul feels it is too late for him to attend a group self-management intervention now, the fact Paul sought out this support through social media suggests that he was seeking this type of support earlier on in his journey. In contrast, others who had their stroke a relatively long time ago said they would still like a group self-management intervention.

As the title of this theme suggests, participants perceived that a 'one size fits all approach' would not be appropriate given the individual needs and experiences of each group member. The right time to implement a self-management intervention varies from person to person, highlighting the range in individual preferences, and the need for an intervention that can be accessed when an individual feels ready.

3.3.3   Theme 3: How's it all going to happen?

The final theme: 'How's it all going to happen?' was identified in discussions about the logistical aspects of a group self-management intervention. The sub themes are (1) course facilitators–who would stroke survivors like to facilitate a group self-management intervention and (2) transport-how will stroke survivors get to a group self-management intervention.

Course Facilitators – 'what do they know?'

Participants suggested facilitators could come from variety of professional backgrounds and have different experiences. For example, some participants suggested practitioners

such as nurses, physiotherapists and counsellors, while others were less enthusiastic about the idea of a health care practitioner, *'what do they know?'* (Ben). The idea of an experienced stroke survivor facilitating a group self-management intervention was seen as a benefit by many participants. Views on this are summed up by Ben who notes, 'they have been me'. In contrast, speaking from her own experiences, Jane says:

> *"Organisationally though for the different stroke things, I do think it would be better if we had somebody non-stroke to help because we do a lot for ourselves but at the same time it is very difficult to organise and remember."*

Henry suggests a combination of both Ben and Jane's ideas:

> *"I think you need both a stroke survivor who can bring really….well. Personal and professional to some extent, a comprehension of what happened. Then a specially trained person could fill in the gaps or put it all in perspective."*

The type of group self-management intervention facilitator that would be acceptable to stroke survivors varies. However, as suggested above a combination of facilitators may satisfy all viewpoints.

Travel to the venue- 'But I haven't even got on the bus yet'.

'Travel to the venue' describes how participant's felt about the practical considerations of getting to a group self-management intervention. Patricia spoke about travelling to a venue as a potential barrier of attendance:

> *"Erm, where it is, you know, it is purely local factors that would determine if people would go…..how easy it is to get to. Transport of course would be a big problem. It can't obviously provide transport as that would be expensive, so it has to use public transport but has to be convenient transport"*

The importance of convenient transport was explained in two ways. Firstly, Jane says travelling any distance after her stroke was difficult as it was 'too tiring'. Secondly, Mukesh highlights the motor difficulties as a result of stroke that make taking public transport particularly difficult.

> *"There is a gym a bus ride away but I haven't even got on the bus yet. I can do a bit of walking but as soon as you go outside the flat, I can walk inside the flat, but as soon as you are outside on uneven pavements, it is a different kettle of fish"*

This final theme, 'How's it all going to happen?' depicts the logistical issues surrounding who could facilitate a group self-management intervention, and the practicalities of how stroke survivors could attend. The skills and experiences needed by a facilitator are complex, but a combination of professional skills and personal stroke experience was important to participants. The importance of holding group self-management interventions somewhere convenient was conveyed by most participants and if people cannot get to the venue easily they may be less likely to attend.

3.4 Discussion

In total 14 stroke survivors were interviewed for this research and three themes were identified from the data: 1), 'A space to share support', 2) 'It's not a one size fits all problem', 3) 'How's it all going to happen?' We found that stroke survivor views were wide-ranging on the relative merits and challenges of a group self-management intervention. In line with previous research, the results suggested that a group self-management intervention may offer stroke survivors a number of benefits, such as, peer support, reduced loneliness and shared problem solving[41,42,111]. There were also a number of contextual issues such as when to implement a group self-management intervention in the stroke recovery pathway.

The findings are in line with previous research which showed stroke survivors acknowledged the benefits afforded from peer support[48,112]. In particular, participants thought that through joint problem solving and empathy that they may feel less alone. However, it is known from previous work that some stroke survivors are reluctant to talk about their stroke in a group self-management setting[48]. This fits with our finding that there is a great significance placed on the trust and relatability between peers, particularly when sharing personal information in a group of strangers. This in turn highlighted the importance of creating a 'safe space' for attendees. One way of doing this is with skilled facilitators who can help manage the group dynamic. Similarly to other studies, this study found that having a peer with the same chronic condition facilitating was viewed positively by attendees[15,47,49].

In addition to group relatability, a stroke survivor's support network can impact their ability to self-management[113]. It is therefore unsurprising that I found participants wanted family and friends to be able to attend a group self-management intervention with them. Previous research evaluating two different group self-management intervention (Living With Stroke, and Moving On After Stroke) found participants felt the presence of family members was beneficial as it helped them understand what it might be like to live with a

stroke[114]. Having the opportunity to attend with and without their family members, and having this flexibility built into the provision of group self-management interventions would be an advantage.

A key area of concern expressed by all participants was surrounding the time to implement a group self-management intervention in a stroke survivor's journey. A previous study investigating perceptions of stroke self-management interventions in the community suggested participants were not ready to manage themselves immediately after post-discharge from hospital[108]. In contrast, our research found some participants saw discharge from hospital as the optimum time for a group self-management intervention. This could be because the ideal time varies from person to person. Delivering a group self-management intervention at the 'wrong' time in an individual's stroke care pathway may be emotionally detrimental to individuals if they are unable to cope with the demands of the program. Therefore, future group self-management interventions may be most effective using self-referral, so each individual can access it when they feel it is the right time in their journey.

Guidelines were followed for the analysis of the data[105], as well as for the design on the study to ensure rigour[107,115]. The description of self-management given to participants was central to the interviews, as were any prior beliefs participants held about self-management. The former was standardised, but the latter could be explored in more depth in future research as this may have influenced the responses. One limitation of this work is that the sample was weighted towards those that had a relatively good level of functional recovery as the study design meant only stroke survivors who could travel to the research venue and had no or very mild aphasia could be included. This is worth considering when designing group self-management interventions as venue accessibility may create an additional exclusion criterion.

The findings of this study contribute to current knowledge about group self-management interventions as a mechanism for providing support. Group self-management interventions were found to be an acceptable format to stroke survivors, and these findings can be used to inform their development. In particular, they offer insight on how create a safe space in which stroke survivors feel comfortable, the impact of the facilitators, the need for self-management interventions to be tailored to the individual, the presence of carers, and the emotional impact of a group self-management intervention.

3.5 Conclusion

Stroke survivors can provide valuable insight and ideas about how the content of group self-management interventions should be constructed and delivered. In particular, the relative merits and challenges involved in creating a space that can increase the reach to more participants and their friends and families. This work, alongside the systematic review presented in chapter four was used to inform the design of a group self-management intervention presented in chapter five.

Chapter Four

4 Chapter four: The key features and role of peer support within group self-management interventions for stroke? A systematic review.

4.1 Introduction

In order to develop a protocol for Bridges when delivered in a group setting, it is vital to have an understanding of what work has already been conducted in the field. At present, the role of peer support within group self-management interventions is understudied and potentially underutilised. The same problem is found when trying to identify the key features of group self-management interventions. Although attempts have been made to isolate the key components of one-to-one self-management interventions, this has not been attempted for group interventions. Therefore, the aim of the current chapter is to conduct a systematic review to 1) determine the key features of group self-management interventions for stroke, and 2) explore the role of peer support in this setting.

4.2 Method

A segregated mixed research synthesis was used to meet the review aims. The methods used for this study can be found on PROSPERO (CRD42016017351) but are also presented below. The review was written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) that are evaluating healthcare interventions to ensure all relevant information was included[116].

4.2.1 Article selection process

The study inclusion criteria were as follows: (1) the intervention was delivered solely in a group setting, (2) the intervention included participants who had suffered one or more strokes (3) participants were aged 18 or over, and (4) the self-management intervention was delivered on more than two consecutive occasions. Studies were excluded if: (1) they were labelled as a pilot, feasibility or a phase one trial as they would have insufficient statistical power to be representative of the wider stroke population, (2) they were unpublished conference literature, (3) they did not specifically mention 'self-management'. A flow chart illustrating the article selection process is shown in figure four.

The search strategy used key terms informed by the aims (e.g. stroke, self-management and group), and was developed using Medical Subject Headings (MeSH) to ensure synonyms were included. Each database was searched from the first available date through to December 2016. The search strategy was used in OvidSP to search EMBASE, AMED and PsychInfo was as follows:*((stroke or strokes or (brain adj3 infarction) or (cerebral adj3 infarction)).ti,ab. or *stroke/ or exp *cerebrovascular accident/ or exp *cerebrovascular accidents/ or *brain infarction/ or *brain stem infarctions/ or *lateral medullary syndrome/ or *cerebral infarction/ or *multi-infarct/ or *infarction, anterior cerebral artery/ or *infarction, middle cerebral artery/ or *infarction, posterior cerebral artery/ or *stroke, lacunar/) and (group or groups).ti,ab. and (("self-management" or "self-care" or "self-treatment").ti,ab. or exp self-care/ or exp self-management/).* As other databases recognise different search terms, a separate search strategy was used in EBSCO to search CINAHL (nursing, allied health, biomedicine, healthcare through Dec 2016, appendix six).

Once duplicate papers were removed using referencing software (Zotero), EC and AM screened the papers independently using the titles and abstracts to determine eligibility. Studies that did not meet the criteria were excluded and the full articles of those remaining were read to determine if they were eligible following the same process as above. Any discrepancies were discussed between EC and AM, with the option to involve the whole research team if required (NW and FJ).

4.2.2 Data extraction

A data extraction template was developed based on the Cochrane Consumers and Communication Review Group's data extraction template[117]. Data were extracted on (1) sample (size, and condition studied) (2) participants (3) the intervention (content, additional materials, frequency, theoretical underpinning, facilitators, delivery mechanism, group size and whether family and friends could attend) and (4) outcomes. The outcomes of interest were the key features of each group self-management intervention being used (e.g. problem solving or goal setting) and qualitative data which could assess the contribution of peer support to the self-management process.

Quantitative outcomes were extracted in the form of P values to indicate significance and confidence intervals (CI, if reported) as well as inferences on clinical significance (based on effect size). Qualitative data were extracted in the form of direct quotes from participants. Information relating to the intervention design was also extracted, including length, frequency, theoretical underpinnings and behaviour change techniques. Where information was missing, studies based on established interventions were assumed to

include the same content. For example, studies using the CDSMP were reported as using the same behaviour change techniques as listed in the original publication[15].

4.2.3 Assessing bias

Studies were assessed for bias using the NICE quality appraisal checklists. Both quantitative (checklist F) and qualitative (checklist H) aspects of intervention studies were assessed. The following items from checklist F were omitted: (i) item 2.4 (were participants or investigators blind to exposure and comparison?), because the nature of self-management interventions makes investigator blinding at delivery impossible, and (ii) items 2.9 (did the intervention or control comparison reflect usual UK practice?) and 2.10 (did the setting reflect usual UK practice?), as none of the studies were conducted in the UK. Each checklist assesses bias across five categories: population, method of selection of exposure or comparison group, outcomes, analysis and internal/external validity. The result is a score that indicates the risk of bias as high (-), moderate (+) or low (++). Two researchers were involved in this process, EC assessed all twelve studies and AM assessed two of the studies. EC and AM drew the same conclusions about the risk of bias for two studies, so no further assessments were made by AM. Publication bias was accounted for by contacting the authors of the included studies and requesting any unpublished data.

4.2.4 Analysis

A segregated mixed research synthesis was used to assess the primary outcomes of interest, the contribution of peer support and the key features of group self-management interventions. Accordingly, the qualitative and quantitative studies were analysed and synthesised separately, and subsequently combined (see Sandelowski et al for more detail)[118]. The quantitative analysis involved frequency counts of the self-management techniques used in each intervention and the reported values for outcomes of interest. Some insight into *clinical* significance can be gained from effect size, and so more weight was given to studies reporting this information when determining the key features of interventions.

Qualitative data were analysed using methods recommended by The Centre for Reviews and Dissemination's guidelines[119]. Thematic analysis was used which ultimately categorises data into key themes[119,104]. The analysis involved highlighting words or phrases that were relevant to the review aims and coding them as follows; a quote such as, 'well, what attracted me was that it was in workshop format as opposed to a lecture format, which I saw as an opportunity to exchange ideas with others'[48] would be coded

as 'sharing ideas' and 'delivery format'. As new data were analysed, previously coded papers were re-examined in an iterative process to enable comparison and further analysis[105]. The process continued until no new codes emerged from the data and 'unique and specific themes' began to emerge[120]. For example, data coded as 'motivation' and 'confidence' contributed to the key theme, vicarious learning. Extracts or quotes were then selected from the coded data to illustrate the themes, creating, "patterns of meaning and issues of potential interest in the data"(pg.15) that address the research question[120].

A segregated mixed research synthesis is acknowledged as a suitable method for exploring complex health services interventions such as a group self-management interventions for stroke[121]. Qualitative and quantitative aspects of the data were synthesised once they had been analysed separately. In keeping with guidance, the findings are not further reduced but are 'organized into a coherent whole' with qualitative work adding detail to quantitative findings[118].

4.3 Results

The most common reasons for study exclusion were: (1) irrelevance, (2) the intervention was not identified as a self-management intervention, or (3) studies were labelled as pilot or feasibility. The study selection process is detailed in figure 4. A total of 12 studies were included (see appendix seven, supplementary table two): Eight were quantitative and all utilised pre-post intervention outcome comparisons, three were qualitative and explored reflections post intervention[13,48,99] and one was mixed methods which utilised both the above techniques to compare two different self-management interventions[114]. Four studies were based in Canada[48,49,99,114], three in Australia[13,50,63], three in America[15,122,123]one in China[47], and one in Hong-Kong[124]. In total, 3298 participants were included across the 12 studies. The length of time post stroke was reported by nine studies[13,15,48,50,99,114,122–124] and ranged from less than three months to 10 years. All studies reported the age of participants with a range of 56 to 89.

Nine of the studies used the CDSMP or an extension of it. All the self-management interventions were delivered in the community and reported the key features used (see appendix seven, supplementary table one). Each qualitative study discussed the extent to which peer support contributed to self-management. All the studies except one[124], either directly mentioned theoretical underpinning, or stated the influencing programme which has a clear theoretical basis (see supplementary table two in appendix seven).

The risk of bias present in each study is indicated in supplementary table two. According to the NICE quality appraisal checklists, all of the studies had good or excellent internal validity rating indicating a low risk of bias.

Figure 4. Article selection process
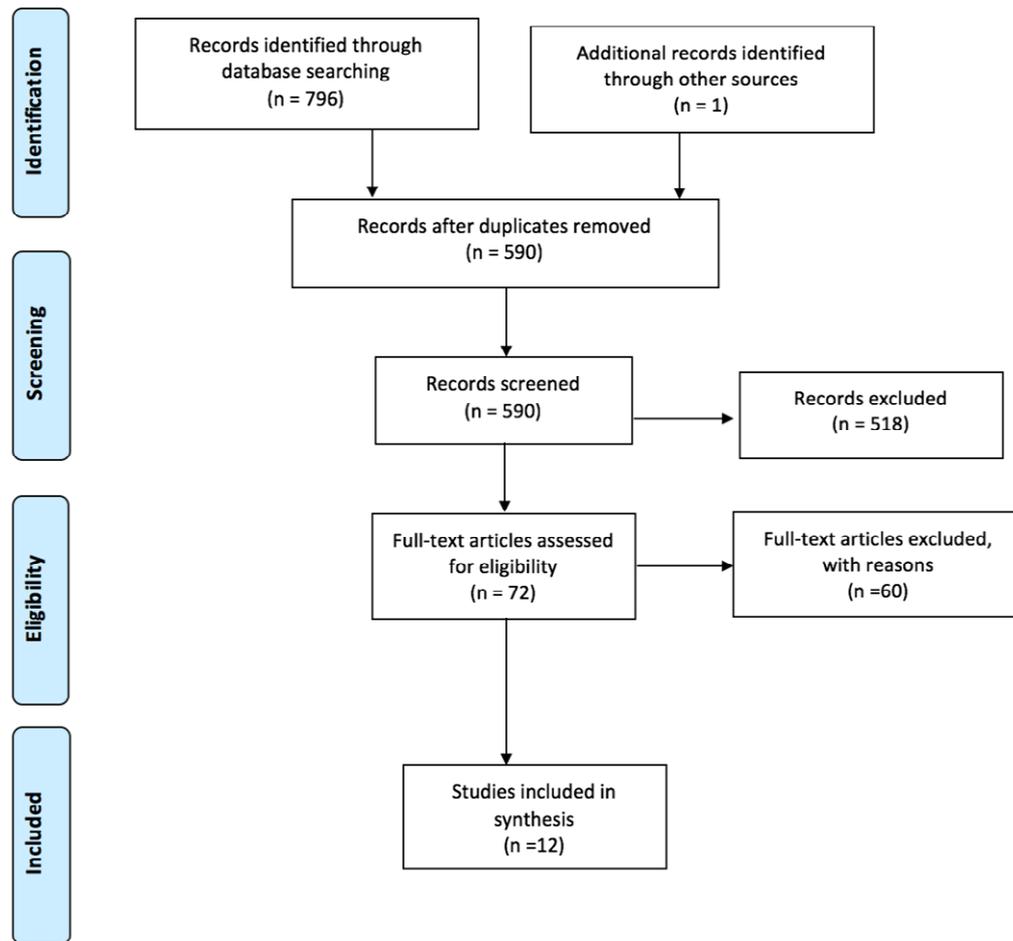
4.3.1 Key features of group self-management interventions

The number of self-management techniques used per intervention was seven with a range of five to nine (see supplementary table one). Frequency counts revealed the most commonly used self-management techniques were education/increasing knowledge which was referenced by nine studies, and collaboration/communication which was referenced by eight. Accessing resources, goal setting and problem solving were each mentioned by five of the studies. Discussing emotional wellbeing and decision making were the techniques used the least and only utilised by three of the studies. Of the studies that reported clinically significant outcomes [47,50,123,124], the most commonly used self-management techniques were increased knowledge which was mentioned by three studies, followed by communication/collaboration and decision making which were mentioned by two studies. The least used self-management techniques for clinically significant studies were the discussion of your future self and discussing emotional wellbeing.

Qualitative data revealed that developing skills in goal setting and how to break these goals down into small steps were important to stroke survivors. Both these techniques were discussed in three of the qualitative studies [13,48,114], for example, "*I think what I got most from the programme was the action plans. For me, I have these great huge goals but I don't ever break them down so I had to think about those kinds of thing'*" (pg.1142)". Enablers echo this sentiment stating the need to, "*break things down into small bits– because if you give yourself a big goal it's too hard, you just don't want to do it*" (pg. 83)[13].

Two of the three qualitative studies discuss the timing of intervention delivery as a key intervention feature. One study suggested a group self-management intervention could fill the gap in care that many stroke survivors experience once they are discharged from hospital[13], whilst the another reported that the majority of stroke survivors thought the group self-management intervention should be available right away*, "If I would have taken the course right away I might have been able to recognise more of those chronic things or seen people that might be having some of the same frustrations*" (pg.1141)[48].

4.3.2   The role of peer support

The role of peer support was explored in all three qualitative studies and the qualitative aspects of the mixed methods study. Four different roles of peer support in a self-management context were discovered: shared experience, social comparison, vicarious learning and mutual gain.

The four studies with qualitative aspects all reference the role that peer support plays in finding a shared experience and creating empathy[13,48,99,114]: "*There are others out there that are the same as yourself and you feel secure in the fact that we all realise what we've been through*" (pg. 83)[13]. The practical side of shared experience is illustrated by one participant who said, "*We're all in the same situation here. If one of us gets stared at, everybody gets stared at. We can all wave at them…*" (pg.514)[114]. Shared experience also helped individuals to, "*not feel so alone in what was going through*" (pg. 1140)[48] which provided emotional comfort.

The second role that peer support played in self-management interventions was to create a platform for social comparison or being able to compare one's self to other group members[13,48,99,114]. Stroke survivors felt that this helped their own ability to problem solve, for example, one stroke survivor said, "*when you talk to other people…you see…how they handle their problems. Yeah, compared to yourself*" (pg.9) [99]. However, it was seen as important that individuals relate to other members of the group, "*I really*

actually think it was very beneficial to put folks who have all had strokes together. It would be harder to relate with people in the group if they had a different chronic condition" (pg.1140)[48]. The importance of relatability was further highlighted by one participant who felt this was lacking in their group: "I*'m in a group with seniors – their concerns and their abilities are different than mine"* (pg.1141)[48]. The findings suggest social comparison was found to be important to stroke survivors, and may be affected by how much peers relate to one another.

The third role of peer support was that it enabled vicarious learning which was referenced by three of the four qualitative studies. Vicarious learning can facilitate feelings of mastery and motivation, "*The woman that was going to knit, you know, her aim was to start her knitting again. And you could see that she was quite pleased with herself. Like quite pleased. I, ah, consider that as a, a motivation for the group. Because they hey, you know, that's really positive [pause] I can, I can feed on that. Good things are happening in my group [pause]. It, it, it builds confidence I guess" (*pg. 9)[99]. Vicarious learning was identified by three studies as increasing motivation and the likelihood of an individual taking action[13,48,99], "*No matter how badly off I am, someone else has difficult challenges too and they can do it so I can too*" (pg.1143)[48].

Finally, the concept of mutual gain was identified by three studies and is the result of the reciprocal nature of peer support[13,48,114]. An individual may 'gain' an increase in confidence through helping others -'giving'[48]. The 'gaining' and 'giving' may also happen independently, for example, one participant described how they had 'gained' from peer support, "*Working with other people makes you see not just their strengths but your own strengths better*" (pg.1143)[48]. Another highlights how they benefitted from 'giving', "*the confidence that comes by knowing that you can actually help other people"* (pg.1143)[48]. Mutual gain is related to the concept of shared experience, as individuals can offer support to one another when faced with a challenging situation[114]. Shared experience, social comparison, vicarious learning and mutual gain represent the different ways in which peer support contributes to the self-management process in a group setting.

4.4 Discussion

The National Clinical Guidelines for stroke (2016) suggest that self-management interventions should be used to better support the long-term needs of stroke survivors[44]. Delivering self-management interventions in a group setting can offer benefits such as shared problem solving and social comparison which are a result of peer support.

However, attempts to implement group interventions on a larger scale are hampered by limited appreciation of the key ingredients of group self-management, and, in particular, by the role that peer support plays (if any).

Twelve studies contributed to the review, all of which were found to be of high quality according to the relevant NICE quality guidelines[125]. The key features of effective group self-management were increased knowledge, communication/collaboration and decision making. This work confirmed previous findings that goal setting and information giving are commonly used self-management techniques[20]. However, there were some differences in these results compared to previous research which identified action planning and homework as the self-management techniques used least in the intervention[20]. This systematic review found that discussing emotional wellbeing and thinking about your future self were used the least. As this review only explored group-based interventions and previous work explored both group and one-to-one interventions this may explain the difference in results. It is also important to point out that while previous work has used statistical significance to indicate an effect, this review incorporated clinical significance which is considered a strength of the work. In future, weight should be given to clinically meaningful effect sizes when assessing health care interventions.

Peer support was found to play an important role in group self-management intervention for stroke as it facilitated shared experience, social comparison, and learning from vicarious experience. All three of these concepts have been identified in previous work by asking what stroke survivors who had not taken part in a group intervention felt the challenges and benefits associated with doing so might be[39]. Peer support also enabled stroke survivors to derive a sense of mutual gain from interactions with peers, which enabled a flat hierarchy of interaction to be created. These findings contrast to the interactions often experienced between patients and health care professionals, even in the context of a self-management setting[62].

A mixed methods synthesis allowed insight into which components were seen as valuable by stroke survivors. The synthesis thus offers insight into some of the challenges that they may be facing in the chronic phases of recovery. The fact survivors valued goal setting and breaking these up into small steps suggests they may experience a difficulty in knowing how to begin their recovery journey. This is in line with previous results from a survey of 2700 stroke survivors, which suggested that individual's 'don't know where to start' when trying to gather information about stroke[8]. Thus future

interventions should focus on offering support that can help stroke survivors feel able to take the first step towards recovery.

It is important to note that while we explored commonly used components of group self-management interventions we cannot infer causation. More work would be needed to further understand whether certain components have a direct impact on outcomes, and to what extent. This is important because it may be that although both knowledge and problem solving are commonly used techniques in self-management interventions, only problem solving is able to cause an increase self-efficacy. It may also be that certain components influence some outcomes but not others, for example, problem solving may increase an individual's self-efficacy whilst the development of communication strategies may influence a stroke survivors' quality of life. It is for this reason that future work should also explore peer support as a potential mechanism of change.

4.4.1 Limitations

A potential limitation of this study was the high level of ambiguity and a lack of detail in the reporting of intervention content. For example, although some studies specified how problem-solving skills should be developed during the intervention, "*problem definition, generation of possible solutions, implementation of a solution, and evaluation of the outcome*" (pg.737)[63], others merely stated, "*facilitators led problem solving sessions specific to action plans*" (pg.1138)[48]. A second example is found for setting small steps or action plans, with some studies offering a lot of detail, "*at the end of each session, participants were asked to make an "action plan" that specified a concrete step they could take to help prevent recurrent stroke. They were encouraged to choose something relevant to what they had learned during the week's session*" (pg.2)[122] and others merely stating the use of, '*weekly action planning and* feedback' (pg.7)[15]. A recently published Template for Intervention Description and Replication (TIDieR) should be used by future work to overcome this problem but we acknowledge this was published after all but one of the included studies[126].

A second limitation is the heterogeneity in both the interventions and outcome measures used, thereby preventing a full meta-analysis from being conducted. However, it is unsurprising that different outcomes are selected when there is such a wide range of effects reported by self-management interventions[20,42,43]. The complex nature of self-management interventions compounds the issue further because as interventions grow in complexity, so does the likelihood of unexpected mechanisms of change occurring.

As a result, researchers are encouraged to use 'a range of measures' to try and capture these mechanisms[24]. The use of mixed methods overcomes this challenge to some extent as it offers a richness of detail which could not have been obtained through a meta-analysis and thus increases the chance that unexpected mechanisms are captured.

A third limitation of the study is that as the search criteria restricted studies to those published in English, the majority of studies were set in western societies which limits how representative the findings are. Finally, none of the studies were conducted in the United Kingdom (UK), so their application to the National Health Service (NHS) is limited.

4.4.2   Future recommendations

Based on the findings of this study, future self-management interventions should maximise peer support if they wish to benefit from shared experiences, social comparison, vicarious learning, and mutual gain. In addition, they should maximise the use of effective self-management techniques including, knowledge, collaboration and decision making. Having an understanding of the factors which underpin effective self-management interventions also offers insight into some of the challenges that stroke survivors are facing in the chronic phases of recovery. The fact survivors valued goal setting and breaking these up into small steps suggests they may experience a difficulty in knowing how and where to start their recovery journey.

Future research should explore whether there any other mechanisms through which peer support can be maximised and ensure future group self-management interventions incorporate the key features identified in this review. In addition, ways to reduce the heterogeneity of content reporting, such as developing comprehensive self-management measures that can capture a range of outcomes, should be explored. Finally, the integration and implementation of group self-management interventions within the UK's NHS should be explored.

4.5   Conclusion

As a result of this systematic review the field now has a better understanding of group self-management interventions for stroke. In particular, the active ingredients of group self-management interventions, greater knowledge of the contribution of peer support and access to the first synthesis of both quantitative and qualitative evidence. The remainder of this thesis should therefore design a self-management intervention that maximises peer support. In turn, the intervention may facilitate shared experiences,

social comparison, vicarious learning, and mutual gain for the stroke survivors who attend. Doing so will strengthen the existing knowledge base on group self-management interventions by exploring what one would look like, and whether or not it would be feasible to implement.

Chapter Five

5 Chapter Five: Development of the Intervention Protocol

This chapter is based on the following publication: Clark, E., Ward, N. S., Baio, G. & Jones, F. Research protocol: investigating the feasibility of a group self-management intervention for stroke (the GUSTO study). *Pilot Feasibility Stud.* **4,** 31 (2018).

5.1 Development of the intervention

A summary of how the development phase contributed to the resulting group self-management intervention is presented in table two below.

Table 2. Summary of how the intervention was developed using insight from a variety of sources

Information Source	More information presented in section (page number):	Influence on the final intervention protocol (not the research design).
Bridges Self-Management team	2.3.1 (45)	• Confirmation Social Cognition Theory was the most appropriate theory to use as the intervention's foundations. • All nine of the core Bridges principles should be included in the group adaptation of the intervention • Three people should facilitate the intervention (stroke survivor, speech and language therapist and a self-management practitioner) • A 15-minute ice breaker was suggested at the start of each session • The intervention should be able to adapt to the context to enable it to be tailored • Friends/family/carers should be able to attend the group
Management Panel (Multidiscipline team)	2.3.6 (47)	• A management strategy for disruptive participants was discussed.
Stroke survivor focus groups	2.3.3 (46)	• Each session would last two hours with a 25-minute break in the middle • There should be a designated social time at the start of each session (also suggested by the Bridges team) • The information sheet was re-written with greater emphasis on the reciprocal nature of relationships that the group may offer after stroke survivors stressed the importance of this

		• Self-management should be defined at the start of the session
Stroke Survivor interviews (chapter three)	3 (55)	• The intervention must remain tailored to each individual • It is important that carers/family friends can attend the intervention as they also play a role in the management of stroke • Ways to facilitate peer support, in particular, the sharing of experiences and problem solving should be maximised. • Some participants may find the intervention emotional and facilitators should be mindful of this • A stroke survivor should co-facilitate the intervention • The group venue must be accessible for stroke survivors and local if possible
Systematic Review (Chapter four)	4 (74)	• Peer support should be maximised to facilitate shared experiences, social comparison vicarious learning, and mutual gain • Knowledge, collaboration and decision making should be incorporated in the intervention

5.2 Resulting Protocol

The novel intervention is described in table three using headings suggested by the Template for Intervention Description and Replication (TiDieR) guidelines[127]. Samples of the pages from the Bridges workbook used in the intervention are found in appendix one. In addition, three factors that relate to the protocol design are discussed below: group size, core concepts of the intervention, and adverse events.

5.2.1 Group size

There is differing literature on suggested group size. The Chronic Disease Self-management Programme has 10-15[15] participants in each group whereas psycho education groups use five to ten[128]. For this group self-management intervention, the group size will be conservative, five-eight stroke survivors. This accounts for the complex nature of stroke. For example, those with aphasia may require the use of additional communication techniques. In addition, family and friends are welcome to attend the sessions which may increase group size.

5.2.2 Core concepts of the intervention

Nine strategies used within Bridges will be translated into a group setting, all of which are used to increase self-efficacy as the intervention is grounded in SCT: reflection, knowledge, decision making, problem solving, goal setting, taking action, using

resources, collaboration and self-discovery. These strategies link together and can be iterative in nature. For example, an individual's goal may be to walk more (setting goals) as they do so less than they used to (reflection), someone else may suggest walking a dog may make the task more enjoyable and recommend a charity that needs dog walkers (collaboration, knowledge, problem solving, using resources). The individual may then decide to go to the charity to sort this out (taking action, decision making). The outcome of this behaviour will then inform future decisions (reflection, mastery, taking action, goal setting). An example of how these core concepts would be integrated into a session plan is illustrated in appendix eight.

Table 3. Intervention protocol reported in line with TiDieR guidelines

Name	Group self-management intervention for stroke
Why (rationale)	To increase self-efficacy and in turn self-management behaviours.
What (materials)	Stroke survivors will receive a user held Bridges workbook which they can take away with them and work through at their own pace. It was designed with stroke survivors and has been reviewed by a communications charity. Family and friends will receive a Bridges carer's booklet containing information about self-management, stories from families living with stroke, the five top tips for supporting target setting and finally, resources and contacts. In addition, flip chart paper, post-it notes, and pens may be needed to capture discussions and facilitate communication with aphasic individuals.
Procedures	Participants are sent the workbook up to two-weeks prior to the intervention and called one to two days before each session to check if they are attending. The session content aims to incorporate the Bridges principles over the four-weeks (reflection, decision making, problem solving, taking action, collaboration, knowledge, goal setting, access to resources, self-discovery). Facilitators should attend Bridges training before session delivery which is one full day followed by a half day a few months later. The first day aims to help individuals build, evaluate and sustain a self-management approach with a focus on person-centred care. The second day allows individuals to reflect on their new practices, enabling the sharing of ideas and collective problem solving, as well as refreshing individuals on the core principles.
Who provided	Each group should have the same three facilitators for each session. One stroke survivor, who will provide empathy and insight as they have experienced a stroke themselves. One speech and language therapist who will provide self-management support and expertise in communication difficulties such as aphasia. Finally, one facilitator trained in Bridges providing self-management support.
How (delivery)	Face-to-face in a group setting.
Where	The intervention will be run in community venues that are convenient for those attending.
When and how much	A four-part intervention running once a week for four-weeks. Each session lasts two hours and includes a break in the middle.

Tailoring	The intervention is tailored to the individual. For example, through individual goal setting. In addition, discussion topics are participant led ensuring they are relevant to those involved.
Modifications	Although there are clear time frames and content listed in the session plans, they are meant as a guideline and thus should be used flexibly in practice. For example, the order of events may vary, and some aspects may be adapted to fit different contexts.
How well (fidelity)	Observations of the intervention will be carried out which will be cross-referenced to the core principles of Bridges and the original session plan. This will enable an assessment of fidelity to the intervention protocol.

5.2.3 Adverse events

As there are no adverse events reported from the Bridges one-to-one intervention or other stroke specific group self-management interventions reported in the literature this study is considered minimal risk. However, severe events may still occur such as a death due to natural disease progression and older age. In addition, the research is at the feasibility stage so unexpected risks may occur. As a result, any adverse events will be documented, and the ethics committee notified. If any patients have clinically relevant scores, for example, the HADS shows severe anxiety and/or depression, we will notify their GP (with their consent).

5.3 Conclusion

In conclusion, the development phase resulted in the protocol for a four-week group self-management intervention based on Bridges. The intervention was developed to be two hours long, and run once a week, with a stroke survivor and two self-management practitioners facilitating. The intervention was underpinned by Social Cognition Theory and the core concepts of Bridges. Once the development phase was complete, the thesis progressed to the second research phase: Implementation.

Implementation Phase

The second phase of my PhD is the implementation phase. It explores whether the newly designed group self-management intervention can be delivered as intended, as this is an essential part of assessing feasibility[24]. A process evaluation was conducted which answered questions three (can a group self-management intervention be implemented in practice?) and four (what mechanisms of change are occurring within the intervention?). A number of sub-questions relating to recruitment and fidelity are also addressed.

6 Chapter six: Process evaluation

6.1 Introduction

Many complex interventions are effective in research settings, yet only half are translated into practice[2] . There are two main reasons for this. Firstly, if interventions fail to produce the desired effect in a clinical setting, they are often disregarded. However, many trials fail to gather the information needed to determine if the failure was due to poor implementation or the intervention itself. An example of this comes from a large trial that found no significant effects of a one-to-one self-management intervention. As the study did not gather information about the implementation process, an additional study was required to determine the reasons for failure[51]. The latter is costly in both time and money. Secondly, stakeholders such as commissioners and policy makers often lack the necessary information to inform policy and practice. According to the Oxford Implementation Index, a description alone will not enable the successful implementation of an intervention, an understanding of the processes at work is also needed[3]. For example, *how, why* and *for whom* is an intervention working (or not).

A process evaluation can offer insight into how an intervention is being delivered, the mechanisms of change at work, and the impact of the delivery contex[5]. The Medical Research Council (MRC) published guidelines for researchers conducting process evaluations, which suggests such work should take place in the feasibility phase[5], as this allows scope to change and adapt the design as necessary. A process evaluation conducted in later stages-such as a fully powered randomised controlled trial-offers researchers minimal scope to deviate from protocol without undermining the study.

One theoretical framework for process evaluations focussing on complex interventions is called Normalisation Process Theory (NPT). The theory was developed for use with complex health interventions to facilitate novel practices becoming 'normalised'[31,129,130]. The theory identifies four areas for consideration (1) meaning and sense making by participants (2) collective action (the work individuals have to do to make the intervention function) (3) reflective monitoring (participants reflect on and/or appraise the intervention) and (4) cognitive participation (commitment and engagement by participants). Cognitive participation, reflective monitoring and coherence all have overlap with the MRC guidelines and could be explored during the feasibility stage of research. However, collective action may not be fully explored in a research setting as the pressures on staff are not the same as in a clinical setting.

Both NPT and the MRC offer guidelines on best practice and agree a clearly defined protocol is essential when implementing a complex intervention such as group self-management: If an intervention does not make sense to those delivering or experiencing an intervention, then it is unlikely to be used in the future[6]. Although NPT does not offer guidance on what a 'good' protocol might contain, the MRC suggest they should be underpinned by a theoretical framework and logic model as these illustrate which causal mechanisms are expected to occur[4].

Once the protocol and logic models are established, MRC guidelines suggest the necessary information is captured during intervention delivery to enable evaluation of the processes in question. Guidance on which concepts could be explored in a process evaluation can be found in two process evaluation frameworks: The first suggests four concepts are explored, "process evaluators should collect data to determine the context (including documentation of recruitment efforts), the reach, the dose (delivered and received), and the fidelity of the intervention" (pg. 15)[7]. The second suggests two additional concepts should be explored, adaptation to context (was the intervention delivered as intended?) and the exploration of unintended consequences (what behaviour change has occurred and how did individuals respond?)[8].

Exploring the above concepts in a process evaluation would help avoid group self-management intervention losing fidelity from research to practice by identifying potential barriers to implementation. For example, previous work exploring the implementation of a one-to-one self-management intervention found that a lack of congruence in goal setting and practitioners feeling they did not have enough time were both challenges that would need to be overcome if such interventions were to be successfully implemented in the future[9,10].

The aim of this thesis is to assess the feasibility of delivering a one-to-one self-management intervention in a group setting. As self-management evolves to incorporate a wide number of innovative delivery mechanisms, so too may the associated implementation challenges and processes. At present, it is unknown if after this adaptation there will still be a "link between theoretical constructs thought to be essential for intervention success and the final study outcomes" (pg. 2)[7].

As delivering Bridges in a group setting is a new concept, there has been no previous research exploring the potential implementation issues or the processes at work behind the scenes. Therefore, a process evaluation will be conducted to explore: recruitment, reach, attendance, adherence, fidelity, context and adaptation, unexpected mechanisms of change and acceptability[5–8].

The specific research questions addressed in the process evaluation were:

1. What is the feasibility of recruiting the sample size in a given time period?
2. Who will be recruited and will block randomisation provide statistically similar demographics across the intervention and control group?
3. What will the levels of adherence and attendance to the intervention be?
4. Is the intervention being delivered as intended (fidelity)?
5. To what extent is the intervention adapted to context?
6. What mechanisms of change are occurring within the intervention?
7. Is the intervention design acceptable to stroke survivors?

6.2 Method

The full method is presented in chapter two. Data contributing to the process evaluation were gathered between February 2016 and April 2017. The process evaluation was conducted in line with MRC guidelines[5] and used a segregated mixed methods approach meaning qualitative and quantitative data were analysed separately[4]. Details about the intervention and associated logic model are presented first, followed by the methods used to answer each individual research question.

6.2.1 Intervention

A detailed description of the intervention is reported in chapter five. Briefly, the intervention aims to increase self-efficacy through supporting stroke survivors to self-manage using a range of strategies including: problem-solving, goal setting, self-discovery and reflection. The intervention comprised of two-hour sessions over four consecutive weeks. Each participant received their own Bridges workbook containing information about stroke and self-management techniques which could be used during the sessions. The intervention was delivered in three community settings across central and north London (a town library, a youth centre, and an educational building). Three facilitators delivered the intervention, EC (thesis author) who is a trainee health psychologist and trained self-management practitioner, a speech and language therapist (ZH or HT) and a stroke survivor (BM, PS or MM). Each group was attended by between four and eight stroke survivors.

6.2.2 Logic model

In order to document the causal assumptions underlying the intervention, a logic model for the intervention is depicted in figure five as recommended by MRC guidelines[5]. The

logic model illustrates the intervention journey from the problem the intervention will address to the outcomes that are expected to occur as a result of the intervention.

Figure 5. Logic model for the Bridges self-management intervention

Problem

Stroke survivors only receive ongoing care for a short time after they are discharged home . Subsequently, many feel abandoned and are left with unmet needs.

Evidence base

| One review suggests SMIs can improve quality of life, self-efficacy, self-care and clinical outcomes for a variety of chronic conditions including stroke[8]. | The National Clinical Guidelines for Stroke (UK) suggest unmet needs may be reduced by providing access to self-management interventions[9]. | It is feasible to deliver Bridges on a one-to-one basis to stroke survivors[10] |

Inputs

| Self-management intervention for two hours a week over four-weeks. | Three facilitators: two trained in Bridges one stroke survivor. | The Bridges workbook, a community venue, paper pens, refreshments. |

Activities

| Bridges training for facilitators | Facilitated self-management techniques e.g. problem solving and reflection with the support of the Bridges workbooks. | Baseline and outcome measures collected |

Short-term outcomes

| Trained facilitaors demonstrate competence in using self-management tools in a group setting | No additional inputs are needed to deliver the intervention | Stroke survivors engage with self-management tools which in turn builds self-efficacy |

Long-term outcomes

Increased self-efficacy, quality of life, and activities of daily living, reduced anxiety and depression.

6.2.3   Methods used to answer each research question

6.2.3.1 Question one: What is the feasibility of recruiting the sample size in a given time period?

The first question was answered by recruitment rates and reasons for exclusion that were documented in the recruitment logs kept throughout the entire enrolment period (February 2015- October 2016). The mean recruitment rate was calculated by tallying how many participants were recruited overall and dividing this by the total number of months. Reasons for exclusion were calculated using frequency counts to enable any patterns to be determined.

6.2.3.2 Question two: Who will be recruited and will block randomisation provide statistically similar demographics across the intervention and control group?

In order to answer the second research question, a range of demographics were collected for each participant: age, gender, ethnicity, time post stroke, comorbidity, aphasia, living situation, initial stroke severity and employment status. For those who participated in the intervention, age and time post stroke were calculated based on the first intervention session. For those who did not participate in the intervention, age and time post stroke were calculated based on the date of study enrolment. Data on mood, self-efficacy, activities of daily living and quality of life were also obtained at baseline using the following measurements: the Hospital Anxiety and Depression scale (HADS), Stroke Self-Efficacy Scale (SSES), Stroke and Aphasia Quality of Life scale (SAQOL-39), and Nottingham Activities of Daily Living Scale (NEADL). Significant differences at baseline between the intervention and waitlist control group, as well as those who took part in the intervention and those who did not, were assessed for using independent T-tests when data were continuous (time post stroke, age, the National Institute of Health Stroke Scale (NIHSS) score, HADS, SSES, SAQOL-39 and NEADL). Levene's test was used to assess for equal variance. Chi square tests were used to enable between group comparisons for nominal data (gender, ethnicity, living situation, employment and co-morbidity).

6.2.3.3 Question three: What will be the levels of adherence and attendance to the intervention?

In order to answer the third research question, a register of attendance was taken for both participants and facilitators. The attendance rate was determined by the number of individual sessions attended as part of the intervention and analysed using frequency counts and associated percentages. For example, 100% attendance would be achieved

by attending all four sessions and 50% by attending two out of four. Adherence to research activity was determined using two data sources. Firstly, the proportion of outcome measures each individual completed. A full list of outcomes is described in chapter two but in brief, participants completed four outcomes which explored mood, activities of daily living, quality of life and self-efficacy. They were collected at four time points, the start and end of the intervention and at two-weeks follow up, plus either the start of the waitlist period (control group only) or six-months post intervention (intervention group). Secondly, whether the outcome measures were completed within a month of the date they were due was calculated: to do so, outcomes collected at the end of the intervention, two-weeks and six-months following the intervention were assessed. Baseline measures were excluded as they had no required completion date. Individuals who withdrew from the study were excluded from calculations.

6.2.3.4 Question four: Is the intervention being delivered as intended (fidelity)?

Six out of eight group interventions (two, three, four, six, seven and eight) were recorded using either a Dictaphone or a live transcription completed by a research assistant (KE) to enable the fourth research question to be answered. The groups that were audio recorded were subsequently transcribed by a research assistant (KE). The first and fifth group were not recorded or transcribed due to a lack of resources. Fidelity was assessed by an independent researcher (KE) using an established fidelity checklist. Piloted in previous work, the checklist was found to be feasible for use in research exploring the implementation of self-management interventions[130]. The checklist enables behaviours and activities occurring as part of the intervention to be recorded against the core Bridges techniques. For example, '*B shared that he contacted a charity to come and support him to get on the bus*', would be recorded as taking action, and, *'A asks the group how they walk around without the use of a specific arm….M demonstrates her walking to the group'*, would be recorded as problem-solving. In keeping with complexity theorists, who argue complex interventions are greater than the sum of their parts[5], the groups were analysed as a whole (as opposed to individual sessions). Frequency counts were used to measure how often (if at all) each unique technique was used per group. A second researcher (EC) then coded a subset of these (10%) to ensure accuracy. If discrepancies arose, an agreement was sought through discussion between KE and EC, with the option to involve the wider research team (NW and FJ) if needed.

Exploring fidelity also involves assessing whether the proposed plan for recruiting stroke survivors can be implemented as intended. The initial stroke survivor facilitator (BM) was recruited through Bridges, and from there it was proposed that an iterative model of recruitment be used. For example, a stroke survivor who had taken part in a group may

wish to become a facilitator themselves. In order to test this model, the number of participants who subsequently went on to become a facilitator was documented using frequency counts.

6.2.3.5 Question five: To what extent is the intervention adapted to context?

In order to answer the fifth research question, and capture whether any adaptations to context had occurred during the intervention delivery two techniques were used. Firstly, documenting any changes to session plans enabled deviation from the intended delivery to be highlighted. Secondly by examining the recordings made during the sessions information about the context that an adaptation occurred within was provided. Literature suggests adaptations can be defined as either 'innovative'-when the adaptation is not intentional but necessary to create a better fit to context- or 'drift'-when facilitators have to intentionally adapt the intervention in reaction to barriers[131]. Accordingly, EC used the session plans and recordings to code adaptation as either 'innovation' or drift'. An example of how adaptations were coded follows: 'Order of the content was changed to follow a natural flow of conversation' would be coded as 'innovation', whereas, 'it was suggested individuals work in pairs as one person was dominating the conversation' would be coded as 'drift'. The frequencies that 'drift' and 'innovation' occurred were tallied up per group to give insight into the extent each group had been adapted to context. The mean average for incidences of innovation and drift per group was then calculated.

6.2.3.6 Question six: Are there any unexpected mechanisms of change occurring as a result of the intervention?

In order to answer the sixth research question and identify whether any unexpected (those not specified in the protocol) behaviour change techniques (BCTs) occurred, a research assistant (KE) analysed recordings and transcripts of each intervention group. The analysis was based on the widely used behaviour change taxonomy[132] which provides descriptions of 93 BCTs[7]. KE coded all the recordings using the taxonomy and then a second researcher (EC) reviewed 20% of these to determine agreement. Verification of 20% or more was used to determine if a second coder was needed as advised in similar health care audits[133]. If discrepancies arose, and could not be resolved between EC and KE, there was the option to involve the whole research team (NW and FJ). If unexpected mechanisms of change were identified, frequency counts were used to determine which techniques were used the most and mean scores to determine the average prevalence.

6.2.3.7 Question seven: Is the intervention design acceptable to stroke survivors?

The current process evaluation answered the final research question by focussing on aspects of acceptability relating to design: group size, the number of sessions and their length. Two data sources were used to determine this, mind maps that were completed in the last session of the intervention, and interviews which were conducted after the intervention was completed.

Mind Maps

At the end of the last intervention session, stroke survivors were asked to give feedback about the intervention's acceptability using two open ended questions designed to maximise the likelihood of participants giving honest answers that were not led by the researcher: 'what are your wishes for the group?' And 'what could we do differently, if anything?'. The questions were written on a mind map and participants were encouraged to add as many ideas as they liked. The mind maps were coded by EC as follows: Answers relating to the length of sessions were assessed first and each answer coded as 'happy as it is', 'would like them to be longer' or 'would like them to be shorter'. The first answer would indicate that the length of the sessions was acceptable to the participant whereas the latter two suggest adaptations could be made to increase acceptability. The same coding format was followed for each theme (e.g. group size and number of sessions). Frequency counts were used to determine the number of participants in each category and percentages were subsequently calculated.

Interviews

A detailed account of the methodology underpinning the post intervention interviews can be found in chapter eight. Briefly, a sub-section of those who took part in the group self-management interventions were selected using purposeful sampling to capture a range of demographics (see table ten in chapter seven)[134]. Participants were interviewed in the space they felt most comfortable (for example, their own house or a University building). In order to minimise bias, an independent researcher not previously associated with the project conducted the interviews (SR). Semi-structured topic guides (see appendix 9) were used to gather data about experiences of the groups, and whether participants had any feedback. Questions asked included, 'do you have any wishes for the group?' And 'If so, what are they? 'All the interviews were recorded using a Dictaphone. The interviews were analysed using thematic analysis, and a subset coded by two researchers (EC and FJ, more detail in chapter eight). Data were coded and combined to form sub-themes and ultimately key themes relating the acceptability of the research

design. Once the themes were identified by EC, the second researcher (FJ) reviewed them against one transcript to ensure that they were reflective of the data source.

6.3 Results

Each research question is answered in chronological order below.

6.3.1 What is the feasibility of recruiting the sample size in a given time period?

A total of 60 participants were recruited over a nine-month period (February to October 2016) with a mean average of 6.6 per month. The number of individuals approached at the start of the study, reasons for exclusion and the numbers of participants retained at each stage of the research is illustrated in a CONSORT diagram in figure two. The most common reason for exclusion was being unable to contact individuals on the permission to contact register (N=171, 42.53%): of these 33 individuals had the incorrect contact details listed, six were missing contact details, and 132 did not respond to correspondence which was attempted through three different methods: post, email and telephone. The second biggest reason for exclusion was individuals declining to participate (N=111, 27.61%): of these, 28 were not interested in the work, 24 declined but gave no reason, 19 were too unwell, 12 were too busy, 11 did not want to take part in research, 10 felt the distance was too far to travel, and seven felt the time commitment was too large.

6.3.2 Who will be recruited and will block randomisation provide statistically similar demographics across the intervention and control group?

Table four shows the demographic details of those who took part in the research compared to the general stroke population. Independent T-tests revealed no significant differences at baseline between the intervention and control group for age, scores on any of the outcome measures (HADS, SSES, NEADLS, and the SAQOL-39), gender, comorbidity, aphasia, ethnicity or living situation. A significant difference was found between these groups for time post stroke, with those randomised to the intervention group having less time post stroke than the waitlist control group. Chi Square tests revealed no significant relationship between employment status, living situation, ethnicity, gender, aphasia, co-morbidity and the intervention condition.

Comparisons using independent T-tests were also made between those who completed the intervention and those who did not. The former showed no significant difference between age, scores on any of the outcome measures (HADS, SSES, NEADLS, and the

SAQOL-39), gender, comorbidity, aphasia or ethnicity. However, there was a significant difference in time post stroke, with those who completed the intervention later post stroke. Chi Square tests showed no significant relationships between employment status, ethnicity, gender, aphasia, and co-morbidity. However, they did find a significant relationship between living situation and whether participants completed the intervention or not, with those living with one or more others being more likely to complete the intervention. For reference table four shows the demographics by group.

Table 4. Demographics by self-management group.

Group	N	Mean age (SD)	Mean NIHSS score (SD)	Mean time post stroke (SD)	Comorbidity		Gender		Aphasia		Employment status				Living situation		Ethnicity
					Yes	No	Female	Male	yes	No	Employed	Retired	Un-employed	Volunteer	Alone	With 1+ others	
1	7	64.14 (11.35)	2.86 (2.19)	13.43 (6.60)	5	2	5	2	1	6	1	2	4	0	4	3	White N=5 Black=2
2	5	66.60 (4.28)	7.60 (8.50)	16.40 (12.93)	4	1	0	5	0	5	1	1	3	0	2	2	White N=5
3	5	67.80 (8.23)	4.75 (5.12)	16.80 (9.15)	5	0	1	4	0	5	0	2	2	1	0	5	White N=5
4	7	68.71 (11.32)	4.50 (7.23)	13.57 (12.80)	5	2	4	3	1	6	0	6	1	0	2	5	White N=5 Black=1 Dual Heritage=1
5	5	62.80 (18.21)	7.00 (2.31)	39.00 (20.53)	2	3	3	2	0	5	0	3	2	0	2	2	White N=2 Black N=2
6	6	71.33 (17.49)	3.40 (3.44)	27.00 (10.71)	5	1	1	5	0	6	2	4	0	0	1	4	White N=6
7	4	60.75 (8.06)	4.00 (2.65)	23.50 (11.15)	1	3	2	2	0	4	2	2	0	0	1	3	White N=4
8	6	69.83 (8.23)	5.50 (4.93)	13.33 (4.13)	5	1	3	3	0	6	0	4	2	0	3	3	White = 5 Rather not say N=1

Note: Missing values are as follows. Group 2 has 1 missing value for living situation, and 2 for ethnicity. Group 5 has one missing value for living situation and 1 for ethnicity. Group 6 has one missing value for living situation.

Table 5. Sample demographics compared to general stroke population

Demographic		Sample					General stroke population SSNAP data [12] N>1.2 million %	Significance difference between: 1.completed SMI v no SMI 2.intervention v waitlist control (independent t-test)
		Whole sample N=60	Completed intervention N=47	Did not complete intervention N=13	Intervention group (N=30)	Waitlist control (N=30)		
Months post Stroke: Mean (SD) Missing		18 (13.49) 0	20.17 (13.6) 0	10.15 (10) 0	12.6 (8.78) 0	23.4 (15.25) 0	N/A	1.t(58)=2.47, p=0.02* 2.t(58)=-3.36, p=0.001*
Average age: Mean (SD)		67.25 (10.87)	66.9 (11.48)	68.53 (8.53)	68.53 (8.79)	65.97 (12.63)	77	1.t(58)=-0.48, p=0.63 2.t(58)=.913, p=0.37
NIHSS score N (%)	0	6 (10)	5 (10.64)	1 (7.69)	3 (10)	2 (6.7)	6.8	1.t(53)=0.43, p=0.66 2.t(53)=-1.02, p=0.31
	1-4	29 (48.3)	21 (44.68)	8 (61.5)	18 (60)	12 (40)	41.7	
	5-15	18 (30)	14 (29.79)	4 (30.77)	9 (30)	12 (40)	35.3	
	16-20	2 (3.3)	2 (4.23)	0	1 (3.3)	1 (3.3)	7.4	
	21-42	0	0	0	0	0	8.7	
	Missing	5 (8.3)	5 (10.64)	0	2 (6.7)	3 (10)		
Employment status N (%)	Employed	9 (15)	6 (12.6)	3 (23.1)	3 (10)	6 (20)	Not reported as a whole but (44% <65 return to work[10135])	1.X^2(4, N=59)=3.61, p=0.46 2.X^2(4,N=59)=3.66, p=0.46
	Retired	35 (58.3)	27 (57.4)	8 (61.5)	17 (56.7)	18 (60)		
	Unemployed	14 (23.2)	13 (27.7)	1 (2.1)	9 (30)	5 (16.7)		
	Volunteers	1 (1.7)	1 (2.1)	0	1 (3.3)	0		
	Missing	1 (1.67)	0	1 (2.1)	0	1 (3.3)		

Living situation N (%)	Alone	23 (38.3)	16 (34)	7 (53.8)	13 (43.3)	10 (33.3)	25	1. X^2(1,N=51)=6.9, p≤0.01*
	With 1+	28 (46.7)	27 (57.4)	1 (7.7)	14 (46.7)	14 (46.7)	75	
	Missing	9 (15)	4 (8.5)	5 (38.5)	3 (!0)	24 (80)		2. X^2(1, N=51)=.22, p=0.64
Gender N (%)	Male	37 (61.7)	29 (61.7)	8 (61.5)	18 (60)	11 (36.7)	51.1	1. X^2(1,N=60)=0, p=0.99
	Female	23 (38)	18 (38.3)	5 (38.5))	12 (40)	19 (63.3)	48.9	2. X^2(1,N=60)=.71, p=0.79
Co-morbidity N (%)	Yes (1+)	40 (66.7)	34 (72.3)	6 (46.2)	21 (70)	19 (63.3)	73.6	1. X^2(1,N=60)=3.14, p=0.76
	No	20 (33.3)	13 (27.7)	7 (53.8)	9 (30)	11 (36.7)	27.4	2. X^2(1,N=60)=.3, p=0.58
Aphasic N (%)	Yes	5 (8.33)	4 (8.51)	1 (7.7)	3 (10)	2 (6.7)	35[13]	1. X^2(1,N=60)=2.53, p=0.62
	No	55 (91.67)	43 (91.49)	12 (92.3)	27 (90)	28 (93.3.)	65	2. X^2(1,N=60)=0.35, p=0.55
Ethnicity N (%)	Asian	2 (3.3)	2 (4.3)	0	1 (3.3)	1 (3.3)	Not reported	1. X^2(5,N=60)=6.79, p=0.24
	Black	5 (8.3)	5 (10.6)	0	2 (6.7)	3 (10)	25.6[14]	
	Dual heritage	2 (3.3)	1 (2.1)	1 (7.7))	2 (6.7)	0	Not reported	2. X^2(5,N=60)=4.22, p=0.52
	White	49 (81.7)	38 (80.9)	11 (84.6)	25 (83.3)	24 (80)	65.9[14]	
	Other	0	0	1 (7.7)	0	1 (3.)		
	Not-stated	1 (1.7)	1 (2.1)	0	0	1 (3.3)		
Hospital anxiety and depression scale (max 42 with lower score desirable) average score	0.85 (0.5) 34 (56%) of sample showed signs of depression and/or anxiety	0.83 (0.48)	0.97 (0.59)	1.02 (0.55)	0.69 (0.40)	1/2 experience anxiety [15] 1/3 experience depression [16]	t(58)=-0.88, p=0.38 t(58)=2.63, p=0.01*

Stroke self-efficacy scale (max 130, higher score desirable) mean average score (SD)	78.24 (16.4)	79.54 (16.18)	73.53 (16.96)	75.12 (17.1)	81.30 (15.35)	Not reported	t(58)=1.17, p=0.25 t(58)=-1.46, p=0.32
Nottingham activities of daily living scale (max score for mean average is 4, higher score desirable) mean average score (SD)	3.34 (0.6)	3.37 (0.63)	3.26 (0.51)	3.26 (0.6)	3.44 (0.6)	Not reported	t(58)=0.57, p=0.31 t(58)=-1.17, p=0.25
Stroke and aphasia quality of life scale mean average score (max score for mean average is 5, higher score desirable) mean average score (SD)	3.92 (0.75)	3.90 (0.75)	3.97 (0.76)	3.76 (0.76)	4.08 (0.71)	Not reported	t(58)=-.271, p=0.6 t(58)=-1.12, p=0.1

6.3.3   What will be levels of adherence and attendance?

Of the 60 participants who enrolled in the study, 47 (78.33%) stroke survivors took part in the intervention. Seven did not attend any aspects of the intervention, and six dropped out after the first session. The reasons for withdrawal are detailed in figure two. Of the 47 who remained, 42 (89.36%) attended all four of the sessions, four (8.51%) attended three, and two people (4.26%) attended two of the sessions. Overall adherence to the intervention was high.

The waitlist control and intervention group each had to complete four sets of measures: at baseline, the end of six-month waitlist (control group only), the end of the intervention, two-weeks post intervention, and at six-months post intervention (intervention group only). In total, 43 of the 47participants (91.49%) completed the measures at all the required time points, and four participants (8.51%) completed the measures at three out of four-time points. Of the 184 sets of measures returned, 176 (95.65%) measures were returned within a month of their due date, 5 (2.72%) in under two-months, and 3 (1.63%) were returned over two-months past the date they were due to be returned.

For the time points that both groups completed outcome measures- the start of intervention (end of the waitlist period for the control group), end of intervention and two-weeks follow up- the intervention group completed 100% (N=30), 76.7% (N=23) and 80% (N=24) respectively, and the control group 100% (N=30), 76.7% (N=23) and 73.3% (N=22). No significant differences were found for questionnaire return rate between intervention or control group at the end of intervention-t(58)=0, p=0.5, or two-weeks follow up-t(58)=0.6, p=0.55.

The measures that were completed after the last session of the intervention took between 10 and 25 minutes to complete depending on communication disorders and how much talking was occurring. Some participants did comment on how long they took to complete, in particular, the SAQOL-39 measure as this was more than double the length of the other questionnaires and the compact layout made it more difficult to complete. One participant who gave written feedback (appendix 10) disliked the SAQOL-39, stating it was the most 'irritating' measure to complete as it did not acknowledge context. She also felt '*frustrated by being asked to complete questionnaires that seem either outdated or not relevant to my own experience of stroke*. For example, "*the HADS Q12 [I have lost interest in my appearance], assumes that I used to be interested in my appearance. I do not think this is the case*". The feedback also offers ways that the NEADL could be improved with the addition of a fifth category, 'with help with difficulty'.

6.3.4   Is the intervention being delivered as intended (fidelity)?

Fidelity checklists were completed for six out of the eight intervention groups. Due to a lack of resources such as staffing and time constraints no fidelity assessments were completed for groups one or five. No discrepancies were found between the first (KE) and second researchers (EC) interpretations of the behaviours in relation to the core self-management techniques. Table six illustrates which techniques were utilised by which intervention group. The maximum number of techniques depicted in the checklist was nine (problem solving, decision making, reflection, collaboration, taking action, goal setting, knowledge, self-discovery and accessing resources). The average number of techniques used was 8.625 with a range of 8-9. Decision making was the technique used least as two of the six groups did not use this technique directly. However, the skill may have been developed indirectly through problem solving or collaboration. The remaining techniques were used by every group, with the exception of collaboration which was not utilised by group eight. As with decision making, it should be considered that collaboration may actually be inherent to some of the other techniques when delivered in a group setting, for example, collectively problem solving may include collaboration. However, for the purpose of this process evaluation, collaboration was only considered utilised when participants specifically discussed how they could work with health care professionals, family and friends or peers to achieve desired outcomes. Based on these results, the interventions were deemed to have high fidelity to the protocol.

The fidelity to protocol for the recruitment of stroke facilitators was also assessed. The intervention provided an iterative model for recruitment. Once an individual had taken part in the intervention they would have the opportunity to become a facilitator for future groups. Two participants subsequently became co-facilitators, both were female, MM was aged 57 and 14 months post stroke and PS was 58 and 24 months post stroke. PS had moderate aphasia at the point of facilitation and took part in the first intervention group ever run. She then went on to facilitate groups two, three and five. MM took part in the third group and subsequently facilitated groups six and seven. Each of the facilitators had made it known that they wanted to be involved with future groups when they took part in the study themselves. They were recruited after an informal discussion with EC about what their role and responsibilities would be as a co-facilitator. A previously recruited stroke survivor (BM) facilitated groups one, four and eight who was identified by Bridges.

Table 6. Illustration of which Bridges techniques were used in intervention groups 2,3,4,6,7 and 8.

Group number	Bridges Techniques								
	Reflection	*Taking action*	*Problem solving*	*Decision making*	*Goal setting*	*Self-discovery*	*Collaboration*	*Knowledge*	*Accessing resources*
2	✓	✓	✓	✓	✓	✓	✓	✓	✓
3	✓	✓	✓	*X*	✓	✓	✓	✓	✓
4	✓	✓	✓	✓	✓	✓	✓	✓	✓
6	✓	✓	✓	*X*	✓	✓	✓	✓	✓
7	✓	✓	✓	✓	✓	✓	✓	✓	✓
8	✓	✓	✓	✓	✓	✓	*X*	✓	✓

6.3.5   To what extent is the intervention adapted to context?

Groups two, three, four, six, seven and eight were included in the adaptation to context assessment. Reasons for the exclusion of groups one and five are listed above (section 6.3.4). Table seven shows the raw data and whether it was coded as innovation or drift (see section 3.2.3.4 in method for definitions). At least one of the four session plans per group was adapted to context, and all six groups had examples of both drift and innovation. The mean average of innovation was 2.16 per group and 2.33 per group for drift which is seen as low. The most common reasons for innovation were that time was running out and because of the group dynamics. The momentum of group conversation was the most common reason for drift occurring.

6.3.6   Are there any unexpected mechanisms of change occurring as a result of the intervention?

Six intervention groups had the necessary data required for KE to assess for any unexpected mechanisms of change using the behaviour change taxonomy (BCT) checklist: groups two, three, four, six, seven and eight. Group one and five did not have sufficient data gathered to allow the assessment to go ahead for reasons listed previously (section 6.3.4). As expected some items on the BCT had overlap with the Bridges techniques, for example, 1.4 action planning, 1.1 goal setting and 1.5 review behaviour goal were identified as being in line with taking action, goal setting and reflection/problem solving respectively. Thus, these BCTS were not included in the analysis as they were 'expected'. All the groups analysed had unexpected mechanisms of change occur within them. In total, 21 unexpected mechanisms of change were identified. A full list of the BCTs identified during each group and the frequency that each technique occurred can be found in appendix 11. Table eight presents the five most commonly used BCTs. The top three techniques were behavioural contracts, social support and commitment.

6.3.7   Is the intervention design acceptable to stroke survivors?

Information from mind maps which explored the acceptability of the intervention design were captured at the end of the intervention for six of the eight groups. An example is shown in figure six. Groups three and six did not have the data gathered due to time constraints. Four of the six groups gave answers about the size of the group. Three of the groups (75%) said they were happy with the size of the intervention group despite having different numbers of attendees: Group one had eight stroke survivors in it, group seven had four, and group eight had six. Group five which had five stroke survivors in said they would like a larger group size of eight to ten. The number of sessions was

mentioned by five of the six groups. Having four sessions was deemed too short by all five groups (100%). Four of these groups (80%) suggested that a follow-up group session could be run three to six-months after the group ends, and one (20%) stated a preference for six sessions as opposed to four. Three groups discussed the length of each session, and they unanimously (100%) requested longer sessions than two hours, with group one suggesting three hours may be better.

Table 7. Codes and raw data for innovation and drift

Group	Innovation	Source: Plan (P), Recording (R)	N	Drift	Source: Plan (P), Recording (R)	N
2	One question was added into s3instead of session four: 'How will you know that this group has been useful to you?' Pair work was suggested as some individuals were facing similar challenges, e.g. difficulty sleeping. There was much discussion among participants after the break in session three about what stroke as opposed to what small steps for the week ahead may be.	P R R	4	Pair work suggested, but people stated a preference for group work when problem-solving, so group work was done. As making concrete goals was challenging for some, the group was asked 'what will you take from this group into the week ahead?' as opposed to, 'what one small step will you do next week?' Discussion in session four began with a discussion on progress instead of reflections on the past week as this was what participants were engaging with. Time shortage meant the q, 'what would you like to remind yourself in six-months' time?' was missed.	R R R P	4
3	Extended the first half of the session as participants had so much to say.	P	1	Discussions around stroke experience happened after the break in session 2 so no time to focus on the concepts of small steps -this could be done next week. As we had a shortened second half, participants were not asked, 'how the groups could be improved/if any opportunities were missed'.	R P	2
4	Group asked to write goals down in the book as the group is very chatty and some have mentioned memory impairment.	R	1	More personalised and targeted questions used as one participant finding it hard to get their voice heard. Flip chart used alongside discussion as one participant is hard of hearing.	R R	2
6	Extended the first half of session four as the discussion was flowing. Discussions around what the researchers hope to get from the project in session four were had.	R R	2	After the break in session one, we encouraged individuals to work individually in the workbook to ensure focus as opposed to the general discussion re future hopes.	P P	4

				Ran out of time in session three and four so didn't ask 'how will you know if this group will be successful?'	R	
				Didn't introduce the workbook until session two but should have been in session one as ran out of time.	R	
				No time to ask, 'what would you like to tell yourself in 6months time?' in session four.		
7	Did not ask the group, what does progress mean to you?' as the discussion was around keeping going and progress in general.	R	2	Didn't ask the group, 'what would your wishes for the group be?' in session four as ran out of time.	P	1
	Small group, so no pair work as discussion naturally became a group conversation.	R				
8	A lot of emotion in s1, so the first half was extended.	R	3	After a minor disagreement within the group, the importance of individual approaches is emphasised in session four.	R	1
	Due to time restraints, there was no discussion around, 'next week is the last week so how will you know if this group has been useful? Said as the end comment instead.	R				
	Introductions got off topic, and so the first half ran over to allow each person to have their say.	R				

Table 8. The five most commonly used unexpected behaviour change techniques used across all six intervention groups. Based on UCLs behaviour change taxonomy checklist.

Behaviour change technique	Frequency
Behavioural contract	17
Social support	15
Commitment	14
Social comparison	6
Restructuring the environment	5

Figure 6. Example of a mind map from group seven session four.
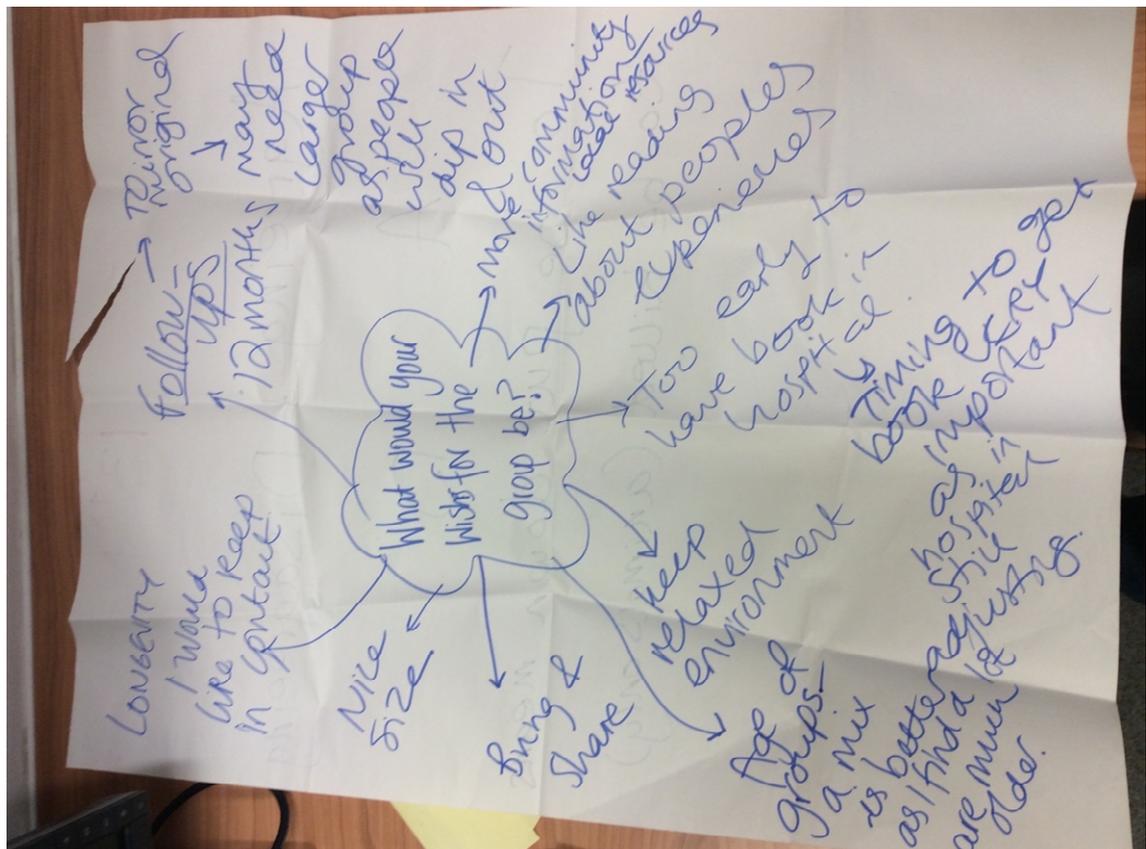
Interviews

Participant demographic details are found in chapter seven in table nine. A detailed account of the method is also presented in chapter seven, section 7.2. Briefly, interviews from 11 stroke survivors were analysed thematically and four key themes were identified in relation to the acceptability of the intervention design: 1. The right time to deliver a group self-management intervention, 2. Bridges workbook, 3. The length of the intervention and 4. Follow up sessions. Each are discussed in turn below.

1.The right time to deliver a group self-management intervention: Seven of the eleven participants felt the intervention was delivered at the right time, despite being at different times post stroke (time post stroke ranging from 1-64 months), *'I think it was right at the right time, I really do, it was as I said like a Godsend in a way, you know….the timing was absolutely spot on, well for me anyway'* (P8- 1 month post stroke). Three of the seven (time post stroke 1, 13 and 38 months) explained why they felt it was the right time, with all agreeing delivering the intervention any sooner would not have been appropriate, *'the time was right because I think there was too much going on like my recovery and the learning process, too much there…and then to go to a group would*

have been too much to take in' (P4). In contrast, P2 and P11 (time post stroke 30 and 37 respectively) suggested that the groups could be run earlier as, '*for me it was probably too late to [attend] the groups because I have made a recovery. I've been through the process. I believe [the right time to be] if somebody was early in to having a stroke*' (P11). Participant 12 suggested that stroke survivors may get something different from the group at the different stages, but that you could always learn from the group,

> '*What oneself would have seen going through [the group], would have been different at different points…you know, you experience it at a particular point with a particular attitude towards your stroke, with a particular amount of knowledge about your stroke, and then you learn things-interim-whatever level you-of understanding of your stroke, of yourself. Whatever you go in as, you come out as different…Generally, that would be the case whether it was three-months after or whether it was a year, 18 months after.*'

2. The Bridges workbook: Six out of eleven participants made reference to the work book that was used as a springboard during the sessions. Two were aphasic and while one said she couldn't read or focus on the workbook, for the other it had become linked to their goal to learn to read, '*I still open it…one day I will read it properly,*' (P1). Three mentioned that the workbook was useful but each for a different reason: One used the workbook as a guide, while another liked being able to write things down as, '*to actually write something down-I sat and wrote my thoughts down which I've never done before and that helped*' (P4). One participant used the workbook but thought having it earlier on in the stroke journey would have been better, '*for someone like me who's at the end of it [stroke], it's, it's not appropriate, but for someone right at the beginning it is, and it gives them those steps to, to help' (P11).* Two participants said they no longer use the book, one had misplaced it and the other said, '*I've got it over there, it's in my cupboard there, (Interviewer: and do you use it?), I look at it sometimes, but not all the time because I forget about it*' (P2).

3. Length of the Intervention: Seven participants spoke about the length of the intervention, and one made reference to the length of the individual sessions. Six suggested that the group to be longer, one stroke survivor's wish was '*that they last longer yeah you know, because as I say I found them very helpful, very encouraging yeah and I looked forward …to going there every week*' (P11). Another participant wanted them to be longer as they felt*, 'people were just getting into what it was about*

when it stopped' (P1). Only two made suggestions for how much longer it should be with one suggesting 10-weeks and the other five or six. Similarly to the findings from the mind maps above, one participant suggested the sessions themselves could be longer than two hours, while another stated, '*Oh the length of the session…was fine you know because I mean there is a limit to the amount you can have with people that you don't know'*. When asked if they would change anything about the groups including the length of the sessions, one individual stated, '*No, I thought it was just perfect'*.

4. Follow up: Of the 11 interviewees, four spoke about wanting a follow up session, *'Everybody said, you know, because Ella said, anybody got any suggestions for future? And I said, 'why can't we all meet up again, say in six-months' time or something like that?''* (P3). One group still meets up once a month and although not every individual goes, one participant who does said*, 'well if every group did that then it'd be marvellous'* (P1). The reasons for wanting a follow up were similar, *'[to] find out, you know, where everyone has you know, how far they've come since we met would be nice you know'* (P8).

6.4 Discussion

The current chapter presented the findings from a process evaluation exploring the Bridges self-management intervention for stroke delivered in a group setting. This is the first process evaluation to explore adaptation to context and any expected or unexpected mechanisms of change within a group self-management setting. The process evaluation used a mixed methods approach to capture data as recommended by the MRC guidelines for complex interventions[4].

6.4.1 Recruitment

Results showed it was feasible to recruit 60 stroke survivors recruited over a nine-month period. However, those with aphasia were under represented. This is a problem which many self-management interventions report[136], and ways to engage under-represented groups to take part in future research should be considered carefully. One option would be to expand recruitment to primary care as well as acute settings. This may enable participants whose aphasia was too severe in the acute phase for them to engage with the intervention at a later date when it is hoped their aphasia would have improved. In practice this may mean having multiple points of access to such interventions. Another option would be to ensure all potential participants have the opportunity for someone

else to express an interest of their behalf, and consent to being contacted in future when they may have improved.

Previous research evaluating Bridges in a one-to-one setting found high levels of measure completion, with 90% of participants in the intervention group and 79% in the control group completing all the required outcomes in a timely manner[12]. The current study found marginally higher levels of measure completion when combining return rates from the intervention and control groups. Results showed 91.45% of participants returned the measures within a month of their due date[130]. The results are similar despite differences in methodological approaches. The current study uses postal measures to collect data whereas the previous work sent researchers to individual's homes. These results suggest that postal methods offered marginally higher retention rates than home visits. Future research should thus consider postal outcomes as a data collection approach. However, those with aphasia and limb weakness may require additional support to complete the measures.

Reasons given for withdrawal were ill health and research burden which is similar to the reasons given in previous research that explored the one-to-one Bridges intervention[130]. The current work also reported other commitments as a barrier to participation which previous work did not. One explanation for this difference may be that current work was delivered in a community setting once stroke survivors were discharged from NHS care. In contrast, the previous work was delivered in the community but as part of standard NHS care. It may be that stroke survivors expected to spend more time committing to rehabilitation activities prior to discharge and thus were more willing to prioritise them over other commitments.

6.4.2 Intervention fidelity

Overall Bridges was deemed to have good fidelity to protocol when delivered in a one-to-one setting[18], and the current study confirms fidelity is still present when Bridges is delivered in a group. It is important to note that complete fidelity may not be possible, as adaptations are inevitable when delivering complex interventions in the real world settings[19]. This process evaluation revealed that adaptations occurred in every intervention group that was run as part of this study in order to better fit the context. For example, when participants were particularly emotional more time was allowed to discuss these feelings. It is not possible to compare the reasons for adaptation with

previous studies exploring stroke self-management as no similar work has been conducted. However, the results are as expected for complex interventions in general[4].

6.4.3 Unexpected mechanism of change

Similarly to the above, there is no previous work exploring whether unexpected mechanisms of change occur during one-to-one or group self-management interventions for stroke. However, as hypothesised in the literature[24], unexpected mechanisms of change were found in all of the intervention groups examined. Therefore, the logic model presented in the methodology of this chapter should be updated in future work to incorporate these. In keeping with the MRC guidelines, future work should explore unexpected mechanisms of change and use the Behaviour Change Taxonomy to do so. This would help researchers distinguish which effects are the result of the intervention, and which may be due to other behaviour change techniques.

6.4.4 Acceptability

The process evaluation explored the acceptability of the intervention design. A previous process evaluation of a chronic disease self-management intervention which consisted of five, two-hour sessions and had groups of six to eight found that 74% of participants were happy with the size of the group and 72% were satisfied with the number of sessions[21]. Similarly, the current study found 75% were happy with the group size, but in contrast, that 100% of those who completed mind maps wanted more sessions. The results may be explained by the fact the current intervention had four sessions while the chronic disease intervention had five.

Acceptability of the workbooks used alongside the intervention was also explored. In line with previous work exploring the feasibility of Bridges in a one-to-one setting, the workbook was seen as acceptable by the majority of participants but was not accessible to all the stroke survivors with communication impairments such as aphasia[46,130]. It is important to remember that Bridges designed the work book to offer a structure to self-management interventions but not to be a standalone tool, as the work book can actually be viewed as a 'limiting factor'[21]. For example, as the workbook is not accessible to those with aphasia, professionals may gate keep, preventing individuals from taking part if they cannot engage with the work book[130]. The current work suggests those who cannot engage with the workbook can still engage with a group self-management intervention. However, had they been given the workbook alone they would not have been able to

engage with the intervention, supporting the widely held view that a workbook alone is not enough[21,23].

6.4.5   When is the right time to deliver the intervention?

Finally, when the right time to deliver a group self-management intervention might be was explored. The current work had no unanimous conclusion relating to when this may be, and neither did previous research which asked stroke survivors to imagine when the right time for a group self-management intervention may be[39]. Previous work has highlighted the importance of timing of self-management interventions for stroke, but the 'right' time is heterogeneous[17]. It remains a point of discussion that perhaps time post stroke is not the right way to determine the ideal delivery point, and perhaps 'point in stroke journey' may be better. The latter has implications for how individuals may access such a service in future, with an 'opt in' access route as opposed to referral being one way to accommodate for these different preferences.

6.4.6   Limitations

The generalisability of the process evaluation is limited due to the differences in demographics between the sample in this research and the general UK stroke population, for example, 5% of the current sample had aphasia, but 35% of the general population do. In order to overcome this, an effort was made to capture the views of those with aphasia, for example, purposive sampling ensured that at least one individual with aphasia was included in the post intervention interviews so their experience could be captured.

Secondly, adaptation can be difficult to capture objectively, and there is limited methodological guidance on how to do so. Therefore, determining whether adaptations are beneficial, and tailored to each unique context, or resulting in poor fidelity to the protocol is a widely acknowledged challenge[24], and compounded by limited resources. For example, only one researcher coded data for innovation or drift. Finally, there were a number of limitations associated with the interviews, but these are discussed in full in chapter eight.

6.4.7   Future work

From a methodological perspective, clear instructions on how to achieve an objective interpretation of adaptation to context should be developed. It is currently unclear how many adaptations would be detrimental to a complex intervention and the thresholds for

high and low levels. The perspectives of the facilitators are important when exploring the implementation of complex interventions[4], but they were not captured here. Future work should explore the reflections of all three facilitators (stroke survivors, self-management practitioners and the speech and language therapist), and their views on what worked and what did not during the intervention delivery. Capturing the views of stroke facilitators is especially important in light of the current drive to involve more service users in research[77].

6.5 Conclusion

The current chapter presents the first process evaluation of Bridges when delivered in a group setting. The intervention was found to be feasible regarding recruitment, attendance, adherence, and fidelity in community settings within the context of research. A number of unexpected mechanisms of change were identified, and the intervention was found to adapt to context on multiple occasions. Now that the development and implementation phases have been completed, the next and final phase presented this thesis is the evaluation phase.

Evaluation phase

Questions five, six and seven were all answered during the evaluation phase (How acceptable to stroke survivors is it to deliver Bridges in a group setting? How acceptable to family/friends/carers is it to deliver Bridges in a group setting? Does the intervention have any preliminary effect on stroke survivor's quality of life, mood, activities of daily living, or self-efficacy?).

The evaluation phase ran from May 2017 to February 2018 and involved conducting three research studies: 1. A qualitative exploration of stroke survivor experiences of the novel group intervention (chapter seven). 2. A qualitative exploration of the experiences of family/friends and carers during the group intervention (chapter eight). 3. Preliminary quantitative analysis of four outcome measures exploring mood, quality of life, self-efficacy, and activities of daily living (chapter nine).

Chapter Seven

7 Chapter seven: A qualitative exploration of stroke survivor experiences of the novel group self-management intervention.

This chapter presents findings from interviews to explore experiences of stroke survivors who took part in the group self-management intervention.

7.1 Introduction

The MRC state assessing acceptability and mechanisms of change is vital to the success of complex interventions[24]. The MRC guidelines for process evaluations suggest one way to understand acceptability is by interviewing the target population[65]. Capturing service user perspectives during the feasibility stage of research helps to ensure research is considered useful by the target population, offers insights that can improve research protocols, and finally, can add credibility to future research proposals making them more likely to get funded[137,138].

While including the perspectives of the target population can offer numerous benefits to researchers, there are some challenges reported. For example, researchers not wanting to relinquish control over their research[139]. One way to overcome this is to embed service users in research from the start so that that they are part of the work as opposed to an add-on. This could be facilitated by inviting service users to be members of a management panel or by conducting qualitative work such as one-to-one interviews[24,65]. One example of this comes from "A Stop Smoking in Schools Trial" (ASSIST) which used post-intervention interviews as an evaluation tool[140]. The findings revealed that not only were participants willing to discuss which aspects of the intervention worked (or not), but they offered invaluable ideas on how it could be improved. The latter were subsequently incorporated in the protocol. This is particularly important when exploring feasibility work as the intervention is still at a stage of development in which suggested changes can be incorporated. In addition, one-to-one interviews may be particularly useful when the topics discussed may be sensitive (such as stroke) or where people may not wish to upset already established group dynamics by saying something they feel others may not like[65].

The second example comes from a complex intervention which aimed to increase exercise uptake in Wales[141]. The expected mechanisms of change were goal setting and motivational interviewing, but the study found service users also valued empathy and a sense of shared understanding between peers when trying to increase their exercise levels. Therefore, both the latter were identified as being acceptable parts of the intervention *and* unexpected mechanisms of change that helped increase exercise uptake. The group self-management intervention explored in this thesis is based on social cognition theory, and as a result, the expected mechanism of change is self-efficacy[33]. However, additional and unexpected mechanisms of change may also occur. These are unlikely to be captured by quantitative outcome measures[24], but could be identified through interviews with the target population.

The idea of a group self-management intervention was explored using semi-structured interviews as reported in chapter three. The findings suggest the concept of group self-management in general was acceptable to stroke survivors. Specifically, stroke survivors felt that groups might offer a shared space for problem-solving and a chance to meet others in the same position as themselves. However, there was concern that a group may be a 'one size fits all' solution to the complex and unique challenges that stroke survivors have to face. The interviews also revealed concerns about who would facilitate the groups and where they would be located. Critically, participants in the study had not previously taken part in a group self-management intervention, so the findings are only speculative[9]. As a result, it is important to gain insights from participants who have attended the intervention to further explore acceptability and mechanisms of change.

The aim of this chapter is to explore the experiences of stroke survivors who took part in a group self-management intervention in order to again insight into 1) the acceptability of the intervention with the target population and 2) the possible mechanisms of change that may be contributing to the intervention effects.

7.2 Method

Post-intervention interviews were used to explore the acceptability and possible mechanisms of change that may be occurring during the group self-management intervention for stroke. The study design was informed by the MRC guidelines for complex interventions[24] and the COnsolidated criteria for REporting Qualitative research (COREQ)[106]. Recruitment, interviews and analysis were conducted over a five-month

period (March 2017-July 2017) and occurred iteratively following established guidelines[119,120].

7.2.1   Recruitment

Participants recruited for the current study were a sub-set of the larger GUSTO sample, and details of the recruitment process and inclusion/exclusion criteria are presented in chapter two. Purposive sampling was used for the non-random recruitment of individuals to the current study from a pool of the 47 participants. The process involved selecting individuals with certain demographics that, based on prior knowledge, are thought to offer a "different or important perspective on the phenomenon in question"(Pg. 32)[142]. In the current study, these were age, ethnicity, gender, living situation, aphasia, time post-stroke, initial stroke severity, research condition (intervention or wait-list), which intervention group they took part in and whether participants were accompanied by a carer to the group.

Stroke survivors were asked to take part by a researcher not previously associated with the project (SR) to minimise participants feeling obliged to take part. Each participant was approached using their preferred method of contact as stated when previously recruited to the larger GUSTO trial (e.g. telephone). Those approached were assured taking part was voluntary, that they did not have to take part, and that their decision would not affect their standard of care within the NHS in any way. If anyone declined the reasons for this were documented so that any patterns could be identified. Recruitment finished only once data saturation was reached as this approach enhances the rigour of research[119,120].

7.2.2   Interviews

Interviews were conducted by a speech and language therapist (SR). SR has experience working with stroke survivors in a research setting and had no previous connection to the GUSTO research project. SR minimised the risk of an observer effect and, maximised the ability for participants with mild to moderate aphasia to take part. Semi-structured interviews enabled SR to explore topics using different communication strategies to aid understanding, and the informal style made it easier to build rapport with participants[143]. The interviews took place where the stroke survivor felt most comfortable, it was expected that the majority of interviews would be held in participants' homes. Each participant was given the opportunity to have someone else present during

the interview if he or she wished, and each interview was recorded using a Dictaphone before being transcribed verbatim.

7.2.2.1 Topic Guide

A semi-structured topic guide (appendix 9) was developed for this study by EC and FJ using guidelines for interviews in a health research context[104,105]. Similarly to previous research[9], the topics covered in the transcript were informed by previous research and questions associated to the feasibility of complex interventions, such as participant experiences, and intervention delivery. For example, Satink et al.'s[108] work and subsequently, Clark et al.'s (chapter three) had explored when a self-management intervention for stroke could be delivered. Thus, a question about the timelines of the interventions delivery was incorporated.

The topic guide explored stroke survivor experiences over four topics, (1) the stroke itself (2) the intervention (3) what happened after the intervention had ended and (4) the research. The first part was designed to ask questions that built rapport with the individual and gave context to the interview. For example, can you tell me about your experience of stroke? The second part related to the group self-management intervention and explored when in their stroke journey the individual took part and what being in a group with other stroke survivors was like. For example, how has the group (if at all) had an effect on you? The third part focussed on what happened once the intervention was finished, in particular, whether there had been any effects of the group and also whether there may be longevity to these effects. For example, if you were having difficulty with something, what would you do now? Is that different to what you would have done before the group? The interview ended with questions exploring experiences of taking part in the research, for example, how did you feel being randomised to a condition? In line with guidelines from the World Health Organisation, the interviewer could change the order of questions and topics if they felt it was appropriate[143].

7.2.3   Data analysis

Inductive thematic analysis was used which has been recommended for preliminary health care research when variations in the data need to be explored[35,36]. An inductive approach was used to ensure the themes identified were 'strongly linked to the data themselves' and to minimise fitting the data into 'a pre-existing coding frame'[144].

Accordingly, six iterative phases were involved in the analysis; 'familiarizing yourself with your data', 'generating initial codes', 'searching for themes', 'reviewing themes', 'defining and naming themes', and 'producing the report'[144]. When searching for themes, researchers gather codes together to see potential themes that are emerging, and then these are reviewed in relation to the entire data set (reviewing themes). An example of a code would be, 'ongoing social support', which could be combined with other codes (e.g. shared problem solving and social comparison) to form the theme, 'reciprocity. The sixth and final phase –producing the report-is the final chance for analysis, and involves the selection of 'compelling extract examples' which illustrate the themes. Themes should "capture something important about the overall research question" (pg. 10)[144].

7.3 Results

7.3.1 Sample

Thirteen participants were interviewed, and a table of their demographic background data are shown in table nine. Chapter six, table five, shows national levels of these demographics in the UK stroke population for comparison. 11 of the 13 interviews were used in the analysis as two were unusable due to a technical fault mentioned previously. Included participants had a mean age of 63.73 (with a range of 39-82), and a mean time post stroke of 26 months (with a range of 1-64). Three had aphasia, one mildly and two moderately. Of the eight intervention groups implemented, seven were represented by a participant. Group eight was not represented due to the technological faults as mentioned previously. All participants took part in the intervention, but those in the control group experienced a six-month waiting period before hand.

During all 13 interviews, only the interviewer (SR) and the participant were present. The interviews lasted between 31 and 73 minutes with a mean of 49.97 (see table nine). Everyone who was approached to take part in the study did so. One participant asked to postpone for a few months until a more convenient time, and the interview was conducted three months after the initial invitation was sent.

Table 9. Demographics of participants who were interviewed post-intervention

ID	Age	Ethnicity	Gender	Living situation	Aphasia	Time post stroke (months)	NIHSS score at onset	Research condition	Group	Included in analysis	Time since Intervention (months)	Length of interview
1	58	White Irish	F	Living with daughter	Moderate	24	6	Intervention	1	Yes	11	64.43
2	56	Indian	M	Alone	No	30	2	Intervention	1	Yes	11	32.11
3	69	White British	M	Alone	No	11	2	Intervention	2	Yes	8	57.45
4	74	White British	F	Alone	No	13	2	Intervention	3	Yes	6	42.40
5	75	White British	M	With partner	Mild	64	6	Intervention	3	Yes	6	36.21
6	47	White British	F	With partner	Moderate	30	NA	Intervention	4	Yes	5	31.48
7	82	White British	M	With partner	No	29	1	Intervention	4	Yes	7	64.31
8	65	Not given	F	With Partner	No	1	1	Intervention	4	Yes	5	60.00
9	70	White British	F	With partner	No	38	NA	Control	5	Yes	3	56.27
10	77	Italian	M	With partner	Moderate	35	0	Control	5	No	3	53.53
11	39	White British	M	With partner and children	No	37	NA	Control	6	Yes	4	28.36
12	66	White British	M	With partner	No	9	5	Control	7	Yes	2	73.13
13	67	Guyanese	F	With partner	No	22	19	Control	8	No	1	NA

7.3.2 Themes

The aims of the interviews were to explore the experiences of stroke survivors who took part in a group self-management intervention in order to again insight into 1) the acceptability of the intervention with the target population and 2) the possible mechanisms of change that may be contributing to the intervention effects. Four key themes were identified following analysis of data, (1) an ongoing journey (2) carrying on under your own steam (3) everyone is different and (4) reciprocity. An example of how key themes were formed from individual codes is presented in figure seven. Each of these themes are discussed in turn below.

7.3.2.1 An ongoing journey

The first theme, 'an ongoing journey' was illustrated in nine of the eleven interviews. It details how participants felt their recovery was an ongoing process. There are two sub-themes, firstly, 'imagining a future' which describes how individuals had started to think about the next part of their journey (or not), and secondly, 'small steps' which represents a possible mechanism they could use to get there.

Imagining a future

During the groups individuals reported they had begun to think about the future, '*Before I attended the group I didn't really have any aim, I just sort of well, just sort of sit here and not think about anything you know, but they've given me the incentive to want to get on with things'* (P4). Similarly, P8 said, '*It taught me so much really and gave me a vision of where to go.*' One participant credits others in the group for enabling them to start to think about the next phase of their recovery and reports a shift in perspective, '*What I liked about your- about the group discussion was that I actually started thinking about the future, and I realised that* what *had been sort of – well revulsion really at the situation I would be in, it's now sort of changed to acceptance'* (P7).

One participant said they did not like to think about their future, but unlike the previous examples, attending the group did not resolve this for them. In contrast, the group was seen to keep the individual busy, so they did not have to think about their future, '*what does the future hold? That's scary, and so I try not to consciously think about it all the time because…it would be very depressing'* (P9).

Figure 7. Breakdown of how the theme 'journey' was formed
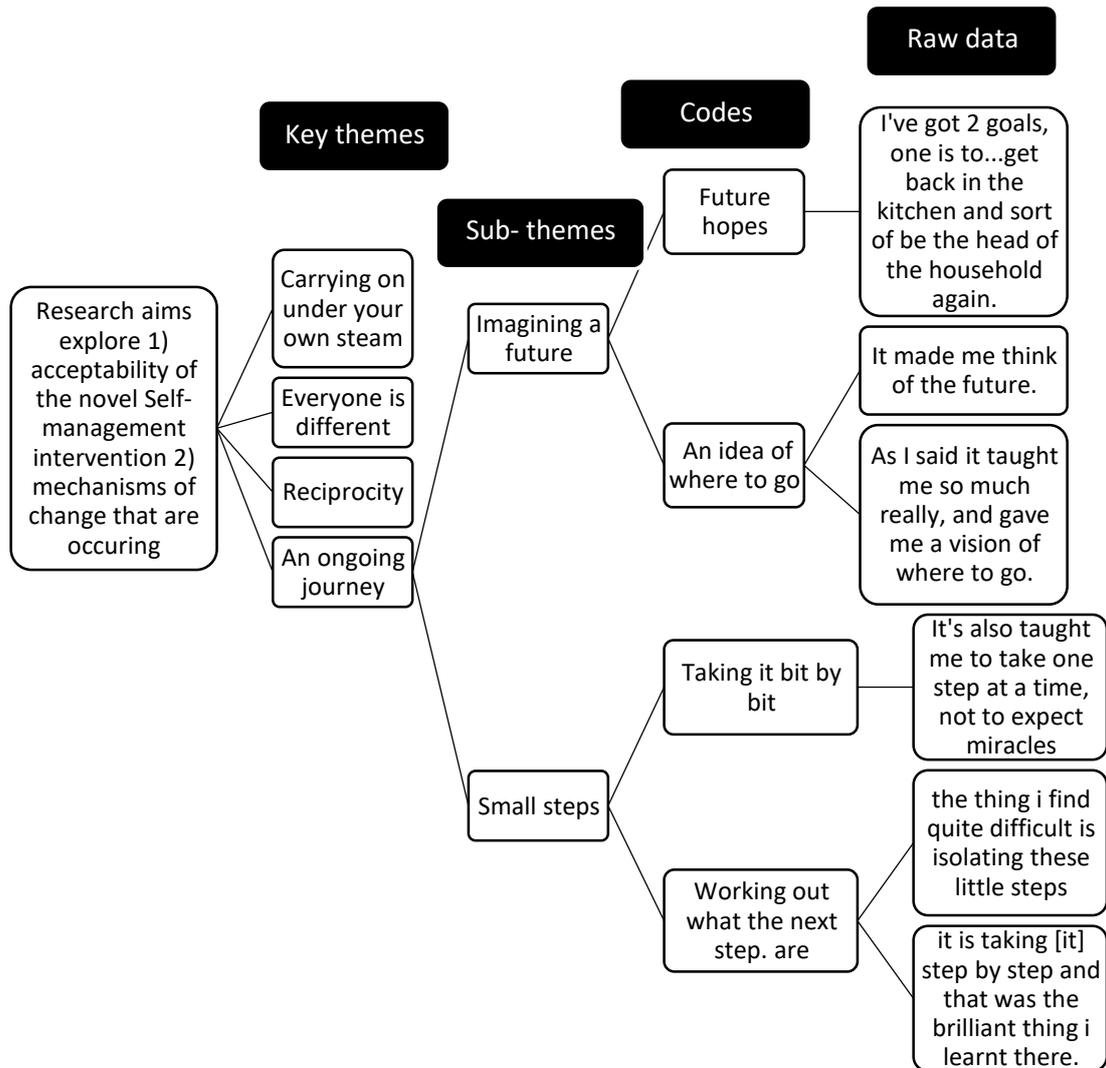
Small Steps

Participants also reported that the groups had supported them to set small steps which in turn had encouraged them to work towards their future hopes:

> *'I tell you; without that group as I said, it wouldn't have even crossed my mind, because how do you know if you don't know about these things you know, and it was really –in a way-it's just taking these little steps, you could apply to any form in our lives really….And [the groups] educate you about taking a step at a time and that was the most important thing I really learnt you know, not to be so…intolerant you know, wanting things to happen straight away'(P8).*

Similarly, seven of the participants gave examples of how they had applied the concept of small steps in their own lives to work towards their future hopes (P's 1,4,6,7,8,9 and 12). Participant 4 gives an example of this, *'so those are my main goals to get back in the kitchen again. I mean I can make a cup of tea, but I have to get somebody to bring it in, and I do try to do my breakfast of a morning which I didn't do before. I'd wait till somebody came down and get them to do it but I do try and do it now.'*

One participant pointed out that planning was not a new phenomenon to him as he had made plans before, including those that may take a long time to complete. However, he found the detail involved with small steps was new, '*The planning that goes into getting your hand back is very important in fine detail, so that was new, and that I, I think was really- I mean I think, I think that definitely came during the groups'* (P12).

However, not all the participants found the concept of small steps easy to grasp, '*the thing I find quite difficult is isolating these little steps. You know, to me, I know where I want to be, but I can't get there*' (P9). In addition, the terminology 'small steps' was questioned by participant 8 who said, '*they're giant leaps for people in my position'*.

In summary, the first theme captured the way the group self-management intervention may provide the space and opportunities for participants to think about their future and how the concept of setting small steps was useful to many of them. However, this was challenging for some participants who felt the concept of small steps was not that easy to grasp, and others felt the terminology undermined the 'big' changes these enabled.

7.3.2.2 Carrying on under your own steam

Ten participants spoke about concepts that contributed to the second theme, 'carrying on under your own steam' in their interviews. The theme is constructed of examples of changes experienced by participants as a result of the intervention, and whether these were maintained once the intervention had finished. The sub-themes represent the three ways this process occurred, 'acceptance and awareness', 'believing in my own capabilities' and 'motivation'.

Acceptance and awareness

Individuals reported changes in their acceptance of living with stroke and their self-awareness after the group self-management intervention. For example, '*I think I am more accepting since the groups. You know the frustration is there, but then again I know now to stop it, I just say it's come but go away, there's more important things and that certainly*

come through [the groups] definitely' (P8). Similarly, when asked whether they would take anything they learnt from the groups forward with them, one participant stated, *'just carry on and don't worry about it, because if it's going to happen, it's going to happen'* (P2). One potential reason for this change was offered by participant four who had seen how peers were behaving and mirrored them, '*they didn't seem to be worried about anything so why should I?'.*

Another change described by participants was an increased self-awareness of their own situation. One participant felt the group, '*helped me acknowledge the fear I've got'* (P9), while another said, '*it made me see I was more competent physically than I thought which in turn sort of changes the platform you're on for the next thing you do'* (P12). Participant 12 suggested these changes may be the result of the groups being, *'a good way of getting people to think about their position, [to] think about how much they are in control and thinking about how they live with themselves, who they are as a result of the stroke'.*

Believing in my own capability

Nine participants spoke about how the group had increased their belief in their ability to do specific things and their confidence in general. Participant four said, *'I think it's brought something out, out of, brought me out of myself'*. When asked how the groups had done this, a number of reasons were given: feeling like people were listening to them, '*being able to talk about what's happened*' and finally, trying and succeeding in their small step for the week. Similarly, participant 12 spoke about how small steps can help with confidence as they support individuals to think back to previous progress, '*planning i-is, it's very good for your confidence. You sort of say well, I think I would have walked from here to here to the end of the table. Well, I can't do it at the moment, how am I going to do it? ….You break it down into each component and you see that o-over a period of time you haven't just done one thing-walk to the end of the table- you've done eight things'.*

The belief individuals had in their own capabilities was also influenced by other group members, one aphasic participant describes how they built their confidence from the attitude of other group members, '*attitude yeah, he's brilliant. **And you learnt from that?** Yeah definitely, yeah because like he yeah oh my god…really good… [before he was] scared everything [but now]… over the road, whoa, you're really good, and everything is, my God OK if you can do it I can do it*'. In contrast, another participant felt bravery

came from within you and that observing others may not be enough, '*It's nice to think of what other people do that are a bit braver but I'm not actually sure it makes you braver. That's inside – that's you'* (P 9).

One participant points out that they may feel more confident but that this doesn't necessarily mean that they would carry on under their own steam once the intervention had ended, '*confident but whether I would do it on my own is another thing, it would be there, and I'd forget and then just go back to my usual routine of what I do. You know, unless someone is there to say …you've got to so this, you've got to do that, then I don't think I'd do it because I'd forget*' (P.2).

Motivation

Nine participants spoke about how the group self-management intervention gave them the motivation to reach their future hopes. For the majority, this motivation came from other people, '*it does give you some sort of motivation because you think someone's actually interested in what you're doing.*' (P9). For some it came specifically from others who had also experienced stroke but may have different residual symptoms, '*there was a chap there he had to learn to speak again. It was amazing …how far he had come and I thought to myself…if he can do it I can because I had to learn to walk again which I found very hard*' (P4). A number of participants gave examples of how others had been putting things off but then came to the group and with the support of others managed to do them, '*he'd been spending like two-months doing that before and all of a sudden he'd done it all within the week you know. So, I think we all, going back to it again, just spurred each other on and encouraged each other*' (P11). Both the latter suggest that the encouragement during the groups was important and pulls into question whether the individual would carry on under their own steam without it.

In summary, the second theme enabled an insight into which components of the group intervention may make an individual feel able to carry on under their own steam once the intervention has ended. The former is particularly important for chronic conditions as by definition they will need to be managed beyond the intervention duration. The first two factors that participants felt might help to keep going were, 'an increase in acceptance and awareness' and 'believing in my own capability'. The final sub-theme was motivation, however, as this largely came from other group members it is unknown what would happen if participants lost contact once the groups ended.

7.3.2.3 Everyone is different.

The third theme 'everyone is different' was discussed in all 11 interviews. Being different to other group members was reported to have three key benefits: it enabled, 'shared problem solving', 'a fresh perspective' and 'social comparison'. Each of these benefits are presented as sub-themes below.

Shared problem solving

The first sub theme captured how 'differences' had enabled a platform for shared problem solving. One participant pointed out*, 'I mean they, th-they might have, have had different physical consequences from their strokes but…we all knew what was what…whereas other people…they didn't quite know what is, what's what. And I found that very good. And that made it, I think, easy to sort of say, well this is what I did, and I did that- did you', why don't you try this?' (P12)'*

A number of participants gave specific examples of shared problem solving, such as participant nine who could no longer put on earrings. Through talking to others, she found they did things differently, '*these other ladies had ones that just hook through...which is easier'*. Another example came from participant two who described a peer who was struggling to learn to write again since her stroke and wanted new ways to learn, '*there was one there – her was quite talkative-….and the lady who couldn't read, write and spell again, he went, when he went home he did the alphabet for her in stencil; so she could put the pen in there and then copy it out so the A would be A and she'd copy it…and she started doing that'.* Shared problem relates to the below sub-theme, 'a new perspective' as peers are able to offer different solutions as a result of their own unique perspectives.

A fresh perspective

Having a group of stroke survivors who were 'different' to one another enabled them to see their own situation from a different angle. One participant felt that they learnt a lot about themselves during the groups.

> *'I think the fact of being in the group a-and, therefore, being exposed to different experiences and y-you'll know I'm sure, but you know, four of us were, were people who, who'd had strokes and were at different stages of recovering, and there was a fifth person who had also had a stroke- a very, very major one… it means they have a very different perspective on everything – or we had a different perspective' (P12)'.*

Seeing things from a different perspective also meant peers might spot things that the individual themselves did not, '*when you live with it every day, 24/7, you don't see it. You need to go in and see people that you don't see very often, and they can…they're more in tune with the fact that if you've had a change*' (P9). In addition, some felt that groups had given them the ability to see things from a different perspective, '*actually doing this particular course of yours, it was very interesting because I was thinking in a way I hadn't been thinking before, and I hadn't been thinking before because I couldn't see anything – I couldn't' see any hope' (P7).* The latter also links to the previous sub-theme, 'imagining a future' as individuals are starting to see that there may be 'hope' ahead of them as opposed to not seeing 'anything'.

Social comparison

The final sub-theme was generated from the perception of 'difference' between group members which had enabled a platform for social comparison. Participants spoke of meeting peers during the group who were 'worse off' than them and those who were 'better off', however, both were seen as positive experiences. The advantage of meeting someone 'better off' is illustrated by the following, '*Yeah they've had the same thing, and they've gone through it, they've come out the other side OK and that, so yeah I think that is important'* (P4). In addition, one participant spoke about the stroke facilitator and why they were beneficial, '*people who have got a little bit more experience of having had as stroke [mean] people see that well you can come out the other end'* (P11).

Meeting those who had suffered more severely from the stroke was also seen as a positive for three reasons. Firstly, one participant described meeting people who '*were 100 times worse than me'* and how she *'learnt so much from them'* (P8). Secondly, those worse off were a source of motivation, '*there was nothing wrong with me compared to them poor people, and they hadn't given up*' (P3). Finally, '*because the thing is with going to the group as well, it sounds really awful, but other people are a lot worse off than you are so it actually makes you feel a bit better, in a way, rather bad way for those people but…'* (P9).

In summary, the third theme depicted the differences that participants saw between themselves and other members of the group, such as, how they may approach a problem, how they see the world, and finally, how well recovered they were in relation to one another (or not). These subthemes helped formulate understanding on how

difference to other group members can provide benefit to participants, regardless of whether they are seen to be 'better' or 'worse' off than oneself.

7.3.2.4 Reciprocity

The concept of reciprocity was illustrated in the transcripts of 10 participants, '*it's a two-way process, you learn so much you know, and you give as well'* (P8). How this reciprocity was experienced during the groups is presented through three sub-themes: 'p*assing the stroke test'*, 'listening' and 'ongoing social support'.

Passing the stroke test

There was one thing that everyone who attended the groups had in common, *'the only thing that, that clearly unites us is that we've had some sort of stroke…you've got to pass a certain test before you're allowed on this course…'* (P12). It was this shared experience that one participant felt created a sense of empathy and a non-judgemental atmosphere within the groups, '*just having that support and talking about things that you know, talk with people that understand what you're talking about and [that] you're not being silly'* (P8). For others, the shared experience of stroke helped people feel less alone*, 'there are other people like you out there' (P11).*

A group of people with similar experiences of stroke also enabled an environment where there was shared understanding, *'O-one of the first things I was aware of at the first session was that, that is was-it felt, it felt good to be among a whole group of people to whom you didn't have to explain anything' (P12).* The shared understanding extended to the challenges being faced by participants, *'it was enjoyable to listen, it wasn't just me that was going through that same fear you know I mean, the same worry, and is it going to get worse or is it going to happen again you know' (P2).* One participant pointed out that they did feel that there was a sense of sharing experiences but that this may not have any real-life benefit, *'I enjoyed sort of listening to other people's experiences and also sharing your own, but whether it's made me any different or not, I'm not really sure'* (P9).

Listening

The second sub-theme refers to the importance of both listening to others and being listened to*, 'there must be a reason that people want to come somewhere [when] they've had the stroke…[to] listen to people and people listening to them as well, listening big time'* (P1). Participant five said that by '*listening to you'* the group made you feel

supported, while participant four said, *'the group taught me that there are people out there who are willing to listen to you. There's a lot of people don't want to know, but they were happy to listen to what you say'*.

The reciprocity of listening interactions is highlighted by one participant who gives an example, *'it was as important to them to get their point over as it was for me to learn from them (P4)'*. Participant one also gives an example of how the process of listening can be reciprocal, *'you learn about people- how they do things if you listen. …they get a lot of valuable information as well… [because others in the group can] tell [them] look if you go there [you] can do this, look carry on and go see if you can do that after that'*.

Ongoing social support

The final subtheme depicts the sense of transition from self-management support to self-help, and how the structure falls away leaving only the blueprints. The intervention was four-weeks long, but some participants reported that they had continued to meet members of their group after it had finished, *'about six or seven of us still meet up you know? So that's not bad…we're supporting each other all the time'* (P5). One participant had taken on the role of coordinating the meetings as it helped her practice her speech, *'I'll go see a different place or whatever and then asking them what's the day, okay sometimes we have to change it okay call back everybody else…I ask them every month do you want another, they say yes'(P1).* When asked what happens during these meet ups, participant four said, *'we all talk to each other or amongst ourselves, just what we've been doing, where we've been. Any major hiccups you know anything, just what's been going on in our lives really'*. Another said, *'I went the other day to one of the other girls in the group, to ask, can you read what they had in the letter because I said please because I can't read it properly'* (P1). When talking about who could offer them support now the groups had ended, participant five said, *'my friends would help if necessary and they, they, the people from the group. We carry on the function from the stroke [group]. We still help each other'*.

The sense of wanting more ongoing support from the groups was mentioned by a number of participants, one said their wish for the group was, *'to meet up and find out you know where everyone has you know, how far they've come since we last met would be nice you know'* (P8). Similarly, participant three said, *'[we were asked] anybody got any suggestions for future? And I said, why can't we all meet up again in six-months' time or something like that?'* Another spoke of a prospective meeting*, '[I] don't know how*

long or whatever but it will happen that we will get to all meet again and have a cup of coffee or something yeah (P11)'.

However, the concept of ongoing support was not for everyone. One reported that some of their group did not come for logistical reasons, '*not all of them because it's impossible, you know? One of them lives in far X or something like that, so it's not easy to come where we are…and a couple didn't have a tremendous amount of mobility' (P5).* Others suggested it was because contact details were lost, *'they were a lovely lot, I did have their, we did exchange umbers and everything but seem to have lost them all' (P2)* or because when invited they said, '*they've had that, that's nice, but they've had enough'* (P1). For some the prospect of ongoing support had resulted in them feeling bad when they had not fulfilled it, one participant said, '*I got on really well with [Jane]. And…she gave me her number, but I never kept in contact with her, and I feel bad about that* (P3).

The final theme, 'reciprocity' contributed to our understanding of the mutual gain participants may get from a group self-management intervention. These included, the sharing of experiences, listening to one another, and ongoing social support. It also highlights that some participants found this reciprocity could lead to them feeling bad if they do not meet the perceived expectation of other group members.

7.4 Discussion

Interviews with 11 stroke survivors contributed to this research which aimed to explore the acceptability and the possible mechanisms of change that may be occurring as the result of a group self-management intervention for stroke. Four themes were depicted in the data, (1) an ongoing journey (2) carrying on under your own steam (3) everyone is different and (4) reciprocity. Together these themes contribute to understanding the processes at work behind the intervention, and how closely it aligns with the theory underpinning it – social cognition theory- and the core Bridges principles.

The first theme, 'an ongoing journey' was formed by two sub-themes, one of which was small steps and related to the principle of goal setting in social cognition theory. It also reflects the Bridges principles of setting goals and taking action. Previous qualitative research exploring group self-management interventions found similar findings that participants valued the concept of small steps to help them achieve their goals[20,21]. The first theme also depicted how the groups encouraged stroke survivors to 'imagine a future'. Despite stroke survivors seeing this as beneficial, thinking about your future self

was found to be one of the least used self-management techniques in the review conducted in chapter four. However, it may be that participants started to imagine their future more organically and as a result of other self-management principles such as goal setting, as opposed to in response to formal discussions on this topic.

The second theme, 'carrying on under your own steam', depicted an increase in self-awareness that came from the group and aligns with the concept of self-discovery and the idea of 'just giving things a go' within Bridges. It depicted three sub-themes, which contributed to our understanding of how a group self-management intervention may enhance self-efficacy-the core principle of social cognition theory. The belief in an individual's own capabilities was increased by encouraging stroke survivors to think about past successes which aligns with the Bridges principle of reflection. However, the current work also highlights that increasing an individual's confidence does not necessarily translate to behaviour change. Social cognition theory also highlights this by suggesting there are mediators between self-efficacy and subsequent actions that may impact whether a behaviour is actually acheived[22] .

The third theme, 'everyone is different', echoed findings from previous work that group self-management interventions provided a platform for problem solving[9] and social comparison[21]. The theme depicts a positivity that surrounded the difference between participants and their fellow group members, but this was at odds with previous research reporting that stroke survivors felt uneasy about attending a group that was not tailored to their own unique needs (chapter three)[9]. The difference in findings may illustrate the lack of understanding in the target population about what a group self-management intervention would be like as the two concepts are not mutually exclusive: a group can have individuals with different needs and circumstance *and* can use techniques that can be tailored to each individual. Future work should aim to broaden understanding of what self-management interventions might look like in practice, and, in particular, how they can be tailored to meet individual need. This is especially important for the target population as perceiving such interventions to be 'one size fits all' may discourage their engagement with such services[9].

The final theme depicted the value of reciprocal relationships that occurred between peers, supporting the inclusion of social support in social cognition theory. To date, there is only one other study which emphasises the value of such interactions[48]. The current work corroborates the previous findings, suggesting reciprocal relationships can

increase confidence by being able to help others[21], and builds on it by exploring the longevity of these interactions. The present study highlights how ongoing reciprocal interactions can help stroke survivors feel supported once the intervention has finished, but also how they may result in stroke survivors feeling 'bad' if offers to meet up go unrequited.

The interactions that came about within the group could infer that stroke survivors who take part in one-to-one interventions may lose out on the associated benefits such as peer support and social comparison. Indeed, it has been noted that one-to-one interventions give "little recognition to the role of social context and the collective value of a group of people with similar experiences coming together for support" (pg. 262)[145]. Although the current work changed the delivery mechanism of an existing intervention from one-to-one to group delivery, seven of the nine original principles were highlighted in these interviews suggesting fidelity to the original intervention is high. However, it also highlights additional mechanisms of change such as social comparison and ongoing social support. Previous work has shown social support also comes from friends and family who are often involved in the self-management process[146]. The acceptability of the intervention should thus be explored with friends and family as they are often involved in the self-management process.

As a final point of discussion, the way in which the phenomena were explored should be considered. While interviews offer valuable information about experiences of change it does not offer insight into the extent of these changes. For example, the results suggest that the intervention may increase an individual's belief in their own capabilities, but it is not known to what extent. It is for this reason that mixed methods approaches are advocated in complex intervention research[24]. The work should be complimented by that which explores this concept quantitatively to overcome this and further advance the field (see chapter nine).

7.4.1   Limitations

There are a number of limitations in the current work. Firstly, it should be acknowledged that the two researchers who coded the interviews were involved with the intervention design which may have biased interpretations. Although every effort was made to code the data without pre-conceptions informing the results, such as highlighting contradictory examples, it would be impossible to free oneself of these 'theoretical and epistemological' commitments entirely. Therefore, the fact that the researchers designed

the intervention based on social cognition theory should be considered when interpreting the results.

Secondly, 13 interviews were conducted as part of this research but only 11 were included in the analysis which is one below the recommended number of 12[107]. However, guidelines for qualitative work suggest that recruitment stops when no new themes are depicted from the data[147] and as this was the case in the current work the limitation was not considered to be detrimental to the findings. It should also be noted that as no one from the eighth self-management group was represented in the interview analysis, the results only apply to the first seven.

Finally, it should be noted that this work recruited participants from a pool of individuals who took part in the GUSTO study. Therefore, the methodological limitations associated to recruitment in the GUSTO also apply here, for example, participants were only recruited from one hospital which limits how representative the sample is of the wider stroke population.

7.5 Conclusion

Group self-management interventions for stroke can provide a platform for shared problem solving and experiences, learning, motivation, social comparison, and a space where stroke survivors can feel listened to. The concept of setting small steps was received well by most but, some found this to be quite challenging. The experience of taking part in the group had also enabled participants to imagine a future, carry on under their own steam, and form reciprocal relationships. Some participants continued to meet once the groups had finished, while others were less enthusiastic about the idea of ongoing support. Future work should focus on broadening understanding of self-management interventions and use a mixed methods approach. In addition, what friends and family thought of the groups should also be explored as they are involved in the self-management process as well as the individual with stroke.

Chapter Eight

8 Chapter eight: A qualitative exploration of family, friends and carer experiences of the group self-management intervention.

This chapter presents the findings from two focus groups. Both explored the acceptability of the Bridges group self-management intervention with the friends and family who attended with a stroke survivor. The analysis provided further understanding of their experiences of the intervention, and whether the intervention was perceived to have resulted in any changes to either themselves or those they attended with.

8.1 Introduction

Informal carers such as friends and family play an important role in the day-to-day management of stroke[108]. Family alone facilitates 54% of the required care[148], and includes emotional, personal and practical support[149]. Caring for someone with stroke can be a challenging process. Two-thirds of carers have experienced difficulties in marital relationships and a third report they have either broken up with a partner or considered doing so[8]. Caring can also have a significant negative effect on one's health, as well as social, emotional and financial well-being[150].

Although becoming a carer can be a complex undertaking that requires nuanced and often technical skills, family members often feel that health care professionals expect them to do so[4]. Equally, studies show there is little practical or emotional support available for carers, and 72% of family members that become a stroke carer report feeling unprepared for this new role[8]. Two decades ago, the high level of unmet needs in the carer population was highlighted[151]. The fact that in 2011 only one in three stroke services offered support for carers makes it clear that little progress has been made[110].

One way to better support carers may be by inviting carers to attend self-management interventions with the stroke survivor they care for. They would not be an observer but an active participant in the group, which would offer a space to share experiences, learn about changes in the spousal relationship and give insight into 'the learning process of stroke survivor's self-management'[108]. One self-management intervention which was attended by both stroke survivors and carers-the Chronic Disease Self-Management Intervention- was shown to provide equal benefit to both parties[13]. Thus, self-management interventions may provide a mechanism through which carers can be supported as well as stroke survivors.

Inviting carers to attend a group self-management intervention would be in line with suggestions from the Stroke Association who feel carers should be viewed as "partners in care" and be included, "in the stroke survivor's ongoing stroke journey towards recovery" (pg. 23)[8]. The move to invite carers to self-management interventions would also be in line with recent literature that shows family member involvement is important as it may encourage carers to support stroke survivors to self-manage and in turn increase quality of life[15,149].

Despite work emerging in the self-management field, the above findings are from the only study which has explored carer experiences of such interventions to date[13]. There has been no work exploring the experiences of carers who have taken part in any other group self-management interventions. Therefore, the aim of the current study is to explore the acceptability of the Bridges group self-management intervention with carers, including the benefits and drawbacks.

8.2 Method

Ethical approval was obtained for this work as part of the GUSTO study (see chapter two). In line with previous research, the term carer is used to refer to both informal (family, friends and carers) and formal (usually paid to care for an individual by external parties) carers[149].

8.2.1 Recruitment

The full recruitment criteria for GUSTO is listed in the methodology chapter of this thesis (chapter two). Once the intervention groups had taken place, each carer that attended with a stroke survivor was invited to take part in a focus group. Carers were recruited by EC in person at the end of their intervention, or by phone at a later date. Eight intervention groups were run in total, and carers were recruited from groups one, three, four and seven as no carers attended groups two, five six and eight.

8.2.2 Focus groups

The focus groups were held in a community venue in central London, and pre-paid transport was available for those who requested it. Each group was facilitated using a topic guide (described below), recorded using a Dictaphone and transcribed verbatim. Focus groups were chosen as they have successfully been used in previous work exploring perceptions of self-management[149]. They are reported to offer three key benefits to the research[152]. Firstly, focus groups can offer participants more flexibility over the discussion topics than interviews as participants can react to comments from other

group members and spark new topics of conversation that interviewers may not have thought of. Secondly, the reflective nature of group discussions mean they can aid exploration of topics that are complex and nuanced such as the different factors that may influence self-management after stroke. Finally, focus groups allow real-time interactions, where group members can raise alternative or complimentary viewpoints that can increase the richness of data gathered.

8.2.3   Topic guide

The topic guide (appendix 12) was developed by EC (thesis author) and HP. HP is the innovation and training lead for Bridges. She has experience facilitating focus groups, especially those which aim to capture service user views. It was based on appreciative inquiry methodology which was chosen for two reasons. Firstly, it facilitates individuals thinking about new ways to do established practices[153] which is particularly important for the current study as data collection occurred after the groups had taken place. This makes it more difficult for participants to imagine a different way of delivery that was not influenced by their prior experience. Secondly, the approach does not advocate a 'top-down' approach but instead a 'whole systems' approach which is essential for the development of self-management interventions[24]. Appreciative enquiry methodology advocates four phases of exploration: discovery, dream, design, and destiny. The first phase 'discovery' aimed to, 'identify and appreciate the best of "what is" and asked questions such as, 'can you describe your absolute highlight of the sessions you attended?'. The second phase 'dream' encouraged participants to think about the future of the intervention, and asked, 'In an ideal world, what would a perfect group session be like?'. This phase draws on other experiences participants have had in their lives to support them to think of alternative delivery ideas. The third phase focussed on 'design' and explored examples of how the dream phase may look in reality, 'What needs to happen to ensure that every single group session has a profound effect on you and the stroke survivor's lives?' The final phase, 'destiny' built on the momentum created in the first three stages and thinks about how these changes could happen, for example, 'what are the next steps to make this happen?'

8.2.4   Analysis

Inductive thematic analysis was used to analyse data from the focus groups. The process was conducted as described in chapter three, section 2.1.2.3, so only a brief overview is given here. EC wrote descriptive summaries following each group during which specific words or phrases with relevance to the research question were noted. Codes were then grouped to form themes and an iterative approach was taken, meaning each group was

re-read to ensure all the data were incorporated where appropriate. An example of how the main themes were reached from the initial coding phase is illustrated in figure eight.

8.3 Results

Of the eight carers invited to take part in the focus group, six agreed. One was unable to commit the time and so declined to take part, and a second was a paid carer who declined as the focus group was run outside of her working hours. Although six agreed to take part, one participant failed to turn up on the day of the focus group. The first focus group took place in December 2016, and three carers attended. The second was held in April 2017, and two attended. The first focus group was run by an external facilitator associated with Bridges (HP). The second was run by a research assistant previously associated with the GUSTO project (KE). EC co-facilitated both the focus groups. The first focus group lasted 62 minutes, and the second 69 minutes. All the carers were female and either married to or related to the person they were caring for. Additional demographic data are presented in table ten.

Table 10. Additional carer demographics.

Participant Number	Ethnicity	Relationship to stroke survivor	Focus Group	Intervention group	Time since partners/family members stroke
1	Black, Caribbean	Daughter	1	3	4
2	Black, Caribbean	Wife	1	1	3
3	White, European	Wife	1	4	29
4	White, British	Daughter	2	1	13
5	White, South African	Wife	2	3	12

8.3.1 Themes

Four themes were depicted following analysis of all data, (1) learning how to co-manage (2) I am not the only one, (3) they can help themselves and finally, (4) ideas for the future. Each is described below.

8.3.1.1 Learning how to co-exist in our new life

The first theme depicts how carers and stroke survivors learnt to co-manage the stroke and what contribution the groups made to this process. Three sub-themes were identified, 'I cannot wrap this man in cotton-wool', 'it helped clear the air over us' and 'you forget you have a life'. All three are explored in turn below, and a tree diagram illustrating how this theme was formed is presented in figure eight.

I cannot wrap this man in cotton wool

The first sub-theme was illustrated by three of the five participants who took part and described what they perceived to be over-protective. Participant five spoke of her maternal instinct and how this influenced her behaviour, '*in the beginning, he said to me 'I am not a child, don't treat me like a child', but it's very difficult not to. It doesn't matter who it is, whether it's your mother, your father, your husband, or your child, the natural motherly thing is to... 'I'll take over'.* Participant four illustrated what this might look like in reality and gave an example of how she tried to protect her mum from things that she was actually able to do, *'I always say to [mum] when we go out of the front door, 'Wait for me so I can hold you, make sure you don't trip downstairs once you've got the handrail'. But she's out the door!'* Both these examples suggest that despite participant's efforts to be protective of family members, the family members may not always be receptive to the idea or require as much protection as carers think.

Participant five spoke about how the groups helped her overcome the constant need to protect her husband as well as the panic that he might have another stroke:

> *'I've got out of that panic-station now and thought to myself well if he does have another one there's not a whole lot I can do about it. I can't prevent it, I cannot wrap this man in cotton-wool and separate all the parts of his anatomy to stop this from happening. If it's going to happen, it's going to happen, I'm going to have to handle it as I've done this one step by step. I think if it hadn't have been for you girls having done this group, to be able to talk to people having gone through the same, I'd still be in the panic stages, waking him up every 10 minutes to check he's all right.'*

Participant four also felt the groups helped her realise she did not need to 'over' care for her mum and spoke about the impact this has had on her mum's life*, 'It's the groups, hearing other people say you've just got to let them do things for themselves. Before I used to run around after my mum, 'I'll do this, I'll do this', now it's like, 'No, make yourself a cup of tea mum'. She makes herself breakfast in the morning...'.* However, participant

one highlighted how nuanced this shift in relationships can be. She described how she felt being more 'hands off' had been good for her mother yet also missed supporting her, *'I miss having her hold on to me all the time, [but] I am happy that she finally got the [walking] stick and that it is helping her'.*

You forget you have got a life

The second sub-theme depicts the forgotten lives of carers. Both focus groups discussed how participants felt they are often hidden behind the stroke survivor, '*no one has actually said to me, 'how are you doing?' it's all, how is your mum doing?'* (P4). One participant pointed out she often forgets she has her own life herself, '*you forget that you're a person, you're a woman, and you've got woman's feelings and woman's needs'* and, '*you forget you have got a life, you're a person in your own right'* (P5). Participants felt that the person they are caring for often forgets this as well, which can create tension in the relationship, '*like I'm not going to be around forever. Some days I can't go around because I've got other things on, she'll go 'Hm', 'Mum I do have my own family, as much as I love you I've got my own family' (P4).* The group self-management interventions provided a space where participants were not forgotten and their experiences were acknowledged as well as the stroke survivors.

> *We felt it made us feel special. It made us feel as if yes someone cares, and they want to know about what we are going through in terms of me being her carer and in terms of her having a stroke, so it was very, we felt loved, we did'* (P1).

Three of the participants had continued to meet up on a monthly basis since the intervention had ended. One participant described how this helped her feel she has a bit of a life again, *'nice to get out and not to be that caring person, you are yourself'* (P5). The quote suggests that the groups may have offered a space for participants to meet each other, but that it was the ongoing support that helped them feel more like themselves.

Figure 8. Coding tree illustrating how the theme 'learning to co-exist' was formed.
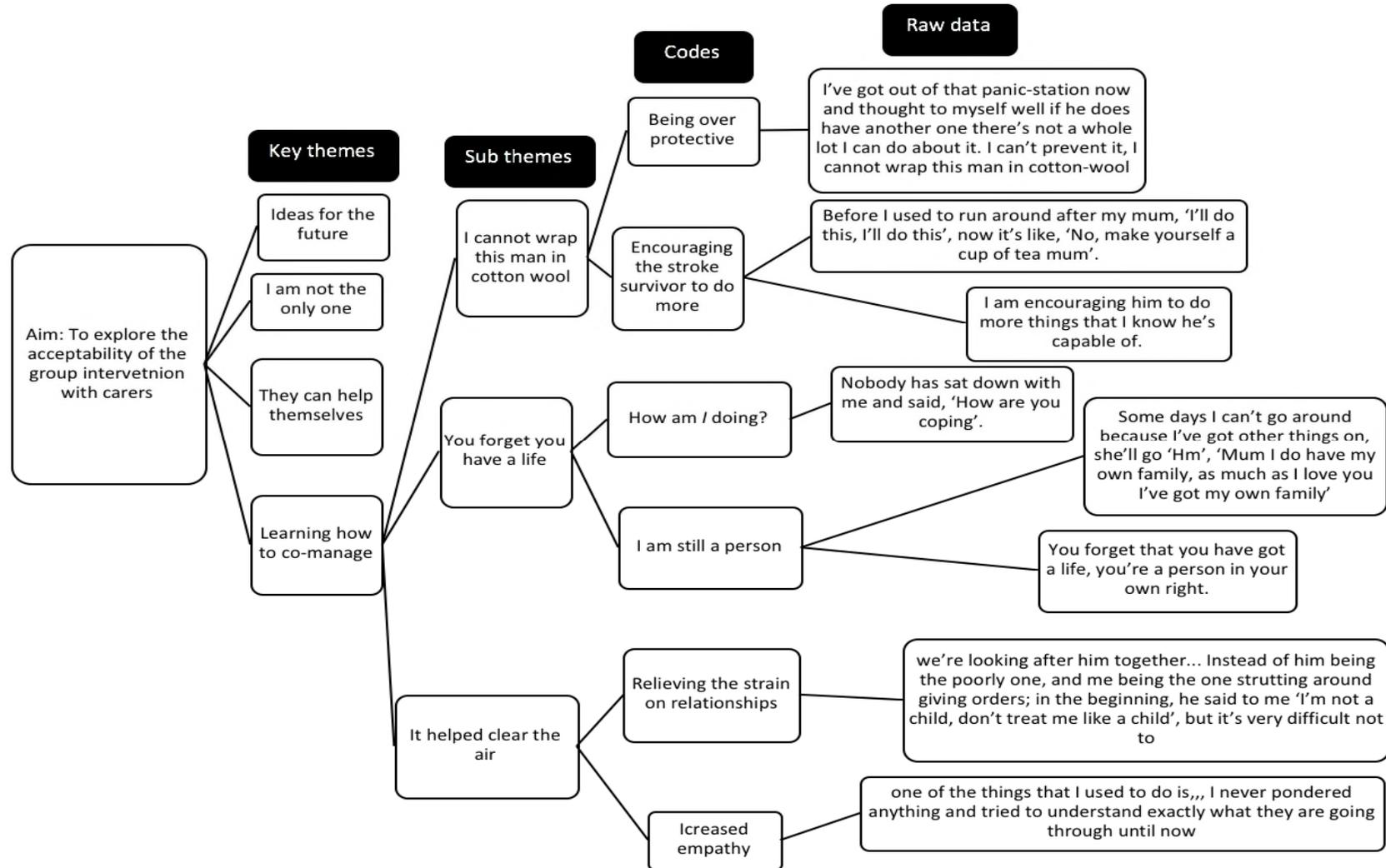
It helped clear the air

The final sub-theme depicts how stroke had put a strain on relationships and how participants felt the intervention 'helped clear out the air a little bit' (P3). Three participants spoke about concepts that contributed to the theme. One participant explains why:

> *'I couldn't deal with it sometimes, but after the session I started to understand, and it made it easier so when she started reacting and behaved in an insulting manner, I got to understand, hey this is not anything personal, it's just what she is going through because of her stroke' (P1).*

Three participants reflected on how the groups had helped them learn about stroke and how it can affect everyone differently, and all three felt that this had improved their understanding of their family member's situation. Participant one felt that the groups also improved communication with her mother which in turn facilitated empathy and understanding:

> '*It was good that both my Mum and I attended, because the understanding sometimes, one would understand one part and one wouldn't understand the other and what she and I did is that we combined, we had a conversation and she explained to me what she understood and then I explained to her what I understood, and it made it easier for both of us* '(P1).

Participant five also felt communication with her partner had improved since the groups, and as a result felt they had formed more of a partnership. She gave an example of how her husband had told her not to treat him like a child which helped their relationship became more collaborative, '*we're looking after him together so to speak. Instead of him being the poorly one, and me being the one strutting around giving orders'.*

Summary

This first theme illustrates the process of developing what could be described as 'co-management' skills and how the intervention contributed to this process. The theme highlights that co-managing may take time to evolve as both carers and survivors have to adjust to life after stroke. Increased empathy and understanding were found to facilitate co-management as they enabled carers and stroke survivors to communicate more clearly with one another. In particular, participants felt the former helped clear the air in relationships that are under pressure to manage stroke on a day-to-day basis.

8.3.1.2 I am not the only one who is caring

The second theme depicts how participants felt the intervention alleviated the feeling that they were the only ones managing a family member's stroke. The theme has two sub-themes, 'I am not alone', and, 'sharing how we all do things'.

I am not alone

The first sub-theme shows how being a carer can feel isolating and was referenced by four of the five participants. Each spoke about how alone they have felt since their family member's stroke, and expressed how meeting others in the same position was comforting:

> *'One of my highlights is that to know that my mother and I were not alone, because when I came, although I know other persons, stories of other persons who had stroke, when I came I felt as if it was just me and my Mum and we were all alone, but when I came to the group session, and I listened to the other persons who were affected by the stroke, and I heard the stories, it gave me some comfort, and it made me realise that my Mum and I are not alone. She is not the only one who had a stroke, and I am not the only one who is caring'* (P1).

Participant five highlighted how meeting others in similar positions normalised their own feelings, '*you do tend to think of yourself as very alone in the situation, nobody else in the world, woe is me. Whereas when you go to something like that, you get chatting to people and you think, 'Oh, I feel like that''*. Participant four points out that this would not be possible without being in similar positions, '*you've got to have walked in these shoes'*.

Similarly to the first theme, the ongoing support once the intervention ended was discussed. The second theme highlighted an additional reason that participants valued this, which was because it maintained the feeling they were not alone. Participant five explained why this was important to her, '*we can talk about absolutely anything, we can laugh about absolutely anything. If somebody in the group needs help with anything, if we can help them we will. It's just very relaxing, it's great'*.

Sharing how we all do things

The second sub-theme depicts how participants could learn from other group attendees by sharing examples of how they cope on a day-to-day basis. In particular, '*how people cope with their relatives, their husbands, how they cope with the strokes' (P4)*. Meeting other stroke survivors also enabled a reciprocal interaction to occur between group members, '*everyone had some satisfaction of coming to the group and learning about other persons who had their stroke and how it affected them, and they also were satisfied*

in sharing what they experienced on their end' (P2). Participant five explains how sharing how they do things may also provide emotional support for carers:

> '*They would give each other therapy, like me talking to another wife; the [husband] I've got now is not the [husband] that I had, our lives are different. So, for me to talk to another wife and hear what she's got to say, and me say what I've got to say about how different our lives have become since this, would be good…. 'Oh, you're also looking after your husband. How are you getting on, how are you coping?'(P5)*

Summary

The second theme revealed how alone carers could feel when managing life after stroke. The theme highlighted that meeting other people in a similar position may alleviate these feelings and create a space to share ideas. Similarly, to the first theme, the opportunity to create ongoing social support networks was seen as a positive outcome.

8.3.1.3 They can help themselves

The third theme depicts the impact participants felt the intervention may have had on the stroke survivors they attended with. The importance of this was evident, with one participant saying, '*you've got to make sure that everything is OK with that person'* (P5). The third theme is split into two sub themes, 'if she can do it why can't I' and 'she was pleased with herself'.

If she can do it why can't I

The first sub theme depicts how participants felt stroke survivors were 'doing more' since the intervention, and that this was because they had seen other stroke survivors succeed:

> *'Well after she saw by attending the group and listening to other persons and listening to the way they talk about being positive about helping themselves, like there was another lady there who had her daughter with her and she had started doing things in the kitchen with her hands, because she had problems with her arms, and it took her some time, and slowly she spoke about making her tea and preparing her own stuff in the kitchen, so Mummy listened to that now, that helped her to finally make the decision to get her walking stick and try it' (P1).*

The power of vicarious learning and modelling of peers is further highlighted by participant five who described how one group member, in particular, influenced her partner's mentality, *'I think she's such an inspiration to the others because they think, 'Damn it, if she can go into London then, why can't I?'.* However, not all participants reported the same success. Participant three highlighted that although her partner had seen how another stroke survivor was practising her speech and language skills and had, in turn, had '*little ideas about reading aloud and all that'*, these had not translated into action. This highlights that although carers felt other stroke survivors motivated their family members, some may require additional support to translate this motivation into behaviour change.

She was pleased with herself

The second sub-theme illustrates how participants felt completing new tasks or activities had a positive effect on stroke survivors. Not only did they perceive task competition to make stroke survivors feel good, but they also felt it encouraged subsequent attempts at activities. On participant spoke about this happening to her mother, '*because she's so pleased with herself that she's done so well that she just wants to go-go-go!'* (P4). As a result of these successes, the same carer described how her mother has set a new goal and is, *'adamant she's going to be out her wheel chair by Christmas'.* Another have a similar example of how her mother had got a walking stick as a result of the groups and how it made her feel more positive, *'she loves it, she feels as if she is on top of the world with her walking stick' (P5).* When discussing what it was that encouraged her mother to take action and buy a walking stick, participant five said they felt the groups were important as they encouraged her mother to have a go at new tasks:

> *'I think if not for the group session, she would have gotten the stick eventually but she would not have got it so soon, so when she actually got feedback from someone else, she realised it's not a bad idea, and now she feels good about it" (P5).*

Summary

The third theme contributes to understanding about the mechanisms and ways in which the intervention could impact on stroke survivors. Participants reported that there had been an increase in their family members taking action since the group, which they felt was the result of seeing other peers succeed. In addition, the feelings of mastery that stroke survivors experienced when they completed tasks themselves was identified as a source of motivation.

8.3.1.4 Insights for future groups

The final theme presents ideas about what a future of the intervention might look like, and is split into three subthemes, 'it's something we should not let die', 'he gives you a lot of hope' and 'a little more support'. Each is discussed in turn below.

It's something we should not let die

The first sub-theme, depicts how participants felt about whether or not the group self-management intervention should be continued. It also discusses what the groups may look like. Participants were unanimous in that the intervention should be on offer for other stroke survivors and carers and this is illustrated by participant one:

> '*It is something that we should not let die, I [hope it is] something that can be passed on. You know to other persons, and it can be shared as widely as possible to the entire world because all over the world, persons are suffering from stroke and there are some places where persons are not that fortunate to get group sessions and to get support'.*

In addition, participants felt the groups should continue beyond the four-weeks they are run for currently, '*once a year have a big get-together. If you could arrange for everyone from that group to get together, have a meal or a drink'* (P4). Two participants (P4 and P5) discussed how follow-ups could be run and felt an informal structure for these follow ups would be best:

> '*I think you'd have a problem having a formal structure. From the sessions as I've written down here, there were times when we all got carried away with our own little stories because we've all got such a role, everybody has so much to say, it was so exciting. I think informal would possibly be best, and the people would feel a lot more comfortable'* (P5).

Similarly, participant three also spoke about follow-up meetings and suggested the groups should try to have attendees who live locally to one another, so it is easier to meet up once the groups have ended. Both the suggestions for follow-up meetings and for the intervention to continue may be because, '*I don't think it could ever be long enough, because obviously there's so much that you want to say'* (P4), and *'stroke is something that would continue to happen to people in different parts of the world and its, I know how special it made me feel and how special it made my mother feel to know that there is a group'* (P1). Thus, participants agreed that the group should continue and that follow up sessions should be considered.

He gives you a lot of hope

The second sub-theme depicts what carers and participants thought about the intervention facilitators. Each group had two self-management practitioners and one stroke survivor facilitating the groups. The role of self-management practitioners was seen as practical, in that they created a shared space for discussion and enabled everyone in the group to be heard which was appreciated, *'one of the things I liked is that… you guys were asking for [post-its], when we did the bullet points, so everyone had an opportunity to give suggestions and talk about experiences'* (P2). The same participant highlighted that the facilitators also created a caring atmosphere, and that without them stroke survivors would be less likely to attend the sessions:

> *'you could see the interest and the care in the facilitators, so you did not feel as if it was a waste of time, because you know, sometimes you go somewhere to do something, and you don't get that positive feedback and then…he doesn't want to be there'.*

However, it was the stroke facilitators that participants felt provided a unique contribution to the groups. For example, one participant spoke of how the stroke facilitator made them feel better about the future, *'He was very good…He gives you a lot of hope because his personality was over the top all the time'* (P3). Participant five spoke of how they found their stroke facilitator to be inspirational:

> '*She's amazing… she can't read, and she can't write, but she's still going on, and she is not scared to say, 'look I'm stuck, I need help', or 'where is this place?' or 'what does this say?' Which is great, it inspires everybody else to think they can do better'.*

A little more support

The last sub-theme relates to when participants felt the group self-management intervention should be delivered. The views of participants were influenced by their own experiences within the United Kingdom's National Health Service, in particular, when they felt support was lacking:

> '*No I think that when you come out of hospital, there should be a little bit more support, you know in your first few days really. The support we got was not, we had one community nurse but that was just a bit of a disaster, and it didn't really build up your confidence in the system'* (P3).

When the interviewer asks, '*You would have preferred to start it earlier than two years after the stroke?'* participant three replied*, 'Yeah, I think, because you are still trying to*

improve, but maybe after two years you have given up. You don't really feel, you are not hoping, or it's not going to really improve that much more'. A second participant agreed the earlier, the better as they had the group a few months after the stroke and that felt like the right time, 'for *Mum and I, the timing was really, really, good. It was really good, and it helped, you know it helped me to continue up to this point, so I liked the timing'* (P1).

Summary

The final theme summarises key ideas about what the future of the group self-management intervention could look like. Participants all expressed a strong sense that the groups should be continued and that there should be a follow-up group run after they had finished. In addition, participants felt that the sooner they could access the groups the better, suggesting that the intervention could be on offer when the stroke survivor is discharged from hospital.

8.4 Discussion

The current chapter presents findings exploring the acceptability of a group self-management intervention for stroke survivors from a carer's perspective. Overall analysis of focus group and interview data found that there were several aspects of the groups which were acceptable to those living with and caring for stroke survivors. Positive aspects of the groups described by participants included feeling less alone, understanding they could not wrap the stroke survivor in cotton wool and learning how other peers coped. In addition, all the participants expressed how they found it useful to compare their family member to other stroke survivors attending the group. No drawbacks to attending the groups were mentioned, and all the carers said the intervention should continue as it has the potential to benefit others in a similar position.

The findings enhanced understanding of how carers have to adjust to the new life they are faced with after a family member has a stroke, and how a collaborative management strategy had to be reached as opposed to one where carers were giving the orders. Similarly, previous work exploring the process that health care professionals go through when learning to practice using a self-management approach, described how their relationship with the stroke survivor changed, "from [a] dictatorship to a reluctant democracy" (paper title)[62]. Participants spoke about how the group helped clear the air in strained relationships, a finding that is crucial in light of the high rates of relationship break down that are reported post stroke[8]. In addition, findings that the intervention was seen to make attendees feel like someone cared, may go some way towards

counteracting the feelings of abandonment reported by the stroke survivors in the literature[8].

The theoretical underpinnings of the intervention were reflected in the carer's experiences of the group. Within Social Cognition Theory, both vicarious learning and mastery are identified as sources of self-efficacy and ways to facilitate behaviour change. In this study aspects of vicarious learning were reported and viewed as a possible mechanism of change for the carers, a finding which has not previously been observed within group self-management interventions. The concepts of collaboration, problem solving, and reflection were also evidenced. All of these are self-management techniques advocated by Bridges., suggesting there was fidelity to the intervention. For example, by asking a peer how they have been coping, reflection is facilitated as well as vicarious learning, then by discussing ways they could apply these skills to their own life they are collaboratively working to problem solve.

Finally, what carers would like the future of the intervention to look like, supported previous findings that a stroke facilitator could be a valuable component to the intervention[39]. However, previous work explored this concept with stroke survivors, and the current work advances the field by exploring it with carers. The final theme also corroborates previous findings that carers would find a follow-up session valuable[13], and expands on these findings by exploring what format this could be delivered in and when they could be run. However, the optimum number of follow-up sessions is still unknown.

8.4.1   Limitations

There are a number of limitations that should be considered when interpreting the results of this research. Firstly, the focus groups had a maximum of three participants which is less than the eight recommended by guidelines[154]. As a result, the discussion may be less varied, and there is a possibility that the data generated was not exhaustive of carer views. Future research could maximise the numbers by holding more intervention groups in the hope more carers would attend and thus be available to give feedback. Secondly, focus groups may have made some participants feel they could not express their true opinions if they differed to others in the group which would bias the data toward the 'loudest' findings in the group.

Thirdly, three of those invited did not take part in the research. As each participant gave a different reason for non-participation, this suggests there was not one particular barrier to recruitment. However, it does mean that all the carers who took part were 'informal' and a family member so the findings cannot be generalised to paid carers, friends or volunteers that take on the caring role. Future research could maximise the inclusion of

these groups by holding focus groups within working hours or using purposeful sampling to ensure different types of carer are included.

Finally, EC was present during both focus groups which may have influenced responses. However, having participants know the facilitator may also have been advantageous as they may have felt more relaxed talking to someone they have an established rapport with, so it is difficult to know which offers best practice.

8.4.2 Implications for intervention development

The research presented in this chapter has generated a number of recommendations for future practice. Carers have provided invaluable insight into the possible mechanisms of impact and how future self-management intervention might evolve. The findings should be interpreted only as preliminary as the work was conducted as part of a feasibility study and may differ to those found from a larger trial. The recommendations are as follows: Firstly, future group self-management interventions for stroke should consider including family and friends as they can also gain a number of benefits from the intervention. Secondly, follow-up sessions should be included to enable ongoing support. Consideration should also be given to whether an informal delivery structure of these follow-ups could gain the same benefits as a more formal one. Finally, both stroke survivors and self-management practitioners should be included as facilitators as they were seen to be a valuable part of the groups.

8.5 Conclusion

The findings provide some insight to the acceptability of the Bridges group self-management intervention with the carers of stroke survivors. The group self-management intervention was found to be acceptable and provide multiple benefits for carers, including a space to share ideas and meet others in a similar position, as well as a way to learn techniques to co-manage stroke. No detrimental effects of the intervention were reported. Future self-management interventions should include both carers and a stroke facilitator, and offer follow up sessions once the intervention has finished.

Chapter Nine

9 Chapter nine: A quantitative exploration of outcome measure effect size, and the intervention effect on mood, self-efficacy, activities of daily living and quality of life.

The previous two chapter explored *how* the group self-management intervention may be working, and this chapter explores *the extent* to which the intervention is working (if at all). For example, chapter seven explored the ways in which stroke survivor's confidence was increased, and the current chapter explores by how much.

9.1 Introduction

The MRC guidelines suggest both qualitative and quantitative outcomes should be used when evaluating complex interventions[24]. Qualitative outcomes are presented in the previous two chapters, so it is now important to capture quantitative outcomes. Doing so is particularly important in feasibility studies as they can provide key information that could facilitate the smooth running of future work. For example, determining the effect size of outcomes is essential for future sample size calculation, and determining the direction of effects is important for formulating future hypotheses. In addition, quantitative data can offer insight into the extent of an intervention effect.

In contrast to fully powered trials that only have one primary outcome, guidelines suggest that feasibility studies should have multiple outcomes of interest[24]. Both the wider literature and theoretical underpinnings of the group self-management intervention offer recommendations for which quantitative outcomes should be explored in the current chapter. For example, as the core concept of Social Cognition Theory (SCT), self-efficacy should be explored[14]. In addition, previous research suggests that mood[13], quality of life[43], and activities of daily living[15], should be explored as all three have been shown to improve as a result of self-management interventions. Previous literature also suggests a cost saving could be made from group self-management interventions. However, the aim of the current work is to explore feasibility, and it does not make sense for commissioners to be told that an intervention can save money before we know whether or not the intervention is feasible. Similarly, it would be unhelpful to know that an intervention has a significant effect if it is not feasible to implement it. With this in mind, the current study will explore the quantitative effect of the intervention and the

direction of change, but not statistical significance (more detail in section 9.2). Thus, the specific research questions are:

1.   Are there any differences between the intervention and control groups in quality of life, mood, self-efficacy, and activities of daily living six-months post baseline?

2.   Are there any within group changes in quality of life, mood, self-efficacy, and activities of daily living between the start of the intervention, the end of intervention and two-weeks follow up?

3.   Does the intervention have a protective effect against decreases in quality of life, mood, self-efficacy, and activities of daily living?

4.   What are the effect sizes of the intervention for the stroke self-efficacy scale (SSES), stroke and aphasia quality of life scale (SAQOL-39), Hospital anxiety and depression scale (HADS), and the Nottingham activities of daily living (NEADL) scale?

9.2 Method

It is important to remember that this study contributes to the wider thesis which explores feasibility and is interested in findings that can inform future work. Therefore, the current chapter does not aim to make inferences about statistical significance, and is not powered to do so. The sample size was calculated based on NIHR guidelines[74]. Accordingly, no formal power calculation was conducted. A sample size of 60 was decided on as described in chapter two, using guidelines for feasibility studies and drop-out estimations based on previous work.

Having said that, the analysis used in this study (described in more detail below) resulted in a P value being given. This value gives insight into the probability that the results occurred by chance, and in a powered study would give insight into whether the results were significant (if $P \leq 0.05$). As this study is not powered, at most the P value can give a weak indication of large effects, as smaller effects may not have been captured.

9.2.1 Recruitment

The full description of the recruitment process can be found in chapter two. In brief, participants were recruited to take part in the group self-management intervention from the UCLH HASU. Participants were included or excluded based on the criteria presented in chapter two (section 2.2.5.1), with one additional exclusion criteria: participants were excluded if they reported a second stroke as this may have impacted their responses on

the outcome measures. For example, a second stroke may lower mood and increase physical impairment thus skewing results[155].

9.2.2 Research design

A randomised waitlist control design was used. Participants were randomised to a condition using a block randomisation chart after they had completed the baseline measures. Those allocated to the waitlist condition completed a six-month wait period prior to taking part in the intervention. Those allocated to the intervention condition took part in the group self-management intervention straight away.

9.2.3 Outcome measures

The outcomes measures were collected at four time points, three of these were the same for both conditions: baseline, end of the intervention and two-weeks post intervention. Those in the waitlist condition also completed outcome measures at the start of the waitlist period, whilst those in the intervention condition completed the measures at six-months post intervention. Four outcome measures were collected (appendix 13) and are discussed in turn below.

(1) The Stroke and Aphasia Quality Of Life 39 (SAQOL-39-39) measure was used to measure the quality of life of participants. The measure consists of 39-items and has been validated for use with the stroke population, including those with aphasia[156]. The measure is shorter than the original 54 item measure, so it reduces participant burden but still maintains good psychometrics and valid subdomains[157]. There are four subdomains which explore different types of quality of life: communication (questions 17-21,34 and 39), psychosocial (questions 23-29, 33, 35-37) energy (questions 22, 30-32) and physical (1-16, and 38). The measure uses a Likert scale from 1-5. The composite score was calculated by summing each individual item in the questionnaire and dividing it by the total number of questions (39) to give the mean average across scores. The higher the score, the higher an individual's quality of life.

(2) The Stroke Self-Efficacy Scale (SSES) is a 13-item measure which was used to assess each participant's belief in their own ability to complete a range of tasks. It was designed specifically for the stroke population and has been recommended for use in research as part of a battery of tests[158]. The composite score is calculated by adding up each unique item to give a total score with a maximum of 130. The higher the total, the higher an individual's self-efficacy.

(3) The Nottingham Extended Activities of Daily Living Scale (NEADLS) was used to indicate which day-to-day activities individuals had done in the week prior to the assessment. The measure covers a range of activities and is thus recommended for use within the stroke population where heterogeneous impairments may be reported[159]. The measure uses a Likert scale with four possible answers. The measure consists of 22 questions, but two were omitted: Question 21 (manage your own garden) and 22 (drive a car) were excluded from the analysis as many participants were told not to drive post stroke or did not have a garden, neither of which would be changed by the intervention. Thus, the maximum score that could be obtained was 20. The higher the score, the more activities of daily living an individual can partake in.

(4) The Hospital Anxiety and Depression Scale (HADS) is a 14-item measure that gave insight into an individual's mood, namely, anxiety and depression. The HADS has been validated for use with the stroke population, and the short length means that it minimises burden for those completing the measure[160,161]. The measure uses a Likert scale from 0 to 3, and integrates reverse scoring to ensure participants are reading the questions. The composite score is calculated by adding up each unique item score to give a total sum, a higher score indicates a higher level of anxiety and depression. The maximum that can be obtained is 42. Scores of 11 or over indicated the presence of anxiety and/or depression. There are two subdomains within this measure, anxiety and depression. Anxiety is calculated by adding the score from questions 1,3,5,7,9,11 and 13 together, and depression is calculated adding together the score from questions 2,4,6,8,10,12 and 14.

9.2.4   Data collection

Where possible, participants completed the outcome measures using an online data collection programme called 'RedCap' which auto uploaded answers to a database to minimise human error. The software was accessed via hand held tablets. If this was not possible (for example, some participants did not want to use the tablets), outcome measures were completed using paper versions of the measures. If participants requested the measures to be posted to them, a stamped addressed envelope was also sent to facilitate their safe return, and participants were called to confirm they had received the measures. In all circumstances, a researcher was with the participant in person or available over the phone to answer any questions that may arise. This was particularly important for people with aphasia as they may have found reading the

questions and completing the measures challenging. Any measures completed on paper forms were subsequently inputted to RedCap by EC or a research assistant (KE).

9.2.5 Analysis

Results from the analysis are to be considered only as descriptive as the study is not powered to detect any significant difference in measurements used. Data were analysed by EC with guidance from a statistician (GB) to ensure best practice.

All data were analysed within SPSS 21[162]. Participants with missing data on the HADS, SSES and NEADL measures were removed in line with Complete Case Analysis (CCA)[163], assuming all data were missing at random. The latter was assessed using Little's Missing Completely At Random (MCAR) test[164]. Missing data were coded in SPSS 21 so that it was accounted for in the calculation of mean scores. The distribution of the data was assessed for normality using the Kurtosis test, where a value between -2 and 2 suggested the data would meet the assumption of normality[165]. A reasonable set of demographics were included as covariates: time post stroke, age, gender, ethnicity, living situation, aphasia, comorbidity and NIHSS at stroke onset. Baseline scores were also included as covariates. Partial eta-squared values of ≥ 0.150 were reported, highlighting covariates to which 15% or more of the variance could be accountable. The method of analysis used for each individual research question is described in turn below.

1. *Are there any differences between the intervention and control groups at six-months post baseline in quality of life, mood, self-efficacy, and activities of daily living?*

Question one was answered using a between groups analysis. Four univariate Analyses of Covariance (ANCOVA) were run to compare the outcome measure scores between the waitlist and intervention group at six-months post baseline. This would be the end of the six-month waiting period for those in the waitlist condition, and six-months post intervention for those in the intervention condition. Potential between-group differences were controlled for by the inclusion of covariates as detailed above. Levene's test indicated where the assumption of homogeneity of variance was met ($P>0.05$), assumptions of normality and whether the data were missing completely at random were explored as described above.

2. *Are there any changes in quality of life, mood, self-efficacy, and activities of daily living between the start of the intervention, the end of intervention and two-weeks follow up?*

Question two was addressed using a larger data set than question one as it includes outcome measures collected at two time points post intervention as opposed to one: the end of the intervention and two-weeks follow up. As both the intervention and waitlist groups completed measures at these time points, data were combined from both to enable a larger sample size. Although this meant no control group was available, answering this question offered preliminary insight into whether any effects could be detected earlier than six-months post-intervention. A repeated measures ANCOVA compared outcome measures and subdomains across three time points: pre-intervention, post intervention and at two-weeks follow up. Time was entered as a categorical covariate (e.g. time1, time 2, time 3). Post hoc pairwise comparisons were conducted to see if there were any differences between each individual time point. This was done using the Bonferroni adjustment for multiple comparisons. As the assumption of sphericity is often broken when using repeated measures analysis, Mauchy's test was used to assess for sphericity. Where the assumption was violated (P ≤0.05) the Greenhouse-Geisser test was used to correct for this[165]. Normality was assessed as described above.

3. *Does the intervention have a protective effect against decreases in quality of life, mood, self-efficacy, and activities of daily living?*

Question three explored whether the intervention could prevent a decline in participant scores. For example, although participant's scores may not improve, if they declined during the waiting period but then returned to baseline post intervention then the intervention could be said to have a protective effect. A repeated measures ANCOVA explored waitlist group scores at four time points: the start of the waiting period, the end of the six-month waiting period, the end of the intervention and finally two-weeks post intervention. Time was entered as a categorical covariate (e.g. time 1, time 2, time 3, time 4). Post hoc pairwise comparisons were conducted as described in question two. Assumptions of sphericity and normality were explored as described above.

4. *What is the effect size of the intervention for the stroke self-efficacy scale, stroke and aphasia quality of life scale, Hospital anxiety and depression scale, and the Nottingham activities of daily living scale?*

In order for this work to progress to a fully powered randomised control trial, the effect size of outcomes is needed to inform the future sample size calculations. As it is unknown what the primary outcome of future randomised controlled trials might be, the effect size of each outcome was calculated using Cohen's d based on pooled standard deviations. Both the waitlist and control group mean scores at six-months post baseline were used in the calculation which was done using an online tool developed by the University of Colarado[166]. In keeping with Cohen's guidelines a small effect size was classified as 0.2, a medium effect size as 0.5 and a large effect size as 0.8[165]. The recommended sample sizes for future work were subsequently calculated using an online tool that considered Cohen's d, probability level (0.05) and desired effect size (0.8)[167]. Calculations were also inflated based on the estimated drop-out rate. The latter was calculated as follows: the total number of participants enrolled in the study minus those included in the analysis. The associated percentage was also calculated.

9.3 Results

Figure six in chapter six illustrates the process from recruitment to the start of analysis and reasons for exclusion. In total, 44 participants were included in the analysis. Baseline characteristics and participant demographics are detailed in chapter six, table five.

1. *Are there any differences between the intervention and control groups at six-months post baseline in quality of life, mood, self-efficacy, and activities of daily living?*

Differences between the waitlist and intervention groups at six-month post baseline for all four outcome measures and sub domains were explored using ANCOVA. Assumptions of normality were met for all four outcomes. Covariates were included as described previously. The Little's MCAR test suggested data were missing at random across all four measures at baseline and six-months follow-up (χ^2=23.158 DF =43, P=0.994). HADS has four missing values at six-months post intervention, the NEADL and SSES had three, and the SAQOL-39 had zero.

Main Domains

Between group differences at six-months post baseline are illustrated in figure nine. All four of the outcome measures showed an improvement in scores in favour of the

intervention group. The intervention group had higher estimated mean scores than the waitlist group at six-months follow up on the SESS by 9.7 ($F_{(1,14)}$=0.133, P=0.389), HADS by 1.4 ($F_{(1,13)}$=0.133, P0.722), SAQOL-39 by 0.2 ($F_{(1,13)}$=0.242, P=0.629), and finally NEADL by 1.2 ($F_{(1,13)}$=0.379, P0.549). Partial eta squared revealed that three of the outcomes had covariates that were attributed to at least 15% of the variance in outcome measures and each of these are shown in table eleven. For example, 55% of the variance in SAQOL-39 scores at six-months was attributable to baseline scores on the SAQOL-39, 26% to comorbidities and 24.7% to aphasia.

Sub Domains

Figure 10 shows the mean scores for each of the subdomains in both the intervention and waitlist conditions. All subdomains of the SAQOL-39 were found to be higher in the intervention group than the waitlist control at six-months post baseline: psychosocial ($F_{(1,17)}$=0.122, P=0.731), physical ($F_{(1,17)}$=0.607, P=0.447), energy ($F_{(1,17)}$=1.166, P=0.295), and communication ($F_{(1,17)}$=0.027, P=0.872). The depression subdomain of the HADS was found to improve in the intervention group ($F_{(1,15)}$=0.842, P=373), but the anxiety subdomain was found to decline ($F_{(1,15)}$=0.842, P=0.373).

Table 11. Amount of variance in the outcome scores for questions 1,2 and 3 that was accounted for by covariates.

Covariate	Outcome Measure										
	Question One			Question Two				Question Three			
	SSES	NEADL	SAQOL-39	SSES	HADS	NEADL	SAQOL-39	SSES	HADS	NEADL	SAQOL-39
Age	0.210	-	-	-	-	-	-	0.150	-	-	0.475
Aphasia	-	0.247	-	-	-	0.190	0.273	-	-	--	-
Comorbidities	-	0.260	-	0.300	0.150	-	-	0.710	-	0.355	-
Employment	-	-	-	-	-	-	-	0.344	0.163	0.482	0.310
Ethnicity	-	-	-	0.356	0.170	0.380	0.306	-	-	-	-
Gender	0.160	-	-	-	-	-	-	1.760	0.206	-	0.245
Group	-	-	-	-	-	-	0.217	-	0.160	-	-
Living Situation	-	-	-	-	0.172	-	-	-	-	--	-
NIHSS	-	-	-	-	0.199	-	-	-	-	-	-
Time post stroke	0.232	-	-	-	-	0.337	-	0.244	-	0.218	0.186
SAQOL-39 Baseline	-	-	0.550	0.547	-	0.510	-	-	-	-	-
HADS Baseline	-	-	-	0.157	0.161	0.188	-	-	-	-	-
NEADL Baseline	-	0.285	-	-	-	-	0.243	-	-	-	-
SSES baseline	-	-	-	-	-	0.290	0.576	-	-	-	-

Note 1. Partial eta squared scores ≥0.150 for each ANCOVA conducted in questions 1,2 and 3. The raw values presented in the table suggest the covariate explained 15% of more of the variance in outcome. For example, a value of 0.210 would mean the covariate accounted for 21% of the variance in outcome scores.

Figure 9. Estimated mean scores of SSES, NEADL, HADS and SAQOL-39 at six-months post baseline for the intervention and control group.
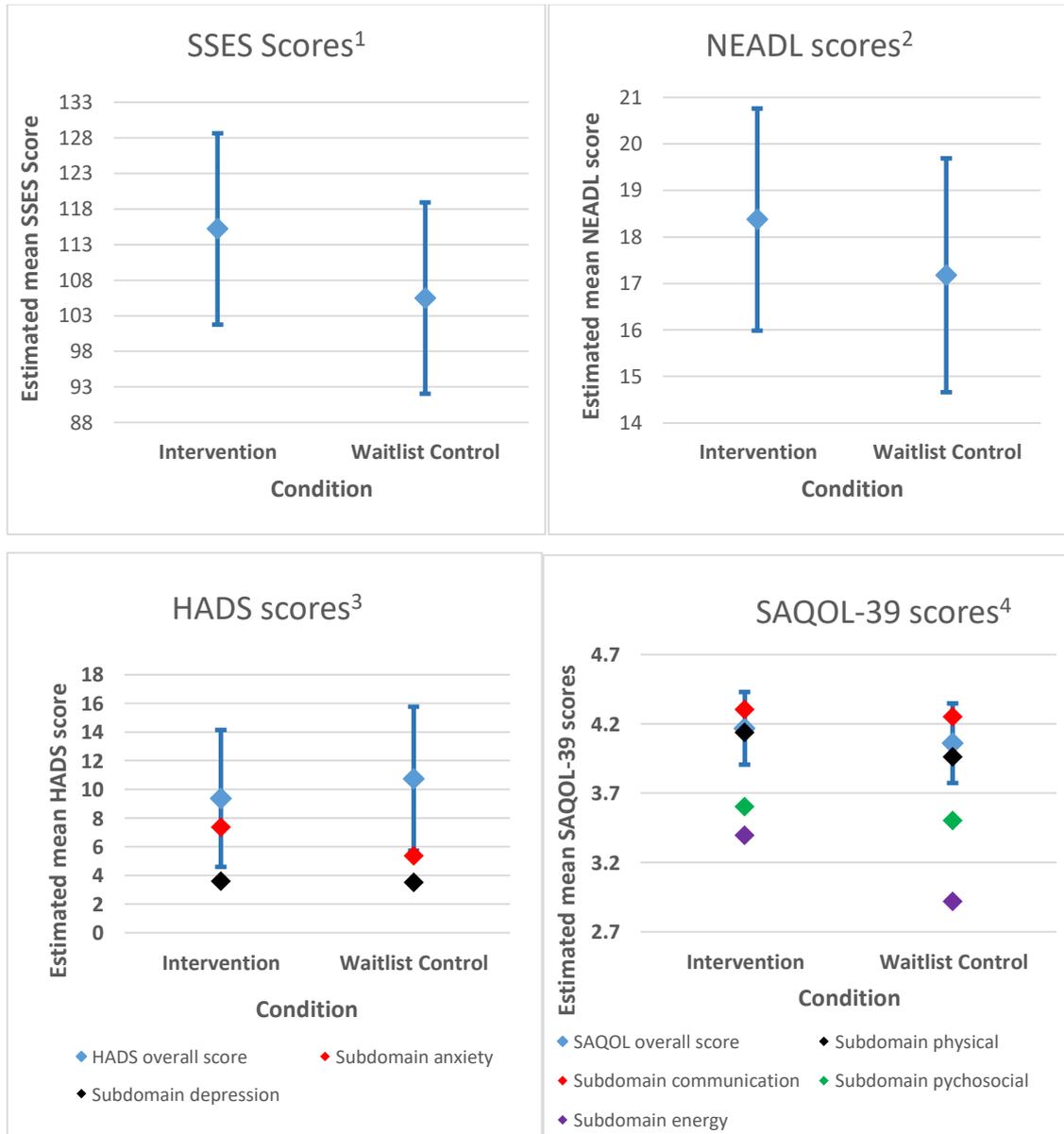
[1]N=15, Levene's test; F=1.177, P=0.287, a higher score suggests higher self-efficacy. [2]Intervention N=15, waitlist control N=14, Levene's test; F=0.146, P=0.705, the higher the score the more activities of daily living completed in the past week. [3]Main HADS domain; Intervention N=15, waitlist control N=14, Levene's test; F=2.858, P=0.102, Anxiety; Intervention N=12, waitlist control N=17, Levene's test; F=10.973, P=0.003 (*violates the assumption of homogeneity but ANCOVA remains robust when the sample sizes are relatively similar),* CIs intervention=4.474-10.240, waitlist control=3.277-7.984. Depression; Intervention N=13, waitlist control N=18, Levene's test; F=2.323, P=0.138, CIs intervention=2.183-7.894, waitlist control=2.900-7.600. The lower the score, the lower an individual's mood. [4]SAQOL-39 main domain; Intervention N= 17, waitlist control N=15, Levene's test; F=0.315 , P=0.579, All subdomains: Intervention N=18, waitlist control N=13. Physical; Levene's test; F=2.062, P=0.162, CIs intervention= 3.747-4.593, waitlist control=3.601-4.296. Communication; Levene's test; F= 0.049, P=0.826, CIs intervention=3.747-4.593, waitlist control=3.601-4.296. Psychosocial; Levene's test; F=0.826, P=0.371, CIs intervention= 3.182-4.027, waitlist control=3.158-3.852. Energy; Levene's test; F=1.462, P=0.236, CIs intervention=2.742-4.051, waitlist control=2.384-3.459, the lower the score, the lower an individual's quality of life.

2   *Are there any changes in quality of life, mood, self-efficacy, and activities of daily living between the start of the intervention, end of intervention and two-weeks follow up?*

Repeated measures ANCOVAs analysed the change in outcome scores across three time points: baseline, end of the intervention and two-weeks follow up. The assumption of normality was met for all variables. Little's MCAR test suggested data were missing at random across all four measures and time points (χ^2=114.309 DF = 126, P= 0.764). The HADS and SSES had nine missing values across all time points, and the NEADL and SAQOL-39 had eight. Of these, 11 were missing at the start of the intervention, eight were missing at the end of the intervention and 15 were missing at two-weeks follow-up. It may be that more data were missing at the two-week follow-up as participants may have been less engaged with the project once the intervention had ended.

Main Domains

Repeated measures ANCOVA revealed the effect of time for the four outcome measures was as follows: HADS-F (2,14)=1.513, P=0.254, SAQOL-39-F(2,15)=2.080, P=0.159, SSES-F(2,13)=2.905, P=0.091, and NEADL-F(2,14)=0.151, P=0.861. Post hoc pairwise analysis revealed the difference for each domain between the following time points (1) the start of the intervention and the end of the intervention, (2) and the start of the intervention and two-week follow-up. All of the outcomes had differences with associated P values greater than 0.05. The estimated mean scores at each of these time points and direction of change are presented in figure 10. Partial eta squared revealed that all the outcomes had covariates that were attributed to at least 15% of the variance (table 10). For example, 30% of the variance in NEADL outcome scores and 15% in the HADS score was accounted for by comorbidities.

Subdomains

Analysis was conducted on the subdomains of the SAQOL-39 (physical, psychosocial, communication and energy), and HADS (anxiety and depression) using repeated measures ANCOVAs. Results revealed the effect of time was as follows: physical-F(2,16)=0.108, P=0.899, energy-F(2,16)=0.628, P=0.546, psychosocial-F(2,17)=0.687, P=0.516, communication-F(2,16)=0.1.031, P=0.379, depression-F(2,16)=0.284, P=0.757, anxiety-F(2,16)=0.151, P=0.861. Post hoc pairwise analysis revealed the difference between the start of the intervention and the end of the intervention, and the start of the intervention and two-week follow-up (see figure 10 for mean estimates). Results of interest were the differences between the start of the intervention and two-weeks follow-up for the psychosocial (P=0.043) and anxiety (P=0.046) subdomains.

Figure 10. Estimated mean SSES, NEADL, HADS and SAQOL-39 scores across three time points. Data were combined from both the waitlist and intervention group to create these line graphs (N=44).
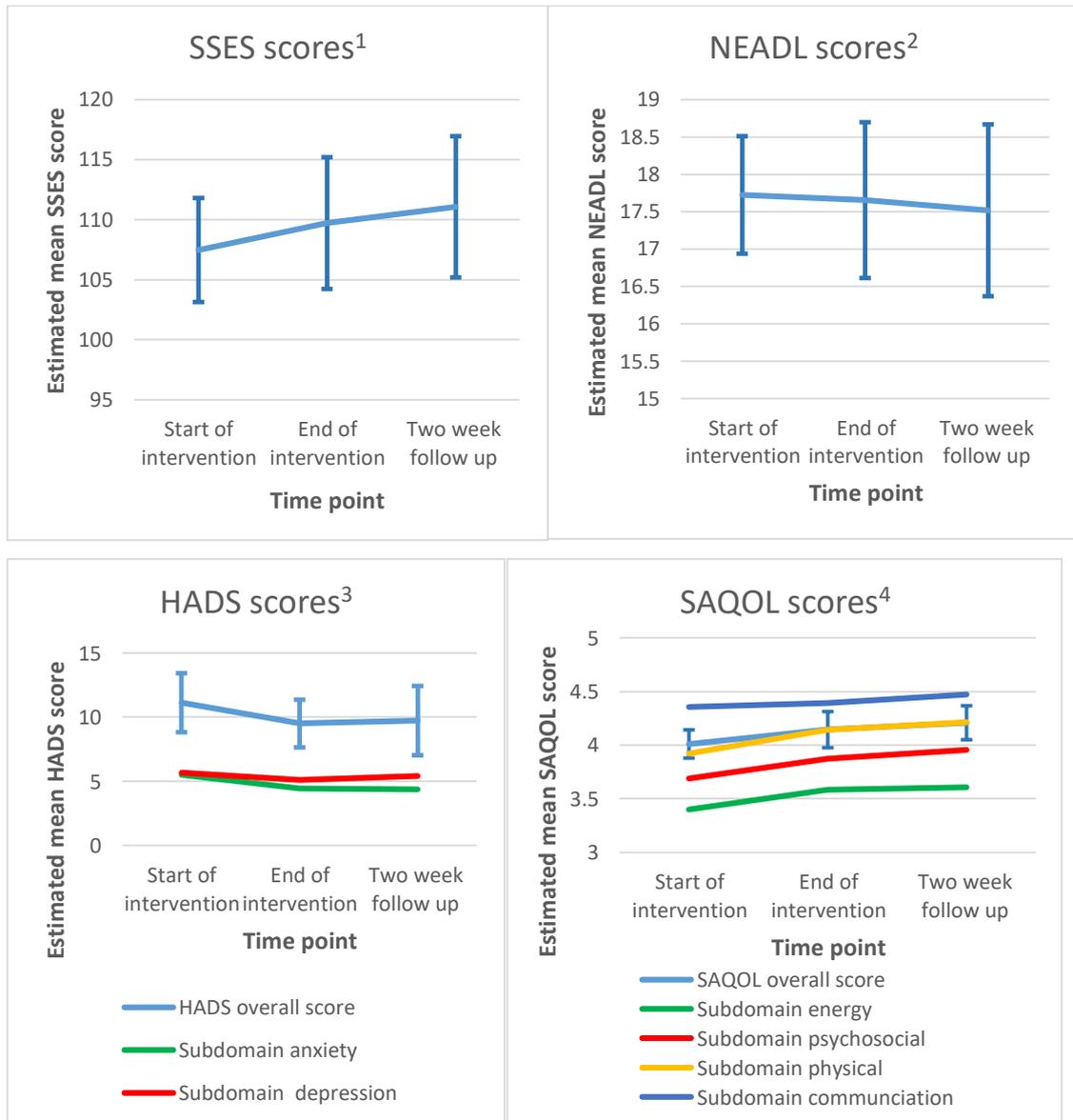
[1] N=28, Mauchy's test; χ^2(2)=1.573, P=0.455, a higher score suggests higher self-efficacy. [2] N=29, Mauchy's test; χ^2(2)=0.662, P=0.718, the higher the score the more activities of daily living completed in the past week. [3] HADS main domain: N=29, Mauchy's test; χ^2(2)=2.492, P=0.288. Depression; N=30, Mauchy's test; χ^2(2)=3.753, P=0.153, CI start =4.556-6.777, end=4.042-6.158, two-weeks=4.305-6.495. Anxiety; N= 30, Mauchy's test; χ^2(2)=2.448, P=0.294, CI start =4.177-6.823, end=3.155-5.712, two-weeks=3.091-5.642, the lower the score the lower an individual's mood. [4] SAQOL-39 main domain: N=30, Mauchy's test; χ^2(2)=1.941, P=0.376. Energy; N= 30, Mauchy's test; χ^2(2)=0.566, P=0.754, CI start =3.020-3.780, end=3.127-4.040, two-weeks=3.280-3.937. Psychosocial; N= 31, Mauchy's test; χ^2(2)=0.397, P=0.820, CI start =3.361-4.017, end=3.484-4.258, two-weeks=3.598-4.314, Physical; N= 30, Mauchy's test; χ^2(2)=0.893, P=0.640, CI start =3.676-4.167, end=3.852-4.430, two-weeks=3.946-4.482. Communication; N= 30, Mauchy's test; χ^2(2)=1.829, P=0.401, CI start =4.093-4.622, end=4.126-4.665, two-weeks=4.227-4.716, the lower the core the lower an individual's quality of life.

3   Does the intervention have a protective effect against decreases in quality of life, mood, self-efficacy, and activities of daily living?

A repeated measures ANCOVA explored whether the intervention may have a protective effect by summarising the scores from the waitlist group only. As one of the four variables had kurtosis values between -2 and 2 and the remaining variable a value of 2.868 the data was considered to meet the assumption of normality. Little's MCAR test suggested data were missing at random across all four measures at the four time points (χ^2=75.175, DF = 87, P=0.813). The SSES had nine missing values across all time points, HADS and NEADL had 8, and SAQOL-39 had six. Two-weeks follow-up had the most missing values across all time points (44.444%) perhaps for the same reasons mentioned in question two.

Main Domains

The effects of time on the four outcome measures were as follows: HADS-$F_{(3,5)}$=3.545, P=0.103, NEADLS-$F_{(1,15)}$=2.565, P=0.161, SSES-$F_{(3,2)}$=0.621, P=0.665, or SAQOL-39-$F_{(3,5)}$=0.628, P=0.627. The direction of change across the four time points is illustrated in figure 12. Post hoc analysis explored the difference between the start of the waitlist period and three additional time points: start of the intervention, end of the intervention, and two-weeks post intervention: Each of these comparisons had a P value greater than 0.05. The mean scores and direction of change is shown in figure 11. Partial eta squared revealed that all four outcomes had covariates that were attributed to at least 15% of the variance (see table 11). For example, 15% of the variance in SSES outcomes and 47.5% in SAQOL-39 outcomes was accounted for by age.

Subdomains

A repeated measures ANCOVA was conducted on all four subdomains of the SAQOL-39 (physical, psychosocial, communication and energy), and both subdomains of the HADS (anxiety and depression). The effects of time were as follows: psychosocial ($F_{(3,4)}$=2.399, P=0.209), energy ($F_{(3,4)}$=3.632, P=0.122), communication ($F_{(3,4)}$=2.195, P=0.231) or depression ($F_{(3,3)}$=0.577, P=0.669). There was weak evidence that, anxiety ($F_{(3,3)}$=8.675, P=0.055) and physical quality of life ($F_{(3,4)}$=5.971, P=0.059) may have a preliminary significant effect across time if the sample size was increased. Post hoc analysis revealed the difference in all four outcome measure scores between each individual time point, but none had a P value of less than or equal to 0.05 (see figure 11 for the direction of change and mean scores).

Figure 11. Estimated mean scores of SSES, NEADL, HADS and SAQOL-39 across four time points: T1-baseline, T2-start of intervention/end of waitlist period, T3-end of intervention, T4-two-week follow-up
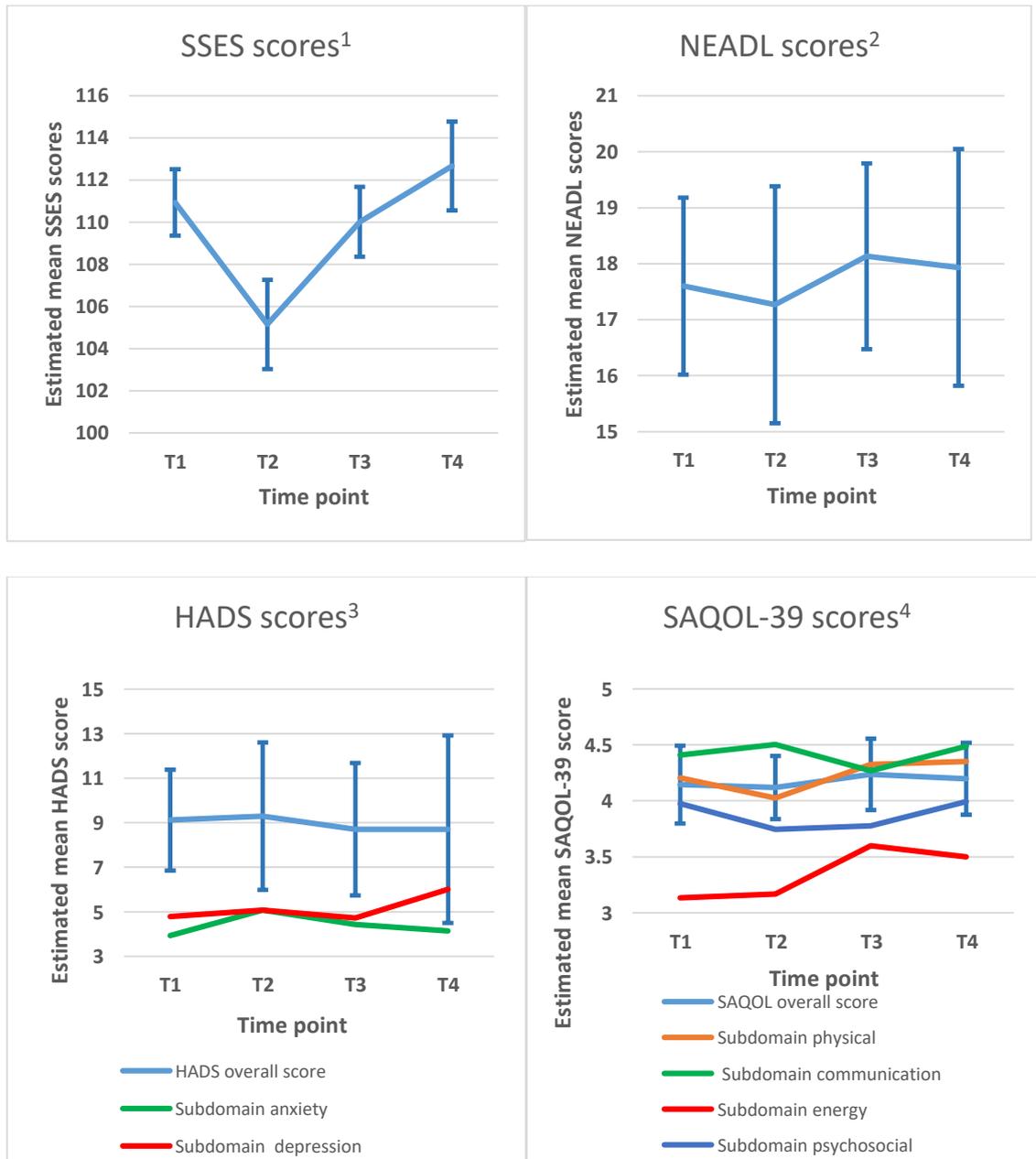
[1] N= 14, Mauchy's test; χ2(5)=5.684, P=0.365, a higher score suggests self-efficacy [2]N= 15, Mauchy's test; χ2(5)=13.882, P=0.020, the higher the score the more activities of daily living completed in the past week. [3]HADS main domain; N= 17, Mauchy's test; χ2(2)=3.463, P=0.633. Anxiety; N= 14, Mauchy's test; χ2(5)=10.141, P=0.080, CI T1=2.377-5.480, T2=2.397-7.745, T3=0.827-8.031, T4=2.499-5.786. Depression; N= 14, Mauchy's test; χ2(5)=3.801, P=0.590, CI T1=3.277-6.294, T2=3.066-7.077, T3=2.434-6.994, T4=3.669-8.33, the lower the score the lower an individual's mood.. [4]SAQOL-39 main domain; N= 17, Mauchy's test; χ2(2)=4.530, P=0.481. Physical; N= 17, Mauchy's test; χ2(2)=4.530, P=0.481, CI T1=3.798-4.493, T2=3.863-4.403, T3=3.919-4.555, T4=4.122-4.584. Communication; N= 15, Mauchy's test; χ2(5)=3.884, P=0.574, CI T1=4.035-4.784, T2=4.229-4.780, T3=3.832-4.701, T4=4.169-4.803. Energy; N= 15, Mauchy's test; χ2(5)=3.832, P=0.581, CI T1=2.539-3.728, T2=2.345-3.989, T3=.078-4.122, T4=2.987-4.013. Psychosocial; N= 15, Mauchy's test; χ2(5)=10.884, P=0.058, CI T1=3.550-4.401, T2=3.366 4.125, T3=3.419-4.132, T4=3.539-4.449, the lower the core the lower an individual's quality of life.

4   What are the effect sizes of the intervention for SSES, NEADL, HADS and SAQOL-
     39?

Cohen's d values revealed that three of the outcome measures had trivial effect sizes:
The SAQOL-39 and HADS (see table 12). The NEADL and SSES measures were found
to have a small effect size. The associated sample sizes required for a fully powered trial
are presented in table 12. Estimated dropout rates were calculated to be 26.667% (16
participants were not included in the analysis out of a total of 60), and the sample size
was inflated accordingly. For example, the resulting sample size required for a trial with
a one-tailed hypothesis using the SAQOL-39 as the primary outcome measure was 1006
with equal numbers in the intervention and control groups. However, if we include the
dropout rate observed in this study of 26.667%, then that would inflate the sample size
needed to 1274.

*Table 12. Cohen's d for SSES, SAQOL-39, NEADL, and HADS and the associated
sample size required for a fully powered trial.*

Outcome measure		N	Mean at six-months post baseline	SD	Pooled SD	Cohen's d	Total sample size required with equal numbers in intervention and control groups.			
							One-tailed hypothesis		Two-tailed hypothesis	
							N	+ drop out of 26.667%	N	+ drop out of 26.667%
SSES	Intervention	15	115.212	22.88	20.797	0.469	114	144	146	184
	Waitlist	15	105.468	18.48						
SAQOL-39	Intervention	17	4.168	0.774	0.681	0.157	1006	1274	1267	1605
	Waitlist	15	4.061	0.573						
NEADL	Intervention	15	18.371	3.218	2.865	0.418	144	182	182	231
	Waitlist	14	17.173	2.463						
HADS	Intervention	15	9.366	7.778	7.451	0.185	724	917	920	1165
	Waitlist	14	10.751	7.109						

9.4 Discussion

The current chapter presented a quantitative exploration of the novel group self-management intervention explored in the wider thesis. The findings are to be considered only as preliminary as the work was not powered to make any statistical inference about quantitative changes. However, the present chapter still contributes to the research field as it answered four research questions that facilitate progression from feasibility to a fully powered trial. General considerations that should be made when interpreting these results are discussed below, followed by considerations specific to each research question.

9.4.1 General considerations

The research design was discussed in detail in chapter two but will also be considered briefly here. One strength of the design is the use of randomisation for condition allocation as it reduces the risk of researchers biasing the decision. A second strength is the use of a waitlist control group which was advantageous for two reasons. Firstly, in keeping with ethical gold standards, a waitlist control group enabled all participants to experience the intervention and any associated benefits[168]. Secondly, it provided a control group for comparison, which enhanced the reliability of results. However, previous research highlights one limitation of a waitlist control group, stating that participants in this condition might improve simply because they know they will have access to the intervention at a later date[101].

There are a number of other factors that may have influenced the results. Firstly, it may be that there is a threshold of exposure to the group self-management intervention that needs to be reached in order to achieve a significant effect. For example, previous work concluded rehabilitation therapies do not make a significant difference to patient outcomes[169], but it has been argued in the public domain that these results were only found because of the minimal hours of therapy the participants were given (eight and a half hours of therapy over three-months). Future work should explore what the optimum dose of self-management is in both a one-to-one and group setting as neither has been explored previously.

Secondly, the optimum length of delivery for the group self-management intervention has not been determined. Perhaps six-weeks would be better than four, two-and-a-half-hour session more effective than two, or multiple sessions in a week more effective than one. In addition, the optimum content has not been designed. It may be that additional concepts could be added to improve how effective the intervention is, or some taken

away. Finally, the optimum time to capture the effect of self-management interventions is unknown. For example, maybe capturing outcomes at one-month post intervention would be better than six. As self-management is such a personal process[149], it may be that the best point of capture may also vary from person to person, making doing so particularly challenging for researchers.

9.4.2 Considerations for each research question

As well as the general discussion points above, there are a number of considerations specific to each research question. These are presented below.

1.   *Are there any differences between the intervention and control groups at six-months post baseline in quality of life, mood, self-efficacy, and activities of daily living?*

The analysis conducted in question one was not powered to look for significant differences between the intervention and control group at six-months post baseline. However, the changes detected were all in favour of the intervention group. Similarly, previous work exploring self-management interventions found improvements in favour of the intervention group for depression[47], self-efficacy[49], quality of life[43] and activities of daily living[123].

In order to be powered for significance, question four suggested much larger sample sizes would be needed to detect differences between groups at six-months post baseline. Indeed, the Shanghai Chronic Disease Self-Management Programme had a sample size of 954 and found significant differences between groups at six-months post intervention for self-efficacy[47]. However, having a larger sample size (e.g. 1274 as recommended for the SAQOL-39 in question four) may be problematic from a practical point of view as it may be harder to recruit and manage this number of participants. Whether it would be cost-effective to invest in research with such small effects should also be considered. Especially as the sample size may not be the reason that no significant results were found. For example, participants may not have continued to use the techniques away from the groups, or the effects may simply last less than six-months. Future work should collect data at earlier time points, such as one-month post intervention (and at the matched time for those in the waitlist group) to determine if there is an effect earlier on. In addition, future work should also consider ways to capture how much participants are using the self-management techniques once the intervention ends.

The second discussion point for question one also applies to questions two and tree as they each identified variables that accounted for at least 15% of the variance in outcome

scores. For example, question one showed that age accounted for 21% of the variance in SSES outcomes. However, the current work was not able to determine the direction of this effect and so it is unknown whether older participants (over 65) or younger participants (under 65) may have responded more positively to the intervention. Future work should explore this in more detail as it may influence who takes part in the intervention. If the intervention shows no effect for people under the age of 65 then they may gain very little from taking part, and researchers could go on to explore how the intervention could be improved for this age group.

In addition to the above considerations, readers should be aware of the limitations associated with the analysis performed in question one. Firstly, no attempt was made to control for contamination in the control group. It may be that people in the control group sought out their own self-management support during the waitlist period. This is difficult to overcome. Having no contact with individuals in the control group enables a truer representation of standard care, but also means researchers are unable to check whether individuals have engaged with additional services. One solution may be for future work to ask participants at the end of the wait list period if they have engaged with any additional support. Those that have could then be excluded.

Finally, it may be that between group differences can explain the results found in question one, as opposed to the intervention. For example, people in one group may all have been older or more confident that then the other. Two things were done to try and overcome this in the current work. Firstly, a range of variables were included as covariates in the analysis. Secondly, a waitlist design was used which enabled a within group analysis to be conducted for comparison (see question three). The waitlist group had scores from both the six-month wait period, and after they had taken part in the intervention. As the same individuals took part at both of these time periods, there was no risk of between group differences explaining the results. Therefore, if the intervention was found to improve outcomes in the within group analysis, it strengthens the case that the intervention also improved outcomes in the between-group analysis (and not between group differences).

2.   Are there any within group changes in quality of life, mood, self-efficacy, and activities of daily living between the start of the intervention, the end of intervention and two-weeks follow up?

There is no previous work exploring whether a group self-management intervention for stroke has an effect on outcome measures at two-weeks post intervention, which makes this work the first in the field to do so. The majority of other research that has explored

group self-management interventions captured outcomes at four, six, or nine months post intervention[15,47,49,63,122]. These previous research studies have found group self-management interventions can significantly improve exercise, cognitive symptom management, energy, health distress and social roles[15,47,49,63,122]. However, there are a number of reasons that the Bridges group self-management intervention may not replicate these significant findings in a definitive trial. Firstly, the majority of these previous studies were based on different interventions, mainly the Chronic Disease Self-Management Programs (none were based on Bridges). Secondly, they all used different outcome measures to the current study. Where possible, future work should try and standardise the use of outcome measures and intervention type as this enables comparison and meta analyses.

One limitation of the analysis used in question two was the lack of a control group. The latter means that the results could be specific just to this group of people, and/or have been seen without participants taking part in the intervention (e.g. they may be due to a natural improvement over time). This consideration also applies to the analysis conducted in question three as it has no control group. However, not having a control group does have one benefit: it removes concerns about between group differences (discussed previously).

3.   *Does the intervention have a protective effect against decreases in quality of life, mood, self-efficacy, and activities of daily living?*

Quality of life, self-efficacy, mood and activities of daily living all declined over the six-month wait period, but the current study was not powered to find out if this effect was significant. Similarly, previous work that explored The Chronic Disease Self-Management Programme found that the control groups scores did significantly decline[63], suggesting the intervention may have a protective effect for family roles and fine motor tasks. A second study, analysed a community-based intervention aiming to improve self-care management in stroke survivors. The results revealed no significant improvements for walking practice in the intervention group. However, when the researchers looked at this in the control group a significant decline was found suggesting the intervention may have a protective effect[124]. Both these former studies had larger sample sizes (100 and 147 respectively) than the current study, which may explain how they were able to detect statistically significant results. However, both also used different interventions to the one explored in this thesis, so it should not be assumed that if the sample of the current work is increased that statistical significance will follow.

In addition to the general considerations discussed previously, one further limitation should be noted regarding the analysis used in question three: The assumption of normality was broken for one of the twelve variables used in the repeated measures ANCOVA. Although non-parametric tests would not be a suitable alternative in this case as the majority of the data was normally distributed, future work could use analysis techniques that do not have pre-requisites for data distribution. These were beyond the scope of this thesis but for an in-depth explanation of these and the limitations of log transformations see Feng et al[170].

4.   *What is the effect size* of the intervention *for the Stroke self-efficacy scale, Stroke and aphasia quality of life scale, Hospital anxiety and depression scale, and the Nottingham activities of daily living scale?*

Effect sizes are particularly important in health interventions as they give insight into whether an intervention would have any significance clinically[171]. Despite this, the current work is one of the first to do. Only four of the 12 papers included in the systematic review presented in chapter three reported effect size. The current study found a small effect size for NEADL, but only trivial effect sizes were found for the three other outcome measures: SSES, HADS and SAQOL-39. The current work does not have statistical power to compare results in a meaningful way with other work, but the SAQOL-39 effect size was much smaller than previous estimations in the general stroke population (0.157 compares to 0.49)[172].These differences could be for a number of reasons. Firstly, the population used the current study is not an accurate representation of the general population as aphasia and women were underrepresented in the sample. It could also be that the sample is self-selecting in that those who are willing to take part in research may behave differently to the general population. Regardless, determining the effect sizes was vital for this feasibility study as it enabled sample size calculations for future work to be made.

In addition to effect size, the dropout rate of the study should be included when planning for future work as this inflates the sample size and thus offers insight into the logistics required for the study to take place. It should also be noted that although the current work found the recruitment approach to be feasible, it may not remain feasible if recruiting for larger sample sizes.

9.5 Conclusion

The results of this chapter are to be considered only as preliminary as they are not powered for significance. However, it is hoped some of the findings will inform future

work by offering insight into the sample sizes required, the direction of change in outcome scores, and whether the intervention may have a protective effect. If a definitive trial is conducted data could be collected at additional time points post intervention, for example, at one-month. Future work should also try to standardise measures to enable the comparison of different self-management interventions and a meta-analysis exploring group self-management interventions for stroke.

Chapter Ten

10 Chapter ten: Discussion

10.1 Summary of work

This thesis has reported on three phases of feasibility research, development, implementation and evaluation. Together, these phases comprehensively assessed the feasibility of a group self-management intervention for stroke. During the development phase, a systematic review of existing literature was conducted, and insight from stakeholders including stroke survivors and the Bridges team were captured. The second phase included a process evaluation which explored how such an intervention might be implemented. The final phase evaluated the intervention and explored stroke survivor and carer experiences as well as quantitative outcomes.

This chapter presents a triangulation of these findings to give a complete overview of feasibility. In the following section a synthesis of the findings is presented, focussing on: the effects of the intervention, the intervention design, and the role of peer support. Secondly, this chapter offers my own personal reflections on the PhD process. Thirdly, recommendations for a definitive trial are presented. Finally, the chapter ends by suggesting avenues of interest for future research.

10.2 Synthesis of findings

Data from the quantitative and qualitative studies will be synthesised using a segregated mixed research approach (see chapter two, section 2.1.5.2). This enables a deeper understanding of the feasibility of a group self-management intervention for stroke - the central aim of the thesis. How the synthesised findings relate to the wider literature is also drawn out. Chiefly, the findings support and build on past research in the field of self-management. The synthesis is split into two parts. Firstly, a synthesis of data relating to the four outcomes of interest that were identified at the start of this thesis (self-efficacy, mood, quality of life and activities of daily living) is presented. Secondly, the most prominent themes across all of the research studies are identified as follows: (1) The intervention design, which is discussed with regard to follow-up sessions and when the 'right' time to implement the intervention might be. (2) The role that peer support plays within the group intervention, in particular, whether this adds anything to the existing Bridges approach.

10.2.1 The effects of the intervention

Four outcomes of interest were explored in this thesis, self-efficacy, mood, activities of daily living and quality of life. The data synthesised below explores whether the intervention had any effect on these outcomes, and if so, how they may have been generated.

10.2.1.1 Self-efficacy

Self-efficacy is the core concept of Social Cognition Theory, and is thus central to the Bridges group self-management intervention. Although the one-to-one Bridges intervention has been found to increase self-efficacy[46], it was previously unknown whether the group adaptation of Bridges would have a similar effect. The work conducted as part of this thesis advances the field by exploring this in detail. Both the qualitative and quantitative findings suggested that the group intervention could increase the self-efficacy of stroke survivors.

The quantitative analysis explored self-efficacy using the SSES. The results revealed those who took part in the group self-management intervention had higher SSES scores than the control group at six-months post intervention (115.2 and 105.4 respectively). The qualitative findings provided a deeper understanding of how these differences in scores may have occurred, demonstrating the value of mixed methods research. The post intervention interviews suggested that the groups had increased the belief that stroke survivors had in their own capabilities. Stroke survivors felt that this was the result of the encouragement given to help them complete their small steps, and as they could see other peers succeed. Carers echoed this sentiment with one family member describing how seeing others succeed made her mother feel more able to have a go at tasks herself. Both vicarious learning and feelings of mastery can thus be identified as mechanisms of change, which are both named as key contributors of self-efficacy by SCT[14]. Therefore, the group adaptation of the Bridges intervention can be said to be in alignment with the theory underpinning it[14].

Furthermore, SCT suggests social support can contribute to an individual's self-efficacy[14]. As the group intervention provided a source of social support, this may also have contributed to the increase in SSES scores described above. Thus, a lack of social support may have a negative effect on a stroke survivor's self-efficacy. In keeping with this, the post intervention interviews revealed one stroke survivor felt less confident about continuing their self-management journey without the encouragement and support of others. This is in line with findings from the process evaluation which suggested stroke survivors would like a follow-up session after the groups had ended to see how everyone

had been getting on (discussed in more detail below). It is also aligned with a previous meta-synthesis that explored the influence of social support on chronic disease self-management[58]. The findings showed that there is a "close interdependence between social and psychological processes in chronic illness management" (pg. 1), thus ongoing social support may offer a mechanism through which improvements in self-efficacy could be maintained.

10.2.1.2   Mood

The thesis also explored whether the intervention had any effect on mood. A previous meta-review of 13 systematic reviews, found some positive effects of self-management interventions on mood when they incorporated interactive information giving[42], such as, workbooks and dynamic teaching. This is important because a large proportion of the general stroke population have low mood, half suffer from depression, and a third from anxiety[9,173]. The mechanisms of change behind this increase in mood gained from group self-management interventions was previously unknown. The research conducted in this thesis has advanced the field by using qualitative data collection techniques that enabled a richer exploration of this phenomena. The post intervention interviews revealed four themes (see chapter seven), from which different mechanisms of change could be identified, these were: a shared understanding, a space for shared problem solving, ongoing social support, and a new-found acceptance of their situation. The extent to which these mechanisms enabled a change in mood was explored quantitatively using the HADS.

Similarly to the qualitative findings, the quantitative results showed that improvements in mood were in favour of the intervention group (9.4 compared to the 10.8). However, this difference was only small, with a difference of 1.4. The fact the improvement was only small is most likely due to an insufficient sample size (chapter nine suggests 1165 stroke survivors would be needed if HADS was the primary outcome). However, there some other reasons that this result may have occurred and these should also be considered: It may be that the wrong outcome measure was used, or that the intervention only had a small effect on mood. The value of a mixed methods approach is apparent here, as even though the quantitative effects are small, it is clear from the qualitative group self-management may still go some way towards reducing the high levels of depression and anxiety in the stroke population.

10.2.1.3   Activities of daily living

The third outcome explored in this thesis was the number of daily living activities an individual is able to do. In the UK, four out of ten stroke survivors require support with this type of activity[174]. Being able to complete activities of daily living not only provides stroke survivors with independence, but it may also ease the strain on those caring for them[175]. A previous systematic review exploring the effects of self-management interventions found that they could significantly increase participation and functional ability in stroke survivors[20]. However, the study did not explore the role that carers may have in this process. This thesis builds on these findings as it found an improvement in activities of daily living was not *just* the result of changes in the stroke survivor's behaviour. It was also the result of changes in their carer's behaviours. These findings fit with previous research that suggests a self-management approach should involve an individual's wider social network and not focus solely on the individual themselves[58]. The study highlights why this is important to activities of daily living, emphasising that social networks often become involved with tasks such as preparing food and medication management.

The negative effect that an individual's social could have on their activities of daily living should also be considered. In one study that explored chronic illness management in a range of conditions (including diabetes and heart disease), social networks were found to behave in a way that was a hindrance to every day activities as opposed to a help[176]. For example, they might try to tempt someone to 'have another beer' or have 'just one little piece' when someone is trying to monitor their diet. Similarly, chapter eight describes how carers feel they were not previously approaching activities of daily living in a way that would facilitate the stroke survivor's ability to self-manage.

The qualitative aspects of this thesis enabled an understanding of how the groups may have supported carers to approach activities of daily living in a manner that is more conducive to self-management. Carers suggested that they were 'doing less' for the stroke survivor. The groups had showed them the importance of co-management, and subsequently carers felt they were encouraging stroke survivors to do things for themselves. Similarly, the literature has emphasised the importance of social networks transferring control away from themselves and onto the individual self-managing[62]. One of the participants in this previous work highlighted this through the old proverb -'you can give a man a fish and he will eat for dinner, if you teach a man to fish he will eat forever' (pg.35). The previous example as well as the carers feedback supports the theoretical basis of the intervention which suggests social support can play a key role in an individual's ability to self-manage[14]. It also highlights how social support networks could

be a barrier to self-management if they are doing things for the stroke survivor, or being overprotective.

Similarly to carers, stroke survivors suggested their motivation and confidence to 'have a go' at activities of daily living had increased as a result of the intervention. In keeping with Bandura's conceptions of vicarious learning, the interviews revealed that when stroke survivors saw peers attempting different activities, it made them feel able to have a go themselves. Additionally, stroke survivors felt shared problem solving had enabled them to complete day-to-day activities, such as putting in earrings, as it offered alternative ways to do previously challenging tasks. Vicarious learning is thought to increase when observations are of others who you perceive to be similar to yourself[27]. It is therefore unsurprising that those who attended the group self-management intervention felt it was important that the group was stroke specific.

The quantitative scores explored the extent to which the intervention had an effect on activities of daily living. The NEADL scale found an increase in scores from 17.2 to 18.4 favour of the intervention group at six-months post intervention. However, it should be considered that a bigger change may have been found if the sample size was larger (for the study to be powered to find significant results using the NEADL measure, a sample size of 231 would be needed). It may also be that the NEADL scale is inappropriate for the exploration of changes in activities of daily living, as it only captures certain behaviours. A measure with space to self-report what one's activities of daily living are, and whether these have changed as a result of the intervention could overcome this problem, but one does not currently exist. Future work could aim to develop such a measure or adapt the NEADL scale to include self-reported daily living activities.

10.2.1.4   *Quality of life*

The final outcome discussed in this section is quality of life, which may be affected by all of the outcomes discussed above (self-efficacy, mood and activities of daily living)[19,61]. The high level of outcome interaction further highlights the complexity of group self-management interventions for stroke[24]. A Cochrane review conducted in 2016 suggested that self-management interventions could increase the quality of life of stroke survivors[43]. Similarly, examples of how the intervention had improved quality of life were found in both the carer focus groups and post-intervention interviews with stroke survivors.

Carers reported that the intervention had helped 'clear the air' in their relationship with the stroke survivor, and suggested this was the result of an increased empathy for their loved one and support from the group to co-manage (as opposed to giving out orders). Stroke survivors spoke about how the groups helped them to 'imagine a future' and think

about what small steps they could take to help it become a reality. In turn, this enabled them to feel more positive about what lay ahead. The phrase 'imagine a future' aligns with the concept of goal setting within SCT, and in particular distal goal setting, as it refers to large and long-term goals that individuals will not be able to complete immediately[14]. The concept of goal setting is routinely used in clinical practice, but stroke survivors and health care professionals often have different opinions on what the 'right' goal might be[53].The use of the phrase 'imagining a future' may encourage health care professionals to reconceptualise distal goal setting, encouraging a more collaborative goal setting process.

In keeping with the findings above - that the group self-management intervention was found to increase stroke survivor's quality of life - analysis of the SAQOL-39 showed that the intervention group had higher quality of life than the control group (4.2 and 4.1 respectively). However, the extent of this difference was only marginal. As above, the reasons this difference was so small may be because the wrong measure was used to capture any changes in quality of life, but it is most likely to be because the changes were too subtle to be detected by the small sample size. To have sufficient power, chapter nine suggests 1605 stroke survivors would need to take part in the intervention, which is over 25 times larger than the number that took part in this study. However, seemingly small quantitative differences may have big effects on the lives of stroke survivors and their carers, as suggested by the interviews and focus groups.

10.2.1.5   Summary

In summary, the synthesis of findings enabled an in-depth understanding of any change in self-efficacy, mood, activities of daily living and quality of life, that may have occurred as a result of the intervention. It also explored how the findings from this thesis fit in with the existing literature. The quantitative findings revealed the extent of any intervention effects, and what sample sizes would be needed in future to determine whether these effects were significant. The qualitative findings enabled an understanding of how these effects may be generated. Having insight into the factors that mediate these outcomes enables researchers to predict potential mechanisms of change in future, and supports the theoretical constructs currently underpinning the intervention. Crucially, the above synthesis illustrates that a group self-management approach can stay true to key theoretical constructs, such as self-efficacy, but can also adapt to the unique needs of individual stroke survivors.

10.2.2 Intervention design

The second part of this chapter presents the most prominent themes that were depicted in the synthesis. Data offering insight into the design of the group self-management intervention is synthesised first, and is presented as two topics: follow-ups and when to deliver the intervention.

10.2.2.1   Follow-ups

Previous research that explored a CDSMP for stroke survivors has suggested that those caring for stroke survivors may find a follow-up session valuable[13]. The current work advances the field by highlighting that the majority stroke survivors (4/5) share this view. Stroke survivors felt they would benefit from a follow-up session run three to six-months after the intervention had ended as it would enable them to see whether their peers had continued to make progress. The post intervention focus groups concur with previous research that carers would like a follow-up session, and adds to them by suggesting an informal structure could be used, for example no pre-defined discussion topics or formal facilitators.

Interestingly, the post intervention interviews revealed that in the absence of formal follow-up sessions, a subset of stroke survivors had started to create their own informal ones. They met up once a month in a local pub with the aim of providing ongoing support to each other. During the meetings they continued to use self-management techniques from the group intervention, such as collective problem solving and celebrating their successes with other group members. Having a space to revel in past success highlights a tangible example of how follow-ups may facilitate feelings of mastery. SCT suggests mastery can increase self-efficacy which was the main aim of the intervention[177]. In addition, SCT suggests that vicarious learning can contribute to an individual's self-efficacy. The informal follow-ups offered a space where stroke survivors could see their peers complete goals on a monthly basis, and may provide an ongoing source from which vicarious learning could occur. Thus, the informal follow-ups provided a real life example of how collective problem solving, the celebration of success, and seeing peers succeed could be mechanisms of change that are encouraged in follow-up sessions.

Both stroke survivors and family members consistently reported concerns about a lack of follow-up sessions once the scheduled groups were completed. As mentioned previously, one stroke survivor felt unsure how they would maintain their progress without the momentum of the group to support them. Feeling apprehensive about support ending is natural[178], but there are some things that the literature suggests may help. For example, therapists could schedule a 'booster' session three to nine months

after the intervention has ended[179]. Similarly, findings from the current thesis suggest that having a follow-up session may partly alleviate this apprehension as the intervention would have a more gradual end. A follow-up would also offer stroke survivors a space to discuss any challenges they may have experienced when trying out their newly learned self-management techniques. The absence of this at present, may in part explain why only small changes in scores on the SAQOL-39 were found between groups at six months post intervention. It is clear that careful consideration is needed to alleviate any apprehension about self-management interventions coming to an end. However, the lack of literature exploring this phenomena and offering best practice guidelines makes this challenging. As such, this opens up a new avenue for exploration for future research.

Conversely, the process evaluation revealed that 1/5 of stroke survivors did not feel the need to attend a follow-up session. Post intervention interviews expanded the understanding of why this may be, and suggested that some stroke survivors felt they had received enough support during the initial intervention. This divergence of opinion highlights the complex and personal nature of self-management, and in keeping with previous work suggests there is not a one size fits all way to manage stroke long-term[145]. It may be that the most appropriate way to deliver a follow-up session would be to make attendance optional. In keeping with the Bridges approach, an optional follow-up session would offer a mechanism through which this aspect of the intervention can remain tailored. As other chronic conditions also report self-management should be tailored to the individuals that take part[16], this recommendation could contribute to the wider field of group self-management.

Overall, having a follow-up session in a group format may provide a mechanism through which stroke survivors can have access to peers, and in turn, provide an ongoing source of vicarious learning, mastery and social support. This thesis contributes to the field by suggesting the mechanisms of change that could be encouraged within follow-up sessions, and by recommending that attendance should be optional.

10.2.2.2 *When to deliver a group self-management intervention*

The findings from multiple chapters are synthesised below to offer insight to when the 'right' time to deliver a self-management intervention might be. Findings from the carer focus groups and pre-intervention interviews with stroke survivors suggest that the intervention could be delivered earlier than discharge from hospital. However, two survivors said they felt that immediately after their stroke might be too soon as they needed time to process what had happened to them. Previous research highlights that

the emotional adjustment to stroke is a personal process, and accordingly will happen at different rates in different individuals[8].

Both stroke survivors and carers did agree that a good time to implement the intervention might be the transition home from the hospital, as this was when they felt support was lacking. The focus groups revealed carers felt this was a time when they started to perform daily activities without the support of health care professionals, and so were learning the full extent of the residual stroke symptoms. In contrast, past research exploring perceptions of self-management revealed that stroke survivors did not feel ready to manage by themselves immediately post discharge from hospital[108]. This variation in opinion on when to deliver the intervention echoes the process evaluation which revealed that seven of the eleven stroke survivors felt the intervention was run at the right time in their stroke journey, despite being at different times post stroke.

There are a number of other reasons why stroke survivors might express different preferences as to when the 'right' time to engage with such an intervention is. For example, mood, social support, cognitive impairment and level of disability all contribute to how ready a stroke survivor is to engage with self-management practices[34,145,173,180]. In addition, individual capacity, support for self-management and the self-management environment have all been found to influence self-management behaviours[149]. Previously, researchers revealed that therapists felt individuals were not ready to self-manage until a few years after their stroke[181], but this concept is challenged by other research which suggests the "timing of when people are ready to take more control and self-manage after stroke cannot necessarily be predicted" (pg. 260)[145]. This thesis supports the this finding and suggests implementing the intervention at a specific point within a stroke survivor's journey may not be appropriate.

However, there may be a number of other factors that are not explored in thesis that contribute to delivery time preference. For example, it may be that the variety of residual symptoms has impact on delivery time preference. As the current work excludes those with severe impairments (as they would be unable to attend the group) it is unknown whether they would have a different preference to those with relatively minor impairments. The wider literature has also been criticised as it excludes this group[145], so ways to facilitate the inclusion of more severely impaired stroke survivors should be considered, for example, delivery as a telehealth intervention.

With the above considerations in mind, researchers could enable a group self-management intervention to remain tailored at point of access if they offer an opt in service (as suggested for the follow-up groups), or multiple access points (for example,

at 6 months, 12 months and 24 months post stroke). Having multiple access points may also have other benefits. For example, if self-management interventions are only available at one time point early on in the stroke pathway, stroke survivors with mild disability, "may not gain access to rehabilitation or self-management programmes as they tend to move through organised care quickly" (pg. 260)[145]. However, asking stroke survivors to opt when they feel ready may be problematic as they may now know themselves. Especially as the term self-management is ambiguous as does not offer a clear insight into what they need to ready for.

Despite this, multiple access points may be the most appropriate option for the delivery of a group self-management intervention and therefore future research should not focus on discovering one 'right time'. The findings of this synthesis may also be beneficial to other chronic conditions as tailored access in the field of self-management interventions is currently understudied and potentially underutilised.

10.2.3 The role of peer support

The final section of the synthesis is presented below, and explores the role that peer support may play in the group self-management intervention. The role of peer support is discussed in relation to three areas: mechanisms of change, the utilisation of self-management techniques and group bonding. Finally, how researchers could isolate the effects of peer support (if at all) is discussed.

10.2.3.1   The relationship to mechanisms of change

Insight into the role of social support within the group self-management intervention was gained from the synthesis of findings from both qualitative and quantitative studies. The previous synthesis of outcomes (section 10.2.1) revealed that the majority of mechanisms of change reported by stroke survivors and carers were underpinned by social support. For example, shared decision making, reciprocal interactions, shared understanding, vicarious learning, and motivation from seeing others succeed. The fact that so many of these mechanisms are grounded in social support is important to note, given many stroke survivors experience a decline in social networks when they return home from hospital[182]. The group delivery of the Bridges self-management intervention may ease this decline, as it provides a platform from which social support can be drawn. This may in part explain why an increase in stroke survivor's psychosocial quality of life was seen on the SAQOL-39 measure at two-weeks post intervention.

Although the original one-to-one Bridges intervention had stroke survivor stories in the workbook, delivery of the intervention in a group setting enabled a more dynamic and

tailored interaction with peers. For example, one lady could no longer use earrings with fasteners. Together the group collectively helped to solve this problem, by proposing using earrings with hooks as they did not require separate fasteners. Obviously, this interaction could not have occurred within a one-to-one setting as there are no other peers to discuss ideas with. The literature conceptualises this as 'collective efficacy', or the "capacity to successfully perform behaviour through shared effort" (pg. 1)[58].

The dynamic interactions enabled by the presence of peers also meant that social support could be reciprocal. As illustrated in the systematic review in chapter four, previous research found stroke survivors valued the opportunity to both 'give' and 'gain' within group self-management interventions[48]. The post intervention interviews gave an example of this in practice, describing how stroke survivors appreciated having a space where they could listen to others, but also be listened to. The original one-to-one intervention provides examples in the work book which stroke survivors can read, but this does not enable the reader to be listened to in return or allow the reader to ask follow-up questions. Thus, when seeking a reciprocal form of social support, a group delivery of Bridges, as opposed to one-to-one, may be advantageous.

10.2.3.2   The utilisation of self-management techniques

The role that social support may have played in the utilisation of self-management techniques should also be considered. As the group intervention was adapted from the one-to-one intervention, both draw on the same nine self-management techniques. However, it was clear from the post intervention interviews and carer focus groups that social support may contribute to how effective they are. For example, a stroke survivor who sets goals in a one-to-one setting would not by design have access to encouragement from peers, a chance to see others succeed, or a collective space to problem solve any barriers they come across. The lack of peer support in the one-to-one delivery offers an example of how the group delivery is perhaps more in line with the theoretical foundations of the intervention, as SCT names social support as one of the factors that contributes to self-efficacy[14]. It is therefore unsurprising that social support has been associated with an individual's readiness to engage with self-management practices[145].

10.2.3.3   Group bonding

The role that peer support plays in group self-management interventions may have been impacted by how much the members bonded. Thus, it is important to be aware of what could facilitate this process. Stroke survivors reported that despite having different

residual symptoms and levels of severity, the shared experience of stroke was enough for group members to relate to one another and facilitate bonding. This supports previous research which advocates for disease specific self-management interventions[50], and challenges self-management interventions that include a range of chronic conditions[15]. Interestingly, difference under the umbrella of stroke, for example different residual symptoms and challenges, was seen as valuable. The post intervention interviews revealed that stroke survivors felt this difference offered a fresh perspective and enabled social comparison, in particular, a feeling that 'it could be worse'.

One concern was shared by past research[145] and stroke survivors in the pre-intervention interviews about involving peers in the intervention: if there is a lot of variation within a group self-management intervention, it may not remain tailored to each individual's unique needs. In particular, there was concern that the intervention would be treated like a 'one size fits all' solution. Although there is risk that other group interventions may become less tailored as they grow in size[145], the current intervention was designed to allow adaptation to context and thus successfully overcame this concern. For example, each individual set goals that were important to them but could gain inspiration or encouragement from other peers in the group. This is a strength of the intervention design, and in keeping with the self-management ethos, allows "the high individualization of the clinical approach with the large-scale applicability of the public health approach" (pg.12)[22].

10.2.3.4 *Isolating the effects of peer support*

When considering the findings of the current thesis, it should be noted that it is limited in its ability to separate the effect of peer support from that of the intervention. Especially without a control group that uses solely peer support as a mechanism of behaviour change. Indeed, previous literature exploring group self-management interventions has highlighted that some programme benefits reflected the social aspects of the group as opposed to the intervention itself[13]. Although, the post intervention interviews suggest that self-management techniques combined with social support can facilitate self-management in stroke survivors, the effect that each of these would have individually is still unknown. Future work should try to isolate the effects of social support and suggestions for how this could be approached are found section 10.7.

10.3 Reflections

In order to ensure research has rigour, the concept of 'reflexivity' should be explored. Reflexivity describes the possible ways that the "researcher and research process have

shaped the collected data, including the role of prior assumptions and experience, which can influence even the most avowedly inductive inquiries" (pg. 51)[183]. It is therefore necessary to consider my own implicit values and draw them to the attention of both myself and the readers[183]. I am a white, British, female researcher from a middle-class background who conducted this research as part of my PhD between 25-28 years of age. I held a pragmatist view throughout the thesis as I felt no single approach would provide the full picture of what was happening. On reflection, this belief may have been one of the factors that led me to use a mixed methods approach. Having worked in both clinical and academic settings may also have made me hyper-aware that different stakeholders prefer different types of outcomes, which also may have encouraged a mixed methods approach.

Bringing these values to the forefront of my own mind was important as it allowed me to consciously try and account for them in my practice. This was particularly important as the group being researched had different experiences to myself, specifically, a lived experience of stroke. I was aware that those attending the groups may have questioned my facilitation skills as I was younger than all of them and am not an expert in any related field e.g. medicine or psychology. In an attempt to make my facilitation skills as good as possible I sought advice from stroke survivors, the multidisciplinary management panel, and the Bridges team throughout my work. Each of these stakeholders made invaluable suggestions. This was a steep learning curve, especially when it generated a divergence of opinion amongst the stakeholders. However, this forced me to carefully consider what *I* believed to be the most appropriate course of action, and not rely on others to tell me what to do. Having seen first-hand the benefits that incorporating stakeholders had on this research, and how much it could expand my own small knowledge base, it is something I will strive to do in my ongoing practice.

In addition to incorporating multiple perspectives, the literature suggests researchers can account for their own biases by being transparent in the decisions that they make throughout the research process[120]. An effort was made to adhere to this where possible, for example, the interview studies presented coding trees which detailed the decisions behind key theme formations, thus exposing any bias in interpretation. Decisions that were made during this thesis were also informed by the wider literature published at the time of working. As interest in self-management has continued to rise, so too has the associated evidence base. Consequently, different decisions may have been made if I were to do this project again. For example, since this work started a scale designed specifically to explore self-management behaviours in stroke survivors has been published by the University of Southampton[184]. The new measure may have captured

self-management more accurately than those currently available. Different decisions may also have been made during this thesis if the research was not so heavily lead by the initial funding application that underpinned it. Although I co-wrote this grant application and thus had a lot of input into the content, it is harder to change the course of research when you are funded to explore one particular avenue.

My own understanding of 'self-management' and the philosophy that underpins it have also developed since I started this work. I have become aware that the four quantitative measures used may be somewhat at odds with the self-management ethos. The reason for this is that they use a predefined set of responses that limits how a stroke survivor can respond. For example, the SAQOL-39 measure asks stroke survivors if they can walk up the stairs, but responses are limited to a number from one to five and does not account for changing contexts. As this is the nature of quantitative data, even if other measures were used the same problem would still exist, and thus this is near impossible to overcome. However, this reflection does further highlight the importance of using a qualitative approach alongside a quantitative one when exploring self-management, and how researchers should pay careful attention to their tools.

My understanding of what 'good' facilitation looks like and how I can provide it has changed dramatically over the course of this PhD. Looking back now it is clear that my ability to deliver the group self-management intervention may have been worse at the start of the intervention compared to the end. For example, I became more familiar with what worked and what did not and more comfortable with silences in the group. Having debriefs with co-facilitators offered an invaluable source of information in terms of areas I could improve in, which also helped fine tune my facilitation skills over the eight intervention groups. I feel that having space to reflect on my practice with colleagues has also been a valuable way to bring my own biases to the forefront of my mind and assist a balanced interpretation. Doing so was particularly important as I was both delivering and analysing the intervention. For example, it may be that my attention was drawn to the aspects of delivery that fitted with both my personal and research hypotheses, or that I was particularly keen in my delivery as I wanted the intervention to be a success.

10.4 Progression to a definitive clinical trial

It is hoped that the findings of this thesis will inform a definitive trial which will explore whether the intervention has any statistically significant effects. General methodological considerations for such a trial, as well as specific recommendations for the research design are discussed in turn below.

10.4.1 General methodological considerations for a future trial

Before this work can progress from feasibility to a definitive trial, is important to consider whether we have all the necessary information. The MRC guidelines for complex interventions present a number of questions which they feel researchers should be able to answer before conducting a fully powered trial[24]. As a result of this thesis we can now answer each of these (see table 13).

Table 13. List of questions posed by the MRC that could facilitate the evaluation of complex interventions.

Question	Answer
Have you conducted a systematic review?	Yes (chapter four)
Who is the intervention aimed at?	Stroke survivors are the target population, but family, friends and carers may also benefit.
Can you describe the intervention fully?	Yes- see chapter five for the protocol
How variable is the intervention? E.g. fidelity	The intervention was seen to have high fidelity to the protocol (see chapter six).
Can you describe the context and environment in which the evaluation is being undertaken?	Non-NHS community-based stroke groups were conducted (see chapters one and two for more detail about the context).
What user involvement is there going to be in the study?	Stroke survivor focus groups could be used to facilitate service user involvement. It would be feasible to have a stroke survivor as a grant co-applicant and for the intervention to be facilitated by a stroke survivor.
Is your study ethical?	Yes, no adverse events were reported, and the intervention was found to be acceptable to stroke survivors, and their family friends and carers.
What arrangements will you put in place to monitor and oversee the evaluation?	A management panel that includes a multidisciplinary team could oversee the project (see chapter two) as well as the relevant ethical body (in this case it is likely that NHS ethical approval will be needed).
Have you reported your evaluation appropriately?	Yes-best practice reporting guidelines were followed e.g. CONSORT.
How will you analyse the data?	Both univariate and repeated measures ANCOVA could be used to analyse the data (see chapter nine for more in-depth discussion of this analysis).

The MRC guidelines do not distinguish between pilot and feasibility, but it is clear from wider reading that the two types of study address different needs[74] (see chapter two for an in depth discussion). In brief, pilot studies are conducted later in the research pipeline than feasibility studies and are a small-scale replica of what the trial would be[75]. Thus, it may be that a pilot study is needed to bridge the gap between the feasibility study and a fully powered trial. Particularly if recommended changes to the research design are included (detailed below), for example, having an opt-in access scheme may have implications for the recruitment strategy used.

In summary, this thesis has provided information which the MRC state is necessary for complex interventions to progress from feasibility to a definitive trial. However, researchers should consider whether a pilot study is required which would involve conducting a small-scale replica of the proposed trial, including any improvements that are made based on the recommendations below.

10.4.2 Recommendations for the design of a future trial

The work conducted in this thesis has generated a number of specific recommendations for a future trial. Box 10.1 presents a summary of these recommendations. First and foremost, a mixed methods approach should be used in order to produce a rich and varied data set. In addition, stakeholders should be consulted where possible to ensure a range of perspectives are captured, and best practice guidelines adhered to.

Two recommendations can be made in relation to the collection of outcome measures. Firstly, the process evaluation suggested that the quantitative outcome measures had a good return rate via post and so face to face visits are not deemed necessary - except for participants with communication difficulties. Secondly, the small effect sizes at six-months post intervention, and the request for follow-up sessions from both stroke survivors and carers may be because the intervention effects wear off over time. In order to explore this in more detail, a fully powered trial could capture outcomes at additional time points such as one-month and three-months post intervention. This would be more in line with previous work exploring group self-management interventions[50,63,124] , but ethically may cause concern as it would increase participant burden.

The thesis also resulted in four recommendations for the recruitment approach that could be used in a future trial. Firstly, as aphasic stroke survivors were under represented in the resulting sample, purposive sampling should be considered as a way to overcome this. Secondly, additional recruitment sites could be used which would offer two benefits,

they may increase the representativeness of the sample and facilitate recruitment rate. The latter is particularly important as the effect size calculations in chapter nine suggest much larger sample sizes would be needed in future work. Sample size should be taken into consideration when discussing the primary outcome of a trial as it may impact how feasible the resulting recruitment target is. When applying for the grant, the funding body (NIHR) expressed a preference to use the SAQOL-39 as the primary outcome, as have the project stakeholders (the Bridges team). It is now known that doing so would require a sample size of 1605. Thirdly, the iterative model of recruitment for stroke facilitators proved to be effective and feasible for use in a larger trial. Finally, a future trial should consider an opt in or self-referral mechanism of access as they would enable a more tailored approach to enrolment. This is important in light of the findings that there may not a 'one size fits all' in terms of the right time to access a group self-management intervention[39].

Box 10.1. Summary of the recommendations for a future trial

Recommendations for a future trial

- A mixed methods approach should be used.
- Stakeholders should be included wherever possible.
- Questionnaires can be sent and returned to participants by post.
- Quantitative measures should be captured at two additional time points, one and three months post intervention.
- Additional recruitment sites should be used.
- Purposeful sampling could facilitate the inclusion of aphasic participants.
- An iterative model of stroke facilitator recruitment is feasible.
- Recommended sample sizes for each outcome measure based on effect sizes should be used.

10.4.3 Recommendations for future group self-management interventions

In addition to the general recommendations for a future trial presented in section 10.4.1, findings from this thesis have generated recommendations for future group self-management interventions. These recommendations are presented below and summarised in box 10.2.

There were a number of aspects of the intervention that were found to be acceptable to stroke survivors, and these should be maintained in subsequent iterations of the intervention. Firstly, the inclusion of both stroke survivors and self-management practitioners as facilitators was seen as valuable by both stroke survivors and carers.

Stroke survivors were valued as they provided a lived experience and source of hope and inspiration. Self-management practitioners were seen to provide more practical support to the groups, ensuring everyone had a chance to speak. Secondly, the intervention structure was found to be acceptable. Stroke survivors thought including the break in the middle and an ice breaker with tea and coffee before each session was important. Thirdly, the size of the group was found to be acceptable when containing five to ten stroke survivors as it enabled enough people to share experiences and ideas with. Fourthly, stroke survivors thought it was important that the groups were stroke specific, but in contrast the pre-intervention interviews, they felt having the same residual symptoms was not necessary. Finally, future interventions should continue to use the nine core self-management techniques advocated by Bridges as these were found to facilitate self-management practices.

Although there were many acceptable parts of the intervention, there were also a number of changes that stroke survivors felt could improve the intervention. Firstly, the process evaluation revealed that 100% of participants suggested each session should be longer than two hours. Secondly, it was felt that attendees should all live locally to one another as this may facilitate ongoing social support once the intervention had ended. Finally, both carers and stroke survivors expressed that they would like to attend more sessions, and a majority suggested this could be in the form of follow-up sessions.

Box 10.2. Summary of the recommendations for the group self-management

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Recommendations for the group self-management intervention Harness the value of peer support – e.g. encourage group work where possible.

- Include stroke survivors as facilitators alongside self-management practitioners.
- Explore having longer sessions than 2 hours.
- Group size should be 5-10.
- Attendees should live locally to facilitate ongoing support.
- Follow-up sessions should be run three to six-months after the intervention has finished.
- The following principles should be incorporated into the intervention content; problem solving, collaboration, knowledge, decision making, accessing resources, reflection, taking action, self-discovery and goal setting.
- Groups do not need to tailor their recruitment to specific residual stroke symptoms but should be exclusively for stroke survivors and their carers.

10.5 Future Research

The findings from this thesis have generated new avenues for research, which should be explored to further advance the field of group self-management for stroke.

This thesis explored implementation within a non-NHS community setting. In order to advance the field further, future work could explore the implementation of the intervention within the UK's NHS. Questions that should be addressed include whether it is feasible and how acceptable the intervention is to multi-disciplinary teams. However, implementing the intervention within the NHS does raise questions about how the group intervention may fit with the existing Bridges one-to-one self-management service already implemented within the NHS. There is insufficient research at present to determine the effectiveness of the group intervention when delivered before, after or alongside the one-to-one sessions. Each of these options should be considered in case they result in a different therapeutic effect. For example, the group may support an individual to imagine their future which in turn facilitates their ability to set goals during the one-to-one intervention. Previous research has already suggested further exploration of how such an intervention may be integrated into stroke care and a whole systems approach is advocated[145,185].

The experience of those who facilitated the group intervention (both stroke survivors and self-management practitioners) should be explored in future work in order to assess whether the intervention is acceptable and feasible for them to deliver. This is especially important in light of recommendations in this thesis such as longer sessions as this would increase facilitator burden. As highlighted by two previous studies that explored the experience of self-management practitioners when delivering a one-to-one intervention[53,62], the facilitation process can be challenging. A group setting confounds delivery further as there are both multiple service users and facilitators. Therefore, the facilitation experience may be different in a group compared to a one-to-one setting. Two other aspects relating to facilitators should also be explored. Firstly, how stroke survivors feel about facilitating and in particular whether they feel they gained anything from doing so. Those facilitating may experience benefits as well as those they were working with. Secondly, the issue of training should be explored as the current intervention offered stroke survivors none. In particular, whether stroke survivors would have liked to attend some formal training in self-management or if they felt confident facilitating based on their lived experience.

The importance of improving access to self-management interventions (especially in more rural areas) has already been highlighted[99]. The former has also shown that

technology can enable those who cannot travel to the venue to take part. [99] Subsequent research could explore whether the Bridges group intervention could be successfully delivered as a telehealth intervention. Another issue which concerns both access and acceptability is the use of the written workbook that accompanies the intervention. A limited number of participants with aphasia took part in the current study, but it was clear that the workbook provided was not as accessible as it could be – despite having been designed with input from a communications charity. In order to overcome this problem, future iterations could explore whether parts of the workbook could be read out to participants via technology, or whether a separate version of the book could be published that is more aphasia-friendly.

As mentioned previously, the penultimate consideration should be how to distinguish between the effects of the intervention and the effects of social support. One way to do this would be to use social meet ups as a control group, for example, those run by the Stroke Association. However, the content of such groups should be considered as if they introduce additional variables such as physical exercise this would further affect the results. A second option would be to compare the group intervention to the one-to-one version, which would hold constant the type of self-management techniques used. Thus, enabling researchers to identify what a group dynamic brings to the intervention.

Finally, future research should explore whether the group self-management intervention based on Bridges is cost-effective when delivered within the UK's NHS. Research which explored the cost effectiveness of the existing CSMP suggests the intervention was cost-effective, saving over ten times the cost of standard care[15]. However, as this research was conducted within the American health care system, and used a different intervention, the findings cannot necessarily be generalised to the UK's healthcare service.

11 Conclusion

This thesis is the first piece of work to explore whether it is feasible to deliver Bridges in a group setting. As a result of the work conducted, researchers now have all the information that the MRC guidelines for complex interventions suggest is necessary to progress to a definitive trial. In particular, access to a newly developed protocol for a group self-management intervention for stroke. In addition, the information gathered as part of this thesis will inform numerous aspects of a definitive trial. The in-depth process evaluation offered insight into recruitment rates, fidelity, and intervention adherence, and the mixed methods evaluation provided insight into how the intervention may be working, acceptability and what sample sizes would be required for future work. Chiefly, the thesis has demonstrated that when Bridges is delivered in a group setting it can stay true to core constructs and remain tailored to the unique needs of each stroke survivors that attends. Whilst undertaking this thesis, a number of avenues for future work have been generated. For example, one could explore the experiences of the intervention facilitators, and whether the intervention can be successfully delivered within an NHS setting. The thesis concludes that a group self-management intervention for stroke survivors based on Bridges is feasible.

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13 Appendices

13.1 Appendix 1. Example pages from the Bridges book

1 REFLECTION

Things I achieved since my stroke ...

Since your stroke you will have made progress in many ways. Consider which of your achievements have given you personal satisfaction.

If you can,
write your progress here.
If you have difficulty
in writing, ask someone
to help you.

PAGE 6

REFLECTION

Other things I have achieved ...

You may want to reflect on other things
you have achieved in life that have given
you a sense of personal satisfaction.

1 REFLECTION

2 EXPERIENCES

3 MANAGEMENT

4 KEEPING ACTIVE

5 FUTURE GOALS

6 CONTROL NOW

PAGE 7

1 REFLECTION

My own contribution ...

Some of the progress you have made so far will be due to recovery and therapy, but most will be down to you and your efforts. Try to describe how you have helped yourself in your progress so far.

If you can, write your progress here or in the Bridges stepping stones opposite and try to think about what works for you. If you have difficulty in writing, ask someone to help you.

PAGE 10

REFLECTION

Bridges

STROKE SELF-MANAGEMENT

1 REFLECTION

2 EXPERIENCES

3 MANAGEMENT

4 KEEPING ACTIVE

5 FUTURE GOALS

6 CONTROL NOW

PAGE 11

A bridge to your target...

It may be helpful to write down some of the steps you would take towards your target.

If you have difficulty in writing, ask your therapist to assist you.

● **Step 1:**

● **Step 2:**

● **Step 3:**

● **Step 4:**

■ **Step 5:**

■ **Step 6:**

■ **Target:**

Step 1

Step 2

Step 3

Step 4

Step 5

Step 6

Your Target

/ /

As you make progress towards your target, you can tick the Bridges stepping stones to record how you are doing.

If you can, also record the date of your achievement.
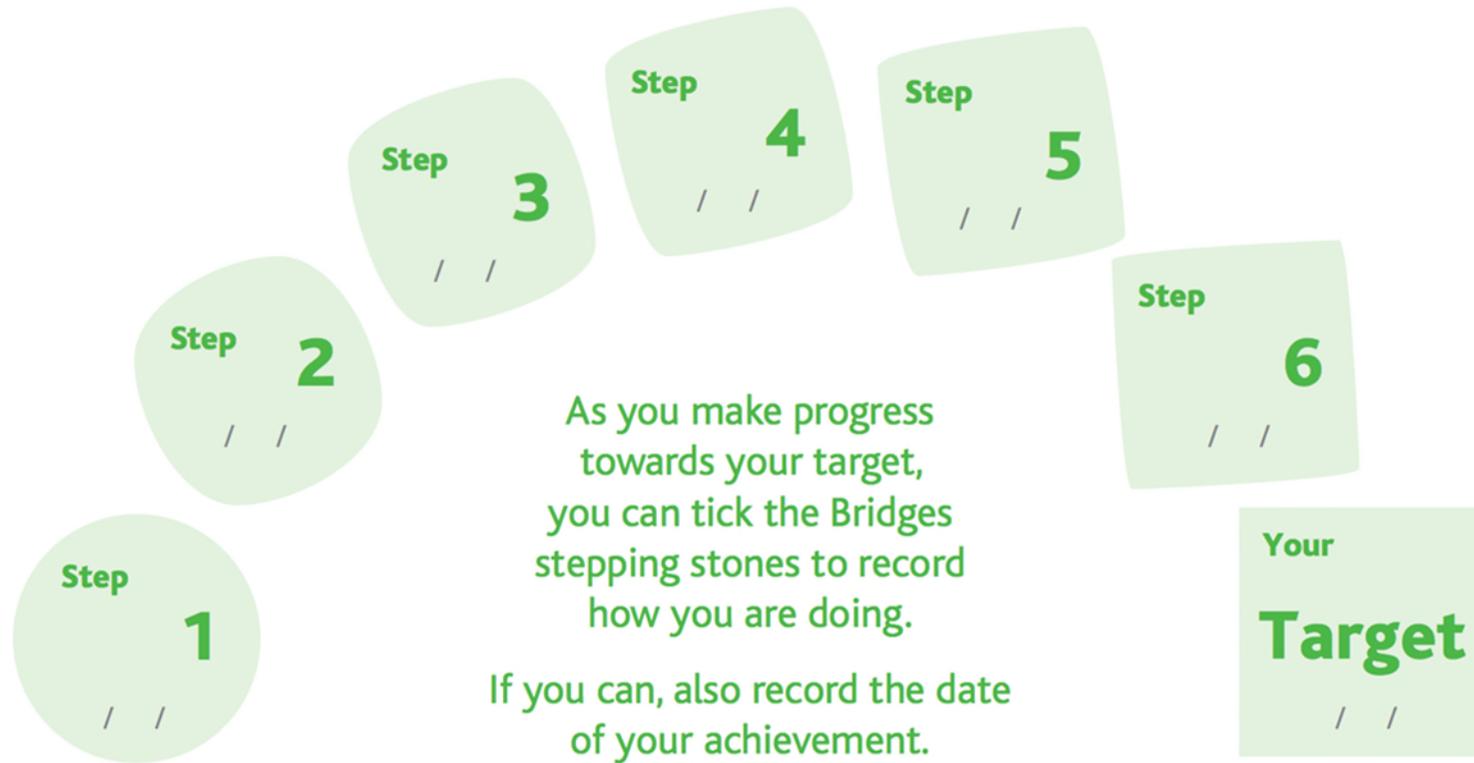
Date started: /   /

Date achieved: /   /

13.2 Appendix 2. Evidence of favourable ethical opinion

13.2.1.1 Letter of favourable opinion with conditions

NHS

Health Research Authority

North East - Newcastle & North Tyneside 1 Research Ethics Committee

Jarrow Business Centre
Room 001
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3565

25 September 2015

Dr Nick Ward
33 Queen Square
London
WC1N 3BG

Dear Dr Ward

Study title:	**Investigating the feasibility of a group self-management program after stroke**
REC reference:	**15/NE/0341**
Protocol number:	**15/0630**
IRAS project ID:	**141894**

The Proportionate Review Sub-committee of the North East - Newcastle & North Tyneside 1 Research Ethics Committee reviewed the above application via email correspondence.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Gillian Mayer, nrescommittee.northeast-newcastleandnorthtyneside1@nhs.net . Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion: Favourable Opinion with Conditions

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Additional conditions:
- The carer participant information should not refer to a GP letter (also: remove section from consent form), stroke etc. relevant only to stroke patients.

- Consent form: delete reference to medical care in the withdrawal section.

You should notify the REC in writing once all conditions have been met (except for site

approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

Ethical issues raised, noted and resolved in correspondence:

The Committees queries were noted and responded to via email correspondence by Miss Ella Clark.

13.2.1.2   Acknowledgement of conditions met

NHS
Health Research Authority
North East - Newcastle & North Tyneside 1 Research Ethics Committee

Jarrow Business Centre
Room 001
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3467

07 October 2015

Miss Ella Clark
33 Queen Square
London
WC1N 3BG

Dear Miss Clark

Study title:	**Investigating the feasibility of a group self-management program afterstroke**
REC reference:	15/NE/0341
Protocol number:	15/0630
IRAS project ID:	141894

Thank you for your acknowledgement on the 7 October 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 25 September 2015

Documents received

The documents received were as follows:

Document	Version	Date
Other [Consent form for carers]	2	05 October 2015
Other [Information sheet for carers]	2	05 October 2015

Approved documents

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

| Document	Version	Date
Covering letter on headed paper [Cover Letter]	1	16 September 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance confirmation letter]	1	10 August 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance]	1	13 July 2015
GP/consultant information sheets or letters [Notification of participant taking part in research]	1	08 August 2015
Interview schedules or topic guides for participants [Topic guide]	1	08 July 2015

A Research Ethics Committee established by the Health Research Authority

IRAS Checklist XML [Checklist_23092015]		23 September 2015
IRAS Checklist XML [Checklist_07102015]		07 October 2015
Letter from funder [Letter from NIHR]	1	08 August 2014
Other [Group Content]	1	22 September 2015
Other [22/09/2015]	1	22 September 2015
Other [Lone working statement of agreement]	1	22 September 2015
Other [NIHR committee responses]	1	29 August 2014
Other [Consent form for carers]	2	05 October 2015
Other [Information sheet for carers]	2	05 October 2015
Participant consent form [Consent form]	2	22 September 2015
Participant information sheet (PIS) [Participant Information Sheet]	2	22 September 2015
REC Application Form [REC_Form_16092015]		16 September 2015
Referee's report or other scientific critique report [Peer Review]	1	08 August 2014
Research protocol or project proposal [Research Protocol]	1	26 August 2015
Summary CV for Chief Investigator (CI) [Chief Investigators CV]	1	11 February 2015
Summary CV for student [Student CV]	1	08 July 2015
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Flow chart of Protocol]	1	23 July 2015
Validated questionnaire [BECK questionnaire]	1	23 July 2015
Validated questionnaire [HADS scale]	1	23 July 2015
Validated questionnaire [SSEQ]	1	23 July 2015
Validated questionnaire [SSQoL]	1	15 September 2015
Validated questionnaire [stages of change]	1	23 July 2015

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

15/NE/0341	Please quote this number on all correspondence

Yours sincerely

Jade Robinson
Amendment Coordinator

E-mail: nrescommittee.northeast-newcastleandnorthtyneside1@nhs.net

Copy to: Ms Tabitha Kavoi, UCLH NHS Foundation Trust

13.3 Appendix 3: Table of demographics who took part in the focus group to facilitate stakeholder involvement in the research design.

Participant number	Time since stroke (months)	Age	Gender
1	13	51	F
2	Unknown	64	M
3	12	58	M
4	29	48	M
5	42	52	M
6	35	69	F
7	22	29	F
8	34	68	M

13.4 Appendix 4: Focus group topic guide

Introduction

- Introduce yourself
- Data collected here today will be used to inform the design of a self-management program for stroke.
- I am interested in hearing from everyone here today so try to be mindful of each other, and make sure everyone gets a chance to speak. We do have a lot to cover so if we are getting off topic I might have to interrupt you and steer us back to the topic. I am not being rude I just want to hear what you have to say on all our discussion points.
- This focus group is being recorded on a Dictaphone and will later be typed up so I can remember what was said. If any data collected is used (e.g. in a paper) it will be anonymous. This means readers will not be able to tell who said it.
- If you want to stop taking part at any time, that is fine, just let me know or sit back and fold your arms so I know not to try and involve you.
- Data collected here today will be used to inform the design of a self-management programmefor stroke.
- Your travel payment has already been arranged.
- The focus group will not last longer than 60 minutes. I will keep an eye on the time and will not run over.
- As you know, we are developing a four-week group self-management program. The aim of which is to help stroke survivors to manage their condition themselves. I will go over what each week entail later. I will tell you about it in more detail and then ask you some questions.
1. What do you think of the programmecontent?
   - Week 1: Facilitator explains content
     Discussion
   - Week 2: Facilitator explains content
     Discussion
   - Week 3: Facilitator explains content
     Discussion
   - Week 4: Facilitator explains content
   - Discussion

2. Why might people be reluctant to attend this group?

3. How could we engage people in the programmewho do not like usually groups?

4. Who would you like to be in the groups with you?
   - Both attending the group and facilitating.

5. How could we sell this group?
   - What do we call it?
   - What would put you off?

6. What would you like to know before attending?
Thank you all for your input. I will be here for a bit if you have any questions.

End.

Prompts

Could you tell me about that? What might other people think about that? Why do you think that is? You have different views here, why might that be? How/why/when/who? What about people with different post stroke difficulties?

13.5 Appendix 5: Interview topic guide

Introduce myself and start with rapport building questions such as, job, where they live, family.

Interviewer will explain what self-management is using the following script:

One relatively new idea is self-management. This aim of this is to equip individuals with both the confidence and skills to manage the symptoms, treatment, physical and psychosocial consequences of living with a long-term condition such as stroke. In doing this the patient is able to take an active (as opposed to passive) role in their health care. There are 3 parts to self-management. Medical management: taking medication, adhering to special diet, and having a useful understanding of your condition. Emotional management: Alteration of one's views of the future. Anger, fear, frustration and depression are commonly experienced, so learning to manage these emotions and they impact on one another, becomes part of the work required to manage the condition. Social Management: Adapting what you do in your daily life, for example changing the way you garden or play sport, or generally doing less.

Here are some self- management skills: (1) Problem solving skills (2) Decision making skills (3) Resource utilisation (4) Forming of a patient/health care provider partnership (5) Taking action

1. **Self-management**
   - If at all, in what ways was self-management or any of its components offered to you?
   - Do you think self-management would have a made a difference to the transitions:
     o From HASU to impatient rehabilitation
     o From inpatient rehabilitation to community care
     o From community care to independent living
   - How do you think it would have made a difference to your current life if you had had this?
   - How would self-management make a difference to your life if you were practicing it now?

2. **How could self-management be implemented?**
   - What do you think about the idea of group self-management programmes? What would barriers/benefits be?
   - What do you think about the idea of one-to-one self-management? What would barriers/benefits be?
   - What would you think about tailored self-management programme, for example, specifically for upper limb recovery? What would barriers/benefits be?
   - Why do you think you would have found something like this useful/not useful?

End of Interview.

Phrases used to prompt participants into expanding on a point:

   - Could you expand on that?
   - What makes you say that?
   - How do you feel about that?
   - How did that make you feel?
   - Why do you think that was?
   - How did that situation arise?
   - How was that issue resolved?

13.6 Appendix 6: Search strategy used in EBSCO to search CINAHL.

((TI (stroke OR strokes OR brain infarction OR cerebral infarction) OR AB (stroke OR strokes OR brain infarction OR cerebral infarction)) OR (MH "Stroke, Lacunar") OR (MH "Stroke+")) AND (((TI ("self-management" or "self-care" or "self-treatment") OR AB ("self-management" or "self-care" or "self-treatment")) OR (MH "Self Care")) AND (TI (group or groups) OR AB (group or groups)))

13.7 Appendix 7: Description of included studies and intervention type based on CRD guidelines

Supplementary table 1: Intervention Content.

Study	Intervention name	Content	Additional material	Theory	Frequency and length	Facilitator	Delivery	Group Size	Family and friends
Cadilhac et al[50]	The Stroke self-management programme (CDSMP + Stroke specific session).	Not specified in paper but reading of original source suggest: Introduction to the SSMI, sharing the stroke journey, how does stroke make you feel? Attitudes to stroke recovery, moving towards a healthy lifestyle, leisure activities, social support, financial matters, working with health professionals, learning to be stroke safe for life and 'where to from here'?	None	Not specified	2.5 hours per week for 8 weeks.	Trained stroke educator and a trained peer facilitator.	Face-to-face	N/A	?
Catalano et al[13]	The Stroke self-management programme (CDSMP + Stroke specific information session).	Course content introduces participants to a range of topics pertaining to health and well-being: Healthy eating, exercise, relaxation. Emphasises group interaction and support and reinforces solution- focused behaviors: Problem solving, goal setting, communication with healthcare team and family. Aims to assist individuals to manage the impact of chronic conditions on all domains of their life such as: emotional, physical and social well-being	Handbook based on the topics covered during the six-weeks of the CDSMP	SCT	1 session a week for 7 weeks each lasting 2 hours.	2 trained leaders according to a structured agenda.	Face-to-face	10-15	Enablers had to attend.
Dongbo et al[47]	CDSMP	Techniques to deal with problems such as frustration, fatigue, pain and isolation, appropriate exercise for maintaining and improving strength, flexibility and endurance, appropriate use of medications, communicating effectively with family, friends and health professionals, nutrition, decision making, how to evaluate treatments, culturally unsuitable aspects for the Chinese population were deleted or replaced.	A help book called 'Living a healthy life with chronic conditions'	SCT	2-2.5 hours per session, one a week for 7 weeks.	2 trained leaders. 1+ non-health professionals with a chronic disease.	Face-to-face	10-15	?
Hirsche et al[48]	CDSMP	Techniques to deal with problems such as frustration, fatigue, pain and isolation, appropriate exercise, appropriate use of medications, communication, nutrition, how to evaluate new treatments	None	SCT	6 weeks once a week for 2.5 hours.	Led by specifically trained lay leaders.	Face-to-face	8-15	?
Huijbregts et al[114]	Moving on after stroke (MOST)	Why self-management and why exercise? Goal setting, how stroke affects you/prevention, relaxation, daily activities and responsibility, recreation and having fun,	None	SCT	17 sessions of 2 hours,	2 trained facilitators.	Face-to-face	≤10	Carers are invited

	telehealth remote.	how stroke affects how you think and feel, with a little help from family and friends, community resources, communication, interaction with helpful professionals, alternative treatments, loving and caring, your doctor and your medications, nutrition, sleep and pain, community-environment			twice a week for 8 weeks, and then a 6-week post programme booster.				to attend
Jaglal et al[49]	CDSMP	Sessions: (1) Identifying common problems among participants, Differences between acute and chronic illnesses, Cognitive symptom management and distraction, making an action plan. (2) Feedback and problem solving, Dealing with negative emotions, physical activity and exercise, action plan. (3) Better breathing, Muscle relaxation, Pain and fatigue management, Endurance exercise, action plan. (4) Planning for the future, Healthy eating, Communication skills, Problem solving, action plan. (5) Use of medication, Making informed treatment decisions, Depression management, Positive thinking, Guided imagery, action plan (6)Working with your health care professional, Review and looking forward	None	SCT	Sessions once week for 6 weeks, 2 hours a week.	Trained course leaders	Tele-health	10-15	?
Kendall et al[63]	Stroke self-management programme (CDSMP + Stroke specific information session).	See Catalano	A handbook based on the topics covered during the six-weeks of the CDSMP	SCT	Once a week for 7 weeks in total. 2 hours a week.	Two trained health professionals.	Face-to-face	10-15	A family member or friend had to attend.
Kronish et al[122]	Modelled on the CDSMP	Didactic components that: Explained the biology of stroke and stroke treatments in lay terms, stressed the importance of adherence to preventative medications to reduce stroke recurrence, offered Suggestions for optimizing medication adherence and working with a health care team, groups ended with an action plan for the following week and were encouraged to choose something relevant to what they had learnt.	None	SCT	Weekly workshop for 6 weeks. Each session lasted 90 minutes.	2 peer facilitators with similar social economical-backgrounds and health problems as the participants.	Face-to-face	8-10	Family, friend or carer welcome to attend
Lorig et al[15]	CDSMP	Topics covered include: Exercise, use of cognitive symptom management, techniques, nutrition, fatigue and sleep management, use of community resources, use of medications, dealing with the emotions of fear, anger,	Course content given as text: Living a	SCT	2.5 hours per week for 7 weeks	Trained lay leaders	Face-to-face	10-15	Family invited to attend

		depression, communication with others including health professionals, problem-solving, decision-making	Healthy Life with Chronic Conditions						
Sit et al[124]	stroke prevention programme	Content was split into 8 topics: Experience of the stroke, self-health monitoring skills, the facts about stroke, current stroke management, secondary prevention, knowing your own medication, stroke prevention through adopting a healthy life style, eating a healthy diet, establishing regular exercise, putting thoughts into actions. Each session opened with 15 minutes' experience sharing and ended with a word of commitment.	Personal log sheets and a pedometer given to each participant	?	8 weeks, 2 hours a week.	3 community nurses	Face-to-face	10-12	?
Taylor et al[186]	MOST – Telehealth	Topics covered were: Self-management concepts (including goal-setting, exercise, medication, nutrition, daily activities, and responsibilities), stroke signs/symptoms and risk factors, relationship changes, community resources and opportunities.Each session contains an hour discussion and an hour exercise.	None	Not specified	Delivered twice a week for 9 weeks. 2 hour sessions.	Delivered by trained health professionals.	Tele-health	4-6 at local site, 4-6 via video-link.	Care giver invited to attend
Wolf et al[123]	CDSMP +Improving Participation after stroke self-management programme (IPASS)	CDSMP: efficacy building that focussed on medical, emotional, role and participation management to guide development of skills related to problem-solving, decision-making, resource utilisation, client/provider/service partnerships, action planning, and self-tailoring over time. IPASS: problem solving structure for participants to improve participation by understanding: Interaction between their health and participation, environmental supports and barriers outside of them, what they want to do. Attendees learn 3 different strategies: change the person, change the activity, and/or change the environment to utilise to manage and support their participation in daily life.	None	SCT	12 sessions in total (1-5 CDSMP and 7-12 IPASS)	Occupational therapists and/or peer with stroke (depending on availability)	Face-to-face	6-7	Not specified

Supplementary table 2: Studies included in the systematic review

Study	Design	Internal validity / quality)	Sample *Size Chronic disease*	Control *Type of control, N*	Time Intervals and Outcomes measured	Results	
						Statistical significance / qualitative outcomes	Effect size/ Clinical significance
Cadillac et al. (2011)[50]	Multicentre single blind phase II, randomized controlled trial (RCT).	++	N=143 Stroke	1. CDSMP N=47 2. Standard care N=48	Baseline and 6 months post intervention. Primary outcomes: Recruitment, participation, participant safety.	6 declined before baseline assessments, resulting in 143 (96%) participants randomised. More individuals in the generic group who withdrew reported the programme was not appropriate for their recovery and/or they were no longer interested.11 severe adverse events reported but none attributed to the interventions.	CDSMP (0.66), SSMI (1.47)
Catalano et al. (2003)[13]	Longitudinal randomised controlled design	++	N=37 Stroke	None	Five intervals spaced evenly over 18 months post stroke. A short structured interview designed to elicit perceptions of recovery, loss, and expectations about the future, using four open-ended questions.	6 themes identified: (1) The importance of social contact and comparison, (2) Increased awareness and knowledge about stroke, (3) Motivation to pursue goals and activities, (4) A sense of achievement, (5) Maintenance of gains, (6) The paradoxical nature of social support	N/A
Dongbo et al. (2003)[47]	RCT	+	N=954 Hyper-tension, heart disease, lung disease, stroke, arthritis, peptic disease, diabetes.	Wait-list control N = 428	Baseline (T1), end of program (T2), 6 month follow up (T3) Chinese CDSM measure: Exercise, cognitive symptom management, communication with doctor, self-efficacy, self-rated health, health distress, shortness of breath, pain, disability, illness intrusiveness, depression, energy, fatigue, social and role activity limitations. Health care utilization measure: Physician visits, emergency room visits, hospital stays, nights in hospital Cost of programme	Treatment group compared with control: Weekly minutes of exercise (P=0.01), cognitive symptom management (P=0.005) communication with doctor (P=0), self-efficacy to manage symptoms and disease (P=0.001), health distress (P=0.31), shortness of breath (P=0.71), pain (p=0.6), disability (P=0.02), illness intrusiveness (P=0.54), depression (P=0.15), fatigue (P=0.12), energy (P=0.83), social role limitations (P=0.36), physician visits (P=0.59), emergency room visits (P=0.93), hospital Stays (P=0.53), nights in hospital (P=0.58). The cost of the programme was just 1/9 of hospital admission savings.	Cognitive symptom management (0.38), depression (-0.1)
Hirsche et al. (2011)[48]	Semi structured interviews	++	N=22 Stroke, MS,	None	Within a week of programme completion. Experiences of the CDSMP, what was learnt, any	5 themes identified: (1) Factors affecting learning opportunities	N/A

				spinal cord injury.		changes in the way conditions are managed, and when to introduce the workshop	(2) Group (3) Workshop content (4) Pre-programme influences (5) Outcomes.
Huijbregts et al. (2008)[114]	Longitudinal cohort design Mixed methods	+	N=30 Stroke	Living with stroke (LWS). N=12.	Baseline (T1), end of the intervention (T2) and 12 weeks follow up (T3). Participation, Reintegration to Normal Living (RNL), activity specific balance scale (ABC), functional independence measure (FIM), abbreviated Geriatric Depression Scale (GDS), Care Giver Strain Index (CSI), Goal Attainment Scaling (GAS) tested in MOST only, Chedoke McMaster Stroke Assessment Activity inventory (CMSA-AI), cost analysis, focus group (one with carers and patients).	Participation: significantly more effective when study information received from health professional ($P < .05$). ABC, RNL, FIM: Between groups change ns. Within group significant changes for MOST (ABC scale (P=0.05), RNL (P<0.05) and FIM (P<0.05). LWS (ns). GDS & CSI: Small sample precluded meaningful examination of change. GAS: 13 met or exceeded their long-term goal, 5 did less than expected. CMSA-AI: Between groups change ns. When exercise participation at T1 accounted for at T3 ($p = .05$). Both groups were glad to meet other stroke survivors, felt less alone, wanted continued contact with group, said it was beneficial that carers could attend. Both groups said the groups helped them problem solve. LWS was cheaper to run than MOST.	Not given
Jaglal et al. (2013)[49]	Pre-post comparison design	+	N=213 Lung disease, heart disease, stroke, chronic arthritis.	CDSMP tele-health multi-site N =109	Baseline 4 months follow up. The six-item self-efficacy scale, Stanford disability scale, adapted social role limitations and mental health index. Visual numeric scales for: Pain/physical discomfort, psychological well-being, energy/fatigue, health distress, self-rated health status.	No statistically significant differences in outcomes between single- and multi-site groups except for self-rated health (P=0.05). Within group changes: Self-efficacy (P<0.01), stretching and strengthening (P<0.001), aerobic exercise (P<0.001), cognitive symptom management (P<0.001), communication with physicians (P<0.001), social role function (P=0.015), psychological well-being (P=0.001), energy/fatigue (P=0.04), health distress (P<0.001), self-rated health (P=0.004), disability (P=0.083), pain/ physical discomfort (P=0.191)	Not given
Kendall et al. (2007)[63]	Longitudinal RCT	+	N=73 Stroke	Standard care. N=42	Baseline(T1), 6 (T2), 9 (T3) and 12 (T4) months after stroke. The Stroke Specific Quality of Life scale (SSQOL), the Self-efficacy Scale.	Between group differences, energy (ns), language (ns), vision (ns), mobility (ns), fine motor tasks (ns), mood (ns), , Personality (ns), thinking (ns), social roles (ns), family roles (ns), work productivity (ns)	Not given
Kronish et al. (2014)[122]	RCT	++	N=600 Stroke	Wait list control N=299	Baseline and 6 months follow up Charlson Comorbidity Index, depressive symptoms, medication adherence, blood pressure (BP), LDL cholesterol	Between groups at 6 months: 3-month stroke prevention measures (P=0.98), LDL cholesterol (P=0.46), BP(P=0.02), systolic BP (P=0.04), taking antithrombotic medication (P=0.61), depression (P=0.16).	Not given

Lorig et al. (1999)[15].	RCT	+	N=952 Heart disease, lung disease, stroke, arthritis	Wait-list control N =476	Baseline and 6 months post intervention. Self-rated health scale, disability, psychological wellbeing scale- MHI-5 (from SF36), pain and physical discomfort, the energy /fatigue scale, health distress, duration of exercise, use of cognitive symptom management, communication with physicians, social/role activity limitations Shortness of breath, utilization measures.	Between groups: Stretching and strengthening (P=0.05), weekly minutes of exercise (P=0.0003), cognitive symptom management (P=0.0001), communication with physicians (P=0.006), less hospitalisations (P<0.05), fewer hospital night stays (P=0.01), self-rated health (P=0.02), health distress (P=0.001), fatigue (P=0.003), disability (P=0.002), social activity/social role limitations (P≤0.001), energy/fatigue (P-0.003), pain/physical discomfort (P=0.27), shortness of breath (P=0.56), psychological wellbeing (P=0.1), visits to physicians (P=0.11).	Not given
Sit et al. 2007)[124]	Quasi experimental design	+	N=147 Stroke	Standard care and health promo leaflet N=70.	Baseline (T0) pre intervention one week after (T1) and three-months after (T2) the completion of the intervention. Stroke knowledge, self-health-monitoring, medication compliance scale, self-reported Alcohol and cigarette consumption, exercise scale, self-reported Dietary intake	Between group differences for: Medication compliance T1 (P=0.004), treatment seeking response at T1 and T2 (both P<0.001), self BP monitoring at T1 and T2 (both P<0.001), stroke knowledge (ns), consuming salted preserved food (P=0.042), eating thick poultry soup (ns), participation in walking exercise at T2 (P<0.001), alcohol and cigarette consumption not reported.	Stroke warning signs (0.28), medication compliance (0.27), salted preserved food intake (0.22), risk factors (0.55)
Taylor et al. (2012)[186]	Semi-structured interviews	++	N=19 Stroke	None	Post intervention. Interview topics: 1. Previous experiences with groups or video-conferencing, 2. Participation in the discussion portion of MOST–TR via video-conference, 3. Participation in the exercise portion of MOST-TR via video-conference, 4, Factors enabling or limiting. Participation in the group.	All participants valued access to the programme without having to travel long distances. They felt safe in discussions and when exercising with the group across videoconference. Participants recognized a loss of subtleties in communication and the group facilitators found it difficult to discern whether participants were finding the exercises too difficult or too easy.	N/A
Wolf et al. (2016)[123]	Randomised clinical study	++	N=185 Stroke	12-week wait-list N=86	Baseline (T1), end of the month wait-list period (controls only-T2), end of intervention, (T3), 6-9 months follow up (T4). Primary outcomes: Chronic disease self-efficacy scale (CDSES), participation strategies self-efficacy scale	Between groups: CDSES: Exercise regularly (p=0.008), get information about disease (P=0.239), obtain help from others (P=0.045), communicate with physician (P=0.010). Manage: Disease in general (P=0.000), symptoms (P=0.058), shortness of breath (P=0.016), depression (P=0.08), do chores (0.001), social/recreational activities (P=0.122) PS-SES: Managing: Home (P=0.04), community (P=0.000), work and productivity (P=0.043), communication (P=0.314), staying organized (P=0.23), advocating for resources (P=0.002)	Exercising (0.57), help from others (0.44), manage disease (0.74), depression (0.66), chores (0.75), work productivity (0.37), advocating resources (0.65)

13.8 Appendix 8: Session 2 plan demonstrating how core self-management concepts are integrated into the intervention.

Time	Group activities	Rationale/self-management principles used
15 minutes	• Arrival, tea and coffee	• Ease group members into new environment and help them to feel welcome
15 minutes	• Meet with support buddy to discuss progress with targets during the previous week, and anything else that came up for them (e.g. successes, challenges, barriers, any support or ideas they would like from the group) *facilitators*	• Learning from and supporting each other • Problem solving • Reflecting on progress
45 minutes	• Group discussion of topics that occurred during 15 minutes with their support buddy. Facilitator to help members pick out the key challenges, strategies and learning	• Sharing ideas and strategies • Learning from each other • Identify existing strengths and resources • Problem solving
15 minutes	• Break, tea and coffee	
30 minutes	• Support buddies work together to discuss and record reflections (Section 1 of Stroke Workbook), future hopes (Section 5 of Stroke Workbook) and small steps for the week ahead • Group shares their targets for the week ahead before ending	• Reflecting on and recording achievements (pre- and post-stroke) and their contribution to them (mastery) • Acknowledge and record future hopes (hope, motivation) • Set small steps/targets (mastery) • Supporting and inspiring each other • Problem solving • Taking action

Facilitator considerations

• Communication needs of members with aphasia and the impact on their ability to contribute to buddy and group discussions
• Allowing members equal opportunity to share and reflect
• Keeping discussions focussed on learning about self-management skills rather than ranting/complaining/moaning about personal experiences

13.9 Appendix 9:Post-intervention interview topic guide

Note: These questions may be asked in different orders depending on the flow of the interview.

Start: *Interviewer introduces themselves and starts with rapport building questions such as, job, where they live, family.*

Your story

- Can you tell me about your stroke/ your experience of stroke
- What support have you said outside the hospital?

Group self-management

- Where were you in your stroke journey when you took part in the group? What was it about this that worked/didn't?
- Could the group have been delivered at a different time in your stroke journey?
- Have you learnt anything about yourself during the group?
- How has the group (if at all) taught you anything?
- What (if anything) have you learnt anything from others in the group?
- Do you think others in the group learnt anything from you?
- How have you felt supported by / supported other group members?

Post group / future

- Are you doing anything differently since the group?
- If you were having difficulty with something, what would you now?
- Is that different to what you would have done before the group?
- What (if anything) will you take from the group into your future?
- How confident do you feel to carry on under your own steam?

Research

- How did you feel being randomised to condition (can explain to participant if needed)?
- Do you have any feedback about research?

Closing question

- If you had two wishes for the groups what would they be?

End

Examples of phrases used to prompt participants into expanding on a point:

- Can you tell me more about that?
- Could you expand on that?
- What makes you say that?
- How do you feel about that?
- How did that make you feel?
- Why do you think that was?
- How did that situation arise?
- How was that issue resolved?
- What were the implications of/for that?
- How did that change over time?

13.10 Appendix 10: Participant feedback on the outcome measures

I have been frustrated by being asked to complete questionnaires that seem either outdated or not relevant to my own experience of stroke. For example: the HADS Q12, assumes that I used to be interested in my appearance. I don't think this is the case; the NEADL only gives me the options of Not at all/with help/on your own with difficulty/on your own. I would have liked the option of "with help with difficulty".

Also, many of my answers are context-based. For example, I can "climb stairs without difficulty" as long as there is a handrail on the right-hand side. If there is no handrail, I can climb them with help with difficulty (and a lot of fear). I can make myself a hot drink, but I don't because I can't carry it to a place where I can sit down and drink it. The same goes for making myself a hot snack. The difficulty is the safe carrying of hot or heavy things, not the making of them in the first place. Similarly, I did not wash small items of clothing not because I can't but because there is no point as someone else will do a full wash. I can't do that because I cannot carry the washing basket out to the line. If I lived somewhere with a dryer next to a washing machine, I would be able to do it. Q 19. Does anyone write letters anymore?

The SAQOL-39 is the most irritating as my answers completely depend on context. E.g some chairs are easy to get out of; some are impossible. I have learned to avoid ones that are very low and don't have arms or a back I can use to help me up. The same goes for buttons. Whether or not I can do them depends on the size & location of the button. As for zips, ones that are fixed at the bottom (e.g. on my jeans) are fine whereas a zip on a jacket is impossible for me. I have never been able to open jars (isn't that why men exist?). I go out a lot, but the difference now is that I always have to arrange for someone to come with me.

The SSEQ has questions that are ambiguous, e.g. I am confident that I can walk about my house but not at all confident that I can do the things I want (note the carrying issues above).

13.11 Appendix 11: Behaviour change techniques used in the group self-management intervention and the frequency at which they were identified.

Group number	BCT reported	Definition	Frequency
2	1.8 behavioural contract	Create a written specification of the behaviour to be performed, agreed on by the person, and witnessed by another	1
	1.9 commitment	Ask the person to affirm or reaffirm statements indicating commitment to change the behaviour	1
	3.1. 3.2 and 3.3 practical and emotional social support	Advise on, arrange, or provide **practical** help and emotional support	7
	5.4 monitoring of emotional consequences	Prompt assessment of **feelings** after attempts at performing the behaviour	1
	6.2 social comparison	Draw attention to others' performance to allow comparison with the person's own performance	2
	8.1 behavioural practice/rehearsal	Prompt practice or rehearsal of the performance of the behaviour one or more times in a context or at a time when the performance may not be necessary, in order to increase habit and skill	1
	12.3 Avoidance/changing exposure to cues for the behaviour	Advise on how to avoid exposure to specific social and contextual/physical cues for the behaviour, including changing daily or weekly routines	1
	13.3 incompatible beliefs	Draw attention to discrepancies between current or past behaviour and self-image, in order to create discomfort	1
3	1.2 Coping planning	Analyse, or prompt the person to analyse, factors influencing the behaviour and generate or select strategies that include overcoming barriers and/or increasing facilitators.	1
	1.8 Behavioural contract	Create a written specification of the behaviour to be performed, agreed on by the person, and witnessed by another	2
	1.9 Commitment	Ask the person to affirm or reaffirm statements indicating commitment to change the behaviour	3
	4.1 instruction on how to perform the behaviour (from peers)	Advise or agree on how to perform the behaviour (includes '**Skills training**')	1

	8.1 Behaviour practice/ rehearsal	Prompt practice or rehearsal of the performance of the behaviour one or more times in a context or at a time when the performance may not be necessary, in order to increase habit and skill	1
	12.1 Reconstructing the physical environment	Change, or advise to change the **physical** environment in order to facilitate performance of the wanted behaviour or create barriers to the unwanted behaviour (other than prompts/cues, rewards and punishments)	1
	12.3 Avoidance /changing exposures to cues for behaviours	Advise on how to avoid exposure to specific social and contextual/physical cues for the behaviour, including changing daily or weekly routines	1
4	1.8 Behavioural contract	Create a written specification of the behaviour to be performed, agreed on by the person, and witnessed by another	6
	1.9 Commitment	Ask the person to affirm or reaffirm statements indicating commitment to change the behaviour	4
	2.1 Monitoring of behaviour by others without feedback	Observe or record behaviour with the person's knowledge as part of a behaviour change strategy	1
	6.2 Social Comparison	Draw attention to others' performance to allow comparison with the person's own performance	1
	6.3 Information about others approval	Provide information about what other people think about the behaviour. The information clarifies whether others will like, approve or disapprove of what the person is doing or will do	1
6	1.8 behavioural contract	Create a written specification of the behaviour to be performed, agreed on by the person, and witnessed by another	4
	1.9 commitment	Ask the person to affirm or reaffirm statements indicating commitment to change the behaviour	2
	3.1. 3.2 and 3.3 practical and emotional social support	Advise on, arrange, or provide **practical** help and emotional support	4
	6.2 Social Comparison	Draw attention to others' performance to allow comparison with the person's own performance	1
	11.2 reduce negative emotions	Advise on ways of reducing negative emotions to facilitate performance of the behaviour	4
	12.2 restructuring the social environment	Change, or advise to change the **social** environment in order to facilitate performance of the wanted behaviour or create barriers to the unwanted behaviour	3

7	1.6 discrepancy between current behaviour and goal	Draw attention to discrepancies between a person's current behaviour and the person's previously set outcome goals, behavioural goals or action plans	1
	1.8 behavioural contract	Create a written specification of the behaviour to be performed, agreed on by the person, and witnessed by another	3
	1.9 commitment	Ask the person to affirm or reaffirm statements indicating commitment to change the behaviour	3
	2.1 monitoring of behaviour by others without feedback	Observe or record behaviour with the person's knowledge as part of a behaviour change strategy	2
	3.1. 3.2 and 3.3 practical and emotional social support	Advise on, arrange, or provide **practical** help and emotional support	1
	4.1 instruction on how to perform a behaviour (from peers not me, ZH or HT)	Advise or agree on how to perform the behaviour (includes '**<u>Skills training</u>**')	1
	6.2 social comparison	Draw attention to others' performance to allow comparison with the person's own performance	2
	8.2 Behavioural substitution	Prompt substitution of the unwanted behaviour with a wanted or neutral behaviour	1
	10.4 social reward	Arrange verbal or non-verbal reward if and only if there *has been* effort and/or progress in performing the behaviour	2
	12.1 restructuring the physical environment	Change, or advise to change the **physical** environment in order to facilitate performance of the wanted behaviour or create barriers to the unwanted behaviour (other than prompts/cues, rewards and punishments)	1
8	1.8 behavioural contract	Create a written specification of the behaviour to be performed, agreed on by the person, and witnessed by another	1
	1.9 commitment	Ask the person to affirm or reaffirm statements indicating commitment to change the behaviour	1
	3.1. 3.2 and 3.3 practical and emotional social support	Advise on, arrange, or provide **practical** help and emotional support	3
	6.1 demonstration of behaviour	Provide an observable sample of the performance of the behaviour, directly in person or indirectly e.g. via film, pictures, for the person to aspire to or imitate (includes 'Modelling')	1

	9.3 comparative imagining of future outcomes	Prompt or advise the imagining and comparing of future outcomes of changed versus unchanged behaviour	1
	13.2 framing/reframing	Suggest the deliberate adoption of a perspective or new perspective on behaviour (e.g. its purpose) in order to change cognitions or emotions about performing the behaviour	1

13.12 Appendix 12: Focus group topic guide (Version 1 – 16/11/2016)

Start

Facilitator introduces the group and what the purpose of the purpose of it is.

Housekeeping

Introduces self and asks group members to do the same.

Questions

The Group

- How did you find the groups? (ice breaker)
- What was it about the groups that you liked, if anything?
- If you were running the groups what would you do differently?
- What did you think of the three facilitators, and one being a stroke survivor?
- How did it feel hearing other people's stroke stories?
- Did you feel supported by other group members?
- Do you think the stroke survivor you attended with learnt anything from the group? If so, how did the group teach them this?
- Have you learnt anything about yourself during the group? If so, how did the group teach you this?
- Thinking about pre/post the group has anything changed for you and the person you went with? If yes, why/how etc
- Do you think the group has changed anything for others in the group? If yes, why/how etc
- Did you feel the group was at a good time or could it have been delivered earlier/later in the stroke journey?
- Are you doing anything differently since the group?

Thoughts about the future

- Is there anything that you will take from the group into your future?
- How confident do you feel to carry on under your own steam?

End

13.13 Appendix 13: Outcome measures.

13.13.1   Hospital Anxiety and Depression Scale (HADS)

Instructions

The Hospital Anxiety and Depression Scale (HADS) is a method to evaluate your anxiety and depression levels. The HADS is a short questionnaire that requires you to agree or disagree with each of the statements below based on how you felt in the past week. To rate the statements choose a number between 0 and 3 (including 0 and 3). A low value (e.g. 0) indicates strong disagreement and a high value (e.g. 3) indicates strong agreement

1. I feel tense or wound up ____

2. I get a sort of frightened feeling as if something bad is about to happen ____

3. Worrying thoughts go through my mind ____

4. I can sit at ease and feel relaxed ____

5. I get a sort of frightened feeling like butterflies in the stomach ____

6. I feel restless and have to be on the move ____

7. I get sudden feelings of panic ____

8. I still enjoy the things I used to enjoy ____

9. I can laugh and see the funny side of things ____

10. I feel cheerful ____

11. I feel as if I am slowed down ____

12. I have lost interest in my appearance ____

13. I look forward with enjoyment to things ____

14. I can enjoy a good book or radio or TV programme ____

13.13.2 Nottingham Activities of Daily Living Scale (NEADL)

Nottingham Extended ADL Scale

The following questions are about everyday activities. Please answer by ticking ONE box for each question. Please record what you have ACTUALLY done in the last few weeks.

DID YOU……….	Not at all	with help	on your own with difficulty	on your own
1. Walk around outside?	☐	☐	☐	☐
2. Climb stairs?	☐	☐	☐	☐
3. Get in and out of a car?	☐	☐	☐	☐
4. Walk over uneven ground?	☐	☐	☐	☐
5. Cross roads?	☐	☐	☐	☐
6. Travel on public transport?	☐	☐	☐	☐
7. Manage to feed yourself?	☐	☐	☐	☐
8. Manage to make yourself a hot drink?	☐	☐	☐	☐
9. Take hot drinks from one room to another?	☐	☐	☐	☐
10. Do the washing up?	☐	☐	☐	☐
11. Make yourself a hot snack?	☐	☐	☐	☐

	No	With help	On your own with difficulty	On your own
12. Manage your own money when out?	☐	☐	☐	☐
13. Wash small items of clothing?	☐	☐	☐	☐
14. Do your own housework?	☐	☐	☐	☐
15. Do your own shopping?	☐	☐	☐	☐
16. Do a full clothes wash?	☐	☐	☐	☐
17. Read newspapers or books?	☐	☐	☐	☐
18. Use the telephone?	☐	☐	☐	☐
19. Write letters?	☐	☐	☐	☐
20. Go out socially?	☐	☐	☐	☐
21. Manage your own garden?	☐	☐	☐	☐
22. Drive a car?	☐	☐	☐	☐

13.13.3 Stroke and Aphasia Quality of Life Scale (SAQOL-39)

Name:_____d.o.b.:_____Date:_____

SAQOL-39 Scoring Sheet

DURING THE PAST WEEK

Item ID	How much trouble did you have (Repeat before each item or as necessary)	Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
SC1.	preparing food?	1	2	3	4	5
SC4.	getting dressed?	1	2	3	4	5
SC5.	taking a bath or shower?	1	2	3	4	5
M1.	walking? (If respondent can't walk, circle 1 and go to question M7)	1	2	3	4	5
M4.	keeping your balance when bending over or reaching?	1	2	3	4	5
M6.	climbing stairs?	1	2	3	4	5
M7.	walking without stopping to rest or using a wheelchair without stopping to rest?	1	2	3	4	5
M8.	standing?	1	2	3	4	5
M9.	getting out of a chair?	1	2	3	4	5
W1.	doing daily work around the house?	1	2	3	4	5
W2.	finishing jobs that you started?	1	2	3	4	5
UE1.	writing or typing, *i.e. using your hand to write or type*?	1	2	3	4	5
UE2.	putting on socks?	1	2	3	4	5
UE4.	doing buttons?	1	2	3	4	5
UE5.	doing a zip?	1	2	3	4	5
UE6.	opening a jar?	1	2	3	4	5
L2.	speaking?	1	2	3	4	5
L3	speaking clearly enough to use the phone?	1	2	3	4	5
L5.	getting other people to understand you?	1	2	3	4	5
L6.	finding the word, you wanted to say?	1	2	3	4	5
L7.	getting other people to understand you even when you repeated yourself?	1	2	3	4	5

DURING THE PAST WEEK:

| Item ID	Did you (Repeat before each item or as necessary)	Definitely yes	Mostly yes	Not sure	Mostly no	Definitely no
T4.	have to write things down to remember them, *(or ask somebody else to write things down for you to remember)?*	1	2	3	4	5
T5.	find it hard to make decisions?	1	2	3	4	5
P1.	feel irritable?	1	2	3	4	5
P3.	feel that your personality has changed?	1	2	3	4	5
MD2.	feel discouraged about your future?	1	2	3	4	5
MD3.	have no interest in other people or activities?	1	2	3	4	5
MD6.	feel withdrawn from other people?	1	2	3	4	5
MD7.	have little confidence in yourself?	1	2	3	4	5
E2.	feel tired most of the time?	1	2	3	4	5
E3.	have to stop and rest often during the day?	1	2	3	4	5
E4.	feel too tired to do what you wanted to do?	1	2	3	4	5
FR7.	feel that you were a burden to your family?	1	2	3	4	5
FR9.	feel that your language problems interfered with your family life?	1	2	3	4	5
SR1.	go out less often than you would like?	1	2	3	4	5
SR4.	do your hobbies and recreation less often than you would like?	1	2	3	4	5
SR5.	see your friends less often than you would like?	1	2	3	4	5
SR7.	feel that your physical condition interfered with your social life?	1	2	3	4	5
SR8.	feel that your language problems interfered with your social life?	1	2	3	4	5

Thank you!

13.13.4 Stroke self-efficacy scale (SSES)

The STROKE SELF-EFFICACY QUESTIONNAIRE

These questions are about your confidence that you can do some tasks that may have been difficult for you since your stroke.

For each of the following tasks, please circle a point on the scale that shows how confident you are that you can do the tasks <u>now</u> in spite of your stroke.

Where 0 = *not at all confident* and 3 = *very confident*

Not at all   Very
confident   confident

0   3
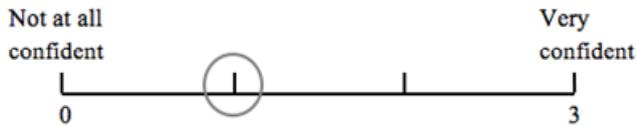
How *Confident* are you *now* that you can

1. Get yourself comfortable in bed every night.

Not at all   Very
confident   confident

0   3
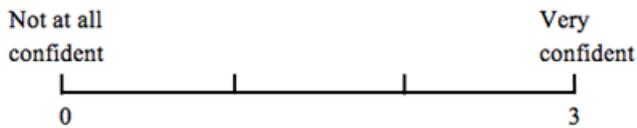
2. Get yourself out of bed on your own even when you feel tired.

Not at all   Very
confident   confident

0   3
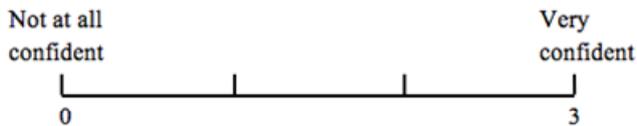
3. Walk a few steps on your own on any surface inside your house.

Not at all   Very
confident   confident

0   3

4. Walk about your house to do most things you want.

Not at all   Very
confident   confident

0   3
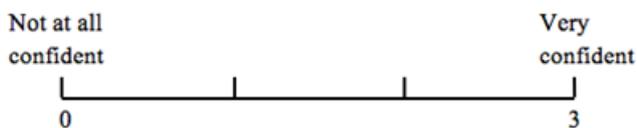
5. Walk safely outside on your own on any surface.

Not at all
confident

Very
confident

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L_____|_____|_____J
0                          3
```

6. Use both your hands for eating your food.

Not at all
confident

Very
confident

```
L_____|_____|_____J
0                          3
```

7. Dress and undress yourself even when you feel tired.

Not at all
confident

Very
confident

```
L_____|_____|_____J
0                          3
```

8. Prepare a meal you would like for yourself.

Not at all
confident

Very
confident

```
L_____|_____|_____J
0                          3
```
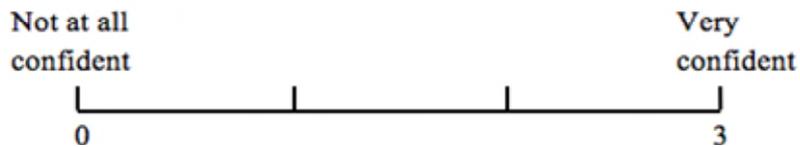
9. Persevere to make progress from your stroke after
discharge from therapy.

Not at all
confident

Very
confident

```
L_____|_____|_____J
0                          3
```
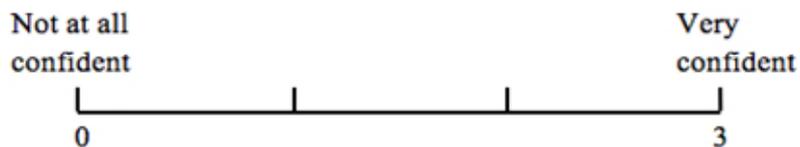
10. Do your own exercise programme every day.

Not at all   Very
confident   confident

```
 L_____|_____|_____J
 0                           3
```

11. Cope with the frustration of not being able to do some things because of your stroke.

Not at all   Very
confident   confident

```
 L_____|_____|_____J
 0                           3
```
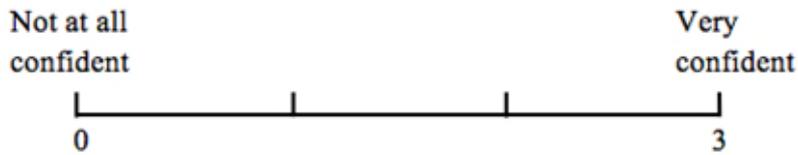
12. Continue to do most of the things you liked to do before your stroke.

Not at all   Very
confident   confident

```
 L_____|_____|_____J
 0                           3
```

13. Keep getting faster at the tasks that have been slow since your stroke.

Not at all   Very
confident   confident

```
 L_____|_____|_____J
 0                           3
```